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A Qualitative Exploration of the Continuum of Help-Seeking among Asian American Breast Cancer Survivors

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Abstract

Breast cancer rates among Asian American women are increasing. Despite this, there are limited studies on help-seeking among this population. Through a qualitative exploration, this paper examines the help-seeking experiences of Asian American breast cancer survivors. Asian American women (n=52) with early-stage breast cancer were interviewed. Findings illustrate a continuum of experiences including: keeping diagnosis personal and not asking for help, keeping diagnosis personal but asking for limited help, and sharing diagnosis and seeking support. Results indicate that seeking support is a complex process for Asian Americans with breast cancer, with implications for survivorship and quality of life.

Keywords

breast cancer survivorship; Asian Americans; help-seeking; family support

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Ethics Approval – Approval was obtained from the Institutional Review Board of San Francisco State University (File #02-0451R1). The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

Consent to Participate – Informed consent was obtained from all individual participants included in the study.

Introduction

Breast cancer rates among Asian American women are increasing (Gomez et al., 2017; Morey et al., 2019). Nearly 1 in 10 Asian American women will be diagnosed with breast cancer in their lifetime (Torre et al., 2016). From diagnosis to survivorship, women with breast cancer face stressors including fear of recurrence and death, loss of control, hopelessness, anxiety, and depression (Ashing-Giwa et al., 2004). While all cancer patients face a bewildering array of treatments, side effects, and emotions, Asian Americans may experience greater burden because of fewer options for understanding and managing their illness, psychological distress and depression, and difficulties adjusting to cancer than White Americans (Lee et al., 2012; Tsai et al., 2020). From diagnosis, treatment and survivorship, Asian American women with breast cancer face unmet physical, financial, and psychosocial needs that impact health behaviors and health related quality of life (Wen et al., 2013). In a study of Asian American cancer survivors, 80% reported at least one unmet need including those related to physical concerns, day-to-day activities, and emotional concerns (Le et al., 2017). Despite the increasing rates of breast cancer among Asian American women, there are limited studies on experiences of help-seeking and social support in this population (Kagawa-Singer et al., 1997; Lee et al., 2013).

Conceptual Framework: Help-Seeking

Help-seeking is an adaptive form of coping that consists of actively seeking help from others (Rickwood & Thomas, 2012). Help-seeking behaviors can be directed towards *formal support services* (e.g. specialists, primary care physicians, social workers), *informal networks* (e.g family, friends, significant others), and *self-help* (e.g online, guided sources) (Kim & Lee, 2021). Individuals perceiving supportive networks may be more inclined to reach out and engage in help-seeking behaviors. Alternatively, members of one's social networks may perceive a need for help, and initiate processes for the recipient to engage in help-seeking behaviors (Thoits, 2011). Thus, perception of the availability of social support may be an antecedent to help-seeking behaviors that predict how individuals will seek assistance and obtain information, advice, and emotional support to address stressful life situations.

Literature Review

Facilitators and Barriers to Help-Seeking among Breast Cancer Survivors

For all breast cancer survivors, a supportive environment can prevent psychological difficulties, develop resilience, benefit general well-being, provide hopefulness, and improve survival (Zhang et al., 2017). Existing literature describes facilitators experienced by breast cancer survivors to engage in help-seeking behaviors. Women who observe positive emotional and financial support from family and friends were more likely to seek treatment and advice regarding their medical condition (Chou et al. 2012). Increased pressure from family members following diagnosis led women to attend to their cancer symptoms and seek support from health professionals and significant others (Unger-Saldana & Infante-Castaneda, 2011).

Despite these facilitators, past research describes barriers in seeking social support (Taib et al., 2011). Women who perceive possible negative consequences from disclosing symptoms are more likely to delay help-seeking and avoid disclosure to family and friends out of concern for burdening others (Chou et al., 2012). Fear of illness may lead to delays in seeking medical attention to avoid confirmation through diagnosis. Conflicting priorities within one's family or career may also prolong help-seeking (Rastad et al., 2012). One's socioeconomic and immigration status may also impede help-seeking (Khakbazan et al., 2014).

Social Support & Help-Seeking among AA Breast Cancer Survivors

Literature on Asian American breast cancer survivors illustrate the challenges that women face in seeking support from their social networks. Culturally unique issues including social stigma, harmony, and gendered caregiving roles may impact the ability of breast cancer survivors to disclose diagnosis and seek help from social networks (Hsu et al., 2020; Warmouth et al., 2017). Ethnically diverse breast cancer survivors may also show reluctance to disclose their needs and burden family members (Yoo et al., 2017). Thus, cultural and familial considerations may contribute to reluctance to seek support from others and engage in help-seeking behaviors.

Despite these barriers, previous research has shown the benefits of help-seeking among Asian American breast cancer survivors (Lee et al., 2013). Positive perceptions of family communication and flexibility may facilitate help-seeking among survivors and improve quality of life (Lim & Ashing-Giwa, 2013). Dyadic studies with survivors and their family members indicate communication as a strong predictor of physical quality of life for all family members (Lim, 2014). Perceptions of social support predicted health-related quality of life among Chinese American breast cancer survivors (Tsai & Lu, 2018). Therefore, help-seeking may be an important coping mechanism to develop among Asian American breast cancer patients and survivors. Social networks and support may be associated with better survival outcomes among women diagnosed with breast cancer. Currently, there is no research on help-seeking experiences and decision making among Asian American women with breast cancer. This paper qualitatively examines the continuum of help-seeking among this population.

Methods

Sample Characteristics

This paper is part of a longitudinal study that examined quality of life, spirituality, mood, and social support among breast cancer survivors from diverse backgrounds (Levine et al., 2017). The study received ethical approval from the Institutional Review Board at San Francisco State University (File #02-0451R1). As part of this larger study, respondents completed quantitative surveys and a semi-structured interview. This sample comes from this larger study of diverse women with early-stage breast cancer who had completed primary treatment (Levine et al., 2017; Yoo et al., 2017). The eligibility criteria for study participants were: 1) diagnosed and treated not more than four years previously; 2) Over the age of 18 at the time of the diagnosis; 3) Stage 0, I or II disease only; 4) able to read and speak English, Chinese or Spanish; and 5) no prior history of breast cancer. The women were recruited from several different sites including major hospitals, ethnic organizations, cancer resource centers, and health fairs. The final sub-sample consisted of 52 Asian American women. Demographic characteristics of our sample are located in table 1.

Procedures

In our larger study, respondents completed quantitative surveys and semi-structured interviews (Levine, Yoo & Aviv, 2017). For this sub-study, investigators identified and interviewed Asian American participants (n=52). Interviews were done in English or Cantonese. Women were asked open-ended questions to understand the psychosocial impact of their diagnoses, response to diagnosis at treatment and post-treatment, and experiences with help-seeking and social support. 90-minute tape recorded interviews were conducted at a location and time that was accessible and convenient for participants. Audiotapes were then transcribed verbatim by a trained transcriptionist. In addition, all responses were translated into English. All transcripts were de-identified. Once completed, all transcriptions were reviewed for accuracy by trained research team members and the investigator.

Data Analysis

A grounded theory approach was used to examine help-seeking and social support among the sub-sample of Asian American women (Strauss & Corbin, 1990). A three-step process was used in conducting qualitative data analysis. First, three different trained coders reviewed transcripts independently to identify themes and coding categories. Second, transcripts were then coded for themes that ran consistently throughout interviews. Qualitative analysis experts (DM, GY) oversaw the analysis. Third, all authors met to review the codes again. At this time, coding was iterative, and changes were made following rigorous discussion until consensus was reached by the research team for each code. Interviews falling within each coding category were evaluated to determine consistency with definitions of codes and the emerging themes.

Results

Respondents (n=52) in this study were Asian Americans of various backgrounds including Chinese, Filipina, Japanese, Korean, Indian, Vietnamese, and Mixed Asian. Participants were primarily foreign-born (73%; n=38)) versus U.S. born (26.9%; n=14). The mean age of respondents was 56 years of age. The majority of respondents were married/partnered (n=35) and had children (n=41). Our findings illustrate a continuum of help-seeking occurring in multiple and non-linear phases among participants.

Phase 0: I am keeping my diagnosis personal and not asking for help

In Phase 0 (9.62%; n=5) respondents discussed keeping their diagnosis personal and not asking or receiving help from others. Participants only sought help from formal healthcare providers during their breast cancer treatment, and not from any other sources or types of support. Many discussed numerous factors that deterred them from seeking help in their informal network encompassing family, friends, and support groups. Main themes that emerged in Phase 0 included feeling a sense of independence and being their own form of support and not wanting to be a burden to their family because they have other familial and work responsibilities.

A major reason why participants did not seek help is that they did not want to burden those in their immediate family. Some even ascribed that this behavior is part of Asian culture because it might be perceived as a weakness due to the belief that "…growing up Asian, you don't ask for help." A 59-year-old Chinese participant shared how her daughters were saddened by the news of her diagnosis; yet she did not want to ask them for help because she recognized that her daughters have other things to worry about:

> Everybody has their own life, have their own family, and live really far. I can't see myself imposing on them for things like this, which I can manage on my own.

Older adults often wrestled with their need to appear self-sufficient. If their family were absent or busy, they would care for themselves on their own, and resisted depending on others. An 81-year-old Chinese American woman talked about her lack of need to ask for support:

> I've had worse crises than cancer without the emotional support. Just depends on my own thinking to get myself over it. Even though my son lives with me, I didn't say, I feel lousy. I just kept it to myself. I went to the office every day. I didn't tell the customers; I was just operated on for breast cancer.

In Phase 0, participants underscored that help-seeking can be a solitary process because of the need to be self-reliant and capable of seeking the information they need independently. Thus, Asian culture may have been a barrier to help-seeking because seeking support was perceived as inconveniencing others.

Phase 1: I am keeping my diagnosis personal and asking for support from a few

Phase 1 (44.33%; n=23) had participants who mentioned they were private about their cancer diagnosis and only relied on a limited number of friends and family. Participants discussed that they did not disclose their breast cancer diagnosis to their extended network because they wanted to maintain a sense of privacy. A 51-year-old divorced Filipina with two children shared how people offered to help her but she was wary of accepting support "…I got some friends who'd bring me food, and they actually offered to clean my house and all that, but I'm [a] very private person, I'd rather do it myself."

Another participant, a widow, discussed that while her children implored her to live with them, she preferred her own privacy and living in her own home while she was recuperating from chemotherapy. She compromised by only staying with her children in limited time periods and being allowed to come and go when she pleases:

> But I prefer my privacy…so I come here [*at her youngest son's house*] quite often. They have [a] bedroom for me, downstairs of course…and my second son Donald, also. I can go any day any time…weekends mostly I go to my sons' house. "Mom, don't stay alone, don't stay alone, you go to Patrick. When Amy comes back you still can live here, don't go home, don't go home." I say, "I want to go home." (Chinese, 73 years old)

A probable reason why participants preferred to keep their breast cancer diagnosis private is because they do not want people's sympathy. A 66-year-old single Chinese participant shared how she only disclosed having breast cancer to two individuals "I didn't tell my friends. I only told two people…one is my boss and the other is a very good friend of mine. And like I said it's because I don't want to have anybody's sympathy."

Others did not want to be reminded of their condition. One participant, a 50-year-old South Asian married with one child, conferred that she kept her diagnosis private because she did not like to be reminded that she has breast cancer:

> I didn't want to think. The more I get open, the more I have to hear about this one, the sympathy, it will keep reminding me that I have breast cancer, that I wanted to forget.

Many of the women in Phase 1 also highlighted that they relied on support from limited networks. A 69-year-old Filipina received all information during treatment from her sister, who is also a breast cancer survivor and shared health-related materials. This allowed the participant to be cognizant of what to expect during the process, "…I knew everything that I had to know before and during and then after. So I didn't need any support group." Some participants highlighted that the abundant support they received from their family and friends was enough to satisfy their basic needs during their breast cancer journey. Thus, they felt it was unnecessary to reach out to their wider network and other formal sources of help and information.

A 68-year-old Japanese participant communicated that while her husband and her son initially had a difficult time with her diagnosis because of their fear of losing her, it also motivated her family to perform daily tasks that allowed her to rest, "…we were doing fine, (I said) my husband was between cooking and – and getting food – take-out food [laughs]." Similarly, other participants also shared how their significant others increased their level of support. A 47-year-old Chinese American participant described the numerous ways that her husband supported her:

> …well, my husband…made it easy for me. By being there, being very supportive, not just mentally, but physically too. He was there to drive me around and he gave me all this information about the chemo. Anything he could find on the internet. He was just there for me, he would do things for me, take care of me…I feel very blessed to have him.

Some participants found support from friends and co-workers. A 67-year-old Sri Lankan participant who is single with no children, found solace from regularly meeting with her friend at work who is a cancer survivor and being able to call her for unexpected side effects:

> …when I was all red and raw and I didn't know what was going on and I got scared and I called. And she said, "No, that's – that happens and that's because you rubbed the dead skin off." The blood came. And she said just put aloe vera gel and it will be ok.

Participants in Phase 1 emphasized that while they have wider formal and informal networks to receive support from, they were fortunate to have family and friends who can provide their basic needs. Nevertheless, many still valued their sense of independence and privacy in managing their diagnosis autonomously.

Phase 2: I am sharing my diagnosis with others and open to asking/receiving help from many

Phase 2 described participants who were willing to share their diagnosis with a wide range and number of networks including family, friends, work, and other organizations in which they participated. Whereas participants in Phase 1 kept their diagnosis personal and received support from their immediate family members and friends, participants in Phase 2 (46.15%; n=24) shared with many and were comfortable asking and receiving support from their extended network particularly after self-disclosing their breast cancer diagnosis.

For these participants, self-disclosure to others meant their own willingness to receive support – sometimes from unexpected sources, and enlisting others for both emotional and tangible forms of support. Disclosure to one’s personal network often meant that there was a response of support from friends, acquaintances, and family. Acculturated Asian immigrants and younger U.S.-born Asians were more likely to disclose widely to family, friends, and co-workers. A 39-year-old Korean American with stage II breast cancer also discusses the overwhelming response she received after telling others of her diagnosis:

> It was just the outpouring of support and the thing that was very most meaningful to me was people saying that “I’m praying for you,” or “I’m thinking about you.” And just to know that people were like kind of sending signals up to God or doing whatever they would for on my behalf just was – was really helpful.

A 58-year-old Japanese American woman with stage I breast cancer stated:

> I just couldn’t believe how compassionate complete strangers would be. I had to meet a client that I never met before and we just met for just a few minutes…I had said that I can’t stay long, because I had to go to radiation, but then she would tell me stories about her husband who had cancer. And she hugged me. I received like over a hundred cards from people, and I had bouquets all over my house. People brought food to me. I belong to the church choir and the church choir sang a song to me. It was absolutely overwhelming. I was very, very moved by that.

Several respondents shared that once they disclosed, it was also much easier to tell others when they were not feeling well, and that help would be enlisted. A 33-year-old Filipina American with Stage II talked about how her work was accommodating:

> I had a client meeting that day, and like I called into work ‘cause I was like a total mess. I couldn’t meet with this guy…called my boss…and he goes, “Is everything okay?” and I started crying, and I’m like, “No.” and he just knew, and he goes, “I’m gonna take your client meeting. You get some rest. We’ll talk tomorrow morning.”

The crisis of a diagnosis brought the opportunity to seek out support and the opportunity for new friends and strengthening existing ties from wider networks. Survivors, especially Asian immigrants, realized there were friends that they never tapped into that they could rely on in this time of crisis. A 50-year-old Japanese immigrant with Stage II breast cancer talked about how culturally, she was led to believe that she was not supposed to ask for help; through joining her support group, she learned to ask for help:

> My culture says, “Do not ask other people to help even in trouble.” Before I joined the support group, I never asked for anything but now I can. I can ask. We help each other. It is still difficult for me. If I go to the doctor, I ask and others I know will go with me.

Participants talked about those at their workplace being extremely helpful by bringing over meals or assisting with work duties, and how such support helped with their recovery. In addition, friends at work were a source of support that was unlike their immediate family. Participants who disclosed their diagnosis to their extended network received an abundance of support from their friends, co-workers, and some acquaintances with loved ones who had cancer. Such responses seemed to satiate the tension and incongruence in Asian culture with help-seeking. Phase 2 showed how unexpected life events may activate an extensive network during moments of need and improve quality of life for breast cancer survivors.

Discussion

Key findings illustrate a continuum of help-seeking through diagnosis, treatment, and survivorship among Asian American women with early-stage breast cancer. The help-seeking continuum included phases from remaining private with their diagnosis and not seeking help, seeking support from a few, and embracing help and support from others. Similar studies with Asian American breast cancer survivors show family challenges, worry over children, and fear of burdening their family as reasons for avoiding help seeking (Lim et al., 2013). Other studies of older breast cancer survivors and ethnically diverse women demonstrate difficulties in disclosing, asking, and receiving social support (Yoo et al., 2009). For women of color, disclosure of diagnosis was often complicated by cultural stigma and the need to manage emotions among family and friends (Levine et al., 2017).

Existing literature on breast cancer disclosure indicates that hesitation to disclose breast cancer diagnosis is often associated with fear of stigma, which may affect relationships with family and peer circles, job opportunities, and insurance security (Raque-Bogdan et al., 2015). Our findings expand motives for vigilant disclosure, which are driven by fear of stigma and the patient’s desire to be treated and live normally. Moreover, our findings show that ample support from close family and friends act as protective factors from pressure of disclosure and seeking support from outside networks. At the same time, participants in phase 2 who disclosed widely were surprised by the width and breadth of support from their social networks. They were surprised that family, friends, co-workers, and acquaintances wanted to offer support. These perceptions may be impacted by US culture, where there is an assumption that even during illness, autonomy, privacy, individualism, and independence are valued (Fraser & Gordon, 1994).

Study Limitations

This study has several limitations to be considered. The study sample is not generalizable to all populations of Asian American breast cancer survivors because the participants are from the San Francisco Bay Area. Recruitment was purposely conducted at major hospitals, ethnic organizations, cancer resource centers, and health fairs resulting in a non-random sample. Despite these limitations, this paper is the first that we know of discussing and exploring social support among Asian American women with breast cancer. This paper also offers a contribution to understanding social support as a continuum among Asian American women with breast cancer.

Conclusion

The findings identified the cultural, social, and familial factors that are considered by Asian American women in disclosing diagnosis and help-seeking. Participants who did not seek help had unmet needs that were fulfilled on their own as they navigated their cancer diagnosis and treatment. The decision to disclose one’s diagnosis and seek help may thus have implications for breast cancer outcomes. Future research is needed to determine whether a significant relationship exists between help-seeking, social support received, and breast cancer survivorship. Our study also focused on the help-seeking experiences of women with early-stage breast cancer. Future research is needed to explore the different experiences of Asian Americans with late stage and advanced cancer.

Within Asian American communities, there are disparities in cancer diagnosis, treatment, and survivorship (Gomez et al., 2017). Our research suggests the need for more outreach to Asian American communities to increase health literacy on breast cancer. Culturally adapted health education is needed for Asian American women to learn about the cancer experience and benefits of support during this difficult time. Our work also suggests variations in help-seeking processes are impacted by cultural, social, and familial considerations. Participants held motives for vigilant disclosure, including not wanting to burden family or be treated differently for their diagnosis. Oncology social workers must be cognizant of these help-seeking processes, which may impact disclosure of distress, assessment of psychosocial needs, and types of interventions needed. Social workers must also understand the cultural and contextual factors that impact help-seeking among AA breast cancer survivors, and serve as patient advocates in multidisciplinary cancer care teams. Social workers’ roles in collaborative care teams may include patient advocacy, culturally responsive assessment of psychosocial needs, psychoeducation on the cancer experience, and coordination of psychosocial and/or family-based interventions to promote quality of life among patients and their families. Social workers providing clinical services must consider the roles of culture, family, and social networks on the emotional and cognitive processes of help-seeking, and ultimately quality of life.

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Availability of data and material –

The authors have full control of all primary data and allow the journal to review if necessary.

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Table 1.

Background of Asian American Women Breast Cancer Survivors (n=52)

Variable	**Number**	**Percentage**
Chinese	23	44.2%
Filipina	11	21.2%
Japanese	5	9.6%
Korean	3	5.8%
Indian	4	7.7%
Vietnamese	2	3.8%
Mixed Asian	4	7.7%
Mean Age at Diagnosis	56	
Birthplace		
U.S Born	14	26.9%
Foreign born	38	73%
Marital Status		
Single	5	9.6%
Married/Partnered	35	67.3%
Divorced/Separated	8	15.3%
Widowed	4	7.6%
Stage of Breast Cancer		
Stage I	22	42.3%
Stage II	25	48.1%
DCIS/Stage 0	5	9.6%
Have children?	41 (78.8)	
Number of children (Mean)	1–6 (2)	