

Social support experiences of breast cancer patients

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KEY WORDS

nursing
breast cancer
patients experiences
social support

ABSTRACT

Breast cancer is the most common cancer in women worldwide. After receiving diagnosis and during treatments breast cancer patients often find themselves vulnerable and in need of social support. Receiving social support may relieve patients' stress, help them cope with the situation and improve their general well-being. The aim of the study was to describe breast cancer patients' experiences of social support during their illness. The purpose was to present most recent information for nurses that can help them to acknowledge patients' individual support needs in order to better meet them. Furthermore, this could improve the outcomes of social support provided by nurses. The study was implemented as a literature review. The data were collected using two databases: CINAHL and MEDLINE, resulting in the selection of seven articles that were analyzed using inductive content analysis. The following four main categories of social support experiences emerged from the analysis: emotional support experiences, informational support experiences, instrumental support experiences and spiritual support experiences. As a conclusion, it was found that breast cancer patients' experiences of social support are highly personal and reflect their individual needs. Women's experiences may further be affected by their native or adapted cultures and also by their religions. Therefore, nurses should provide breast cancer patients with more personalized care that would pay attention to their personality, age, religion and cultural background. Nurses could also routinely contact women who are waiting for surgery and make a follow-up call after treatments, which would improve both emotional and informational support for breast cancer patients.

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1 Introduction

Breast cancer is the most common cancer in women worldwide (Joensuu 2015, 6.) Each year a million women are diagnosed with breast cancer and the number is predicted to grow with 20 % by 2020 (Kaarnalehto 2014, 125.) Receiving breast cancer diagnosis is a highly stressful experience for women (Drageset, Lindstrøm & Underlid 2009, 149-150; Stanton & Bower 2015, 232). The diagnosis may seem life-threatening and causes feelings of anxiety and depression. Initially women are usually shocked and find themselves in disbelief or denial, psychological distress also causes them to have problems with sleeping, eating, and concentrating. (Stanton & Bower 2015, 232.) Breast cancer patients may experience fatigue after the cancer treatments. They often suffer from depression as they are faced with a serious illness and other problems concerning their femininity after surgery or problems due to the treatments. (Joensuu & Rosenberg-Ryhänen 2014, 27.)

Adjusting to the new situation relieves the problems with psychological and physical dysfunctions (Stanton & Bower 2015, 232), especially if women actively accept the diagnosis (Drageset & al. 2009, 150). However, due to individual variation, significant number of women face a risk for persistent distress that may linger on even for years, disrupting their lives (Stanton & Bower 2015, 234). It is vitally for patients to receive support during hospitalization, since it relieves their stress, helps them cope with the situation and improves their general well-being. Nonetheless, several studies show that these patients feel that they do not receive adequate support in the hospital. (Mattila, Kaunonen, Aalto, Ollikainen & Åstedt-Kurki 2010, 734.) Therefore, the aim of the current study is to conduct a literature review to describe breast cancer patients' experiences of social support during their illness.

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2 Conceptualization of Social Support

Social support refers to the interactions between an individual and his/her social environment. The concept is also used to describe the resources generated from social interactions. These resources promote health and wellbeing of the individual. Moreover, social support portrays the process in which support is formed and delivered. (Mikkola 2006, 24.) The first definitions of social support emerged in the 1970's. While researchers' definitions of the concepts varied, they still shared the notion that social relationships could reduce stress and consequently have a positive effect on a person's health. (Vangelisti 2009, 40.) Like his colleagues, Cobb (1976) acknowledged that social support offered protection against negative health consequences of various life crises (Cobb 1976, 310). According to Cobb (1976), the recipient of social support receives information that makes him/her feel cared for and valued, furthermore giving him/her a sense of belonging to a network of communication (ibid., 300-301). Cobb's (1976) early concept of social support portrays one-way communication, information being received, whereas a later definition by Kahn and Antonucci (1980) emphasizes reciprocity in communication (Mattila 2011, 16-17). Kahn and Antonucci describe support as an interpersonal exchange that highlights expressing positive feelings and offering help. Simultaneously, it stresses recipient's perception of receiving help as a strengthening experience. (ibid., 17.)

Another way of approaching social support is through its objectives. Support is thus perceived as actions or resources whose goal is to support well-being and coping of the recipient. (Mattila 2011, 17.) In breast cancer care this kind of social support may be realized by using psychosocial interventions. These interventions have been developed to support the patient and her family during the course of the illness (Idman & Aalberg 2013, 860.) However, access to this type of hospital based support has been reduced since breast cancer patients' stay at the hospital has been shortened and their care shifted to outpatient facilities (Hewitt & Holland 2004, 161). Social support is also associated with social networks and contacts. Being a member of a social group may create feelings of belonging and sustain perceptions of support. (Mattila 2011,17.) Still, having several personal contacts is no guarantee for receiving adequate support (Leino 2011,43). Sometimes social contacts may even increase feelings of stress (Mattila 2011,17). Furthermore, received support is not always seen as a positive experience (Leino 2011,43). Support might not be wanted nor regarded helpful by the recipient (Vangelisti 2009, 42). He/she may perceive support either as a positive or a negative act depending on the social context and the nature of his/her relationship with the provider of support (ibid., 43, 45).

When defined through its functions, social support is usually divided into three different types: emotional, informational and instrumental (Mattila 2011, 18). Some studies consider that emotional support is the most important form of support due to its established connection to health. Besides, according to other studies patients have also experienced emotional support to be the most beneficial type of support. (Mattila 2011, 18.) Receiving this type of support may relieve patients' emotional burden, increase their emotional resources and facilitate coping (Mikkola 2006, 44). Emotional support entails listening, encouraging, showing empathy and acceptance (Mikkola 2006, 44). These interventions are all employed in nursing care, with empathy as a prerequisite (Kuuppelomäki 1999, 143). Other methods include being present, showing respect, acknowledging patient's feelings and discussing them (Mattila 2011, 35). It is also important to pay attention to patients' individuality in order to recognize their specific support needs (Mattila, Kaunonen, Aalto & Åstedt-Kurki 2010, 32). In addition, research has shown that it is easier for patients to express their informational needs rather than voice their emotional needs (Mattila 2011, 25).

Patients' informational needs relate to their illness, its treatment and self-care (Mattila 2011, 25). Information should be based on individual needs and delivered both in verbal and written forms (Browall et al. 2006, 40; Mattila 2011, 25). Receiving informational support from nurses reduces insecurity and increases feelings of trust and hope. However, if received information is inadequate, patients may feel highly distressed. (Leino 2011, 56.) Resulting from the shortened treatment periods, informational sources outside the hospital are becoming more significant for patients. Therefore, women are searching for information from literature and especially from the Internet. From the latter, they expect to find factual information rather than emotional or individual information. They may also obtain informational support from friends and acquaintances with experiences of breast cancer or from support groups. (Leino 2011, 56-57.)

Instrumental support is a concrete form of support that involves offering help and services (Mattila 2011, 19). Practical support may mean assistance with daily activities, such as making meals or driving the patient to the hospital (Hewitt & Holland 2004, 61).

3 Effect of breast cancer on women

Waiting for surgery can be equally stressful as receiving the diagnosis (Drageset & al. 2009, 149-150). During surgery a sentinel lymph node biopsy is performed in order to find out whether the cancer has spread to the axillary (underarm) lymph nodes and also to discover the cancer's stage. This includes the removal of one or more lymph nodes. (American Cancer Society 2017a.) However, in some cases, a more extensive number of lymph nodes (10-40) is removed by axillary lymph node dissection. (American Cancer Society a 2017.) After surgery women often experience various symptoms that also have an effect on their quality-of-life. Usually they feel tired and have difficulties sleeping. (Maukonen, Salonen, Rantanen, Suominen & Kaunonen 2011, 276.) Both sleeping and movements are limited due to the pain in the wound areas. The arm on the side of the surgery may have poor range of motion or swelling caused by build-up of lymph fluid. These symptoms can complicate daily activities like showering or driving. (Leino 2011, 28.) Limited physical functioning affects women's self-esteem, alters their sexual functioning and may induce sexual inhibitions. Changes that surgery has inflicted on their bodies may lead them to feel less "normal", less perfect, and make them question their womanhood and the image they had of themselves. (Berterö & Wilmoth 2007, 200.)

Over time, breast cancer treatments have become less damaging and at the same time more complicated and time consuming. Long lasting treatments interrupt social life, daily activities and complicate planning ahead. (Ganz 2008, 642, 644.) For example, radiation therapy usually lasts for several weeks and is given five days a week (Syöpäjärjestöt n.d.-a). It is a daily commitment that requires traveling, which in part increases fatigue caused by the treatment.

Browall, Gaston-Johansson and Danielson (2006) disclosed that women undergoing chemotherapy treatment perceived the treatment as an attack on their bodies. Loss of hair felt worse to them than the loss of a breast. They experienced constant fatigue that affected their bodies and minds. It was also difficult for them to concentrate and some experienced memory impairment (Browall et al. 2006, 34-41.) For younger, premenopausal women, chemotherapy induces slightly different side-effects. They may experience changes in menstruation and are at risk for infertility. (American Cancer Society 2017a.)

After the breast cancer treatments, some women experience feelings of loneliness and uncertainty as they face the future (Boehmke & Dickerson 2006, 1124, 1126). They may still suffer from treatment-related symptoms that affect quality of life (Janz et al. 2007, 1349.) Furthermore, some women exhibit fear of cancer recurrence (Boehmke & Dickerson 2006, 1121; Janz et al. 2007, 1349 Stanton & Bower 2015, 231). The fear is reportedly stronger in younger women (Boehmke & Dickerson 2006, 1126; Stanton & Bower 2015, 235) and in women with limited social support (Stanton & Bower 2015, 235). Lack of social support additionally presents a risk factor for psychosocial distress (Ganz 2008, 645; Hewitt & Holland 2004, 61).

4 The Purpose of the study

The purpose of the current study is to describe breast cancer patients' experiences of social support during their illness through a literature review.

5 Methodology

5.1 Literature Review

The current literature review is a selected compilation of evidence-based data that are available on breast cancer patients' experiences of social support during their illness. (Hart 1998, 13.) Analyzing individual research papers in comparison to other papers creates a more complete view of the research area and provides new insights into the topic (Aveyard 2014, 6). The present literature review systematically followed the steps below in order to give the research process clarity and transparency: 1) Defining the aim and the research question, 2) searching for and selecting literature, 3) appraising literature, 4) analyzing and synthesizing literature and 5) reporting results. (Niela-Vilén & Hamari 2016, 23.)

5.2 Literature Search

Preliminary literature searches were conducted by one researcher in June 2017. After making readjustments, such as limiting the scope of search more suitable for a single researcher, the final literature search was conducted on September 2017 using two databases: CINAHL (Ebsco) and MEDLINE (Ovid). Both databases are recognized as highly valuable databases for nursing research (Moule, Aveyard & Goodman 2017, 46).

The first search term was a MeSH (Medical Subject Heading) term *breast neoplasms*. The second one (connected with the boolean operator AND) was a free search term *social support* that was searched for in the abstract (AB) of the article. Some limiters were applied already at the beginning of both searches: full text available, published between 2008 and 2017, English language, gender: female and peer-reviewed. The subsequent search in CINAHL yielded 87 results and in MEDLINE 33 results. Thus a total of 120 studies were yielded from the database searches. The studies were then screened to see whether their titles and/or abstracts appeared to meet the inclusion criteria. Full texts of the 9 remaining studies were then assessed resulting in the final selection of 7 studies. The screening process is described in Table 1.

TABLE 1. The screening process.

Database	Search terms	Results	Chosen based on title and/or abstract	Chosen based on full text
CINAHL (Ebsco)	MH breast neoplasms AND AB social support	87	6	4
MEDLINE (Ovid)	MH breast neoplasms AND AB social support	33	3	3
Total		120	9	7

5.3 Appraisal of Data

The 7 included studies were appraised by the reviewer using the Critical Appraisal Skills Program (CASP) for qualitative research. The CASP tool helps in systematic evaluation of qualitative research and consists of 10 questions. The first two questions are screening questions appraising the aims and the methodology of the research. The rest of the questions assess following aspects: research design, recruitment strategy, data collection, relationship between researcher and participants, ethical issues, data analysis, findings and research value. The questions are answered with yes, no or unclear. (CASP 2017, 1-5.) All 7 analyzed articles addressed the two screening questions on the aims and the methodology of the research. Out of 7 studies, 5 addressed 5 of the remaining questions. As the overall quality of the studies was good, all were included in the present review.

5.4 Data Analysis

In the present literature review the data from research articles were organized and processed by qualitative content analysis in order to retrieve the essential information and meaning embedded in the data (Moule et al. 2017, 370-371). The content analysis was conducted in an inductive way by extracting specific, smaller units from the data and combining them into larger entities (Elo & Kyngäs 2008, 109). Data for the analysis were extracted from the findings of the selected articles. Coding was then executed by highlighting words or sentences and making notes. The expressions were then combined into categories, first into many sub-categories that were further grouped into fewer main categories. Formulation of the categories created an overall description of the research question through a process called abstraction (Elo & Kyngäs 2008, 111). Finally, as the data in the formulated categories addressed the research question (Aveyard 2014, 153), the question was placed on top of the main categories.

6 Research results

The seven included research articles were conducted in the USA (n=3), Norway (n=2), Jordan (n=1), and Israel (n=1). The articles were published between 2008 and 2017. All studies were qualitative in nature. The findings revealed 4 main categories of social support experiences described by breast cancer patients as: emotional, informational, instrumental and spiritual support experiences. The main categories and their subcategories are illustrated in the Figure 1, and are discussed in detail below

6.1 Emotional support experiences

Emotional support was highly valued by the women in the studies, as one of them expressed: "I need care above all; the fact that somebody loves me and says something nice to me." (Drageset et al. 2012, E43). It was demonstrated by empathy, understanding, appreciation, respect and love (Drageset et al. 2012, E43) and usually provided by closest **family and friends** (Buki et al. 2008, 165; Drageset et al. 2012, E43; Drageset et al. 2016, 342; Jones 2015, 8; Yoo et al. 2010, 1526). Sometimes the mere knowledge of available support made women feel strong and secure. (Drageset et al. 2012, E43.) In Palestinian society, emotional support was also shown in the form of physical presence, by "just being there" (Alqaissi & Dickerson 2010, 356). Informants felt that receiving emotional support from the family was positively related to their psychological well-being, meaning "feeling good, feeling self-assured, and not feeling depressed" (Buki et al. 2008, 165). On the other hand, they experienced rarer, unsupportive acts within families as emotionally devastating (Hammoudeh et al. 2017, 492). Sometimes, showing sympathy was construed as pity or could make women feel scared and vulnerable. Paradoxically, women wanted company, but also needed some time alone. (Drageset et al. 2012, E43.)

It was important for Norwegian women to share their breast cancer experiences with their families. However, some of them felt that their families worried too much over them and chose to talk to their friends instead. (Drageset et al. 2016, 342.) Contrastingly, Jordanian women preferred not to talk about breast cancer and expected their friends to do the same. Avoiding the subject was considered as an act of support. (Alqaissi & Dickerson 2010, 356.) Some informants reported that receiving support and care from the family instead of providing it was a welcomed experience: "It is good to lean on a shoulder without having to ask for it. I'm used to being strong and a comfort to others." (Participant quote Drageset et al. 2012, E43). For others, it was not easy to accept support from the family (Drageset et al. 2012, E44; Yoo et al. 2010, 1525). Women over the age of 70 were reluctant to ask for help from their

younger family members. They would rather appear self-sufficient than emotionally needy. Nevertheless, some, especially ones who were treated with chemotherapy, learned to ask for support and were pleased with the outcome. (Yoo et al. 2010, 1525-1526.)

Husbands were recognized as main sources for support during diagnosis, treatments (Alqaissi & Dickerson 2010, 356; Hammoudeh et al. 2017, 492) and in long-term survivorship (Buki et al. 2008, 166). Palestinian men provided emotional support by reassuring their wives and by accepting the physical changes caused by cancer (Hammoudeh et al. 2017, 492). Jordanian husbands, by contrast, showed emotional support mainly by being physically present at the time of surgery and chemotherapy (Alqaissi & Dickerson 2010, 356, 359). Still, many Jordanian women experienced that their husbands were unsupportive and did not accept breast cancer or resorted to emotional and physical abuse (ibid., 356). In the Norwegian study, husbands were sometimes perceived overprotective or the amount of support seemed excessive: "My husband is so caring I think it is simply too much of a good thing." (Participant quote Drageset et al. 2012, E44).

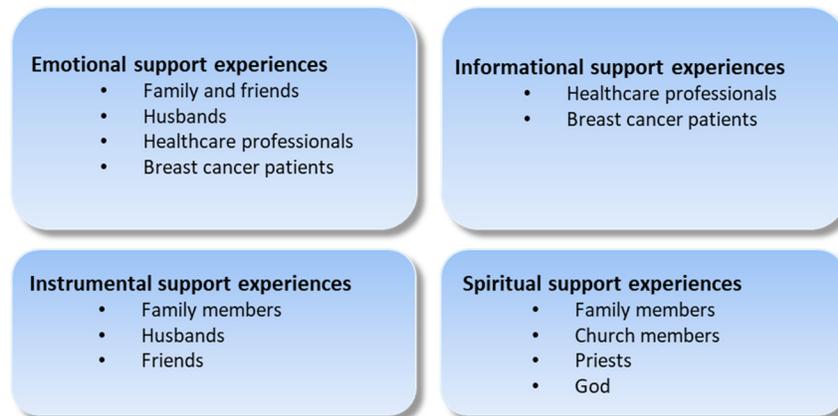


FIGURE 1. Four main categories of breast cancer patients' social support experiences

Although emotional support was mainly received from husbands/partners, family and friends, **healthcare professionals** were also recognized as important sources of emotional support: "It is important that nurses and doctors are skilled and give me care and comfort." (Participant quote Drageset et al. 2012, E44). Particularly patients who waited for surgery craved for contact from the hospital as a sign of caring (Drageset et al. 2012, E44). Similarly, older women needed emotional support from nurses during chemotherapy and other treatments. After learning to receive support, they were satisfied with the emotional care from the staff. (Yoo et al. 2010, 1526, 1528.) Some women wanted to talk to professionals since they were perceived as more neutral parties than families or friends. However, reaching for emotional support by calling to the hospital was difficult for these women, especially, if they were not familiar with the nurses. Some contacted their family doctors for more personalized support and were pleased with the outcome. (Drageset et al. 2012, E44.) On the whole, being treated as an individual by professionals was important. In some cases, women felt that doctors had treated them more as an object or a diagnosis than a person. (Drageset et al. 2016, 343.)

Alongside individual support, women also needed continuity of support. Patients who were treated by same nurses or doctors as before were feeling comforted and satisfied with the hospital care, as one woman stated: "The doctor asked what had happened since last time. It gave me confidence". Some patients met new doctors who communicated poorly with them. These experiences made them uncertain and doubtful of professional care. Continuity of support also meant that nurses were available by phone to patients after treatments, which was realized for most women and welcomed as a positive experience. (Drageset et al. 2016, 343.)

Women often recognized professionals as a possible source of emotional support, but preferred emotional support to be sourced from their social network (Drageset 2012, E41). The form of support they mainly sought from professionals was informational support (discussed further in the following chapter). Information from nurses could also be perceived as emotional support since knowledge brought consolation to women. (ibid., E43.) The Palestinian study showed that lack of emotional support from family and friends could not be replaced by professionals due to the deficiencies in the local health care system. For example, psychosocial care could only be provided by one hospital. (Hammoudeh et al. 2017, 494.) Availability of hospital based emotional care was also a dilemma in the Jordanian study. Women were treated in two hospitals, those who were in the cancer center hospital experienced positive supportive care, whereas women from the public hospital did not report similar experiences (Alqaissi & Dickerson 2010, 359). In Norway, emotional support from the hospital included a possibility to attend a nurse-led peer support group. Most women reported that attending this group helped them because they could share experiences by talking with other **breast cancer patients** and gain perspective by listening to their stories. (Drageset et al. 2016, 342.) Some informants found talking in a group therapeutic (ibid.) and others felt empowered by the experience (Buki et al. 2008, 166). However, some participants felt that the members of the support group were too different (Drageset et al. 2016, 342) or only complained about their negative experiences (Alqaissi & Dickerson 2010, 357). In addition to group support, women accessed individual support from breast cancer survivors among family or friends (ibid.) or from the peers in the internet chat rooms (Drageset et al. 2016, 342).

6.2 Informational support experiences

Breast cancer patients received informational support mainly from **healthcare professionals** (Drageset et al. 2012, E41). Women who received professional support were mainly satisfied with the amount of gained knowledge (Alqaissi & Dickerson 2010, 357; Drageset et al. 2016, 345) and trusted it more than information from nonprofessionals (Drageset et al. 2012, E45). Patients appreciated information on their diagnosis, the care plan and possible treatment options (Alqaissi & Dickerson 2010, 357). They also valued repetition of forgotten information with a nurse (Drageset et al. 2012, E43), hospital leaflets (Drageset et al. 2016, 345) and gaining information from a nurse-led support group (ibid.). Overall, women reported that receiving informational support during diagnosis and treatments had positive effect on their mental health (Buki et al. 2008, 166). However, some participants found deficiencies in informational support. They felt that the support could have been more personalized. One realization of individual care could have been a phone call from the nurse after the diagnosis. Patients had been advised to contact nurses when necessary but they were hesitant about calling themselves as one explained: "I don't want to disturb. Physicians and nurses are busy; they don't attend only to me. I don't know what is expected of me in a situation like this." Consequently, patients preferred that the nurses would take the initiative. (Drageset et al. 2012, E45.) Women also felt that they needed more information especially on issues that stressed them like pain and treatment side-effects (Drageset et al. 2016, 343-344).

In some Jordanian health care settings patients reported that their doctors gave inadequate, false or no information regarding diagnosis and treatment options. Here, due to cultural influences, information was controlled by physicians by for example not disclosing the diagnosis. In the Jordanian culture, doctors are perceived as professionals, whose decisions are not to be questioned and who are only protecting the patients by their non-disclosure. For these reasons, patients accepted any information given without questioning it, though several stated that they needed full disclosure of their illness. However,

within the same study, patients of the cancer center hospital received full informational support, probably due to the hospitals funding being tied to the requirement of full disclosure. These women felt they were given adequate information and a chance to make their own decisions concerning treatments. (Alqaissi & Dickerson 2010, 357-359.)

In several studies, informants automatically associated breast cancer with death (Alqaissi & Dickerson 2010, 355; Buki et al. 2008, 165; Hammoudeh et al. 2017, 491; Jones 2015, 7), avoided talking about it (Alqaissi & Dickerson 2010, 356) and refrained from using the word “cancer” (Hammoudeh et al. 2017, 491). This could be caused by poor local prognosis for breast cancer (Alqaissi & Dickerson 2010, 358), cultural beliefs or lack of knowledge (Alqaissi & Dickerson 2010, 360; Buki et al. 2008, 167; Jones 2015, 7). Some African American respondents had no knowledge of, for example, breast self-examinations and additionally their culture discouraged them from touching their bodies. These women learned about breast cancer mainly through their experiences and also from the experiences of other **breast cancer patients**. (Jones 2015, 7.) Many informants appreciated informational support from their peers (Drageset et al. 2012, E44; Drageset et al. 2016, 342) and one suggested that breast cancer survivors could best deliver information on the illness to the general public (Jones 2015, 9).

6.3 Instrumental support experiences

Family members provided instrumental support by helping breast cancer patients in daily chores. This practical help came from immediate or extended family and most often from female family members (Alqaissi & Dickerson 2010, 356; Hammoudeh et al. 2017, 492.), as one woman stated: “At time of chemotherapy, my sister and my sister-in-law used to do everything for me. They cooked for me, they gave me bath, and they took care of my daughter.” (Alqaissi & Dickerson 2010, 356). Many informants appreciated tangible help as it alleviated their emotional strain (Jones 2015, 8) and assisted them in providing for their families’ everyday needs (Hammoudeh et al. 2017, 492). However, some women felt guilty for not being able to manage their families by themselves (Hammoudeh et al. 2017, 492). Older women found it also difficult to ask for practical help, like rides to the hospital during chemotherapy. Still, most accepted their immediate families’ assistance since it was vitally important for them. (Yoo et al. 2010, 1527.)

For Jordanian women, the most essential form of instrumental support was financial aid that came from their families and **husbands**. For example, according to their cultural roles, Jordanian husbands were expected to financially support their wives. Some respondents also received money from **friends**, which they interpreted as an act of caring, especially, if they came from less wealthy families. Moreover, poor women found out that they were in desperate need of monetary assistance, as one explained: “I cannot afford the transportation. It costs me 7 dinars to reach the cancer center.” (Alqaissi & Dickerson 2010, 357.)

6.4 Spiritual support experiences

Participants from most studies regarded spirituality as an important source of support during their illness (Alqaissi & Dickerson 2010, 359; Buki et al. 2008, 166; Hammoudeh et al. 2017, 493; Jones 2015, 9; Yoo et al. 2010, 1527). Women received prayers from, for example, their **family members** (Alqaissi & Dickerson 2010, 358; Drageset et al. 2012, E43) or other **church members** (Yoo et al. 2010, 1527). In one study, prayers were used by **priests** as a part of spiritual healing, an African American ceremony. Most informants trusted the priests and would have chosen spiritual healing over medical treatment. (Jones 2015, 9.) An opposite view was presented by Palestinian women, as both Christian and Muslim participants regarded treatment as part of **God’s** will. As one patient expressed: “I came here to the hospital knowing that God is the one that cures, God created the treatment and God created the medicine (cure).” (Hammoudeh et al. 2017, 493.)

For Jordanian women, spiritual support from God was realized as they talked and prayed to Him. Religion gave meaning to their experiences: breast cancer was seen as a token of God’s love, a gift and a test of faith. In order to pass the test of faith women thankfully accepted their condition (Alqaissi & Dickerson 2010, 358-359.) Similarly, Palestinian women perceived cancer as test of faith and as God’s will. They, too, accepted their illness, though some experienced weaker moments that led them to question their fate. Overall, women were being active by using spiritual support as a coping tool instead of being passive and blindly submitting to destiny. (Hammoudeh et al. 2017, 493-494.) Spiritual support was also employed successfully by Latina women. As a result they developed a closer relationship to God and religion and started to see God’s love manifested in their experiences of social support. (Buki et al. 2008, 166.)

7 Discussion

7.1 Discussion of key results

Results revealed experiences from 4 categories: emotional support, informational support, instrumental support and spiritual support. A previous study by Mattila (2011, 18) also employed same categories, except for the category of spiritual support that could also have been placed here under the social support category. However, the present study’s findings showed the importance of spiritual support to the informants and thus it was presented separately. According to Mattila (2011, 18.), breast cancer patients experienced emotional support as the most helpful type of support. Similarly, the present study showed that emotional support was greatly valued by the women. This type of support relieved their stress, empowered them and enhanced their coping, as verified by Mikkola (2006, 44). However, in consistent with previous research by Leino (2011, 43) and Vangelisti (2009, 43, 45), the current study’s findings suggested that emotional support could also be perceived as a negative experience. Findings further indicated, in agreement with Lehto-Järnstedt (2000, 18), that the quality of perceptions was dependent on the personalities of the patients.

Consistent with previous research (Salonen et al. 2013, 397), the current review confirmed that patients’ main sources for emotional support were their spouses, families and friends. The present study further showed that most women readily accepted help from their families, with the exception of older women, who were hesitant to ask for either emotional or instrumental support. For some women it was also difficult to ask for emotional support from the hospital. Accordingly, Mattila (2011, 25) stated that it was more difficult for patients to voice their emotional needs than it was to express their informational needs. The present study’s findings indicated that women turned to health care professionals mainly for informational support, as confirmed by Salonen et al (2013, 397).

According to a previous study, patients felt that the support they received from the hospital was insufficient (Mattila et al. 2010, 734). Correspondingly, the current review revealed inadequacies in hospital based support. Results showed that patients desired more personalized care that would, for example, include a call from a nurse prior to surgery and also a check-up call after the treatments. Furthermore, a previous study suggested that paying attention to patients’ individuality would help in recognizing their specific support needs (Mattila et al. 2010, 32). Possible shortcomings in professional support were probably partly caused by developments in local health care systems leading to shorter hospitalizations (Hewitt & Holland 2004, 161). They could have also resulted from underdevelopment of local health care systems leading to inadequate support resources as presented by the two Middle Eastern studies

of this review. Lack of informational support could also be due to cultural influences like in the case of the Jordanian doctors' non-disclosure. The present study indicated that availability to professional, both emotional and informational support was vitally important to breast cancer patients. Mattila and others (2010, 734) reported that receiving support from professionals relieved patients' stress, helped them cope with the situation and improved their general well-being. The current study's findings coincided with this and further concluded that informational support could also provide patients with emotional support. In effect, receiving information gave patients comfort and had a positive effect on their mental health. Correspondingly, Leino (2011, 56) found that informational support reduced patients' insecurity and increased their feelings of trust and hope. However, present study revealed that women needed more information on stressful issues like pain and treatment side-effects. Receiving adequate information could relieve patients' fears of, for example, side-effects as pointed out by Leino (2011, 34).

According to the present study, patients could experience fear not only caused by inadequate information but also caused by cultural beliefs. Findings from four studies showed that breast cancer was culturally associated with death, which could make women avoid talking about the illness or even mentioning the word "cancer". It seems that women from cultures with adequate public education and information on breast cancer were more open and less fearful than their less educated peers. Interestingly, findings from the same four studies, revealed that spiritual support was regularly employed and highly valued by informants in these studies.

Compared to other types of support, instrumental support was in a minor role in the findings of the current study. However, practical help was essential for women in cooking, housekeeping and getting transportation to the hospital. It also served as emotional support as it relieved patients' emotional burden. Another form of tangible support was financial support from families, husbands and friends. For example, Jordanian women's experiences of care and support were dependent on the wealth of their husbands and families. As mentioned earlier, the importance of spiritual support emerged strongly from the findings of this study. For many women, religion provided meaning to the breast cancer experience and made them accept and embrace the illness. Interestingly, spiritual support could function in collaboration with health care or against it. For Palestinian informants, breast cancer treatment embodied God's will, whereas their African American peers would choose traditional spiritual healing over medical treatment.

7.2 Ethical consideration

As this literature review collected secondary data and had no contact with the participants from the published studies, no ethics approval was needed (Aveyard 2014, 16). However, the original articles were deemed reliable, since they were accessed using the Critical Appraisal Skills Program (CASP) for qualitative research. One article stated the research design but failed to discuss whether it was appropriate to address the aims of the study (Jones 2015). None of the 7 studies examined the relationship between researcher and participants. Researchers from one of study asked informed consent from the participants through a nonprofit cancer support organization and did not contact the participants themselves for confidentiality reasons (Buki et al.2008). However, compensation was given to the informants, which seems to violate ethics of research (ibid. 2008). Also concerning ethics, another study failed to mention getting informed consent from the informants. The recruitment was executed by local cancer organizations and by a local Cancer Registry, so presumably permission was asked from the participants. (Yoo et al.2010.) The present study followed the instructions of the Finnish Advisory Board on Research Integrity by presenting results without changing or omitting any information relevant to the conclusions. All accessed data were also referenced to in order to avoid plagiarism. (TENK 2012, 33).

7.3 Strengths and Limitations

The protocol of the present study was carefully planned in advance. Furthermore, it presented the research methods employed in the review and aimed to minimize errors at every stage of the process. (Valkeapää 2016, 64.) As the research methods, the inclusion and the exclusion criteria were set beforehand. Thus, the risk of introducing bias was reduced (CRD 2009, 6). The research process was also documented with care, which ensured repeatability that is essential to the reliability of the review. (Valkeapää 2016, 64.) Furthermore, the strength of the present study was the richness of data in the included studies. Informants came from diverse cultural and religious backgrounds, which provided more variation to the results. Limitations included using only published data, which could produce publication bias. Possibility of language bias also existed, since the review included only articles published in English. (Pudas-Tähkä & Axelin. 2007, 53.)

7.4 Conclusions and recommendations for further studies

The present study showed that breast cancer patients' experiences of social support were highly personal and reflected their individual needs. Furthermore, women's experiences seemed largely bound to their native or adapted cultures. Surprisingly, religion also played a major role in their experiences. Consequently, breast cancer patients would benefit from a more personalized support that would pay attention to their personality, age, religion and cultural background. As many countries are becoming more multicultural, there is a growing need for culturally sensitive care. Further research could be conducted to study breast cancer patients from different nationalities to find out their individual support needs in order to provide culturally competent care. Emerging from this study, were further recommendations for practice: nurses could routinely contact women who are waiting for surgery and also make a follow-up call after treatments. These relatively small interventions would provide major effect by improving both emotional and informational support for breast cancer patients.

Appendices

Appendix 1. Methodological details of the included studies.

Author/s (year), country	Research objective	participants	Design/Methods	Key Findings
Alqaissi et al. (2010), Jordan	To explore the common meanings of social support by Jordanian women after diagnosis and throughout the treatment	20 Jordanian women diagnosed with stage I, II, or III breast cancer; between 24-72 years old	Qualitative interpretive phenomenological research design with semi-structured interviews	Instrumental support was provided by female family members in the form of practical help and from husbands in the form of financial assistance. Availability of informational support from professionals depended on hospital resources. For Muslim women, spiritual support assisted coping with breast cancer and they accepted the disease as a test of their faith.
Buki et al. (2008), USA	To examine the experiences of Latina breast cancer survivors from diagnosis to long-term survivorship in order to develop psychosocial interventions	18 breast cancer survivors; between 35-67 years old Latina women	Qualitative research. Grounded theory with in-depth, semi-structured focus groups	Social support from the family, professionals and peers was critical at all stages of the breast cancer experience. During diagnosis and treatment women's psychological well-being was also related to receiving informational support from the professionals. After treatments women valued peer support and spiritual support. During long-term survivorship women appreciated support from the family, especially coming

Drageset et al. (2012), Norway	To describe women's individual experiences of social support during the time between diagnosis and surgery	21 newly diagnosed breast cancer patients; between 41-73 years old women	Qualitative, descriptive design with individual semi-structured interviews	from the husband It was important to have support available, if needed. Some also required emotional support by physical presence. Sometimes emotional support was perceived intrusive or "overprotective". After surgery, some needed continued support from health care professionals. For many, the amount of individualized information from the professionals felt inadequate. Women valued peer support from breast cancer survivors. All appreciated emotional support from family and friends. Most accepted the "normalization" of support from social network one year after surgery, others still felt in need for support. Informational support from professionals was considered adequate, but could have been more personalized. Informational support also functioned as emotional support.
Drageset et al. (2016), Norway	To describe women's individual experiences of social support during their first year after primary breast cancer surgery	10 women who had undergone breast cancer surgery 1 year before; between 48-68 years old	Qualitative descriptive design with semi-structured interviews	
Hammoudeh et al. (2017), USA/ Israel	To explore women's experiences of breast cancer in the occupied Palestinian territory	35 women at various stages of breast cancer, coming from West Bank and Gaza Strip; between 25-71 years old	Inductive qualitative design semi-structured interviews, Thematic analysis	Husbands were vitally important in providing women with emotional support, whereas instrumental support was mainly provided by female relatives. Both Christian and Muslim women relied on their faith and God for spiritual support
Jones (2015), USA	To develop an understanding of the knowledge, beliefs and attitudes of breast and breast cancer from the perspective of young women of African descent and their biological mothers	Young (between 20-40 years old) African American women with breast cancer (n=8) and their mothers (n=6)	Naturalistic qualitative research Semi-structured interviews.	Emotional support from the immediate and extended family was crucial for survival. Young women also received support from partners, friends, classmates and friends. Spiritual support in the form of spiritual healing was regarded more important than medical treatment, women also prayed and received prayers
Yoo et al. (2010), USA	To describe the impact of breast cancer diagnosis on older, racially/ethnically diverse women and their subsequent need for social support	47 older African American, Asian American, Caucasian and Latina women; between 65-83 years old	Qualitative, grounded theory approach with in-depth interviews using inductive and deductive analysis	Women were reluctant to accept or ask for emotional or instrumental support, but learned to receive and seek support during chemotherapy. They needed mostly tangible support and received it from their immediate family. Many women sought out spiritual support from church leaders and members. Some also obtained peer support from church members who were cancer survivors.

Additional Information:

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