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Thanks for the “Mammaries”:

Breast Cancer Survivorship Among Pilipino American Women

A thesis submitted in partial satisfaction

of the requirements for the degree Master of Arts

in Asian American Studies

by

Lindsay Rene Gervacio

2012

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ABSTRACT OF THE THESIS

Thanks for the “Mammaries”:

Breast Cancer Survivorship Among Pilipino American Women

by

Lindsay Rene Gervacio

Master of Arts in Asian American Studies

University of California, Los Angeles, 2012

Professor Marjorie Kagawa-Singer, Chair

Pilipino Americans comprise the second largest Asian American subgroup in the United States and experience the highest rates of breast cancer compared to any other Asian American subgroup for which data is available. However, literature specific to the social support experience of Pilipino American breast cancer survivors is minimal. Utilizing a qualitative research approach, this thesis investigated three areas of the social support experience among Pilipino American breast cancer survivors: (1) How social support is perceived and received; (2) Role of support groups; and (3) Role of religion. One semi-structured focus group interview was conducted with eight participants from the greater Los Angeles area. Emergent themes included sources of support, survivorship, relationships and ways of coping. Participants' discussion surrounding these topics was contextualized by cultural values specific to the Pilipino American population. Thesis findings can inform future projects that build the social support literature on breast cancer survivorship.

The thesis of Lindsay Rene Gervacio is approved.

Gilbert Gee

Valerie Matsumoto

Marjorie Kagawa-Singer, Committee Chair

University of California, Los Angeles

2012

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INTRODUCTION

Breast cancer ranks as the most common cancer among females across all ethnic groups in Los Angeles County,¹ and breast cancer survivors number about 2.6 million of the nearly 12 million cancer survivors in the United States.^{2,3} Multiple definitions of survivorship exist, but for this thesis, cancer survivorship is identified as a multidimensional construct, in which an individual is recognized as a cancer survivor from the point of diagnosis and throughout the remainder of her life.^{4,5,6,7}

The growing number of cancer survivors speaks to the critical and immediate need for further scholarship on this stage of the cancer care continuum. The past few decades have witnessed a growth in literature on cancer survivorship and the contribution of social support to the quality of life of the patient. In fact, many studies establish a link between social support and the survival of cancer patients. Specifically, research reveals that social support positively contributes to chances of survival for breast cancer patients.^{8,9} Depending on the nature of social support practices (e.g., quality of social network, social interactions), social support appears to increase survival length.¹⁰ However, the majority of empirical studies highlight the experience of Non-Hispanic White breast cancer survivors.¹¹

To provide context, a total of 4,079 scholarly articles focusing on cancer and social support were found on PubMed, a primary search engine for biomedical literature.¹² In comparison, PubMed yielded only 82 citations specific to Asian Americans. This vast discrepancy in the volume of social support literature between mainstream and Asian American ethnic groups confirms non-representative investigation of the impact of social support. (Refer to Table 1 on page 9 for further details.)

The current state of cancer survivorship studies poignantly speaks to the limitations of these studies that fail to adequately account for the social support experience of ethnoculturally diverse groups. How to make relevant the survivorship needs of diverse groups

of women within this process of knowledge production becomes the critical point of concern. This argument becomes even more compelling given that breast cancer represents the second leading cause of death from cancer for women of all racial and ethnic populations.^{13,14} However, given that breast cancer signifies the number one cause of death for Asian Americans in particular, the need for disaggregated data collection and the study of the needs of these women becomes critical in distinguishing the unique stories for the heterogeneous ethnic subgroups located under the overarching “Asian American” identifier.¹⁵ For example, of the 82 studies on Asian Americans and cancer, only two were specific to Pilipino Americans. Findings on communities of color in aggregate according to the current six racial and ethnic categories further hamper efforts to effectively address the unique and specific needs of each racial and ethnic group, Asian Americans included.

Much of the burden of cancer for Asian Americans can be characterized as unique, unusual and unnecessary. For example, breast cancer diagnosis occurs in some groups at a more advanced stage compared to Non-Hispanic White women.¹⁶ Pilipino Americans have the highest rates of breast cancer than any other Asian American group for which we have data. Thus, attention to the impact of breast cancer on Pilipino American women must be emphasized, especially given the paucity of data on this area of focus.

According to the 2010 United States Census, Pilipino Americans comprise the second largest Asian American subgroup in the United States, numbering more than 3.4 million individuals.¹⁷ The highest proportion of Pilipino Americans is concentrated in the state of California (43%).¹⁷ In looking at the top metropolitan areas in California with the largest Asian American populations, more than 450,000 Pilipino Americans live in the greater Los Angeles area (i.e., Los Angeles, Long Beach, Santa Ana) and nearly 400,000 live in the Bay Area.¹⁷

Pilipino Americans experience a significant proportion of the breast cancer burden in comparison to other Asian American subgroups.¹⁸ In Los Angeles County, age-adjusted incidence rates of breast cancer among Pilipino American females approximate 125 per

100,000, ranking third across all ethnic groups.¹ Pilipino Americans in California also present with the highest mortality rate for breast cancer (17.3 per 100,000) compared to other Asian subgroups (i.e., 12.7 per 100,000 for Chinese, 15.2 per 100,000 for Japanese, 7.6 per 100,000 for Korean, 8.8 per 100,000 for Vietnamese).¹⁹ Moreover, breast cancer represents the leading cause of death from cancer for Pilipino American women.²⁰

While breast cancer accounts for 38.1% of all cancer cases among Pilipino American females, current literature on the social support experience of Pilipino American breast cancer survivors is nearly non-existent.¹ Despite the clear need to understand this situation for the women and their families, there is a severe lack of resources and information regarding Pilipino American breast cancer survivors. The anticipated growth of this population calls for greater attention to this group's perceived health care and social support needs to minimize the unnecessary burden of suffering and reduce the mortality rates.¹⁸

This thesis explores how social support is related to survivorship for Pilipino American breast cancer survivors. This qualitative study is designed to investigate three areas of the social support experience: (1) How social support is perceived and received by breast cancer survivors; (2) Role of support groups; and (3) Role of religion. In overview, this thesis simultaneously contributes to the discourses on Asian American Studies and Public Health by augmenting existing scholarship on breast cancer survivorship and social support. More importantly, this project accounts for the experience of individuals who have traditionally as well as historically been marginalized.

RESEARCH QUESTIONS

As previously mentioned, in order to assess the social support experience of Pilipino American breast cancer survivors, this thesis poses three research questions that address certain aspects of social support, especially as they pertain to Pilipino Americans in particular:

(1) Social support perceived and received by breast cancer survivors; (2) Role of support groups; (2) and (3) Role of religion. While the first two aspects directly address the minimal existing data pertaining to the social support needs of Pilipino American breast cancer survivors, the third aspect signifies a cultural element integral to this population (as corroborated by Schmit's study).²¹

Research Question (1): What are the expected and actual forms of social support that Pilipino American breast cancer survivors receive?

This research question addresses the social support needs of Pilipino American breast cancer survivors and points to any discrepancies, if any, between identified needs and actual support received. Identifying the perceived needs of breast cancer survivors could minimize any discrepancies in the social support experience and improve cancer care for such patients. Furthermore, this research question expounds on the construct of social support through an ethnic-specific lens – How do Pilipino breast cancer survivors view support from their respective social networks?

Research Question (2): How do Pilipino American breast cancer survivors perceive the role of an ethnic-specific support group with respect to their breast cancer experience?

Given the predominance of Pilipino Americans in the Los Angeles, Long Beach, Santa Ana region, as well as significant breast cancer incidence rate for this group,^{1,17} there is an implied need for a breast cancer support group tailored to Pilipino Americans in the greater Los Angeles area. However, only one exists in this region that has been facilitated through the research project referenced in this thesis. The other known support group targeting Pilipino American breast cancer survivors was located in Northern California (Bay Area).²²

Research Question (3): What role does religion play in the social support experience of Pilipino American breast cancer survivors?

The unique colonial history of Pilipino Americans references the longstanding inculcation of Roman Catholicism and subsequent cultural practices introduced under Spanish rule.²³

Despite the predominantly Christian culture of Pilipino Americans, diversity in religious background is maintained given the population's historical roots in Indo-Mayan spirituality prior to Spanish colonialism. The significance of religion in the Pilipino American culture necessitates the incorporation of a relevant research question on this cultural domain. How religion plays a role, if at all, in identifying the social support needs of Pilipino American breast cancer survivors is explored within this thesis.

The thesis was a sub-study of a larger research project that was designed to evaluate support groups specific to Asian American and Pacific Islander breast cancer survivors in the greater Los Angeles area – “Evaluation of Support Groups for Asian American and Pacific Islander Cancer Survivors” (Principal Investigator: Marjorie Kagawa-Singer – University of California, Los Angeles [UCLA] School of Public Health; Grantor: Susan G. Komen Foundation [Grant Number: POP0600298]). The larger study evaluated existing support groups in the Chinese American and Samoan American communities in the greater Los Angeles area and determined whether a support group curriculum could be developed and modified for other groups like the Pilipino American community. Data for the thesis were collected from a focus group interview conducted with Pilipino American breast cancer survivors.

LITERATURE REVIEW

Although the past few decades have witnessed a growth in literature on cancer survivorship and social support, the majority of empirical studies highlight the experience of Non-Hispanic White breast cancer survivors.^{12,24,25} This non-representative investigation of the impact of social support overlooks the influence of ethnicity and culture in survivorship studies. As a result, it becomes critical to build a knowledge base that accurately portrays the social support experience of *all* women, including diverse ethnic groups. This argument becomes even

more compelling given that breast cancer represents the second leading cause of death from cancer for women across all ethnic populations, let alone the leading cause of death for Asian American women.^{13,14,15}

While the burden of cancer for Asian Americans can be anecdotally characterized as unique, unusual and unnecessary,¹⁶ attention on the impact of breast cancer on Pilipino American women must be emphasized, since this is an unrecognized and thus underserved population in cancer survivorship research and service. Focus on the study of Pilipino American breast cancer survivors becomes paramount given the unique demographic profile of this population.

In order to arrive at an understanding of the social support experience of Pilipino American breast cancer survivors, this literature review provides findings from the following existing scholarship:

- General social support literature that primarily focuses on mainstream breast cancer survivors (i.e., Non-Hispanic White women)
- Social support literature specific to Asian American breast cancer survivors

Note: While health-related literature focusing on the Pacific Islander population is sometimes linked with that for the Asian American population, for purposes of this examination (and given the lack of social support-related data for the primary group indicated), only information on Asian American breast cancer survivors will be elucidated.

Prefacing the two objectives listed above for this literature review requires the operationalization of the following key constructs: (1) Survivorship; and (2) Social support.

Definitions of Cancer Survivorship and Social Support

Within the discourse of *cancer survivorship*, the term cancer survivor initially entailed an understanding of living a certain number of years beyond the point of either diagnosis or

treatment (e.g., five years). In particular, survival demonstrated three specific time intervals beyond the cancer diagnosis: (1) Acute survival, (2) Extended survival, and (3) “Permanent” survival.²⁶ However, current employment of the term survivor within professional literature acknowledges a more dynamic construct of survivorship.²⁴ This literature review adopts the expressed multidimensional construct of survivorship, in which an individual is recognized as a cancer survivor from the point of diagnosis and throughout the remainder of her life.^{4,5,6,7} This definition equates cancer survivorship as a fluid process and not as a static concept with specific time points for survival.

With the operationalization of cancer survivorship outlined above, *social support* represents one aspect that is prevalent throughout the survivorship continuum. Social support acts as a protective and buffering mechanism against perceived and realized health outcomes that are associated with life stressors.^{26,27} Access to social resources and capital allows survivors to cope more effectively in stressful situations. Utilizing a comprehensive definition for this concept, social support is characterized vis-à-vis the following four modalities.^{26,27}

- Emotional support
- Instrumental or tangible support (e.g., a form of aid or assistance)
- Appraisal support (e.g., peer-provided support that improves a survivor’s self-esteem)
- Informational support (e.g., feedback, advice)

Knowing that social support is a form of interpersonal transaction or exchange of resources, social support can be obtained from a variety of sources (e.g., spouse or significant other, family members, friends, support groups, spiritual and/or religious groups, spiritual beings, organizational entities).^{28,29} Furthermore, a breast cancer survivor’s social network is the pool of social contacts that she identifies as critical for social support.

The major thread in the dialogue on the social support experience of breast cancer survivors is a profound absence of literature on ethnic populations. Although substantial

information has emerged on Asian American women with breast cancer, only a few ethnic subgroups have been highlighted (e.g., Chinese American, Japanese American). In considering the ethnic heterogeneity of the Asian American population, the disaggregation of health data becomes crucial in understanding how best to attend to and address the survivorship needs of multiple Asian American subgroups. Data disaggregation can provide further context and meaning to the breast cancer experience that is specific to Asian American subgroups, especially in light of possible cultural nuances and variations. Increasing attention must be placed on Pilipino American women, given their disproportionate burden of breast cancer as well as exponential rates in population growth. The following sections underline findings gleaned from the social support literature for mainstream and Asian American breast cancer survivors (including Pilipino American breast cancer survivors).

General Social Support Literature

The social support literature affirms the positive effect of social support on health status, in which an established link exists between social support, positive health outcomes and well being.^{29,30} Studies have shown that certain types of social support are needed at various points through the cancer experience continuum.³¹ A number of studies argue that the availability of social support contributes to decreased levels of stress.^{32,33,34,35} In particular, support group interventions (i.e., an identified source of social support) that target patients with metastatic cancer prove beneficial from a psychological perspective.³⁶ Religion and spirituality provide a means through which breast cancer patients can obtain social support, including emotional support.³⁷

Social Support Literature Specific to Asian American Breast Cancer Survivors

As noted earlier, social support studies are highly prevalent for Non-Hispanic White breast cancer patients, but a dearth of literature exists for ethnic groups of color.^{38,39} As noted,

however, the few studies that focus on Asian American breast cancer survivors focus on only a few Asian American ethnic subgroups (e.g., Chinese Americans, Japanese Americans). It is important to note that the entire spectrum of Asian American subpopulations is not represented in this specific body of literature.

The following table details the results from an online search on PubMed of existing literature on cancer and social support, as outlined by ethnic group. Administered by the National Center for Biotechnology Information and housed within the National Library of Medicine through the National Institutes of Health, PubMed is a comprehensive biomedical literature database that includes more than 21 million citations gleaned from sources such as MEDLINE, life science journals and online books.¹²

Table 1: Social Support Literature Search

PubMed Search Name	Number of Results
Cancer Social Support Group	4,079
Cancer Social Support Group and Ethnic Group	
African Americans	448
Asian Americans	82
Chinese Americans	10
Filipino Americans	2
Japanese Americans	2
Korean Americans	6
Vietnamese Americans	7
Latinos	259
Hispanics	277
Pacific Islanders	47
American Indians	47
Native Americans	48
Total for Ethnic Groups	1,208 (29.6%)

While more than 4,079 citations were retrieved for general social support literature (utilizing “cancer social support group” as the search terms), less than one-third (1,208 citations = 29.6%) were identified for social support literature focusing on ethnic groups other than Non-Hispanic Whites. Closer inspection of these results indicate that many of the citations referenced for Asian Americans focused on screening practices and incidence rates (as opposed to latter parts of the survivorship continuum). For the two citations that were specific to

Pilipino Americans, one study focused on cervical screening while the other addressed breast cancer screening – None looked at support groups in particular. (In comparison, a preliminary overview of the 4,079 results attributed to the general PubMed search on social support literature yielded citations that varied in scope, focusing on issues such as social support, support groups and quality of life.)

While the social support literature specific to Asian American breast cancer survivors may contribute findings that initially appear similar to that for Non-Hispanic White women, cultural differences may account for how differences in social support are provided and experienced by Asian Americans.⁴⁰ In a cross-cultural study of Chinese American, Japanese American and Non-Hispanic White breast cancer patients, the two Asian American groups expressed the following differences in social support:

- (1) Chinese American and Japanese American women identified sources of social support that differed from that for Non-Hispanic White women⁴⁰
- (2) The structure of the social support network differed between all three groups with respect to size, composition and perceived adequacy of support⁴¹

The above findings may be due to differing cultural constructions of self as well as interpersonal relationships. In this case, the perceived Asian construction of the self as familial-based contrasts with the American construction of the self as individualized.⁴² Moreover, definition of the self in relation to others also differs according to Asian and American cultural contexts. While Asian cultural values generally emphasize interdependence, Non-Hispanic White American culture values independence.⁴² Cultural influences on the experience of illness (i.e., cancer) can impact the depiction of an individual's or group's social support experience.

Although support groups have served breast cancer survivors for more than 30 years, the framework for these services are rooted in European American cultural constructs.^{43,44} Usually, mainstream support groups are unable to address cultural and linguistic barriers, thereby preempting Asian American women from participating in mainstream support group

opportunities.¹³ Support group services that are specific to Asian American ethnic subgroups are few and far between nationwide.

Social Support Literature Specific to Pilipino American Breast Cancer Survivors

Although findings from studies for certain Asian American groups differed from that for Non-Hispanic White women, it would be presumptuous to generalize these assertions to Pilipino American breast cancer survivors. Therefore, this exploratory study was designed to focus on this unique Asian American subpopulation, while comparing resultant findings to extant literature. At this time, only one singular study (i.e., Burke et al.) exists that explores the social support experience of Pilipino American breast cancer survivors. Burke et al.'s seminal study explores meanings of survivorship and support among Pilipino American breast cancer survivors in Northern California. In this study, four dimensions of survivorship were identified as well as five dimensions of support:²²

- Dimensions of survivorship
 - (1) Cancer is one of many trials
 - (2) Survivorship is not about self, but about family
 - (3) Survivorship is rebirth, a second chance
 - (4) Survivorship means being cancer-free, having “passed through”
- Dimensions of support
 - (1) Different definitions of “caregiving”
 - (2) Family support dynamics
 - (3) Patients as caregivers
 - (4) Transnational aspects of support
 - (5) Spiritual and religious support

In particular, Burke et al. point to the lack of discourse on immigration and poverty when considering disparities in support received by breast cancer survivors.²² Addressing such

culturally based contexts becomes critical in considering the support needs among Pilipino American breast cancer survivors. The following section outlines those Pilipino cultural values that can inform this thesis and its exploration of the breast cancer experience of Pilipino Americans.

Pilipino Cultural Values

Pilipino Americans' survivorship needs are informed by their attitudes and beliefs towards health care as well as notions of illness, in which cultural constructs and values play a critical role. How Pilipino Americans approach notions of health and wellness becomes paramount in informing their survivorship experience. However, identifying cultural nuances relevant to Pilipino American women's social support experience can be obscured through the imposition of constructs informed by the Westernized health care model. The integration of family, religion and hope appear universal in response to the cancer experience, but the Pilipino cultural expressions of these domains represent critical elements that must be accounted for in the care of Pilipino Americans, especially within health care settings.²¹ According to Schmit in her study of the palliative care nursing implications for Pilipino patients, the ways in which Pilipino Americans uniquely portray their perspectives on health through a cultural lens are highlighted in the three constructs of family, religion and hope.²¹

While the importance of family can be witnessed across ethnic groups, Pilipino American culture follows a bilateral structure where extended family members from both the maternal and paternal sides are privileged and play prominent roles in the family unit.^{21,45} Hope also surfaces as a significant concept when considering the cultural reaction to illness. Traditional Pilipino beliefs, in conjunction with Westernized approaches to medical care, emphasize continued optimism for a cure regardless of the severity of an individual's medical condition.^{21,46}

Furthermore, the diversity of the Pilipino American population must be acknowledged given its unique cultural and historical contexts. The ways in which Pilipino Americans form their

cultural identity is rooted in its colonized histories in the Philippines as well as migration patterns to the United States, thereby informing their religious and linguistic practices. Beginning in 1521, the Philippines remained under Spanish colonial rule for more than 350 years. During this time, the Spanish inculcated its Christian, Roman Catholic religion within the Pilipino culture.²³ Prior to this period of Spanish colonization, the Philippines was rooted in the practice of Indo-Mayan spirituality.²³ The diversity in religious backgrounds in the Philippines is still apparent to this day, despite the predominance of Christianity among Pilipino Americans.

The Philippines' history of colonization continued with the United States annexing the Philippines after the Spanish-American War in 1898, subjecting the Philippines to American imperial rule through 1946.²³ Pilipinos' migration history to the United States was documented as early as 1700s with Louisiana Manilamen travelling to the Bayou areas by way of the Spanish galleon ships.²³ Coupled with the United States' presence (especially militarily) in the Philippines, these documented intersections yield a unique, transnational social, economic, and cultural relationship between Pilipinos and the United States.

Language also represents a cultural factor to consider when appreciating the diverse background of the Pilipino American population. The Philippines is an archipelago comprised of 7,107 islands, with more than 100 languages and dialects represented. While the national language is designated as Filipino, a blend of Tagalog and other major languages in the Philippines, "Taglish" is a colloquial form often recognized in Pilipino American culture (i.e., a mix of Tagalog and English). To note, an indigenized form of the Pilipino alphabet does not include "c" or "f," in alignment with pre-Spanish colonial era. (Rather, the "k" and "p" letters, respectively, are utilized.) For purposes of this thesis, the "p" is privileged in the spelling of "Pilipino American," which is considered interchangeable with Pilipino, Filipino and Filipino American in this thesis.

Another cultural construct that is deemed significant in the consideration of the Pilipino American population is the idea of "loss of face," which is associated with the loss of status or

social value for the family more so than the individual. While “loss of face” is readily identifiable not only with other Asian American cultures but other ethnic groups as well, variations can be located within Pilipino American culture through the following cultural values: (1) *Hiya*; (2) *Amor propio*; (3) *Pakikisama*; and (4) *Utang ng loob*.⁴⁷

The literal translation of *hiya* from Filipino to English is “shame.” Within the context of “loss of face,” Pilipino American culture ascribes the shame and fear associated with losing face, thereby affecting how an individual behaves and interacts with others.^{47,48} *Amor propio* addresses the idea of “face” by representing concepts of self-esteem and self-image.^{47,48} How an individual presents herself to others and expresses this construct of *amor propio* directly references the idea of the “loss of face.” *Pakikisama* translates into the notion of group belonging, where members seek to please other members of the group and meet social expectations.^{47,48,49} *Utang ng loob* references the debt and obligation an individual holds in her relationships with others.^{47,48,50} By considering the Pilipino American cultural values of *hiya*, *amor propio*, *pakikisama* and *utang ng loob*, prevention of the “loss of face” refers to an individual’s desire to seek social acceptance and harmony based on her perception of self as well as perception with and by others on a group level.

In considering cultural aspects of the Pilipino American population as specified above (i.e., histories of colonization, religion, language and values pertinent to the idea of “loss and face” in relation to social expectations), we can appropriately contextualize the findings obtained from this thesis. It is important to recognize as well as acknowledge the cultural variations inherent to the Pilipino American population.

RESEARCH DESIGN AND METHODS

As mentioned earlier, the research design and methods for this thesis were informed by a parent study that evaluated support groups specific to Asian American and Pacific Islander

breast cancer survivors in the greater Los Angeles area – “Evaluation of Support Groups for Asian American and Pacific Islander Cancer Survivors” (Principal Investigator: Marjorie Kagawa-Singer – UCLA School of Public Health). Funded by the Susan G. Komen Foundation (Grant Number: POP0600298), the larger study was designed to evaluate the structure of existing and successful support group sites located in the Chinese American and Samoan American communities in the greater Los Angeles area via semi-structured interviews and focus group interviews. This study was also designed to develop a support group curriculum that could be modified for other Asian American and Pacific Islander populations (e.g., Pilipino Americans, Korean Americans) based on findings regarding culturally specific support group elements.

This thesis followed a qualitative research approach that employed an inductive, exploratory design. Data were collected from one focus group interview with Pilipino American breast cancer survivors. The UCLA Institutional Review Board (IRB) granted approval in the execution of the research study sponsored by the Principal Investigator (IRB Number: G06-02-030-02).

Study Sample

The setting for the thesis was the greater Los Angeles area. According to the 2010 Census, this geographic setting represents the top metropolitan area in the United States with the greatest number of Pilipino Americans (more than 450,000 total).¹⁷ The Asian Pacific Health Care Venture (APHCV) was identified as an appropriate site from which to recruit Pilipino American participants. Established in 1986, APHCV is a federally qualified community health center that aims to provide culturally appropriate medical and health care services within the Los Angeles County area.⁵¹ In particular, APHCV focuses its health care delivery and health education outreach efforts towards low-income and underserved Asian American and Pacific Islander populations.⁵¹ Given the population focus of APHCV and its proximal location to

Historic Pilipinotown in Los Angeles, APHCV signified a suitable collaboration site. APHCV bicultural staff, who were fluent in Tagalog and English (i.e., Nursing Department Manager, Adult and Senior Services Project Coordinator, and Breast Cancer Care Coordinator/Pilipino Outreach Worker), were integral in the recruitment of prospective Pilipino American participants for this project. Recruitment for participation occurred through the following means: (1) Referrals from APHCV providers; (2) Outreach through the Pilipino Outreach Worker's personal networks; and (3) Word of mouth. APHCV staff were equipped with the following recruitment tools (as approved by IRB) so as to assist them in their recruitment efforts:

- Recruitment Flyer (English, Tagalog)
- Consent to Be Contacted Form
- Recruitment Script (English, Tagalog)

(Refer to Appendices B-D for these forms.)

Eligible participants for the focus group interview met the following criteria: (1) Age \geq 30 years; (2) Breast cancer diagnosis only (and no other cancer) at Stages 0-III; and (3) Time from diagnosis at the point of participation may span from one to five years. (Refer to Appendix A for further details on eligibility criteria.) In accordance with IRB guidelines, measures to ensure confidentiality and human subject protection were enforced throughout the duration of the study.

Data Collection

Data were collected from one focus group interview conducted with Pilipino American breast cancer survivors at APHCV on February 21, 2009. (Refer to Appendix E for a sample Sign-in Sheet that was used at the time of the focus group.) Two Pilipino American, bilingual, and bicultural co-facilitators moderated the focus group – the Nursing Department Manager and Adult and Senior Services Project Coordinator at APHCV. Prior to the implementation of the focus group interview, the Adult and Senior Services Project Coordinator was trained on

appropriate guidelines for facilitating the focus group, including a comprehensive review of the focus group interview guide.

Guidelines for the semi-structured focus group interview were developed and structured according to the following domains: (1) Diagnosis; (2) Support during diagnosis; (3) Support during treatment; (4) Support during post-treatment; (5) Sexuality; (6) Support group; (7) Support group services and resources; and (8) Religion and spirituality. (Refer to Appendix I for the Focus Group Guide.) Through the semi-structured approach, the two co-facilitators utilized the focus group interview guide while having the opportunity to pose probing, follow-up questions to elicit further detail from the participants as necessary. The co-facilitators practiced discretion in addressing all question domains included in the interview guide without having to follow a specific order, thereby adapting to the flow of the focus group discussion.

Prior to the focus group, the co-facilitators first outlined the intent of the study with each of the participants individually, including any perceived risks and benefits and the option to withdraw participation at any point during the study without penalty. The co-facilitators also reviewed the guidelines to obtain the participants' consent. (Refer to Appendices F-G.) Upon expressing their consent to participate in the focus group interview, participants were instructed to complete a Survivor Questionnaire to obtain relevant demographic information. The focus group was then convened, and the interview was recorded for purposes of documenting the data as well as transcription and translation of the data afterwards. Participants were assured by the project team that all data collected during this focus group remained confidential and anonymous. While project team members were on hand to support the co-facilitators as needed, they also took notes and any pertinent observations throughout the focus group interview that may add to the data already collected through the audio recording.

At the completion of the focus group interview, participants received a nominal stipend (i.e., \$40) as compensation for their participation. (Refer to Appendix J for the Receipt of Gift

Form.) Participants were encouraged to continue socializing after the focus group over a late lunch provided by the project team.

Data Analysis

The completed interview was translated from Tagalog to English as necessary and transcribed verbatim. Any notes taken during the interview provided more context for the interview transcript. Analysis of the data collected from the focus group interview with the Pilipino American breast cancer survivors followed the content analysis approach described by Willms et al., which systematizes the application of qualitative methodology in research.⁵² With this data analysis plan, the focus group interview transcript was reviewed for emergent analytic categories, in which these categories were organized using ATLAS.ti data management software.⁵³ Utilizing the focus group interview guide, a codebook was developed to assist in the organization of any emergent analytic categories. (Refer to Appendix K.) According to Willms et al.'s framework, the identification of relevant theoretical themes allows for interpretation of the data within their specific sociocultural contexts.⁵²

RESULTS

A total of eight individuals participated in the focus group – i.e., seven females and one male. Participants completed an informational questionnaire at the time of the focus group, in which their demographic profile as well as responses to various questions are summarized in the tables below. (Refer to Appendix H for the Survivor Questionnaire completed by focus group participants.) Note that participants may not have completed all question prompts indicated in the Survivor Questionnaire.

Demographic Profile of Participants

At the time of the focus group, the majority of the participants were over 50 years of age (n = 7), had or had had a partner (n = 7), had children (n = 4), and were insured (n = 7). All eight cited the Philippines as their country of birth, with the majority living in the United States for at least eight years (n = 7). Seven of the eight participants completed education at a college or university in the Philippines. Most participants did not have full-time employment status either at the time of the focus group (n = 5) nor at the time of their breast cancer diagnosis (n = 4). In regards to religious background, the majority identified with a Christian denomination (n = 7). Five out of the eight participants indicated attending religious group meetings or gatherings.

Table 2: Demographic Profile of Participants

	Number of Participants
Age	
40-49	1
50-59	2
60-69	2
70+	3
Marital Status	
Never Married	1
Divorced	4
Separated	1
Widowed	2
Number of Children	
0	4
2	2
4	1
5	1
Years Lived in the United States	
2	1
8	2
18	2
20	1
25	2

Table 2: Demographic Profile of Participants (Continued)

	Number of Participants	
	Philippines	United States
Highest Grade of Education Completed		
Grade School	1	1
Four-year College or University	2	
Graduate or Professional School	3	
Two-Year Junior or Community College	1	
Vocational, Business or Trade School		3
ESL/Adult School		1
Religious Background		
Christian		2
Catholic		2
Dominican		1
Evangelical Christian		1
Protestant		1
Employment Status	At Focus Group	At Diagnosis
Full-Time	1	1
Part-Time	2	2
Unemployed	2	1
Disabled		1
Retired	1	
Health Care Insurance		
Private		1
Medicare		1
Medi-Cal		5
Medical Service for Indigents		1

Note: For “Religious Background,” the above table indicates the actual responses provided by the participants for this prompt on the Survivor Questionnaire.

Summary of Findings Relevant to Breast Cancer Diagnosis

The majority of focus group participants indicated the year of their breast cancer diagnosis as 2007 or later (n = 5), with four participants identifying that their breast cancer diagnosis was in the early stage. At least four participants received treatment in the United States.

Table 3: Breast Cancer Diagnosis and Treatment

	Number of Participants
Year of Breast Cancer Diagnosis	
1975, 1981	1
2007	3
2008	1
2009	1
Stage of Breast Cancer Diagnosis	
Early	4
Middle	1
Late	1
Treatment(s) Received	
Radiation	1
Chemotherapy	3
Mastectomy	4
Lumpectomy	1
Herceptin	2
Other (Not Listed)	1
Site of Treatment(s) Received	
Philippines	1
United States	4

Summary of Thematic Findings from Focus Group Interview

The focus group interview primarily followed a formal, question-and-answer format that may have presented a concern in regards to stimulating further, follow-up discussion among the focus group participants on the outlined interview domains. Despite this, the participants expressed a sincere interest and desire to discuss various topics. For instance, while assumed constraints may be inferred in discussing sexuality within this mixed-gender, predominantly Christian demographic setting for the focus group, the participants debunked such assumptions by portraying a great willingness to discuss issues around sexuality and their own breast cancer experience. Also, the impact of the solo male participant in the focus group did not appear to adversely impact the relational dynamic of the focus group. Even as the topic of sexuality was broached later on in the focus group discussion, the male participant shared many contributions on his own experience. The participants established positive rapport with one another in this

mixed-gender setting. The participants' desire to contribute to the discussion overrode any perceived hindrances that would impact their individual participation in the focus group.

Based on the coding of the focus group interview transcript, Table 4 identifies the prevalent themes. (Refer to Appendix K for a general outline of the codebook.)

Table 4: Emergent Codes from Focus Group Interview

	Number of Coded Instances
Sources of Support	49
Non-specified Instances	14
Medical Community	22
Other Family Members	13
Survivorship	36
Perspective About Survivorship	12
Sexuality	13
Sexuality and Intimacy	11
Relationship	14
Ways of Coping	33
Non-specified Instances	13
Receive Prayers/Religious Attribution	20
Personal Reaction to Diagnosis	11
Treatment	11
Total Number of Coded Instances	154

Note: A total of 605 instances were coded throughout the focus group interview transcript.

Sources of Support

During the focus group, participants discussed at length the various sources of support at different points along the cancer care continuum. Such discussion directly speaks to the first research question posed for this thesis: What are the expected and actual forms of social support that Pilipino American breast cancer survivors receive?

Generally speaking, participants referenced the discrepancy in receiving support in the Philippines compared to in the United States. For instance, while the American Cancer Society was identified as a source of support and resources in the United States, no such support was available in the Philippines. Specifically, the American Cancer Society contacted patients directly to offer any assistance that these patients may have needed:

“And also the Cancer Society sent people and been calling myself, my phone, and asking me [if] there is, if there’s anything they could do.”

The geographic discrepancy alluded to by participants was similarly mirrored with regards to family members as a source of support. The actual presence of family members was acknowledged as a desired but often absent source of support:

Naghirap ako, ang buhay dito sa Amerika, kahit ang pamilya ko ay nasa Pilipinas. (“I struggled, here in America, even though all my family members are in the Philippines.”)

No, iba talaga. Kahit ako ay nurse, iba rin talaga. Wala ako pamilya dito, but I need somebody. (“Even though I’m a nurse, it is really different. I don’t have any family here, but I need somebody.”)

One participant identified her daughter as an important source of support, but alluded to a sense of loss with this lack of support:

Yung anak kong bunso, yoon ang good listener. Yoon ang sumbungan ko ng problema ko. Ngayon at wala na, ano pang... (“My youngest daughter, she’s a good listener. She is the person I confide the most to. Now that she’s not here, what am I...”)

Those participants who received support from their family members readily acknowledged the importance of such support:

“My family was very supportive. My sister in Florida, my brother in Arizona, flew just to be with me in the hospital. And then my mom and my dad will call me every now and then.”

The above participant’s experience confirmed how the physical presence of her family members played a prominent role in her social support experience.

Medical Community. Participants acknowledged, for the most part, their physicians as well as medical staff that they have interacted with during the course of their breast cancer experience as positive sources of support. In particular, participants referenced the relationship building efforts of their physicians (e.g., oncologist) as a positive aspect. Patients identified the perceived support that these medical professionals actively provided to participants as positive:

“And everybody was so nice that it also makes your life easier to deal everything that you’re going through.”

Other Family Members. Participants also referred to their family (e.g., immediate family members, relatives, etc.) as an ongoing and readily available source of support. One participant even referenced how her children served as a source of support since her spouse at the time was with another woman. Moreover, one participant noted how her physician alluded to support from family as a culturally specific factor:

“The [P]ilipinos are so blessed to have strong family ties, because my breast surgeon called me and asked me if I can do volunteer work, once in a while in her office. Because, according to her, she has patients, Caucasian, Afro-American and other race of which the family is not supportive to them.”

The idea of locating support from one’s family, whether from immediate or extended family members, served as a positive aspect during participants’ respective breast cancer experiences.

Survivorship and Internal Strength

Perspective About Survivorship. While participants readily acknowledged external sources of support during their breast cancer experience (e.g., family, medical professionals, religion), they also spoke to an individualized perspective about survivorship. For example, one participant emphasized maintaining a “positive outlook” rather than “playing like a victim.” Referencing such tones of survival in this focus group interview segued into participants’ approaches to coping:

Sino pa ang tutulong sa atin kung hindi tayo rin? (“Who is going to help us but ourselves?”)

Participants’ positive perspectives about survivorship informed more proactive approaches to coping with their breast cancer experience.

Sexuality. Participants reflected on the lack of sexual desire, especially after the receipt of treatment and/or medication for their diagnosis. The theme of sexuality was also referenced in regards to sexuality and womanhood – For example, how “sexy” is perceived. For the single male participant in this focus group, his breast cancer diagnosis impacted his perception of self

as well as sexual drive. He mentioned feeling effeminate upon losing his sexual “urge”: “I thought I was a woman now.”

Sexuality and Intimacy. Intimacy was referenced in relation to the lack of sexual desire as well as relationship with others. For instance, the sole male participant revealed how his lack of sexual desire impacted his relationship with his spouse and concurrently, feelings of intimacy. He acknowledged the connection between his lack of sexual desire and his changed relationship dynamic with his spouse, which served as a point of concern for his spouse. While his spouse wanted to maintain a sexual relationship with him, his interest in sexual intimacy was non-existent. This participant’s identified loss of masculinity through his breast cancer experience represented a point of frustration in his inability and lack of motivation to have a sexual and intimate relationship with his spouse: “But of course I’m upset at this point because I don’t deliver.” In spite of this acknowledged tension in his physical relationship with his spouse, his spouse began to understand his own situation with his “lessening desire.”ⁱ

In regards to the impact of breast cancer on the female participants’ sexual relationships with their partners (if they had a partner at the time), the findings were varied and dependent on the participant’s situation at the time of the focus group. For instance, one participant married after her breast cancer diagnosis and treatment. While she was concerned that her relationship with her spouse-to-be would change when she shared with him about her breast cancer experience, her spouse accepted her as she was.

Another participant differentiated between the concepts of sexuality (i.e., sexual desire) and love, in which a sexual relationship did not necessarily interfere with sustaining a meaningful relationship with one’s partner: “That’s not the most important thing. The important thing is that, you know, love.” The male participant corroborated this statement in his own

ⁱ After the focus group, this male participant was provided names of counselors to discuss this issue if he so desired.

personal experience by affirming that “the love [was] still there” with his spouse despite the lack of a sexual relationship.

Relationship

Discussion focused on an individual’s relationship with a partner within the context of losing one’s breast, in which some parts of this dialogue also overlapped with themes of survivorship (including perspective about survivorship and sexuality).

“Because as a person, people will look to you as a person. If the person really loves you, the person really loves you of who you are, not because of your breast.”

“[Once] a man loves you, he will love you for [who] you are, not because of what you’re lacking. Especially if you have someone who’s been with you prior to your diagnosis and still is with you until after. He will still continue to love you.”

In these coded instances, participants affirmed that a relationship can be sustained with one’s partner despite the physical loss of one’s breast and that the love of one’s self transcended the physical.

Ways of Coping

In overview, the mention of “deal” or “dealing” with one’s breast cancer experience was indicated as ways of coping. As previously shared, such references to coping informed the discussion surrounding one’s perspective about survivorship: “[B]ut the thing is, we have to live with it.”

Receive Prayers/Religious Attribution. Participants readily acknowledged religious forms of support during their breast cancer experience, especially in regards to receiving prayers from others (e.g., religious congregation) and citing religious attributions. For instance, participants “thank[ed]” and “praise[d]” God when referencing such attributions, underlining God’s healing powers.

Sabi ko, bigyan mo ako ng laksa. At saka, bigyan mo ako ng laksa na tanggapin ko para ma-, ano man yang ibigay mo sa akin... Sabi ko noong pag-dating ko sa trabaho ko, salamat Lord at hindi mo ako pinabayaan. (“I said, God give me strength. Give me strength to accept this thing that you gave me... I said, when I arrived to work, thank you Lord God for not forsaking me.”)

Through such discussion, participants emphasized the relevance of their religious backgrounds within the context of the third research question: How does religion play a role in the social support experience of Pilipino American breast cancer survivors?

Personal Reaction to Diagnosis

While participants referenced their personal reactions to their breast cancer diagnoses during the focus group interview (i.e., 11 coded instances total), the range of responses were diverse and varied. Participants revealed the following emotions:

- Surprise versus no surprise
- Worry and self-pity
- Uncertainty in how to react to the diagnosis
- “Blessing in disguise”

Note: For the participant who indicated that her diagnosis was a “blessing in disguise,” her diagnosis revealed the discovery of a heart condition that required further, immediate follow-up.

Some participants expressed concern in sharing their diagnosis with family members as this might serve as a source of anxiety for their loved ones. For example, one participant expressed worry about sharing her diagnosis with her older mother, fearing that the news would worsen her mother’s health status. Per the participants’ responses, feelings of guilt and worry arose with regards to sharing their diagnosis, which might impact their relationship and communication dynamic with other family members. To avoid the prospect of burdening loved ones, participants affirmed the need to identify others outside of their family with whom they could confide in about their breast cancer experience.

Mas mabuti yung ibang tao. Maysasabi mo yung kuwan, kesa sa magulang mo eh, kasi anak ka niya. Dahil ikaw, ma, sister, may anak ka. Ayaw mo magkasakit yung anak mo. Siyempre guilty ka na. (“There are times that it is better to open up to other people because you can say things you would not be able to say if it’s for instance your parents because you are their kid. Because you, sister, you have a child. You don’t want your child to get sick. Of course, you will feel guilty.”)

Treatment

In these coded instances (i.e., 11 total), participants primarily reference in more general terms the need for an “operation” in response to their breast cancer diagnosis. This informed other coded instances of specific treatment types throughout the focus group interview transcript (e.g., chemotherapy, radiation, etc.).

Support Group

Participants also alluded to the second research question posed for this thesis when briefly referencing the concept of support groups during the focus group interview: How do Pilipino American breast cancer survivors perceive the role of an ethnic-specific support group with respect to their breast cancer experience? While participants did not speak to personally participating in a support group, the idea of becoming involved with fellow peers was discussed. While one participant was recommended to attend a support group, she acknowledged not having participated in one. Some participants expressed desire for support by participating in a peer support group, especially as this venue would provide a safe and trusting space with which to explore their personal experiences.

“And then interaction like this, like discuss my thing with everyone.”

“Since we have already developed intimacy with[,] among each other...”

(Note that all participants were strangers to each other at the beginning of the focus group.)

CONCLUSION

Discussion of Results

While the initial findings gleaned from the focus group corroborate the existing literature on social support (including the role of religion and spirituality), the data were not sufficient to expound on the role of support group therapy for Pilipino American breast cancer survivors.

However, the following interpretations address each of the research questions posed for the thesis within the context of extant literature on social support.

Research Question (1): What are the expected and actual forms of social support that Pilipino American breast cancer survivors receive?

Emergent findings regarding sources of support (i.e., medical community, other family members) align with conclusions drawn from general social support literature as well as social support literature specific to Asian American breast cancer survivors (including the sole study on Pilipino American breast cancer survivors and social support by Burke et al.). In this regard, social support appears to positively impact the breast cancer experience of survivors across race and ethnicity (e.g., religion). Specifically, while focus group findings parallel Burke et al.'s study findings with respect to family as a source of support during the breast cancer experience, these findings are modulated by the sense of burden that some participants expressed.

Research Question (2): How do Pilipino American breast cancer survivors perceive the role of an ethnic-specific support group with respect to their breast cancer experience?

Findings from the focus group interview were minimal as participants could not discuss their personal experiences with participating in ethnic-specific support groups since such groups do not exist in the greater Los Angeles area for Pilipino/as. None reported trying mainstream support groups either. Rather, the focus group served as a venue to briefly discuss the plausibility of convening Pilipino American cancer survivors within a support group setting. While the support group literature continues to grow for ethnic groups other than Pilipino Americans,²² the desire expressed by the focus group participants indicates that this body of literature and services needs to be further developed and addressed for Pilipino American breast cancer survivors.

Research Question (3): What role does religion play in the social support experience of Pilipino American breast cancer survivors?

Under the emergent theme of ways of coping, focus group findings underline the importance that religion plays in the social support experience for Pilipino American breast cancer survivors. This conclusion corroborates the findings drawn from existing social support literature for multiethnic groups. For instance, in Burke et al.'s study, God and prayer are acknowledged as valid and valued forms of support.²²

Culture Specific Issues

Cultural values specific to the Pilipino American population in regards to the construct of "loss of face" (*hiya*, *amor propio*, *pakikisama*, *utang ng loob*) all play an integral role in addressing the findings outlined above for this thesis' three research questions. How these participants seek and define social support as breast cancer survivors is evident in the relationships they navigate with others to avoid a "loss of face" and affirm their sense of self-worth. Participants directly addressed the constructs of *hiya* and *amor propio* when discussing their perceived self-image especially within the context of losing one's breast as well as sexuality and intimacy. As shared earlier, one participant feared that her spouse-to-be would approach her differently once she shared her breast cancer experience, since she "[didn't] have anything anymore." The fear and shame of losing face with one's loved ones directly references the idea of *hiya*.

Moreover, the participants' responses regarding the concept of *pakikisama* (i.e., sense of belonging) directly informs Research Questions (2) and (3). The participants' desire to participate in a support group with fellow peers where they can establish trusting relationships in a safe space references the desire to belong and feel accepted by other members in the group. To a certain extent, this sense of belonging is similarly revealed in the support received through one's religious community, where participants attested to the support of their congregation and religious leaders as a positive aspect of their breast cancer experience. While participants

referenced the desire to actively receive support in a peer group setting, the support received within the church setting was identified more as a passive form of support on the part of the participants.

Last, *utang ng loob* is evident in how the participants personally navigated their relationships with others, especially within the context of how they coped with their breast cancer experience. The “indebtedness” and “obligation” that these participants experienced in their relationships with their family members became apparent in some instances where participants chose to shield their loved ones from the news of their breast cancer diagnosis. This sense of burden and worry rested with the participants and not their loved ones, in which the participants avoided losing face. By avoiding the appearance of being a burden on others, participants avoided expressing signs of weakness. Instead, participants were able to affirm their ability to handle their own “situation” and avert any indications of “loss of face” with others. This sense of obligation on one’s self in also reflected in how the participants utilized proactive forms of coping where they avoided adopting a victim-oriented mindset.

Study Limitations

In light of the explanatory findings indicated above, one significant limitation to this study was the small sample size ($n = 8$). For future projects that are similar in scope, findings from this thesis could be tested through the stories shared from multiple focus groups.

Another limitation included the lack of clarifying data on the ethnic demographic profile of the participants. Given the geographic and linguistic diversity of the Philippines, it would be informative to delineate which regions as well as dialects these participants identified with – e.g., Tagalog versus Visayan, etc. Such findings would address the consideration of the cultural variations within this heterogeneous target population.

Next Steps

In order to further build the literature on social support as it impacts Pilipino Americans as well as breast cancer survivors from other ethnic groups, the following areas must be addressed to begin to fill gaps in research:

- Increased participation of ethnic minorities in cancer survivorship research programs^{13,54}
- Development of a culturally-oriented model of social support such that culturally validated measures of social support are appropriately utilized⁵⁵
- Consistent operationalization of survivorship and social support across multiple studies, especially in regards to how breast cancer patients themselves perceive the meanings of such terms
- Adequate exploration of the possible culturally based effects of social support, especially from a relational context (e.g., “loss of face”)

Given the findings obtained from this thesis, additional questions that attend to the impact of social support on Pilipino American breast cancer survivors could inspire further research and policy recommendations as they pertain to the public health realm as well as Asian American Studies discipline.

Appendix A: Recruitment Information

	Patient/Survivor Focus Group
Number of Participants	6-10
Incentive Amount	\$40
Required Criteria	<ul style="list-style-type: none"> • Age: 30+ years • Breast cancer only (No other cancer) • Stage I-III (Can also include Stage 0) • Time from diagnosis: 1-5 years
Additional Criteria	<ul style="list-style-type: none"> • Treatment <ul style="list-style-type: none"> ○ Lumpectomy <ul style="list-style-type: none"> ▪ Adjuvant chemotherapy ▪ Adjuvant radiation ○ Mastectomy <ul style="list-style-type: none"> ▪ Chemotherapy ▪ Radiation ○ Reconstruction <ul style="list-style-type: none"> ▪ Yes ▪ No • Immigrant duration (Time in United States) • Marital status • Educational level • Religion <ul style="list-style-type: none"> ○ Catholic ○ Christian ○ Iglesia • Occupation

The background of the flyer features a large, stylized graphic of pink ribbons, which are a symbol for breast cancer awareness. The ribbons are arranged in a way that they appear to be tied and draped across the page, with some overlapping. The color is a soft, light pink.

**Asian Pacific Health Care Venture
seeks**

**Breast Cancer
Patients & Survivors**

**for group discussion in
Filipino/Tagalog
about cancer experiences**

For more information please contact:
[Name & Contact Information of Agency Representative]

UCLA IRB Number: G06-02-030-02

**Nananawagan ang
Asian Pacific Health Care Venture
sa mga**

**Pasyenteng may kanser
sa suso o
Mga pasyenteng naligtasan
ang kanser sa suso**

**Mangyari pong sumali sa grupong talakayan ng
mga kapwang Pinay ukol sa mga karanasan sa
kanser**

**Para sa dagdag na impormasyon, paki-tawagan si:
[Pangalan at telepono ng representative]**

UCLA IRB Number: G06-02-030-03A

CONSENT TO BE CONTACTED FORM

Evaluating Support Services for Asian American &
Pacific Islander Cancer Survivors

Marjorie Kagawa-Singer, Ph.D., M.N., R.N.
UCLA School of Public Health and Asian American Studies

You are asked to participate in screening procedures in order to determine whether you may be eligible for a research study conducted by (*agency name*) and the UCLA School of Public Health, Department of Community Health Sciences. You were selected as a possible participant in this study because you have had breast cancer.

PURPOSE OF THE STUDY – What is the study?

The study will ask you questions about your experiences with breast cancer. It will also ask you about how you have managed to overcome many of the challenges encountered throughout your cancer experience.

PROCEDURES

If you agree to participate in the screening, we ask you to do one of the following:

- 1) Complete the 3rd page of these forms by providing your contact information and returning it to the address below, using the attached stamped, addressed envelope. You will then be contacted by either Dr. Kagawa-Singer or her Research Coordinator.

Marjorie Kagawa-Singer, R.N., M.N., Ph.D.
Principal Investigator
UCLA School of Public Health
650 Charles Young Dr. South
Community Health Sciences
Box 951772
Los Angeles, CA 90095-1772

- 2) Call Dr. Marjorie Kagawa-Singer or her Research Coordinator, (*name of Coordinator*), Monday through Friday between 8am to 5pm:

Marjorie Kagawa-Singer at (310) 825-9481
[*Name of Coordinator*] at (310) 794-6604

The total length of time for your participation in the screening will be 15 minutes. You will be asked questions to confirm your eligibility to participate in the study and will be given detailed information about the group interview.

POTENTIAL RISKS – What are the risks and possible problems if I take part in this study?

The possible risks involved may be temporary feelings of emotional discomfort related to the questions being asked. We will try to ease any discomfort by calling you at the phone number you provide, during a time that is most convenient for you, and our study investigators are experienced in working with women who have had breast cancer. If you would like to have further assistance, we can talk more privately or give you a list of community resources.

POTENTIAL BENEFITS TO SUBJECTS – How will this study help me?

You will not directly benefit from the screening. However, if you qualify to participate in the study, you will learn about the experiences of others going through this experience.

PAYMENT FOR PARTICIPATION – What will I receive?

You will not receive payment for your participation in the screening.

CONFIDENTIALITY – Who will know about what I say?

Your answers will be confidential. No one will know your responses to the questions or your contact information, except for the research team. Demographic information (for example: age, ethnicity) will be collected to determine the characteristics of those interested in participating in the study. The demographic information and responses collected during the screening will be kept in a locked cabinet in the study investigator's office.

If you qualify to participate in the study and you decide to participate in the research project, your contact information will be retained so that we may provide you with information about the discussion group. Your contact information will be kept separate from your responses.

If you do not qualify to participate in the study, your contact information will be destroyed and you will be referred to (*agency name*) for possible future involvement.

PARTICIPATION AND WITHDRAWAL – Can I stop answering if I don't want to continue?

Your participation is **VOLUNTARY**. If you volunteer to participate in the screening, you may withdraw at any time without consequences of any kind.

IDENTIFICATION OF INVESTIGATORS – Who can I talk to about this study?

If you have any questions or concerns about your participation in the research, please feel free to contact Dr. Marjorie Kagawa-Singer. She has had over 30 years experience working with women of all ethnic groups with breast cancer.

Marjorie Kagawa-Singer, R.N., M.N., Ph.D.
Principal Investigator
UCLA School of Public Health
650 Charles Young Dr. South
Community Health Sciences
Box 951772
Los Angeles, CA 90095-1772
(310) 825-9481
mkagawa@ucla.edu

If you are not comfortable speaking only English, please ask a friend, family member or outreach worker who speaks English to make this call with you.

RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights of remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact the Office for Protection of Research Subjects (OPRS), 11000 Kinross Avenue, Suite 102, Box 951694, Los Angeles, CA 90095-1694, (310) 825-7122.

Appendix C: Consent To Be Contacted Form

CONTACT INFORMATION

<i>Name:</i>
<i>Phone Number:</i>
<i>Best time to call:</i>

Please return the form to Dr. Marjorie Kagawa-Singer or (*name of research coordinator*) by using the attached stamped, addressed envelope and mailing it to:

Marjorie Kagawa-Singer, R.N., M.N., Ph.D.
Principal Investigator
UCLA School of Public Health
650 Charles Young Dr. South
Community Health Sciences
Box 951772
Los Angeles, CA 90095-1772

You may also call Dr. Marjorie Kagawa-Singer or (*name of research coordinator*) Monday through Friday between 8am to 5pm:

Marjorie Kagawa-Singer at (310) 825-9481
[*Name of Coordinator*] at (310) 794-6604

FOCUS GROUP - RECRUITMENT SCRIPT

(Breast Cancer Patient or Survivor)

Evaluating Support Services for Asian American &
Pacific Islander Cancer Survivors

Marjorie Kagawa-Singer, Ph.D., M.N., R.N.
UCLA School of Public Health and Asian American Studies

My name is (outreach worker's name). I am working in partnership with the UCLA project on "Evaluating Support Groups for Asian American & Pacific Islander Cancer Survivors" with (name of the community agency). The purpose of this research study is to understand how ethnic specific cancer support services have assisted patients and their families in overcoming many of the challenges encountered throughout the cancer experience. We hope to use this information to develop programs in other communities for Asian American and Pacific Islander women who have or have had breast cancer.

Through discussion groups with members of the Filipino community who are breast cancer patients and survivors, we hope to find out how your community's social support resources and services helped, or could be improved to help you or your loved one's, through the cancer experience.

I am inviting you to participate in a discussion group with 6-10 other Filipinos because you are: a Filipino woman who has had Stage I-III breast cancer 1-5 years ago; a breast cancer survivor in remission; have not been diagnosed with another type of cancer; do not have any other major disabling medical or psychological disabilities that would prevent you from participating; and are 30 years or older. The discussion group will last about 1½ to 2 hours. We will hold this meeting at (designated location and time).

Your participation is totally voluntary and will be confidential. Your decision whether or not to participate will not affect your relationship with the community group in any way. If you decide to participate, you are free to withdraw your participation at any time without penalty. You will receive \$40 as a token of appreciation for sharing your thoughts and ideas for this project.

We hope you will consider helping us with this effort to assist us in learning about the needs of women with breast cancer and their families in your community.

UMPUKAN – PANGANGALAP NA SALITA
(Pasyente ng Kanser sa Suso o Naligtasan ang Kanser)

Suriin ang mga Suportang Serbisyo para sa mga Asyano Amerikano at
Taga-Isla Pasipikong mga Pasyenteng Naligtasan ang Kanser

Marjorie Kagawa-Singer, PhD, MN, RN
UCLA School of Public Health and Asian American Studies

Ako po ay si (pangalan nang empleyado). Ako po ay nagtatrabaho kaugnay ng proyekto sa UCLA tungkol sa “Suriin ang mga Suportang Grupo para sa mga Asyano Amerikano at Taga-Isla Pasipikong mga Pasyenteng Naligtasan ang Kanser” kasama ng Asian Pacific Health Care Venture. Ang layunin nitong sasali ay para maintindihan kung paano ang mga serbisyong pang-kanser na laan sa isang angkan o lipi ay nakatulong sa mga pasyente at kanilang pamilya, para malampasan ang mga hamon na kanilang nakaharap habang dinaranas ang kanser. Inaasahan namin na gamitin ang impormasyong ito upang bumuo ng mga programa sa iba pang mga komunidad para sa mga Asyano Amerikano at Taga-Isla Pasipikong babae na mayroon o nagkaroon ng kanser sa suso.

Sa pamamagitan ng umpukan o grupong talakayan ng mga Pilipino na may kanser sa suso o mga pasyenteng naligtasan ang kanser sa suso, inaasahan naming malaman kung paano kayong natulungan ng mga sosyal na suporta at serbisyo sa inyong komunidad, o kung paano mapabuti ang mga ito upang matulungan kayo at ang inyong mga minamahal, habang pinagdadaan ninyo ang kanser.

Inaanyayahan ko kayong sumali sa talakayan kasama ng 6-10 na kapwa-Pilipino kasi kayo po ay: Pilipina na nagkaroon ng Stage I-III na kanser sa suso nitong nakalipas na 1-5 taon; pasyenteng dating may kanser sa suso na pagbabawa? na; hindi nasabihan ng inyong doktor na kayo ay may iba pang uri ng kanser; walang ibang mahalagang medikal o sikolohikal na kapinsalaan na makakahadlang sa inyong pagsali; at kayo po ay 30 taon gulang o higit. Ang talakayan ay tatagal ng 1½ hanggang 2 oras. Ang miting ay gaganapin sa (napagkasuduan na lugar at oras).

Ang inyong pagsali ay lubos na kusang-loob at tratratuhin naming kompidensyal. Ang disisyon ninyong sumali o hindi ay hindi makakaapekto sa relasyon ninyo sa komunidad. Kung ang disisyon ninyo ay sumali, malaya kayong iurong ang inyong pagsali sa ano mang oras na walang kaparusahan. Kayo ay tatanggap ng \$40 bilang tanda ng pagpapahalaga sa pagbabahagi ng inyong mga palagay at ideya para sa proyektong ito.

Inaasahan naming isaalang-alang ninyo ang pagtulong sa aming pagsisikap para kami’y asistihan na malaman ang tungkol sa mga pangangailangan ng mga kababaihan na may kanser sa suso at ng kanilang mga pamilya sa inyong komunidad.

Evaluating Support Groups for Asian American & Pacific Islander Cancer Survivors

Focus Group
February 21, 2009
Asian Pacific Health Care Venture

SIGN-IN SHEET

First Name

Signature

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

INFORMATION SHEET TO PARTICIPATE IN RESEARCH
(Focus Group – Breast Cancer Patient or Survivor)

Evaluating Support Services for Asian American &
Pacific Islander Cancer Survivors

Marjorie Kagawa-Singer, Ph.D., M.N., R.N.
UCLA School of Public Health and Asian American Studies

You are invited to participate in a research study conducted by (*agency name*) and the UCLA School of Public Health, Department of Community Health Sciences. You were selected as a possible participant in this study because you are:

- 1) A Filipino woman who has had Stage I-III breast cancer 1-5 years ago,
- 2) A breast cancer survivor in remission,
- 3) Have not been diagnosed with another type of cancer,
- 4) Do not have any other major disabling medical or psychological disabilities that would prevent participation in the group discussion, and
- 5) Are 30 years or older.

PURPOSE OF THE STUDY – What is the study?

We would like to learn about you and the various ways in which you have been able to obtain the support and assistance you needed, and how other women might be helped through this experience.

PROCEDURES INVOLVED IN PARTICIPATING IN THE STUDY – What do I have to do?

If you volunteer to participate in this study, you will be asked to do the following:

- 1) Participate in a focus group, which is a group discussion with 6-10 other Filipino women who have had breast cancer. The group discussion will last about 1½ to 2 hours. The group discussion will be audiotaped, and you will have the opportunity to review, edit and erase any portion of the audiotapes that you do not want your comments noted.
- 2) Complete a questionnaire that will ask general information about you and about your experience with breast cancer. The questionnaire will take approximately 10-15 minutes to complete.

The study will ask you questions about your experiences with breast cancer. It will also ask you about how you have managed to overcome many of the challenges encountered throughout your cancer experience. Some examples of questions that will be asked in the focus group include:

- 1) How have you found the support you needed through the cancer experience?
- 2) What are other areas in which you feel women going through this experience might need assistance?
- 3) After being diagnosed with breast cancer, how has your everyday life changed?

POTENTIAL RISKS – What are the risks and possible problems if I take part in this study?

The possible risks involved may be temporary feelings of emotional discomfort related to the topic being discussed. We will try to ease any discomfort by conducting the discussion group in a place that would be comfortable and private, in which our group leader is experienced in working with women who have had breast cancer. If you would like to have further assistance, we can talk more privately or give you a list of community resources. At the beginning of the focus group session, the group leader will ask that all participants respect the confidentiality of the discussions; he/she, however, cannot guarantee that everyone will do so.

POTENTIAL BENEFITS TO SUBJECTS – How will this study help me?

Benefits to you include increased knowledge and understanding of other women's experience with breast cancer and their needs regarding social support groups and services, as well as other services and programs in your community.

PAYMENT FOR PARTICIPATION – What will I receive?

You will receive \$40 as a token of appreciation for your participation.

ANONYMITY – Who will know about what I say?

Your participation in this project is anonymous. No information that can identify you as an individual will be collected in this study. Your responses will be recorded on a form that does not have your name on it and cannot be connected to you in any way to anyone outside this research project.

PARTICIPATION AND WITHDRAWAL – Can I stop answering if I don't want to continue?

Your participation is **VOLUNTARY**. Your decision whether or not to participate will not affect your relationship with the community. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time without penalty. The investigator may withdraw you from this research if circumstances arise which warrant doing so. One example of such circumstances would be emotional discomfort or anxiety.

IDENTIFICATION OF INVESTIGATORS – Who can I talk to about this study?

If you have any questions or concerns about your participation in the research, please feel free to contact Dr. Marjorie Kagawa-Singer. She has had over 30 years experience working with women of all ethnic groups with breast cancer.

Marjorie Kagawa-Singer, R.N., M.N., Ph.D.

Principal Investigator

UCLA School of Public Health

650 Charles Young Dr. South

Community Health Sciences

Box 951772

Los Angeles, CA 90095-1772

(310) 825-9481

mkagawa@ucla.edu

If you are not comfortable speaking only English, please ask a friend, family member or outreach worker who speaks English to make this call with you.

RIGHTS OF RESEARCH SUBJECTS – What are my rights?

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this

Appendix F: Information Sheet

research study. If you have questions regarding your rights as a research participant, please feel free to contact the:

Office for Protection of Research Subjects (OPRS)
11000 Kinross Avenue, Suite 102
Box 951694
(310) 825-7122

Receipt of copy is indication that we have discussed each of the items listed on this information sheet.

FOCUS GROUP - PARTICIPANT CONSENT FORM
(Breast Cancer Patient or Survivor)

Evaluating Support Services for Asian American &
Pacific Islander Cancer Survivors

Marjorie Kagawa-Singer, Ph.D., M.N., R.N.
UCLA School of Public Health and Asian American Studies

You are invited to participate in a research study conducted by (*agency name*) and the UCLA School of Public Health, Department of Community Health Sciences. You were selected as a possible participant in this study because you are:

- 6) A Filipino woman who has had Stage I-III breast cancer 1-5 years ago,
- 7) A breast cancer survivor in remission,
- 8) Have not been diagnosed with another type of cancer,
- 9) Do not have any other major disabling medical or psychological disabilities that would prevent you from participating, and
- 10) Are 30 years or older.

PURPOSE OF THE STUDY – What is the study?

The study will ask you questions about your experiences with breast cancer. It will also ask you about how you have managed to overcome many of the challenges encountered throughout your cancer experience.

PROCEDURES INVOLVED IN PARTICIPATING IN THE STUDY – What do I have to do?

If you volunteer to participate in this study, you will be asked to do the following:

- 1) Participate in a focus group, which is a group discussion with 6-10 other Filipino women who have had breast cancer. The group discussion will last about 1½ to 2 hours. The group discussion will be audiotaped, and you will have the opportunity to review, edit and erase any portion of the audiotapes that you do not want your comments noted.
- 2) Complete a questionnaire that will ask general information about you and about your experience with breast cancer. The questionnaire will take approximately 10-15 minutes to complete.

We would like to learn about you and the various ways in which you have been able to obtain the support and assistance you needed, and how other women might be helped through this experience. Some examples of questions that will be asked in the focus groups include:

- 4) How have you found the support you needed through the cancer experience?
- 5) What are other areas in which you feel women going through this experience might need assistance?
- 6) After being diagnosed with breast cancer, how has your everyday life changed?

POTENTIAL RISKS – What are the risks and possible problems if I take part in this study?

The possible risks involved may be temporary feelings of emotional discomfort related to the topic being discussed. We will try to ease any discomfort by conducting the discussion group in a place that would be comfortable and private, in which our group leader is experienced in working with women who have had breast cancer. If you would like to have further assistance, we can talk more privately or give you a list of community resources. At the beginning of the focus group session, the group leader will ask that all participants respect the confidentiality of the discussions; he/she, however, cannot guarantee that everyone will do so.

POTENTIAL BENEFITS TO SUBJECTS – How will this study help me?

Benefits to you include increased knowledge and understanding of other women's experience with breast cancer and their needs regarding social support groups and services.

PAYMENT FOR PARTICIPATION – What will I receive?

You will receive \$40 as a token of appreciation for your participation.

ANONYMITY – Who will know about what I say?

Your participation in this project is anonymous. No information that can identify you as an individual will be collected in this study. Your responses will be recorded on a form that does not have your name on it and cannot be connected to you in any way to anyone outside this research project.

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If you have any questions or concerns about your participation in the research, please feel free to contact Dr. Marjorie Kagawa-Singer. She has had over 30 years experience working with women of all ethnic groups with breast cancer.

Marjorie Kagawa-Singer, R.N., M.N., Ph.D.
Principal Investigator
UCLA School of Public Health
650 Charles Young Dr. South
Community Health Sciences
Box 951772
Los Angeles, CA 90095-1772
(310) 825-9481
mkagawa@ucla.edu

Appendix G: Consent Form

If you are not comfortable speaking only English, please ask a friend, family member or outreach worker who speaks English to make this call with you.

RIGHTS OF RESEARCH SUBJECTS – What are my rights?

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research participant, please feel free to contact the:

Office for Protection of Research Subjects (OPRS)
11000 Kinross Avenue, Suite 102
Box 951694
(310) 825-7122

In signing this document, I state that I have been given verbal and written information about participating in the group discussion on support group services for breast cancer survivors. This information that was give to me includes the fact that my participation is voluntary, a description of everything I will be asked to do, how the information about me will be kept anonymous, what I will gain, and what concerns I may have from participating. I have also been told that I can call the UCLA Office for the Protection of Research Subjects listed above with questions about the research and with questions about my rights as a research subject.

Signature of Participant

Date

Komen – “Evaluating Support Groups” Project
Survivor Questionnaire

DATE: _____

EVENT SITE: _____

1. Age Group: 18-29 30-39 40-49 50-59 60-69 70+

2. What is your current marital/relationship status?

- Never Married* *Married* *Living with Partner*
 Divorced *Separated* *Widowed*

3. Who lives in your household? (Please check all that apply)

- Spouse/Partner Sibling Child Friend
 Parents Relative (Cousin, Aunt, Nephew, etc.) Other

4. How many children do you have? _____ None

5. In what country were you born?

6. About how many years have you lived in the United States?

7. What is the highest grade of education you have completed and received credit for?

In your home country	In the United States
<input type="checkbox"/> No formal education in home country	<input type="checkbox"/> No formal education in the U.S.
<input type="checkbox"/> Grade school (1-8)	<input type="checkbox"/> Grade school (1-8)
<input type="checkbox"/> High school (9-12)	<input type="checkbox"/> High school (9-12)
<input type="checkbox"/> 4-year college or university	<input type="checkbox"/> 4-year college or university
<input type="checkbox"/> Graduate or professional school	<input type="checkbox"/> Graduate or professional school
<input type="checkbox"/> 2-year junior or community college	<input type="checkbox"/> 2-year junior or community college
<input type="checkbox"/> Vocational, business or trade school	<input type="checkbox"/> Vocational, business or trade school
<input type="checkbox"/> ESL/Adult School	<input type="checkbox"/> ESL/Adult School

8. Do you attend any religious group meetings or gatherings?

- Yes No

Appendix H: Survivor Questionnaire

9. What is your religious background? _____

10. What is your current employment status?

- | | |
|---|--|
| <input type="checkbox"/> Working full-time | <input type="checkbox"/> Working part-time |
| <input type="checkbox"/> Laid-off/On strike | <input type="checkbox"/> Retired |
| <input type="checkbox"/> Unemployed (looking for work) | <input type="checkbox"/> Unemployed (not looking for work) |
| <input type="checkbox"/> Disabled-on permanent disability | <input type="checkbox"/> Disabled-on temporary disability |
| <input type="checkbox"/> Full-time student | <input type="checkbox"/> Other (please specify): |
- _____

11. What was your employment status at the time of your breast cancer diagnosis?

- | | |
|---|--|
| <input type="checkbox"/> Working full-time | <input type="checkbox"/> Working part-time |
| <input type="checkbox"/> Laid-off/On strike | <input type="checkbox"/> Retired |
| <input type="checkbox"/> Unemployed (looking for work) | <input type="checkbox"/> Unemployed (not looking for work) |
| <input type="checkbox"/> Disabled-on permanent disability | <input type="checkbox"/> Disabled-on temporary disability |
| <input type="checkbox"/> Full-time student | <input type="checkbox"/> Other (please specify): |
- _____

12. At the time of your breast cancer diagnosis, did you have any family member(s) who depended on your income? Yes No

13. What type of health insurance do you have?

- Private Medicare Medi-Cal Medicare & Medi-Cal
 MSI (Medical Service for Indigents) Other (please specify):
- _____

14. Is your insurance adequate to cover your medical care? Yes No

15. What year were you diagnosed with breast cancer? _____

16. Was your breast cancer diagnosed at an early or late stage?

- Pre-Stage (Stage 0) Early stage (Stage 1 or 2) Middle stage (Stage 3)
 Late stage (Stage 4) Refused Don't know

17. What were your treatment choices? (Please check all that apply)

- Radiation Chemotherapy Lumpectomy
 Mastectomy Herceptin Hormones
 Other (please specify): _____

18. What type of treatment(s) did you receive?

- Radiation Chemotherapy Lumpectomy
 Mastectomy Herceptin Hormones
 Other (please specify): _____

Appendix H: Survivor Questionnaire

19. Where did you get treatment?

Country _____

Location (Examples: Hospital, Clinical, etc.) _____

20. When did you get treatment (timeframe)? Month(s) _____

Year _____

21. Did you experience any side effects from your treatment? Yes No

22. Are you taking any medications now for your side effects? Yes No

22a. If YES, which medications and for which side effects?

23. In what ways are you/have you been connected with or become more aware of breast cancer among the Filipino community? (Please check all that apply)

I have/had breast cancer

Immediate family member has/had breast cancer

Extended family member has/had breast cancer

Friend has/had breast cancer

Work with patients with breast cancer

Facilitate a breast cancer support group

Member/participant/volunteer/advocate of a health organization dedicated to eliminating cancer (American Cancer Society, American Lung Association, etc.)

Other _____

Thank you for completing this questionnaire!!!

FOCUS GROUP GUIDE for PATIENTS/SURVIVORS

Introduction: Thank you so much for coming to assist us with this effort! Your ideas and needs are very important to this project and will help improve the social support services available to other Filipino patients and survivors like you who are dealing with cancer. We hope your discussions will help us to work with your community leaders to improve the resources and services to assist you and other Filipinos most effectively.

Please answer the questions truthfully and to the best of your ability. There are no right or wrong answers. We are here to facilitate the discussion and learn from you. Our main goal is to hear about your experiences and your opinions.

DIAGNOSIS

1. How was your breast cancer first detected?
Probe: When, where, why
2. What do you think caused the cancer?
3. What was your reaction when you were told you had cancer?

SUPPORT DURING DIAGNOSIS

4. When you were first told about your diagnosis of cancer, what kinds of support did you receive, and from whom?
Probe: Kinds of support (social support, psychological support, medical, informational, functional); supporters (partner, family member, caregiver)
5. What was the most helpful for you during your diagnosis?
6. What would have been helpful for you during your diagnosis?
7. What support, if any, did you expect from your partner/family members?
Probe: What did you need that they did not or were not able to provide?
8. If they provided support or help, how did they know what you needed?

SUPPORT DURING TREATMENT

9. What type of treatment did you receive for the breast cancer?
Probe: Treatment types, duration, completion date
10. Who made the decision for the type of breast cancer treatment you had?
Probe: Who was involved? Were there any cultural aspects that affected your decision making process?

Appendix I: Focus Group Guide

11. Did you experience any side effects from your treatment?
12. What types of traditional treatments did you use?
13. How do you feel about the different kinds of healing treatments that you have used? Did they help you?
14. What types of help/support/assistance did you receive during your cancer treatments?
Probe: In addition to the support/assistance (social support, psychological support, medical, informational, functional) that you described that your partner/family/caregiver provided, who else offered assistance and how did they help?
15. What was most helpful for you during your treatment?
Probe: Who was most helpful?
16. In looking back, what more could have been done?
17. Without this help, how did you manage?
18. How has breast cancer affected your life?
Probe: Cultural pride, stigma associated with illness, traditional view of Filipino women having to uphold an image of strength (i.e., gender roles), loss of identity, role as partner, role in the family, etc.
19. What did doctors/medical staff tell you or suggest you do or go to?
20. Did you have any problems understanding what the doctors or nurses told you about breast cancer?
Probe: Did you address these problems? If so, how?
21. What was unclear in the doctor's explanation to you about your breast cancer diagnosis? Treatment(s)? Afterwards for follow-up care?
22. Overall, how would you describe the resources and support that the doctors and medical staff gave you during your cancer diagnosis and treatment?
23. How has your health condition affected your ability to fulfill your roles and responsibilities to your partner/family/friends?
Probe: What are your perceived roles and responsibilities?

SUPPORT DURING POST-TREATMENT

24. Since completing your cancer treatments, what kinds of follow-up care are you receiving?
25. What kinds of help/support/assistance, if any, have been helpful for you since completing your treatment?
Probe: Was anyone critical in providing such help?

26. What kinds of help/support/assistance would be helpful for you now?
Probe: Kinds of support (social support, psychological, medical, informational, functional); supporters (partner, family member, caregiver)
27. Without this help, how did you manage?

SEXUALITY QUESTIONS

Now, I would like to ask you some questions about a sensitive topic. We are seeking your thoughts and experiences about your feelings about your femininity and sexual relationship with your husband/partner to gain a sense of how we can best meet the needs of other Filipino cancer patients and survivors. Some of the questions may be embarrassing, but they are important questions because many women with breast cancer report such changes. We would greatly appreciate your honest opinions, feelings, and experiences.

28. What was the effect of breast cancer on how you feel about your body?
- Probe #1: How has breast cancer affected how you feel about your body and your sexuality (interest in sexual intimacy, sense of womanhood)?
- Probe #2: Does your partner embrace, kiss or caress you? Has this changed?
- Probe #3: Has the frequency of sexual activity decreased?
- Probe #4: Have you been sexually active since your cancer diagnosis?
- Probe #5: Do you have difficulty becoming sexually aroused?

SUPPORT GROUP

Now, I'd like to ask you about your experiences with support groups.

29. During your cancer experience, did you ever join a support group?
30. What did you consider in making the decision to join a support group?
Probe: Was there anyone who helped you in the decision making process?

SUPPORT GROUP SERVICES AND RESOURCES

31. What types of support group services have you attended?
Probe: Provide examples of support group services
32. What did you feel it might provide for you?
33. What motivated you to go?

Appendix I: Focus Group Guide

34. What were your expectations and needs of this support group?
35. How often did you attend the support group meetings?
36. Did your participation in the support groups change your view of life after cancer treatment ends?
37. Did your participation in the support groups change your view of survivorship?
38. How has this group helped you during your cancer experience?
39. How does this support group experience differ from the support you have received from your partner/family?
Probe: What has been gained from the support group process? (Increased confidence and healing)

RELIGION/SPIRITUALITY

40. Are you religious/spiritual?
Probe: Denomination, church
41. In what way did faith help you during your breast cancer experience?
42. In what ways did your church help you?
43. What else might have been provided to you by your church that would have helped you during your breast cancer experience?

CLOSING

44. Are there any areas we haven't covered that you feel would be important for us to know about Filipino breast cancer patients and survivors and their social support networks?
45. Closure

Thank you very much for your time and help with this interview. [*Distribute \$40 gift of appreciation to participants*]. Your answers are very important in our efforts to improve the resources and services available for cancer patients and their families. Thank you for your help in this effort. If you think of any other suggestions you would like to tell us, please call me or (*referring agency staff member*). We appreciate your help very much.

Receipt for Gift of Appreciation

Evaluating Support Services for Asian American &
Pacific Islander Cancer Survivors

Marjorie Kagawa-Singer, Ph.D., M.N., R.N.
UCLA School of Public Health and Asian American Studies

I have been offered and accept the Thank You gift for participating in the *UCLA Evaluating Support Services for Asian American & Pacific Islander Cancer Survivors Project* group discussion.

(Print Name)

(Signature)

(Date)

I have been offered and **do not accept** the Thank You gift for participating in the *UCLA Evaluating Support Services for Asian American & Pacific Islander Cancer Survivors Project* group discussion.

(Print Name)

(Signature)

(Date)

Appendix K: Codebook

SUPER CODES	MAJOR CODES	MINOR CODES	SUB-CODES	NOTES
A. Support Group (SG)	1. Elements of Support Group (Elements)	a. Supportive-Expressive (SE)	i. Feel (Feel) ii. Share emotions (ShareEmot) iii. Want to be understood (Understood)	
		b. Psycho-Educational (PE)		
		c. Coping Skills (CS)		
		d. Health Education/ Informational (HE/Info)		
		e. Empowerment (Empower)		
		f. Advocacy (Advoc)		
	2. Experience (Exper)	a. Comfort level (ComfLevel)		
		b. Family Support (FamSupp)		
	3. Reason for Attendance (Reason)	a. To attend (Attend)	i. Educational information provided (EduInfo-Prov) ii. Suggested by others (SuggOthers) iii. Share cancer experience (ShareCAExp) iv. Learn from others (Learn) v. Build community (BldComm) vi. Chance to do other activities (ChanceOthActs) vii. Services & resources provided (SrvsResProv) viii. Language (Lang)	Share cancer exper.: - Normalization (Normalize) - Support (Support) - Remove stigma (Remove Stigma) - Ability to discuss difficult topic (DiscussDiffTop) - Common beliefs & practices (CommonBel-Prac) - Community inclusion of family (CommInclu-Fam)

Appendix K: Codebook

SUPER CODES	MAJOR CODES	MINOR CODES	SUB-CODES	NOTES
		b. Not to attend (NotAtt)	i. Time (Time) ii. Transportation (Transp) iii. Lack of cultural sensitivity (LackCultSens)	
	4. Feedback & Suggestions (FeedSugg)	a. Changes/ Improvements (Change- Improve)		
B. Stages (Stages)	1. Detection (Detection)	a. Self (Self)		
		b. Partner (Part)		
		c. Provider (Nurse, Physician) (Prov)		
		d. Screening (Screen)		
		e. Recurrence (Recurr)		
		f. Pain (Pain)		
		g. Other (Other)		
		h. Support during Detection (Support)	i. Social (Soc) ii. Psychosocial (Psych) iii. Medical (Med) iv. Informational (Info) v. Functional (Includes Financial) (Funct) vi. Religious (Relig)	<i>Financial:</i> - Work - Insurance - Child care
		i. Reaction to Detection (Reaction)	i. Personal (Personal) ii. Family (Family) iii. Friends (Friends)	
		j. Worries about Detection (Worries)	i. Accuracy of tests (Accuracy- Test)	

Appendix K: Codebook

SUPER CODES	MAJOR CODES	MINOR CODES	SUB-CODES	NOTES
B. Stages (Stages)	2. Diagnosis (Diag)	a. Support during Diagnosis (Support)	<ul style="list-style-type: none"> i. Social (Soc) ii. Psychosocial (Psych) iii. Medical (Med) iv. Informational (Info) v. Functional (Includes Financial) (Funct) vi. Religious (Relig) 	<i>Social:</i> - Church - Community - Family/Friends - Work <i>Financial:</i> - Work - Insurance - Child care
		b. Services & Resources (SrvsRes)	<ul style="list-style-type: none"> i. Religion/Spirituality (Relig/Spirit) ii. Conferences (Confer) iii. Education (Educ) 	
		c. Cause (Cause)	<ul style="list-style-type: none"> i. Genetic (Genetic) ii. Food (Food) iii. Stress (Stress) iv. Lifestyle (Life) v. Environmental (Environ) vi. Hormones (Horm) vii. Metaphysical /Spiritual (Meta/Spirit) viii. Don't Know (DK) ix. Other (Other) 	<i>Metaphysical/ Spiritual:</i> - Curse
		d. Reaction to Diagnosis (Reaction)	<ul style="list-style-type: none"> i. Personal (Personal) ii. Family (Family) iii. Friends (Friends) iv. Meaning of cancer (MeaningCA) 	<i>Personal:</i> - Followed prevention/ screening practices - Guilt (Guilt) - Religion/Spirituality

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SUPER CODES	MAJOR CODES	MINOR CODES	SUB-CODES	NOTES
B. Stages (Stages)		e. Worries about Diagnosis (Worries)	i. Pre-treatment side effects (PreTxSideEff) ii. Accuracy of mammogram (AccurMamm) iii. Survival/death & dying (Surv/Death-Dying)	
	3. Treatment (Tx)	a. Support during Treatment (SuppDurTx)	i. Social (Soc) ii. Psychosocial (Psych) iii. Medical (Med) iv. Informational (Info) v. Functional (Includes Financial) (Funct) vi. Religious (Relig)	Social: - Church - Community - Family/friends - Work Financial: - Work - Insurance - Child care
		b. Treatment Modalities (TxModal)	i. Radiation (Radiation) ii. Chemotherapy (Chemo) iii. Lumpectomy (Lump) iv. Mastectomy (Mastect) v. Herceptin (Hercep) vi. Hormones (Hormones) vii. Other non-traditional medication (OthNon-TradMed) viii. Traditional medication (TradMed) ix. Other (Oth)	Traditional medication: - Tamoxifen

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SUPER CODES	MAJOR CODES	MINOR CODES	SUB-CODES	NOTES
B. Stages (Stages)	3. Treatment (Tx)	c. Effects on Daily Living (EffDailyLive)	i. Fatigue (Fatigue) ii. Activities of daily living (ActDailyLive) iii. Depression (Depress) iv. Change in eating/sleeping (ChangeEat-Sleep) v. Financial (Finan) vi. Emotional (Emot) vii. Pain (Pain)	<i>Financial:</i> - Work - Insurance - Child care <i>Activities of daily living:</i> - Feeding self - Using Bathroom - Bathing Self - Dressing Self
		d. Decision (Decision)	i. Self (Self) ii. Partner/Family (Part/Fam) iii. Barriers/Challenges (Barr/Chall) iv. Provider (Prov) v. Gender roles (Gend-Roles) vi. Provider Recommendation (Prov-Recommend) vii. 2 nd opinion (2ndOp) viii. Religious community (ReligComm) ix. Reaction to decision (ReactDecis)	

SUPER CODES	MAJOR CODES	MINOR CODES	SUB-CODES	NOTES	
B. Stages (Stages)	3. Treatment (Tx)	e. Reaction to Treatment (ReactTx)	i. Family (Family) ii. Anxiety (Anx) iii. Side effects (SideEff) iv. Care received (CareRecd) v. Attitude/concern (Att/Conc) vi. Appearance (Appear) vii. Effects on faith (EffFaith)		
		f. Timeliness (Timeliness)	i. Delayed care (DelayCare) ii. Access to Care (AccessCare)		
	4. Post-Treatment (PostTx)	a. Support Post-Treatment (Support)	i. Social (Soc) ii. Psychosocial (Psych) iii. Medical (Med) iv. Informational (Info) v. Functional (Includes Financial) (Funct) vi. Religious (Relig)	Financial: - Work - Insurance - Child care Social: - Church - Community - Family/Friends - Work	
		b. Types (Types)	i. Check-ups (ChkUps) ii. Medication (Med) iii. Activities (Activ)	Activities: - Attendance at educational/informational forums	
	C. Survivorship (Surv)	1. Quality of Life (QOL)	a. Well Being (WellBeing)	i. Diet (Diet) ii. Exercise (Exer) iii. Pampering (Pamper)	
			b. Social (Soc)	i. Self (Self) ii. Family (Family) iii. Friends (Friends)	
c. Emotional (Emot)					

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SUPER CODES	MAJOR CODES	MINOR CODES	SUB-CODES	NOTES	
C. Survivorship (Surv)	1. Quality of Life (QOL)	d. Functional (Funct)	i. Physical (Phys) ii. Fatigue (Fatigue)		
		e. Occupational (Occup)			
		f. Independence (Indep)			
	2. Perspective about Survivorship (Perspec)	a. Caring for Others (CareOth)			
		b. Death & Dying (DeathDying)			
		c. Ways to Create Meaning (WaysCreate-Mean)			
		d. Lifestyle (Lifestyle)	i. Reprioritization (Reprior)		
		e. Strength/Confidence (StrenConf)			
	3. Feelings about Survivorship (FeelAbSurv)	a. Normalcy (Normalcy)			
		b. Fear of recurrence (FearRecurr)			
		c. Feeling less than (FeelLess-Than)			
	4. Religion/Spirituality (Relig/Spirit)	a. Prayers (Prayers)		i. Increase in religious/spiritual activities (IncrRelig-SpiritAct)	
		b. Denomination (Denom)			
		c. Support/Encouragement (Supp/Encour)		i. Spiritual (God) (Spirit/God) Material (Congregation) (Mater/Congre)	
	5. Sexuality (Sexuality)	a. Intimacy (Intimacy)			
		b. Womanhood (Womanhood)			
		c. Sexual activity (Sex-Act)			

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SUPER CODES	MAJOR CODES	MINOR CODES	SUB-CODES	NOTES
C. Survivorship (Surv)	5. Sexuality (Sexuality)	d. Appearance (Appear)	i. Insecurity (Insecurity) ii. Shame (Shame)	
		e. Priority is self care (PriorSelfCare)		
D. Cultural Tailoring (CultTail)	1. Assets/ Successes (Assets/Succ)	a. Cultural connectedness (CultConnect)		
		b. Familial Connection (FamilyConn)		
	2. Barriers/Challenges (Barr/Chall)	a. Language (Lang)		
E. Communication (Communi- cate)	1. Patient/Provider (Pat/Prov)	a. Verbal (Verb)	i. Language (Lang) ii. Ability to have questions answered (QuestAnswer) iii. Ability to obtain/ provide information (Obtain/Prov- Info) iv. Inclusion of family (IncluFam) v. Cultural sensitivity (CultSensitiv)	
			b. Nonverbal (NonVerb)	
	2. Family (Family)	a. Verbal (Verb)		
		b. Nonverbal (NonVerb)		
	3. Friends (Friends)	a. Verbal (Verb)		
		b. Nonverbal (NonVerb)		
	4. Employer (Employ)	a. Verbal (Verb)		
		b. Nonverbal (NonVerb)		
	5. Survivors (Surv)	a. Verbal (Verb)		
		b. Nonverbal (NonVerb)		

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SUPER CODES	MAJOR CODES	MINOR CODES	SUB-CODES	NOTES	
F. Ways of Coping (WaysCope)	1. Support from Family/Friends (SuppFam/Fri)	a. Responsibilities Shared (Respon-Share)			
	2. Receive Prayers/ Religious Attribution (RecPray/-ReligAtt)				
	3. Avoidant Behaviors (AvoidBehav)	a. Isolation (Isolation)			
	4. Impulsivity (Implusiv)				
	5. Seek Support (SeekSupp)				
	6. Seek Information (SeekInfo)	a. Social (Soc)			<i>Examples of info sought:</i> - Website - Hospital - Support group - Family/friends - Provider - Spiritual healer
		b. Psychosocial (Psych)			
		c. Medical (Med)			
		d. Functional (Includes Financial) (Funct)			
		e. Religious/- Spiritual (Relig/Spirit)	i. Ghosts/Spirits (Ghost/Spirits)		
	7. Indigenous Healer (IndigHeal)	a. Social (Soc)			
		b. Psychosocial (Psych)			
		c. Medical (Med)			
		d. Functional (Includes Financial) (Funct)			
		e. Religious (Relig)	i. Ghosts/Spirits (Ghost/Spirits)		
8. Problem Solving (ProbSolv)					

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SUPER CODES	MAJOR CODES	MINOR CODES	SUB-CODES	NOTES
F. Ways of Coping (WaysCope)	9. Humor (Humor)			
	10. Help Others (HelpOth)	a. Walks (Walks)		
		b. Spokesperson (SpokesPer)		
		c. Advocacy (Advoc)		
		d. Other (Other)		
	11. Religious (Relig)			
	12. Self-Care (SelfCare)			
	13. Self-Sufficiency (SelfSuf)			
14. Emotional Expression (EmotExp)				
G. Belief about Cancer (BeliefAbCA)	1. Cause (Cause)			
	2. Meaning (Mean)			
	3. Attitudes (Att)	a. Killing Cancer (KillICA)		- May include acceptance
H. Relationship (Relation)	1. Family (Family)	a. Family responsibilities (FamRespons)	i. Worried about others first (WorryAbOth1st) ii. Burden on others (BurdenOth)	
		b. Gender Roles (GendRoles)		
	2. Friends (Friends)			
	3. Change in Relationship Dynamics (ChangeRelationshipDynam)			
I. Trust (Trust)	1. Family (Family)			
	2. Friends (Friends)			
	3. Provider (Prov)			
	4. Medical Community (MedComm)			

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SUPER CODES	MAJOR CODES	MINOR CODES	SUB-CODES	NOTES
I. Trust (<i>Trust</i>)	5. Religious/ Spiritual Community (Relig/Spirit- Comm)			
	6. Support Group Community (SGComm)			
	7. Ethnic community (EthnicCom m)			
J. Needed Services & Resources (NeedSrvs- Res)	1. Medical (Med)			
	2. Professional (Prof)			
	3. Education (Educ)			
	4. Empowermen t (Empower)			
K. Sources of Support (SourceSupp)	1. Spouse/Part- ner (Spouse/- Part)			
	2. Children (Child)	a. Adult children (AdultChild)	i. Male (Male) ii. Female (Female)	
		b. Young children (YoungChild)	i. Male (Male) ii. Female (Female)	
	3. Other Family Member(s) (OthFam- Memb)			
	4. Friend(s) (Friend)			
	5. Provider (Prov)			
	6. Medical Community (MedComm)			
	7. Religious/ Spiritual Community (Relig/Spirit- Comm)			
	8. Support Group Community (SGComm)			

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SUPER CODES	MAJOR CODES	MINOR CODES	SUB-CODES	NOTES
K. Sources of Support (SourceSupp)	9. Ethnic Community (Ethnic-Comm)			
	10. Media (Media)	a. Internet (Internet)		
		b. Other (Oth)		
L. Valence (Valence)	1. Positive (Pos)			
	2. Negative (Neg)			

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