“Cancer changed my life”

Women’s experiences 1 and 9 years after primary breast cancer surgery

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Abstract
Breast cancer is the most common form of cancer among women worldwide. Despite considerable research, there is still need for improved patient-centred care. The aim of this study was to investigate whether there were any typical experiences that characterized the lives of the women that we interviewed. Information was collected 1 year after and 9 years after primary breast cancer surgery. Interview data were analysed using Kvale’s method of qualitative meaning condensation. The findings were discussed in light of Martinsen’s philosophy of caring. Three main themes were prominent both 1 and 9 years after surgery: being changed, being unprepared, and living in suspense. However, these typical experiences were often expressed differently. A profound understanding of both similarities and uniqueness in women’s experiences when being treated for breast cancer is vital for health care professionals when supporting women to live with a cancer diagnosis. More information about side effects is needed to prepare these women for a changed life.

Keywords
breast cancer, health care professionals, philosophy of caring, qualitative research, survivors

Introduction
Being diagnosed with, and treated for, breast cancer is an individual experience. Research has shown that this experience may have some typical features, both short and long term, such as existential awareness and fear, as well as menopausal symptoms, pain, cognitive problems, fatigue and depression (1-4). Long-term survival after breast cancer in Norway is high; 9 of 10 women are alive 5 years after the initial diagnosis (5).
These women’s lives change at diagnosis (6-8) and particularly during the first year (4,9). Treatment begins shortly after diagnosis and, depending on the stage of the disease, commonly includes surgery and adjuvant therapies such as chemotherapy, radiotherapy, and hormonal therapy. Chemotherapy and radiotherapy are usually completed during the first year (5).

The treatments can make the woman feel sick and change her body (2-4,9,10). Surgery, the primary treatment for early-stage breast cancer, may result in lymphoedema, functional impairments (1,11) and negative body image (12-14). Chemotherapy is often associated with fatigue, hair loss, weight changes, concentration problems, cardiac diseases, nausea and vomiting (9,15). Hormonal therapy, which may continue for several years, may result in menopausal symptoms (1,2). Because of uncertainty regarding the long-term prognosis, many express fear of cancer recurrence, anxiety and death anxiety (4,16,17). Living through this taxing process and experiencing various side effects of treatment means that these women need continuity in professional care. There is an increasing focus on the long-term effects of treatment and how to live with cancer, in addition to the “user participation experience” of treatment (18).

Kari Martinsen’s philosophy of caring and person-oriented professionalism (19) was used as the theoretical framework in the present study. Martinsen (20 p.18-29) emphasizes that philosophy may elaborate and provide perspectives for empirical research. She outlines care as a three-dimensional concept consisting of relation, action, and morality, which must develop simultaneously. Care is primarily relational. We are born in dependency and have responsibility towards each other, and especially to those in need. The second dimension of care is action; without action, care is reduced to sentimentality. The nature of “action” will vary according to the situation, context, and culture, but is always based on the unique situation of the person in need. But although an action is properly conducted, it may still be experienced as humiliating. The third dimension, morality, refers to our way of being in the relationship and to the manner in which the actions are performed. Care is an important aspect of life in general and is not restricted to particular professions, yet is particular for health professionals caring for people in vulnerable situations (21). Another aspect in Martinsen’s philosophy of care is how context and culture influence to what extent others are met as objects or as subjects. Martinsen differentiates between seeing the other with “the heart’s eye” versus “the recording eye”. When seeing with a “heart’s eye”, the nurse is present with the attention directed towards the other’s total life situation. Martinsen calls this “person-oriented professionalism”, meaning that the health professional combines professional and human skills. In contrast, “the recording eye” classifies, ranks, and puts information about patients within a rigid system, risking making the patient an object.

Martinsen’s philosophy of caring is, among others, inspired by Løgstrup’s phenomenological philosophy (20,22). According to Løgstrup (23), we all face situations in life that evoke certain universal emotions, such as hope and grief in the face of death. He emphasizes that one should make a significant distinction between “universal” and “typical”. The word “typical” should be reserved for statements that describe persons in an open or closed group, such as “typical” for women, whereas the term “universal” should be reserved for what is the same in every individual. Sorrow or grief are universal feelings that are expressed differently and may be in “typical” ways within certain groups.

Both Løgstrup and Martinsen emphasize the duality of any situation. A situation is “typical” when it has features that are recognizable in similar situations, but at the same time, “unique” to the individual (24). Women with breast cancer have both short-term and long-term symptoms due to treatment (2-4,12,16). There is reason to believe that some of their experiences are “universal”, but also “typical” and “unique”.
Women’s unique and individual experiences obtained through a qualitative research interview can provide insight into their individual experiences and provide important information for the development of enhanced breast cancer care (25). The aim of this study was to investigate whether there were any typical experiences that characterized these women’s lives 1 year and 9 years after their primary breast cancer surgery.

**Methods**

**Design, sample and setting**

A qualitative descriptive design was used. Twenty-one women who had participated in our previous studies (6,26,27) and had undergone primary breast cancer surgery at a Norwegian university hospital were invited to this follow-up study 1 year and 9 years after surgery. After 1 year, the women received an invitation to participate along with the information regarding their regular 1-year follow-up examination. Ten women participated; of these, 7 participated after 9 years. Before recruitment after 9 years, we were informed by the outpatient clinic that 4 of the 21 participants in our previous studies could not be invited (3 were dead and 1 was seriously ill). The remaining 17 were invited; 15 agreed to participate and 2 refused. We had no access to information about those who declined. According to the participants’ preference, all interviews after 1 year were conducted at the hospital at the time of their regular 1-year follow-up examination. After 9 years, the interviews took place in different places according to the patients’ preferences (interviewer’s office, participants’ workplace, the hospital, or a coffee shop).

All participants were ethnic Norwegians with a cultural background from western Norway. All surgery, except reconstructive surgery, was completed 1 year before the first interviews. Their cancer at diagnosis 9 years earlier was stage I to II. Participants’ ages at 1 year ranged from 48 to 68 years (mean, 56.8 years), and 9 years later from 51 to 75 years (mean, 62.5 years). The participants’ characteristics are presented in Table 1.

**Table 1.** The participants’ characteristics after 1 and 9 years

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Participants’ characteristics after 1 year (n = 10)</th>
<th>Participants’ characteristics after 9 years (n = 15)</th>
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<tbody>
<tr>
<td>Age (years) (mean)</td>
<td>48–68 (56.8)</td>
<td>51–75 (62.5)</td>
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<tr>
<td>Marital status</td>
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<td>Widowed</td>
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<td>No. with children</td>
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<tr>
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Data collection
Individual interviews took place in 2007, 2008 and 2015. The interviews after 1 year lasted from 54 to 100 minutes, and those after 9 years from 75 to 140 minutes. A semi-structured interview guide was developed based on our previous research (6,26,27), consisting of 3 open-ended questions about experiences, social support, and coping. The same themes were explored at 1 and 9 years. The findings from our previous studies focusing on social support and coping (8,28,29) influenced the last interview guide. In this article, we focus on the overarching question: “How have you experienced these years after breast surgery?” This topic was probed further according to each participant’s responses. Qualitative data analysis software QRS-NVivo 11 (http://www.qsrinternational.com/) was used to organize the text. The transcribed interviews were imported into NVivo. All authors read the transcribed interviews. The first author used this as a tool to code the interviews. The second and third authors discussed the different codes with first author, and in collaboration, the various themes were identified.

Data analysis
Qualitative meaning condensation analysis was used (30). The interviews were analysed on 3 levels: self-understanding, common-sense understanding, and theoretical understanding. At the first level, the transcribed interviews were read to get a sense of the whole, meaning units were identified, and the information was condensed. The theme of self-understanding developed as the women’s statements were condensed in correspondence with our understanding. This was done separately for the 1-year and the 9-year follow-up study. At the second level, the transcripts were re-read to get a common-sense understanding, thereby providing a broader context of comprehension. The different themes in the 2 studies were identified separately and transformed into meaningful units, then coded into major themes. Then, the major themes from the 2 studies were re-analysed in combination to identify common elements and patterns. At the third level, theoretical understanding implied uncovering deeper meanings, whereby the mutual relationships between the whole and the parts became clearer. Levels 1 and 2 from the different studies are presented together in the Results and level 3 is presented in the Discussion. At level 3, Martinsen’s philosophy of caring (19,31) made sense with regard to interpreting the various themes that appeared. In addition, we found Løgstrup’s (23) distinction between unique, typical, and universal experiences appropriate, because there were both individual and common traits in the women’s experiences.

Trustworthiness
Trustworthiness was established using the guidelines by Kvale and Brinkman (30). The interviews were conducted and audiotaped by the first author. The interviews after 1 year were transcribed verbatim by the first author, and after 9 years by an authorized transcriber. Notes were written during the interviews to ensure that impressions, ideas, and reflections were not lost. All interviews were read independently and analysed together. Throughout the analysis process, the findings were discussed by all the authors. New ideas and inputs were considered and reconsidered in a continuous dialogue to reach agreement.

Ethical considerations
Approval was obtained from the Regional Committee for Medical Research Ethics (2014/49REK vest). Participants received verbal and written information and gave written informed consent. The participants’ need for emotional protection was respected by not dwelling too much on distressing issues. The outpatient clinic offered a special follow-up consultation, but none requested it.
Results
Themes
Three main themes were prominent both 1 and 9 years after surgery: being changed, being unprepared, and living in suspense.

Being changed
Being diagnosed with breast cancer changed the women’s life. The side effects of treatment after both 1 and 9 years brought major changes and were experienced as “tough”, but as something that had to be endured. Some of the changes that were described after 1 year were still present after 9 years, such as the side effects of chemotherapy. After 1 year, the immediate side effects of chemotherapy were particularly difficult.

It has been a tough process. Chemotherapy, I never want that again. In the end, it was horrible. Now, I have somehow managed to recover a bit. You are nauseous, vomit, and so uncomfortable. It tears your body apart. You feel distant and forgetful. In addition, all the fuss with chemo: you have to change linen every day and clean the toilet after each use. The poison disgusted me. Things that you have never considered before, became ‘big things’ during this process.

After 9 years, the side effects of treatment, in particular chemotherapy, had caused lasting ailments and a changed life:

I wish I could have been without the chemotherapy. The chemotherapy treatment has obviously altered my health.

After both 1 and 9 years, most of the women found that changes due to breast surgery (mastectomy or lumpectomy) affected their feelings regarding femininity, attractiveness, and sexuality. All the women who had undergone mastectomy had been offered breast reconstruction after surgery. They all had concerns about disfigurement and reduced womanliness, regardless of age and regardless of whether they had a partner or not. But their needs and decisions varied a lot. Existing or potential partners’ reactions were important.

After 1 year
I’ve said from day one that I will have a new breast. I am single. I’m not in a hurry to find a man. That will have to wait until I get a new breast. Being sexy, being attractive, that is the only thing I feel is left on hold. Everything will be much better when I get a breast reconstruction.

In contrast:

Reconstruction is not the most important thing for me. I have reconciled myself to the loss of my breast, and so has my husband.

After 9 years
Breast reconstruction was something everyone had considered, but the reason for accepting it, or not, varied:

It was very nice to have a new breast. I have never regretted it. I have gotten breast reconstruction and that’s fine. I made that decision myself, and both I and my husband are pleased with that.
In contrast:

I did not want breast reconstruction. I have heard that there are so many complications. It’s not vanity that matters most.

After both 1 and 9 years, concerns regarding their sex life were expressed, particularly by those who were, or had been, treated with hormone therapy.

**After 1 year**

Suddenly I lost interest in sex. I think it is because of the hormone pills. After breast surgery I do not feel as attractive.

**After 9 years**

I would have removed my breast if I could have avoided the hormone treatment. I have lost all sexual desire. It is clear that it is serious.

Lack of energy, sexual desire, and other changes in life due to loss of physical capacity were described after 1 year, and was even more prominent after 9 years. Lack of energy affected the experience of being around people in daily life, but also affected how much, and what, they managed to do during the day. This was experienced differently according to different life situations.

**After 1 year**

I’m more tired than before. At home, I may suddenly fall asleep sitting in my chair. It never happened before. I am a little depressed and apathetic, a bit negative. I’m not the way I used to be.

I had no energy and was tired, particularly the first weeks after returning to work. Also much later, after a hectic day at work, I’m very tired when I get home.

**After 9 years**

During these years, some had retired, but for others lack of energy still led to major changes in their social life and work situation. Being at work was important, but varying energy influenced capacity for working. Some had to quit their job entirely due to bodily ailments.

I have much less energy. It affects me so much. I don’t have the same pleasures while meeting friends.

I’m not sleepy, I’m just so incredibly tired. I don’t feel I’m back to the person I was. I quit my job.

These concerns were also expressed in relation to physical activity.

**After 1 year**

I have a special walk I like to take. Normally, I was not out of breath. But now when I go up that hill, it feels hard. No matter how often I walk it, I don’t improve.
After 9 years

I really want to be physically active, but I notice that my body is no longer able to.

Being unfocused and forgetful was also a concern, particularly during the first year. It was particularly problematic at work. Over the years, this forgetfulness lead to quitting work.

After 1 year

When I’ve started something, I suddenly start doing something else. I am a little forgetful and unfocused. I notice it particularly at work. It started when I got cancer.

After 9 years

I’m having trouble concentrating. I have not managed to work afterwards. I had to quit my job 2 years ago.

Weight changes related to hormone therapy were emphasized both 1 and 9 years after their surgery, but the impact of this varied from a major concern to one of minor importance. This concern was more evident after 9 years, but in the context of still being alive, it was described as less important.

After 1 year

I have gained weight. It is probably due to the pills, I don’t like it.

I have gained some kilos that I have not gotten rid of. I don’t know if it has anything to do with the hormone therapy. But, still I’ve been lucky. I feel privileged to be alive.

After 9 years

I have used hormone pills and I have gained weight. I hope I get rid of it, but it takes time.

I have gained weight after chemotherapy. I’m trying to lose weight, but it’s not easy. I love food. But this is little to worry about in this context.

Changes in arm strength and uncertainty regarding improvement were described after 1 year. After 9 years, decrease in arm strength was more evident.

After 1 year

I don’t have the same strength in my arm. I am getting lymphatic drainage and the inside of my armpit is quite tender. The professionals have said that my strength hopefully will improve, but I’m uncertain.

After 9 years

Due to treatment I have less muscle strength in my arm than before.

Being unprepared

The changes were experienced and dealt with in a variety of ways, but a need for better understanding and being more prepared for side effects and a changed life, were prominent.
All the women had been given information about breast cancer and different treatment options before surgery. Some would have liked to be more involved in the decision making. They felt that their treatment was already decided upon and that fear of recurrence gave them no real choice.

**After 1 year**

The doctor told me that it wasn’t necessary to remove my whole breast. I should have been given the choice whether to remove it or not. Thinking about what may happen in my breast over time scares me. I would have chosen not to keep it.

**After 9 years**

I missed information about breast preservation or not. That someone would tell me that it is actually an option. If my breast had been removed, I would have had no more to worry about. My mother chose to remove the breast and she had no cancer worries after that.

Information to prepare the women for the side effects of chemotherapy was of no help.

**After 1 year**

The chemotherapy was particularly terrible. You may read pamphlets and get lots of information, but it’s impossible to be prepared for it.

One woman described an unpleasant experience when asking professionals for advice to alleviate nausea and vomiting during chemotherapy:

The treatments just got worse every time. I vomit. I was given some pills that didn’t help. I called the hospital for advice on whether I could take more than the recommended amount. The nurse answered me in a way I didn’t like. I was quite put down. I was in a vulnerable situation. The nurse was in doubt, but she finally said I could take one pill more.

Some developed lymph fluid in the breast, but were not informed that this might happen, or about the pain it might cause. One said:

I had lymph fluid in my breast. It was terrible and painful. I knew nothing about it.

After 9 years, information regarding side effects was still important because they still felt unprepared for the ensuing bodily ailments.

I needed more information about side effects and what I could expect, and not only that: “everything is just okay”.

**Living in suspense**

Being diagnosed and treated for breast cancer made them always alert to signs of recurrence. Not knowing what the future would bring contributed to a feeling of living in suspense.

After 1 year, consideration of terminating hormone therapy because of its side effects was described, but they decided to continue due to fear of recurrence:
When I started on hormone therapy, I went into menopause. I wanted to discontinue the treatment, but decided to go on, because my doctor said that there was a 30% increased risk of metastasis if I quit. Now I wonder whether my fear of getting cancer again would be greater than the gain of terminating the hormone treatment.

After 9 years, most women accepted their situation while still feeling insecure and fearing recurrence:

Even though it is many years since I had surgery, I’m still afraid of cancer relapse.

Both 1 and 9 years after surgery, despite trying to avoid thinking about cancer, fear of recurrence was always present. Meeting and knowing others whose cancer had recurred also led to disturbing thoughts and emotions.

**After 1 year**

Going to radiotherapy was difficult, especially when I met people with throat cancer. I reacted strongly and had to leave the waiting room.

**After 9 years**

Before mammogram checks, I’m a little nervous although it is many years since my operation.

I know people who have been through breast cancer surgery 20 years ago: Now it has returned! So I know that relapses can happen.

The experiences of having cancer could only be partly shared with, and understood by, others. This gave a sense of loneliness and fear. The following quotes illustrate this.

**After 1 year**

I was afraid. I was so alone with the cancer experience, despite having my family and, to some degree, health professionals, to share it with.

I had such an unfathomable feeling of sadness and fear.

**After 9 years**

I could not share it, I did not manage. It was impossible to share the fear, anxiety, the emptiness, the feeling of being alone.

**Discussion**

Our participants’ descriptions of these years after primary breast cancer surgery made us wonder if there were things about our participants’ personal and unique reflections that were “universal”, and “typical”. According to Logstrup (23 p. 121-154) the words “universal” and “typical” are often used interchangeably, but there is a difference. “Universal” is experienced by everybody, such as fear in relation to taxing life events. But how the universal is expressed is nevertheless also individual, situational, and influenced by culture. The “typical” is something we recognize as being similar within a specific group; for instance, symptoms that are typical of a patient group with the same disease. However, a typical experience is also unique to the individual and is expressed in various ways.
Being changed

Everybody changes during life. This is a universal condition of life. However, sometimes we are exposed to sudden changes, such as the changes caused by being diagnosed and treated for breast cancer (2,4,10,12). Some of our participants’ experiences of being treated for breast cancer appeared typical, such as being sick of chemotherapy, as also confirmed by other studies (7,14,32). It caused emotional suffering. This was evident after 1 year and confirmed 9 years later.

To endure suffering is also a universal phenomenon, but is expressed differently, yet in typical ways that should be recognizable to health professionals. According to Martinsen (31 p. 90) every patient is equally entitled to good care, professionals should not differentiate. But the actions taken in care must be different in order to meet individual needs. This may constitute a challenge for health care professionals (33,34).

Our participants’ treatment-related bodily changes typically involved changes in body image and self-esteem, and altered feelings regarding femininity, attractiveness and sexuality (2,4,9,14,35,36). However, our participants expressed contrasting attitudes towards breast reconstructions, which could help to restore body image and self-esteem, showing that even this was a highly individualized experience. Negative impact on feelings of body image and femininity and attractiveness are typical among younger women (7,37). However, these aspects were also a major concern for some of the older women, meaning that we have to be careful when generalizing typical findings to the individual. In addition, lack of sexual desire, which become more prominent over the years, also threatened their self-esteem and was experienced as a threat to their sexual and marital lives (35,36), as well as to their perceived personal integrity and dignity (38).

Dignity consists of inherent and external dimensions, which are partly common to all (universal) and partly unique to each person, relating to social and cultural aspects. Care is primarily relational, but also practical and moral (21). Good individual counselling and sensitive listening are of enormous importance (10). However, although a nursing action such as counselling may be conducted properly and professionally according to the hospital guidelines, it may still be experienced as humiliating to the individual patient. This refers to the moral dimension in care and to the subtle interpretations of our “way of being” when performing health care actions such as counselling.

Tiredness and lack of energy were typical side effects, as reported previously (1,3), and were very problematic. Such fatigue also led to depression and indifference, to avoidance of social contact and changes in working capacity. Some had quit their work during these 9 years. Invisible bodily changes can have a great impact on survivors’ self-confidence, quality of life, and social relationships (2,7,14,17). Health care professionals need to be aware of typical symptoms such as fatigue, and that it manifests itself in a variety of ways. This means that the patients need individualized person-oriented support and advice throughout their treatments, and for some, even beyond that.

Feeling unfocused and forgetful was also troubling. These were particularly distressing side effects for those who worked. Other typical bodily changes experienced included weight gain and reduced muscle strength, as also reported by others (2,32). Over the years, these changes become more prominent.

However, despite weight gain and other typical problems, our findings revealed that our informants generally expressed an optimistic attitude and gratitude for still being alive. According to Logstrup (23 p. 124) “life comes alive” when opposing tendencies collide and influence each other. Death can give meaning to life. Sorrow and joy are opposites but can co-exist. In this way, joy of life became more significant for our participants in the light of their fear of death.
Being unprepared
Previous studies have emphasized the importance of allowing patients to discuss their treatment with their health care professionals (10,39). Although the doctors’ advice was important, the women expressed a need for greater involvement, particularly in making decisions about surgery, in accordance with their unique situation. In such situations, it is important to ensure that patients are involved in the decision-making processes (33). However, this requires that patients are given realistic and person-centred information about the possible effects as well as the possible side effects of different treatments (10,37,39).

Insufficient information and advice from professionals that was too general contributed to our participants’ suffering. Our participants reacted differently to side effects, and they needed individual, trustworthy, professional advice in order to alleviate their ailments (8,10). Martinsen (31 p. 73-79) calls this “person-oriented professionalism”, meaning that the health professional must combine professional and human skills when informing patients, and always base this on the patient’s own, individual understanding of the illness. Information may then alleviate fear and provide reassurance of continued care (10,28,32).

Living in suspense
To be afraid when life is threatened is universal. For our participants, this was experienced individually and was typically associated with fear of recurrence. We found that fear of recurrence restricted the women’s choice of treatments and that re-experiencing cancer-related negative events triggered anxiety even 9 years after surgery. According to Løgstrup (23 p.121-154) emotions can be universal and unique and individual simultaneously. Fear is experienced by everyone. The feeling is universally shared, unique for those with a serious diagnosis, but individually experienced and expressed. However, for women with breast cancer, these feelings may have some other typical features (4,12). According to Martinsen (22 p.120), nursing is a practical profession in which the patient’s life courage is to be promoted. Thus, it is essential that the patient-nurse relationship is person oriented and sensitive to each woman’s individual experiences, or in other words: it is essential to see the patients with a “heart’s eye”, with the attention directed towards the other’s individual life situation (31p.82).

Although our participants had health care professionals and family members around them who listened willingly and gave advice, they felt scared and alone in their cancer experiences (34,40). There is a unique human being, with a distinct life story, behind every diagnosis. In our health care system, a rapid course of treatment is emphasized (18). In this speed-emphasized efficiency, health care professionals may easily come to regard the patients with a “recording eye” only, thereby ignoring the patients’ need for individualized and empathic care (31 p.86-103). A “recording eye” puts itself in an external position, looking for typical physical signs in order to systematize, rank, and classify. This is a necessary position for adequate treatment, but may de-personalize the patient, or at least, be experienced as such. The opposite is to see with the “heart’s eye”, which allows the patient to emerge as a significant other. A professional attitude and professional expertise should acknowledge both ways of “seeing” and should consider the medical condition, as well as the person behind it, as unique (38).

Methodological considerations
The small sample size and the fact that the participants were all from one geographic area, of similar ethnicity and from a relatively homogeneous culture may reduce the transferability of our findings. Patients who were severely ill or those who felt quite healthy may have
declined to participate. To what extent the statements in the interviews after 9 years were related to increasing age is hard to say. In addition, the participants’ experience of the hospital as a non-neutral setting during the interviews after 1 year may have affected the findings. Despite these considerations, we still claim that our participants’ unique, typical, and universal experiences provide relevant and important information.

Conclusions
Living after breast cancer surgery is a “tough” process. Typical experiences for our participants were: being changed, being unprepared, and living in suspense. However, there were great individual variations in how these typical experiences were expressed. So, regardless of whether our findings were typical for the whole group, they were always unique experiences for each participant. Even though the women had received a lot of information, they still did not feel prepared enough for the changes that living with breast cancer entailed. Thus, care has to be individualized in order to meet the needs of each patient.

Clinical implications
Despite the desire for a rapid course of treatment, it is still vital to be able to meet each patient as a unique individual and to be aware of the variations in women’s reactions to breast cancer in order to help them deal with both the treatment and its side effects. More information about side effects is needed to prepare these women for a changed life. Treatment guidelines and recommendations should be adjusted to each individual.

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References


