

“Continuous Shadow of Mother’s Breast Cancer”: Exploring the Voice of Daughters

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Abstract

Purpose: Women whose mothers have been diagnosed with breast cancer are concerned about their mothers' illness and fear developing cancer themselves. This study aims to understand daughters' lived experiences after their mothers have been diagnosed with breast cancer in Taiwan.

Method: In-depth interviews were conducted to understand the daughters' emotional reactions to their mothers' diagnoses, their challenges with taking care of their mothers, and their concerns or perceptions regarding their own risks of developing breast cancer. Themes were identified through a content analysis.

Results: An analysis of 18 transcripts revealed six themes: "taking care of my mother is my responsibility", "desiring sufficient information/support", "feeling helplessness in providing care", "expecting a cancer diagnosis in fear", "anticipating a resolution other than surveillance", and "worrying about myself is not a priority".

Conclusion: The daughters prioritized the responsibility of caring for their mothers physically and psychologically rather than managing their own cancer concerns. Health care professionals should be aware of these priorities to provide education regarding the care of high-risk populations and psychological support to the adult daughters.

Introduction

Family history is a risk factor for breast cancer. The incidence of breast cancer is two to three times higher for those whose first-degree relatives have breast cancer than for those with no family history [1,2]. Research has confirmed that breast cancer is strongly correlated with breast cancer gene (BRCA1/BRCA2) mutations [3]. However, BRCA1/BRCA2 mutations are not the only risk factor for familial breast cancer. A meta-analysis found that the relative risk of breast cancer in the daughters of women with breast cancer was two times higher than that in the normal population. If the mother had breast cancer before the age of 45, the risk increased 2.47-fold [2]. Excluding BRCA1/BRCA2 gene abnormalities, women with a family history have a significantly higher risk of breast cancer than those without a family history of breast cancer [4]. Therefore, if a mother has had breast cancer, her adult children should be concerned about getting breast cancer throughout their lives, which may affect their physical and mental health.

When a mother develops breast cancer, her adult daughters not only worry that their mother will die from cancer but also fear that they themselves will develop the same cancer [5,6]. Mothers also worry that their children will develop cancer [7]. Any cancer-related experience of affected mothers may provoke their daughters' awareness of their cancer risk [6]. The fear of developing cancer is like a ticking time bomb [8].

Hereditary breast and ovarian cancer (HBOC) clinics have been established to assist high-risk subjects with a family history of breast cancer or ovarian cancer by providing cancer-related counselling in Western countries. Although several hospitals in Taiwan provide cancer genetic testing and counselling

services, most hospitals have no care and counselling channel for groups at high risk for breast cancer with a family history. Therefore, adult daughters' needs are rarely met. Given the annually increasing incidence of breast cancer, which occurs in a younger population in Taiwan, the number of adult daughters who are at risk of breast cancer is likely to increase. Furthermore, culture, values, and beliefs among Asians render women more likely to endure hardship and to remain silent regarding their wishes if they believe that their true desires would inconvenience or disturb others [9]. As a result, mothers with breast cancer in Asia have difficulties describing their emotions during the survivorship period. Because good communication about cancer between family members may be helpful for improving adaption in both survivors and family members [10], the issues of adult daughters' experiences in caring for their mothers in Asian countries requires closer attention. Given that the majority of primary family caregivers are female in Taiwan but most studies have focused on women's partners, this study aimed to understand the concerns of adult daughters and the impacts of their mothers' breast cancer on their lives and to discover the care needs of adult daughters.

Method

Study design

A phenomenological approach guided by van Manen was selected for this study because we aimed to understand daughters' lived experiences after their mothers were diagnosed with breast cancer. A phenomenological approach was employed to gain a more nuanced and in-depth understanding of the participants' personal and social contexts.

Sample

The participants were the biological daughters of women with a breast cancer diagnosis. They were recruited through convenience sampling from the XX University Hospital by a research team member (breast surgeon) and website advertisement. Potential participants were registered using the study application form to provide their contact information. The researcher then contacted them via telephone to make an appointment for an interview. The inclusion criteria were (1) Mandarin-speaking, (2) aged 20 years or older, and (3) unaffected by breast or other cancers. The exclusion criteria were (1) cognitive dysfunction and (2) a diagnosis of severe psychiatric disease with a limited ability to communicate.

Data collection

This study was conducted after permission was obtained from the Institutional Review Board of the XX University Hospital. Interviews were held from August 2019 to August 2020. After providing informed consent, the participants were first asked to provide demographic or disease-related information about themselves and their mothers. We developed an interview guide (Supplemental Table 1) to elicit participants' experiences and perceptions. Participants were encouraged to use key events to describe their feelings and how their mothers' cancer had influenced their daily lives. A summary of each interview

was written by the researcher immediately after each interview. Each interview lasted approximately 40 to 90 min.

Data analysis and rigour

The researcher (X.X.), who was familiar with psychological care of women with breast cancer and had more than 10 years of experience in performing qualitative studies, conducted a content analysis after the audio-recorded interviews were transcribed verbatim. Three steps of coding were used. Meaningful words and related content were first identified, and then recurring information was grouped based on keywords, phrases, emotions, and thoughts. Finally, we integrated the codes to define the themes elucidating meanings underlying the transcripts. Analysis of the data also involved comparing and contrasting within and between the participants. A careful line-by-line analysis of the transcripts, peer debriefing, and detailed memo writing were performed to enhance methodological rigour. Preliminary findings were developed following 10 interviews because no new information was being shared and the data appeared to have reached saturation. Additional interviews of 8 participants confirmed the analysis results. To ensure rigour, the themes were discussed with the members of the research team, who had a nursing and psychology background.

Results

Participants

The 18 daughters invited to participate had an average age of 31 and ranged in age from 23 to 52 years. In addition to their mothers being diagnosed with breast cancer, 6 daughters also had other family members with breast cancer. At the time of the interviews, 15 of the participants' mothers were still alive (Supplemental Table 2).

Themes

Taking care of my mother is my responsibility

After a mother becomes ill, taking care of her seems to be the daughter's obligation. There is no exemption even if the daughter is living abroad or married.

"My mother stayed with us even after we were married ... so I insisted on taking care of her even before I got married ... so I could monitor her condition." (B-6-18)

Daughters who have not yet married must sacrifice their work to accompany the mother for hospitalization and follow-up visits. They need to care about their mother's emotional responses in addition to shouldering housework previously done by their mothers.

"... I need to watch her closely and monitor her state. If she is in a bad mood today, I need to know why and make sure she will not be emotional or cry." (G-4-15)

"... It means that you must ... cook and ask Dad to bring dishes to Mom. Helping Mom wash clothes ... became doing the laundry for the whole family ..." (O-3-1)

Living together for a long time may increase conflict and pressure between daughters and mothers. Daughters usually endure and tolerate their mothers to avoid increasing their mothers' psychological stress and self-blame.

"Sometimes, I am impatient. I just say 'why can't you understand and show sympathy to us?' ... Sometimes when we are at a stalemate, I think ... 'fine ... forget about it, just let her do whatever she wants!' Then, I feel self-blame when I am impatient. Now I just comply with her. Yeah, I am ... already ... already used to the situation!" (F-3-15)

Feeling helplessness to provide care

In the process of taking care of the mother, the daughter may often feel incapable because of limited understanding of treatments or inefficient communications with the mother.

"... Because my mother felt that she could handle everything, she never asked us to help. ... She did not want to interfere with our life. We did not even know that she had a fever and needed to be hospitalized. We were slightly overwhelmed, we had no way to prepare for what may happen." (C-3-11)

Mothers often have emotional distress because of illness. Daughters often feel that their comfort does not make mothers feel relieved but, on the contrary, unhappy.

"I think my intention is good. I talk to give Mom a positive outlook, but I may not express it well. My mother thinks it is none of my business." (K- 5-11)

Some mothers are in the stage of relapse but are resistant to treatment. The daughters feel conflicted and struggle with whether to encourage mothers to undergo further treatment while knowing it would be difficult.

"From the perspective of saving her life, you certainly hope she continues the treatment, but ... she is one who has the medication and suffers the pain, right? We could only support and persuade her orally: 'hey ... you must hold on! we will all accompany you!' However, she suffers the real pains. ... In fact, I don't feel like saying: 'Well, you ... only need to cheer up! Keep going! ... after all, it is not me who suffers the discomfort and sadness.' (H-7-8)

Desiring sufficient information/support

The information daughters require is based on their mothers' treatment stages. They want to know in advance in order to prepare.

"... At the beginning of the diagnosis, doctors should let the patient and her family know ... the course of the disease and then the conditions that may be encountered, ... how long the treatment will be, and then

follow up. I need to have a general idea..." (O-39-7)

The online information is unclear, not trustworthy, or inconsistent with the hospital's report, which causes troubles for the daughter.

"Sometimes, I read online, but some information conflicts with that from the hospital. ... I feel confused." (G-15-22)

In addition, the process of care is stressful. Daughters consider it important to reduce their own burden as well.

"The family members themselves are already ... stressed! Either financial or disease or whatever ... the patient needs consultation, and so do the family members." (D-37-5)

Expecting a cancer diagnosis in fear

The daughters considered themselves as potential cancer patients. Using a scale from 0-10 to describe their concern about developing breast cancer, the daughters rated their concern at 7-8 points at the moment their mother was diagnosed with cancer. Daughters with breast abnormalities, such as fibroids or adenomas, felt they would soon develop cancer.

"Just being mentally prepared at any time. ... I feel like it will be me sooner or later. I've already mentally prepared, so I will not be surprised if cancer is found in my body." (A-19-19)

"I think that I truly started to worry about it when I heard 'the number of patients grows annually.' Especially seeing that my mother and my aunt have cancer, I feel the disease is very close to me." (C-12-1)

When the daughter accompanies her mother to the hospital, the medical staff will remind her that she is in a high-risk group and recommend an examination. Some daughters may arrange the test at an appropriate time, but some hesitate.

"... I still don't have the courage... I'm afraid to say that if I ... have cancer, what should I do?" (F-26-7)

Or the daughters believe that regular inspections only provide short-term ease.

"... I checked so I feel relieved. At least my concern drops from 10 to 8 points... I think because of my family history, ... there will still be a little uneasiness in my heart ..." (N-35-4)

Some daughters used more aggressive approaches to manage their worry, such as understanding the genetic factors and considering prophylactic mastectomy or direct removal of fibroids. Some thought they still needed to breastfeed and did not consider these options. Others were more passive and tended to avoid another follow-up breast exam. Those who were more pessimistic believed that despite knowing the genetic factors, they could not do anything.

"... I want to remove them (breasts) soon, just like ... Angelina Jolie ... After my mom was diagnosed with cancer, I have had such thoughts. It's recent! When my mother's cancer metastasizes, I feel like I can ..." (C-17-18)

"...even though I know about this gene ... as possessing this gene puts you in a high-risk group, ... Well! I will get married, give birth to babies, and breastfeed. I cannot remove it so early ..." (L-19-9)

"If you have something now ..., you can slice the gene! Then, you can stop BRCA1 and BRCA2 from mutating, or you can fix it! ... Stop it from following the cancerous path. I think this is valuable ... Instead, I am thinking about when these two genes will be mutated, and then I will be like my mother." (E-24-17)

Some daughters denied the concern and tried to avoid thinking of consequences. They reduced their concerns by limiting their access to information or by employing positive thinking to reduce anxiety.

"I think it's better not to follow it (fb) all the time. The more I read, the more I worry about it ..." (C-28-1)

"... I always try hard to persuade myself: think positively. ... I don't think I can choose when the disease happens.... then you can only prevent and... think positively ..." (O-17-15)

Anticipating a resolution other than surveillance

Limited health education on breast cancer prevention was provided. Most of the knowledge is based on diet, exercises, or lifestyle adjustments.

"It's... something with high oestrogen, ... usually yam, taro, and soy are not recommended in the diet, and we should eat them in moderation." (A-10-17)

Other modifiable risk factors on breast cancer were also empathized by the daughters.

"... I know one way to reduce cancer is to adjust my mood ..." (G-22-1)

"... My mother had breast cancer. Was it because she didn't breastfeed? ... I breastfed my baby ... but I don't know how much it can lower the risk ..." (E-18-5)

Most daughters used breast self-examination or ultrasound to determine whether they have abnormal conditions or to monitor breast abnormalities from time to time.

"... I would check my breasts a little bit in a shower. Well! ... I cannot say every time, but whenever I think of it, I will do ... just like that!" (J-12-20)

Some daughters adopt strategies to force them to remember routine annual inspections.

"I set the breast ultrasound on my birthday, then I might also do ... a Pap smear and breast ultrasound..., then I will not forget to do it." (L -17-11)

Inspection may be the only step the daughters can think of to do, but it still fails to meet their personal demands.

"I asked her (doctor) ... if the breast ultrasound is normal this year, will it be normal next year? She said it was possible. ... She said the breast lesions proceed quickly ... but we (family members) found it early (in the early 40s). ... then I asked her whether ... it is enough to do only a breast ultrasound?" (N-24-13)

Even when acknowledging that knowing too much information may increase their anxiety, daughters look forward to learning more professional and accurate information.

"If the hospital can provide me with information now, ... I don't need... to find it myself. ..., the information given by the hospital should be more accurate than we could find online" (L-29-13)

Worrying about myself is not a priority

Although the daughters worried about getting cancer, some daughters reported that worrying about themselves is not the priority.

"I'm less worried about myself. I'm more worried about my mother! ... I'm more concerned about whether her cancer has been controlled!" (A-16-17)

Daughters whose mothers have passed away may focus on their children.

"...I am concerned that my mother got cancer today, and so did my aunt, I was just not diagnosed. However, what about my daughter?" (N-41-18)

Discussion And Conclusion

Discussion

The results of this study revealed that the daughters took their responsibility to care for their mothers as a given, regardless of whether the daughters were married or not. Because of poor communication between mothers and daughters, these daughters felt powerless and helpless to support their mothers and desired more support and information that would be beneficial to their mothers. During the care process, daughters also worry about their own possible cancer diagnosis. This worry may be exaggerated when abnormal findings are found or before regular annual examinations. They may adopt healthy activities to reduce the possibility of developing cancer. They may monitor their breasts with self-examinations or ultrasound. However, they expected additional solutions to decrease their worry other than regular examinations. Finally, they considered that worrying about themselves was not a priority at the moment. This finding is unique in that, in contrast to previous qualitative studies conducted in Western countries, the primary concerns of the daughters in this study were related to their mothers instead of their own risk [6,8,11]. This finding may also reflect the nature of Confucian and collectivistic value in Asian culture [12].

Care needs for mothers

The first theme—“taking care of my mother is my responsibility”—was similar but revealed a different level of responsibility compared to previous studies. Daughters experienced shock and fear and felt overwhelmed by receiving news of their mothers’ breast cancer diagnosis. They also worried about the possibility of losing their mothers and took care of their mothers without hesitation [13,14]. However, carrying out household duties was also regarded as an obligation for the daughters during the mothers’ treatment period in the hospital. This finding reflected the fact that family is the centre of a woman’s life in Chinese culture [15]. It also reflected gender role expectations in Taiwan, which was also proposed by another study; family members take responsibility for most long-term care duties, and more than 70% of primary family caregivers are female [16]. As a result, adult daughters have multiple role demands, but studies have only focused on the caregiver burden of partners of patients with breast cancer in Taiwan [17,18]; therefore, more attention should be given to adult daughters of mothers with breast cancer.

The theme “feeling helpless to provide care” suggested that daughters would like to do something for their mothers, but their offers were refused or declined by their mothers. This situation made the daughters feel helpless and powerless. Moreover, the daughters’ emotions were influenced by witnessing the suffering and the illness trajectory of their mothers [19]. However, as the level of perceived support provided to mothers by daughters increased, the reported depression levels decreased [20]. Participants experiencing their mothers’ refusal to receive treatment may have experienced increased feelings of helplessness in this study. This finding reflected the poor communication between mothers and daughters. Mothers in Taiwan are accustomed to enduring their suffering to avoid disturbing their daughters’ routines. The lack of communication to express their emotional or physical needs also made the daughters feel confused and helpless.

In this study, the daughters not only expected information about breast cancer and its treatments but also wanted to understand ways to decrease the possibility of cancer recurrence for their mothers, such as diet, nutrition, or physical activity. These findings were documented in previous studies [21,22]. Furthermore, the daughters desired to know how to encourage their mothers and provide psychosocial support beyond physical care, which highlights the necessity to improve communication between mothers and daughters in Taiwan.

Care needs for daughters

This study found that participants worried about developing breast cancer themselves after their mothers’ diagnoses, and the concern was stronger if additional family members had breast cancer. Although their daily lives were not interrupted by cancer worry, some of them prepared for the worst and lived in the shadow of cancer, especially when they discovered a lump in their breasts or faced an upcoming screening appointment. This finding is consistent with a previous study [8] and revealed that cancer in mothers increases daughters’ awareness of their perceived risk of breast cancer [6,13]. To decrease worry regarding their own risk of breast cancer, the daughters searched for strategies, such as adopting healthier eating habits and performing regular screenings. These coping strategies were supported by several studies [6,8,11,22,23]. However, an interesting finding in this study was the daughters desired

more control over their risk, rather than simply adhering to annual screenings. Daughters also expressed an interest in more validated information about decreasing their risk and sought pamphlets or other convenient ways to access this information. These findings emphasized the importance of providing appropriate information to reassure the daughters.

Our study revealed the limited resources available for providing genetic information in Taiwan. Even though six participants in our study had more than one family member with breast cancer, they had not accessed a genetic counselling service. Some daughters considered genetic information to be useless because nothing could be changed, but others focused more attention on information about genetics and preventive treatments. These results highlight the individualized needs of daughters and the variance in these needs according to family history. Developing stratified interventions according to the risk level of these daughters is important. Establishing genetic counselling services for the high-risk population is also critical.

Study limitations

The participants recruited in this study were all willing, and selection bias may exist, as daughters with better or poorer adaption to their mothers' diagnoses would be excluded. In addition, the average age of our participants was relatively young, which may have biased the sample population to a less diverse group.

Study Implications

It is important to provide evidence-based information according to the survival stage of mothers. As there are limited hereditary breast cancer services in Taiwan, developing pamphlets or a web-based platform for daughters to access reliable information including self-care as well as care for their mothers would be helpful. Establishing support groups for daughters to share their emotions and provide psychological support is also recommended. Because some daughters have multiple family members with breast cancer, improved mother-daughter communication during the survival period and the establishment of a high-risk clinic associated with genetic counselling or treatments is also necessary.

Conclusion

The daughters of mothers who have breast cancer prioritized the responsibility of caring for their mothers physically and psychologically rather than managing their own cancer concerns after their mothers were diagnosed. Health care professionals must be aware of these priorities to provide education on the care of high-risk populations and psychological support to the adult daughters of women with breast cancer in Taiwan.

Declarations

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Data availability statement

The data that support the findings of this study are available from the authors upon reasonable request. The data are not publicly available due to privacy or ethical restrictions.

Compliance with ethical standards

Conflict of interest: The authors have no conflicts of interest to declare.

Ethical approval: Ethical approval was obtained from the Institutional Review Boards in the National Cheng Kung University Hospital (BER-107-392). All procedures involving human participants were performed in accordance with the ethical standards of the institutional and/or national research committee and the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Consent to participate: Informed consent was obtained from all individual participants included in the study.

Consent for publication: Participants signed informed consent regarding publishing their data and interview content.

Code availability: Not applicable

Author contributions

All authors were responsible and accountable to all part of works related to the study. More specifically, SYF had the original idea, contributed to the conception and design of the study, collected data and acquired the funding. SYF, YMW analysed and interpreted the data. KTL provided the resource of participants and gave feedback of the preliminary results. SYF, YMW contributed in writing the manuscript. All authors revised the manuscript and gave the approval to the final version to be published.

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