ORIGINAL ARTICLE

Sexual identity following breast cancer treatments in premenopausal women

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Abstract

The phenomenon in focus for this study was the sexual identity preserved in premenopausal women due to breast cancer treatments. During the last decade the methods of breast cancer treatments have become more aggressive and many women have had to undergo surgery, radiation, and chemotherapy, as well as three to five years of hormone therapy. All these forms of treatment can have negative side effects on their sexual capability. The purpose of this study was to describe the meaning structure and the constituents of sexual identity in the lifeworld of premenopausal women. Six informants who had become menopausal following cancer treatment were interviewed about their experiences related to their sexual identity. Their ages varied between 38 and 48 years. The empirical phenomenological psychological (EPP) method was used. The meaning structure of the phenomenon could be symbolized using the metaphor of a bird which is pinioned and unable to fly. The women perceived their sexual identity as being inhibited in different ways. They felt odd and marginalized as women, and it was only within a support group that they felt completely confirmed. A future challenge for the health care professionals would be to care for their patients on the basis of their lifeworld experiences.

Key words: Breast cancer, lived experience, premenopausal, sexuality identity

Introduction

Today, breast cancer is the most common cancer among women, world wide, and the numbers are increasing. Approximately 15% of all cases occur before women reach 45 years of age (Stewart & Kleihues, 2003; Patient Directory of The National Board of Health and Welfare, 2004).

Young women with a breast cancer diagnosis are a vulnerable group, not least because they are often heavily involved with their female roles in their private and social life. They do not have so much experience from earlier life events and breast cancer is rare among the younger population. Therefore, breast cancer comes unexpectedly for them, and sometimes this means that their cognitive and behavioural efforts to manage their new life-situation are inadequate (Lazarus, 1993; Balneaves & Long, 1999; Wenzel et al., 1999; Wilmoth, 2001). The methods of treatment have, during the last decade, become more aggressive and many women have had to undergo surgery, radiation, and chemotherapy, as well as three to five years of hormone therapy (Stewart & Kleihues, 2003; Karolinska Institutet, 2006). As a consequence, mortality in breast cancer is decreasing, particularly among the younger population (Stewart & Kleihues, 2003; Patient Directory of The National Board of Health and Welfare, 2004). Unfortunately, all these methods of treatment can have severe negative sexual side-effects (Young-McCaughan, 1996; Wilmoth & Ross, 1997; Wilmoth 2001).

Sexuality is an integral aspect of being human and is relevant to nursing care due to the holistic nature of the concept (Sheerin & McKenna, 2000). Research on breast cancer has focused on the psychological and sexual effects of breast cancer from a quantitative and biomedical perspective. Little
seems to have been documented concerning the individual experiences of the women with breast cancer and in relation to WHO’s definition of sexuality (Wilmoth & Ross, 1997; WHO, 2002). Sexuality encompasses sex, gender identities and roles and it is not unambiguous with reproduction, our sexual orientation and ability for eroticism. Pleasure and intimacy is a central aspect of being human throughout life (WHO, 2002). Ontological sexuality can be identified both as sexual impulse and as embodiment and is therefore highly complex (Merleau-Ponty, 1995/1945). In their article, Sheerin and McKenna (2000) try to define the concept of sexuality essential to nursing care. Their definition is not only built on interpretations taken from the literature but also from media, magazines and films. Four concepts are essential: sexual identity as perceived at any given time, then communication associated with this identity, followed by interaction with other people and finally reciprocation, reception and interpretation of all outcomes connected to their sexual identity (Sheerin & McKenna, 2000).

Surgery due to breast cancer can damage a woman’s body-image which is a central aspect in the concept of sexual identity (Price, 1995, 1998; Rowland et al., 2000). An important observation is the fact that women who have felt they have some control over their treatment options before being operated when they could decide themselves if lumpectomy or mastectomy should be carried out, have been more satisfied with their sexuality afterwards (Rowland et al. 2000). Another finding is that women who think positively about the sexual aspects of their identity before receiving their diagnosis remain more satisfied with their sexuality after treatment (Andersen & Cyranowski, 1994). Women in a Swedish population were interviewed after breast reconstruction with the view to understanding their motivation for their choice of treatment. The study found that it was important for women to be seen to have two breasts and the consideration of the use of loose prostheses, therefore, was almost as important as the breast reconstruction (Sandell, 2001). In Western culture, women are caught between the cultural view that breasts are important for both femininity and motherhood (Kasper, 1995; Sandell, 2001). The inscription of femaleness on the womanly body is thus similar irrespective of whether the method used is reconstruction or the use of prostheses (Sandell, 2001).

Women who become menopausal after receiving chemotherapy are perhaps the most vulnerable group among all breast cancer patients (Ganz, Rowland, Desmond, Meyerowitz & Wyatt, 1998; Watskins Bruner & Boyd, 1998; Avis, Crawford & Manuel, 2004). The physical and psychological effects of breast loss, alopecia, nausea and fatigue, may leave little energy for relationships. At the same time decreased sexual desire is moreover a direct consequence as the lubrication of the vagina deteriorates which may lead to painful intercourse if the woman on the whole wished to be intimate (Ganz et al. 1998; Watskins Bruner & Boyd, 1999; Avis et al., 2004). The experience of hot flushes and artificial menopause are another neglected issue which affects the women’s sexuality in a broad psychological and social way (Kobf, 1998; Fenlon & Rogers, 2007). Qualitative data suggests that women’s perceptions, different gender roles and feelings of femininity are most important for healthy sexuality (Wilmoth & Ross, 1997; Thewes, Butow, Girgis & Pendlebury, 2004).

Western societies idealise health and youth. Therefore bodily change due to aging can be perceived as an existential threat (Toombs, 1992; Ogle & Damhorst, 2005). Women who are confronted with breast cancer are not mentally prepared for the rapid bodily changes that come with the treatment. In addition, they fear other changes such as; their roles in their private relations and at work may change, not to mention the fear of death. All these things make them particularly vulnerable (Toombs, 1992; Ogle & Damhorst, 2005).

The purpose of this study was to describe the meaning structure and the constituent parts of sexual identity in the premenopausal women’s life-world.

Method

The empirical study

The phenomenon in focus for this study was the sexual identity status of premenopausal women following their treatment for breast cancer. A phenomenological approach aims at describing or elucidating such experiences of a phenomenon as experienced by the individual, the so called lifeworld experiences (Karlsson, 1995). In this study we chose the empirical phenomenological psychological (EPP)-method, which is grounded in Husserl’s phenomenological philosophy (Karlsson, 1995). The EPP-method has been developed within a psychological perspective, which in this study has been substituted with a nursing perspective. The focus for the researchers has been the participants’ daily life and concepts within nursing ontology.

Participants

The women in this study all belonged to a support group for women with breast cancer. This can be a
strength but even a limitation for the study. The strength is the fact that the women had identified themselves as breast cancer patients and felt secure and confident as group members. They were also very keen on the issues for the study and had discussed it before with other group members. The limitation is, of course, the fact that people attending a group are perhaps not representative of the population.

The first author had, during the period of planning the study, contacted the chairperson of this group and according to her there was a high interest level among the group members relating to sexuality issues and the members looked forward to being invited to the study. Ten women were later approached by the chairperson who sent a personal letter inviting them to take part in an interview study. Finally six women agreed and were interviewed by the first author (KK). The participants’ ages were between 38 and 48 years, with a median of 45 years and all of them had become menopausal due to breast cancer treatment. Four of the women were in the earlier stages of the disease, i.e. within 12–38 months since their diagnosis. Two women were diagnosed nine and 11 years ago and one of them had a relapse a couple a years earlier. Five of the six women were treated with chemotherapy and all of the women were treated with hormones at the time of the interviews. Five of the participants had had a mastectomy and two of them had had breast reconstruction. They were all Swedish-speaking and married or in long-term cohabiting relationships except for one woman who was a widow.

The interviews

The interviews were carried out between June to September 2003, at a place of the participant’s choice. In most cases, this was where the support group had its meetings, with the exception of two participants who chose the park outside. Before the interview started, the first author (KK) explained the purpose and the topic of the interview once again and endeavoured to make the participant comfortable (Kvale, 1996). Phenomenological interviews were conducted in order to obtain expressions of the women’s lived experience (Kvale, 1996). This meant that the interviewer tried to be as open as possible to the phenomenon ‘sexual identity’. In order to introduce the topic, the women were asked to talk about memories and feelings about their first brassieres and menstrual period. During the interview the participants were asked to describe situations where any change in there sexual identity was noticeable and how, if at all, this affected their lifeworld (Karlsson, 1995). The interviews lasted 55–120 min and they were tape-recorded and transcribed verbatim.

Analysis

The analysis consists of five steps where every single text from each interview is processed and separated until the last step (Karlsson, 1995).

In the first step, the first researcher tried to grasp the entirety of the text, by reading the text several times until she reached an understanding and could continue the second step of the analysis. Already in step 1 the reduction was implemented which meant the need of an open and curious mind where the researcher, although aware of the theories, does not let them influence the analysis process. 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 the researchers identified a shift of meaning. To illustrate step 2 some original text 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 as a relief (MU 1) but of course I would prefer not being in this situation, but … (MU 2).

In this protocol we considered MU 1 as describing the situation after becoming menopausal. After MU 1, a temporal change occurs in the description to which we as researchers must pay attention. In step 3, we used eidetic induction through interpretation which is the move from the particular fact to its psychological meaning from (in this study) the ontology for nursing. The point at this time in the analysis was to trace the implicit and explicit psychological meaning that the subject had experienced and describe it in the protocol. In step 3 this quote 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. In step 4, the transformed meaning units were synthesized into a so-called “situated structure” presented in the form of a synopsis. In this step you are free to arrange the constituents in a phenomenological way. It can include both how the phenomenon is experienced (the noetic side) or what the phenomenon is (the noematic side) (Karlsson, 1995). The quote above could fit in the constituent being in an existential vacuum. In step 5, the documents from all of the interviews were compared and a “general structure” was formed. The movement between the whole and the parts played a major role in the analysis. It is in
the tension between the researchers’ pre-knowledge and endeavour to be as open as possible during the analysis, that the interpretation in the EPP-method develops (Karlsson, 1995).

The aim for this study was to trace the meaning structure of the phenomenon ‘sexual identity’ in premenopausal females with breast cancer. The criteria of validity in the EPP-method depend on three most important tasks: (1) The degree of success in the implementation of the partial phenomenological psychological reduction; (2) the horizontal consistence of interpretations; and finally (3) the vertical consistence of interpretations (Karlsson, 1995).

1. The main researcher has tried to be open and curious while collecting data, making the analysis and rewriting. By keeping a research diary during the process and cooperating with the co-writer, the main researcher has been aware of her pre-understanding and not allowing this to effect any interpretation reached during the research process. This is almost an impossible issue and according to Merleau-Ponty the researcher always functions as a subjective filter (Merleau-Ponty, 1995/1945). The complexity of the phenomenon ‘sexual identity’ is perhaps impracticable to catch throughout the phenomenological approach.

2. Each interview has been written in a separate protocol and the researcher has worked on each protocol with the purpose of finding the noema. The noema is the real object perceived through its meaning or sense (Karlsson, 1995).

3. Later on, the protocols were compared with each other and the constituents appeared.

When the findings were presented back to the women in the support group, each of them felt that they could recognize the meaning structure and the constituents.

**Ethical considerations**

The study was approved by the Regional Ethics Committee in Gothenburg (S 197–03). In accordance with the Helsinki declaration, the main researcher tried to be as careful and sensitive towards the informants needs as possible (Medical Research Council, 2000). All the informants signed an informed consent form and were advised that whenever they felt the need to talk to someone, for instance about feelings arising out of the interview, they could call the psycho-social department at a hospital nearby.

**Results**

To be menopausal due to treatment was an attendant phenomenon and nothing the participants could anticipate. After being diagnosed with a life threatening disease this problem was secondary and nothing they reflected on. Life itself seemed constrained, as it was threatened, as was their normal sexual behaviour and feelings. Suddenly their femininity was gone and certain taken-for-granted ways of interacting with others now felt unfamiliar. Their body which was well known to them had changed in a moment and they no longer recognized their bodies and their feelings. They felt inadequate as females and had an overwhelming feeling of not having control over their bodies. Their experiences were mostly not verbalized because it was nearly impossible to put them into words. Other areas of life took a backseat as the struggle to survive and go through surgery and other treatment became the only thing that mattered or the only thing they could think about. The women’s sexuality was in fluctuation and this constrained their autonomy and inhibited them in expressing their sexual identity. The meaning structure of the phenomenon under study could be symbolized using the metaphor of a bird that is pinioned and unable to fly anymore. The intentionality threads were loose and their lifeworld felt unknown for them. They seemed to be totally restricted in their ability to communicate their sexual feelings and needs associated with their sexual identity and also in interaction with their partners. Their capacity to interpret media and in the long term how to act as females within their community was also inhibited. It was only when together with the other women in their support group that they felt completely confirmed. They felt that they did not have to talk about female experiences because everybody in the group had the same insight. Decreased sexual desire made them long for just being held and hugged, their intimacy increased when these needs were requited. The meaning structure in this study consists of three typological constituents: not recognizing oneself, being in an existential vacuum and new strength in intimate relationship.

All the informants’ names are assumed.

**Not recognizing oneself**

The women in this study became menopausal within a couple of months of their treatment. Loss of menstrual bleeding was a kind of relief. The women felt free by not having to carry extra underwear, sanitary towels and tampons during their periods or thinking about menstruation, for instance, when making holiday plans. It also meant freedom from menstrual cramp and premenstrual syndrome.
(PMS). However, menstruation was something familiar—something they could share with other women, and something that signified health, fertility and femininity.

During and after treatment, the women felt their bodies had changed in unwanted ways. Fatigue, nausea, dizziness, pain and sleeping difficulties due to treatment now occupied their whole life. Their bodies also aged, their skin became wrinkled, their muscles wasted and body fat was re-distributed to the stomach, and their hips became stiffer:

And then such a simple thing really, the breast you still have drops down a level, because the breast tissue changes very quickly. It is like someone pulling out the plug in an air mattress if I may put it like that. It just falls down and the fat below the skin becomes like, becomes different. And it happens really quickly (Klara).

The menopausal symptoms were the most frequent symptom in this study. The participants, somewhat shocked, discovered that they had become like their mothers. In order to understand their new situation the women reverted into the past, seeking information from their mothers and grandmothers about their menopausal experiences. By identifying themselves with their mothers their intentionality threads were tightened. They also seemed to be very active and responsible in reducing flushing and sweating by changing their way of dressing, thinking about what to eat and drink and finally, when applicable, receiving acupuncture treatment.

The health care professionals focused on the biomedical aspects. No one actually felt that the information they received was adjusted to their personal experience. Klara for example remembered the important medical aspect of ceasing her periods:

They were hoping that my ovaries would be knocked out. And if they weren’t they were going to kill them by ... they talked about radiating the ovaries so they died ... or taking them away (Klara).

The women could not recognize themselves as females any longer. Loss of youthful appearance, fertility and energy made them feel old, less attractive and it seemed to them that they lost their womanhood. They mourned these losses but were unable to verbalize their feelings which sometimes led to their emotions becoming out of control.

Their capacity to interpret media and in the long term how to act as females within their community also became inhibited. They made efforts to feel attractive. To arrange wigs or in some cases scarves, and to adjust their makeup to replace the loss of their eyebrows and eyelashes, all took a lot of energy. The increasing stomach fat and sweating made some of them change their clothing style. They felt odd and marginalized as women: “No, today I have clothes which I’d earlier never, never would have worn outside my home” (Klara).

**Being in an existential vaccum**

The threat to the women’s existence made them lose their intentionality threads to their sexual identity. Not only the women’s perceived body and human relations were affected, but also their perceived sense of space and time. Becoming menopausal at their age was nothing natural and it was confusing for them not knowing how much the medical treatment effected them and what it should be like when they were older and had less natural hormones. Knowing instinctively how to act as females in all their different roles was suddenly gone and they felt inadequate. The media picture of the ideal woman made it sometimes impossible for them to visit beaches in the summertime or for example watch television, films, music videos etc. together with their partners. It seemed to be impossible for them to create an identity which was familiar and secure. Their living space seemed to be limited by the concept of being a patient subordinated to treatment:

Then, well, I don’t know. I felt myself neither as a woman nor a man. I didn’t feel myself as being anything. I felt myself as a prisoner. I don’t know why, it can’t be explained (Maja).

After chemotherapy treatment, the women expected to be healthy and strong again, to be re-established as normal. They often felt there was no preparation within the community for their rehabilitation after treatment. The participants struggled to adapt to their new identity, while feeling that nobody understood what they were going through. All the vague symptoms they experienced and complained about were overlooked as being psychological and therefore not “real”—at least not a problem that the health care system should deal with. The women felt that they were expected not to pity themselves. Instead they were supposed to be happy to be alive and to able to carry on with their lives: “And I felt I was never allowed to ... I wasn’t allowed to be the person I was, I mean like, I was actually so frail at first” (Maja).
New strength in intimate relationship

The partners or other close friends and the support group members played a major role for the women’s well-being. The women needed practical support to manage their daily obligations including motherhood. They also needed someone who could reassure them by offering psychological support. In the support group they felt confirmed in their perceived uniqueness and loss of femininity.

Their love life with regular intercourse was suddenly gone, however for these women this was so secondary that they hardly reflected upon it. Later on, all the women, except two, continued with their love life but for the majority the pattern had changed and love making had become more passive. Sometimes the women felt it was like they had to climb over obstacles to get aroused. Little things their partner had done before the illness that the woman had not paid much attention to, suddenly became important. This re-evaluation of their situation helped them feel satisfied with their close relationship. But sometimes their lifeworld could feel so chaotic and their bodies so destroyed that both their verbal and body language had changed which had an essential impact on their intimate relationship:

So he thinks it is only me that … He wants sex as often as before and he likes me and wants to hug and all that stuff. So it’s me who has withdrawn. It’s not like he is disgusted by me or so … Ehh, instead it’s me sort of who feels … disgusted. (Laughter followed by silence) (Anna).

Anna had to use alcohol to feel comfortable with her femininity and to be able to feel as sexy in interaction with her partner as before. Otherwise she felt that she had to make arrangements in the bed with cushions, blankets etc to hide her body.

The participants expressed feelings of being responsible for the well-being of other members of their families. In some cases the lifeworld experiences of these women were so traumatic and painful that it was almost impossible for them to share them with their partners. In respect to their partner’s well-being the women limited themselves further in expressing their fears for the future: “Had I taken away his defence (psychological) and he had broken down, where had we then been standing … with all the children” (Klara).

The women’s need for hugging and closeness to their partners increased and this often improved their intimacy. In turn this also amplified the women’s bodily pleasure, even if their sexual desire was lacking. The relief of getting through this life threatening disease together with their partner increased their intimate relation and also increased their feeling of being loved and confirmed: “It is as though we have, in some way, become stronger together” (Hanna).

One participant in this study was different from the others regarding her experiences. She was a midwife by profession and had a more mature attitude towards her body and her sexuality. She had reflected on what sexuality meant for her before she was diagnosed for breast cancer and was convinced that sexuality was something that came from inside the body. This conviction made her feel less inhibited to express her sexual identity and made it easier for her to accept the changes connected to the menopause.

Discussion

The meaning structure of the phenomenon under study could be symbolized using the metaphor of a bird that is pinioned and unable to fly anymore. The women’s sexual identity was perceived as being inhibited in different ways. Their lifeworld had changed dramatically and feelings and emotions made them feel limited when expressing their sexual identity. It is well known that cancer and other diseases threaten a person’s identity (Price 1995, 1998; Rowland et al., 2000). Although the bodily changes were losses both explicitly and implicitly, the women had no time to reflect and did not receive sufficient support for reflection. The women, therefore, were unable to create a new meaning and understanding in their life. This affected their experiences of their femininity and sexuality in their role as mothers, partners and in their work, all of which made them feel stigmatised and vulnerable.

One aspect of vulnerability is the lack of autonomy. Nordenfelt (2000) considers that being autonomous is the same as having the resources to govern oneself and secondly having the sense of actually achieving this resource. Nordenfelt also considers that a person has to have both the ability and the opportunity to govern themselves. This is highly complex. Ability is always an ability in relation to a particular set of circumstances and therefore central to nursing epistemology.

Not being confident in their sexual identity made the women, in this study, aware of their now unfamiliar body. Similar experiences related to sexuality have been found in a group of women with artificial menopause without medical reasons as well as in a group of women undergoing natural menopause (Bannister, 1999; Boughton, 2002). The women in our study have much in common with other women going through midlife transitions. According to Schumacher and Meleis (1994) the
conditions for transition include meaning, expectations, level of knowledge and skill, the environment, level of planning, and emotional and physical well-being. A subjective sense of well-being, a mastery of new behaviours and the happiness of interpersonal relationships are the indicators of healthy transition relevant across all types of transitions (Schumacher & Meleis, 1994). The participants in our study were going through a hazardous transition because of the existential vacuum that occurred and which made them incapable of self-reflection and having the ability to absorb knowledge connected with their new sexual identity.

Something which was very beneficial and was expressed by five of the six women in this study was that their intimate relationship with their partner grew stronger after their cancer diagnosis, even though sexual arousal and patterns of intercourse may have changed. This was described as an increase in the feeling of trust for their partner which although they could not express in words, balanced the sexual pleasure they had felt before. This friendship and deep personal sharing constitute a meaning from a phenomenological view. The feeling of intimacy, trust and understanding also occurred in the support group. The losses related to the phenomenon as expressed by the women could in some way be compensated for by the new strength in their intimate relationship with their partner and the help from the support group. These findings have been observed in previous studies of women with breast cancer but they have never been connected to sexual pleasure. Sometimes bodily needs are misunderstood and interpreted as sexual desires because people are used to interpret these needs as being sexual (Gudorf, 1994). The new life situation offers new opportunities and can help people to re-evaluate their intimate relations and strengthen love and understanding in a deep, however, not necessarily in verbally communicated way (Gudorf, 1994).

In our study we observed that lifeworld experiences were mostly overlooked during the women’s encounters with health care professionals. Similar experience was found in a Swedish qualitative interview study describing the lifeworld situation of eight women with myocardial infarction (Johansson & Ekebergh, 2006). The women’s health process is complex. They are in a vulnerable position when reliant upon professional health carers. A future objective would be to care more about patients on a holistic basis taking into account their past and future daily life and experiences and to invite partners and other close friends to be involved at hospital level. To succeed in this we need to have a paradigm shift in health research. Cooperation with supportive groups can also be a beneficial way of reassuring the patients safe and secure health care in the future.

This article may be seen as a step towards filling the gap between the premenopausal women’s unique experiences of sexual identity following breast cancer treatment and the discurses connected to sexuality issues regarding cancer care. The meaning structure of the phenomenon could be symbolized using the metaphor of a bird which is pinioned and unable to fly. The constituents: not recognizing oneself, being in an existential vaccum and new strength in intimate relationship symbolise the stigma surrounded the phenomenon but also the strengthened intimate relations which was very beneficial for the informants well-being. All professionals who meet these women must, as far as possible, be aware of their vulnerability and give them customized rehabilitation after the most active period of cancer treatment.

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