


Unmet Needs of Asian American and Pacific Islander Cancer Survivors

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Abstract In the USA, cancer is the leading cause of death for Asian Americans and Pacific Islanders (AAPIs), but little is known about the unmet needs of AAPI cancer survivors, especially from a national perspective. Using a community-based participatory research approach, we partnered with the Asian and Pacific Islander National Cancer Survivors Network and the Asian American Cancer Support Network to design and conduct a cross-sectional survey to understand the unmet needs of a national sample of AAPI cancer survivors. We assessed unmet needs in 10 domains: day-to-day activities, financial expenses, emotional concerns, medical treatment, cancer information, home care, nutrition, physical concerns, family relationships, and spirituality. We also assessed self-reported measures related to quality of life. This national sample of AAPI cancer survivors included people from 14 states and two territories who had been diagnosed with a broad range of cancers, including cancer of the breast, ovary/uterus/cervix, prostate, blood, and other sites. Over 80 % reported at least one unmet need.

Participants reported an average of 8.4 unmet needs, spanning an average of 3.9 domains. Most commonly reported were unmet needs pertaining to physical concerns (66 %), day-to-day activities (52 %), and emotional concerns (52 %). This is the first report of unmet needs in a national sample of AAPI cancer survivors with a range of different cancer types. It describes the areas of greatest need and points to the importance of devoting more resources to identifying and addressing unmet needs for the underserved population of AAPI cancer survivors.

Keywords Cancer · Cancer experience · Unmet needs · Cancer survivorship · Quality of life · Asian American and Pacific Islander (AAPI)

Introduction

Cancer is the primary cause of death for Asian Americans [1] and Pacific Islanders [2]. As of 2014, the cancer incidence rate was 326.1 per 100,000 for Asian American and Pacific Islander (AAPI) males and 282.6 per 100,000 for AAPI females. The mortality rate was 132.4 per 100,000 for AAPI males and 92.1 per 100,000 for AAPI females [3]. The most prominent type of cancer is prostate cancer among Asian American men and breast cancer among Asian American women, and recent studies show that there has been an increase in the incidence rates of prostate, colorectal, liver, and stomach cancer for Asian American men and uterine, colorectal, lung, and thyroid cancer for Asian American women [2–4]. Pacific Islanders are at higher risk for stomach, liver, and uterus cancer, with Samoan women, in particular, at higher risk for breast and uterus cancer [5]. Asian Americans and Pacific Islanders face disparities in cancer survivorship

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[6], but the literature on this topic is limited, often qualitative, and focused primarily on breast cancer [7–9].

Work done on cancer survivorship in broader communities is relevant to the experience of cancer survivors in AAPI communities. In a study of unmet psychosocial needs of Pennsylvanians with cancer, Barg et al. found that nearly two-thirds of cancer survivors reported experiencing at least one unmet psychosocial need, particularly emotional, physical, and treatment-related needs [10]. A 2009 systematic review of cancer survivors' unmet needs noted that issues surrounding activities of daily living were most often reported, followed by psychological problems [11]. Furthermore, in a recent study of 1514 cancer survivors who were surveyed nationally, issues such as personal control (16.4 %), emotions and mental health (13.7 %), social support (12.7 %), societal responses to cancer (10.0 %), and communication (8.5 %) were identified as still needing to be addressed [12]. Unmet needs may vary by cancer type. For colorectal cancer survivors near the end of treatment, physical and financial problems appear most prominent; physical issues include fatigue, nausea/vomiting, appetite loss, diarrhea, and pain [13]. For prostate cancer survivors, one-on-one support from peers and support from partners are important [14]. Meanwhile, young breast cancer survivors in Japan reported high rates of unmet information needs [15]. AAPI communities often suffer from delayed cancer diagnosis due to low screening rates [16], and late diagnosis may result in greater levels of unmet need among AAPI cancer survivors.

Except for limited research on breast cancer survivors, the unmet needs of AAPI persons with cancer have not been studied. Certainly, cultural barriers exist. Studies of Korean Americans, Chinese Americans, and mixed groups of Asian Americans show that AAPI cancer survivors' primary concern is often the fear that their illness will place an emotional burden on their family [17–19]. Many AAPI cancer survivors said that receiving additional emotional support would have helped them to get through their diagnosis and treatment and that open communication among family members would have improved their quality of life [20, 21]. For Vietnamese American and Chinese American breast cancer survivors, English proficiency deters them from finding resources, communicating effectively with health care providers, and advocating for post-cancer care [22, 23]. Among religious AAPIs, prayer also helps cancer patients and survivors to cope with their situation by fostering a sense of acceptance and providing spiritual and community support [24, 25]. Approaches such as expressive writing have also been found to alleviate physical and psychological stress among Chinese-speaking breast cancer survivors [26].

Asian Americans are the fastest-growing major racial or ethnic group in the USA [27]. As the AAPI population continues to grow, so too does the number of AAPI cancer survivors. Research is needed to identify the need for support among AAPI cancer survivors and to broaden the discussion

of what the health care community should be offering to this understudied population.

Research Design and Methods

A cross-sectional survey was conducted of AAPI cancer survivors using a community-based participatory research (CBPR) approach, which emphasizes collaboration between academic and community partners, taking advantage of the strengths of all partners in a process of co-learning and mutual transfer of expertise, shared decision-making, and mutual ownership of results [28].

The research team collaborated with two AAPI community-based organizations that provide cancer support and advocacy for cancer patients and their families: the Asian and Pacific Islander National Cancer Survivors Network (a nationwide organization; hereafter, the Network) and the Asian American Cancer Support Network (a regional organization in northern California; AACSN). The Network has 164 individual members and 207 institutional members. While individual members are not required to have been diagnosed with cancer, many of the Network's members are cancer survivors. The institutional members of the Network include cancer care organizations and cancer support groups, each with access to larger communities of AAPI cancer survivors. For example, the AACSN has served more than 800 cancer survivors and their families in northern California. The research team worked closely with community partners in the development and implementation of the study.

The research protocol and data collection received approval by the Institutional Review Boards of both San Francisco State University and the University of Pennsylvania. The survey was fashioned after one previously developed for the study of a general population of cancer survivors in Pennsylvania [10]. The original survey included 92 items, characterizing several domains of need (activities of daily living, transportation, financial issues, employment issues, insurance, emotional concerns, relationships with medical staff, cancer information, home care, nutrition, treatment-specific issues, social relationships, and spiritual issues). The research team recognized that the length of this instrument had been a barrier to participation among patients in Pennsylvania and would likely be an even greater barrier for our study population, which includes individuals with low health literacy and limited experience with lengthy surveys. Therefore, we reached out to members of the National Advisory Council (NAC) from the Network and shared with them the domains of need described in the work by Barg et al. [10]. The NAC members (all of whom are AAPIs) included cancer survivors, caregivers, health professionals, and cancer advocates. The NAC members identified the most salient items for inclusion and helped the study team to craft a questionnaire that was

appropriate to the literacy level of the study population. The questionnaire was translated into Chinese and Vietnamese, based on our understanding of the linguistic needs of the AAPI population in the USA as well as the direct experience of the Network staff. The top five Asian subgroups in the census were Chinese, Filipino, Asian Indian, Vietnamese, and Korean. Since the majority of Asian Indian and Filipino Americans understand and speak English; and since our resources were limited, we only translated the questionnaire into Chinese and Vietnamese. The materials were evaluated by the Network's NAC and other community members for readability, linguistic accuracy, and ease of use prior to implementation.

The questionnaire was self-administered to AAPI cancer survivors who were over 18 years old and who could read English, Chinese, or Vietnamese. The research team defined cancer survivors as individuals who had been diagnosed with cancer. A snowball sampling design was used due to our community partners' strong connection with the target population. Study participants were recruited through the Network and AACSN and were given a \$20 gift card to complete the questionnaire. Questionnaires were distributed to all members of the Network. In addition to a paper-based version, the questionnaire was also available online in all three languages. Links to the web version were provided in postal mailings as well as via e-mail and social media.

To identify the unmet needs of AAPI cancer survivors, the questionnaire included 27 individual items in 10 domains of need: day-to-day activities, financial expenses, emotional concerns, medical treatment, cancer information, home care, nutrition, physical concerns, relationships, and spiritual issues (each domain consisted of up to 4 individual problems or areas of need). Specifically, participants were first asked the degree to which each item was problematic since their cancer diagnosis, using a 4-point Likert scale (no problem, small problem, moderate problem, and significant problem). When a problem was reported as being encountered, participants were asked how much assistance they received in dealing with it (none, some but not enough, and enough). An "unmet need" was defined as the experience of having at least a "small problem" related to that need, while not receiving "enough" assistance. In addition, a domain of need was considered "unmet" if at least one unmet need was identified within that domain. Finally, total unmet need was assessed for each participant by calculating the sum of unmet items and unmet domains, with a potential maximum of 27 items and 10 domains. Frequency analysis was used to describe the proportion of participants suffering from unmet needs within each domain.

Participants were also asked to provide demographic information, medical history, and insurance information. In addition, they completed an assessment of quality of life (QOL) that included 6 positively worded indicators (for example,

"How hopeful do you feel?") and 9 negatively worded indicators (for example, "How distressing has this illness been for your family?"), each using a 10-point Likert scale. Numerical values of negative indicators were transformed during analysis so that all indicators could be examined on a scale from 0 (worst) to 10 (best). To evaluate overall QOL, a QOL index was computed as the mean of all 15 indicators. Cronbach's alpha was calculated to assess reliability.

Descriptive statistics were computed using frequency for categorical variables, while mean and standard deviation (SD) statistics were computed for numeric variables. Numeric data were also plotted to assess for skewness. All analysis was performed using STATA for Windows version 14 (StataCorp, College Station, TX).

Results

We received 119 responses from AAPI cancer survivors. This national sample included participants living in 16 states and territories; the largest number lived in California (23.1 %), New York (19.7 %), Texas (15.4 %), Minnesota (10.3 %), Pennsylvania (7.7 %), and Georgia (6.8 %), while the remaining lived in Arizona, Louisiana, Maryland, Massachusetts, Michigan, New Jersey, Virginia, Hawaii, the Northern Mariana Islands, and American Samoa (some participants did not share their state of residence). Table 1 shows general demographics of the sample, which included 11 ethnicities and an age range of 22 to 83 years. About 82 % were female, and 71 % were living in a married or married-like relationship. Foreign-born people accounted for 73 % of participants, and more than 54 % could not speak English "very well." Nearly two-thirds had graduated from college and had an annual household income of \$40,000 or more. However, less than half of the participants were employed full-time or part-time. Almost 90 % had some type of health insurance, and nearly 67 % had private health insurance. More than half of the participants reported being in good or excellent general health at the time of the study. Among those who shared their specific cancer diagnosis, the most common type of cancer was breast cancer, either alone or in combination with another type (61 %), but participants also reported cancers of the ovary, uterus, cervix, prostate, blood, colon, lung, liver, stomach, and other unspecified sites.

Responses pertaining to the 10 domains (and 27 types) of need are summarized in Table 2. At least half of AAPI cancer survivors reported unmet needs in the domains of physical concerns (66 %), day-to-day activity (52 %), and emotional concerns (52 %). Among the specific types of unmet needs, the most commonly reported were "getting tired easily" (51 %), "difficulty dealing with illness" (44 %), "feeling down or depressed" (42 %), "pain" (41 %), trouble "preparing meals

Table 1 Sample characteristics: Asian American and Pacific Islander Cancer Survivors (*n* = 119)

Participant characteristics	% or mean ± SD*
Demographics	
Age (years) [range 22 to 83]	56.6 ± 13.3
Female	81.5 %
Foreign-born	72.5 %
Age at immigration (years) [range 9 to 65]	31.9 ± 13.1
Ethnicity	
Chinese	41.4 %
Korean	11.2 %
Vietnamese	11.2 %
Filipino	10.3 %
Japanese	10.3 %
Chamorro	6.9 %
Asian Indian	3.5 %
Hawaiian	2.5 %
Samoan	0.9 %
Tongan	0.9 %
Cambodian or Khmer	0.9 %
Living in city (vs. suburban or rural)	61.7 %
Living alone	11.5 %
Married or married-like relationship	71.2 %
Graduated college	66.1 %
Annual income ≥ \$40,000	60.7 %
Currently employed (at least part-time)	43.9 %
Language	
English-speaking ability	
Not at all	4.3 %
Not well	18.8 %
Well	30.8 %
Very well or fluently like a native	46.1 %
Speak English at home	46.6 %
Prefer to receive printed cancer information in English	65.3 %
Insurance	
Private insurance with and without Medicare or Medicaid	66.4 %
Medicare or Medicaid without private insurance	22.1 %
No insurance	11.5 %
Medical history	
Age at first diagnosis with cancer (years) [range 8 to 79]	48.4 ± 13.4
General health	
Poor	9.5 %
Fair	32.7 %
Good	50.9 %
Excellent	6.9 %
Cancer type	
Breast cancer alone or combined with others	61.1 %
Ovarian, uterus, or cervix	8.0 %
Prostate	7.1 %
Blood	4.4 %

Table 1 (continued)

Participant characteristics	% or mean ± SD*
Colon	2.7 %
Lung	2.7 %
Thyroid	2.7 %
Bone	2.7 %
Other (liver, head and neck, kidney, skin, stomach, brain, combined without breast)	8.6 %

*Missing responses were excluded when calculating frequencies and means

or doing light housework or yardwork” (42 %), and “changes in physical appearance” (41 %).

Each cancer survivor had, on average, 8.36 unmet needs out of 27 items. There was a broad standard deviation, however, and plotting of the data (not shown) demonstrated a highly skewed distribution, with the median at about 6 unmet needs. Overall, 93 participants (78.8 %) reported at least one unmet need, and one in three (32.3 %) of the 93 AAPI cancer survivors reported more than half of the 27 items as an unmet need.

Responses for QOL indicators are shown in Table 3. The responses varied dramatically for each self-rated indicator, with broad standard deviations between 2 and 3. Overall, the data demonstrated acceptable reliability (Cronbach alpha = 0.87). The mean of QOL index was at about 6, suggesting that the overall QOL is about in the middle, neither outstanding nor incredibly poor.

Discussion

Approximately 8 out of 10 AAPI cancer survivors in this study reported experiencing at least 1 unmet need, slightly higher than the 75 % observed in the general population by Barg et al. [10]. While Barg et al.’s findings point to emotional concerns as the top unmet need of cancer survivors in the general population, our data reveal that, for AAPI cancer survivors, physical concerns (66.4 %) are the primary area of unmet need, while emotional concerns are a tertiary need (52.3 %), just behind needs associated with day-to-day activities. This is similar to the findings of Burg et al. [12] for the general population. Perhaps the disparity is tied to the tendency of AAPI cancer survivors to keep their emotions to themselves in order to protect their family members from emotional distress [17–19], although past studies suggest that they have a high level of need for emotional support [20, 21]. Further studies are needed exploring emotional expression among cancer survivors within the AAPI cultural lens.

Table 2 Unmet needs of Asian American and Pacific Islander Cancer Survivors ($n = 119$)

Domain of unmet needs	Frequency (%) [*]
Day-to-day activities (≥ 1 unmet need in this domain)	51.9 %
Preparing meals or doing light housework or yard work	41.8 %
Getting transportation for medical treatments	22.9 %
Getting transportation for work or household activities	22.0 %
Other problem with everyday activities or transportation	32.4 %
Financial expenses (≥ 1 unmet need in this domain)	43.3 %
Paying for prescription medications	24.4 %
Paying for other medical treatments	34.8 %
Meeting basic living expenses	36.6 %
Other financial problems	34.6 %
Emotional concerns (≥ 1 unmet need in this domain)	51.8 %
Feeling down or depressed	42.1 %
Difficulties with family or spouse	32.5 %
Difficulty dealing with illness	43.6 %
Medical treatment (≥ 1 unmet need in this domain)	36.6 %
Feeling you did not have enough say in decisions about your medical treatment	25.0 %
Wondering if the medical staff was being honest	24.1 %
Feeling as though medical staff was uncaring or insensitive	27.9 %
Cancer information (≥ 1 unmet need in this domain)	32.1 %
Getting information about treatments or medications	25.9 %
Knowing which information is most reliable and up-to-date	31.3 %
Home care (≥ 1 unmet need in this domain)	29.5 %
Learning how to care for your medical needs at home	20.2 %
Knowing how to access groups or agencies that could help you at home	25.7 %
Nutrition (≥ 1 unmet need in this domain)	42.3 %
Changes in weight	35.4 %
Knowing what foods to eat	34.2 %
Physical concerns (≥ 1 unmet need in this domain)	66.0 %
Getting tired easily	51.4 %
Changes in physical appearance	40.5 %
Nausea or vomiting	31.6 %
Pain	41.4 %
Family relationships (≥ 1 unmet need in this domain)	43.0 %
Increased tension or arguments at home	38.6 %
Increased emotional problems at home	38.6 %
Spirituality (≥ 1 unmet need in this domain)	
Feeling a need for spiritual help	22.4 %
Total unmet needs of AAPI cancer survivors	Mean (SD)
Unmet needs (needs with at least “small problem” and not “enough support”) [potential range 0–27]	8.36 (8.29)
Unmet domains (domains with ≥ 1 unmet need) [potential range 0–10]	3.91 (3.32)

*Missing responses were excluded from analysis

More than one in four participants in our study said that they do not have enough authority in making medical decisions regarding their health. Several factors can shed light on this issue. For example, language may be a barrier between AAPI cancer survivors and their physicians especially for patients whose first language is not

English [22, 23]. Cultural sensitivity among health care providers is imperative to provide not only an accurate translation but also a respectful approach that takes into account the patient’s cultural beliefs, which may include the perception that Western medical practices are too invasive.

Table 3 Self-reported quality of life (QOL) of Asian American and Pacific Islander cancer survivors (*n* = 119)

QOL indicators	Mean (SD)*
Positive QOL indicators (range: 0–10, not at all to a great deal)	
Rate your overall physical health	6.50 (1.96)
How good is your quality of life?	7.30 (2.09)
How hopeful do you feel?	7.79 (2.16)
To what extent has your illness made positive changes in your life?	6.94 (2.70)
Do you feel like you are in control of things in your life?	7.09 (2.44)
Is the amount of support you receive from others sufficient to meet your needs?	7.03 (2.69)
Negative QOL indicators (range: 0–10, great deal to not at all)	
To what extent is fatigue a problem for you?	5.43 (2.72)
To what extent are you fearful of future diagnostic tests?	4.81 (2.96)
To what extent are you fearful of spreading (metastasis) of your cancer?	4.74 (3.07)
To what degree has your illness and treatment interfered with your employment?	5.63 (3.36)
To what degree has your illness and treatment interfered with your activities at home?	5.47 (3.03)
How much financial burden have you incurred as a result of your illness and treatment?	5.48 (3.32)
How much uncertainty do you feel about your future?	4.96 (2.96)
How difficult is it for you to cope today as a result of your disease and treatment?	6.66 (2.36)
How distressing has the illness been for your family?	4.21 (2.91)
QOL index ^a (range: 0–10 from worst to best)	6.00 (1.63)

^aQOL index is the composite score averaging all 15 indicators for each individual respondent (Cronbach’s alpha = 0.87)

*Missing responses were excluded from analysis

Notably, less than a quarter of our sample reported unmet needs surrounding payment for prescription medications (24 %), but a slightly higher percentage indicated that they have difficulty meeting basic living expenses (36 %). Considering that 43 % of our sample said that they have some type of financial difficulty, it is important to remember that having health insurance and medication coverage alone is not enough to address the financial needs of AAPI cancer survivors, especially if physical health prevents them from participating fully in the workforce.

The domain of spirituality is also notably lower in our findings, with only 22 % saying that they need additional spiritual help. Past literature revealed that AAPI cancer survivors find solace and acceptance through religion [24, 25]; however, this belief may be tied to specific religions and may not reflect the wide variety of religions that AAPI cancer survivors may or may not be practicing.

With regard to quality of life, participants in our study said that they feel very hopeful (with a score of 7.79 out of 10). The feat of surviving cancer may be contributing to their resilience and outlook. However, the reality of dealing with fear, uncertainty, and family distress means that ongoing support is needed, even after remission is achieved. Among negative QOL indicators, the area that scored best was coping with the disease and treatment, suggesting that this is an area that does is less often a problem (higher scores suggest a better QOL); meanwhile, the area that scored worst was “How distressing

has the illness been for your family? This score accentuates the importance of the family unit to AAPI cancer survivors and the need to ensure that distress is ameliorated not only for patients, but also for their family members.

This study is limited by its relatively small sample size. Even though we worked with community partners that have access to these communities, recruiting participants for this study was challenging, which underscores the difficulty of conducting this type of research. First, a significant number of the respondents were female, foreign-born, and breast cancer survivors rather than a representative cross-section of the population of cancer survivors. They also had a high level of English-speaking ability and private health insurance availability. Most participants were recruited through community-based organizations, which might potentially miss geographically isolated AAPI cancer survivors who are not connected with any community-based organization or who do not want to disclose their cancer diagnosis with others in their ethnic community. The study was based on a non-randomized sample, which limits the generalizability of the findings. It also did not ask questions about the time since diagnosis and treatment, about their needs throughout the cancer experience, or about the stage of cancer. Since these questions were not asked, this study is limited in understanding needs throughout the cancer trajectory. Future studies on changing needs following cancer diagnosis, during treatment, after treatment, and in survivorship are imperative.

Despite these limitations, this study contributes to several missing gaps in the literature on cancer survivorship. It is the first national comprehensive survey that not only addresses unmet needs of AAPI cancer survivors but also includes multiple types of cancer and multiple preferred languages. Some of the study's findings reinforce those of past research, where cancer survivors reported lack of control during medical decision-making, difficulty dealing with their cancer diagnosis, physical reactions such as nausea, and psychosocial stressors at home. This suggests that AAPI cancer survivors have both different and similar unmet needs in relation to the general population. It also suggests that culturally specific and linguistically appropriate interventions are essential to addressing the unmet needs of AAPI cancer survivors effectively. In addition, this research reveals unmet needs pertaining to emotional concerns and family relationships. The stigma of burdening other family members is a genuine barrier that deters many cancer survivors from seeking help from loved ones and from physicians regarding psychosocial concerns and physical symptoms that they may face at diagnosis, during treatment, and post treatment. This study has implications for health care providers who work with AAPI cancer patients to identify support and resources for unmet needs. Ultimately, unmet needs have a negative impact on the quality of life of AAPI cancer patients.

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