“I just have to move on”: Women’s coping experiences and reflections following their first year after primary breast cancer surgery

Sigrunn Drageset a, b, *, Torill Christine Lindstrøm c, Kjell Underlid d

a Faculty of Health and Social Sciences, Bergen University College, Inndalsveien 28, N-5063 Bergen, Norway
b Betanien University College, Vestundveien 19, N-5145 Fyllingsdalen, Norway
c Faculty of Psychology, University of Bergen, Christie st. 12, N-5020 Bergen, Norway
d Faculty of Health and Social Sciences, Bergen University College, Møllendalsveien 6, N-5009 Bergen, Norway

A R T I C L E  I N F O

Article history:
Received 18 April 2015
Received in revised form
14 October 2015
Accepted 15 October 2015

Keywords:
Breast cancer
Coping
Post-surgery
Healthcare professionals
Qualitative research
Interviews
Follow-up

A B S T R A C T

Purpose: The purpose of this qualitative follow-up study was to describe women’s individual coping experiences and reflections following their first year after primary breast cancer surgery.

Methods: Using a qualitative descriptive design, we collected data through individual interviews with ten women at a Norwegian university hospital between August 2007 and April 2008. We employed Kvale’s method of qualitative meaning condensation analysis.

Results: Themes identified were: existential concerns and finding meaning, ways of thinking and feeling about the disease, taking action, and returning to normal life. Most women experienced an increased appreciation of life and greater confidence in themselves, were more caring and compassionate towards others, and focused more on their life priorities. Their family and close relationships became more important. They accepted their situation and made the best of it. Positive thinking, physical activity, self-care, nature, hobbies and work helped. Generally, they were optimistic despite a fear of cancer recurrence and uncertainty about their future. The women wanted to return to a “normal” and healthy life by distancing themselves from both the cancer environment and information about cancer.

Conclusion: Uncertainty and anxiety about a potential future cancer relapse was a major undercurrent one year following surgery. Our findings emphasize the richness in these women’s coping strategies, their different coping profiles and different needs, as well as some general adaptive strategies, which all fluctuated over time. Not all managed to cope equally well. Through awareness of these women’s individual experiences and coping strategies, healthcare professionals can enhance these women’s coping endeavours.

© 2015 Published by Elsevier Ltd.

1. Introduction

The estimated incidence of breast cancer worldwide is 1.7 million yearly and the five-year prevalence is 6.2 million. Both are increasing (World Health Organization, 2015). Considering the large number affected and that studies have reported that the women’s coping is a crucial factor across the breast cancer trajectory (Silva et al., 2012; Stefanic et al., 2015), exploring the coping strategies adopted by these women is important.

Post-surgery, women with breast cancer must cope with both physical and emotional reactions to the disease and its treatment (Ho et al., 2013; Hofso et al., 2013). Common emotional reactions recorded are: uncertainty (Garofalo et al., 2009; Hagen et al., 2014), anxiety and depression (Ho et al., 2013; Lewis et al., 2015; Saboonchi et al., 2014), and fear of recurrence (Kvale et al., 2015; Melchior et al., 2013). Women who had been diagnosed with breast cancer for a year reported greater uncertainty than those newly diagnosed (Hagen et al., 2014). These emotional reactions are often severe, and persist beyond completion of treatment (Jarrett et al., 2013; Saboonchi et al., 2014).

Coping strategies are commonly classified as “appraisal-focused coping”, “problem-focused coping”, and “emotion-focused coping” (Lazarus, 1999). People use these strategies to varying degrees depending on the type of stressor, personal factors, and the context.

Several ways of coping are identified related to breast cancer...
Coping in response to breast cancer varies over time and across situations during the first year post-surgery (Geyer et al., 2015; Wang et al., 2014). According to Hervatin et al. (2012), emotional coping responses remained stable shortly after breast cancer surgery and 12 months later while cognitive coping showed considerable variability, primarily influenced by environmental factors. Problem-focused coping, particularly personal control, has been reported to correlate with lower distress, better adjustment to breast cancer and better physical function immediately post-surgery. One year later, problem-focused coping was associated with less distress but not with better adaptation to breast cancer or physical functioning (Heppner et al., 2009). Emotional-coping efforts of disengagement, denial, self-blame and helplessness/hopelessness correlate with increased distress and depression during and after treatment (Alcalar et al., 2012; Bussell and Naus, 2010). Disengagement forms of coping seem to be more maladaptive for women undergoing treatment for breast cancer than for women not treated (Kvillemo and Branstrom, 2014). Studies show that during and after breast-cancer treatment, a fighting spirit and acceptance correlate with lower depression and distress (Alcalar et al., 2012; Jenssen et al., 2014), while acceptance and a positive reappraisal correlate with increased well-being and health (Kvillemo and Branstrom, 2014). Over time, a strong desire for control at four and eight months post-diagnosis was found to increase the likelihood of recurrence 20 years later (Astin et al., 2013). Problems with sleep deprivation, appetite disruptions and an inability to adequately use available medical care systems after diagnosis in depressed and helpless patients were related to increased risk of death and cancer recurrence five to ten years later (Watson et al., 2012).

How women cope with diagnosis and treatment impact on both their immediate emotional distress and well-being (Heppner et al., 2009; Kvillemo and Branstrom, 2014), and their long-term adjustment (Astin et al., 2013; Watson et al., 2012). Coping strategies vary both between women and over time post-surgery (Geyer et al., 2015; Hervatin et al., 2012). In contrast to quantitative research that focus on coping strategies, this study provides useful information about women’s post-surgery perspectives regarding individual coping experiences and reflections. Such information on a detailed, subjective level is important if we are to facilitate psychological well-being across the cancer trajectory. The purpose of this follow-up study was to describe women’s individual coping experiences and reflections following their first year after primary breast cancer surgery. To our knowledge no studies have been done with a similar aim and design.

2. Methods

A qualitative descriptive design was employed with data collected through individual interviews between August 2007 and April 2008. The participants could choose where to be interviewed: all chose the hospital setting. All interviews took place in a meeting room at the hospital at the time of the regular one-year follow-up examinations. The interviews lasted from 54 to 100 min. Based on our previous research (Drageset et al., 2011, 2012, 2010), we chose a semi-structured interview with four fixed questions: “How have you experienced the first year after surgery?”, “How have you coped during this year after surgery?”, “What gives you strength to move on?”, “What are your thoughts about the future?” These questions were probed further. Non-verbal communication and the interview atmosphere were recorded immediately after each interview.

2.1. Recruitment and sample

Twenty-one women who had participated in our previous studies and had undergone primary breast cancer surgery at a Norwegian university hospital were invited to this follow-up study, 12 months post-surgery. Ten agreed to participate. For ethical reasons we had no access to information about those who declined, or the option to increase our sample by recruiting other women with breast cancer in similar situations. A good saturation was attained from these ten interviews, because the participants were open and reflective. All were Caucasian, had similar cultural backgrounds and came from one geographical area. Participants’ ages ranged from 48 to 68 (mean: 56.8). Eight were married or co-habiting and two were divorced. Eight women lived with somebody (spouse/partner/children); nine had children. Four had completed lower secondary school education, three had completed upper secondary school and three held academic degrees. Eight were in full-time or part-time employment and two were retired. Three were on partial sick-leave. Stages of the disease at diagnosis were I–II. Of the ten participants, seven had undergone unilateral mastectomy, three lumpectomy, four both chemotherapy and radiotherapy, three radiotherapy and five were on hormonal therapy. Every participant’s surgery was completed one year before the interviews except reconstructive surgery. All participants had been invited to join a nurse-led support group at the hospital around the end of their treatment, in which six had participated.

2.2. Data analysis

The method of qualitative meaning condensation analysis was used (Kvale and Brinkmann, 2015). This form of qualitative content analysis, used to identify prominent themes and patterns among themes, is much used in health research and well-founded within phenomenology (Kvale and Brinkmann, 2015). The interviews were analysed in three steps: self-understanding, common-sense understanding and theoretical understanding. In step one, the transcribed interviews were read to acquire a sense of the whole. Meaning units were identified. Self-understanding emerged as the researchers condensed the women’s statements according to the researchers’ understanding. The second step involved re-reading the transcripts while focusing on the content of the meaningful units. Interpretations were discussed in order to achieve a common-sense understanding. The researchers searched for patterns and variations in the women’s experiences. Kvale’s first and second steps are integrated in “Findings”. The third step, theoretical understanding, implied uncovering a deeper comprehension, where the relationships between the whole and the parts became clearer. That is found in “Discussion”. The themes are discussed in light of Lazarus’ (1999) theory of coping and other relevant theoretical concepts and research.

Guidelines were used to ensure trustworthiness (Kvale and Brinkmann, 2015). The interviews were conducted, audio-taped and transcribed verbatim by the first author. After each interview memos were written containing ideas and reflections for analysis. Data were analysed independently. To ensure consistency, the authors were continually in dialogue regarding the three steps of analysis. The meaningful units were discussed, and we assessed whether the intended focus was covered. Representative quotations from the transcribed text served as a reminder of the women’s voices in relation to each theme.

2.3. Ethical considerations

The Regional Committee for Medical Research Ethics approved this study. The participants signed a consent and confidentiality
form. Needs for emotional security were assured by not dwelling too deeply on threatening issues. The outpatient clinic offered a follow-up consultation, but none requested it. All participants reported having benefitted from the interviews.

3. Findings

Four themes were identified: existential concerns and finding meaning, ways of thinking and feeling about the disease, taking action, and returning to normal life. These themes were expressed by the women in their retrospective accounts of coping during the first year after their primary breast cancer surgery. Their retrospective accounts were not segmented into stages during that year, as the women did not connect significant different coping efforts to specific periods. However, a certain process differentiation in coping will be presented under “Discussion”.

3.1. Existential concerns and finding meaning

After diagnosis and surgery, the outlook on life and way of living changed for all. Their cancer experience led to thoughts about death. One said: “I think of death. I’m not so afraid of dying, but of losing my life.” Another said: “I think about life after death. I have my own philosophy about death. I don’t think it’s terrible. Perhaps it’s better than here.”

One woman expressed that her cancer experience had been good for her self-development: “The process I’ve been through has been good for me and my self-development. I’m not particularly religious, but I have found inner peace. When you find peace with yourself then you can give more to others and then others will also find peace.”

Some felt more appreciation and joy and no longer took life for granted; they now knew what was really important. One said: “Little things now mean a lot to me. I don’t take life for granted; they now knew what was really important. One said: “I’m depressed won’t help. Another said: “When I look in the mirror, I wonder daily, has the cancer spread?” Thinking ahead and making plans could be difficult for some, and they handled this by taking things gradually: “The furthest I can think is the coming weeks and months. I don’t make long-term plans.”

Fear of recurrence was particularly activated at the women’s routine checks at the hospital. “I think a lot about the future, especially when I have to go to check-ups once a year. I experienced this when I was here for a mammogram of the other breast and they found something. I have this constant fear: have they succeeded in removing my cancer?” For some, the fear of recurrence led to uncertainty concerning breast reconstruction. They feared that it might hide a recurring cancer. One said: “Recurrence is my concern. I’m unsure whether I want breast reconstruction.”

3.3. Taking action

Most dealt with the situation by taking action. Some were satisfied with their mastery and self-care. One said: “I’ve done what was right, in terms of support groups, talking about it, exercising a lot and not returning to work too soon. I recommend anyone who has been through this to focus on themselves for a while. It gives energy.”
For others it was important to return to work quickly, although it took some time before they felt in good physical and mental shape. One said: “I think the way I’ve coped has suited me well. I returned to work fairly quickly. Not because I was working so much, but it was important to return soon, have colleagues around me and be in action, although I had little energy immediately after radiation therapy.” Another, living alone, said: “I just looked forward to recovering and starting working again. I think being occupied helped me. I live alone and had plenty of time to delve into the depths of my misery if I wanted to.”

Returning to work early despite ongoing chemotherapy in order to feel in control was also expressed: “Throughout the treatment I was at work. I was sick during chemotherapy treatment and shouldn’t have been at work. But it was vital for me. With the chaos I felt, I needed to be at work. At least I had control over something.”

Some women coped by focusing on activities. Some enjoyed listening to music and various hobbies. Activities kept frightening thoughts about cancer away: “If I have nothing to do, I think about it more. If I listen to the radio or music, I'll sing and manage to push away thoughts about the cancer. When I sit in silence, thoughts arise.” In contrast, another woman preferred silence in dealing with the situation: “When walking in nature I find peace. At home I turn off the radio and television. I enjoy silence. I found help in meditation: “I’ve taken up meditation. It enables me to find peace. It has helped me.” Some were energized by activities with others, which seemed particularly important when living alone: “I try to do something, not just sit on the sofa. Get outside and do something with others. That works. One must not be immobilized”. Another focused on health and gaining new experiences: “I try to live healthily and be active. I travel and experience a lot. Seeing new places feels good.”

Physical activity was particularly important. One said: “It’s very important that I exercise. It feels wonderful to know that I’ve really used my body, even though I struggle when doing it.” One claimed that this was particularly helpful when undergoing chemotherapy, but it was also a way of showing her family that she was recovering: “Every day I took long walks in nature. That improved my mood. Of course, I’ve had days when I felt I had to lie on the couch, but just managing to get out of the front door felt good. I pushed myself a bit, because I knew I would feel good. I also wanted to show my family that I was getting better.”

### 3.4. Returning to normal life

The participants wanted to move on, put the cancer behind them and resume being as healthy as before their diagnosis and treatment. Therefore, some wanted to distance themselves from the cancer environment, patient role and all general cancer information. One said: “I feel sick just being in the hospital corridors. It evokes lots of emotions.” Another said: “I feel I have gone through enough stages. One is the treatment and the other is my psyche. I have reached a point where I have to move on. I think it’s dangerous to dwell on situations like this and on the disease. I joined the Cancer Society and attended some meetings. But now I need distance. I have to get back into normal contexts and out of the cancer context.” Another said: “People talk about cancer. One becomes reminded. I’m scared of hearing about other cases.” One said: “I read a lot when I was diagnosed and during the treatment period. No matter what magazine or newspaper I read, there was someone with cancer. Now I read mostly about health, about healthy food. I read about a young woman who died of breast cancer recently. It affected me. It doesn’t do me any good to read about cancer.”

### 4. Discussion

This study, in contrast to quantitative studies, provides in-depth, detailed, subjective and individualized process-related information about women’s coping experiences and reflections following their first year after primary breast cancer surgery. Themes that were identified include: existential concerns and finding meaning, ways of thinking and feeling about the disease, taking action, and returning to normal life.

#### 4.1. Existential concerns and finding meaning

Our participants’ outlook on life and their way of living changed. For most the cancer experience led to thoughts of death and loss of present life. A cancer diagnosis highlights the existential threat that life cannot be taken for granted (Curtis et al., 2014; Drageset et al., 2011). However, the illness experience can also generate positive change and give more meaning to life (Scheffold et al., 2014; Silva et al., 2012). Meaning-focused coping helps individuals to drop trivial problems, focus on important ones, and appraise benefits whenever possible (Folkman, 1997; Folkman and Greer, 2000). We found that the women’s cancer experience enhanced self-development by increasing their self-confidence and finding inner peace. Those who managed to find inner peace experienced that it helped not only in coping with the threat of death but also in calming others. Some felt more joy and a greater appreciation of the “little things” in life, as also reported by others (Salander et al., 2011; Silva et al., 2012), which is also found to improve coping with future stressful events (Folkman, 1997, 2008). Some participants re-evaluated their life priorities, and decided that their health was more important than their work.

Improved relationships have been reported post-diagnosis (Salander et al., 2011). Our participants revealed that family and close relationships had become more important, as had caring and compassion for others. Our findings reflect post-traumatic growth (Silva et al., 2012; Wang et al., 2014). Our participants transformed their traumatic experiences into positive life attitudes (Folkman, 2008). Looking at the processes over time, existential anxiety was most prominent soon after surgery, then reduced somewhat but remained “in the background” continuously. “The other side of the coin” was an enhanced gratitude for being alive, caring for others and, for some, a positive self-development over time.

#### 4.2. Ways of thinking and feeling about the disease

Treatments have side-effects to endure and psychological reactions to cope with (Khan et al., 2012; Montazeri et al., 2008). Our participants’ thoughts about having undergone breast cancer surgery had become increasingly distant. Most of them accepted their situation, and their partner’s acceptance was essential. Accepting the disease as part of one’s life is regarded as a coping resource with breast cancer (Jensen et al., 2014; Kvillemo and Branstrom, 2014). It implies cognitive restructuring to come to grips with the situation (Carver et al., 2010), a coping strategy which aims at maintaining positive emotions by adjusting values and re-conceptualizing goals (Folkman, 2008). A focus on mental strength enabled our participants to move on with life. However, accepting having had cancer and the loss of a breast could be difficult due to its relevance for femininity. Feelings of guilt about being absent from work could also be difficult.

Suppression of negative emotions and inadequate control following breast cancer surgery have been reported to increase psychological distress and depression (Heppner et al., 2009; Iwamitsu et al., 2005; Nakatani et al., 2013). Emotions are an integral part of the coping process, implying responses to new
information and continuous reappraisals of the situation (Lazarus, 1999). We found that talking and paying attention to emotions was important, as well as having adequate emotional regulation and control.

Positive thinking, a willingness to fight the disease and having hope are reported as important coping strategies among women with breast cancer (Alcalar et al., 2012; Rotegard et al., 2012; Wang et al., 2013). Hope is essential for coping with serious and prolonged psychological stress (Folkman, 2010; Hammer et al., 2009).

Similar characteristics contributed positively in our participants. However, these characteristics may be attributed to stable personality characteristics pre-surgery (Dragset and Lindstrom, 2005; Drageset et al., 2010).

However, we also found feelings of pessimism, depression, loss of energy and motivation, and inclinations to give up. Whereas a “fighting spirit” is related to lower depression and a better quality of life, hopelessness/helplessness leads to increased depression and a reduced quality of life (Alcalar et al., 2012; Schou et al., 2005). Good spirits and having previously successfully dealt with suffering and illness were important for our participants’ coping expectations (Dragset et al., 2010). Comparison with others who struggled with problems also helped. Having no problems with sleep or pain also promoted positive thinking and emotions. Similarly, several studies have reported that women who are burdened by somatic complaints after treatment suffer more anxiety and depression (Harrington et al., 2010; Ho et al., 2013). The importance of a supportive social network has been previously reported by us (Dragset et al., 2012). Now we also revealed that the family’s welfare was important for some of our participants’ well-being.

The women’s thoughts and feelings concerning the future manifested in both positive and negative forms. A healthy lifestyle contributed to positive expectations about the future. “Healthy living” may represent problem-focused coping in Lazarus’ theory (1999). However, we also found that some had pessimistic attitudes and prepared themselves for a short life. Our participants’ uncertainty and fear of recurrence were not irrational. The risk of metastatic cancer is a possibility, and therefore this fear is reasonable (Kvale et al., 2015; Simard et al., 2013). We found that fear of recurrence was intensified at routine check-ups at the hospital, and that information about those women who declined to participate. It might be that those who had considerable problems wanted to distance themselves, or that those who were continuously ill declined to participate. Finally, we cannot rule out that the answers may have been influenced by social desirability, and that the hospital setting may have been a non-neutral setting.

4.4. Returning to normal life

Returning to normal life was a highly motivating factor for recovery and an efficient way of coping with the situation. The women wanted to leave their cancer experiences and return to life as it was before diagnosis and treatment — clearly a problem-focused coping strategy as reflected in Lazarus’ theory (1999).

This desire for “normality” is an important factor in coping with breast cancer (Dragset et al., 2010; Husebo et al., 2015). Reminders of cancer caused fear and increased insecurity. The media also had an effect. Some felt bombarded by information about cancer and cancer deaths. Our participants wanted primarily to get information about improving their health. Over time there was a radical shift from having been deeply involved in treatment regimens to wanting to distance themselves as much as possible from the cancer patient role, cancer environment and cancer information.

4.5. Limitations

A major limitation in our study is the small sample size, which limits the possibility of drawing generalizations. We had no access to information about those women who declined to participate. It might be that those who had considerable problems wanted to distance themselves, or that those who were continuously ill declined to participate. Finally, we cannot rule out that the answers may have been influenced by social desirability, and that the hospital setting may have been a non-neutral setting.

5. Conclusion

Uncertainty and anxiety about a potential future cancer relapse was a major undercurrent even one year after surgery. For some this implied living from day to day, not trusting they would live long. However, the majority showed an increasing appreciation of life. Our findings emphasize the richness in these women’s coping
strategies, their various coping profiles and different needs as well as some general adaptive strategies – all of which fluctuated over time. However, not all managed to cope equally well. Therefore promoting adaptive coping is essential for further practice. Our recommendation for further studies is intervention studies focusing on coping increments and anxiety reduction. Our findings might be used in planning such intervention studies.

6. Implications for practice

Through awareness of these women’s individual experiences and coping strategies, healthcare professionals can improve care, and hopefully enhance these women’s ability to cope. It is important to be aware of the process-related changes in the women’s lives over time adapted to individual needs and situations and always with individual respect.

Conflict of interest statement

None.

Acknowledgements

The authors thank the patients who participated in the study, and who gave us the privilege of sharing their stories. We also thank Haukeland University Hospital, Breast Clinic Department, Surgical Outpatient Clinic for valuable support and cooperation.

References


