UC Irvine
UC Irvine Previously Published Works

Title
Needs and experiences of Samoan breast cancer survivors in Southern California.

Permalink
https://escholarship.org/uc/item/86p826s0

Journal
Hawaii Medical Journal, 70(11 Suppl 2)

ISSN
0017-8594

Authors
Tanjasiri, Sora Park
Mata'alii, Sala
Hanneman, Marion
et al.

Publication Date
2011-11-01

Copyright Information
This work is made available under the terms of a Creative Commons Attribution License, available at https://creativecommons.org/licenses/by/4.0/

Peer reviewed

eScholarship.org Powered by the California Digital Library
University of California

Needs and Experiences of Samoan Breast Cancer Survivors in Southern California

Sora Park Tanjasiri DrPH, MPH; Sala Mata'alii, RN, MSN, MBA/HCM; Marion Hanneman; and Melanie D. Sabado MPH, BA, BS

Abstract

Objective: *Breast cancer rates are increasing among Samoan and other Pacific Islander women, yet studies of their social support needs are nearly non-existent. The purpose of this paper is to report on the cultural dimensions of social support among Samoan breast cancer survivors in Southern California.*

Methods: *Data for this paper came from a larger one-and-a-half year study of the social support needs of Samoan breast cancer survivors and their family and friends. In-depth, retrospective, qualitative interviews were conducted with a purposeful sample of 20 Samoan survivors who were recruited from an existing social support program as well as the general community.*

Results: *We documented important informational needs and behaviors, social support needs and experiences, and spirituality issues for the Samoan breast cancer survivors.*

Conclusions: *Our findings underscore the need for culturally-specific social support services for Samoans, as well as the necessity of community-based participatory research to define and explore social support and other survivorship needs in this understudied population. Recommendations from the community report-back, stressed the importance of expanding community Samoan cancer social support groups through collaborations with Samoan leaders and churches.*

Introduction

There are an estimated 9.8 million cancer survivors in the United States, approximately 2.2 million (22%) of whom are breast cancer survivors.[1] The psychosocial needs of breast cancer patients and survivors are well-documented in the literature.[2,3] Unfortunately, little research exists on the needs of ethnically diverse women with breast cancer, many of whom have unique fears relating to family and caregiving, coping, and spirituality.[4,5] One significantly unstudied population in cancer survivorship is Samoan Americans. Of the nearly half a million Pacific Islanders (PIs) in the United States, Samoans comprise the second largest population after Native Hawaiians. In 2004 there were 60,520 Samoans living in the United States, over 80% of whom resided in California.[6,7] Breast cancer is the leading site for cancer among Samoan women in California, comprising approximately 27% of cancer cases.[8] Both national and local data suggest that PI breast cancer rates are increasing, and that the cancers are found at later stages of diagnosis compared to white women.[9,10] Studies of the psychosocial needs of Samoan breast cancer survivors, however, are nonexistent. The purpose of this paper is to describe the findings from an exploratory study of the social support needs and experiences of Samoan breast cancer survivors in Southern California.

Methods

Partnership

Data for this paper come from a larger 1.5 year, cross-sectional retrospective study of breast cancer experiences among Samoan survivors, and their family and friends, in Southern California.[11] We engaged in a community-based participatory research effort between two entities: the Samoan National Nurses Association (SNNA) and the California State University, Fullerton (CSUF). SNNA is a nonprofit organization founded in 1996 by a group of Samoan nurse professionals to promote health education and services, including monthly cancer social support groups, for the Samoan community. CSUF is a teaching university, and members of both SNNA and CSUF had successfully collaborated on two past CBPR efforts, with the principles and activities described in previous publications.[12,13] In addition, a Community Advisory Board (CAB) comprised of eleven leaders (including ministers, social workers, health professionals, and breast cancer survivors) was convened by SNNA and met quarterly with community and academic researchers to inform, review, and approve all aspects of the study implementation and evaluation.

Participants

Eligibility for study participation included adults 18 years or older, of Samoan descent, and having been diagnosed with breast cancer and completed treatment for that cancer. We recruited 20 Samoan breast cancer survivors using stratified purposeful sampling to include those who participated in SNNA's monthly social support group program (n=10), and those who did not. The latter women were found through announcements of the study at outreach activities, through personal contacts (such as family, friends, and church members), and through community referrals. SNNA staff approached each woman individually to introduce the purpose of the study, and ask for their participation in one face-to-face interview; women who agreed were scheduled for an interview at a location convenient to the interviewee (usually the woman's home).

Interview Questions

The interview guide was developed based upon existing literature and social support theory,[14] as well as from consultation with experts in multiethnic breast cancer survivorship.[2] Two focus groups (one with SNNA staff and the other with Samoan community leaders) were conducted with 13 individuals to explore their views about what topics (particularly cultural) should be included in the survivor interviews. Lastly, the CAB revised and approved the final interview guide, which included questions about needs during diagnosis, treatment, and post-treatment, as well as impacts on feelings of sexuality and body image, relationships with significant others, and spirituality/relationships with God and church. The guides were translated into Samoan by a bilingual nurse at SNNA, reviewed by one CAB member, and discrepancies were discussed and resolved by the two. Instruments and procedures were approved by an IRB at CSUF, and written informed consent (in English and Samoan) was obtained from each survivor prior to the start of the interview.

Procedures

Four bilingual SNNA staff, each of whom was born in Samoa and

had over 20 years of clinical and community experience in the continental US, were recruited and trained by study research staff on qualitative interview methods. These training sessions were held over two days for a total of 8 hours, and covered how to put participants at ease, why and how to ask open-ended questions and probes, how to address issues such as reticence or distress, and how to obtain informed consent. Each interview was conducted in the language of preference of the survivor, tape recorded, and lasted approximately 2 hours. At the conclusion the survivor received a small monetary honorarium as a token of appreciation.

Data Management and Analyses

All interview recordings were transcribed and translated verbatim by the study team. A set of transcripts were read by the entire study staff, with major coding schemes developed during a total of five meetings with study staff and consultants. All transcripts were then analyzed by one researcher using Atlas.ti to identify and code emergent themes, with weekly meetings between the university researchers to refine codes and ensure appropriate application to the transcripts. Once preliminary analyses were complete, summaries were created and shared with study staff and CAB members for comments and reflections. A final report-back session was held with study participants and approximately 30 other community members at a local restaurant in order to obtain further feedback regarding study findings, generate overlooked areas for analysis, and discuss implications for future services.

Results

Of the 24 survivors who were invited to participate in this study, 20 agreed to participate for a response rate of 83.3%. As shown in Table 1, survivors were generally born in Samoa, married, and had a high school diploma or less. Some survivors told study staff that they felt a responsibility to participate because they belonged to a rare group of Samoan survivors and had an important story to tell. Several also shared with us that their life experiences did not adequately prepare them to deal with their breast cancers, and that through discussing their emotional experiences they would hopefully help themselves and others in the future.

Table 1. Demographic Characteristics of Samoan Survivors (N=20)

	n (%)
Age	
30-49 years	4 (20.0)
50+ years	16 (80.0)
Born in Samoa or American Samoa	18 (90.0)
Marital Status	
Married	12 (60.0)
Widowed/Divorced	8 (40.0)
Single	0
Highest Level of Education Attained	
High school or less	11 (55.0)
Some college or more	9 (45.0)
Health Insurance	
None	2 (10.0)
Private/Medicare	16 (80.0)
Medicaid	2 (10.0)
Number of Children	
None	5 (25.0)
1-2	6 (30.0)
3+	9 (45.0)
Years Since Diagnosis	
< 5 years	8 (40.0)
6-10 years	6 (30.0)
11+ years	6 (30.0)
Stage of Breast Cancer	
Early (Stage I or II)	14 (70.0)
Middle (Stage III)	4 (20.0)
Late (Stage IV)	2 (10.0)
Social Support	
Member of SNNA's cancer support group	10 (50.0)
Not a member of SNNA's cancer support group	10 (50.0)

Informational Needs and Practices During Diagnosis and Treatment

Many survivors discussed problems stemming from their perceived lack of education and familiarity with cancer. One survivor whose highest level of education was a high school diploma told her interviewer, "I didn't go to school that taught anything about a woman's body. So I think [breast cancer] happened because I didn't take care of myself." Survivors also talked about how little cancer is discussed in Samoa, and how they perceived it to be automatically fatal. One survivor shared, "I kept asking, what is cancer? Can anybody explain to me exactly what cancer is all about? I know for a fact that during that time back home, they never heard of cancer. But right here in America, there's a lot of people that go through and die from cancer."

For women diagnosed in Samoa, their lack of knowledge may be exacerbated by the lack of infrastructure to be screened and treated in a timely manner. A survivor shared her experience after being screened in Samoa: "[The doctor]did a biopsy and sent the specimen to Hawai'i, and it was almost three months after the biopsy was done and I still hadn't received a word from the doctor. And the next thing I know, the janitor from [the hospital] told me that I have breast cancer." A few other survivors shared frustrations with getting information from their doctors. In one case, a survivor described that after having a negative experience with her doctor during diagnosis in the United States, she ran into a friend who also served as a nurse at the hospital. Luckily, the friend not only recommended a different doctor but was able to make an appointment for the woman to see him. These kinds of informal connections were commonly used among Samoan survivors to access information that influenced their diagnosis and treatment decisions.

Support groups play an important role, with many survivors crediting SNNA's monthly cancer support group program for providing information during and after their treatment. For all of the women (n=10) who participated in SNNA's support groups, being with people who were the same ethnicity is part of the benefit, as in the words of one younger, married survivor who said, "With my own I can kind of adjust and kind of weigh out some of the things

someone may say, versus being somewhere openly put on the spot. I think I am more comfortable here." Additional benefits were the ability to talk about their treatment processes, and maintaining the motivation to follow-up with treatment regimens. For women who were not participants in the SNNA program (n=10), some still found support groups that helped them better understand their disease and treatment options. A younger divorced survivor described looking for information with her sister for more information by stating: "I found [the support group] through my medical team at Torrance Memorial. They referred me to a couple of cancer support groups and I studied, I read, I attended a lot of meetings and that's how I found out a lot more and more about cancer and [now] understand it." However, it appeared that fewer of these women relied on family members or friends for support, suggesting that they either did not need support or were unable to find needed support for their concerns. Younger survivors appeared to be more comfortable than older ones in using support groups, regardless of language spoken.

Traditional Samoan treatments were not widely used among the survivors. "My grandma … knew the best *fofo* (massage)," stated one relatively younger survivor. "But she…just told me to keep going to the doctor. She more or less told me that *fofo* is for something else and that 'this kind of sickness is for you to go to the doctor. That's what the doctor is for.'" According to another older survivor, Samoan treatments could also be harmful, stating, "I'm afraid the more they massage [the breast] when they manipulate the tissues so much, it kind of spreads [the cancer] around." In only one case did the survivor use Samoan treatment, after receiving radiation for her early stage cancer.

Social Support Needs

Over three-quarters of the survivors talked about how losing their breast was not the major concern of theirs. According to a younger, married survivor diagnosed with stage IV breast cancer, "I told [the doctor] you took my breast away. I don't really need it now, I can go without it. It doesn't make me less of a woman than I am now, so fine." Similarly, an older widow of four explained that she was less concerned about the cancer and more concerned about the loss of her hair. "You know, so I thought that's the only way I can get on, get rid of this cancer. Then I was thinking, oh my God, when I have a surgery I'm going to have chemo. What will happen if my hair all falls out?" Only one younger Samoan survivor described the change of her breast appearance as important. According to her, "[The doctor said] oh you're beautiful. But when I see myself in the mirror and I think about the things that I went through, I can't see what is so beautiful. For me being alive is beautiful, but just the physical part is what I have to get over."

Breast cancer influenced the ways that survivors were able to fulfill their roles as mothers and spouses. According to one widowed survivor, being a mother and attending her only child's graduation was more important than getting immediate treatment for her stage III breast cancer. She shared, "I asked if we can postpone [the surgery] until after…my oldest son's graduation. My brother said, 'your surgery will be done and you will make it for your son's graduation. The longer it will not be done the bigger it gets. We will schedule your surgery before the graduation and I promise you will go.' So I said okay." The survivors, however, discussed the need for assistance with routine chores such as doing the laundry, washing dishes and cooking meals became challenging for many because of the fatigue from chemotherapy. Many women shared that they were not prepared to adjust their life from being the major source of caretaking for the family, to being the one who needed support and care from spouses and children. Most appreciated it when others offered to help, although the survivors also recounted the burden they felt by imposing on others. Dealing with her stage IV cancer diagnosis soon after her husband's death, this mother of nine said, "I went through all [with] the support of my children and I didn't want to be a handicap to them, or like even going to my appointments, the doctor said I'm not to drive…but I managed to drive with my left hand. So this is how stubborn we are sometimes."

Financial concerns were also important. Sixty percent of the survivors were working full-time when they were diagnosed with their breast cancers, and many shared the pressure they felt to go back to work in order to support their husbands, children, and /or larger community responsibilities. Women talked about how money was a stressor, often because they were an important source of financial support for their families. In the words of one middle-aged mother of two who felt comfortable sharing her financial problems: "[During treatment] I guess, I was going through a lot…and I was really kind of forced … back to work, cause at the time my family needed support from me work wise because now my husband was gone and financially that put us in a bind."

Other important areas of assistance included language, transportation, and child care. For instance, several Samoan-speaking survivors relied on family to interpret with doctors. As briefly stated by one Samoa-born survivor of stage III breast cancer, "I did not fully understand what [the doctor] was telling me, but my daughter was the one I spoke to and she explained what the doctor was telling me." Similarly, survivors described spouses and older children as taking care of younger ones, with distance (eg, in the case of the survivor who was diagnosed in Samoa but received treatment in Hawai'i) posing an added challenge.

As we expected, survivors experienced many different kinds of emotions throughout their diagnosis and treatment processes, including depression associated with the fear of dying (during diagnosis) and fear of recurrence (after treatment was completed). In addition, some women described the strain breast cancer treatment put on their relationships with their family members. In the case of a young married woman who lived with her parents and other siblings: "I had this one cousin who…was there to advise my parents on things that they can help me. Because, you know, we as Samoans, [parents] sometimes kind of talk down to you, and say 'maybe you shouldn't have done that,' or 'if you would have listened.' But they didn't do that, because they were advised by my cousin who was close to me at the time. She talked to them, and so we had a [positive] time because my parents were understanding, and they knew what I was going through."

Another problem a few survivors discussed was the influence of breast cancer on their relationships with their spouses. The younger survivor, who thought her spouse felt guilty when they had sex, stated, "For a while he thought he did something that caused me to get cancer. I said 'no, I don't think so,' but it changed a lot. Our intimacy with each other wasn't the same… it felt different. He was afraid he might hurt me or something."

Social Support Experience

With regards to who helped the survivors cope with their many stressors, the Samoan survivors we interviewed talked at length about the emotional support they received from their family members. Most often, survivors told only their spouses or children about their diagnoses and treatments, and these family members helped the survivors cope. "I feel my family should know about it. I need them to pray for me." Not all family and community members, however, were able to provide the support that the survivors wanted. In the case of many who lived in Samoa, breast cancer treatment meant traveling and living abroad for extended periods of time apart from their families. She said, "I was lonely because my husband was in Samoan and only my kids were here. Every time he called from Samoa I get home sick; it was really hard to stay here and go through all this without my spouse…. Of course my kids were here but it wasn't the same." In another survivor's case, the spouse was with her but was not as supportive. She shared, "Because I was trying to get comfortable with the whole idea of the way that I look underneath…. I just kind of felt uncomfortable. And then, for me when I look at him, he felt uncomfortable. We never talked about it…. I wish there was somebody that can talk to us."

A few survivors, however, believed that strong Samoan women should be self-reliant and take care of themselves, including cancer. In one Samoan-born survivor's words, "I didn't feel like I needed somebody, even my kids…. I'll be strong enough to do my own things, you know, in order for me to have somebody help me out or anything like that." Part of the reason was because women did not want to burden others with their own problems. According to the survivor who had previously described her role as the family breadwinner, "I don't want no one to think, 'Oh I need to go and help her do this, do that.' I don't want that. I don't want no one. I don't want to burden." Some believed that their cancer was a private matter that others should not know. According to one survivor, this meant not telling her family: "It was my decision to remove my breast and I didn't even think about telling my daughter or kids." None of the women who described the desire to be self-reliant shared any depressive thoughts or feelings during their diagnosis or treatment experiences, suggesting that the cultural value of self sufficiency may be viewed as a cultural asset rather than a negative coping mechanism for women.

Spirituality

All of the survivors referred to spiritual strength throughout their cancer experiences. For some, the spirituality helped them to find meaning and reason for what was happening to them. "I was strong and fearless because I wanted to live for my kids and use my life for Christ." For others, spirituality helped them cope with the challenges they faced. For instance, a young woman expressed how she dealt with her diagnosis of stage III breast cancer: "My courage came from God. That's basically what helped me through a lot of different obstacles I was going through, is the courage to let go and you know there were just things you can't fix." Spiritual strength came not only from the survivor's prayers, but also from feeling the support from their family and friends. According to an older, widowed survivor, "The most helpful thing to me…was my children's prayer and support for me. You know, because all these things, my surgery and everything, there's no one [else in] my family [who] knows about it." A previous publication describes these results in more depth.[11]

Conclusion

This was the first study to explore and document the social support needs and experiences of Samoan breast cancer survivors. First, we found a lack of knowledge regarding cancer in the Samoan community, particularly among women who were more recent immigrants from Samoa, which has been previously described among the general Samoan population in the past.[15] Clearly, however, the need for information becomes paramount for women faced with making crucial treatment decisions without understanding the basics of breast cancer disease and progression, and we found evidence that programs such as SNNA serve as trusted sources of needed information and assistance. Second, we found that many survivors prioritized their family roles and obligations many times over the timely receipt of treatment for themselves. In some cases, it was not until trusted sources (such as family and SNNA) underscored the importance of treatment in order for survivors to continue fulfilling their roles did they agree to be treated. While some women described the comfort they received from supportive spouses and/or children, some also described their desire to remain self-sufficient (often in order to remain the family care-taker rather than the care-receiver). Also, sexual issues of intimacy were discussed by several women, with younger age a possible indication of higher body and sexual intimacy needs. Lastly, spirituality was a source of support for all of our study participants, underscoring the important potential role the church plays for not only Samoans but many other ethnic populations.[16] All of these themes point to the need for culturally appropriate and timely support from trusted family and community sources to minimize distress for future Samoan breast cancer patients.

In a community where breast cancer is a highly stigmatized disease, the fact that Samoan survivors shared the breadth and depth of their experiences regarding sensitive subjects was a testament to the CBPR process and the trust they felt toward the SNNA interviewers. Despite this significant study asset, however, we faced many challenges in planning and implementing the study design. Designing the questionnaire proved to be challenging due to the highly sensitive nature of discussing sexual relationships, and the CAB provided invaluable guidance on how to ask this of women in culturally appropriate ways. Another challenge was recruitment of a purposive sample of Samoan survivors, particularly the 10 women who did not participate in SNNA's cancer support group, and the interviewers had to draw upon their considerable knowledge of the community in order to assure survivors of their privacy and confidentiality. Scheduling also proved a challenge, and the interviewers estimate0 that it took an average of four hours per survivor to contact, schedule, and conduct each interview in a private atmosphere. Lastly, we realize that our sample was biased toward survivors who could be called "thrivers," since so many of them were long-term survivors who had successfully completed their treatments.

Despite these challenges and limitations, however, we feel very fortunate to have learned so much about the cultural dimensions of social support needs for Samoan survivors. For instance, at the community report-back session, both study participants and general community members expressed their overwhelming support for not only continuing SNNA's cancer support groups, but expanding them

by working closely with Samoan churches and other community organizations. This may be particularly important for survivors who do not naturally become members of SNNA's support group because of their own interests. In these cases, the churches can help promote the importance of support groups. For instance, the minister of a Samoan church recommended that church leaders make announcements to their congregations about the service and the need to support Samoan cancer survivors. Based upon this and other recommendations, study staff have proposed the creation of a community navigation program in collaboration with such organizations. We hope this study spurs more research on, and services for, survivorship among Samoans and other ethnic-specific populations.

The authors report no conflicts of interest.

Acknowledgements

Our deepest gratitude to all the Samoan breast cancer survivors and their supporters who participated in this study. In addition, we would like to thank the many people who contributed their time and efforts to the implementation of this study. Additional research support and consultation was provided by Michelle Wong, Annalyn Valdez, Dr. Kimlin Ashing-Giwa, and Dr. Marjorie Kagawa-Singer. This study was supported by the California Breast Cancer Research Program (grant numbers 12AB-4100 & 12AB-4101), and the National Cancer Institute's Center to Reduce Cancer Health Disparities (grant number U01CA114591). The contents of this paper are solely the responsibility of the authors and do not necessarily represent the official views of the funders.

Authors' Affiliation:
- Department of Health Science, California State University, Fullerton, CA (S.P.T.)
- Office of Samoan Affairs, Carson, CA (S.M.)
- Samoan National Nurses Association, Carson, CA (M.H.)
- Claremont Graduate University, Claremont, CA (M.D.S.)

Correspondence to:
Sora Park Tanjasiri DrPH, MPH; CSUF Department of Health Science,
800 N. State College Blvd., Fullerton, CA 92834-3599; Ph: (657) 267-4592;
Email: stanjasiri@fullerton.edu

References

1. Cancer survivorship--United States, 1971-2001. *MMWR Morb Mortal Wkly Rep.* Jun 25 2004;53(24):526-529.
2. Schmid-Buchi S, Halfens RJ, Dassen T, van den Borne B. A review of psychosocial needs of breast-cancer patients and their relatives. *J Clin Nurs.* Nov 2008;17(21):2895-2909.
3. Vivar CG, McQueen A. Informational and emotional needs of long-term survivors of breast cancer. *J Adv Nurs.* Sep 2005;51(5):520-528.
4. Ashing-Giwa KT, Padilla G, Tejero J, et al. Understanding the breast cancer experience of women: a qualitative study of African American, Asian American, Latina and Caucasian cancer survivors. *Psychooncology.* Jun 2004;13(6):408-428.
5. Wellisch D, Kagawa-Singer M, Reid SL, Lin YJ, Nishikawa-Lee S, Wellisch M. An exploratory study of social support: a cross-cultural comparison of Chinese-, Japanese-, and Anglo-American breast cancer patients. *Psychooncology.* May-Jun 1999;8(3):207-219.
6. US Census Bureau. The American Community: Pacific Islanders 2004. Washington, DC: US Department of Commerce; 2004.
7. APALC. *The Diverse Face of Asians and Pacific Islanders in California.* Los Angeles: Asian Pacific American Legal Center;2005.
8. Mishra SI, Luce-Aoelua P, Wilkens LR, Bernstein L. Cancer among American-Samoans: site-specific incidence in California and Hawaii. *Int J Epidemiol.* Aug 1996;25(4):713-721.
9. Edwards BK, Brown ML, Wingo PA, et al. Annual report to the nation on the status of cancer, 1975-2002, featuring population-based trends in cancer treatment. *Journal of the National Cancer Institute.* October 5 2005;97(19):1407-1427.
10. Marshall SF, Ziogas, A., Anton-Culver, H. *OC Komen Affiliate & UCI Data Project: Breast Cancer Incidence & Prevalence in Orange County, Monograph I.* Irvine,California: University of California, Irvine; 01/31/08 2008. Monograph 1.
11. Sabado M, Tanjasiri SP, Mata`ali`i S, Hanneman M. Role of spirituality in coping with breast cancer: a qualitative study of Samoan breast cancer survivors and their supporters. *Californian Journal of Health Promotion.* 2010;8:11-22.
12. Tanjasiri SP, Kagawa Singer ML, Nguyen T-UN, Foo MA. Collaborative research as an essential component for addressing cancer disparities among Southeast Asian and Pacific Islander women. *Health Promotion Practice.* April 2002 2002;3(2):144-154.
13. Tanjasiri S, Tran J, Palmer P, et al. Developing a Community-Based Collaboration to Reduce Cancer Health Disparities among Pacific Islanders in California. *Pacific Health Dialog.* 2008;13(2):101-107.
14. House JS. *Work Stress and Social Support* Reading: Addison-Wesley Pub Co.; 1981.
15. Mishra SI, Aoelua PL, Hubbell FA. Knowledge of and attitudes about cancer among American Samoans. *Cancer Detect Prev.* 2000;24(2):186-195.
16. Levine EG, Aviv C, Yoo G, Ewing C, Au A. The benefits of prayer on mood and well-being of breast cancer survivors. *Support Care Cancer.* Mar 2009;17(3):295-306.