

Everyday Life in Breast Cancer Survivors Experiencing Challenges: A Qualitative Study

Klara Jakobsen¹, Eva Magnus¹, Steinar Lundgren^{2,3}, Randi J Reidunsdatter¹

Abstract

Background. Early diagnosis and treatment of breast cancer results in an increasing number of survivors, some of whom face new challenges in their transition to daily life. *Aim.* Based on these experiences, the aim of this study was to describe the everyday life in breast cancer survivors experiencing challenges. *Material and Method.* Eleven women recruited from a follow-up study of breast cancer patients participated in qualitative interviews about their everyday occupations seven years after ending treatment. The inductive analysis revealed ten categories that were organized into five subthemes under the two main themes ‘bodily and mental loneliness’ and ‘new centre of gravity in everyday life’. *Results.* Findings showed how relevant information and guidance; active support to the client and their relatives; and a balance between occupations at home and at work were important matters to handle their everyday life challenges. *Conclusion and Significance.* By assisting these women in finding new patterns of meaningful occupations that positively affect their everyday life, the study suggests some central elements to be included in future follow-up practice for breast cancer survivors. Approaching this goal, occupational therapists should contribute to more involvement assisting cancer survivors and their partners in finding new patterns of meaningful occupations that positively affect their everyday life.

¹Department of Health Science, Faculty of Health and Social Science, Norwegian University of Science and Technology (NTNU), ²Department of Oncology, St.Olavs University Hospital, ³Department of Cancer Research and Molecular Medicine, Faculty of Medicine, NTNU
Keywords: Everyday occupations, follow-up process, occupational therapy

Everyday Life in Breast Cancer Survivors Experiencing Challenges: A Qualitative Study

Introduction

Breast cancer, the most frequently occurring cancer in women, represents 22% of all cancer cases in Norway, with an incidence of 3,324 patients in 2014 [1]. Surgery is the primary treatment, while chemotherapy, radiation, and endocrine therapy are the most used adjuvant treatments. Early diagnosis and improved treatment have led to higher survival rates; nearly 90% are still alive five years after their breast cancer diagnosis [1]. This group is often called ‘breast cancer survivors’ in research literature on the subject [2]. Most health personnel who treat breast cancer patients are familiar with the acute and late effects of cancer treatment. The experience of living an everyday life as breast cancer survivors, however, is still less explored [3].

Symptoms after breast cancer treatment may differ. Some women experience no bodily or mentally changes and are therefore able to participate in the same occupations as before the cancer period, while others experience major ailments that seriously affect their everyday lives [4]. For this group of women, prolonged and bothersome symptoms can lead to an imbalance in everyday life occupations, which in turn can cause a change in roles and routines [5] that has a serious negative influence on daily life.

Current research literature describes how physical, cognitive, social, and mental problems may arise [6-14]. Physical symptoms like lymphedema, hot flashes, and sleep disorder are often reported [6]. Fatigue, the most frequent and bothersome reported symptom is strongly associated with physical, cognitive, and emotional functioning [7-9]. Emotional stress, problems with relationships, and reduced sexual identity are well documented [10-12]. Reduced physical and mental function can also challenge the return to work for cancer survivors as well as for other groups with impaired physical and mental function [13-17]. The follow-up care and services after treatment for breast cancer patients vary considerably across industrialized countries [18-22]. However, since the physical and mental symptoms can cause a disruption in the women’s

everyday life structure, the content and structure of the follow-up services should be discussed [19].

Since the symptoms after breast cancer differ, the occupational consequences affect the everyday lives of these women differently, but changes in cognitive and bodily function are rather common following chemotherapy [4]. Research also shows how women with breast cancer respond mentally and behaviourally differently to their everyday situations, and how they periodically shift between mental modes [3]. Especially younger women have to deal with how their change in physical appearance can be experienced as a threat to their femininity [23-26].

Wilcock [27] noted that a balance between people's everyday occupations could be linked directly to health. By describing the narrative experiences of Icelandic women with breast cancer, Palmadottir [28] also found that occupational participation and the environment contributed to these women's perception of health and well-being. The study also stated that participation in everyday occupations in spite of their bodily and mental ailments appears to have a special meaning for how breast cancer survivors deal with their new life situations. Environmental features were also perceived to be essential for maintaining control and stability in the everyday life of cancer patients [29, 30]. The recognition of the expectations in the socio-cultural environment will then be decisive [31].

Everyday life can be defined as 'people doing little things in local places' [32]. It consists of many daily routines, but also occupations chosen based on personal interests and desires [33]. Polatajko et al. [34] conceptualizes, by the Canadian Model of Occupational Performance and Engagement (CMOP-E), occupational performance and engagement in everyday life as the mutual dynamic interaction of person, occupation and environment. In response to the opportunities and challenges in this model, each person's occupational life course will be shaped by the relationship between persons, the occupation, and the environment [34].

Knowledge of breast cancer survivors' challenges in everyday lives is paramount to developing appropriate occupational therapy services and may therefore enrich the follow-up processes for an exposed group of breast cancer survivors. The aim of this study was to describe everyday life in breast cancer survivors experiencing challenges.

Design and Method

The present study has a qualitative descriptive approach using in-depth semi structured interviews [35]. Time geographic diary notes [36] were used in the selection of participants who described a challenging everyday life, and their notes were later used as a stimulus material for the interviews.

Participants and Recruitment Procedures

This study is part of an on-going, seven-year clinical follow-up of breast cancer patients. Baseline recruitment procedures and the characteristics of the total original sample are published elsewhere [37]. When patients attended the follow-up at the outpatient clinic, an oncologist informed them about this qualitative study of everyday life.

In the main study, the patients agreed to write a diary for seven days and, if selected, to participate in an in-depth interview. In the diary, the women were asked to describe their occupations at different times and places, and to indicate with whom they were spending their time. For each new occupation, they could add private notes elaborating on their own impressions and experiences.

The completed diary was sent back to the study group in a prepaid envelope. The diary data described the women's routines and occupations, including their personal comments. The diaries revealed that some informants lived their everyday lives with little impact from prior cancer treatment, while others described how their physical or mental capacity negatively influenced their everyday lives.

This latter group were strategically selected for participation in the present study, and these women were contacted for an in-depth interview. To approach important topics describing challenges in each of these women's everyday lives, their diaries with relevant information were used as a starting point and a stimulus material during the interviews.

The Interviews

A semi-structural interview guide was developed to ensure consistency in all interviews and contained an outline of main topics and suggested subtopics to be explored. The main topics included how the women chose to spend their time, including their routines and habits, and prompted them to describe daily occupations of importance for them. They were also asked to elaborate on how the cancer and treatment had influenced their everyday lives, and how they would describe their present health. Examples of questions asked were: Can you talk about your everyday life today? Could you say something about the occupations you chose to spend time on today? Please try to describe actual changes in everyday occupations because of your cancer period and the life you live today. Questions about relationships with others and environmental factors of importance in everyday life were also emphasized. To test the feasibility of the methods and the usefulness of the interview guide, an implementation of a pilot study based on two diaries and interviews were conducted, and consequently some of the questions had to be rewritten.

The interviews were conducted during the spring of 2016. The sampling ended when the authors decided that saturation was reached and the informants provided no new information [38]. As shown in table 1, the final sample consisted of 11 women, aged 48 to 74 years. Seven of the women were married or lived with a man, and some of the informants had children living at home. Two of the interviews were conducted at a meeting place for cancer patients, while the others were performed at the women's homes or work sites. Each interview lasted between one and two hours. They were all audio recorded, and field notes were made after each interview.

Ethical considerations

The study was conducted according to the guidelines of the Helsinki Declaration. Written informed consent was obtained from all the participants after oral and written information was provided prior to participation at the outpatient clinic. Participation in the study was voluntary and the informants could withdraw from the project at any time without any impact on their further contact with the hospital. To safeguard confidentiality, the informants' names and indication of localities were replaced with notional names, and the data were stored on a research server. The main study was approved by The Regional Committees for Medical and Research Ethics in Central Norway

Data Analysis of the Interviews

The interviews were transcribed verbatim. Then analysed with the intention of exploring the women's everyday life experiences. Content analysis [38] was conducted using analytic methods consisting of meaning categorisation, meaning condensation, and structuring of meaning through narratives.

In this process, all transcribed interviews were first read one by one several times in order to get an overall impression of the interview data. When familiar with the text, the researchers started the process of identifying meaning units, or a meaning categorisation, through clustering expressions reflecting the same meaning. Categories identified in the first interviews were expanded upon as the meaning categorisation process progressed. By a meaning condensation, each category was then condensed to bring out its essential theme by extracting comprehensive expressions into one sentence. Some of these categories were dropped when they were not associated with the women's everyday life situations, but the relevant units were sorted and organized into clusters of categories (Table 2). A reconsideration of the data and the categories was then performed to capture the essential elements described as subthemes and main themes.

This process was iterative and continued as the data were collected. Three of the authors collected the data, all with credentials as a PhD or professor, while the first author was responsible for the coding and identification of themes. To enhance the credibility of interpretation of the data, three of the authors actively conducted a peer debriefing.

Findings

The aim of this study was to describe the everyday life in breast cancer survivors experiencing challenges in everyday life. The two main themes; ‘bodily and mental loneliness’ and ‘new centre of gravity in everyday life’, and five subthemes emerged in this process.

Bodily and mental loneliness

The breast cancer survivors clarified how bodily and mental challenges influenced their performance capacity and endurance, and thereby their daily occupations. Lack of time-relevant information from health personnel was demanding and influenced disturbingly on their daily life occupations.

Bodily and mental challenges

The women commonly expected to live their daily life as before their diagnosis. However, distressing bodily symptoms, like a swollen and painful arm or decreased muscle strength, restricted some of the women's household and leisure occupations. Pain and hot flashes made it difficult to fall asleep or frequently caused them to wake up very early in the morning. Some breast cancer survivors described a feeling of constant tiredness, as Mary expressed in these terms: *‘I'm usually up two to three times each night, and since I sleep so badly at night, I never feel properly rested’*. Similarly, Helen shared the following statement: *‘I also think it's sad that I can wake up in the morning and feel tired. The energy is gone since I have problems with nocturnal sleep’*.

Those who experienced disturbed sleep patterns explained how their energy was reducing during the daytime and, consequently, affected their occupations negatively. In order to handle a daily life with pain and less energy, they described a variety of strategies. Some found that regular visits to their manual therapist could be useful to uphold their energy and reduce pain, while Janie attended water gymnastics classes. Mary explained that, due to pain in her fingers and numbness in her feet, she used a vibration machine at night and in the mornings to increase blood circulation. When sleeplessness and burdensome symptoms affected some of the women's energy, they seemed to really search for meaningful occupations to uphold an active everyday life.

Besides their bodily ailments, the ability to concentrate declined after the cancer treatment. The breast cancer survivors described situations where they were dizzy and forgetful. Gail told how it became difficult to stay focused while watching TV. Maintaining concentration over time was complicated, and some described this phenomenon by 'fading out'. As a result, several women with impaired cognitive functions avoided social situations and settings.

Others reported a hypersensitivity to light. Elisabeth had to permanently wear sunglasses when outdoors, while Clair had to replace all the lamps at her office to be able to work there. The hypersensitivity to cognitive stimuli seemed to cause burdensome symptoms for many respondents. As an example, Susan told how she no longer appreciated going to concerts anymore, and she even avoided watching TV:

'I react negatively to the TV, because it has a loud sound, which is uncomfortable. Since the light and the images are changing frequently, I also feel light-headed and giddy when watching'.

Along the same lines, Gail told of how she needed more time to finish a book, and in order to concentrate, she preferred total silence when reading.

Due to reduced memory, important tasks could be difficult to remember. Some were unable to assume the same responsibilities at home and at work. Janie told how she was unable to perform

important matters at work after the cancer period, like speaking English when helping the foreign customers. The possibility to change work tasks and other adaptations was described as crucial for their work participation. Loss of memory seemed likewise to be a rather common experience, as Helen explains: *'I do remember very little sometimes, names and such. One might blame the age, I don't know!'*

These women experienced reduced bodily capacity due to physical and mental changes, and they missed information from the healthcare services as to whether these changes were due to the cancer treatments or to natural ageing. As a result, they easily sought to avoid certain situations in which they previously participated. Thus, to uphold their individual lifestyle, they all tried to participate in daily occupations for which they had mental and bodily capacity.

Information and timing mismatch

Most of the women were satisfied with the follow-up during the treatment time at the hospital. During this stay, they were given updated information related to their personal situation and the care process. However, some were still striving to utilize the information given during the treatment period at the hospital. As Anna stated: *'The information could easily go in one ear and quickly out of the other'*. She also expressed a need to get more information later in the ongoing recovery path.

For some of the breast cancer survivors questions appeared after a while, when their everyday realities emerged. Lack of information and difficulties in finding relevant and comprehensible information seemed to be rather common experiences and many stated a strong need of having someone who could answer their questions. Some women described how difficult it was to understand why they were so tired or why they felt it so hard to concentrate.

By searching the medical literature on the Internet, several women tried to get answers to their questions about bodily changes and ailments. However, this information could often be difficult to

understand and interpret. Caroline reported: *'The information I read scared me. I believed I was much sicker than I actually was!'*

While Susan said:

'I had many questions I wanted to ask, so much I gradually discovered, but I did not know who I could ask. When you have terminated your treatment at the hospital, you then are finalized. I did not have a permanent doctor at the hospital, and different people told me different things. When I had finished the last radiation, I was told to come back in a year. I then got the feeling of being alone and by myself'.

The close relationship with the healthcare professionals and the help offered at the hospital during the treatment period seemed difficult for many to let go. To gain access to relevant information, some joined the Breast Cancer Association while others consulted acquaintances or associates, or other people who had experienced cancer.

Relationship and partnership

The possibility of having good and open communication about their ailments with those closest to them was described as important. As Eve said: *'I have been open about my situation, and therefore I do feel that all my family and friends take good care of me!'* However, because of reduced physical and mental capacity, some explained how they were less socially active. Helen describes:

'I've always been a social person. I normally used to spend much energy on being nice, and I tried to make every situation cosy. I really want so much to behave like all the others! However, now I have become more selfish and less patient and tolerant. I am therefore more careful with how I spend my time. Earlier, I participated in various organizations, but now, when the energy is less, I'm not so socially active as before. The cancer might be the reason, or it may have to do with age - or a bit of both, I would think!'

Their social lives seemed to either have changed totally or at least found other constitutions, as Caroline stated

'I notice that I don't want much contact with the people who don't 'give me' anything. Because I think, my life is too short to have relations with people who only suck energy out of me'.

Meanwhile, Eve conveyed how she would often meet unpleasant situations in social settings with many strangers. When people became aware of her diagnosis, some individuals spontaneously gave her well-intentioned advice on how she best could make priorities in her daily life. To avoid unwanted questions and well-intentioned tips, Eve told of how she learned to be socially selective.

Several breast cancer survivors disliked their bodies and felt unattractive after the breast surgery. As Caroline expressed: *'I didn't feel as attractive as a woman after the surgery; one feels a little dismembered. I therefore used clothes that hid my body'*. Breast reconstruction was therefore described as of great importance for their appearance and their perceived value as a woman. The partner relationship could also in some way be affected by the cancer period, and for some participants it resulted in a crisis in their marriage. As Anna shared:

'The illness has not changed my social relationships [with friends and family]; it is the relationship to my partner I find troublesome. I do have a good guy. He is responsive and kind. However, our sexual life was changed completely after the surgery and treatment, and my mucosal membranes do not exist anymore!'

Even if these women described their sexual life as important, several told how sexual situations, and especially sexual initiation, were challenging and difficult. As for their sex lives, there were varying experiences. Clair described her situation as follows: *'I was not happy with my body after the surgery, because it [the surgery] did a lot with me. Then sex was not the activity that tempted me most!'* As an example of how the cancer period had affected her sex life negatively, Clair described:

'I haven't had sex for many months - or years, maybe. My husband treats me in a way as I am still ill and have pain. I think that's terrible. Guidance in this area is important. And if we both could come [to this conversation]...It [sex] is an important part of our life, because a marriage can simply be destroyed'.

Accordingly, some expressed how sex might become a taboo topic, affecting the partnership negatively. The usefulness of supervision sessions for partners was emphasized, and by this, the need of support was requested.

New centre of gravity in everyday life

Even if reduced mental and bodily capacities seemed to have an impact on their daily routines, the participants were all striving to maintain a meaningful everyday life. For those who were working or who had just stopped working, the job was of great importance.

The meaning of work

As long as the cancer survivors managed to meet the expectations during a workday, they all described employment as a meaningful activity. In this situation, employment seemed to give energy and could represent a 'free space' where they could forget their pain and bodily limitations.

When returning to work after cancer treatment, the women named supportive elements like 'a well-organized work situation' and 'a leader who understood' as being of great importance for their employment career. Adaptations at the job, such as getting new work tasks or having the possibility to lie down during lunchtime, were some examples of adjustments or strategies necessary in order to maintain their employment status. However, for some, these actions were not so easy to initiate, and they explained how they gradually became exhausted. Due to the total work strain, Janie and Clair who started a full-time job directly after the treatment period, found it necessary to reduce their work time after a short while.

To avoid criticism of their work performance, the women explained how they actively tried to update their skills after their period of absence. Clair told that she, on her own initiative, had hired a consultant to assist her with new or altered job tasks, while Helen emphasized that the way her leader and colleagues' responded to her presence at work—with care and sympathy, or with a reaction of stress and resignation—was important to her. The leaders' attitudes and behaviours seemed to be of special importance for how these women felt comfortable with the work situation. If the chief was supportive and helpful, they were more easily able to uphold the expectations. The value of having encouraging and supportive leadership was expressed in this way by Anna: *'I previously had a well-organized work situation, but now, since I just have a new boss, then I am worried for my future at work'*.

For many cancer survivors, staying employed seemed to be strenuous, as Gail uttered:

'In my opinion, I could manage to get through the workday. I also performed what I was supposed to do at work. After work, however, I just laid down. I was not social because I didn't manage anything more than my job. Since I had to spend so much energy at the job, I pulled myself together these days when I was working, but I had no energy afterwards'.

However, most of these breast cancer survivors really wanted to work. Caroline explained her situation by this expression: *'I clung firmly to my job as long as possible because I didn't want to quit. It was therefore tough to resign from the job'*. Meanwhile, Linnea expressed the meaning the job had for her in this statement: *'The day I had to leave my job was a very strange day. Life then became different...I do miss my colleagues—because work is the real life'*. Employment seems therefore to be hard to let go for these women. Nevertheless, for many, quitting their jobs seemed to be the only reasonable strategy in order to preserve their health.

Being jobless, many of the breast cancer survivors found new and important occupations as a replacement for paid work. Some sought out new occupations for themselves, such as invigilators

at the university's exams, or volunteers in different organizations, while others were active members in the local breast cancer society.

Reorientation of daily occupations

Most of the breast cancer survivors stated that they had a clear understanding of the importance of being physically and mentally active. This issue seemed to become even more important when they experienced bodily changes after the breast cancer period. They appreciated having regularity and routines in their daily life. In this regard, former and well-known occupations could be of importance to rediscover.

For Linnea, however, it seemed difficult to participate in the same occupations as before, or to uphold her daily routines. As she stated,

'The life became different when I had to quit my job; I had to learn to relax and prioritize differently. Some days I wake up and just sit in a chair without managing anything, which for me is a rather tough situation'.

In order to find a new balance between meaningful occupations and some of their daily household duties, a reorientation was necessary. The weekend occupations with their friends and family seemed then to be of extra importance. Caroline told how she regularly invited her family to dinners and coffee parties to keep close contact with her children and grandchildren, while Eve greatly appreciated inviting her family members to her cabin by the fjord.

Some women, however, expressed grief over not being able to engage in the same occupations they previously enjoyed, or to act with the same energy as before their diagnosis. Helen described how she no longer was able to tend the garden as she used to, and consequently it was not as well kept as previously, with her vegetables and flowers. Meanwhile, Susan and Gail described the difficulties in adapting to a lower level of energy. Consequently, their desire to be active easily

outdid their body's capacity, as expressed by Anna: *'I still try to find a balance of how I want to live, because I easily act like a Duracell rabbit!'*

Those breast cancer survivors who had to stop working after the cancer period also described how this new situation and status gave them time to participate in new occupations, such as popular fitness walking with friends and doing training occupations like trim groups and yoga. Some participated in organized exercises designed for breast cancer survivors, and for those who were lucky to have a dog, the walking tours seemed to be of special importance in maintaining regularity in their daily routines. As Eve explains:

'I do need someone [the dog] that drags me out. We do not walk fast, but we walk for a long time. I can't sit at home until my husband comes home from work and wait for the occupations we might do together'.

Eve also told how she found landscape photography to be a new and interesting hobby. She travelled around the community with her camera in search of new and exciting pictures and explained how she thus learned about new places and people, which she did not know about before. Meanwhile, Gail described how she learned to observe and appreciate the change in seasons; this was something she did not notice so much before she got cancer. These examples illustrate occupations, interests, and active choices these breast cancer survivors prioritized.

Discussion

The breast cancer survivors in the present study reported how reduced bodily and mental function affected their ability to perform everyday life occupations as before. The consequences of cognitive changes, pain, decreased energy, and a reduced range of movement had restricted their capacity and thereby influenced their everyday life. The findings illustrated how a balance between work and leisure occupations, and time-relevant

information, guidance and support, were important issues for their engagement in daily occupations. Late effects can for many become permanent [3-9] and may negatively affect the everyday lives of many cancer survivors [3].

This section will discuss how bodily and mental capacity actively can influence the reorientation process when it comes to partnership and relationship, the meaning of work, and the reorientation of daily occupations.

The *relationships to others* and a stable and supportive social network were valuable for the breast cancer survivors' everyday life in the present study. A positive relation to family and friends were essential for everyday life experiences. However, reduced bodily and mental capacity and reduced energy made the women more selective in which activities they participated, and consequently with whom they socialized. Some therefore avoided social settings and arrangements where they could run the risk of negative experiences. Loss of functionality and control over time, as consequences of cancer treatment are in other studies shown to have a profound impact on the relation to other people and the partnership.

However, social support and good social relationships can act as a buffer to the impact of stressful life events in breast cancer survivors [18]. Rewarding and self-affirming relationships with others could therefore support their everyday life positively.

The *partner relationship* was essential in the breast cancer survivors' everyday life. Although most women in the present study had adapted and coped well with the marital relationship, some perceived how bodily changes after the breast surgery negatively influenced on their sexual initiation. Intimate relationship and sexual issues were for many in the present study perceived as a taboo topic to discuss, both with partners and with health care personnel. In line with research, perception of diminished femininity and sexually attractiveness are influencing sexual activity in breast cancer survivors [9, 11]. Because a reduced sexual life may influence negatively on cancer survivors' quality of life [10], couple-based psycho-educational interventions are suggested [39].

Consequently, this group of survivors and their partners should receive special attention by health care professionals.

The meaning of work was of great importance for these women's everyday life experiences. Staying employed was essential for their identity and a situation where they saw themselves as active participants in society. Quitting job could therefore be in conflict with their self-image and perception of social and cultural attitudes. Work was also a place to forget ailments. However, in order to handle everyday life expectations, many of the informants had to reduce their working hours or to quit their job entirely.

Due to tiredness and concentration problems, for many it became too strenuous to start a full-time job after the cancer treatment. Even if cognitive problems after breast cancer treatment is well known [3, 6, 8], the women in the present study were not prepared for how reduced concentration and memory could affect employability. Since cognitive competences is of great importance in today's constantly changing working life, many women in the present study found the work situation very demanding. Participating in supportive environment could enhance self-development and a sense of self-worth [29], and a tailored support and necessary adaptations to work and work tasks are suggested to be helpful elements in cancer survivors' engagement in work [40]. Such adaptations would probably influence positively on the ability to create a balance between work and leisure time for breast cancer survivors.

By a *reorientation of daily occupations*, the feeling of having enough time and energy for the most important and meaningful everyday occupations was valuable for the women in the present study. Instead of spending too much energy on housework, some prioritized occupations like reading books, listening to music, walking in nature, or working in the garden to rest and get new energy. Palmadottir [28] described how creativity, mainly by craft or creative occupations, created continuity in the lives of the Icelandic breast cancer survivors. In addition, she found that maintaining daily routines was helpful to control negative feelings and emotional stress. Finding

time for engagement in meaningful occupations has been emphasized as important ways to manage everyday life for cancer patients [29]. Polatajko et al. [34] describe how occupational engagement can be health promoting through participation in valued social occupations. In line with COPM-E [34], the findings in the present study also indicates how a reorientation of daily occupational patterns at work and leisure time are influenced by a mutual impact, shaped by each person's personal resources, occupations, and by the environment in which they spend their time. Time-relevant information turned out to be essential for how the participants were able to handle everyday challenges. Many of the women described that health professionals had recommended them to live their everyday lives as usual. However, as daily life turned out differently, they expressed a state of uncertainty and a lack of clarity related to health personnel's' information and follow-up responsibility. Based on this information the role of follow-up is worth attention. The findings clarifies how information must be provided in a manner that can be perceived by the individual, and at a time when the person is able to understand and benefit from it. The overall everyday life patterns and the mutual influence shaped by each persons' personal resources may be an entry to acquire a deeper understanding of important issues for a desirable life. Writing a diary of daily activities for some days may be a helpful tool and an empowering process for survivors to create awareness of their own practice and thereby a stronger involvement in their own follow-up care. As noted by one of the women in present study: 'I was not aware of how I prioritized my time and my energy, until I read it in my own diary'. Based on diary information, an occupational therapist could more easily initiate a customized information on actual changes or adjustments of the client's everyday occupations.

Methodological limitations

The study includes a relatively small and strategic sample of women who described a rather strenuous everyday life. Consequently, findings cannot be generalized to breast cancer survivors

in general, but has to be interpreted and hopefully implemented in supporting this vulnerable group. Secondly, our study are mainly focusing on breast cancer survivors experiencing challenges in everyday life and might probably overlook the recourses the survivors might possess. Future research should therefore more strongly emphasize good coping strategies and other health promoting occupations when studying everyday life in breast cancer survivors. Third, the age of our participants ranged from 48 to 74 years, and most were older than 55 years. Younger breast cancer survivors often experience more severe physical and mental impairment than older survivors [24]. Since age seems to influence bodily capacity and everyday routines differently [24-26], the results has to be interpreted in a middle age and older breast cancer population. More research on everyday life in younger breast cancer survivors are recommended.

Conclusion

Cancer treatment can change the occupational everyday life course and take people into unexpected areas of life, and the present study describes how many of the breast cancer survivors became more selective about how and with whom they chose to spend their time and energy when experiencing challenges in everyday life. Due to bodily and mental changes, some described their work situation as demanding, while others experienced the intimate relationship to their partner and sex life as difficult. Nevertheless, even if the survivors had to reorganize their everyday occupations, it appeared that they all tried to uphold a dignified everyday life. Some women then were able to change everyday occupations and routines themselves, while others asked for more assistance from the health care system. The present study therefore suggests some central elements to be included in future follow-up practice of breast cancer patients: providing relevant information when the person is able to receive and utilize the advices, and more involvement of partners. Occupational therapists supporting patients to find new patterns of meaningful occupations that positively affect everyday life is

then essential. If a balanced engagement in everyday life occupations can be a precondition for health, approaching this as a goal could therefore be a low-threshold but a highly significant effort in the follow-up care of cancer survivors.

Disclosure of interests.

The authors report no conflicts of interests.

References

1. Cancer registry of Norway 2014. [Cited 2017 January] Available from: <http://www.kreftregisteret.no/en/General/Publications/Cancer-in-Norway/Cancer-in-Norway-2014/>.
2. Kelly KM, Shah N, Shedlosky-Shoemaker R, et al. Living post treatment: definitions of those with history and no history of cancer. *J Cancer Surviv.* 2011;5:158-166
3. Harrington CB, Hansen JA, Moskowitz M, et al. It's not over when it's over: long-term symptoms in cancer survivors--a systematic review. *Int J Psychiatry Med.* 2010;40:163-81.
4. Arman M, Rehnsfeldt A, Carlsson M, et al. Indications of change in life perspective among women with breast cancer admitted to complementary care. *Eur J Can Care.* 2001;192-200.
5. Ridner SH, Bonner CM, Deng J, et al. Voices from the shadows: living with lymphedema. *Cancer Nurs.* 2012;35:E18-26.
6. Boykoff N, Moieni M, Subramanian SK. Confronting chemobrain: an in-depth look at survivors' reports of impact on work, social networks, and health care response. *J Cancer Surviv.* 2009;3:223-32.
7. Berger AM, Gerber LH, Mayer DK. Cancer-related fatigue. *Cancer.* 2012;118:2261-9.
8. Schagen SB, Muller MJ, Boogern W, et al. Change in cognitive function after chemotherapy: a prospective longitudinal study in breast cancer patients. *J Natl Cancer Inst.* 2006;98:1742-5.
9. Sprung BR, Janotha BL, Steckel AJ. The lived experience of breast cancer patients and couple distress. *J Am Acad Nurse Pract.* 2011;23:619-27.
10. Manganiello A, Hoga LAK, Reberte LM, et al. Sexuality and quality of life of breast cancer patients post mastectomy. *Eur J Oncol Nurs.* 2011;15:167-72.
11. Hauken MA, Larsen TM, Holsen I. Meeting reality: young adult cancer survivors' experiences of reentering everyday life after cancer treatment. *Cancer Nurs.* 2013;36:E17-26.
12. Hagedoorn M, Kreicbergs U, Appel C. Coping with cancer: the perspective of patients' relatives. *Acta Oncol.* 2011;50:205-11.
13. Calvio L, Peugeot M, Bruns MA, et al. Measures of cognitive function and work in occupationally active breast cancer survivors. *J Occup Environ Med.* 2010;52:219-27.
14. de Boer A, Taskila TK, Tamminga SJ, et al. Interventions to enhance return to work for cancer patients: a cochrane review and meta-analysis. *Psycho-Oncol.* 2015;24:258-58.
15. Fløtten T. Cancer and living conditions: summary of findings from a study among people with cancer in Norway. *Fafo-report.* Oslo: Fafo;2009.
16. Lindbohm ML, Kuosma E, Taskila T, et al. Early retirement and non-employment after breast cancer. *Psycho-Oncol.* 2014; 23:635-641.
17. Jakobsen K, Lillefjell M. Factors promoting a successful return to work: from an employer and employee perspective. *Scand J Occup Ther.* 2014;21:48-57.
18. Collins RF, Bekker HL, Dodwell DJ. Follow-up care of patients treated for breast cancer: a structured review. *Cancer Treat Rev.* 2004;30:19-35.
19. Egan MY, McEwen S, Sikora L, et al. Rehabilitation following cancer treatment. *Disabil Rehabil.* 2013;35:2245-2258.

20. Ockerby C, Livingstone P, O'Connell B, et al. The role of informal caregivers during cancer patients' recovery from chemotherapy. *Scand J Caring Sci.* 2013;27:147-55.
21. Kornblith AB, Herndon JE, Zuckerman E, et al. Social support as a buffer to the psychological impact of stressful life events in women with breast cancer. *Cancer.* 2001;91:443-54.
22. Hewitt ME, Bamundo A, Day R, et al. Perspectives on post-treatment cancer care: qualitative research with survivors, nurses, and physicians. *J Clin Oncol.* 2007;25:2270-3.
23. Lindberg P, Koller M, Steinger B, et al. Breast cancer survivors' recollection of their illness and therapy seven years after enrolment into a randomised controlled clinical trial. *Cancer.* 2015; 15:554-66.
24. Champion VL, Wagner LI, Monahan PO, et al. Comparison of younger and older breast cancer survivors and age-matched controls on specific and overall quality of life domains. *Cancer.* 2014;120:2237-46.
25. Lyons KD, Lambert LA, Balan S, et al. Changes in activity levels of older adult cancer survivors. *OTJR: Occupation, Participation and Health.* 2013;1:31-37.
26. Cimprich B, Ronis DL, Martinez-Ramos G. Age at diagnosis and quality of life in breast cancer survivors. *Cancer Pract.* 2002;10:85-93.
27. Wilcock AA. Population health: an occupational rationale. In Scaffa ME, Reitz SM, Pizzi M, editors. *Occupational therapy in the promotion of health and wellness.* Philadelphia: FA Davis; 2010. P. 110-121.
28. Palmadottir G. The role of occupational participation and environment among Icelandic women with breast cancer: A qualitative study. *Scand J Occup Therp.* 2010;17:299-307.
29. la Cour K, Johannessen H, Josephsson S. Activity and meaning making in the everyday lives of people with advanced cancer. *Palliat Support Care.* 2009;7:469-79.
30. Palmadottir G. The road to recovery: Experiences and occupational lives of Icelandic women with breast cancer. *Occup Ther in Health Care.* 2009;23:319-35.
31. Backman CL. Occupational balance: exploring the relationships among daily occupations and their influence on well-being. *Can J Occup Ther.* 2004;71:202-9.
32. Scott S. *Making sense of everyday life.* Cambridge: Polity Press;2009.
33. Law M. Participation in the occupations of everyday life. *Am J Occup Ther,* 2002;56:6409.
34. Polatajko HJ, Davis J, Stewart D, et al. Specifying the domain of concern: Occupation as core. In Townsend EA, Polatajko HJ, primary authors. *Enabling Occupation II: Advancing an Occupational Therapy Vision for Health, Well-being & Justice Through Occupation.* Ottawa: CAOT Publications ACE; 2007. p.13-36
35. Denzin NK, Lincoln YS. *The SAGE handbook of qualitative research.* 4th ed. Los Angeles: Sage. XVI;2011.
36. Wihlborg E, Ellegård K. *Fånga vardagen : ett tvärvetenskapligt perspektiv. [Catching the everyday life in a interdisciplinary perspective] [In Swedish],* Lund: Studentlitteratur; 2001.
37. Reidunsdatter RJ, Rannestad T, Frengen J, et al. Early effects of contemporary breast radiation on health-related quality of life - predictors of radiotherapy-related fatigue. *Acta Oncol.* 2011;50:1175-82.
38. Kvale S, Brinkmann S. *Det kvalitative forskningsintervju. [The qualitative research interview].* Oslo: Gyldendal Akademisk; 2012.

39. Taylor S, Harley C, Ziegler L, et al. Interventions for sexual problems following treatment for breast cancer: a systematic review. *Breast Cancer Res Treat.* 2011;130:711-24.
40. Duijts S, vanEgmond MP, Spelten E, et al. Physical and psychosocial problems in cancer survivors beyond return to work: a systematic review. *Psycho-Oncol.* 2014;23:481-92.

Table 1. Characteristics of study participants (N=11), age 48-74.

Participants	Age [years]	Marital status	Education	Employment
Caroline	66	Cohabited	Secondary Vocational School	Retired
Susan	68	Lives alone	Secondary Vocational School	Retired
Eve	48	Married	University Graduate	Disability pension
Gail	64	Lives alone	University Graduate	Retired
Elizabeth	74	Lives alone	High School	Retired
Linnea	72	Married	Secondary Vocational School	Retired
Janie	67	Married	Secondary Vocational School	Part time
Anna	56	Married	High School	Full time
Clair	59	Married	University Graduate	Part time
Mary	59	Married	Secondary Vocational School	Full time
Helene	56	Lives alone	University Graduate	Part time

Table 2. Example on thematises and categorization based on meaningful units.

<p><i>The body is not like before; I easily get tired. I do not need to sleep for a long time. A half-hour nap is OK</i></p>	<p>-Resting needs -Exhausted -Bad sleep -Less energy</p>	<p>○ Bodily and mental challenges</p>	<p>Bodily and mental loneliness</p>
<p><i>After the surgery, the doctor said I should live normally, so I went home and washed all the windows All the information I have sought out myself</i></p>	<p>-Searching for relevant information -Follow up requested -Hyperactive</p>	<p>○ Information and timing mismatch</p>	
<p><i>After my sickness, I do feel sex life was a bit difficult. It is the relationship to my partner I find troublesome. I am more careful with whom I spend my time</i></p>	<p>-Bodily changes affect attractiveness -Reduced sex life -Relations to partner and other people</p>	<p>○ Relationship and partnership</p>	
<p><i>I tried my full-time job, but it did not work I was so bad I had to reduce to 50%</i></p>	<p>-Trials and job experiences -Work capacity reduced -Identity and work</p>	<p>○ The meaning of work</p>	
<p><i>I do try to uphold my fitness, and some of us are cycling once a week I have to adjust myself down, by not doing so many things as before</i></p>	<p>-Upholding bodily fitness -Creating new routines -Adjustment of daily occupations to capacity</p>	<p>○ Reorientation of daily occupations</p>	