A Shared Journey To a Better Future: Mutual Support Among Breast Cancer Survivors and Their First-Degree Relatives

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Abstract

Purpose

Breast cancer affects survivors and their first-degree relatives. They face breast cancer together as a unit. This study aimed to explore the mutual support of breast cancer survivors and their first-degree relatives in their joint coping with breast cancer.

Methods

A qualitative case study with purposeful sampling was conducted. Ten breast cancer survivors and 21 of their first-degree relatives were recruited for in-depth interviews. Data were analyzed by thematic analysis using MAXQDA software.

Results

Three themes were extracted under the overarching theme “a shared journey to a better future”: 1. “Mutual support is needed as we are in the same boat,” suggesting mutual support in responding to breast cancer; 2. “We experience stormy and windy weather during our journey,” emphasizing challenges encountered in providing support; and 3. “Sunny and breezy days are a gift for both of us,” indicating they perceived reciprocity during the process of mutual support.

Conclusions

Mutual support was an important feature of breast cancer survivors and first-degree relatives coping with breast cancer and beneficial to both groups. However, significant challenges in supporting each other were reported, indicating the necessity of external support in coping with breast cancer. Health professionals should not ignore first-degree relatives of breast cancer survivors, and need to support both of these groups.

Introduction

Breast cancer (BC) is the most common form of cancer and the leading cause of cancer-related deaths among women worldwide [1]. Several studies [2–5] have indicated that BC and its related treatment can have a strong negative impact on breast cancer survivors (BCSs). They might have experienced pain and body changes and continue to suffer from insomnia, isolation, and mental health issues.

However, the impact of BC is not confined to patients but also affects their families. According to Alexander et al. [6], BC and its treatment and management can impose a significant financial and psychosocial burden on patients’ immediate family, as they provide crucial support to BCSs [7–8]. Among
them, female first-degree relatives (FDRs) (mothers, sisters, and daughters) of BCSs are most worthy of attention. Not only do they experience the same burden as other family members, but they are also at high risk of BC as it is a disease with a genetic predisposition. Women with a family history of BC may have a 2.5-fold or higher risk of developing this disease than women without such family history [9], highlighting the importance of heredity. Research has shown that FDRs of women with BC may perceive risk, especially when they are involved in caring for someone with BC [10]. They may be at particularly high risk for distress and worry related to their BC risk, which may, in turn, lead to physical symptoms (e.g., persistent breast pain) and psychological distress [11]. FDRs of BCSs express the need for more factual information and emotional support, both of which are only met at a low level [12]. Sinicrope et al. [13] showed that adult daughters received BC risk reduction advice from their mothers with BC, and Ginter and Radina [14] reported that 30 mothers of BCSs tried their best to support their daughters with BC, with both of them emphasizing their “mother” and “daughter” roles and protecting each other. Fisher and colleagues [15] explored the experiences of 78 women (41 BCSs; 37 mothers/daughters) who indicated that mothers and daughters share information about BC, and their relationship was central to both parties’ adjustment to BC.

It is clear that both BCSs and their FDRs have to face BC together, and mutual support between them is considered to be particularly important during the process of coping with BC, especially when genetic factors have been identified as important determinants of BC incidence [16]. Research on support of BCSs and their FDRs has largely centered on BCSs supporting FDRs [12–13] or FDRs supporting BCSs [6, 10, 14]. However, their experiences as both recipients and providers of support at the same time may be different. The experience of BCSs and their FDRs supporting each other in jointly coping with BC is unclear.

Women of different social and cultural backgrounds may have different responses to cancer, especially as a disease that may affect both them and their FDRs. Chinese culture advocates the family network with people in the same family forming “a community that shares honor and disgrace” via deep cooperation [17]. When a family encounters difficulties, they prefer to overcome them together with the closest blood relatives—including parents, children, and siblings—then gradually extending outward. Thus, taking Chinese BCSs and their FDRs as an example, we aimed to gain a better understanding of their mutual support experiences. This knowledge may ultimately provide professionals with essential information for designing interventions that strengthen mutual support among BCSs and their FDRs to improve their quality of life.

**Methods**

As little is currently known about the mutual support of BCSs and FDRs when coping with BC, it was appropriate to begin with a qualitative case study design. A case study allows in-depth, multi-faceted explorations of complex issues and enables researchers to understand the nature of mutual support, as well as the meaning it holds for the BCSs and FDRs [18]. In this study, we viewed the BCS and her FDR(s) as a unit.
Purposive sampling was carried out in two large public hospitals in northern and southern China to obtain maximum variety. A total of ten BCSs who had been fully apprised of their BC were recruited for the study. They had at least one female FDR. Meanwhile, 21 FDRs of the ten BCSs agreed to participate in the study. All of the participants were older than 18 years. The characteristics of participants are presented in Table 1.
Table 1
Characteristics of breast cancer survivors and their first-degree relatives

| Family number | BCSs (age in years) | Disease duration (months) | FDRs (age in years) | Educational level | Religious beliefs | Medical insurance\(^{b}\) |
|---------------|----------------------|---------------------------|---------------------|------------------|------------------|--------------------------|
| 1             | Min\(^{c}\) (65)     | 9                         | Sister              | Primary school   | Buddhist         | NRCM                     |
|               | Qiao (63)            |                           |                     |                  |                  |                          |
|               | Qing (60)            |                           |                     |                  |                  |                          |
|               | Ding (55)            |                           |                     |                  |                  |                          |
|               | Meng\(^{a}\) (38)    |                           |                     |                  |                  | MI                       |
|               | Yan (37)             |                           |                     |                  |                  |                          |
|               | Cani (34)            |                           |                     |                  |                  |                          |
| 2             | Fong (55)            | 125                       | Fong (55)           | Middle school    | Christian        | NRCM                     |
|               | Mei\(^{a}\) (52)     |                           |                     |                  |                  |                          |
|               | Nini (31)            |                           |                     |                  |                  | MI                       |
| 3             | Zhang\(^{c}\) (74)   | 73                        | Zhang (74)          | Higher education | None             | GF                       |
|               | Hong\(^{a}\) (47)    |                           |                     |                  |                  | MI                       |
|               | Lan (42)             |                           |                     |                  |                  |                          |

Breast cancer survivors (BCSs); First-degree relatives (FDRs); pseudonyms have been used.

\(^{a}\) Main caregivers of BCSs. Seven of ten BCSs were mainly cared for by their FDRs in the study.

\(^{b}\) There are four types of medical insurance: New Rural Cooperative Medical system (NRCM), Medical Insurance (MI), Government-Funded (GF), and Student Insurance (SI).

\(^{c}\) Six of the BCSs have a family history of breast cancer.
| Family number | BCSs (age in years) | Disease duration (months) | FDRs (age in years) | Educational level | Religious beliefs | Medical insurance\(^b\) |
|---------------|---------------------|---------------------------|---------------------|-------------------|------------------|------------------|
| 4             | Wu (45)             | 2                         | Sister: Lian\(^a\) (40) | Higher education  | None             | MI               |
|               |                     |                           | Daughter: Ya (20)    | Higher education  | None             | MI               |
| 5             | Hei\(^c\) (50)     | 27                        | Father: Ting\(^a\) (29) | Primary school    | None             | NRCM             |
| 6             | Chen\(^c\) (65)    | 3                         | Father: Qin\(^a\) (40) | Primary school    | Buddhist         | NRCM             |
| 7             | Lei\(^c\) (42)     | 15                        | Father: Shan (40)   | Middle school     | Buddhist         | NRCM             |
|               |                     |                           | Daughter: Bing (19) | Middle school     | None             | SI               |
| 8             | Xun\(^c\) (49)     | 6                         | Father: Juan (26)   | Primary school    | Catholic         | NRCM             |
|               |                     |                           | Sister: Yue\(^a\) (23) | Middle school     | None             | NRCM             |
| 9             | Zhen (42)           | 13                        |                      | Middle school     | Buddhist         | MI               |

Breast cancer survivors (BCSs); First-degree relatives (FDRs); pseudonyms have been used.

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| Family number | BCSs (age in years) | Disease duration (months) | FDRs (age in years) | Educational level | Religious beliefs | Medical insurance^b |
|---------------|---------------------|--------------------------|---------------------|-------------------|------------------|---------------------|
|               |                     |                          | Sister              | Daughter          |                  |                     |
| 10            | Jing (50)           | 6                        | Hui (46)            | Primary school    | Buddhist         | NRCM                |
|               |                     |                          |                     |                   |                  | MI                  |
|               |                     |                          | Peng (44)           | Middle school     | Buddhist         | MI                  |
|               |                     |                          | Ying (26)           | Middle school     | None             | MI                  |

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^c Six of the BCSs have a family history of breast cancer.

Thirty-one in-depth interviews were conducted based on the semi-structured question guide (Table 2) between January and December 2020 by the first author, who is experienced in cancer care and qualitative research. Interviews were held in small, quiet rooms in the two wards, with each interview lasting for 31 to 82 minutes. Data collection was stopped when saturation was reached. The recorded data were immediately transcribed verbatim in Chinese, then counter-checked line by line. The transcribed data were managed by MAXQDA software using thematic analysis [19]. Two authors read and reread the data to gain familiarity with it. They then generated initial codes independently for theme searching. Concepts relevant to mutual support were developed and then condensed into three organizing themes (Fig. 1). In this study, an audit trail was set up, including clear outlines of the sampling, data collection and analysis, memos, and notes on personal reflections. Meanwhile, member checking was performed among all authors during the research. Additionally, this manuscript was prepared according to the SRQR standards for qualitative research reports [20].
Table 2
Semi-structured question guide for interviews

| Participants                  | Questions                                                                                                                                                                                                 |
|------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| For breast cancer survivors  | 1. When and what kind of support have you received from your first-degree relative(s) (mother/daughter/sister)?  
2. How do you find the support you have received?  
3. Have you provided support to your first-degree relative(s)?  
4. Were there any challenges? How did you cope with them?  
5. Are there any other things about mutual support between you and your first-degree relative(s) you would like to share that we have not covered? |
| For first-degree relatives   | 1. When and what kind of support do you provide to her (breast cancer survivor)?  
2. How do you rate the support you have provided?  
3. Were there any challenges? How did you cope with them?  
4. When and what kind of support have you received from her?  
5. Are there any other things about mutual support between you and her you would like to share that we have not covered? |

The review committee of the associated university approved this study. Approval for access was obtained from the two hospitals in which this study was conducted. At the beginning of the study, written informed consent was obtained from all participants. They were assured that their participation was completely voluntary, and they could withdraw at any time. Participants’ names were replaced with pseudonyms.

Results

Three themes were extracted from the reflections of BCSs and their FDRs under the overarching theme “a shared journey to a better future”: 1. “Mutual support is needed as we are in the same boat”; 2. “We experience stormy and windy weather during our journey;” and 3. “Sunny and breezy days are a gift for both of us.”

Mutual support is needed as we are in the same boat

Mutual support meant that FDRs and BCSs supported each other in response to BC to get a better outcome. Participants perceived mutual support and faced BC together through it, just like Ying said, “Mutual support is needed as we are in the same boat.” Mutual support occurred when there was a “leader” between/among them, who would “urge them to actively face BC” (Yan). Families with such leaders are more supportive of each other.

Mutual support among FDRs and BCSs could be divided into informational, emotional, and practical. In addition, it was obvious that practical support was the main type that FDRs provided to BCSs. While for
BCSs, information support to their FDRs was the most common. In reciprocal support between/among FDRs, the three kinds of support were parallel (Fig. 2).

Support provided by FDRs to BCSs

FDRs provided support to BCSs, with practical support being the main type, as “treating the BC is the top priority at that time” (Meng). According to Chen, Qin was her primary caregiver and provided much support, especially practical support including “personal caring, taking over household chores, and paying for all the treatment.” Besides, Qin also “helped me connect with the doctor to get timely information.” As for Mei, her strong support of her sister Fong was mainly emotional, especially offering encouragement:

I always encourage her that we struggle with BC together as if we are grasshoppers tied to the same rope.

Support provided by BCSs to FDRs

Although what BCSs can do for FDRs is “very limited” (Xun), they do what they can to support their FDRs. Information support was the first step in their becoming “more familiar with BC” (Fong) because of their disease. They shared their health-related knowledge with FDRs, including “information about BC prevention and public health” (Fong). Meanwhile, BCSs shared their experiences, such as “expressing gratitude, acknowledgment of their [FDRs] efforts” (Min), and “reminding them [sister and daughter] about healthy behavior – hoping my misfortune will serve as a warning to them” (Wu).

Reciprocal support between FDRs

FDRs indicated that mutual support between/among FDRs was common, as they are in a very similar situation. Not only do they need to care for BCSs but they also “bear the same risk of BC” (Cani). Thus, they were more likely to have emotional connections. In the case of their mutual support, the three kinds of support were equally important. Yan did her best to support her sisters and aunts, reminding them about healthy behavior, information sharing, and emotional support.

I asked my sisters and my aunts to go to the hospital for a check-up after mother’s diagnosis... Whenever I learn something new about BC, I share it with them immediately. I hope all of us can keep away from it.

We experience stormy and windy weather during our journey

“Stormy and windy weather” (Yue) was used to emphasize challenges encountered in the provision of support. All participants mentioned the challenges they confronted when providing mutual support. These challenges including disruption of daily life, limited resources, lack of knowledge, and cognitive conflict.

Disruption of daily life
Disruption of daily life referred to the loss of normal life because of BC and its treatment. Participants reported experiencing life disruption, including resigning, leaving home and roles changing in life. Life disruption was a reality that participants “have to face” (Lan), and it was the biggest challenge that Yue had faced:

*We came here [Beijing] for better treatment. Beijing is far from my home, so I had no choice but to quit my job ... All in all, normal life has disappeared completely. Really stormy and windy weather.*

For BCSs, BC treatment was “the most important thing” (Jing). Thus, they “have to go to hospital and be shuttled between home and hospital for a long time” (Hei) after diagnosis. They lost the normal life, which made it “impossible to take care of others” (Jing).

**Limited resources**

Limited resources were repeatedly emphasized by participants. These limitations manifested in the financial burden of treatment and the inability to obtain support from public health systems. For some of them, “financial burden needs to be considered.” Hong is a housewife, and she expressed how she could not give her mother economic support as she had no income. As for Lei, she experienced limited public health support and reported:

*I once shared information about free BC screening opportunities with my sister Shan. And I hoped she could receive the chance. However, she didn't get it as there were no places left.*

**Lack of knowledge**

Adequate knowledge of BC is a key element of mutual information-related support. Participants complained of the uncertainty and lack of knowledge. Wu expressed her uncertainty as it was “difficult to sort and evaluate all the information” she gathered. She felt overwhelmed and confused and wondered if some of the information was even true.

*I learnt a lot about BC from the Internet, other patients, and my doctor. However, I'm confused as the statements are sometimes inconsistent ... Because of uncertainty, I cannot remind my daughter and sister accurately.*

**Cognitive conflict**

Cognitive conflict meant that participants have different perceptions, which can hinder mutual support. Different perceptions among BCSs and FDRs mainly related to the necessity of sharing information and BC risk awareness. Lan described her different view of the need to share information with her mother and how she had initially concealed her mother’s illness:

*Finally, my mother knew I had hidden her diagnosis [from her], and told me, ‘you should have shared it with me at the time.’ Actually, I was just trying to protect her from being sad.*
Similarly, Cani experienced unpleasantness because of different risk awareness between her and her aunt:

One day, I called my aunt Qing to remind her about screening. She got very angry and roared at me, ‘Don’t bother me about BC anymore! I don’t care! Don’t tell me about the high risk of it either! I don’t believe it at all’.

**Sunny and breezy days are a gift for both of us**

“Sunny and breezy days” (Peng) indicated that BCSs and FDRs perceived reciprocity during the process of mutual support. They crossed the difficult barriers they encountered, improved their relationships, felt a sense of accomplishment, and gained a more positive outlook on life.

**Crossing the difficult barriers**

With mutual support, participants “get through the difficult days with limited physical mobility because of surgery” (Fong), gained “spiritual support” from each other when they felt “helpless about [their] mother’s illness” (Juan), and “adjusted to the loss of life normality together” (Xun). Min recalled this memory and summarized the support she received from her FDRs:

*My daughters do everything for me. In fact, I was really miserable when I was diagnosed. I feared BC and worried about their risk. Everything went haywire... Fortunately, we have crossed the difficult barriers together.*

**Improved relationships**

By mutual support in dealing with BC, they gain the same “Tao,” which means they have the same purpose and belief. They then struggle together toward the same goal, which eventually improved relationships. Nini felt closer to her aunt Mei. They “shared concerted efforts to face BC risk by making regular appointments to exercise.” Similarly, Ting felt a closer bond with her mother:

*I was too busy to go to see my mother often. However, her illness made me learn to slow down and stay with her. It was a long-lost feeling, as if I was her little girl. I enjoy the feeling and am happy to see my mother’s smile.*

**A sense of accomplishment**

BCSs felt that they were not a “worthless person” (Xun) and got a sense of accomplishment by providing support to FDRs. After BC diagnosis, some BCSs defined themselves as “a burden” who “needs help from others and can’t do anything for family” (Zhang). However, as Xun explained, offering support to FDRs, such as “sharing useful information with them [daughters],” can alleviate the idea that they are a burden. Moreover, they gain a sense of accomplishment and become more willing to “help them, if only a little,” which benefits both.

**A more positive outlook on life**
Participants reported having “a more positive outlook on life” (Bing), such as “being grateful” (Zhen), “deeply loving and cherishing the present” (Ting), and starting to “pay attention to BC screening” (Nini). Peng was a typical example who demonstrated her love of life by choosing a healthier lifestyle:

*What happened to my sister Zhen and what she has done for me is let me know the necessity of loving life and cherishing the people around. Now, influenced by her, I’ve adjusted my diet, take exercise, be kind to others.... All of this, I believe, like the sunny and breezy days, is a gift for both of us.*

**Discussion**

The current study investigated the experience of mutual support among BCSs and their FDRs. “A shared journey to a better future” depicted their overarching perception of the mutual support during BC coping, which could be further classified into three distinct themes. Based on these themes, two areas for discussion were identified: 1. Mutual support and reciprocity; and 2. Challenges for BCSs and FDRs coping with BC.

**Mutual support and reciprocity**

From participants’ narratives, it was clear that BCSs faced with the diagnosis of BC were accompanied by their FDRs. Both parties do their best to provide informational, emotional, and practical support to each other. Similar to previous research [14, 21], our findings reflected that both BCSs and FDRs benefitted from acceptance and provision of mutual support. Their relationships became closer through their joint coping with BC. Some BCSs and FDRs transformed their attitudes toward BC and life. They made changes (e.g., daily behavior adjustment and BC screening) that could be helpful for both recovery from BC and prevention of BC [22–23]. The family network is a typical phenomenon in China. Whenever there are difficulties, a family member tends to ask for help and other family members will offer assistance [17]. Furthermore, it was perhaps what Confucius [24] called “Xiao” (filial piety) and “Ti” (fraternal duty) that enables participants to deal with BC as a joint team in a spontaneous way. When FDRs heard of the BC diagnosis, they would volunteer to provide support. More than half (7/10) of the BCSs were mainly cared for by their FDRs, consistent with prior findings that about 52% of BCSs have their mother, daughter and/or sister as caregivers [10]. Although what BCSs could do was limited, we found that they chose to do their best to help their FDRs, and gain a sense of accomplishment. Moreover, this informational support can especially decrease the risk of experiencing anxiety and depression in the context of cancer care among FDRs [25]. A similar situation exists between FDRs in the same family. These family members tried their best to support each other through information, emotional and practical aspects (“misery loves company”), which were vital to them. As prior research confirms, FDRs need support in BC risk reduction [26]. They also require support from other family members and help with caregiving responsibilities [27–28].

**Challenges for BCSs and FDRs coping with BC**
Our findings delineated that “stormy and windy weather” happened to all participants. Their lives were disrupted because of the BC diagnosis, making it more challenging to provide support. Previous research [14] explained similar findings in terms of the challenges of coping with BC. Notably, Andic and Karayurt [29] found that FDRs regarded information support as very important. Aunan et al. [30] revealed that BCSs expressed the need for information along with fear of misinformation. Nevertheless, a survey among 264 Chinese BCSs showed a great unmet information need [31]. Some participants in our study described obtaining BC knowledge from the Internet. They noted that the quality and readability of BC websites were not satisfactory [32]. This mismatch between information needs and available information sources can pose extreme demands on their knowledge, which may explain why lack of knowledge was the biggest challenge cited.

Cognitive conflicts reported by participants were due to lack of knowledge. Rabin and Pinto [33] indicated that BCSs and FDRs with rich knowledge of BC were more likely to have accurate perceptions of health risks and modify the relevant behavior accordingly. Medical professionals should give information about BC to both BCSs and FDRs, such as causes of BC, diagnosis, treatment options, and prevention. Specifically, ways to obtain high quality and accessible knowledge should be introduced. According to Wright [34], health education interventions that focus on BC knowledge via social media are worth considering.

Another challenge was limited resources. Participants described a shortage of resources provided by available health systems. As the most common malignant tumor among women worldwide, the treatment and prevention of BC is a great challenge for many governments [1]. In 2009, the Chinese government launched a nationwide “Two Cancer Screening” project for breast and cervical cancer among women aged 35 to 59 years. This program covers the screening of 10 million women for cervical cancer and 1.2 million women for BC each year [35]. However, as a proportion of China’s large population, this is still a relatively limited screening program. Therefore, how to allot these limited resources deserves serious consideration. It seems logical to let high-risk groups, like FDRs of BCSs, have priority access to such opportunities. Another key point is making information about health systems widely known. Wang et al. [31] discovered that lack of information regarding health systems was the most common concern among BCSs. The unmet informational need may deprive FDRs and BCSs of health care and community services that may be available to them [36]. Hence, professionals and community staff are advised to keep the public informed of health-related information.

**Limitations**

Despite the rich findings, there were limitations to this study. Reporting biases could potentially influence some participants’ responses, especially those who value “Xiao” and “Ti” and want to show their strength, filial piety, and fraternal duty. Such participants might emphasize support-offering rather than challenges encountered. Further, even though participants were recruited from two cities in China for maximum variety, future studies are needed to explore whether the mutual support experiences and issues described
in this study apply to BCSs and FDRs in other places in China (and beyond) with different cultural customs.

**Conclusion**

Mutual support was an important feature of the journey of coping with BC, and was beneficial to both BCSs and FDRs. The findings indicate the interchange of support and the need for additional outside support to overcome the challenges encountered. Health professionals should not ignore FDRs of BCSs as both groups require support and should be encouraged to share their concerns with each other. The findings are valuable for the development of appropriate interventions to strengthen the ability of BCSs and FDRs to support each other through the journey of coping with BC.

**Declarations**

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**Ethics Approval:** This study was approved by the Ethics Committee of Capital Medical University (No. 2015SY46).

**Informed Consent:** Informed consent was obtained from all of the participants in this study.

**Consent for Publication:** Not applicable.

**Availability of Data and Material:** The datathat support the findings of this study are are available from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

**Author Contributions:** Conceptualization: JEL, SHC; Methodology: JEL, SHC; Formal analysis and investigation: SHC, DMG, YFL, YLS, JEL; Writing - original draft preparation: SHC, JEL; Writing - review and editing: SHC, JEL; Funding acquisition: JEL; Resources: DMG, YLS; Supervision: JEL

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Figures
Figure 1

Initial thematic map, showing the conceptual structure of the shared journey to a better future by mutual support BCSs: Breast cancer survivors; FDRs: First-degree relatives
Figure 2

Features of mutual support among BCSs and FDRs BCSs: Breast cancer survivors; FDRs: First-degree relatives