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Exploring Coping Strategies Among Young Asian American Women Breast Cancer Survivors

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Abstract

In recent years, breast cancer rates among young Asian American women have been increasing. Despite increases in breast cancer among young Asian American women, little is known about how this population copes throughout diagnosis, treatment, and survivorship. This study was a qualitative exploration of how young Asian American women cope with breast cancer diagnosis, treatment, and survivorship. In-depth interviews with 22 young (under the age of 50) Asian American women diagnosed with early stage breast cancer were conducted. Through qualitative data analysis, three major themes emerged including moving from managing the emotions of others to expressing emotional vulnerability, moving from work and productivity to work-life balance, and moving beyond the family and reaching out to breast cancer survivors. At diagnosis, participants worked to maintain normalcy including caring for others and working during treatment. Once treatment was over, women worked to find ways to use their experience as a transformative one and also to develop more positive coping skills including expressing emotional vulnerability and reaching out to others. Further studies are needed to create and test culturally tailored supportive interventions that enhance positive coping tools among young Asian American women diagnosed by breast cancer.

Keywords

Breast cancer; Asian American; Young women; Coping

Introduction

Breast cancer is the most commonly diagnosed form of cancer for women, regardless of ethnic background. In 2013 alone, more than 232,340 women in the USA were diagnosed with the disease [1]. For the last 20 years, breast cancer incidence has been increasing among young women; 26 percent of women with breast cancer are under age 50 at diagnosis [1]. Remarkably, between 2006 and 2010, rates of breast cancer among women under the age of 50 increased the most for Asian American women compared to any other racial/ethnic group [1]. In previous years, from 1998 to 2008, rates of breast cancer among young Asian

American women were consistently higher than those among White women [2]. Among young Asian American women diagnosed with breast cancer, rates appear to be highest among the following ethnic groups: Indian/Pakistani (12.6 %), followed by Vietnamese (12.6 %), Korean (11.8 %), Chinese (9.4 %), and Filipino (7.4 %) [2].

Most young women with breast cancer experience emotional distress as they face a bewildering array of treatments and side effects that can adversely affect quality of life. At the time of initial diagnosis, women face emotional stressors including fear of death, loss of control, hopelessness, and depression [3]. During the first 2 years of survivorship, an estimated 30–45 % of women with breast cancer experience substantial psychological morbidity including anxiety and depression [4]. Compared to older women, younger women with breast cancer face additional physical, social, and psychological stressors including premature menopause, infertility, fears related to risk of recurrence, weight change, loss of hair from chemotherapy, and body image insecurities, including concerns about surgery and reconstruction [5]. Younger women of color with breast cancer are also known to experience greater financial distress and more pronounced family distress than young White women diagnosed with breast cancer [6].

Coping Strategies and Breast Cancer

The concept of coping is complex and comprises several types of coping, including cognitive (e.g., how one thinks about the diagnosis) and behavioral (e.g., what one does about it) efforts to lessen and control the impact of stressors [7]. Coping approaches can be active or avoidant. Whether a person chooses active or avoidant coping strategies is partially influenced by his or her ethnic background and traditions [8]. As studies of women of color have demonstrated, women from diverse cultures respond differently to their breast cancer diagnosis, with negative forms of coping, such as emotional repression and behavioral disengagement, being associated with worse outcomes [9-11]. Public health research outside of breast cancer corroborates the idea that culture impacts coping responses for Asian American women: those who are acculturated to the USA utilize more active coping strategies, while individuals who are less acculturated tend to use more avoidant coping strategies [12]. Initial research exploring stress management among Asian American breast cancer patients has demonstrated that these women generally tend to utilize more avoidant coping skills, including being reluctant to tell others because of the cultural stigma associated with cancer [13-17]. Other studies have shown that Asian American breast cancer patients were also less likely to seek out help from formal services or from spouses and partners, than White breast cancer patients [18]. On the other hand, studies examining effective practices for survival have reported that Asian American women with breast cancer who are trained to use more active coping strategies, including the use of both negative and positive emotional expression, can see improvements in their health [19, 20]. Despite increases in breast cancer among young Asian American women, relatively little is known about this population in terms of how young Asian American women cope with breast cancer [10]. Therefore, the purpose of this study was to qualitatively explore how young Asian American women cope with breast cancer at diagnosis, during treatment, and after treatment.

Methodology

This sample is a subsample of a larger study of spirituality, quality of life, mood, and social support among breast cancer survivors in the San Francisco Bay Area. To be eligible for the overall study, the participant needed to (1) have had a diagnosis of early stage breast cancer (stage 0, I, and II) within the past 4 years, (2) have completed primary treatment, and (3) speak and or write English, Cantonese, or Spanish. An initial qualitative in-depth interview and quantitative surveys were conducted. For this sub-study, the investigators identified women who were under the age of 50 at time of diagnosis and who identified as Asian American (n=22) for further analyses. Age 50 is generally used as a cutoff between older and younger women, since the average age of menopause is 51 [5].

The research team conducted interviews at the participant's home or at a public place convenient to her. Tape-recorded interviews were conducted in English and/or Cantonese and lasted approximately 1.5 to 2 h. The women were asked open-ended questions. An interview guide was used and participants were asked about the psychosocial impact of their diagnoses, as well as how they and their family and friends responded to their diagnosis, treatment, and survivorship. The audiotapes were then transcribed.

The analysis was based on a grounded theory approach with the focus on a core category: coping strategies and responses following a breast cancer diagnosis, during treatment, and after treatment. Following the procedures for grounded theory analysis [21], open coding was first utilized in order to identify types of categories and domains based on the emerging themes found repeatedly throughout the data. The codes that emerged were not forced or fixed. Investigators independently reviewed transcripts for commonalities and differences. Text within a coding category was then evaluated to determine whether it accurately fit the definition of the code. Next, axial coding was conducted, which identified relationships between the major categories and subcategories. The emerging themes reported in this paper centered on methods of coping. Thus, verification of the accuracy of the coding scheme (conceptual categories, their definitions, and the observations coded within each category) occurred using both inductive and deductive methods [21].

Results

Twenty-two Asian American women with early stage breast cancer participated in these indepth interviews. Age at diagnosis ranged from 31 to 50 (*M*=42, SD=10.5). The majority of women were partnered or married (77.3 %) and most (71.8 %) had a college education or higher. The majority of women (81.8 %) were born outside the USA (see Table 1). All women had surgery and the majority (68.2 %) were diagnosed with stage II breast cancer, had radiation (63.6 %), and received chemotherapy (81.8 %) (Table 2). Women were asked how they reacted to and coped with their diagnosis and treatment and what they learned from their breast cancer experience. The following three major themes emerged: (1) moving from managing the emotions of others to expressing emotional vulnerability; (2) moving from maintaining work and productivity to work-life balance; (3) learning to reach out to non-family for support, in particular other breast cancer survivors.

Moving From Managing the Emotions of Others to Expressing Emotional Vulnerability

One of the first reactions women diagnosed with breast cancer can have is worry about how their diagnosis might affect others [13]. Since most of the interviewees in our study were diagnosed at peak childbearing age, many were the primary caretakers of not only young children but, also, due to the extended family structure of Asian American households, siblings, and aging parents. As a result, several of the women interviewed continued to care for others during their treatment. This was often out of necessity, but also due to a need to maintain their identity as caretakers; as a result, women reported that they often managed their own emotions so others would not feel burdened by their diagnoses. For example, a 39-year-old Korean American respondent explained:

I'm more of the person who comes and brings you a meal when you're sick. Or you know—I'm the mother who...organizes all the other mothers to do stuff. So it was a little bit hard. Like or when people would call me and they would say you know, 'Can I bring over some food? Is there anything I can do for you?' You know I never say yes. I always say, 'Oh no, that's fine,' you know that kind of thing...I have trouble asking for help.

Several women also discussed how they did emotion work by managing the grief and anxiety of their loved ones. For example, a 35-year-old Indian American described framing her diagnosis in constructive terms, so as to ease the worry that her brothers and mother might feel:

...I was always on the positive side, I would always tell [my mother], look at those people in Iraq. I mean at that time you would hear about these...freak accidents, a girl...crossing the street from [San Francisco] State and she got hit by a car and she just died, and she did not even have a chance. So I kind of tell them those kinds of things to make them feel better. So I have to take care of them more than I have to take care of me.

At times, this management of familial anxiety led respondents to delay informing their family of their cancer, as in the case of a 44-year-old Chinese American respondent, who waited to tell her mother about her diagnosis until a full week after her mastectomy.

Because I know my mom's loyalty, she will worry even though I tell her not to. That's why I planned not to tell her until after the surgery. She really couldn't help with anything. She would just worry. I told her after one week because at that time I felt better. I can walk around by myself. When she saw me, I could tell her 'I'm okay'.

Due to the transnational nature of many Asian American families, in which parents and children often live oceans apart, the need to manage the concern of relatives was even more intense for those whose families lived far away. A 45-year-old Chinese American woman chose to only share her diagnosis with local friends and family. Keeping her cancer diagnosis a secret from her relatives who lived abroad helped her retain a sense of normalcy as she underwent treatment:

I didn't tell the relatives in China because they didn't need to know. If I have told them about it, it would only cause them to worry....The more people who know about it, the more care and concerns you would have received. You would be constantly reminded that you are a patient, a terminally ill patient. This impacts your confidence. One needs to live as normal as anyone else.

In coping with breast cancer, these respondents revealed how the most common challenge for young Asian American women was negotiating their identity from caretakers to patients. Often women had to find the best way to care for themselves, and still care for others. For most of the women in this study, caring for themselves included not telling others so that others would not worry or so that the anxieties of friends and family would not affect the patient.

Although many of these women began their cancer journeys by managing and caring for the emotions of others, respondents consistently reported that their experience with cancer helped them discover the motivation to live courageously and to express emotional vulnerability. Through their diagnosis and treatment, women learned new, adaptive coping strategies to get through their treatment and navigate the uncertainty of survivorship. As a result of having cancer, most of the interviewees expressed an inspired sense of freedom to live life as they want and to risk speaking up about feelings that they had repressed before their diagnosis. Several women commented that their cancer experience caused them to *transform* their initial coping instinct of maintaining emotional self-sufficiency, as the positive reappraisal of one 41-year-old Vietnamese American woman reveals:

I actually think it was a good experience and I'm actually glad that it happened. Because it changed my life so much that I'm a lot happier right now. I think one of the things, I mean my marriage has always been good but it actually improved it even a lot more. And then my family, I feel that I've become closer to all of my sisters and even my friends. I mean, suddenly, I mean there are things that I won't or can't say before and now I'm able to say them. I've just become less afraid and more confident and I'm not afraid to share my emotions.

Despite the shock of accepting one's lack of control over their mortality, many women echoed the sentiments of the respondent above, asserting that choosing different ways to approach life and relationships served as a source of empowerment. One 37-year-old Chinese American respondent even felt that surviving breast cancer treatment finally gave her the conviction to follow through with her desire to divorce her abusive husband. "The breast cancer for me is like a turning point," she explained. "In terms of my personality, I'm a much stronger person. I realized that I don't want to stay in that bad marriage anymore." For a 47-year-old Chinese American woman, the focus on making positive choices for a happy life was directly related to reducing the stress that she identified as a cause of her cancer:

Breast cancer is a lesson in life to...not to get too hurt or too emotional—easier said than done though....If the person stresses out from all these hurts, then the body, immune system, cannot fight the cancer cell, so that's how come [sic] the cancer, you know, just multiplies and grows and spreads.

By stepping out of their emotional and physical comfort zones, speaking openly with friends and family, and taking up new activities such as dancing, snowboarding, or breast cancer walks, these survivors managed to focus on the benefits of their cancer experience.

Moving From Work and Productivity to Work-Life Balance

A second theme that emerged from these in-depth interviews was the need to maintain work and productivity in order to continue living a "normal" life during treatment [22]. While cancer is generally understood to be an age-related disease that affects those at or near retirement, a unique challenge of receiving a cancer diagnosis in your 30s and 40s is balancing treatment with the need to continue working and earning income. Accordingly, nearly every respondent took a minimal amount of time off of work through disability (an average of 3–6 months) and then returned to work at least part-time. Given the high cost of living in the Bay Area, working was an absolute financial necessity for most interviewees, with some women choosing to work throughout their treatment. Consequently, a concern of working Asian American breast cancer patients was the way their treatment might be received by coworkers. One 48-year-old Japanese American respondent related how she attempted to carefully balance a new job with the physical changes caused by chemotherapy:

[W]hen I started [my new job], I told the boss about the cancer but pretty much no one else in the company knew. I lost my hair but I wore a wig. I made friends with a couple of people in the company and I had told the group, the people that reported to me, but other than, not many people...I don't know if I wasn't comfortable [telling coworkers about my diagnosis] or it was because it was a new job and I didn't want people thinking the treatment was gonna affect the way I was able to do my job.

Even among those respondents who were not financially obligated to work, many continued their jobs during and after treatment because their work provided them with a fulfilling sense of purpose. A 47-year-old Korean American educator explained that she never took disability and worked throughout her chemotherapy "...because I love those little kids. I'm a type of person that needs to keep busy. Not that being a mom is not being busy but I like working with special ed kids." For another respondent, a 39-year-old Korean American legal professional, the social nature of her workplace provided an important source of social engagement and interaction. She appreciated the affirmation and encouragement she received from coworkers during her treatment, and felt that working kept her busy and challenged, versus feeling isolated at home, where she might dwell on her health. "I felt like I was being a productive member of society," she explains.

Although most interviewees valued working during and after treatment, nearly every respondent also experienced a changed perspective about *prioritizing* work and career in their lives. Most survivors reprioritized their health and time with family over their jobs. As one 46-year-old Filipina American woman notes, "I don't take work too seriously because it's really not the most important thing in my life." Other respondents changed jobs to cut back on work-related stress. This was the case for a 33-year-old Filipina American legal professional, who recalled that she barely saw her husband before her diagnosis due to her

heavy case load and long commute. After her diagnosis, she sought greater balance between her home and work life:

I went job searching too when I took time off from work [through disability]...and I actually found like a new job and a better job that pays more and is closer to home. [I]f I was never diagnosed with breast cancer I would probably be too scared to do anything. I would probably still be working at that same law firm.

As these responses make clear, young women navigating treatment experienced not only a responsibility towards children and family members who rely on them but also an additional responsibility to an external community of coworkers and managers. Yet, while work-related concerns emerged as a key theme for young women navigating treatment and survivorship, the varied responses to work among interviewees reveals the way socioeconomic diversity impacts Asian American breast cancer patients and survivors differently. At the same time, many of the women developed motivation to pursue better work-life balance and more personally fulfilling career paths.

Moving Beyond the Family: Reaching Out to Breast Cancer Survivors

As a way to cope with their diagnosis and treatment, respondents often discussed the need to reach out to non-family for support. Despite the prevailing desire for self-sufficiency that most interviewees expressed, nearly all the women sought out some form of social support outside their family. Some gratefully recalled how husbands, parents, children, and siblings stepped in to take over chores such as picking up children from school, cooking, and cleaning at home. However, for most, this transformation of caretaking roles was challenging for family members. Children were either too young to take on household chores, or husbands and aging parents responded to respondents' diagnoses with shock and silence.

As mentioned above, for many Asians, cancer is viewed as a stigma, a cultural perspective that affects people's reactions to cancer [13-17]. For example, a 41-year-old Vietnamese American woman recalled that the cultural shame around cancer led to tension between her and her mother.

Well my mom is kind of—you know like people have some...I don't know if prejudice is the word or some stigma about this kind of disease and...so my mom is kind of like wanting me not to tell it to many people. And that was just kind of hurtful...I was thinking, "Why don't you be more supportive than that?"

As a result, respondents reported that peer support, either through informal advice from coworkers or neighbors with a breast cancer history or through formal cancer support groups provided a much-needed opportunity for patients to both discuss their emotional reactions to their diagnosis and weigh treatment options. As a 46-year-old Filipina American woman explained, meeting other survivors "provided tremendous support...[T]here was a commonality between us and you feel like, 'Ok, I'm not alone. Somebody has gone through it and they're doing okay.""

In some cases, peer support networks stepped in to provide not only emotional support but also tangible assistance in terms of food and shelter, as well. A 50-year-old Japanese American woman recalled that her husband "could not deal" with her cancer diagnosis and was unable to properly care for her after her mastectomy. "[S]o after the mastectomy one of [the] support group members took me in her house," and took on the role of serving as a primary caregiver.

While social support from family members was a clear benefit for respondents, even those interviewees who received strong and compassionate aid from spouses and family emphasized the importance of seeking out non-familial peer support. A 35-year-old Indian American woman regularly attends conferences and luncheons organized through the American Cancer Society's "Reach to Recovery" program. Meeting survivors at these events has felt like an important way to find others with whom she can relate. While she said that her husband "understands everything," the support she receives from Reach to Recovery is necessary because her husband "has never been through [cancer treatment]."

Age-specific peer support was also important for several women. For example, a 47-year-old Korean American woman sought out other survivors during breast cancer walks, but did not find formal support groups helpful because the women she met there tended to be older:

I went to two different ones, and I just found that it was a lot of—a lot of older women. And I think that's great, but I think that with our age group, it's harder to find—I hate to be stereotypical, but the generational is different.

In addition to groups focused on young survivors, hospital and community-based support groups for Asian American breast cancer patients were also mentioned. In some cases, community support programs helped in practical ways, such as when volunteers could accompany patients to doctor visits and could translate across language barriers that impeded communication between them and their oncologists. Overall, the emotional and social support that fellow patients and healthcare professionals or social workers provided helped normalize the experience of cancer for Asian American women as they adjusted to the myriad shifts that treatment created in their work and home lives.

Conclusion

As demonstrated by this qualitative study, caretaking has been found to be a major concern for Asian American women with cancer, especially younger women. Other studies of Asian American women with breast cancer have substantiated that caretaking of family members is a burdensome worry [13-17]. Like this study, research focusing on Chinese American women diagnosed with breast cancer found that because they could not solely rely on their families for emotional needs, culturally tailored support from other cancer survivors was vital to their emotional well-being [23]. Unlike other reviews of Asian American women's experience with cancer [15], women in our study chose to reach outside of their families for support. This could be because women in our study included many who were American-born and acculturated, and therefore more aware of resources that allowed them to reach out to others for social support. However, like other studies of Asian American women with cancer, the respondents in our study chose to take care of day-to-day responsibilities by

themselves [13, 24]. With the right balance, the women in this study found that caretaking and work created a sense of normalcy that helped them cope with their breast cancer diagnosis and treatment. Other studies of young women of color diagnosed with breast cancer have shown that women needed more emotional support at and after diagnosis, along with more informational support on fertility and cancer-related sexual dysfunction [25].

At the same time, this study shows that these young Asian American women also used their breast cancer experience to make changes in their lives. Rather than put cancer behind them and move on, the interviewees in this study overwhelmingly chose to make their cancer experience a transformative one through which they were able to change their work and personal priorities and access greater depth of emotional honesty and expression. Women in this study moved towards expressing their emotional vulnerability much more honestly than before. This choice may prove especially beneficial, considering studies that have found that expression of emotions among Chinese American breast cancer patients may contribute to long-term improvements in health outcomes [23, 26]. The respondents in our interviews found growth during and after their cancer experience by finding new ways of coping with difficulties, including expressing emotional vulnerability and reaching out to non-family members for support.

The study has several limitations. First, the sample of Asian American women was small and a non-random sample. The majority of the study population also consisted of highly educated women with college and post-graduate degrees. Therefore, these findings cannot be generalized to all young Asian American breast cancer patients. Second, this study examined the young Asian American breast cancer experience in the aggregate and not among subgroups of Asian Americans. In addition, acculturation was not assessed. It is possible that women who were more acculturated to the USA had differing levels of distress, quality of life, beliefs, etc. than recent immigrants. The women who were born in the USA were more likely to say that they had received support from others outside their family. Level of acculturation combined with cultural beliefs may influence many aspects of the cancer experience, including to whom one reaches out for support and to express fears and worries [27, 28]. Therefore, future studies should include measures of acculturation.

Despite these limitations, this study is a contribution to the literature in terms of how young Asian American women cope with breast cancer. Asian American women have tended to believe that their culture and family dynamics affect their health [20]. Therefore, cultural, familial, and relational aspects are integral to recovery and wellness [17]. As this study demonstrates, stress, coping, and their correlates are concepts that should not be studied in isolation from relational, social, and cultural contexts. Supportive interventions that help young Asian American women cope with their caretaking should be considered. In addition, many people with cancer suffer because health care professionals lack understanding of the cultural and environmental contexts in which they live. Further research into specific types of coping that are supportive can be used to educate healthcare professionals on how to relate to diverse cancer patients, including young Asian American women with breast cancer.

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Table 1

Background of young Asian American breast cancer survivors (n=22)

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Background	N (%)
Age at diagnosis (M, SD, range)	42 years of age, SD=10.5, range 31 to 50
Birthplace	
US born	4 (18.2)
Foreign born	18 (81.8)
Ethnic background	
Asian Indian American	2 (9.1)
Chinese American	6 (27.3)
Filipino American	6 (27.3)
Indonesian American	1 (4.5)
Japanese American	2 (9.1)
Korean American	2 (9.1)
Vietnamese American	2 (9.1)
Multiracial/mixed	1 (4.5)
Marital status	
Single	2 (9.1)
Married/partnered	17 (77.3)
Divorced	3 (13.6)
Highest grade completed	
Some high school	1 (4.5)
High school graduate	1 (4.5)
Some college	2 (9.1)
College graduate	14 (63.6)
Post graduate work	4 (18.2)
Have children?	16 (72.7)
Number of children (mean, SD, range)	2, SD=1.26 (range 1 to 5 children)

 Table 2

 Health status of young Asian American breast cancer survivors (n=22)

1 (4.5)
9 (40.9)
7 (31.8)
4 (18.2)
1 (4.5)
22 months, SD=1.26 (range 7 to 48 months)
6 (27.3)
15 (68.2)
1 (4.5)
14 (63.6)
18 (81.8)
11 (50.0)
11 (50.0)
11 (50.0)
1 1 1 1 1 1