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Information and communication needs of Chinese American breast cancer patients: perspectives on survivorship care planning

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Abstract

Background—The existing knowledge on the survivorship experiences of Chinese American breast cancer survivors (CABCS) has arisen largely from aggregated data across multiethnic or multicancer studies that have focused on quality of life. Little is known about Chinese American perspectives and preferences for survivorship care.

Objective—To examine the experiences of CABCS to better understand their information and communication needs and their preferences for survivorship care plans (SCPs).

Methods—16 CABCS, aged 37-72 years, were recruited through community-based organizations in the Northeast United States to participate in one-on-one telephone interviews about their breast cancer survivorship experience. The semistructured interviews were conducted in Mandarin, Cantonese, or English. Two investigators transcribed and translated the audio recordings into English and analyzed the interview transcripts using established methods of qualitative content analysis.

Results—Three main themes were identified through analysis of interview transcripts: the need for evidence-based and culturally and linguistically appropriate health information; the role of language or communication barriers and culture in accessing care and communicating with providers; and preferences for SCP elements and format.

Limitations—The sample may not be representative of the entire population of CABCS.

Conclusions—The findings provide insight into the information and communication needs and SCP preferences of CABCS. Understanding the cultural nuances that underlie these needs and preferences is critical for improving CABCS's quality of life after treatment for cancer. SCPs that incorporate Chinese-language resources and address the unique cultural needs of this population should be developed and they should include information about diet and nutrition as well as traditional Chinese medicine.

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Incidence rates of breast cancer for Chinese Americans have been increasing significantly compared with rates in other US populations¹ and it is the highest of all cancers in Chinese Americans.^{2,3} Given the advances in the early diagnosis and treatment of breast cancer and the increasing number of Chinese American breast cancer survivors (CABCS),⁴ there is demonstrated need for further research to inform our understanding of the needs and coping experiences in this minority group after cancer treatment.⁵ The Institute of Medicine (IOM) has recommended that cancer patients be provided with a comprehensive care summary and follow-up plan that is clearly explained upon discharge.⁶

Emerging research reports that survivorship issues may vary for ethnic minorities because of their unique cultural beliefs and that ethnic minorities can face added challenges because of language barriers and cultural factors.^{8,9} Given that 70% of Chinese Americans are immigrants and that half do not speak English fluently,⁷ challenges to coping with cancer distress may be further amplified for many Chinese immigrants because they live in a different cultural environment.^{13,14} However, there is little research to inform our understanding of CABCS preferences for follow-up care and survivorship care plans (SCPs) so that their needs can be addressed.^{15,16} Such an understanding of their needs and preferences would help guide the development of culturally sensitive SCPs and follow-up care interventions as survivors make the transition back to seeing their primary care physicians (PCPs). To respond to that need, we conducted a qualitative study to examine the information and communication needs as well as survivorship care preferences of CABCS.

Methods

Recruitment

The study was approved by the Fox Chase Cancer Center Institutional Review Board. Eligible participants were women who met the following criteria if they had completed treatment for breast cancer (stages 0-III) within the previous 5 years; had completed primary treatment (surgery, chemotherapy, and/or radiation therapy) in the United States, self-identified as Chinese, were older than 18 years, and were able to give informed consent. The participants were primarily recruited through the community partners, Asian Community Health Coalition in Philadelphia, and the American Cancer Society-Asian Initiative in New Jersey and New York. The study was announced at cultural events, support groups, and educational seminars that had been organized for the Chinese community. In all, 20 breast cancer survivors who were interested in the study were screened, of whom 2 were ineligible because their treatments had been completed outside of the United States. Another 2 declined to participate because of schedule conflicts when trying to arrange an interview. In all, 16 women completed a telephone interview; each received a \$40 gift card for their time and effort.

Interview procedures

Interview guides were developed by the research team in conjunction with input from Chinese community advisers and reviews of existing literature on breast cancer survivorship. The following topics were discussed during the interview: overall survivorship experience (sample question, *Could you share with me the impact of breast cancer and*

treatment on you after primary treatment completion?), health care access (*Could you share with me your experience of finding your breast cancer providers?*), doctor-patient relationship (*What do you think about your relationship with your breast cancer [care] providers?*), communication and informational needs (*What type of information have you looked for to improve your recovery?*), and SCP preferences (*If a care plan was given to you upon completion of your cancer treatment to help your recovery, what information should be included in it?*). Semistructured interviews were conducted in English, Cantonese, or Mandarin, allowing for natural conversation flow and use of probing questions to clarify or elaborate on points. The interviews were audiorecorded and were 30-90 minutes in length, with a mean duration of 40 minutes.

Content analysis

Interviews were transcribed and translated into English by a bilingual translator and verified by investigators through direct comparison to audio files. The initial analysis was conducted using inductive analysis techniques, allowing themes and patterns to emerge from the data, rather than applying a predetermined coding scheme.¹⁷ Themes were identified which consisted of broad categories (eg, doctor-patient communication, and subthemes) under each category (eg, language and communication barriers). Two independent coders qualitatively analyzed each transcript and discussed the patterns and research implications to consensus. Quotations were chosen to accurately represent subthemes based on their context within the whole transcript.

Results

Participant characteristics

Table 1 summarizes participants' demographic and medical characteristics (N = 16). The mean age of the participants was 58 years, with a range of 37-72 years. Most of the participants had completed high school (87.5%), reported an annual household income of less than \$15,000 (50%), were unemployed (68.8%), and were married (81.2%).

Content analysis results

Analysis of interview data, which was guided by our research question, identified 3 central themes: the need for accurate and relevant health information; the role of language, communication barriers, and culture in accessing care and communicating with providers; and preferences for SCP elements and delivery format.

Health information needs

Information-seeking topics and sources—All of the women who were interviewed wanted basic information about their diagnosis, treatment options, and the common side effects of treatment. They also noted that their information needs changed over time during the cancer continuum. Women supplemented the health information they received from their providers with information from various types of media. The Internet was the most commonly used source of information both during and after treatment, followed by pamphlets, books, and educational lectures. Friends and family also provided survivors with reference materials from websites or books. Some women also described using the Internet

and books to understand medical terms and comprehend what they were told by their English-speaking providers.

The Internet is so important, because at my first visit I didn't really understand anything they told me. Before and after every visit I had to do my homework online. Anything he said that I didn't understand I would write down and then look it up when I got home. I ended up learning a lot of words.

6-month to 1-year survivor, aged 37 years

Many women also reported that they valued the knowledge and information that they received from other CABCS, either through individual social network referrals or through the local cancer support group volunteers.

I'm most thankful that a Chinese volunteer called me from the American Cancer Society the day before my surgery to tell me what I needed to do, and that if I felt any pain I had to tell my doctor. It really made an impression and helped me a lot.

3- to 5-year survivor, aged 65 years

Need for linguistically appropriate and evidence-based information—Some women reported difficulty in finding information that was linguistically and culturally appropriate. Language was the most commonly discussed barrier to their being able to understand the information they were given.

Most of the time, the articles go over my head. If I could understand what I'm reading in English, then I'd be more willing to spend more time understanding the information.

3- to 5-year survivor, aged 53 years

However, women who had access to breast cancer information in Chinese were concerned with the credibility of these materials. Some women described their needing to compare information from a number of websites or resources to verify both the information's validity and applicability.

But if others are in my position, I want to warn them that Chinese materials, while they give you a lot of information, are just far too unorganized. In my experience, Chinese materials are not scientific enough. They'll write whatever they hear with no scientific explanation.

0- to 6-month survivor, aged 50 years

Lack of consensus and clear understanding of traditional Chinese medicine—Participants expressed a strong desire for more reputable information on traditional Chinese medicine (TCM), and noted a lack of cohesive information on TCM's appropriate use. Some participants reported using traditional Chinese herbal medicine (eg, ginkgo) or alternative therapies (eg, acupuncture) to control side effects and improve their immune health both during and after their treatment. Few participants believed TCM could replace conventional

cancer treatments, but many stated their confusion over the use of TCM and were uncertain about what constituted credible and trustworthy TCM information.

Because at the time your breasts are swollen but also hard, the Chinese doctors will show you how to massage yourself to allow the blood to flow ... But the doctors here, I don't know whether they want me to massage them or not. Even when I ask them, they don't know.

3- to 5-year survivor, aged 70 years

Language, communication barriers, and culture in cancer care

Authority of medical professionals in Chinese culture—Women frequently reported respecting the authority of their providers, to the point of feeling unable to make decisions about their care or unable to share their concerns. Most of the women reported complying with their provider's recommended breast surgery and every other aspect of their treatment. Many participants reported that their providers did not routinely proffer information or initiate broader discussion of treatment options, which prevented them from knowing what to ask to initiate more meaningful discussions.

I'm from Taiwan, so I don't know if it's because I'm Taiwanese, but we're very respectful toward doctors. Whatever the doctor says, I didn't dare to say another word. So even when I had my concerns, I wouldn't say anything.

6-month to 1-year survivor, aged 37 years

Language and communication barriers—Language barriers and poor communication with providers were commonly reported as interfering with access to health care. Many women reported experiencing language difficulties that affected their ability to navigate the health care system and interact with their providers. Some women received assistance from family members during clinical encounters, but still experienced unmet informational needs.

I can't speak English, and I don't know anything about seeing a doctor. My daughter would tell me what to do, and I just listened to her. I had no say whatsoever. If I had a real translator, things would have been different. The translator would be able to translate every single sentence.

3- to 5-year survivor, aged 70 years

Lack of guidance on continuity of survivorship care—Few women reported having received any form of recovery planning beyond information on medication and the scheduling of follow-up appointments and tests. It was common for no supplemental information or instructions to be proactively offered by providers either in the form of a discussion or take-home materials.

They did talk about my recovery, but they mostly focused on the medication I'd be taking. They talked very little about the other things.

1- to 2-year survivor, aged 66 years

Some women also expressed the need to be assertive to receive information from providers about guidelines for follow-up care.

In my experience, if you don't ask about these things [recovery planning], sometimes doctors and nurses won't bring it up. So therefore, every visit, every time you think of a question, you need to ask it ... It's the only way to get information.

0- to 6-month survivor, aged 50 years

Some women were concerned about the lack of coordination in their survivorship follow-up care and the challenges of clinical communication between providers with different specialties.

I don't think my family doctor and my oncologist had any contact. Every visit, they're supposed to have a record. I ask them to transfer the records, but they won't do it.

3- to 5-year survivor, aged 70 years

Cultural perspectives in cancer care—Women also reported cultural preferences for fewer medications, smaller doses of medications, or TCM, which are usually under-recognized by providers in the US system. Some participants also believed that racial concordance would contribute to better treatment outcomes and doctor-patient relationship.

My doctor, since he used Western medicine, had prescribed me large doses of four different drugs: drugs to treat the cancer, drugs to manage the side effects and my nerves, and also drugs to regulate my hormones ... it was a large quantity. It's too much for Chinese people to handle.

6-month to 1-year survivor, aged 55 years

Even though I had a Korean doctor, and he couldn't speak Chinese, we could still communicate in English. But I think seeing an Asian doctor is better because you have more in common. With an American doctor, they would just give you to one of their students. I think Asian doctors are more respectful. They are more likely to understand our bodies, it's easier to communicate with them, and they're more understanding.

1- to 2-year survivor, aged 66 years

Preferences for SCPs

Diagnosis and treatment summary—A summary of personal breast cancer diagnosis characteristics and treatments received, with emphasis placed on an individualized SCP, was reported as helpful by participants, either as a reference to provide to family doctors or to share with other family members.

When I saw the oncologist he didn't give me any special instructions. What the oncologist gives me is just, 'Eat more fibrous foods, exercise regularly, take

vitamins, take calcium, et cetera.' Just very typical stuff. No specific recommendations, nothing individual.

3- to 5-year survivor, aged 57 years

Information about expected side effects—Many participants reported that they did not anticipate the intensity or duration of some of the symptoms that they experienced following treatment, stating their need to be prepared for potential posttreatment side effects and coping strategies.

My chemotherapy drugs have caused me to lose feeling in my feet. When I'm going up stairs, my feet won't work.

6-month to 1 year survivor, aged 67 years

Information about recurrence—Participants reported a preference for a list of signs and symptoms of breast cancer recurrence as a means to reduce unnecessary anxiety.

Sometimes my back would hurt, and then I would worry that the cancer cells have spread...When I had my X-ray, nothing was wrong ... I would want to know what to watch for.

1- to 2-year survivor, aged 66 years

Information about lifestyle changes and TCM—Diet and nutrition were important concerns for our participants during survivorship. Many women reported their strong desire to learn more about how to use a healthy diet to improve their health.

... most importantly to hear more about nutrition. I want to better understand how to better coordinate my medicines and what I eat, to improve my health even further. Even though I'm recovered, I feel much weaker compared to before.

–1- to 2-year survivor, aged 40 years

Some participants reported that survivors would benefit from physical activity after treatment and that information about that should be communicated to them more clearly and earlier on.

You have to exercise. At home, I do a few simple exercises. After your surgery, since your lymph nodes are removed, the circulation in your hands is very poor.

0- to 6-month survivor, aged 50 years

Further, many women requested more information on and safety guidelines for TCM use throughout survivorship.

People will tell you that the drugs you take are highly toxic. After your treatment, you should take Chinese medicine to help regulate your body and cleanse the toxins.

3- to 5-year survivor, aged 53 years

Survivorship information format and delivery—Participants indicated that it would be ideal to review the survivorship summary in person with a provider. For supplemental information, written information in lay language and offered in both English and Chinese would be preferred and should include the survivor's personal diagnosis and treatment summary and expected long-term side effects, as well as signs of recurrences, healthy lifestyle tips, and TCM information.

Of course, face-to-face [discussions] would be the best, because if you use the Internet, you only have your own interpretation. You won't have a complete understanding.

1- to 2-year survivor, aged 69 years

Chinese is best [for survivorship information]. If it's in English, it's harder to understand.

1- to 2-year survivor, aged 69 years

Some participants reported the possibility of using web-based patient educational programs to understand breast cancer and survivorship information in the Chinese language but in the context of the US health care system.

[You] need to have a Chinese website. No matter how educated you are, even if you have a doctorate degree, there will still be medical terms that you don't understand.

1- to 2-year survivor, aged 66 years

Conversely, some women cautioned against the use of web-based information and preferred written care-plan and survivorship information in booklet format and to have continuous access to health care professionals to discuss questions as they arose.

I don't think you can realistically expect a patient to use a website, because when they're finishing their treatment, they're in no state to go online and read this information. One way they could do it is to talk to you. I think it'd also be best for them to include some handouts for you to take.

6-month to 1-year survivor, aged 67 years

Discussion

The IOM has recognized cancer survivorship as a distinct phase of cancer care and recommends implementation of a comprehensive survivorship care plan.⁶ Despite this recommendation, even when comprehensive SCPs are implemented, they do not take into account specific needs and issues relevant to CABCS, and to date, no other studies address CABCS perceptions of SCP. The present study explored the survivorship information and communication needs of CABCS, and the authors have suggested preferred elements and formats for an SCP for this population, taking into consideration the unique social, cultural, and linguistic differences that affect these needs. CABCS's information-seeking behaviors are critical to better understanding and to meet their information needs. This is especially

true when one considers that many of our interviewed CABCS reported never having received any type of recovery planning, either in the form of a discussion or take-home reading materials. They identified the need for information on their treatment summary, posttreatment side effects, signs of recurrence and lifestyle changes, which is consistent with the literature for other populations.¹⁸⁻²⁰ Further, the participants stated that survivorship information should include content on healthy lifestyle practices that are relevant to CABCS. Given that food remedies and Chinese herbal medicine are common Chinese methods of illness management,²¹ information on the use of such remedies for managing the side effects of cancer treatment and prevention was frequently requested by the interview participants. Diet and nutrition recommendations should include foods that are commonly used and enjoyed by CABCS, such as sweet potato, rice bran, and seaweed. Obtaining diet and evidence-based TCM information relevant to these women's cultural beliefs and norms is clearly valued by the participants.

Consistent with previous research,²² the CABCS in the present study reported difficulty in communicating with health care providers, and some felt unable to ask questions because of language barriers and differences in cultural norms, which might have impeded their information-seeking and decision-making processes. It is important for oncology professionals to be aware of these cultural differences when communicating with CABCS so that they can encourage or enhance patient participation in their care while respecting unique cultural and individual communication preferences and styles. As found in this study, using a family member as a translator is not the best means to address language barriers, as family members might leave out relevant information so as not to worry the patient or because of their own limitations with medical terminology. To facilitate clear, language-concordant communication, professional translation should be offered during clinical encounters.¹¹ To meet patients' changing needs, their understanding of their illness, treatment, and side effects also should be assessed at different points during the cancer continuum.

With respect to the preferred format of receiving survivorship information, a combination of individualized and evidence-based information, in-person discussion with health care providers, and ongoing access to advice is greatly needed in this group. Some women indicated the potential of using web-based systems for survivorship information if barriers to access and comprehension could be resolved and issues of credibility addressed. These findings echo the need for flexibility in the format of SCP and survivorship information for minority breast cancer patients.^{8,26} Studies of multimedia approaches, such as online support groups and web-based educational programs, have shown efficacy in increasing women's information and emotional support.²⁷⁻²⁹ Further, we recommend leveraging the capabilities of the Internet or mobile technologies to customize the SCP format and providing survivorship information that overcomes language barriers and addresses the unique cultural needs of CABCS.

One of the limitations of the current study is that the sample may not be representative of the entire population of CABCS. All of our participants were immigrants, and their life experiences may have differed significantly from US-born CABCS. Some of our participants routinely participate in community breast cancer programs organized by the ACS–Asian Initiative; therefore, their experiences may not be reflective of other CABCS

who do not have access to, or are less involved with, local Chinese community resources. However, this is one of the first studies to report on the survivorship information and communication needs and preferences of CABCS and to identify the preferred elements and format of an SCP for the CABCS population while taking into their cultural and social backgrounds into account. As efforts are currently under way to develop online, interactive SCPs that can be populated with medical data, follow-up guidelines, and patient resources for the general population,³⁰ the findings of this study can inform the development of linguistically appropriate and technologically enabled SCP formats. The findings can also inform the development of survivorship programs that integrate the clinical characteristics and the social and cultural contexts of CABCS, such as the inclusion of a TCM library with evidence-based knowledge and specific Chinese community supportive care resources. It is anticipated that these types of patient-centered and culturally tailored SCPs and survivorship programs may improve SCP adherence and survivorship outcomes in CABCS.

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Table 1
Demographic and medical characteristics of participants (N = 16)

Characteristic	n (%)
Average age, y (SD): 57.9 (11.7)	—
Average time since diagnosis, y (SD): 3.5 (2.4)	—
Education	
Less than high school	2 (12.5)
High school	4 (25.0)
Some college	3 (18.8)
College graduate	4 (25.0)
Master's or higher degree	3 (18.8)
Household income	
<\$15,000	8 (50.0)
\$15,001-30,000	2 (12.5)
>\$30,001-45,000 ^a	1 (6.2)
>\$75,001	5 (33.3)
Employment status	
Employed	5 (31.2)
Unemployed/disabled	2 (12.5)
Retired	3 (18.8)
Homemaker	6 (37.5)
Marital status	
Married	13 (81.2)
Separated/divorced	1 (6.2)
Widowed	1 (6.2)
Never married	1 (6.2)
Cancer stage ^b	
0	2 (12.5)
I	2 (12.5)
II	7 (43.8)
III	5 (31.2)
Cancer treatment ^c	
Lumpectomy	8 (50.0)
Mastectomy	9 (56.2)
Chemotherapy	12 (75.0)
Radiation therapy	11 (68.8)
Hormonal therapy	7 (43.8)
Time since treatment completion ^d	

Characteristic	n (%)
0-6 months	3 (18.8)
6-12 months	4 (25.0)
12-24 months	4 (25.0)
24-60 months	5 (31.2)

Average time lived in US, y (SD): 17.8 (9.8)

^aNo participant reported income between \$45,000 and \$75,000.

^bBased on self-report.

^cParticipants could select multiple responses.

^dTime since treatment completion was estimated based on the intervals between the completed date of primary treatment and the interview date. Completed treatment dates were based on participants' self-report.