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Experiences of Social Support Among Chinese Women with Breast Cancer: A Qualitative Analysis Using a Framework Approach

Authors' Contribution:
Study Design A
Data Collection B
Statistical Analysis C
Data Interpretation D
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Background: Breast cancer and its treatment provoke a series of emotional changes in patients during their breast cancer journeys. Social support is critical in helping women cope with their negative emotional responses. However, few studies have described the experiences of women with breast cancer within the Chinese context. This qualitative study explored the experiences of Chinese women with breast cancer regarding social support.

Material/Methods: This qualitative study was based on constructivism epistemology. Chinese women with breast cancer were invited to interview between June and August 2016. Purposive sampling was used, and the women were recruited until data saturation was reached ($n=25$).





Results: We found that all participants expressed the importance of social support during their breast cancer journeys. The thematic framework of social support was identified, which included the following 4 interrelated themes: providers, types of support, outcomes of support, and challenges for care.

Conclusions: Social support is important in the health care of women living with breast cancer. Healthcare professionals should provide more individualized support and care to women during this vulnerable period.

MeSH Keywords: **Breast Neoplasms • Qualitative Research • Social Support**

Abbreviations: **PTG – post-traumatic growth**

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Background

Breast cancer has become the most common malignant tumor in developed countries worldwide [1]. In China, more than 169 000 females are diagnosed with breast cancer every year, and approximately 45 000 females will die from it [2]. It has been reported that the diagnosis and treatment of breast cancer put great pressure on patients during their breast cancer journeys, especially emotional changes, such as anxiety, depression, and fear [3,4]. These changes seriously affect the patients' quality of life. Studies have shown that social support is effective in helping women cope with these negative emotional responses [5].

The international literature reports that women who receive good social support have less stress, anxiety, and depressive symptoms; lower risk of recurrence; and longer survival during their diagnosis and treatment [6,7]. On the contrary, a lack of social support is related with stress, maladaptive adjustment, cancer-related fatigue, and depressive symptoms [8,9]. At present, several quantitative studies were designed to address this topic. However, few qualitative methods were used to gain deeper insight into these patients' experiences of social support. Especially with the background of Chinese culture, there have been no studies that explore the experiences of women with breast cancer. Moreover, little attention has been paid to using a framework analysis to describe women's experiences when they feel supported. This method can provide an in-depth systematic and comprehensive analysis based on participants' original accounts and reflections [10]. Thus, we performed the present study.

Material and Methods

Participants

The team comprised 2 nursing graduate students (HLZ and LX) with training in qualitative research methods as investigators and a Nurse Scientist (GSR) with rich experience in qualitative research. Twenty-five women ($n=25$) were recruited from the First Affiliated Hospital of Chongqing Medical University,

China. Purposive sampling was used. The eligibility criteria were as follows: 1) age 18 years or older, 2) a confirmed diagnosis of breast cancer, 3) Chinese-speaking, and (4) able to express their ideas clearly. Participants' demographic and clinical characteristics were also collected, such as participants' age, marital status, number of children, education level, employment status, and monthly income (in RMB).

Data collection

The semi-structured interviews were conducted between June and August 2016. The interviews were between 30 to 45 minutes in duration and were conducted in a private room. A semi-structured interview guide was used (Table 1). All the interviews were recorded using a digital voice recorder, and the participants' nonverbal behaviors and the interviewers' thoughts on the interviews were also recorded as field notes.

Data analysis

The interview data were analyzed using a framework analysis based on qualitative content analysis methods [10] (Table 2). Seven discrete stages were included in this method, which aims to summarize and classify all data. Eventually, a methodical and rigorous thematic framework was formed.

The trustworthiness of the data involved 4 aspects: credibility, dependability, conformability, and transferability. Investigator triangulation was used to increase credibility. For purposes of dependability, the analysis process was reviewed by 2 researchers and with the participants. To ensure conformability, a systematic data collection method was used, including the use of field notes and recordings. The researchers also provided a comprehensive description of the study population to enhance transferability.

Ethical consideration

This study was approved by the First Affiliated Hospital of Chongqing Medical University Ethics Committee (Approval number: 2016-125). Prior to each interview, informed consent was

Table 1. Semi-structured interview guide.

Interview questions
1. How did you feel when you were first told that you had breast cancer?
2. Have you received any support during this period?
3. How did you feel about the social support you have received or not?
4. What changes have occurred in how you feel about yourself?
5. Is there anything more you would like to add or share about social support?

Table 2. Procedure for framework analysis.

Transcription	Interviews were transcribed verbatim
1. Familiarization with the interview	All of the data were read a few times for familiarization. Key ideas and recurrent themes were recorded resulting in an overview of the collected data
2. Coding	After familiarization, transcripts were read line by line, applying a paraphrase or label ('code')
3. Developing a working analytical framework	The labels were compared by all researchers. Codes were grouped together into categories using a tree diagram. This formed a working analytical framework
4. Applying the analytical framework	The working analytical framework was then applied by indexing subsequent transcripts using the existing categories and codes
5. Charting	According to the themes and subthemes drawn from the thematic framework, all of the above data were organized thematically
6. Interpreting the data	The relationships between categories were explored

Table 3. Demographic and disease-specific characteristics of participants (n=25).

Characteristic	n	%	Range
Age			32–61
Marital status			
Married	21	84	
Divorced	2	8	
Widowed	1	4	
Single	1	4	
Children			
Yes	23	92	
No	2	8	
Education level			
Below primary school	3	12	
Junior high school	11	44	
High school or Some college	6	24	
University or above	4	16	
Employment status			
Full-time/part-time	9	36	
Retired/unemployed	10	40	
On leave due to illness	6	24	
Family income(in RMB)			
<1,000	7	28	
1,000–3,000	8	32	
>3,000	10	40	

Table 3 continued. Demographic and disease-specific characteristics of participants (n=25).

Characteristic	n	%	Range
Current living arrangement with			
Husband and children	12	48	
Parents	10	40	
Siblings	3	12	
Months since cancer diagnosis			1–13.5
Stage of breast cancer			
0	2	8	
I	6	24	
II	10	4	
III	4	16	
IV	3	12	
Type of surgery			
Lumpectomy/breast conserving surgery	3	12	
Modified radical mastectomy	22	88	
Treatment type*			
Mastectomy	23	92	
Chemotherapy	25	100	
Radiotherapy	2	8	
Chemotherapy and radiation therapy	2	8	

* Total adds up to more than 100% because women reported more than one type of treatment.

signed by each participant. Pseudonyms were used to maintain the anonymity of the participants.

Results

Twenty-five Chinese women with breast cancer participated in the study during their inpatient stays. Participants ranged in age from 32 to 61 years. All of them were Chinese-speaking women. Sample characteristics are provided in Table 3.

All participants in our study expressed the importance of social support through their experiences. The framework was organized into 4 themes – providers, types of support, outcomes of support, and challenges for care – and all of the themes were further divided into 3 or 4 subcategories. The common thread running through each theme formed an integrated and hierarchical conceptual framework that evolved from the analytic process (Figure 1). These are further described below.

Providers of support: Family members/Important others/Health professionals

Family members, important others, and health professionals were the main providers of support, and they played important roles in the support care system. All participants indicated that they had good support from their family members, particularly from their husbands and children. Most of the support was provided during the participants' diagnoses and throughout their treatments, which was the most stressful time for them. The support from family members significantly helped them reduce anxiety and depression in the hospital.

My husband always accompanies me and takes care of me during my treatment. I can share some feelings with him, such as fear and worry. He still tells me that my medical condition is very good now and that my breast cancer can be cured. He gives me a lot of help that increases my confidence and courage against the disease. It makes me feel better.

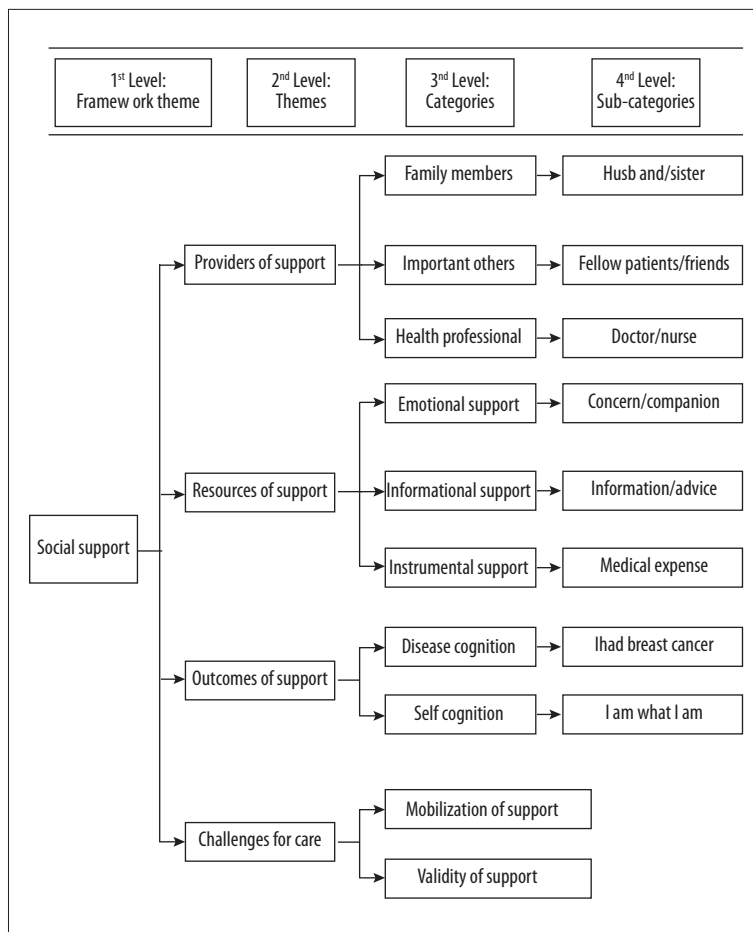


Figure 1. Conceptual framework of social support among Chinese women with breast cancer.

Interestingly, most of the participants in our study also emphasized that their fellow patients provided them with medical information associated with breast cancer and its treatment. The most important thing was to make them realize that they were not 'alone' in having breast cancer. However, some felt insecure when exposing themselves to others.

Sharing experiences with each other in the room is helpful for most during the breast cancer journey. They told me to follow the doctor's instructions, and taught me some important things in life that we need to be aware of. I will not feel lonely and afraid, because there are many other people like me in this world.

In addition, friends provided strong support to the women during times of need. Being contacted by friends was beneficial for improving the symptoms of breast cancer treatment and relieving negative emotional responses caused by the illness.

After chemotherapy, friends usually get together to play mah-jong and attend the dam dance in the evening. I am pleased.

Mixed social support from health professionals was revealed through the participants' descriptions. During the treatment

periods, health professionals were very friendly, and they continued to visit the participants. However, most participants hoped the doctors and nurses could explain more disease-related knowledge to them.

Doctors and nurses come to see me every day, and I am half sick. If the doctors and nurses responded to our symptoms in a timelier manner, I would be more at ease. Sometimes, as long as my body has some discomfort, it is difficult to sleep.

In fact, the participants received the most support from family members, but what they craved most was support from health professionals. Regardless of the support from family members, important others, and health professionals, there would be positive and negative aspects.

Resources of support: Emotional support/Informational support/Instrumental support

Emotional support, informational support, and instrumental support were the main resources of support. Many participants reported emotional disturbances ensuing from the initial shock of receiving the disease diagnosis and experiencing

the negative side effects of treatment (e.g., anxiety, fear, and insecurity). The presence of companions who express concern was very important to reassure them during their current crisis.

When I learned that I had the disease, I felt that the day was gone. When life is difficult, a companion who shows concern is good help. An arm and a hug are better than any words.

Most of the participants felt that they received inadequate information and explanations if needed. They wanted to understand the disease-related information and the possible side effects of treatment. They needed to take responsibility for self-monitoring their recovery, and they feared cancer recurrence.

I feel like I did not receive enough information related to cancer after being diagnosed. When I have a question, I go online to search even though I know that I could ask someone. If I could have more communication with the health professionals, I would not always suspect the worst. Did the cancer move to the liver, lungs, or kidneys?

The majority of participants had medical insurance, which provided them with some security when they were diagnosed with breast cancer. They expressed that the current medication fees were too expensive for them to afford, and their insurance status affected the treatment options available to them.

To be honest, our medical expenses are really expensive. Like now, a surgery costs tens of thousands. Chemotherapy and long-term treatment will cost more. If there is no medical insurance, we really can only choose to give up. So, for now, medical insurance is really important to us.

Outcomes of support: Disease cognition/Self-cognition

In the face of the great uncertainty and fear of death accompanying a breast cancer diagnosis, self-cognition and the ability to understand the disease will affect the patient's decision-making and safety. The following quotes exemplify how participants emphasized these 2 aspects as outcomes of support:

When I was diagnosed with breast cancer, I could not accept it. I always felt that it was difficult to say aloud that I had the disease. Every day, I thought a lot. But later, by looking at the internet and by other ways, I realized that many other people have the same disease. Now, I can say loudly that I have breast cancer.

Growth has become the biggest harvest during this anti-cancer process. Cancer enhanced my life. I have turned around a situation that was bleak into a positive one for my own growth and development. I am what I am, and I have to live better.

Challenges for medical care: Mobilization of support/ Validity of support

Mobilization of support and validity of support make sense of social support. The former refers to improving the initiative of providing and receiving social support during medical care. Chinese women with breast cancer as the receivers of support feared judgment by family members and friends because of having cancer-related female sexuality. Some of the participants were ashamed to seek help from other people. Low self-esteem was the most important barrier to mobilizing support among Chinese women.

I do not want to say anything to ask for help. I do not talk with anyone about my frustration or disappointment. I felt embarrassed so that I do not know how to express all I need. I am afraid of being looked down upon by others. Actually, I really need more help.

Additionally, the latter refers to ensuring the efficacy of support, which is also a big challenge for medical care. Social support involves communication, which is a dynamic process. Especially, several participants identified the need for health professionals to sustain positive relationships with the patients/families through effective communication.

I hope that the health professionals can explain medical issues in plain language, involving patients and families, and taking particular care when breaking bad or sensitive news. In addition, I also hope they can give me more care besides the treatment.

Indeed, building a good interpersonal relationship with the patient was viewed as fundamental for social support. Health professionals who were perceived to be genuine and kind, had good listening skills, and used an appropriate tone of voice were highly praised and were perceived as providing good medical care to breast cancer patients.

Discussion

In this study, our core objective was to gain a rich understanding of the social support for Chinese breast cancer patients. To this end, we attempted to build a conceptual frame of social support through eliciting patients' experiences of social support. The conceptual framework includes the following 4 parts: providers of support, resources of support, outcomes of support, and challenges for medical care.

We found that husbands and children were the major providers of support for the women in our study. In Asian cultures, the relationships among family members are interdependent, which is different from individuals' independence in

Western cultures [11]. Family relationships are the most intimate relationships for Chinese women [12]. These family ties and obligations have also been emphasized in other studies from non-Western societies [13,14]. In addition, women seek help outside the immediate family, violating interpersonal etiquette and embarrassing the whole family in the context of Chinese communal culture [11]. As expected, the home can be a significant place where women receive more support from their husbands and children. Of course, this finding has also been confirmed in other studies from Asia [15]. Our findings add to the strong evidence of the important role of men and children in social support provided to breast cancer patients.

Some participants emphasized that their fellow patients were also sometimes the best sources of information and support. Consistent with other studies, most of the fellow patients who provided social support in different ways gave some assurance about the illness to the women [16]. However, our study (along with many previous studies) concluded that the women received mixed support from the healthcare professionals [16]. Being treated with dignity is what they really desire. Some of them were satisfied with the level of support from the healthcare professionals, but some women still had negative experiences related to the lack of medical informational support from them. Previous studies have shown similar findings [17].

We also found that self-cognition and ability to understand the disease were affected by social support. Positive cognition can mobilize patient participation with enthusiasm and initiative, which is conducive to understanding health concepts, and can promote patient safety [18]. From a clinical point of view, it is suggested that women with breast cancer who receive a cognitive-behavioral intervention have more post-traumatic growth (PTG), defined as positive psychological growth and change after experiencing traumatic events [19]. PTG seems to be very dependent on social resources. One study revealed that high social support and active cognitive processing promote PTG in long-term breast cancer survivors [20]. Therefore, internal and social resources are essential to derive benefits from breast cancer.

However, self-esteem became the most important barrier to mobilizing support among Chinese women. People with lower self-esteem tend to receive less social support [21]. Patients, especially Chinese patients, are ashamed to ask for help. They do not want to bother others, and hope to maintain harmony [22]. Therefore, patients with lower self-esteem cannot take the initiative to express their needs, which is detrimental to receiving

appropriate and timely support and treatment. Of course, other factors, such as personality, sense of control, and optimism, should also be considered. Interpersonal communication became the main barrier for validity of support among social networks. The central importance of communication skills (both verbal and nonverbal) and relationship-building was very important for communication. These findings concur with those of other authors who identified the link between social support and interpersonal communication [23].

There are limitations to the present study. The sample size may not be representative of larger populations because the participants came from a single geographical area with similar ethnicity and culture. In addition, the specific interview situation in the hospital might have influenced the interview answers. We also found that using personal interviews has an impact on the conceptual framework drawn from this study.

Conclusions

By understanding women's individual experiences, social support should be valued for the healthcare of women living with breast cancer. Based on our findings, we suggest that support from larger and more effective social networks would help women to have better quality of life by providing emotional, informational, and instrumental support. On this basis, we constructed the conceptual framework of social support, which helps caregivers find ways to develop positive social support strategies. More importantly, healthcare professionals need to be aware of the importance of social support for women with breast cancer. Therefore, healthcare professionals should provide support by trying to build trusting therapeutic nurse-patient relationships with patients in a professional way, and the patients should be encouraged to call if needed. Finally, healthcare professionals should provide more individualized support and care to women during this vulnerable period of life.

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Conflict of interest

None.

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