



Journal of Health Disparities Research and Practice
Volume 10, Issue 1, Spring 2017, pp. 181- 203

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Chinese American Immigrant Breast Cancer Survivors and Their Experiences with Post-Treatment Care

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ABSTRACT

This study examined the experiences of Chinese American immigrant breast cancer survivors with post-treatment breast cancer care and surveillance in New York City. As part of a mixed methods approach, in-depth interviews were conducted with 11 Chinese American immigrant breast cancer survivors treated in a public hospital setting regarding their final breast cancer treatment visit, perceived risk of breast cancer recurrence, and experiences with social and family networks following the completion of treatment. Several salient and shared themes emerged from the interviews including two areas of particular concern regarding the transition from the treatment to post-treatment setting: survivors' lack of access to information regarding post-treatment cancer surveillance and resources for psychosocial and health system support. Findings provide insight into the complex ways in which health system and sociocultural factors intersect and shape Chinese American immigrant women's experiences with post-treatment care and point to the importance of patient-centered information exchange. Oncology treatment specialists should take into consideration specific sociocultural factors and contexts, including communication and available social support of their patients, in the practice of post-treatment care for Chinese American immigrant breast cancer survivors.

Keywords: Chinese American; Immigrant; Breast cancer; Post-treatment; Survivorship; and Sociocultural factors

INTRODUCTION

Breast cancer is the leading cancer diagnosis among women in the United States, with more than 3.5 million survivors as of January 1, 2016 (American Cancer Society, 2016). Breast cancer survivors, along with other cancer survivors, experience a range of unmet supportive care

needs following treatment (Carey et al., 2012), and research shows unmet needs among survivors include assistance with the activities of daily living and psychological, informational, psychosocial, and physical support needs (Harrison, Young, Price, Butow, & Solomon, 2009). Research also shows racial disparities in access to informational support in cancer survivorship (Kent et al., 2012) and breast cancer survivorship (Janz et al., 2008), specifically. Information about cancer recurrence is one of the most reported information needs among breast cancer survivors (Kwok & White, 2014).

Information needs are critical because breast cancer survivors are at risk for breast cancer recurrence and increased risk for a second primary cancer compared with women in the general population (Breslau et al., 2010; Jacobson et al., 1995; McIntosh et al., 2003; Neff et al., 1996; Touboul et al., 1999; Weight, Windle, & Stotter, 2002). Breast cancer survivors are also 2–6 times more likely to develop a second primary breast cancer in the contralateral breast compared with women in the general population (Chen, Thompson, Semenciw, & Mao, 1999; Dawson, Chow, & Goss, 1998). The American Society of Clinical Oncology has established evidence-based guidelines for post-treatment breast cancer surveillance that include more frequent physical examinations and symptom histories in the first 5 years post-treatment, monthly breast self-exam, regular pelvic exams, and annual mammography (American Society of Clinical Oncology, 1997; Khatcheressian et al., 2013). Studies indicate that adherence to surveillance guidelines among survivors is low (Doubeni et al., 2006; Geller et al., 2003; Keating, Landrum, Guadagnoli, Winer, & Ayanian, 2006; Krishnaraj, Yankaskas, & Stearns, 2006; Lash & Silliman, 2001; Schapira, McAuliffe, & Nattinger, 2000). Studies also reveal differences in adherence to surveillance guidelines in medically underserved racial and ethnic groups (Breslau et al., 2010), particularly mammography surveillance (Advani et al., 2014; Keating et al., 2006; Mandelblatt et al., 2006), though “comparisons of racial and ethnic minority groups have typically focused on health-related disparities between blacks and whites” (Breslau et al., 2010:9).

There is limited work examining post-treatment care and surveillance among Asian American cancer survivors (Le et al., 2015), generally, or among Chinese American breast cancer survivors, in particular. Chinese Americans are the largest subgroup of the Asian American population (Hoeffel, Rastogi, Kim, & Shahid, 2012). Although surveillance adherence data specific to Chinese American breast cancer survivors are not reported in the literature, there is ample evidence that adherence to post-treatment surveillance and care declines over time, regardless of race or ethnicity (Advani et al., 2014).

As an ethnic group, Chinese American breast cancer survivors may experience more pronounced challenges in survivorship compared with White breast cancer survivors. For example, in their study Palmer et al examined the follow-up care experiences of 1,196 long-term cancer survivors (294 African American, 272 Asian/Pacific Islander, 161 Hispanic and 469 Non-Hispanic White) and found Asian survivors reported poorer medical test communication and lower self-efficacy in medical decisions compared with White survivors (Palmer et al., 2014). In another study, Wang et al explored the post-treatment experiences of 71 breast cancer survivors (37 Chinese immigrant, 7 US-born Chinese, and 27 non-Hispanic White) and found that Chinese immigrant breast cancer survivors may be at risk for greater distress compared with other ethnic groups due to cultural norms for communication where they are less likely to express their needs or unmet needs to physicians (Wang et al., 2012). Similarly, in their study of a Chinese breast cancer survivor population, Lu et al found that Chinese American breast cancer survivors with ambivalence over emotional expression (AEE) or the conflict of wanting to express emotion yet

fearing the consequences of such expression, may have an increased risk for depressive symptoms (Lu, Man, You, & LeRoy, 2015). Further studies are needed on Chinese American breast cancer survivors and how specifically their survivorship experiences may differ from other racial and ethnic groups.

Studies of Chinese American breast cancer survivors suggest that communication and relationships between Chinese American breast cancer patients and their family members are associated with survivors' quality of life (Ashing, 2015; Lim, 2014; Lim & Ashing-Giwa, 2013; Lim & Paek, 2013; Sun, Wong-Kim, Stearman, & Chow, 2005; Wong-Kim, Sun, Merighi, & Chow, 2005). Other work demonstrates that socioeconomic well-being is a dominant concern among Chinese American breast cancer survivors (Wang et al., 2013), as well as, concerns regarding the potential negative impact of a cancer diagnosis on how survivors are perceived or accepted within their social networks (Lee et al., 2013; Wong-Kim et al., 2005). For example, in their study of Chinese American immigrant women, Lee-Lin et al found that cultural sensibilities regarding stigma and shame were perceived by women as a barrier to the disclosure of a cancer diagnosis to family members, employers, and others (Lee-Lin, Menon, Nail & Lutz, 2012). Similarly, in another recent study which developed and tested the first social support intervention specifically designed for Chinese American breast cancer survivors, women from the sample reported feelings of inferiority, powerlessness, and loneliness in survivorship as a result of their cancer diagnoses (Lu, You, Man, Loh, & Young, 2014). Disparities in the post-treatment cancer care setting are far more complex than "cultural differences" or "language barriers." Importantly, the ways in which cancer health communication, social support, and post-treatment surveillance care occur and with what regularity also matter in Chinese American women's perceptions of and experiences with survivorship.

The study that we report here is the qualitative component of a mixed methods study that explored Chinese American immigrant women's experiences and attitudes about post-treatment breast cancer surveillance in New York City. The larger goal of the study was to identify factors potentially related to women's post-treatment needs and behaviors, including access to modalities of surveillance care and opportunities for culturally appropriate surveillance information and adherence. Chinese American immigrants are an understudied and vulnerable subgroup within cancer research (Leng et al., 2014) and face several barriers to cancer care and quality of life in cancer survivorship (Leng et al., 2012). Following a presentation of our methods and findings, we discuss how the experiences of Chinese American immigrant cancer survivors may be used to inform the delivery of post-treatment surveillance care among ethnically and linguistically diverse breast cancer survivors.

METHODS

Participants and procedure

Study participants were approached via telephone from a randomized, de-identified list of Asian American patients who had completed treatment at a collaborating public hospital in New York City. Eleven Chinese American breast cancer patients were consented to participate in the study. Eligibility for participation was based on a diagnosis of in situ or invasive breast cancer (stages I-III), no history of previous cancer, and no diagnosis of breast cancer recurrence or a second primary. A lower limit of 12 months was selected to enable assessment of breast cancer surveillance practices in the past year. An upper limit of 60 months was selected because the ASCO guidelines call for the most vigilance in the first five years post-treatment and 70% of recurrences occur within the first 5 years after treatment (Khatcheressian et al, 2006). For the

purpose of this study, primary treatment was understood to include: unilateral mastectomy, breast conserving surgery (lumpectomy, segmental mastectomy, quadrantectomy), adjuvant radiotherapy, and adjuvant chemotherapy. Possible adjuvant hormonal therapy was not included in the definition of primary treatment. Potential participants also had to have a working telephone number for contact.

Forty-four Asian American women were identified in the Tumor Registry database who also met the study eligibility criteria. Among these women, we contacted and identified twenty women who were of Chinese ethnicity, who spoke Chinese or English, and for whom we had up-to-date phone numbers. We invited these twenty women to participate in the study; eleven women agreed. Due to the in-depth quality and duration of the interview (2.5 hours on average) we provided a study incentive of \$45 to each participant.

Data for the study were collected through an IRB-approved broader mixed method interview that included both quantitative and qualitative components. For the purpose of this report, we will only focus on the qualitative findings. Interviews were conducted with participants in a private office located several blocks from the hospital in which participants completed their treatment, in the participants' preferred language. Informed consent was obtained at the time of the interviews. Five of the interviews were conducted in Cantonese, four in Mandarin, one in Fuzhounese, and one in English. As a prerequisite to IRB approval, the survey and qualitative interview guide were translated into Chinese and back-translated into English by certified translation providers.

Guiding questions for assessment

The qualitative interview was developed to investigate survivors' perceptions about and experiences with post-treatment care and to explore the various ways participants draw from cultural expectations and idioms to make sense of risk (i.e., long-term effects of treatment (good and bad), remission and recurrence), survival, emotional outlook on life and well-being, access to or exclusion from a clinical setting, experiences with a health system, and post-treatment care seeking behaviors including recurrence surveillance. Specifically, we invited women to recall and describe their experience on the last day of treatment as well as discuss the following:

1. Perceptions and knowledge regarding risk of recurrence, quality of life, and survival, e.g., participants were asked, "at the time you completed treatment, did your treatment provider discuss long-term breast health needs with you?"
2. Experiences of post-treatment survivorship in the context of participants' broader social world, including their familial, social, and professional spheres, e.g., participants were asked, "What factors affected your ability to seek follow up care?"
3. Survivorship and its relationship to identity, e.g., participants were asked if the term "cancer survivor" was a term they would use to describe themselves and why or why not

Data analysis

The 11 digital audiotapes were transcribed into text files, and the transcripts of the interviews conducted in Chinese were transcribed into English. The interview text files were then entered as primary documents into ATLAS.ti (7.0), a qualitative data analysis software program that allows for the cross-referencing, searching, and retrieval of text-based data through semantic and thematic coding. A qualitative content analysis of the transcripts was performed using a grounded theory approach that was inductive and based on the experiences of the participants (Bradley, Curry, & Devers, 2007). Content analysis began with a line-by-line review of participant responses across all of the transcripts for the identification of concepts and patterns, which were then defined and organized into codes (themes). This process was done several times

using the “constant comparison method,” wherein previously coded text segments of a certain theme are compared with other text segments of the same theme to ascertain if the segments reflect the same concept (Bradley et al., 2007; Glaser, 1965). This iterative method enabled the refinement of existing codes and identification of emergent codes (Bradley et al., 2007), as well as, an understanding of the possible relations between codes (Thorne, 2000). Upon finalization of the code list, all of the data was re-reviewed using the finalized code structure for coding reliability.

When the coding was complete, codes were aggregated into major thematic categories based on how the codes relate and link to one another (Hsieh & Shannon, 2005) for interpretation of the qualitative data. The thematic categories provide a higher level of contextual framing for the code results. The categories are not exclusive, that is, codes can belong to more than one thematic category. To assist in the finalization of the analysis, ATLAS.ti was used to sort the coded results from several perspectives and explore the code composition of the thematic categories. This included an examination of code prevalence (the proportion of participants with interview content related to a code) and occurrence (the number of times interview content related to a code was identified across the entire sample) to understand code frequency and distribution. It also included evaluating the co-occurrence of codes, which refers to instances when some portion of a selected quotation within a transcript is coded with two different codes at a common point in the quotation, indicating a strength or relatedness between themes. Finally, the codes were grouped into code families, a utility within ATLAS.ti that allows a researcher to filter codes, perform code queries, and visualize codes in network views (Friese, 2013).

RESULTS

Sample characteristics

Participant characteristics are presented in Table 1. The mean age of the 11 women in the sample was 52.4 years of age. All of the women had immigrated to the US from China or Taiwan and had spent an average of 12 years in the US. Most of the women were married or living with a partner and had children. Only about half were currently employed. About half of the sample had an 8th grade education or less, and the majority reported a household income of less than \$10,000 a year. Most reported having some type of health insurance at the time of the interview. The majority of women reported some type of either mastectomy or breast conserving surgery as part of the breast cancer treatment they had received, along with adjuvant therapy (radiotherapy and/or chemotherapy following surgery). Also, all of the women were within three years since the end of treatment.

Table 1. Participant Characteristics (N=11).

		Mean (SD) Range
Age		53.2 (10.9), 34-67
Years in the U.S.		12.2 (10.7), 1-28
		% (n)
Married or living with partner?	Yes	72.7 (8)
Have children?	Yes	81.8 (9)
Employed?	Yes	45.5 (5)
Education level	8 th grade or less	54.6 (6)
Household income	< \$10K	63.6 (7)
Have health insurance?	Public insurance (e.g., Medicaid, Medicare)	81.8 (9)
	Not currently insured or other	18.2 (2)
Time since end of treatment	0-3 years	81.8 (9)
	4-5 years	18.2 (2)

Development of codes and thematic categories

The inductive coding of the qualitative data resulted in the identification of 59 themes labeled as codes (see Appendix), which were then aggregated into five primary thematic categories: 1.) perceptions of recurrence and survivorship, 2.) psychological distress and psychosocial stressors, 3.) social communication about diagnosis and social support, 4.) patient-provider relationship, and 5.) post-treatment care experience. 29 out of the 59 codes guided the composition of the five thematic categories. The table below summarizes these 29 codes and includes the prevalence and occurrence information for each of the codes in the sample.

Table 2. Key Codes of Post-Treatment Care Experiences.

Code No.	Code Name	Corresponding Thematic Category 1) Perceptions of recurrence and survivorship 2) Psychological distress and psychosocial stressors 3) Social communication about diagnosis and social support 4) Patient-provider relationship 5) Post-treatment care experience	Prevalence (proportion of participants with interview content related to code)	Occurrence (number of times interview content related to a code was identified across the entire sample)
01	Cancer "recovery" preferred over "survival"	Category 1	54.5%	6
02	Cancer is private	Category 3	54.5%	15
03	Cancer taboo	Category 2 & 3	54.5%	29
04	Comfort discussing cancer with other cancer patients	Category 3	72.7%	13
05	Communication problem with provider	Category 2, 4 & 5	63.6%	19
06	Dedicated to follow-up care	Category 1, 4 & 5	90.9%	21
07	Discuss cancer only with close family and friends	Category 3	36.3%	14
08	Does not ask the provider questions	Category 4	45.4%	5
09	Does not identify as a "survivor"	Category 1 & 2	81.8%	22
10	Emotional concern in post-treatment	Category 1, 2 & 5	72.7%	10
11	Emotional concern in treatment	Category 2	72.7%	10
12	Family history of cancer	Category 2	54.5%	9
13	Family supportive in treatment	Category 3	72.7%	19
14	Financial concern	Category 2 & 5	45.4%	7
15	Follow-up not recommended last day of treatment	Category 4	63.6%	8
16	Follow-up recommended by provider	Category 4	100.0%	38
17	Language barrier	Category 2, 4 & 5	63.6%	23

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18	Long wait time for care	Category 2, 4 & 5	72.7%	19
19	Negative evaluation of care	Category 2, 4 & 5	72.7%	15
20	Non-surveillance instructions from the provider	Category 4 & 5	81.8%	15
21	Physical pain in post-treatment	Category 2 & 5	54.5%	13
22	Physical pain in treatment	Category 2	45.4%	13
23	Positive evaluation of care	Category 4	100.0%	58
24	Prefers not to discuss cancer in post-treatment	Category 3 & 5	18.1%	5
25	Recurrence fear	Category 1, 2 & 5	81.8%	19
26	Recurrence information not provided by provider	Category 1, 4 & 5	100.0%	32
27	Social network supportive in treatment	Category 3	54.5%	8
28	Trust in provider	Category 4	72.7%	20
29	Treatment cures cancer	Category 1	90.9%	26

The analysis of the five primary thematic categories identified several cultural beliefs, values, and norms of behavior related to the post-treatment care experiences of the participants. These encompass perceptions of cancer recurrence risk and survivorship, sources of stress, social communication about cancer and one's diagnosis (e.g., with family or larger social network), trust in provider judgment and communication with providers, and evaluations of the quality of post-treatment care. Overall, the analysis revealed a mixed evaluation of cancer treatment and post-treatment among the participants. While all of the women reported at least one or more positive evaluation of the care they received from either their provider, provider treatment facility, or the broader setting of their treatment (New York City or the US as the country of their treatment), a large majority also reported negative evaluations of the care they received. For example, the women described communication problems with their care providers, such as language barriers and a lack of surveillance instructions provided at the end of treatment, including a lack of information about recurrence or long-term breast health. A summary for each of the five primary thematic categories follows next.

Thematic Category 1: Perceptions of recurrence and survivorship

The key codes that inform this primary category are code numbers: 01, 06, 09, 10, 25, 26, and 29 (See Table 2). The most salient finding from the data regarding breast cancer recurrence is that all of the women reported receiving limited or no recurrence information from their provider. Participants stated their desire for more recurrence information and most women stated breast cancer recurrence is a risk or fear of theirs. For a few of the women, fear of cancer recurrence was an emotional concern of theirs in post-treatment. See Table 3 below for interview data that illustrate this finding. Nearly all of the women stated that they are dedicated to follow-up care for their cancer.

Through data analysis and, in particular, co-occurrence queries, our team also identified an association between cancer recurrence fear and the perception of survivorship among the participants. When asked questions about whether or not they would refer to themselves as a "cancer survivor," most of the women explained that they do not and would not identify

themselves as breast cancer survivors. Reasons provided for this include a discomfort with the illness severity associated with the term, rarely or never having heard of the term used within their communities, and the belief that the term applies only to those who have been cancer free for a long time (and thus does not apply to those more recently treated). See Table 3 for interview data of this finding.

Table 3. Interview Data Illustrating Findings from Primary Thematic Categories.

Thematic Category	Key Finding	Participant Quotation
Category 1: Perceptions of recurrence and survivorship	Recurrence fear	<i>Interviewer:</i> What is the primary reason for you to follow up? <i>Participant:</i> To prevent recurrence. I come to see my doctor with this mindset. Otherwise why bother to see the doctor?
Category 1: Perceptions of recurrence and survivorship	Does not identify as a “survivor”	<i>Participant:</i> Rhonda, she is a survivor. <i>Interviewer:</i> Why did you say that? <i>Participant:</i> She has been (cured) for very long. <i>Interviewer:</i> Oh, so you think she is a survivor? <i>Participant:</i> Right, a survivor. <i>Interviewer:</i> Did she introduce herself this way? <i>Participant:</i> She said she has been cured for several years and I think since it has been this long, she is one (survivor). <i>Interviewer:</i> Oh, so you think being a survivor means having been cured for a long time? <i>Participant:</i> Yes.
Category 1: Perceptions of recurrence and survivorship	Cancer “recovery” preferred over “survival”	<i>Interviewer:</i> Which term do you prefer? <i>Participant:</i> Recover. <i>Interviewer:</i> Why? <i>Participant:</i> Because I feel like...being a survivor is pretty tough. It’s like, you had little chance to live initially but after many struggles, you managed to survive. But being a “kang fu zhe” (someone who recovered) is different...it didn’t seem that serious. In other words, I can recover my health through my treatments. That’s how it is. If the term “survivor” were used, I will feel the breast cancer was late stage with little survival chance. You need to try hard and survive. So it sounds severe. I was early stage, so I prefer to use “kang fu zhe” (someone who recovered). <i>Interviewer:</i> Do you think “xing cun zhe” (survivor) is associated with negative feelings? And “kang fu zhe” (someone who recovered) is more positive? <i>Participant:</i> Yeah, yeah.
Category 1: Perceptions of recurrence and survivorship	Recurrence fear	<i>Interviewer:</i> Would you introduce yourself as “kang fu zhe” (someone who recovered) when you meet family or other cancer patients? <i>Participant:</i> I don’t dare to say that, because I don’t know if I will have recurrence all of sudden. So I won’t tell people that I am a “kang fu zhe” (someone

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		who recovered).
Category 3: Social communication about diagnosis and social support	Discuss cancer only with close family and friends	<i>Participant:</i> You cannot control others' mouth. You know... rumors will spread all over the place. I am under pressure so I rarely talk to people about it. <i>Interviewer:</i> So only close friends know and you will not tell others? <i>Participant:</i> Yes. I know she will keep the secret, so I told her about my cancer.
Category 3: Social communication about diagnosis and social support	Cancer is private	<i>Interviewer:</i> Do you prefer to share thoughts about breast cancer with others, or keep it to yourself? <i>Participant:</i> I prefer to keep it to myself, because some people don't like to be told about even if you want to tell. A lot of people are scared, and don't like to listen to the stuff. So, I didn't tell my friends at all. Only my family knows.
Category 4: Patient-provider relationship	Trust in provider	<i>Interviewer:</i> So you simply follow doctor's opinion? What about yours? <i>Participant:</i> I don't have my own opinions. I let the doctors make the decisions.
Category 4: Patient-provider relationship	Trust in Provider	<i>Interviewer:</i> So how often do you think you should follow up to check your breast health? <i>Participant:</i> I will follow what the doctor said.
Category 4: Patient-provider relationship	Positive evaluation of care	<i>Participant:</i> Well, medicine in America is so advanced and so good...doctors are also good.
Category 4: Patient-provider relationship	Communication problem with provider	<i>Interviewer:</i> Overall, do you think the information given by your doctor(s) is not sufficient? <i>Participant:</i> I told you earlier, it's because the doctor is non-Chinese. If you need to ask her something, you need to do it through a translator, that's troublesome. It's not like she speaks Chinese, and I can tell her whatever I like. It's a bit troublesome to convey my thoughts again by a translator. <i>Interviewer:</i> You can also ask the translator your questions, and she/he can communicate for you. <i>Participant:</i> It's better to have face-to-face conversation. It's not that convenient to work through a translator. I don't like to ask more questions that way (via phone translator in exam room). I only ask questions that I feel are necessary.
Category 4: Patient-provider relationship	Does not ask the provider questions	<i>Interviewer:</i> Did you tell your doctors that you wanted to know more? <i>Participant:</i> No <i>Interviewer:</i> Why not communicate with your doctors? <i>Participant:</i> Because they're non-Chinese doctors; I didn't get to see them except my surgeon. Only the doctors in lower positions [likely she meant] "residents" saw me...I was never seen by doctors in higher positions.

<p>Category 5: Post-treatment care experiences</p>	<p>Follow-up not recommended last day of treatment</p>	<p><i>Interviewer:</i> Who performed the radiation for you? When you finished radiation on the last day, did any doctor come out and talk to you? <i>Participant:</i> No, I went home directly. <i>Interviewer:</i> Then who talked to you that day? There must be somebody who talked to you, right? <i>Participant:</i> He only told me that, after the last radiation session, no need to come again.</p>
<p>Category 5: Post-treatment care experiences</p>	<p>Recurrence information not provided by provider AND Dedicated to follow-up care</p>	<p><i>Interviewer:</i> Ok, around the time you completed your treatment, had any of your doctors such as surgeon, radiologist, or oncologist discussed with you about long-term breast health? Long-term breast care plan? <i>Participant:</i> Long-term breast care plan is...to follow up here. <i>Interviewer:</i> Regularly? <i>Participant:</i> Right, follow up regularly. <i>Interviewer:</i> Did he/she provide you with additional information? <i>Participant:</i> No, no other information. I come back on a regular basis. <i>Interviewer:</i> Has he/she discussed with you about your current situation, survival rate or things to watch for? <i>Participant:</i> None of these. <i>Interviewer:</i> Not discussed at all? <i>Participant:</i> Not discussed. <i>Interviewer:</i> Do you wish your doctors have more discussions with you? <i>Participant:</i> I hope so. I hope to know more about my disease so I can pay more close attention.</p>

Over half of the women stated a preference for the self-description that they have “recovered” from cancer rather than “survived” cancer. Reasons they gave for this preference include a lower illness severity associated with recovery compared with survival, a belief that to “recover” means to be 50% cured or still in the process of regaining one’s health (an appropriate descriptor of their current status, according to some participants), and the belief that the risk of recurrence is more likely for someone who is still recovering from cancer compared with someone who has been a survivor for many years. See Table 3 for interview data that support this finding.

Beyond personal preference or semantic choice, the distinction between “survival” and “recovery” suggests the influence of broader social ideas about cancer as an unfavorable or unlucky condition. The perception being that one who “recovers” from something does not have the same (otherwise intractable) malignancy associated with cancer. Hesitation or reluctance to use the term “survivor” or “survivorship” may also be related to uncertainty regarding recurrence. See Table 3 for an example of this.

Thematic Category 2: Psychological distress and psychosocial stressors

The key codes that inform this primary category are code numbers: 03, 05, 09, 10, 11, 12, 14, 17, 18, 19, 21, 22, and 25 (See Table 2). Most of the women interviewed reported sources of emotional concern in their lives and feelings of being “unhappy”, “sad”, “depressed”, “worried”,

“afraid” or “scared” in the context of their cancer diagnosis, treatment, and post-treatment. The sources of stress that they identified in this study include financial concerns, physical pains in treatment and in post-treatment, the taboo quality of cancer within one’s social networks or community, and a family history of cancer. With respect to relationships with their medical providers specifically, women described language barriers, communication problems, long wait times for care, and other negative evaluations of care, including feeling ignored by reception staff or physicians and perceiving rudeness or possible racial discrimination from their providers, as sources of concern or stress in the post-treatment setting. Finally, a majority of women also mentioned cancer recurrence as a personal risk, concern, or fear of theirs. The same percentage of women preferred not to identify themselves as breast cancer “survivors” when asked questions about survivorship. Taken together, interview data revealed a number of concerns and stressors experienced by women in dealing with cancer, indicating diverse psychosocial supportive care needs among this cultural group.

Thematic Category 3: Social communication about diagnosis and social support

The key codes that inform this primary category are code numbers: 02, 03, 04, 07, 13, 24, and 27 (See Table 2). When asked about sources of social support, the majority of participants mentioned at least one family member being supportive during their cancer treatment, such as assisting with transportation to clinic visits. The majority of women in our study also reported finding comfort in talking about their disease with other cancer patients (e.g., in the clinic waiting room) while at the clinic for treatment. Over half of the women stated they found support from a trusted friend in their social network during treatment. Concurrently, over half of the women described a diagnosis of cancer as a taboo topic and something best kept private from others (e.g., extended family members, co-workers, neighbors, and acquaintances), suggesting a stigma associated with the disease. In general, participants’ responses pointed to significant concerns about how to either discuss or conceal a cancer diagnosis within their communities.

Patients also described cancer diagnosis as a private topic, even secretive, and typically discussed information about their illness only with close family and friends. Fear of how others might react (e.g., perceptions that others do not want to hear bad news or that they may spread rumors) appeared to be a key motivation for concealment. See Table 3 for survivor interview data that illustrate these findings. Participant responses in this thematic category demonstrate reluctance to discuss their illness or treatment with others and, by extension, the influence of broader sociocultural norms about cancer as a socially circumscribed topic. For the women in the sample, cancer is a taboo subject (a stigma) that is inappropriate to discuss with others, outside of close family or friends. Furthermore, women did not include their extended social networks, religious communities, or work environments when asked about social resources in the survivorship setting.

Thematic Category 4: Patient-provider relationship

The key codes that inform this primary category are code numbers: 05, 06, 08, 15, 16, 17, 18, 19, 20, 23, 26, and 28 (See Table 2). Interview responses revealed a complex relationship between women and their care providers, consisting of trust in and respect for provider judgment but also dissatisfaction with provider communication and, in particular, a perceived lack of information regarding their disease, treatment, and post-treatment care. At the same time, when asked about their providers’ role in their health care, most participants expressed trust in their providers’ clinical decision-making and authority, a dedication to follow-up care, and voiced a willingness to comply with providers’ instructions for care, as indicated in Table 3.

As was discussed above, all of the women described at least one or more positive evaluation of the care they received from either their provider, treatment facility, or the broader location of their treatment (see Table 3). All of the participants reported receiving the recommendation for a follow-up appointment at some point during treatment. Most of the women also explained they received various types of non-surveillance instructions from their provider during treatment, which included instructions related to treatment side effects, diet, medications, or breast reconstruction. Conversely, most of the women also described one or more negative evaluations of the care they received, ranging from feeling ignored by reception staff or physicians, perceiving rudeness or possible racial discrimination from their providers, or dealing with long wait times for care. Over half of the women reported experiencing communication problems with their providers. This included difficulty understanding information given by providers, dealing with language barriers, and in many cases, not receiving enough information about their disease, as indicated in Table 3.

Almost half of the participants in our study reported that they do not typically ask their providers questions during clinic visits, despite noting a lack in receipt of health information regarding their disease. See Table 3 for interview data that support this finding. Participant responses in this thematic category underscore the potential cultural and linguistic challenges Chinese American immigrant women encounter in US cancer treatment institutions. The effects of these culturally and socially-shaped interactions should be further explored since differences in expectations about patient-provider communication may affect the exchange of vital information.

Thematic Category 5: Post-treatment care experience

The key codes that inform this primary category are code numbers: 05, 06, 10, 14, 17, 18, 19, 20, 21, 24, 25, and 26 (See Table 2). In looking more closely at women's experiences with post-treatment care, a number of challenges are evident given the majority of participants having negative evaluations of their post-treatment care. First, the women in our study reported long wait times for follow-up care, language barriers, and other communication problems with providers, including perceived provider rudeness. Secondly, participants described a decrease in social support in the post-treatment setting compared with support received during the treatment period. For example, in post-treatment, the women no longer received the emotional support and comfort derived from speaking with other cancer patients that they formerly interacted with at the clinic during treatment. Additionally, most of the women expressed emotional concerns after completing treatment and no one described instances in which one or more members of her social network (non-family) were supportive during the post-treatment phase of her cancer experience. This contrasts with women's treatment experience, where over half of the women described instances of one or more members in their social networks showing them support. Some of the women stated that in the post-treatment period they prefer not to discuss their history of cancer with others or even think about their cancer if possible. Other concerns that women reported during post-treatment included fear of cancer recurrence, experiencing late- or long-term physical pain due to treatment, financial concerns, fertility concerns, and needing to depend on family for support, such as financial assistance.

Regarding follow-up activity for post-treatment care, over half of the women reported that their provider did not recommend any type of follow-up appointment for post-treatment care on the last day of treatment, as illustrated in Table 3. Regardless of whether a provider recommended a follow-up appointment for post-treatment care, all of the women stated that they received limited or no information about long-term breast health or the risk of recurrence at the

end of treatment, despite expressing dedication to follow-up care and the desire to receive more information about their disease. See Table 3 for interview data that support this finding.

Interview data reveal that the most common instructions given to women for post-treatment care were non-surveillance related including, for example, instructions for ameliorating the side effects of treatment (e.g., lymphedema), suggestions regarding diet and medications, and advice regarding breast reconstruction surgery. This suggests that the practice of recommending follow-up care is not standardized or performed in the context of ASCO recommended recurrence surveillance. In addition to a reported lack of provider recommendations for surveillance and follow-up appointments at the end of treatment, women reported additional barriers to participation in post-treatment, including: a prior bad experience with a provider, family responsibilities, emotional distress, work obligations, and difficulty with remembering to schedule or attend follow-up appointments.

DISCUSSION

There are few studies of Chinese American breast cancer survivorship (Wang et al., 2012). The current study identified five primary thematic categories relevant to Chinese American immigrant experiences in the post-treatment setting: 1.) perceptions of recurrence and survivorship, 2.) psychological distress and psychosocial stressors, 3.) social communication about diagnosis and social support, 4.) patient-provider relationship, and 5.) post-treatment care experience. These thematic categories help to capture and summarize several key findings regarding post-treatment surveillance and psychosocial support experiences among Chinese American immigrant breast cancer survivors in New York City.

First, the participants in this study reported unmet informational needs at the completion of their treatment for breast cancer in that they did not receive sufficient recurrence information, or information in line with ASCO guidelines for post-treatment surveillance. All of the women in the sample reported that recurrence information was not adequately provided to them at the end of treatment by their providers, despite the women's dedication to follow-up and fear of recurrence. This is consistent with other work that found unmet informational needs among Chinese immigrant cancer patients (Leng et al., 2012). Lack of recurrence information at the end of treatment represents a significant gap in care during the critical transition between treatment and post-treatment, a time when recurrence information and surveillance adherence should be top priorities. Other recent work has found language and communication barriers to be a crucial impediment to information and care delivery among Chinese American breast cancer patients (Wen, Hu, Ma, Fang, & Daly, 2014) and Chinese immigrant cancer patients (Leng et al., 2012). Furthermore, self-efficacy in patient-physician communication was found to be directly and positively associated with health related quality of life in breast cancer survivorship among Chinese Americans (Lim & Paek, 2013). It is unclear from study data whether cultural factors such as language differences were related to patients receiving insufficient recurrence information, though findings definitively reveal that women experienced language barriers and other communication problems with providers. The lack of recurrence information does, however, contravene the IOM recommendation that, at the end of treatment, all cancer survivors should be provided with a comprehensive survivorship care plan that includes a treatment summary and follow-up recommendations to prepare survivors for the post-treatment period and their long-term health (Hewitt, Greenfield, & Stovall, 2005).

Second, results from this study show that although follow-up recommendations were provided to women, these recommendations were not delivered in the context of recurrence

surveillance. Rather, scheduling of follow-up surveillance care was primarily provided in the context of managing treatment side effects and recommendations regarding diet, medication, and breast reconstruction. In addition, women reported several barriers to surveillance adherence. The schedule of follow-up outside the context of recurrence surveillance and women's reported barriers to follow-up are particularly concerning, given that breast cancer survivors are at considerable risk for local breast cancer recurrence (Breslau et al., 2010) and a second primary breast cancer (Chen et al., 1999; Dawson et al., 1998).

Third, our findings showed that the women faced social and emotional challenges in communicating about their cancer in both treatment and post-treatment settings. All of the participants in our study attested to the difficulty of speaking about cancer within their social networks due to perceived associations of cancer as a "taboo" topic of conversation or social identity. This is consistent with other research that has found a social stigma and shame associated with cancer in Asian American communities (Lee-Lin et al., 2012; Lee et al., 2013; Sun et al., 2005; Wong-Kim, Sun, & DeMattos, 2003; Wong-Kim et al., 2005) and the lack of social support for survivors (Tam Ashing, Padilla, Tejero, & Kagawa-Singer, 2003). The majority of participants also reported a variety of concerns and sources of stress pertaining to cancer in survivorship. This is consistent with another study that found breast cancer has a significant impact on the mental health of Asian American breast cancer survivors (Lee et al., 2013). These data have implications for the tailoring of survivorship interventions for Chinese American immigrant breast cancer survivors, which are cognizant of community norms and values regarding cancer communication. Resources and information for managing social reintegration, job security, integrity of social relationships, and other psychosocial challenges during post-treatment are key areas of emphasis in the IOM guidelines for survivorship care plan components (Hewitt et al., 2005). Ethnically tailored stress management skills for Chinese American breast cancer survivors has also been suggested in other work (Lim, 2015).

Fourth, although evaluations of care were mixed, participants viewed their treatment providers and corresponding clinical setting (including other cancer patients and the treatment itself) positively as a resource for effective care and support. This finding is consistent with other studies that found that Asian American breast cancer survivors view their oncology specialists with trust and confidence (Lim, Baik, & Ashing-Giwa, 2012) and as sources of support (Ashing-Giwa et al., 2004). In the clinical space, participants in our study reported feeling supported and comfortable speaking with other patients about their cancer. This contrasts with the feelings of stigma or discomfort that women described when discussing their diagnosis in their social networks. Thus, study results point to the need for culturally relevant approaches to post-treatment care for breast cancer survivors in Chinese American immigrant communities. Survivorship care and surveillance may be best supported and promoted by medical providers and perhaps close family or friends of survivors, apart from patients' larger social networks where such discussion may be unwelcome, uncomfortable or stigmatizing. Findings also suggest special consideration should be given to provider delivery of survivorship and recurrence information and care, given the presence of language barriers, communication problems, and the tendency for some women to refrain from asking questions of their providers.

Finally, participants reported a lack of identification with the "survivor" concept. The Chinese American immigrant women in our sample did not describe themselves as being or becoming a breast cancer "survivor," a preference that was correlated with an expressed fear of cancer recurrence. This reinforces other research on resilience and coping among Chinese women with breast cancer (Cheng, Sit, Twinn, Cheng, & Thorne, 2013). The women in our

study were hesitant to accept the finality associated with being a “survivor” when the risk of recurrence is uncertain, reflecting an association of survivorship with a lack of recurrence or new cancers, as opposed to a more clinical definition of survivorship beginning with a diagnosis of cancer (Rowland et al., 2013). Also, some of the women expressed preference for the idea of being identified as a person who has “recovered” from cancer rather than someone who is a “survivor”, similar to results from another study in which South Asian breast cancer survivors reported dislike for the term “survivor” and preference for being called a “thrivor” instead (Singh-Carlson, Wong, Martin, & Nguyen, 2013). This finding suggests that women’s self-understandings are diversely understood in the post-treatment setting and is consistent with other studies that show the term “survivor” has unique historical and cultural connotations for different people (Bell & Ristovski-Slijepcevic, 2013). How a cultural group interprets survivorship may have implications for the design of culturally appropriate surveillance adherence information as well. Providers of post-treatment care should consider the linguistic nuances between recovery and survival in the design of surveillance information for this cultural group.

Our results were consistent with others who found cultural factors to be relevant in how Chinese American and Asian American women view cancer (Ashing-Giwa et al., 2004; Facione, Giancarlo, & Chan, 2000; Gonzalez et al., 2016; Lee-Lin et al., 2012; Tam Ashing et al., 2003; Wong-Kim et al., 2003; Wong-Kim et al., 2005). Recent work suggests that cultural health beliefs are important for the adoption of health-promotion behaviors and health-related quality of life after breast cancer treatment among Asian American survivors (Lim et al., 2012; Lim, Gonzalez, Wang-Letzkus, & Ashing-Giwa, 2009). Our findings reveal the need for more culturally and individually oriented information exchange with providers that will enable survivors to stay in touch with clinic-based resources and recurrence information in the post-treatment setting.

Study limitations

The participants in our study were all recruited from a single public hospital and urban area (New York City), which may limit generalizability. It is possible that some of the concerns raised, particularly those related to interactions with providers, may be specific to that specific institution. However, these concerns are similar to those described in other studies. For example, similar to the findings reported here, recent work in other settings has found language and communication barriers to be crucial impediments to information and care delivery among Chinese immigrant cancer patients (Leng et al., 2012).

CONCLUSION

This study’s findings point to the importance of cultural beliefs and patient-centered information exchange in promoting post-treatment surveillance adherence among Chinese American immigrant breast cancer survivors. Recent work has identified the need for culturally and linguistically appropriate interventions to address the specific support needs of Chinese immigrant cancer survivors (Lee et al., 2013; Leng et al., 2014; Wong-Kim et al., 2005). As an understudied subgroup within cancer research, future study of Chinese American immigrant breast cancer survivors and how specifically their survivorship experience may differ from other racial and ethnic groups is needed. It is recommended that recruitment of Chinese American cancer survivors for studies be culturally-targeted, utilizing culturally and linguistically competent research personnel, materials and instruments (Lim & Paek, 2016). We further suggest oncology treatment specialists take into consideration specific sociocultural factors and

contexts, including communication and available social support of their patients, in the practice of post-treatment care for Chinese American immigrant breast cancer survivors.

People's cultural perceptions of illness may require different approaches with regard to survivorship (Cheng, Sit, & Cheng, 2016; Lim, Gonzalez, Wang-Letzkus, Baik, & Ashing-Giwa, 2013; Singh-Carlson, Nguyen, & Wong, 2013). Given health disparities in cancer outcomes and consistent with other reports regarding the significance of cultural factors in quality of life and health-behaviors following cancer treatment (Lim et al., 2009; Singh-Carlson et al., 2013), including among Chinese American breast cancer survivors (Gonzalez et al., 2015), our study findings demonstrate the need for further qualitative studies of the relationship between provider delivery of surveillance information to linguistically diverse patients, patient-provider communication (particularly during the final phase of primary treatment), and patients' self-perceptions and cultural expectations regarding "survivorship."

ACKNOWLEDGEMENTS

This study was funded by the Avon Foundation (#07-573).

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APPENDIX

Complete List of 59 Study Themes (Codes)

Bad provider experience interferes with follow-up
Cancer "recovery" preferred over "survival"
Cancer is private
Cancer is terminal
Cancer taboo
Cancer taboo_will not talk with family
Cancer taboo_will not talk with friends
Celebrate end of treatment
Comfort discussing cancer with other cancer patients
Comfort talking about cancer socially
Communication problem with provider
Coordination of care problem
Dedicated to follow-up care
Dependence on family in post-treatment
Depression causes cancer
Desires more recurrence information
Discuss cancer only with close family and friends
Does not ask the provider questions
Does not identify as a "survivor"
Emotional concern in post-treatment
Emotional concern in treatment
Emotional distress interferes with follow-up
Environment is health risk
Family cancer not a risk
Family history of cancer
Family issues interfere with follow-up
Family not supportive in treatment
Family supportive in treatment
Fate causes cancer
Fertility concern
Financial concern
Follow-up not recommended last day of treatment
Follow-up recommended by provider
Food and diet cause cancer
Forgetting appointments interferes with follow-up
Genetics causes cancer
Importance of diet in post-treatment
Independent health decisions
Language barrier
Long wait time for care
Mention of Chinese provider
Negative evaluation of care
No choice
Non-surveillance instructions from the provider

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Physical pain in post-treatment
Physical pain in treatment
Positive evaluation of care
Prefers not to discuss cancer in post-treatment
Recurrence fear
Recurrence information not provided by provider
Recurrence information provided by provider
Social network supportive in treatment
Spousal conflict
Spousal disinterest after diagnosis
Supernatural causes of cancer
Trust in provider
Treatment cures cancer
Unhealthy lifestyle causes cancer
Work interferes with follow-up