

Women's experiences of social support during the first year following primary breast cancer surgery

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Aim: The aim of this qualitative follow-up study was to describe women's individual experiences of social support during their first year after primary breast cancer surgery.

Method: Individual semi-structured interviews with 10 women 1 year after surgery analysed by Kvaales' meaning condensation method.

Findings: Sharing experiences, being understood as an individual, continuity, and information and explanations were themes identified. Sharing mutual experiences increased the women's knowledge regarding cancer, increased experience of support and minimised rumination. After 1 year, the women felt that the network

around them had 'normalised' and was less supportive. Being seen as a person, not as 'a diagnosis being treated', and continuity of professional support were important, giving feelings of security and trust. The women felt uncertainty after loss of professional support post-treatment. Information and explanations regarding treatment and treatment-related problems were essential.

Conclusions: Mutual sharing of experiences is an important part of social support. Continuity, availability, information and respect were essential aspects of experienced professional support.

Keywords: breast cancer, patients' experiences, healthcare professionals, social support, social network, qualitative research, follow-up study, nursing.

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Introduction

Breast cancer is the most common cancer in women worldwide. Women affected by breast cancer go through different phases during their first year after surgery which require various types of support (1–3). However, it is reported that the diagnostic phase, treatment period and initial recovery period are particularly stressful (4, 5). Women confronting breast cancer have treatment-related problems that may need special attention and support, such as fatigue, pain, changed body appearance, distress, depression (6–8), anxiety and uncertainty (5, 9), and fear of recurrence (3, 10). This means that these women may need social support in new and different ways.

Social support is a multidimensional concept comprising emotional, instrumental and informational

components (11–13). It is characterised by a reciprocal exchange of information, is context specific and results in improved mental well-being. Necessary resources for social support include a social network and conducive climate (14). According to Finfgeld-Connett (15), the concepts of social support and care share common attributes, but substantive differences exist. Caring in nursing lies within the perspective of expert nursing providers, while social support is primarily within the domain of lay providers.

Social support is regarded as important in adjustment to breast cancer (16, 17). The need for social support varies (2, 18, 19), with the highest support needs during treatment (20, 21). Good social support at diagnosis and treatment is associated with lower distress (4), fewer depressive symptoms (22), a lower risk of recurrence (23) and longer survival (17, 23). Lack of social support is associated with distress (24), maladaptive adjustment (22, 25), cancer-related fatigue (7, 26), depressive symptoms (27) and more supportive care needs (7).

The main sources of social support among women with breast cancer are generally their spouses, children,

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relatives and friends (28). Healthcare professionals also provide social support. Professional information and having someone to talk with personally are essential (3, 18, 29). Peer support and psychosocial group intervention can also be important (1, 30, 31) although mixed findings are reported (32, 33). While patients receive much support close to the diagnosis period, helpful support decreases significantly within the first year (16, 19, 28). Patients with cancer expressed feeling left in a 'vacuum' after being discharged from hospital, and living with serious unmet informational needs (3).

Although there are several quantitative follow-up studies addressing this topic, few use qualitative designs to gain deeper insight into these patients' experiences of social support in the year following surgery. Qualitative interviews can provide insight into women's experiences of when they feel supported and when not, and also into the impact of their social situation. In addition, an in-depth understanding of social support is needed to provide best social support postsurgery. Therefore, the aim of this follow-up study was to describe women's individual experiences of social support in their first year after primary breast cancer surgery.

Methods

Design, sample and setting

Using a qualitative descriptive design, 21 women who had participated in our previous studies and had undergone primary breast cancer surgery at a Norwegian university hospital were invited to this study 1 year after surgery. Of these, 10 agreed to participate. For ethical reasons, we had no access to information about those who declined, so comparisons between these groups could not be made. The participants received the invitation to participate with the information regarding their regular 1-year follow-up examination. All had similar ethnic and cultural backgrounds and came from western Norway. All interviews took place in the hospital. 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.

Data collection and analysis

Data were collected from August 2007 to April 2008. Based on our previous research (9, 18, 34), a semi-structured interview guide was developed. The interviews lasted for 54–100 minutes. The informants were asked: 'How have you experienced social support during this year?', 'How have you experienced support from health care professionals?' and 'What did you experience as supportive?' These questions were further probed according to each participant's answer. The interview atmosphere

and nonverbal communication were noted after each interview.

Interviews were analysed in three steps using the method of qualitative meaning condensation (35). The levels are as follows: self-understanding, common-sense understanding and theoretical understanding. The first and second levels are integrated in Findings. The third level is elaborated in Discussion. First, the transcriptions were read several times to get a sense of the whole through the singular expression. The meaning units were identified, and the data were condensed. Self-understanding occurred as the women's statements were condensed in line with the researchers' understanding of the expressed meanings. At the second level, the transcriptions were read several times to achieve a common-sense understanding and a broader comprehension of the expressed meaning. Different themes were identified and transformed into meaningful units and then coded into major themes. At the third level, theoretical understanding aimed to reveal a deeper meaning, and the relationships between the whole and the parts were scrutinised. The themes were discussed in the light of relevant research and theoretical concepts of social support and caring.

To increase the trustworthiness of this study, the interviews were conducted, audio-taped and transcribed verbatim by the first author. Memos were written during the analysis to ensure that impressions, ideas and reflections were not lost. The authors analysed the data independently, and the findings were discussed by all the authors to reach agreement.

Ethical considerations

The Regional Committee for Medical Research Ethics approved this study. Participants were safeguarded through written consent and confidentiality. The women's needs for emotional protection were respected by not dwelling too deeply on threatening issues. The outpatient clinic offered special follow-up consultations with professionals, but this was never requested.

Findings

Demographics. The participants' mean age was 56.8 years old (48–68). Eight were married or cohabiting and two were divorced. Eight lived with somebody (spouse/partner/children); nine had children. Eight were in full-time or part-time employment, and two had retired. Three women were partially on sick leave. Four women had completed lower secondary school education, three had completed upper secondary school, and two held degrees from university colleges and one from university. Of the total sample, seven had undergone a mastectomy, three a lumpectomy, four chemotherapy, seven radiotherapy, and five were on hormonal therapy.

Themes. Four themes emerged as important for social support: sharing experiences, being understood as an individual, continuity, and information and explanation. These themes may appear to be very different, but are connected in various ways within the multifaceted experiences of social support in our participants.

Sharing experiences. Sharing experiences and being open about their cancer were important for most of the women: 'I need to talk about it to someone who is actually interested. This is my story. It's an essential part of my life'. Sharing experiences with others who had been through the same thing was essential. Some used the internet to join the breast cancer organisation and to chat with other women with cancer. Gaining more knowledge through others' experiences felt good: 'It feels good to hear about others' experiences. I can learn something'. Talking about their cancer *if* it could help others was also emphasised. In contrast, one woman did not want to talk to others with similar experiences: 'We are so different and received different treatments'.

Sharing experiences with family members was essential for all. However, not all could share their experiences with their family: 'I cannot share my concerns with my family. They're so concerned about me; they are more anxious than me. I ventilate mostly with my friends'. Some women carefully considered to whom in their social network they could talk about their cancer: 'I wouldn't tell everybody. Some are more anxious than others'.

At work, sharing experiences was essential for some, but could also be experienced as difficult. Those who wanted to keep things to themselves found their colleagues to be curious, while others experienced their colleagues as insecure. Openness about their cancer helped: 'If I met colleagues and they asked how I felt, I said exactly how I felt. When I met them again at work, they talked to me more'.

Sharing experiences with other women with breast cancer in the nurse-led support group at the hospital was helpful for most. Realising that they were not 'alone' in having breast cancer and gaining different perspectives were beneficial. They experienced that each had their own story and was concerned about different aspects of their situation: 'I'm glad I joined the support group, hearing the others' stories. I saw it from different angles and not just my own'.

For some it was 'therapy' to talk as much as they wanted without others being tired of listening. The group processes increased the women's openness and respect for the others' experiences: 'It's important that one is open and respectful of each other's experiences. We are all suffering, each in our own way'. Talking in the group about the cancer at an early stage after surgery to get clarification on common issues was important: 'I think

it's important to talk about it, especially at an early stage. I have many silly questions, but others have them too'. Getting to know others in the group was emphasised. One woman with a limited network said: 'I met one woman in the group who I will continue to have contact with'.

Talking with others who received treatment at the same time was important: 'Having others for company certainly helped me. It reduced much of my fear. Otherwise I would have undergone radiation therapy and gone home to ruminate'. However, sharing experience in a group was experienced in varying ways. One woman preferred to share experiences when doing physical activities outdoors: 'I would talk to them when doing physical activities outdoors instead of sitting indoors'. For some the invitation to participate came too late in their process: 'I would have participated if it had not been "digging up" the past instead of looking forward'. Another could not find anyone in the group she wanted to share her experiences with: 'We were not on the same wavelength, we were so different. I found no one there I wanted to contact later'.

Being understood as an individual. Support and understanding, primarily from closest family and friends, were important for all. Emotional support was most important for some: 'Closeness, and that someone is with me mentally and talking to me when life is difficult, is good support. But they trivialise what I have gone through. I want them to ask about how I feel and take me seriously'. Another said: 'It's not always necessary to say much, just to put an arm around my shoulder and give me a hug. That's better than words. It's important to let the person with a cancer diagnosis talk'. In contrast, others felt that people around them showed too much concern. One said: 'They must not feel sorry for me – it makes me cry'. Another said: 'I'm not the kind of person who asks for much support'.

Some experienced changes in social support from close family members during the first year. One woman felt protected by her family: 'If I feel unwell or tired, they overreact and overprotect. But they don't talk about my cancer'. Another experienced close family members becoming distant and making little contact: 'My husband's mother and sister have been distant in this process. It's disappointing'.

Some women experienced similar changes in their network: 'I notice that some stay away when they discover I have cancer'. However, some had gained unexpectedly closer relationships: 'Some people have been surprisingly attentive and understanding. That has pleased me'.

For most of the women, the support from family and social networks had almost 'normalised'. For some that was fine: 'Now the support has almost normalised. They know I can manage fine'. Another said: 'Obviously there

was more care before. Now a year has passed, and the support must normalise a bit'. For others, the 'normalisation' came too early. Some experienced that their family and social network had forgotten their cancer and still wanted attention: 'I seem so healthy, my social network and particularly my family have forgotten that I have been ill'. Another said: 'I felt that people thought I recovered quickly. It was like: there's nothing more to worry about and she doesn't need comfort'.

Having contact with colleagues and superiors at work during sick leave was essential for most: 'It's very important to have good colleagues. Returning to work has really helped me'. Being understanding about a reduced physical capacity was also important: 'It's important that my colleagues understand that I may have to rest sometimes'. Another said: 'My employer has been very generous. I could come and go as I wanted during this period'. However, one woman said: 'My colleagues have not been in touch with me. At work I felt drained of energy'.

Regarding healthcare professionals, being understood and seen as a person rather than as 'a diagnosis being treated' was expressed as highly important. However, some felt they were treated more as an object than a person. One said 'Even though I met many doctors, I felt that it was just a cancer diagnosis that was treated and nobody saw the cancer was *mine*. They followed standard procedures regarding what they said and did. It was a kind of indifference. Nobody saw me as a *person* having cancer. I felt so alone. They were efficient'.

Some felt dehumanised; one said: 'The doctor looked only at the screen. I felt that I was not a person who was present'. Another said: 'It didn't matter what I said or wanted, the doctor met me in a stereotyped way'. In contrast, it was appreciated when somebody in the healthcare team said they had undergone similar experiences: 'It felt so good that she understood my situation. Meeting her was important because she knew how it felt'. Others felt that their doctors were compassionate: 'You have doctors who see that you suffer and ask you the right questions: do you feel that it has been difficult? Not just questions about cancer'.

Continuity. Having continuity, seeing the same professionals during treatment at the hospital, was important as an experience of social support: 'The doctor who took the biopsy was also the one I met when being operated on. I felt secure'. Another said: 'The doctor asked what had happened since last time. It gave me confidence'. Continuity also engendered a feeling of satisfaction with the health care: 'I had the same doctor before surgery, during surgery and when I received my treatment plan after surgery. I was very content'.

However, some women met various doctors during their treatments. This lack of continuity led to poor communication, a distrust of the healthcare system and

uncertainty. One woman met a temporary doctor who was poorly prepared for informing her about her treatment: 'I had an incredibly unpleasant experience. The doctor hadn't read my papers properly, and told me that I should only have radiotherapy. Later the doctor called and said it was wrong. Maybe the doctor had mixed up the papers? I felt that they were not being responsible'.

Continuity of support from the hospital after treatment was important for all. Most were satisfied with the availability and care of nurses when they telephoned. To know that their healthcare professionals were available and had time for them was essential. One said: 'Simply knowing that they follow me up and take me seriously – it's very important that they have time if there is something I need to ask'.

However, some felt uncertainty and a loss of support when left to themselves after treatment. Some worried about their inability to distinguish pain from signs of possible cancer recurrence. 'If I felt pain my first thought would be: is this a cancer relapse?' One felt she complained too much if she asked for more follow-up examinations: 'It was as though it was my responsibility. I felt I was complaining if I asked: aren't you going to check that everything is okay?' Another experienced helplessness at being completely entrusted to her own self-care: 'I feel helpless having to rely on myself. They won't waste more time on me. There are others who need it more'.

Information and explanation. However, most of the women felt that they received adequate information and explanation from healthcare professionals and were able to call the hospital if needed. Information leaflets from the hospital were also helpful for most, particularly concerning physical activities. One said: 'I used that information daily after surgery. It was really informative and gave results'. Some felt that the information they received was primarily given in the support group. One was uncertain whether she had sufficient information: 'I sometimes feel that I have not received enough'. For some, information regarding pain was most important. Having pain made them think it meant new cancer growth: 'I should have been told that I might have pain. I've been a bit insecure. Why do I have pain?'

Information about possible side effects of treatment was stressed by some. One woman was afraid of the side effects of radiotherapy and wondered why she had not been informed about possible side effects: 'Why has nobody told me this before? When I received treatment health professionals made "the programme" for me. Now, I wonder what might happen to me in the future'. Another was afraid that she was not properly investigated after radiation therapy and did not know what to ask about: 'I felt like I wasn't properly investigated after the radiation therapy. Had the cancer moved on to the

liver, lung or kidneys? I didn't know what to ask about'. One talked about the follow-up controls and did not understand how the doctors could know whether or not she had developed metastases. One said: 'I've had my follow-up and the doctor was pleased. I don't understand how they can know whether I have a metastasis or not, and say there is nothing in my lymph nodes'. Some also wanted more information regarding the financial and social security rights they had as a patient with cancer.

Discussion

Sharing experiences with others who were interested in their story, both in social networks and through the breast cancer organisation, was important for most. It enhanced well-being and knowledge (36), and helping others could be an extra benefit. However, depending on the situation and individual characteristics, we also found that sharing experiences was not always wanted or needed (24, 37).

Sharing thoughts and concerns with family and social networks may reduce stress and uncertainty (24, 34, 38). Surprisingly, even 1 year postsurgery, some participants experienced that their family and friends became so anxious they felt obliged to be silent about their cancer. However, despite our participants' need to share, they were primarily sensitive to their family's and network's needs. Sharing experiences at work was essential for some but difficult for others. One important finding was that the women's own openness about their cancer helped their colleagues to communicate.

Sharing experiences in the nurse-led support group at the hospital was experienced as helpful for most. It also gave an opportunity to bond with other group members (1, 30). It created an atmosphere of unconditional acceptance and respect where no questions were considered stupid. Other research supports these findings (39).

Rumination is associated with increased symptoms of anxiety and depression (40, 41) and a poorer adjustment to breast cancer (25, 40, 41). We found that sharing experiences, particularly between those who had received the same treatment in the same time period, helped to minimise fear and rumination. Talking in a supportive environment is important in the cognitive processing of cancer (25). However, sharing experiences in the group could be experienced negatively: it is not possible to control the interactions that may occur in a support group, so there is no guarantee that the interaction will be helpful for all (11). Furthermore, some may be good at coping on their own and may not need help from others. Sharing experiences when engaged in physical activities together was often preferred; physical exercise can enhance psychological health and can help to manage emotions (34, 42–45).

Social support is a multidimensional concept which has been defined in various ways (12–14). The theme of sharing experiences encompasses particularly expressive and emotional functions of social support, such as intimacy, attachment, reassurance of worth and confidentiality, within a framework of trusting relationships. It also promotes guidance and informational support.

Being understood as an individual primarily by family and friends was important for all. Attributes of social support resemble care, which includes expressing understanding, respect, empathy and compassion (14, 15). Our participants wanted emotional closeness and understanding and objected to others trivialising their problems.

Depending on the circumstances, emotional support can be shared nonverbally through attentive listening and nonverbal empathy (14). Simply being present and giving hugs was often better than words. However, 1 year after surgery, most women wanted to be treated as normal. Too much attention and consolation could lead to self-pity. Some perceived themselves as persons who usually did not ask for, or need, much support.

Social support needs are dynamic and change according to the circumstances (12, 14). Some experienced the support offered by close family to be 'overprotective', implying overreacting or avoiding openness. Inappropriate support has been reported to increase emotional distress (18, 24, 46) and is associated with poor psychosocial adjustment (25, 47).

In contrast, some women experienced that close family members and friends made little contact and that their network became distanced. Social support providers may need some psychological distance to avoid becoming emotionally vulnerable (14, 18, 39). As shown in previous research (38, 47), avoidance of problems and a non-supportive attitude were associated with negative feelings among those in need of support. Unexpected attention, understanding and encouragement, and new friendships were particularly positive experiences.

Most of our participants reported that the social support from family and social networks had 'normalised' and that the amount of attention had declined. This is normal after recovery (16, 19, 28) and was acceptable to most. Others wanted continued attention and felt people had forgotten their cancer too soon.

Poor social support from colleagues and superiors at work following breast cancer surgery has been found to be associated with sickness absenteeism (48). We found that regular contact and support from colleagues and supervisors during sick leave made it easier to return to work. Unfortunately, we also found experiences of poor support at work, which is reported to create negative feelings about returning (49).

Regarding being a patient in health care, being seen as a person and not as 'a diagnosis being treated' was very important. Caring reflects expert nursing practice and is

an interpersonal process characterised by interpersonal sensitivity (15). Interpersonal insensitivity occurs in nursing and medical practice when it is hurried, mechanical and lacking 'the human touch'. Increased focus on financial constraints may reduce the time for caring and individual attention, leading to greater emphasis on procedures and cost-effective treatment protocols (50). In such situations, patients can easily be seen as medical objects, with healthcare professionals not relating to the patients' more personal concerns. Caring should be personalised for each person (18, 51), and interpersonal sensitivity can be demonstrated through simple gestures such as attentive listening, making eye contact and offering verbal reassurance (50).

Being understood as an individual is a theme that comprises attachment, social integration, opportunity for nurturance, reassurance of worth, and a sense of reliable alliance (12), all of which contribute to the quality of social support and the feeling that one is cared about. As with sharing experience, being understood as an individual is a form of emotional support.

Continuity, seeing the same professionals during treatments, was an important component of social support and gave feelings of security, trust and satisfaction with the healthcare system. Health professionals' responsibility for delivering information and support in a way that is understandable is highly important throughout the cancer trajectory (24). Discontinuity led to poor communication, insecurity and distrust. This made some participants feel that they were responsible for their illness and recovery (3). To know that healthcare professionals had time to provide care if needed also after treatment was essential. However, many felt uncertainty and the loss of continued monitoring once treatment had ended. Other studies have reported similar findings (52). Our participants feared the responsibility of self-monitoring their recovery, and being aware of possible cancer recurrence. Patients' fear of recurrence is almost universal (2, 3) and triggered by physical symptoms of varying origins (52). In this, some felt helpless, fearing being labelled a 'complaining patient' wasting professionals' time when requesting more follow-up examinations. Our findings are in line with previous studies reporting that many patients become distressed over the loss of this 'safety net' (2, 52).

Continuity, seeing the same professionals during treatments and follow-ups, corresponds in many respects to tangible support in the relevant literature (13). Such continuity builds intimate relationships (50), communicates security and conveys trust, in contrast to discontinuity, which conveys insecurity and distrust.

Information and explanation were adequate from the health professionals, in particular in the nurse-led support group. This was an important aspect of social support. As also reported in other studies (53), the hospital

leaflet gave useful information. Information about physical exercise adapted to their special needs was particularly helpful. The importance of healthcare professionals as a source of informational support is reported in several studies (3, 54), but patients also need information tailored to their individual personal needs (16, 18). In particular, having persistent pain led patients to think it was related to recurrent cancer. We also found that information about possible side effects after treatment was important. Physicians and nurses need to take an active role in offering information, instead of expecting patients to ask questions (29). Caring involves listening, providing adequate information and offering reassurance and help (50).

Similar to a previous study (55), we found that some wanted not only medical information but also information regarding financial and social security rights they had as patients with cancer. Proper care includes helping patients express these concerns openly. Only if patients are frank about their worries can adequate and individualised information be given.

Information and explanation as a theme correspond to what has been called informational support (11, 13). As such, it appears to be a more 'technical' and instrumental form of social support. However, it can also function as emotional support in that it can reduce anxiety and rumination.

Clearly, the four themes reported in this study have similar aspects, just as the various components of the social support concepts overlap. Additionally, the concepts of social support and care share common attributes (15). However, there is a differentiation between social support and caring. Social support is a more global term and more used within the social sciences, whereas caring as a concept is developed within nursing theory. Caring is more intimate, holistic and within the perspective of expert nursing; social support is more private in nature (15). However, some participants expressed that major elements of social support were provided by healthcare professionals, and more was needed.

Limitations

Some possible limitations have to be presented. We had no information about the women who declined to participate. It is possible that the most articulate, socially open and healthiest patients participated. The participants came from the same geographical area with similar ethnicity and culture. Another possible limitation is that the data were collected in 2007–2008 and some changes in the hospital's organisational procedures have since been made. However, this involves no significant changes in the content of information following discharge that may have an impact on the conclusions drawn from this study.

Implications for practice

By understanding women's individual experiences and support needs, healthcare professionals can be important resources in providing support and information. Based on our findings, we can suggest that healthcare professionals could offer women with breast cancer opportunities to share experiences in support groups. Health professionals could also recommend that the patients keep in touch with their workplace during sick leave to facilitate their return. The need for continuous individualised and professional support during and after treatment should be acknowledged. Information tailored to women's individual needs is essential to the care and can best be given in dialogue with these women. Having the opportunity to call the hospital if needed was valued. To provide adequate health care it is essential to treat patients as persons and not as 'cases' and thereby includes women's psychosocial support needs along with their need for medical treatment.

Conclusion

Sharing mutual experiences appears to be important in women's experiences of social support. Continuity and availability of care and information, and being met with respect, were experienced as essential elements in professional support. Both private networks and health professionals tended to withdraw support too early. Caring for these women's psychosocial support needs should be integrated with medical treatment and procedures.

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Author contributions

Sigrunn Drageset and Torill Christine Lindstrøm were responsible for the study conception and design. Sigrunn Drageset performed the data collection. Sigrunn Drageset, Torill Christine Lindstrøm, Tove Giske and Kjell Underlid performed the data analysis, were responsible for drafting the manuscript and made critical revisions to the paper.

Ethical approval

The Norwegian Regional Committee for Medical Research Ethics approved this study (REC West). The reference number is 199.05.

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