



Nina Mikhailenko. *Net Fishing*. Watercolor, 10" × 14".

*Breast cancer patients and survivors of Chinese descent face culturally specific obstacles that affect quality of life.*

## Understanding Quality-of-Life Issues in Chinese Women With Breast Cancer: A Qualitative Investigation

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*Little is known about the cultural beliefs and quality of life (QOL) of US-born and foreign-born Chinese women with breast cancer. We conducted individual semistructured qualitative interviews to explore the meaning of QOL, identify beliefs about cancer, and make comparison between US-born and foreign-born survivors. Women in this study identified the stigma of breast cancer that exists in the Asian community. They also described interpersonal support as central to a good QOL. However, when describing QOL, foreign-born Chinese women referred to wealth more frequently, while US-born Chinese women indicated friendship more frequently. The study findings support the need for culturally appropriate interventions that take into consideration the cancer-related beliefs and QOL of breast cancer survivors in the Chinese community.*

### Introduction

Breast cancer remains the most commonly diagnosed cancer among women living in California, despite the fact that the incidence of breast cancer in the United States has not increased since 1988 and the mortality rate has

dropped by 24%.<sup>1</sup> These trends indicate that women are now diagnosed with breast cancer earlier and living longer. However, the decrease in breast cancer-related mortality is not equally distributed among ethnic minority women,<sup>2-4</sup> especially women who encounter barriers to cancer screening that result in late-stage diagnosis.<sup>5-7</sup>

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*Abbreviations used in this article:* QOL = quality of life.

For instance, cancer remains the leading cause of death for Asian American women.<sup>8-10</sup> Among Asian American women in San Francisco, the annual age-adjusted incidence rate is 83.2 per 100,000 for invasive breast cancer and 24.6 per 100,000 for in situ breast cancer. Between 1995 and 1999, a total of 774 Asian American women were diagnosed with breast cancer in San Francisco, with 599 having invasive breast cancer and 175 having in situ disease.<sup>11</sup> According to the national surveillance, epidemiology, and end results data from 1988-1992, the breast cancer rate among Chinese women was 55.0 per 100,000.<sup>12</sup>

According to the 2000 Census, Chinese make up the largest Asian group in the United States, comprising 23.8% of the nation's total Asian American population. Among the 50 states, California has the largest population of Asian Americans, and Chinese outnumber other Asian groups in the state — 980,642 (2.9%) of the state's total population.<sup>13</sup> Foreign-born Asian women generally have a lower breast cancer rate compared with US-born Asian women,<sup>14</sup> and Chinese immigrants are at a higher risk of being diagnosed with breast cancer compared with their peers living in China.<sup>15,16</sup>

Research on cancer-related beliefs indicates that some Chinese people believe cancer is contagious<sup>17</sup> and that breast cancer is due to tragic luck.<sup>18</sup> These beliefs, combined with a low compliance with breast cancer screening,<sup>19,20</sup> may compromise the survival rate and quality of life (QOL) of Chinese women. Further, little is known about the perceptions of QOL among Chinese women who recently immigrated to the United States, as well as how breast cancer may influence the QOL of this population. For instance, a breast cancer diagnosis may be more detrimental to the well-being of foreign-born Chinese women compared with Chinese women who are born and raised in the United States. Research conducted in other foreign-born ethnic groups indicates that this disparity may be due to the lower socioeconomic status and limited English proficiency of immigrants<sup>21,22</sup> and their limited understanding of the Western medical system.<sup>23</sup> In this study, QOL is conceptualized as a multidimensional construct that entails a person's psychosocial well-being in addition to physical, socioeconomic, and interpersonal factors.<sup>24</sup>

Studies involving patients with breast cancer found a decrease in QOL due to pain and treatment side effects.<sup>25,26</sup> Other studies found that variables such as tumor location, pain intensity, depression, and diet are correlated with reduced QOL in cancer patients.<sup>27,28</sup> However, psychological problems and inadequate role functioning appear to have a greater influence on QOL compared with the effects of physical problems.<sup>29</sup> For example, in a study of cancer patients receiving chemotherapy, Redeker et al<sup>30</sup> found that insomnia, fatigue, anxiety, and depression were positively correlated with one another and negatively correlated with QOL. Women reported poorer QOL and more anxiety and fatigue, while older age was associated with better QOL and less insomnia, fatigue, anxiety, and depression.<sup>30</sup> Other stud-

ies found that elevated levels of depression or distress appeared to be related not only to QOL, but also to nonadherence to the recommended treatment regimen, thus jeopardizing the outcomes of cancer therapies and increasing the costs of health care.<sup>31,32</sup> However, factors that are important in determining QOL among white middle-class cancer patients may not be as important to foreign-born Chinese women with breast cancer. Conversely, factors that do not affect QOL for cancer patients from other ethnic groups may be important to foreign-born Chinese women with breast cancer. For example, shared medical decision making is an important factor influencing QOL in white patients, but this may not be as important for Chinese patients who identify with a system that values professional opinions.<sup>33,34</sup> On the other hand, a belief in fatalism — defined as a philosophical doctrine holding that all events are predetermined in advance for all time and human beings are powerless to change them — is fairly widespread among Chinese immigrants. Research studies on the relationship between fatalism and cancer screening have reported mixed results; they have typically identified this construct as a negative adjustment style associated with poor outcomes, eg, increased mortality.<sup>35</sup> This may be due to the fact that fatalistic breast cancer patients are less likely to be screened and more likely to be diagnosed with late-stage cancer when treatment is less effective and mortality is greater. For Chinese women with breast cancer, acceptance of fate may be a coping mechanism that enables them to accept a terminal diagnosis more readily, but a diagnosis of breast cancer also may be regarded as prophecy of death that causes a patient's health to decline more rapidly.

To address important issues that are culturally relevant to this group of women, we conducted a qualitative study of QOL in Chinese women who were diagnosed with breast cancer within the past 2 years. Specifically, we explored their cultural beliefs, their experiences of survivorship, and their definition of QOL. To guide this investigation, we asked the following research question: *How do perceptions of quality of life and beliefs about cancer differ between US-born and foreign-born Chinese women with breast cancer?*

## Methods

### Research Design

A qualitative design was used to explore cancer-related beliefs and QOL among Chinese women with breast cancer. In-depth, semi-structured face-to-face interviews were conducted with 30 Chinese women (15 were foreign-born and 15 were US-born).

### Sample

The sample included Chinese women who were diagnosed with breast cancer at any stage within 24 months of study initiation. Their primary language was English, Mandarin,

or Cantonese, and they were no longer on active treatment such as chemotherapy, surgery, or radiation therapy. Women taking tamoxifen ( $n = 10$ ) were included in this study because it is considered a noninvasive treatment. To ensure that the foreign-born participants reflected Chinese cultural beliefs, eligibility was limited to those who resided in the US for less than 15 years. US-born Chinese women were used as a comparison group so that acculturation and the effect of immigration could be studied.

The sample was recruited from oncologists serving the Chinese community in the San Francisco Bay area. Each oncologist compiled a list of their Chinese patients who satisfied the study's inclusion criteria and who did not have a mental health condition that would affect their participation. Each woman received a standardized letter in her preferred language explaining the purpose of the study and indicating that a member of the study team would call to invite her to participate in a face-to-face interview. The letter encouraged the women to review an enclosed copy of the informed consent document and to contact the researchers if they had questions. It also indicated that their decision to participate in or decline this study would not affect their right or access to medical treatment.

A research assistant fluent in English, Mandarin, and Cantonese contacted each woman within 2 weeks to answer questions about the study and determine her interest in participation. If she was interested, the research assistant administered a brief screening interview to verify the woman's ethnicity, place of birth, immigrant status, and length of time she lived in the United States. An interview appointment was arranged for women who were eligible for the study and who agreed to participate. This process continued until the sample consisted of 15 US-born and 15 foreign-born Chinese patients. Because two of us (E.W-K. and A.S.) have extensive work experience in the Chinese community, it only took 4 months to recruit the foreign-born Chinese sample. However, due to the limited access in recruiting US-born Chinese women, it took 8 months to complete recruitment this sample.

### **Interview Guide**

A semistructured interview guide was used to guide the participants in a discussion about the following topics: (1) beliefs about the causes of cancer, (2) the meaning of a breast cancer diagnosis, (3) the effects of breast cancer treatment, (4) faith and spirituality, (5) fate and fatalism, (6) the effect of cancer on the patient's family role, and (7) cultural perceptions of QOL. Probes were used to obtain additional information and get specific examples from the participants.

### **Procedure**

Bilingual interviewers were recruited and trained in interviewing techniques and study procedures. Once a participant was screened for eligibility and had verbally consented to the interview, an appointment for a face-to-face interview

was arranged by telephone. Patients were interviewed for approximately 90 minutes at their residence or in a mutually convenient location. At the start of the meeting, the interviewer introduced herself, briefly repeated the study purpose, reviewed the elements of informed consent, and asked the patient to sign an informed consent document. Participants were given a \$35 gift certificate to compensate them for their time spent taking part in this study.

Each interviewer followed a standardized protocol to ensure that all the interviews were conducted in a similar manner and that an identical set of questions was discussed. Interviewers wrote notes and audiotaped the interview. Also, they rated the quality of the interview on a scale of 1 (poor) to 5 (excellent). They also recorded information about any factors that might have affected the information provided, eg, the presence of another family member. Two of us (E.W-K. and A.S.) reviewed the notes and audiotape for each interview immediately after it was completed and talked with the interviewer to clarify any ambiguous notes or interview segments on the audiotape.

### **Data Analysis**

To facilitate data analysis, verbatim transcriptions of interviews were prepared. Because two of us (E.W-K. and A.S.) are fluent in Chinese, the interviews conducted in Chinese were transcribed and analyzed in Chinese to preserve linguistic meanings and enhance the trustworthiness of the data. The narratives from these transcripts were analyzed using a constant comparative approach<sup>36</sup> to identify concepts and develop categories that provide a structured framework for organizing the data.

## **Results**

The Table summarizes the demographic profile of the study sample. Although both groups were composed of Chinese women, the foreign-born women reported a lower level of education than the US-born sample, and they earned much less than their US-born peers. In this study, foreign-born and US-born Chinese women described the effect of breast cancer on their self-perceptions, personal lives, and interpersonal relationships. Overall, the study findings provide important insights into the participants' perceptions of their QOL in the context of having cancer, how their beliefs about breast cancer are influenced by cultural worldviews, and how diagnosis and treatment interface with family relationships. In addition, the foreign-born Chinese women offered stories about their struggle with the dual pressure of being an immigrant in the United States and having breast cancer.

### **Quality of Life**

Participants from both groups of women in this study described family relationships and family support as central to a good QOL. Furthermore, some indicated that their

cancer diagnosis improved their family relationships, deepened their sense of self and life priorities, increased their spirituality, and facilitated personal growth. The following are two examples of how a cancer diagnosis affected two women's QOL:

*It [cancer] improved my relationship with my husband and my daughter. I really try to look at people and see who they are and where they're at ... and myself, too. So, in that way, cancer's a gift because I'm much more in tune with what's important to me and what does bring me quality of life. So I'm very grateful for that. [US born]*

*Now that my financial situation is not good, cancer made me value myself. Immigration had changed me from someone who has everything to someone who has nothing. Yes, I didn't know how to care for myself before cancer; I only take care of everyone and everything else in the family. But now I know how to take care of myself. I know life is valuable. [Foreign born]*

**Study Sample: Demographics of Chinese Women With Breast Cancer (N = 30)**

	US-born (n = 15)	Foreign born (n = 15)
Age (mean)	57	51
Marital status		
Single	5	2
Married	10	13
Education		
6th grade or below	0	3
Elementary school	0	1
Middle school	0	4
High school graduate	1	6
Some college	1	0
College graduate	7	0
Graduate school	4	1
Annual household income		
\$10,000 or less	0	6
\$10,001–\$20,000	0	3
\$20,001–\$35,000	3	2
\$30,001–\$50,000	2	2
\$50,001–\$60,000	2	2
\$60,001 or more	5	0
Unknown	3	0
Health insurance		
Medicaid	0	6
Private insurance	15	9
Number of visits with Western medical doctor in past 6 months		
Fewer than 10	9	11
10 or more	6	4
Number of visits with Chinese medical doctor in past 6 months		
Fewer than 10	13	6
10 or more	2	9
Treatment*		
Radiation therapy	12	7
Chemotherapy	8	7
Lumpectomy	11	5
Mastectomy	4	8

\* Some participants in the sample received more than one type of treatment.

Compared with the foreign-born Chinese women, more of the US-born Chinese women described the importance of friendships, and they used words such as “independence,” “freedom,” and “peace” to describe a good quality of life. For the foreign-born women, having wealth was cited frequently as a way of achieving a high-quality life.

### Beliefs About Cancer

The participants' beliefs about cancer — which included the terminal nature of the disease, the stigma associated with the diagnosis, and the role of fate or karma — varied between the foreign-born and US-born women. Specifically, foreign-born women were more likely to believe that cancer was a terminal rather than a treatable disease. One foreign-born woman stated: “At the time [of the diagnosis] I was so scared. I was so scared I thought I was going to die, I can't sleep and I can't eat.”

The stigma associated with having breast cancer was reported by women in both groups, with foreign-born women reporting more incidents of stigma than their US-born peers. A US-born participant summarized her thoughts about the stigma associated with having breast cancer as follows: “I know that a lot of Asian women are very alone because they're ashamed to talk about the illness with other people, and they don't want to spread it around; they're very private about physical illnesses.”

One foreign-born Chinese woman explained that cancer is considered incurable and therefore associated with death: “My landlord found out I had cancer because of chemo and I lost all my hair. She told me I had to move out because she did not want anyone to die in her apartment; it was considered to be bad luck. As cancer patient I still feel uncomfortable telling other Chinese people I have cancer.”

Finally, the role of fatalism or karma figured prominently in the narratives for women in both groups. In particular, these women shared their perceptions that cancer was predetermined or caused by the immoral behavior of oneself or one's ancestors.

*I think everything is due to fate. It is destiny that I immigrated to the US. I am now a true believer of fate. And because I believe in fate I realize I am a happier person. I don't have to struggle anymore. That means I feel really tired, I don't want to struggle to get control. I just accept fate and now that I accept fate I feel much better. [Foreign born]*

We also found that most participants expressed a fear of cancer and a disbelief of their diagnosis, whether they were US-born or foreign-born Chinese. Asking “why me?” was a common reaction to the breast cancer diagnosis.

*Why did I get it? Cause I'm pretty healthy, I take care of myself, I go for my checkups, and I do a self-breast exam. But why me? I just think fate is just telling me to slow down, reassess yourself. [US born]*



## Family Influences

The role of the family was a salient theme in the interviews. In many situations, the immediate family was viewed as a source of primary support. According to one of the foreign-born women: "It's important to tell others what you need. You're the only one who knows what you need. If you don't know and you don't ask people, you're trapping yourself. I feel that the most important thing is to get support from my family." Family involvement also can extend to influence a woman's decision about which treatment procedure to pursue. In the case of one US-born woman, her parents' support for complete breast removal seemed to strongly influence her ultimate decision: "My parents are very strong advocates of getting mastectomy. They persuaded me with their thoughts and all. I think that's why I chose the mastectomy."

In contrast to the positive influence families can have on a woman's overall coping decision making, the narrative below describe how a spouse's wishes may be in conflict a woman's desire to pursue the more aggressive treatment.

*He [spouse] would have preferred I had a lumpectomy, because one of the doctors said you know that the chances of survival are essentially the same. So, he said if the chances of survival are the same, then why go through all of that and disfigure yourself? The difference was like three percent or whatever and I said, "Well, I want to maximize my chances of survival." And, it was three percent, which may seem insignificant, but it may not be. It is three percent. [US born]*

Most of the women received support from their spouses and immediate family members; however, for women who were single, most identified their extended family and friends as their support system. One US-born woman stated, "Ah, friends and family... I mean, for me my friends are my family." A foreign-born woman who is not comfortable in group settings underscored the role of family and close friends after being diagnosed:

*I'm not a group kind of person, you know. I mean, I got support from my family and friends who are close to me. And I just — I tend to work things out myself so it's more — I'm not a group talker kind of person. [Foreign born]*

## Immigration Experience and Illness

Due to the lower socioeconomic status among the foreign-born participants in our study, the dual pressure of being an immigrant in the United States and dealing with a life-threatening illness figured prominently for some of these women in this study. They all expressed great difficulty in adapting to the American lifestyle, and their QOL before being diagnosed with breast cancer was already poor. Many of the foreign-born women considered breast cancer as another traumatic event that compounded the day-to-day difficulties in their lives. For some of the foreign-

born women, a stressful life in the United States was perceived as one of the possible causes of their breast cancer diagnosis. Below is one foreign-born woman's interpretation of the link between immigrating to the United States and her breast cancer:

*My husband came to the US with us and didn't like living here so he moved back, right. So I had to support my daughter all by myself. Sometimes it was so difficult — so difficult because I had no support. I couldn't even find someone's shoulder to lean on when things got tough. I think my heart was suffering, and when all the bad feelings added up, I then got sick [with breast cancer]. [Foreign born]*

This connection between harboring "bad feelings" and developing cancer, like the belief in fatalism and karma described above, underscores the relevance of cultural experiences and world views of Chinese women with breast cancer, as well as the need to pursue studies that will enhance the public's understanding of their lived experiences.

One noteworthy finding in our study was that some foreign-born women felt that breast cancer is less traumatizing than the immigration process. They indicated that they experienced many difficulties when adjusting to the new American culture, and by comparison, breast cancer was considered a less stressful event. Unlike moving to a new country with little support or assistance, these survivors found support, comfort, and assistance from health care professionals during the process of diagnosis and treatment.

## Discussion

The study findings suggest important differences between US-born and foreign-born Chinese breast cancer survivors in their beliefs about, perceptions of, and experiences with breast cancer. One of the most striking differences between these two groups of survivors is how they perceived the breast cancer experience and how this experience affected their QOL. For example, foreign-born Chinese survivors more frequently mentioned the insight gained from the diagnosis. Although both groups of women described their breast cancer diagnosis as a "wake-up call" and as a reminder to take better care of themselves, foreign-born survivors indicated that this diagnosis made them realize the importance of self-care and how this type of care is not a selfish act on their part. Many traditional Chinese women sacrifice their own health, such as annual medical checkups and mammography, so that they can use the time to be caregivers for their family.<sup>37</sup> The breast cancer diagnosis provided a reason for foreign-born survivors to shift their focus from others to themselves, and for older women, it became a legitimate reason to re-examine their life and their priorities.

Unlike the difficulties experienced in another study of Chinese women,<sup>38</sup> we found that the survivors who participated in our investigation were open to discussions about spousal relationships during the interview. Marital problems and strains were also revealed to the interviewer. This may be due to the fact that the interviewees were Chinese women who shared a similar cultural and linguistic background. In this study, family support was considered to be an important factor when assessing QOL. US-born survivors were more likely to identify friends to be their “family,” while foreign-born survivors defined family more traditionally. Younger women who had children worried about their longevity and questioned if they would be able to see their children grow up and become independent. Older women worried about their health and did not want to burden their families with their deteriorating health. Consistent with another qualitative study that compared Asian American, African American, Latina, and Caucasian cancer survivors, families were considered a source of both support and strain for cancer survivors.<sup>24</sup> As a consequence, women identified cancer support groups as a way helping them cope with cancer so that they would not be solely dependent on family members for support. For foreign-born survivors in this study, family strain could be linked to financial hardship that resulted from the immigration process prior to their diagnosis. For example, foreign-born survivors often described relationship changes after they came to the United States. Family members who used to be supportive became less likely to help due to their own adjustment needs. Some foreign-born survivors explained this change in family relationship as part of an inescapable part of immigration. In comparison, US-born women were more likely than their foreign-born peers to explain family relationship strain as a generational conflict, which reflected cultural and value differences between the older generation and the younger generation. Both groups identified a need for additional supportive services, especially in-home support services, to ease the reliance on family that sometimes created more problematic family relationships.

Family members also played a significant role in a survivor’s decision-making process. Few survivors in our study decided on their treatment independently, and many chose a more drastic surgical option such as mastectomy instead of lumpectomy and radiation therapy; this decision was somewhat due to family influences rather than a personal choice. Also, two survivors in our study chose lumpectomy rather than mastectomy due to their husband’s preference rather than an individual choice of preserving their breasts.

We were not surprised to find that many foreign-born survivors mentioned a reluctance to disclose their breast cancer diagnosis. However, we were surprised to discover that even US-born Chinese women had the same issues relating to feeling shame of having this diagnosis. This finding underscores the importance of understanding the nature of this feeling. From our US-born par-

ticipants it appeared that the feeling of shame came mostly from the English-speaking Chinese community. Therefore, it is important to measure level of acculturation rather than identify birthplace as a proxy for acculturation when conducting studies with ethnic minority populations. Compared with recent immigrants who become westernized even before their immigration to the United States, some women who were born and raised in the United States may still be traditional if they were raised by foreign-born parents or grandparents who maintain cultural beliefs and practices.

## Conclusions

This study offers important conceptual understandings of QOL in Chinese breast cancer survivors. However, the study findings must be interpreted with caution because of the small purposive sample and the effects of selection bias. Women who chose not to participate in this study may have beliefs about cancer and life experiences that differ dramatically from those who took part in this study. One key lesson that we learned from this study is that women who are cancer survivors need culturally appropriate interventions that will help improve their QOL. These interventions should include culturally tailored supportive services designed for women with a low level of literacy.<sup>39,40</sup> For instance, foreign-born women in this study who tend to define QOL in terms of financial security may benefit more from in-home supportive and concrete services provided in their own languages, whereas US-born women who frame QOL in terms of interpersonal relationships may benefit from interventions that focus on strengthening relational communities and friendship networks.

From our interviews with foreign-born women who had a lower level of education and were struggling with breast cancer and survival, we learned that having a breast cancer diagnosis might allow them to start taking better care of themselves. Some found breast cancer to be less traumatic than their experiences in adjusting to life in the United States. The attention and warmth they received from health care professionals further emphasized the importance of formal support. In addition to providing medical treatment to patients who are foreign-born Chinese women, health care providers need to also acknowledge the challenges associated with the immigration process. These problems can potentially affect the patient’s overall well-being and treatment compliance. By providing culturally appropriate services to Chinese women with breast cancer, the possibility of their achieving a better QOL and more positive health outcomes is enhanced.

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