

# A qualitative exploration of the trajectory of help seeking among Asian American breast cancer survivors

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## Research Article

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# Abstract

Breast cancer rates among Asian American women are increasing. Despite this, there are limited studies on help-seeking and social support in this population. This paper examines qualitatively the trajectory of help-seeking among Asian American breast cancer survivors. A subsample of Asian American women (n = 52) from a larger study of spirituality, quality of life, mood, and social support was examined. To be eligible for the study, participants needed to: 1) have had a diagnosis of breast cancer (Stage 0, I & II) within the past four years, 2) have completed primary treatment, and 3) speak and/or write English, Cantonese, or Spanish. In-depth interviews and surveys were conducted. Key findings illustrate a trajectory of help-seeking among Asian American women diagnosed with early stage breast cancer. Stages in this trajectory move from keeping their diagnosis personal and not asking for help (Phase 0), maintaining their diagnosis personal but asking for help (Phase 1), and sharing their diagnosis to others and are asking for help (Phase 2). Findings illustrate that seeking support is a process for Asian American with breast cancer, with implications for health and service providers who offer social support to this population.

## Background

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 [1]. From diagnosis to survivorship, women with breast cancer face stressors including fear of recurrence and death, loss of control, hopelessness, anxiety, and depression [2–5]. While all cancer patients face a bewildering array of treatments, side effects, and emotions, Asian Americans may experience greater stress and burdens because they may have fewer options for understanding and managing their illness [6–7], experience more psychological distress and depression [8–9], and difficulties adjusting to cancer than Whites [10]. In a study of Asian American cancer survivors, 80% reported at least one unmet need including those related to physical concerns (66 %), day-to-day activities (52 %), and emotional concerns (52 %) [11]. 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 [8–12].

Help-seeking is defined as an adaptive form of coping of actively seeking help from others. Help-seeking includes communication to receive understanding, advice, information, treatment, and support in response to problems or negative experiences [13]. Individuals that perceive having 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 [14–15]. Perception of the availability of social support may thus be an antecedent to help-seeking behaviors that predict how individuals will seek assistance, obtain information, advice, and emotional support to address stressful life situations [16].

For all breast cancer survivors, a supportive environment can prevent psychological difficulties [17], development of resilience [18], benefit general well-being [19], provide hopefulness [20], and improve

survival [21]. Existing literature describe facilitators experienced by breast cancer survivors to engage in help-seeking [22–23]. Women who observe positive emotional and financial support from family and friends were more likely to seek treatment and advise regarding their medical condition [22]. Furthermore, increased pressure from family members following diagnosis led women to attend to their cancer symptoms and seek support from health professionals and significant others [23].

Despite facilitators to help-seeking among breast cancer survivors, past research also describes barriers or difficulties in seeking help [24–25]. 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 bothering others [22]. Fear may lead to delays in seeking medical attention to avoid confirmation of diagnosis. Conflicting priorities with one's family or career, and the prioritization of significant others may also prolong help-seeking [26]. One's socioeconomic and immigration status may also impede help-seeking [27].

Literature on Asian American breast cancer survivors illustrate the challenges that women face in seeking support from their social networks. Culturally unique issues such as social stigma, goals for harmony, and gendered caregiving roles may impact the ability of breast cancer survivors to disclose diagnosis and seek help from social networks [28–30]. Ethnically diverse breast cancer survivors may also show reluctance to disclose their needs and burden family members [31]. Cultural and familial considerations may contribute to reluctance to seek help from others, and engage in help-seeking.

Despite these barriers, previous research has shown the benefits of help-seeking among Asian American breast cancer survivors [32–35]. Positive perceptions of family communication and flexibility may facilitate help-seeking among survivors, and improve quality of life [33]. Dyadic studies with survivors and their family members indicate communication as a strong predictor of physical quality of life for all family members [34]. Perceptions of social support may predict health-related quality of life among Chinese American breast cancer survivors [35].

There is no research on what choices Asian American women with breast cancer make in terms of help-seeking. This paper examines qualitatively the trajectory of help-seeking among Asian American women breast cancer survivors.

## Methods

This sample comes from a larger study of spirituality, quality of life, mood, and social support among breast cancer survivors in the San Francisco Bay Area. For this sub-study, the investigators identified women who were Asian American (n = 52). To be eligible for the overall study, the participant needed to: 1) diagnosed with breast cancer (Stage 0, I & II) within the past four years, 2) completed primary treatment, and 3) speak and/or write English, Cantonese, or Spanish. An initial qualitative in-depth interview and quantitative surveys were conducted.

A 90 minute tape recorded interview was conducted at a location and time that was accessible and convenient for participants.

In the qualitative interviews, women were asked open-ended questions to understand the psychosocial impact of their diagnoses, response to diagnosis, treatment and post-treatment, and experiences with help-seeking and social support. Audiotapes were then transcribed.

Grounded theory analysis was used to examine help-seeking and social support [36].

Each team member reviewed transcripts for similarities and differences.

Transcripts were then coded for themes that ran consistent throughout interviews. Coding was iterative and changes were made following rigorous discussion until consensus was reached for each code. Interview testimonies falling within each coding category were evaluated to determine consistency with definitions of codes. Finally, emerging analyses were mapped according to conceptual categories, their definitions, and observations within each category. Inductive and deductive methods were used.

## Findings

The fifty two (n = 52) respondents in this study made up Asian Americans of various backgrounds including Chinese, Filipina, Japanese, Korean, Indian, Vietnamese, and Mixed Asian who were primarily foreign born versus U.S. born. 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 trajectory of help-seeking occurring in multiple phases.

### **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 for others. Participants only sought help from formal healthcare providers during their breast cancer treatment and not for any other sources or types of support. Many discussed numerous factors that deterred them from seeking help in their informal network that encompassed their 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, "...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. Moreover, Asian culture may have influenced help-seeking insofar that it can be a barrier to help-seeking because it is perceived as inconveniencing others.

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

The next thematic trajectory were those participants who remained personal about their diagnosis but are open to asking and receiving support from others.

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 that she lives with them, she preferred her own privacy and live in her own home while she was recuperating from chemotherapy. But 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 do 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 clandestine 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 may want to remain unaware of their condition such as one of the participants, 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 attributed all the information that she needed during her breast cancer treatment originated from the experiences of her sister who is a breast cancer survivor who shared with her health-related materials that she accumulated during her treatment. This provided the participant awareness and confidence in being 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 that 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 had a difficult time with her diagnosis initially because of the 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 other 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 a wider formal and informal network to receive support and help 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 and receiving help from many**

Phase 2 describes 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 those on Phase 2, self-disclosure to others meant their own willingness to receive support – sometimes in surprising ways and from unexpected corners, and enlisting others for both emotional and tangible forms of support. Disclosing 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 having 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 discussed 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 such as co-workers. Survivors, especially Asian immigrants, realized that there were friends that they had 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.

Women 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 to sympathize or empathize during moments of needs, challenging the notions of American individualism and self-reliance at all costs, and the assumption that survivors do not ask for help and prefer isolation and privacy.

## **Conclusion And Discussion**

The key findings illustrate a trajectory of help-seeking among Asian American women diagnosed with early stage breast cancer. This trajectory was often in parallel to these women’s disclosures of their diagnosis. The willingness to tell others also followed a help-seeking trajectory from private and not seeking help, cautiousness and reluctance, and embracing help and support from others. Similar studies with Asian American women breast cancer survivors show family challenges, worry over children, and fear burdening their family [37]. Other studies of older breast cancer survivors and ethnically diverse women also show the difficulties of disclosing and asking and receiving of social support [38–39]. For women of color, the disclosure of diagnosis was often complicated by cultural stigma and the need to manage perceptions of family and friends [39].

Existing literature on breast cancer disclosure found that being wary of disclosing breast cancer diagnosis is often associated with the stigma of having breast cancer which they deem can affect their relationship with their familial and peer circles, job opportunities, and insurance security [40–41]. In addition, our findings expand their motives for vigilant disclosure not necessarily driven by the repercussions of stigma, but wanting to be treated normally and live a normal life. Moreover, our findings show that ample support from close family and friends act as protective factors from pressure of disclosure and seeking support from a broader network. At the same time, participants in phase 2 who disclosed widely were surprised by the width and breadth of support from their social networks [42]. They were surprised that family, friends, co-workers, and acquaintances wanted to offer support. In the US, there is an assumption that even during illness that autonomy, privacy, individualism and independence are valued [43].

Studies have shown that social networks, support and breast cancer is associated with better survival outcomes among women diagnosed with breast cancer [44–45]. For a woman encountering a breast cancer diagnosis, an antecedent to being able to receive support is to disclose and to ask for help. This research has implications for health disparities and breast cancer survivorship. In this study, those who did not seek help often had needs that were ones they needed to fulfill on their own as they navigated their cancer diagnosis and treatment. Future research is needed to determine whether a significant relationship exists between help-seeking, social support received and health outcomes. Disparities exist in Asian American communities in terms of information regarding cancer and survival and the impact of social support in easing diagnosis, treatment and survivorship. At a practical level, this research suggests that there needs to be more information and outreach to Asian American communities on surviving breast cancer, and that there needs to be more awareness directed towards cancer patients on the benefits of seeking help and support during this difficult time.

## Declarations

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

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## Supplementary Files

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