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The experience of distress in relation to surgical treatment and care for breast cancer: An interview study

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A B S T R A C T

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Purpose: A diagnosis of breast cancer is a key turning point in a woman's life that may lead to her experiencing severe and persistent distress and potentially presaging a psychiatric disorder, such as major depression. In Denmark an increased standardization of care and a short hospital stay policy minimize the time of medical and nursing surveillance. Consequently, there is the potential risk that distress goes unnoticed, and therefore, untreated. Therefore, the purpose of this study was to explore the experience of distress in Danish women taking part in surgical continuity of care for breast cancer.

Methods and sample: A phenomenological-hermeneutic approach inspired by the French philosopher Paul Ricoeur was conducted to explore the experience of distress in relation to surgical treatment and care for breast cancer. Semi-structured interviews were conducted with 12 women who recently had surgery for breast cancer at six departments of breast surgery in Denmark from May 2013 to November 2013.

Key results: The understanding of the experience of distress in the period of surgical continuity of care for breast cancer is augmented and improved through a discussion related to four identified themes: A time of anxiety, loss of identities, being treated as a person and being part of a system, drawing on theory and other research findings.

Conclusion: Distress experienced by women in the period following diagnosis arises from multiple sources. Support and care must be based on the woman's individual experience of distress.

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Introduction

Breast cancer is the most common cancer affecting women worldwide with an estimated 1.67 million new cases in 2012 (International Agency for Research on Cancer, 2012). In Denmark, one in every 9 women will be diagnosed during their life corresponding to 4549 women in 2012 (Statens Serum Institut, 2012). Receiving a diagnosis of breast cancer is a key turning point in a woman's life that may lead her to experience significant distress. Women in this situation are confronted with a number of challenges, particular the spectre of their own mortality. Furthermore, they are likely to experience distinct changes in their physical

appearance, such as loss or disfigurement of one or both breasts, scars from surgery and skin changes from radiotherapy (White, 2000).

Distress is commonly reported in the context of cancer, and extends along a continuum ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling as depression, anxiety, panic, social isolation and existential and spiritual crisis (The National Comprehensive Cancer Network, 2013). Rates of distress differ between research studies depending upon a range of methodological issues such as different tools used to measure distress, and/or different time frames, but findings indicate that between one-third and one-half of all patients experience significant distress, particular in the first six months following diagnosis. Initial distress can be extreme, persistent and presage a psychiatric disorder such as major depression (Hegel et al., 2006). Up to 25% of breast cancer patients have been reported to use antidepressants at some time following

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their diagnosis even though the rates of prescriptions do not entirely reflect the rate of depression (Suppli et al., 2011). Failure to detect and treat severe distress may affect the outcome of cancer therapy, and adversely impact on the woman's quality of life both of which ultimately add cost to health care systems (Snowden et al., 2011). In Denmark, the average length of hospital stay is declining (Mertz et al., 2009). The short stay policy reduces the available time during which the health care team can monitor the women's progress and increases the risk that distress in the early period following diagnosis will go unnoticed and therefore untreated. There is evidence that the supportive care needs of the majority of women with breast cancer are not being adequately met, placing these women at even greater risk of developing distress (McGarry et al., 2013). Understanding the experience of distress in women taking part in surgical continuity of care is important for being able to identify the key concerns of these women and to inform development of appropriate interventions (Remmers et al., 2010). Surgical continuity of care is defined as the time period from diagnosis to start of adjuvant treatment or follow up. The purpose of this study was to gain an in-depth understanding of the experience of distress in women taking part in surgical continuity of care for breast cancer in Denmark.

Method

A phenomenological-hermeneutic approach inspired by the French philosopher Paul Ricoeur was used to explain and understand the experience of distress in women taking part in surgical continuity of care for breast cancer (Ricoeur, 2002). Semi-structured interviews were applied to encourage the participants to talk about their experiences of distress in order to uncover the meaning content. According to Ricoeur a description is not sufficient to obtain a profound understanding of the life experience. The interview texts contain a surplus of meaning which necessitates an interpretation process. This process seeks to generate an understanding that exceeds the actual interviews (Ricoeur, 1979, 2002).

Ethical aspects

All participants had previously provided informed consent to participate in a survey, which was included in a mixed methods study together with this interview study. Twelve women from the survey study additionally agreed to be interviewed by the first

author. They were given written and oral information and informed that the data would be anonymised. The study was approved by the Data Protection Agency (journal number 2008-58-0028).

Data collection

Data collection was obtained through individual interviews with 12 women aged 37–87 years who had recently undergone surgery for breast cancer in one of six breast surgery departments in Denmark. The women were interviewed before the start of adjuvant treatment or follow-up, except for one woman, who had just started chemotherapy. The phenomenological perspective was expressed as the participants were asked to tell about their experience of distress in relation to the time period of surgical continuity of care for breast cancer in a descriptive and clarified way. The approach was open with the interviewer asking supplementary questions to elaborate the experience of distress. Furthermore, an interview guide was used to deepen the answers that the woman gave in the survey to further explore the experience of distress. The interviews were conducted from May through November 2013 and the participants were given a choice regarding the location of the interview. Ten interviews took place at home, and two in the hospital. In order to capture variation in the sample a purposeful sampling strategy was chosen to cover demographic and clinical characteristics, such as age, children living at home, method of surgery and level of distress. Clinical characteristics are presented in Table 1. The duration of the interviews varied between 15 and 68 min and were taped and transcribed verbatim to text by the first author.

Data analysis and interpretation

The text comprised the data that was subject for the analysis and interpretation. The analytic and interpretation process consisted of three levels: a naive reading, structural analysis, and critical analysis and discussion. The naive reading was a first reading of the interview texts to achieve an immediate understanding of the meaning content. Next, the structural analysis was describing units of meaning (what is said) and next identifying and formulating units of significance (what is talked about) leading to development of themes and patterns (Ricoeur, 1979). In this step of the analysis the explanatory aspect is seen (Ricoeur, 1973). The final step, the critical analysis and discussion, was to make a

Table 1
Clinical demographics of participants.

Number	Age	Marital status	Children living at home or not	Employment	Surgery
1	45	Married	2 Living at home <14 years	Nurse	Mast. + SN
2	37	Married	2 Living at home <10 years	Sales assistant	Lump. + Axil.
3	87	Living alone	2 Adults, not living at home	Retired	Mast. + Axil.
4	47	Living with a partner	2 Living at home <18 years	Factory worker	Lump. + SN
5	61	Living alone	2 Adults, not living at home	Retired	Lump. + SN
6	48	Married	1 Living at home and 1 not living at home <23 years	Clerk	Lump. + SN
7	69	Married	2 Adults, not living at home	Retired	Mast. + Axil.
8	70	Living alone	2 Adults, not living at home	Retired	Mast. + SN
9	52	Married	1 Adult, not living at home	Therapist	Mast. + SN
10	48	Married	2 Living at home <14 years	Teacher	Lump. + Axil.
11	47	Living with a partner	1 Living at home <21	Kitchen assistant	Lump. + SN
12	67	Married	2 not living at home <19	Clerk	Mast. + Axil.

Mast. = mastectomy means that the breast is removed.

Lump. = lumpectomy means that the tumour and the surrounding tissue are removed.

SN = sentinel node is based on the assumption that the removal of the lymph from the breast to the armpit takes place in a certain order. SN is the first lymph node(s) that receive lymph from the breast.

Axil. = axillary clearance – the tissue situated caudally for vena axillaris is removed containing 10–20 lymph nodes.

comprehensive interpretation taking into account the structural analysis. The themes were discussed by relating to the quotations from the interviews and to the text as a whole incorporating theories and other research findings to obtain a deeper understanding of the experience of distress in these women. The text was analysed and interpreted independently by the first and the last author and subsequently discussed to enhance trustworthiness.

Findings

Our findings are presented according to the levels in the process of analysis and interpretation. The presentation is a summation of the findings.

Naive reading

What immediately appeared in the text was the experience of women's distress as they were in a time characterized by anxiety: anxiety regarding spread of the cancer, dying, recurrence, the unknown, possible loss of a breast, thoughts about chemotherapy, risk of additional operations and new tests, repeated waiting time for further operations and/or test results, discharge, the risk of developing lymphoedema, possible job loss, and not being able to get help from professionals after discharge. The women also experienced distress regarding loss of roles and identities as women, mothers, and caregivers, and loss of control of one's body and the many aspects of existence. Moreover, they were distressed if they could not handle their usual activities and if they felt they were a burden for their families.

The relationship with families and friends were of great importance for the experience of distress. The women identified those individuals who could help diminish their distress, for example those who could tell good stories related to survival of breast cancer. Another topic was the relationship with health professionals. It was important to the women that they were regarded as persons, and that the health professionals tried to learn about the person in relation to treatment and care for the cancer illness. It mattered that the health professionals had time to talk with them and it was essential that the health professional showed humanity and was not just providing information about practical issues.

Structural analysis

The process of deriving themes is exemplified in Table 2 and the critical analysis and discussion of the derived themes are presented separately below.

In the structural analysis two rectangular brackets “[]” mean that the researcher has put in some words to give a better understanding of the meaning. Points “.....” indicate that there is a break, and if the word is written in uppercase it means that the word is emphasized.

Critical analysis and discussion

The critical analysis and discussion are structured to the four themes that emerged from the structural analysis: 1) A time of anxiety, 2) loss of identities, 3) to be seen as a person, and 4) to be part of a system. The quotations (written with italic letters) are expressions of the interviewees.

A time of anxiety

Our findings suggest that anxiety was a very essential and overwhelming experience to women taking part in surgical continuity of care for breast cancer. In this study the experience of

anxiety was related to many factors such as: fear of recurrence, dying and death, the unknown, repeatedly undergoing tests, being discharged, losing one's job and/or breast, losing confidence in the health system, and losing control. In addition, the women felt anxious about responsibility and duties in their families after discharge, about being a burden to the family, and thoughts about children. This signifies that these women were experiencing a period of anxiety that contributes to their experience of distress.

One of the most frequent distressing issues was fear of recurrence, a negative emotional response to a potential life-threatening disease as exemplified in the following quotes: *You have to be convinced that the cancer is gone: That is does not recur, but on the other hand, that I once got diagnosed with cancer ... I wasn't supposed to. You can get it again even if you feel healthy* (4). This quotation may be due to doubt regarding whether the cancer is truly gone or the possibility that it does recur. Fear of recurrence decreases overall quality of life, as well as lower self-reported physical and mental health, causing considerable disruption in social functioning and relationship (Tewari and Chagpar, 2014).

Mothers express greater fear of recurrence regardless of their age or that of their children (Lebel et al., 2013). In the present study, this was exemplified by one woman, who started to cry as the interview focused on her children: *As soon as I speak about the kids ... well, there are something.....*(6). This quote combined with the mother's reaction, indicated that this was a very sensitive topic that needs to be addressed to reduce anxiety and increase well-being. It may relieve the women if they don't have to explain their feelings or to hide them.

Sheppard et al. (2014) demonstrated that levels of anxiety were lower among breast cancer patients who experienced better communication with their health care providers. In contrast, women who had medical mistrust experienced a higher level of anxiety. This is in accordance with the findings of the present study illustrated with the following quote: *I didn't look at the dark side, but it is difficult not to continue doing this, because as they [the doctors] said the first time I got the tumour examined, you don't need to worry. There is nothing wrong. They kept saying that. OF COURSE there is nothing wrong. And now, after this first operation you try to convince yourself that they have removed all cancer, but they didn't, so now I will need a second surgery, then it is.....* (4). The metaphor used in this quote indicates that she is trying not to mistrust the information and be positive, but that is not easy, because she receives bad news with every test result. Until final histological result is known, it is uncertain if further treatment is recommended. Women taking part in surgical continuity of care are afraid of further surgery Remmers et al. (2010), which might signify that the disease is more serious or that they will experience more bodily changes such as losing or disfigurement of a breast. Good communication skills and person centered care are crucial to improve women's interactions with health professionals, which may help to reduce mistrust and anxiety. Trustworthiness is primarily shown through the constant presence of health professionals and if the patients avoid contradictory information and do not have to answer the same questions repeatedly to all health professionals (Ibid.). For example, this can be achieved by the continuous contact from a contact person.

Wilkes et al. (2003) demonstrated that adequate support has a positive effect on women's sense of control, which was a topic in this study: *Well, I need to have something that I can control, I need to have some sort of control no matter what.....just to convey a feeling of security* (2). A sense of control affects psychological adaption to the disease (Cousson-Gelie et al., 2005).

The women were anxious about losing their job: *I am worried whether I have a job, when I have finished treatment. Will they dismiss me, when I have been away for such a long time? This is one of my*

Table 2
Example of structural analysis.

Meaning units (What the women says)	Units of significance (What the women talks about)	Themes
I was really distressed, when we got the diagnosis. I think it is fear of dying, it really is fear of dying (9)	Fear of dying	Time of anxiety
I started to realize, what this was about, I think, what it implied, but I was frightened and uncertain, and sad and of course I was afraid of the future. Scared that, I would not be here next summer. I didn't know how aggressive the cancer was and I didn't know if it was all over my body.... so I was very unsafe ... I didn't talk to anybody about this. It was a little frightening, it was not okay to say it out loud, because it was such a bad experience (2)		
I had surgery and was just discharged. It was too much ... maybe I was afraid of ... would I become weak or unwell.....I was scared of getting sick (1)	Fear of the time period after discharge	
I am worried whether I will still have my job, when I come back [from treatment]. Will they dismiss me, when I have been away for such a long time? This is one of my biggest worries. Do I have a job or do I also have to find energy to find a new job. My social life revolves around my colleagues.....you get the diagnosis of breast cancer, which is life-threatening. Another thing is that you don't know if you have an income (2).	Anxiety regarding loss of job	
Will I be able to be a good mother to them....I have got others to think of ...my husband and my siblings and especially my mother (1)	Loss of the role as the primary care giver for the children, husband, siblings and parents	Loss of identity
Well, I was touchier. I just started yelling or raising my voice. I felt I did this very quickly. I was sad, I wasn't a very happy mother, because everything was very impacted (2)	Loss of being a happy mother	
To find out that you are discharged as another person than you felt before. The world just keeps going and the neighbour does as usual, but I come home as another person (2)	Being discharged as another person than the one who entered the hospital	
I haven't had the energy to have sex or dared.... to take off my clothes in front of my husband even if we know each other so well and he is so sweet to me (2)	Loss of femininity, attractiveness, sexuality	
All my delicate underwear and things like that. I can throw it away, because I am never going to be sexy anymore (4)		
I was very happy to see, that it was the same nurse, who had accompanied me to an earlier consultation, because I didn't need to spend that much energy to find out who she was, what her name was and she didn't know how I reacted as I got the diagnosis. She did know and that mattered a lot to me (1)	I know her and she knows me	To be treated as a person
I think it matters a lot, that you don't have to repeat anything, because it is another person (12)		
Everybody I have been in touch with in this department has given more than being a nurse on the human level and also forward-looking. I was very happy about one particular nurse. She asked me a lot of questions, questions that I could feel I had, but that I wasn't able to articulate. I haven't ever felt like a number. There has been very good support on the human and professional level (2)	An individual person centered human and professional communication and support	
It was fantastic that everything went so fast, but it was as if I couldn't keep my head about meI couldn't make head nor tail of it all. I was very chocked (2)	When everything is accelerated	To be part of the system
The waiting time was just awful.....I just froze; I waited almost 4 months. I was sad and completely froze in myself the way I was feeling. I couldn't pull myself together. I just sat there every day, just always looking in the mail box for a letter. It is the worst thing that I have ever experienced. It was this waiting time (5).	The repeated waiting times affect distress	
The focus was on practical issues. You have breast cancer; you are going to have chemotherapy and surgery. Fine, this is important too, but they didn't ask about how I felt. I wasn't able to focus on practical issues, because of my emotional situation that was presence (1)	Practical information comes before the emotional situation	

biggest worries. Do I have a job or do I also have to find energy to find a new job. My social life is also my colleagues.....you get the diagnosis of breast cancer, which is life-threatening. Another thing is that you don't know if you have an income (2). Not only are these women experiencing anxiety regarding their job situation, but losing their job may also affect their social lives and/or income. Possible job loss is considered to impact on a woman's decision about working during treatment (Tiedtke et al., 2010). This issue arose in the present study: *As I told my manager, that I was ill, then she told me, that she was expecting me to work....not full time....she didn't need to say it in that way* (10). Beforehand, the women experience fear of being a burden to the family due to the effects of the disease: *It was at discharge that I got a real letdown because how would I be able to manage everything at home, would I be a burden if I just could not do anything at home* (4). The experience of being a burden to the family may increase, if the risk of job loss and thereby loss of income become present.

Loss of identities

Another finding in this study was loss of identity. A diagnosis of breast cancer precipitates complex changes in a woman's identity: *To find out that you are discharged as another person than you felt before. The world just keeps going and the neighbour does as usual, but I come home as another person* (2). This also includes the change in identity as a mother: *That I am able to be a good mother to them....* (1). This issue was very important to all mothers in this study and talking about it was very emotional. Often, women confronting breast cancer are unable to fulfil their everyday mothering role. They may get the feeling that they let their children down, because they do not respond or behave in the usual manner: *I hope I can be a happy mother as usual* (1). As such, the impact of a breast cancer diagnosis and treatment ostensibly can lead to changes in identity. Women construct and reconstruct their identities as mothers in the context of living with breast cancer. The objectification for example, that is present in the healthcare systems, of being a patient and not

a mother suffering from breast cancer may imply that their identity as a mother no longer is bound up to the mothering role, which can cause distress (Fisher and O'Connor, 2012). This signifies that the impact of breast cancer on the mothering role should be an integral part of the support provided by health care professionals, to ensure mothers with breast cancer are recognized as mothers, and not just as patients.

The present study indicates that body-image is closely related to identity, self-esteem, attractiveness, change in clothing and sexual functioning: *Before surgery I had thoughts about losing my breast that it wouldn't mean a lot to me, but OF COURSE it does. It isn't the same as it was before ... now I only have one breast..... now I'm not longer as fit as I used to be. When I look in the mirror, I don't have the same body as before* (1). Dahl et al. (2010) indicated that poorer body image was associated with loss of breast, breast reconstruction, and change in clothing, poorer self-rated health, chronic fatigue and distress. A significantly greater proportion of women who underwent reconstruction experienced poorer body image. This may indicate that body image is a complex phenomenon not only related to physical appearance, but also related to psychological factors such as self-compassion (Przedziecki et al., 2013). This is in concordance with our study that reconstruction or plastic surgery was not necessarily associated with better body image: *There are those people, who tell me, that it can be build up again. They are right, but it isn't the same.....Your self-image has to be changed for the rest of your life. It just has changed forever* [even if you get reconstruction] (4).

Women felt anxious if they had to change their style of clothing due to scars or removal of a breast as they saw their style being a part of their identity: *It is that particular type of clothing that I usually wear. If I had to change that, to cover everything* [because of scars], *it is not ME* (4). A change in clothing was also a factor in relation to sexuality: *All my delicate underwear, I could just throw it away, because I will not feel sexy anymore* (4). A critical factor for the shift in identity is the sexual relationship: *I don't think that I'm, let me say, attractive anymore...I don't feel I have energy for a sexual life...or dare to take off my clothes in front of my husband, even if we know each other very well and he is my husband.....so sweet to me* (2). If the women had to have their breast removed, they had the feeling of being amputated, which also had an impact on their feelings as a feminine woman: *You have just been amputated, so you can't feel feminine at all* (9). The feeling of not being feminine and attractive also had consequences on their social life: *It was in my thoughts, FUCK if they take my breast and I have to wear a compression garment* [because of lymphoedema] *and I will lose my hair* [because of chemotherapy] *I couldn't bear it, and then I just could be buried. To walk outside and look like that. I couldn't relate to it* (4). This woman is using a strong metaphor to illustrate how much her body image means to her, that she would rather be dead if her identity had to change in such an extensive way, but she also expresses her experience of how her body image would affect her social life. The change in identity and experience of an altered body image may have extensive consequences for women with breast cancer.

Body image, change of identity or sexuality are not typically discussed or addressed by health professionals. The lack of discussions around these topics may arise from cultural taboos, shame, and shyness, a lack of suitable language, or discomfort in discussing these issues. However, one important aspect in nursing care for women with breast cancer confronting changing in identity is to facilitate their understanding of living with this illness. It is through listening and dialogue that this can happen. Open dialogue about these concerns help the woman to feel that she is understood and having her feelings validated. It can be empowering to the woman to realize that she is in a process of transition in her life (Landmark et al., 2008).

To be treated as a person

The findings of this study also indicated that being treated as a person impacts on women taking part in surgical continuity of care for breast cancer: *Everyone that I have been in touch with at this department have delivered something besides just being a nurse. This is on the human level, if you can say so, but also forward-looking* which I was very happy about. Especially I was happy about one nurse, because she asked me a lot of questions, which I could feel I had, but I couldn't articulate these. I have not at all felt as a number. I have got excellent support on a professional and human level (2). This quotation expresses the meaning of a caring humanistic process to support this woman expressing her feelings of concern. In addition, it expresses the attribute of the nurse's interpersonal and communication skills, and also her professional competencies. Nurses can communicate effectively with the patients if they adopt a person centered approach (McCabe, 2004), bringing patient's perspective to the foreground regarding the woman's cancer experiences and related challenges. This means that the health professional not only have to communicate about disease-oriented dimensions, but also to reorientate to a more life-oriented dimension (Zoffmann et al., 2008) as one woman experienced and stated in this way: *We were talking about my thoughts – also regarding my daughter and things like that. And she just was there to talk with me for a while. I just felt they had time to talk to me, that is wasn't JUST about the disease, but also regarding concerns of other things* (4) The ability to do person-centered care is heavily influenced by the context. It has the greatest potential to either limit or enhance the facilitation of this (McCormack, 2004).

The findings from our study indicated that it was very important to be known as a person: *It is essential that you know who to talk to, that there are some persons, who know you and know YOUR story.....and who know what has happened to me* (8). Verbal and non-verbal communication and use of your senses are effective tools to enhance the knowledge of patients. This enables the health care provider to tailor a person-centered approach (e.g. the exact concerns related to the person) (Bundgaard et al., 2012). Continuity in care was an important factor to some women: *I was happy to see, that it was the same nurse that have joined me at the last consultation, then I didn't need to use a lot of energy to explore who this person was, what was her name and so on. If it was a different person she wouldn't have known who I was either or she wouldn't have know how I reacted or responded when I got the diagnosis of breast cancer, but this nurse.....I think it matters a lot* (1). The perception is that the health professional knows you and knows your case history, but also that the communication can be based on former conversations and that future care and communications are informed by that.

Situational awareness can be seen as a part of person-centered care: *I shouldn't be in the hospital, because all other patients are admitted and discharged, but I didn't feel well and wanted to stay until Thursday. The doctor told me on Wednesday, when I crouched down in my bed. You don't look well; I think you need one more day in here. JUST that HE told me. That I didn't have to ASK for it* (4). It signifies that situational awareness is very important in relation to person-centered care, but this quotation also exemplified that to be aware of the needs of a person without being forced to express them, seems very important.

Person-centered care is prominently positioned on the political agenda especially related to discussions about quality of care. Lost in many of these discussions are the different perspectives on what it means to be person-centered. Thus, patients are known as persons in context of their own world, which needs to be considered via good communication.

To be part of a system

Another finding in this study was related to the theme of being part of a system. According to the German philosopher Jürgen

Habermas the modern society is divided into a system world and a life world. In his terminology the health care system is part of the system world (Habermas, 1987). The system world is organized according to economy and administration and human action is formal and impersonal and does not presuppose understanding of the situations women are experiencing in for example surgical continuity of care for breast cancer: *In the communication the focus was only on practical issues. You need to have chemotherapy, you get surgery. Fine, that is important too, but they didn't exactly focus on how you are feeling now.....I wasn't able to focus on practical stuff, because it was my emotional situation that was presence* (1). This quotation from the present study expresses that the health professional did not incorporate the perspective of the woman's life world, which is the world in which the woman lives. In this world, human action is based on mutual understanding of each situation (Habermas, 1987). According to Habermas, the tendency is that the system world is dominating the life world, which is expressed in terms of accelerated surgical continuity of care, that nursing practice is mostly based on standards, accreditation and so on. A person-centered communication may be overlooked or even impossible in the system world: *It was fantastic that everything went so fast, but it was as if I couldn't keep my head about meI couldn't make head or tail. I was too choked* (2). This quotation indicates that it is good that surgical continuity of care is accelerated according to waiting times (e.g., for test results, surgery, adjuvant therapy) but the metaphor used in this quotation also exemplifies that this woman didn't really understand what was going on. If waiting times aren't reduced it can cause a lot of distress: *The waiting time was awful.....I just froze, it was almost 4 month that I had waited. I was sad and did completely freeze. I couldn't pull myself together. I just sat there every day, just always looking in the mail box for a letter. It is the worst thing that I have ever experienced. It was this waiting time* (5). A lot of distress was being expressed, which influenced the whole life of this woman. She was using the freezing metaphor to indicate that she could not do anything else in her life – just sit and wait for a letter to inform her if she needed more investigations telling her that she might have breast cancer. In contrast, reducing waiting time and feeling that women are treated as persons, who include the perspective of their life world means that distress is reduced: *Friday I communicated with nurses and doctors and was prepared for surgery. It went very very well, there was no particular waiting time and I got answers to all my questions* (2).

If the system world is colonizing the life world there may be a risk that nursing practice mainly is based on standards, which can cause distress: *I got so many papers, books, brochures, questionnaires and all that stuff.....groups for this and groups for that, I thought oh my god this is really serious* (6) indicating that every woman independent of who she is, is having the same information no matter what. This quote also exemplifies that not giving person-centered information may increase distress. According to Remmers et al. (2010) the patients desire to be treated as individual persons, feeling addressed personally with their needs and wishes. Therefore health care providers need to be sensitive and not just do what the standards tell them to do, as stated in this quotation: *They didn't tell you anything, when you had surgery. You were just discharged. You didn't know if they had taken all the lymph nodes or not. I asked if they had taken all my lymph nodes or not, but they just told me that everything went well. It isn't an answer. I asked to get a clear answer, but I didn't feel that I got an answer. Then you just went home to wait and wait - again* (11). This woman experienced being part of the system world without integrating her life world, which results in an impersonal communication leading to increased distress.

This finding suggests how important it is for health care professionals to take an active part in strengthening the life world to

achieve a more person-centered clinical practice, which may influence distress in women taking part in surgical continuity of care for breast cancer.

Study limitations

Women who were included in this in-depth analysis were participants from a larger study sample. It is possible that women declining to participate in the present study may have done so because they were experiencing high levels of distress. In addition, participants only represented six out of possible 11 different breast department recruitment sites. The organizational factors in the other five non-participating departments of breast surgery may have had an influence on distress. On the other hand, the women that participated varied on different clinical characteristics.

Conclusion

This phenomenological-hermeneutic approach generates some perspective on the life situation of women who take part in surgical continuity of care for breast cancer. The findings indicate that these women are in a complex life situation where distress is caused by several issues as e.g. anxiety and loss of identities. These women are in need of more than just objective assessments, which are dominated in the system world. They need to be treated as persons, whose life worlds are included in treatment and care situations. Being aware of individual issues influencing distress may contribute to the improvement of surgical continuity of care.

Implications for practice

The findings from this study can help increase the knowledge and understanding of distress in women taking part in surgical continuity of care for breast cancer to inform the caring process even though nursing care always should be based on the individual patient's life situation. The source of caring support is in knowing the patients specific life situation and needs. However, health care professionals are only able to provide the adequate care if they have sufficient knowledge about issues due to distress. As surgical continuity of care for breast cancer is rapidly accelerated and standardization of care is in progress, this study emphasizes the importance of taking into considerations e.g. life phenomena experienced by the individual woman to reduce distress. To be aware of life phenomena as e.g. anxiety health care professionals may endeavour to use situation determined attentiveness. The health care professionals must take a more active part in strengthening the life world perspective to achieve a more person-centered communication and care approach in health care systems to improve surgical continuity of care for breast cancer. Future research should concentrate on how to implement person-centered care in a system world, which focus is on productivity and effectiveness.

Conflicts of interest

None declared.

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