

## Developing *Tautai Lavea'i*, a Breast Cancer Patient Navigation Program in American Samoa

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### Abstract

This article focuses on development of the psychosocial-cultural components of a breast cancer patient navigation program (PNP) in the medically underserved, albeit culturally-rich Territory of American Samoa. Efforts to reduce cancer morbidity and mortality in American Samoa must necessarily consider the territory's limited cancer resources and indigenous culture, as well as the individuals at risk for poor health outcomes and premature death. Within this complex set of challenges resides the prospect of health equity and opportunities for advancing service innovations that meaningfully plait native ways of knowing with Western evidence-based practice. Increasing adherence to diagnostic and treatment procedures is of significant concern to the American Samoa Cancer Community Network who initiated this inquiry to assess patients lost to follow-up, describe treatment-seeking influences, and identify cultural preferences for inclusion in a PNP tailored on *fa'aSamoa* or the Samoan worldview.

### Keywords

adherence • American Samoa • breast cancer • indigenous population • patient navigation • social work intervention

## **BACKGROUND**

### **BRIEF HISTORY**

The Samoan archipelago sits at the equator in the west central region of the Polynesian Triangle, or that area formed by Hawai'i at the northern apex, Rapa Nui (Easter Island) at the southeastern vertex, and Aotearoa (New Zealand) at the southwestern vertex (Polynesian Voyaging Society [PVS], 2010). Settled in about 1000 B.C., the indigenous people of the Samoan archipelago perpetuated a thriving society characterized by a highly organized social structure and a culture rich in collectivist values with traditions that included medicinal healing and oceanic navigation (American Samoan Government [ASG], Department of Commerce, 2006; Whistler, 1996). The Samoan archipelago is sometimes referred to as the cradle of Polynesia because ancient people from this region spawned the earliest migratory voyages which resulted first in the settlement of the Cook, Marquesas and Society Islands and in the subsequent settlement of Hawai'i, Rapanui, and Aotearoa (PVS, 2010). Samoan contact with the US began 1827 when the US Navy first used Pago Pago (on Tutuila island) as a fueling station. US occupation of the eastern Samoan archipelago has been continuous since that time. In 1929, the US assumed sovereignty of Tutuila, the largest and most populous island, as well as the four islands and two coral atolls in immediate proximity of it. These islands and atolls became known as the Territory of American Samoa (AS). Through the covenant agreement binding the US and AS, the territory is subject to US federal laws and eligible to apply for US federal funding. Natural born residents are considered US Nationals who may travel freely between AS and the US (American Samoan Government [ASG], Department of Commerce, 2006).

### **CULTURALLY-RICH, RESOURCE-CONSTRAINED**

Currently, there are about 68,000 territorial residents, 96% of who are indigenous Samoan (i.e., of full or part Samoan ethnicity) (ASG, Department of Commerce, 2008). AS remains rich in indigenous cultural and linguistic traditions and *fa'aSamoa* (Samoan worldview, culture) permeates every aspect of modern life. In the contemporary idiom, *fa'aSamoa* is reflected in the land tenure and village governance systems. Approximately 90% of the land is held in communal (village) ownership and administered by *matai* (titled head of *aiga* or extended family) through a centuries-old family governance system. This system and its concomitant rituals and practices are sustained by an intricate network of relationships that prize family/community well-being and relational reciprocity (ASG, Department of Commerce, 2006, 2008). While rich in tradition, the territory is resource-poor with about 73% of the indigenous population living at or below the US federal poverty level (American Samoa, Office of the Governor, 2007). In recognition of the population's

low socioeconomic status and constrained medical resources, the US Federal and AS governments provide block Medicaid payments (i.e., Medicaid eligibility is not determined on an individual, case-specific basis as it is in the US) to Lyndon Baines Johnson Tropical Medical Center (LBJ TMC), the territory's sole medical entity. Built in 1968, LBJ TMC is a 150-bed tertiary acute care facility with a mission to serve the entire AS population (American Samoa Medical Center Authority, 2009). Funding constraints at LBJ TMC have resulted in a lack of provider continuity and case coordination which contributes to fragmentation in service delivery and the likelihood that patients may be lost to follow-up by the healthcare system. Over the last several years, the AS government has functioned with a yearly deficit of \$10 million and this has necessitated difficult choices in health services financing (ASG, Department of Commerce, 2006). Thus, patients are not designated a primary care physician who might oversee their overall clinical care, social workers must focus on discharge of acute care patients to the exclusion, *defacto* of patients seen on an outpatient basis, and outreach by public health nurses is limited (American Samoa Medical Center Authority, 2009).

#### CANCER CARE AND SERVICE NEEDS

In this environment of scarce health services, cancer is emerging as the second leading cause of death. Breast cancer is the single most commonly detected neoplasm among indigenous Samoan women and accounts for about eight percent of all cancer-related mortality (Ruidas, Adaoag, Tofaeono, & Seseapasara, 2004). AS is able to provide the three service components—screening mammograms, diagnostic mammograms and other tests, treatment—acknowledged as essential to reducing breast cancer mortality and morbidity (Ell et al., 2002; Press, Carraspquillo, Sciacca, & Giradina, 2008). By agreement, the AS Department of Health offers routine screening mammograms and LBJ TMC provides diagnostic testing after an abnormal screening and treatment when cancer is detected. However, preventive medicine and cancer screening are underutilized by AS patients; this potentiates delayed diagnosis and treatment of breast and other types of carcinoma (Hubbell, Luce, & McMullin, 2005).

While AS shares with the US a commitment to quality cancer care, the range of diagnostic tests and treatments options available to AS cancer patients are considerably more limited than what is available to patients in the US. Pathology reports are produced by the local laboratory, but all suspicious, abnormal, or inconclusive results must be sent to Hawai'i for confirmation, the latter of which may result in critical delays. Further, there is an absence of trained specialists (i.e., only one physician trained and board certified in oncology) and advanced treatment options (i.e., radiation, chemotherapy, hormonal therapy except for Tamoxifen, and clinical trials are not available). Patients with conditions that cannot be properly treated at LBJ TMC are considered for

subsidized off-shore referral. However, there is an average of about 400 referrals made each year and funding for off-shore care is limited. A written policy defines eligibility for transfer. Notably as ineligible are cases of terminal cancer and other conditions for which the expected survival rate, even with treatment, is less than six months. Patients not subsidized by the hospital must rely on their own financial resources if they wish to continue care (Ruidas et al, 2004). Given that the majority of families live at or below the poverty level, the cost of off-shore care is prohibitive.

AS has a tumor registry, but continuous documentation of unduplicated cancer cases and treatment outcomes has been compromised by funding constraints; thus, hindering the planning of a more coordinated system of care that might facilitate patient adherence and minimize patients lost to follow-up (Ruidas et al., 2004). Anecdotal provider accounts consistently suggest that many AS women do not complete breast cancer treatment and are lost to follow-up by the healthcare system. These women may return to care when disease symptoms are advanced and when the likelihood of treatment success is limited (personal communication with V. W Tofaeono, MD, Assistant Medical Director and Oncologist, LBJ TMC, on October 1, 2008). Multiple and interacting factors are speculated to influence patients' non-adherence to cancer care procedures, including: (a) health systems-related factors such as the lack of care continuity, case coordination, and uncertain access to essential chemotherapy, radiation, and other advanced treatments, (b) individual and family factors such as negative beliefs about cancer and its treatment, and (c) cultural norms that preference use of indigenous Samoan medicine over Western allopathic care, or sporadic use of both Samoan and Western medicine which may cause critical delays in treatment (Little, 2009; Mishra, Hess, & Luce, 2003; Puaina, Aga, Pouesi, & Hubbell, 2008). Patients using indigenous Samoan medicine may delay seeking treatment from LBJ TMC or may initiate cancer care services, but not complete treatment to therapeutic endpoints. Both scenarios potentially, contribute to cancer mortality and morbidity. Patient non-adherence and lack of systems follow-up are of significant concern to the AS cancer care community.

## RESEARCH AIMS

The complexity and impersonal nature of conventional Western healthcare systems are known to discourage cancer-related adherence of minority/indigenous women, even when positive intent is present (Schwaderer & Itano, 2007). Patient navigation is a health services innovation that focuses on the interaction of the individual patient in the healthcare system and was designed to assist medically underserved, minority women referred to cancer care (Freeman, 2006). Empirical evidence suggests that patient navigation programs (PNP) are a promising means for promoting timely completion of recommended diagnostic and treatment

services and decreasing the number of patients lost to follow-up (Darnell, 2007; Ell, Vourlekis, Lee, & Xie, 2007; Freeman, 2006, Masi, Blackman, & Peek, 2007). While navigation programs in the US vary with regard to services offered, central to most programs is the use of a trained navigator who assists health services consumers through the barriers and complexities of the healthcare system and who serves as a critical point of contact between patients, families, and members of the multi-disciplinary health care team. Navigation may be an important adjunct to cancer care services in AS. The preliminary research described in this article is part of a larger effort to develop and test the feasibility of *Tautai Lavea'i*, a hospital-based breast cancer patient navigation program in AS. The name "*Tautai Lavea'i*" is grounded in the Samoan tradition of oceanic navigation, with "*tautai*" referring to steering or navigating (a canoe) and "*lavea'i*" referring to "rescue or help that extricates one from harm." By extension, "*Tautai Lavea'i*" refers to help that extricates a patient from the harm of advanced cancer or death and navigates a safe and healthy course. Preliminary research efforts were initiated by the American Samoa Cancer Community Network (ASCCN), a community-based research organization supported by the National Cancer Institute, Center to Reduce Cancer Health Disparities (U01CA114590, V. W. Tofaeono, Principal Investigator). LBJ TMC collaborated as an organizational partner and University of Hawai'i researchers assisted in data collection and analyses. Aims of this preliminary research were to: (a) assess adherence to diagnostic and treatment procedures and lost to follow up of women presenting at LBJ TMC with abnormal or suspicious breast cancer screening results, symptoms suggestive of breast cancer, and tentative or confirmed breast cancer diagnoses, (b) describe influences to treatment-seeking from the perspective of women receiving at least some of their breast cancer care at LBJ TMC, and (c) describe cultural constructs for use in the delivery of navigation services.

### **THEORETICAL – CONCEPTUAL FRAMEWORKS**

This research was informed by two theoretical-conceptual frameworks: DiMatteo and DiNicola's (1982) model for achieving patient compliance and Mulitalo-Lauta's (2000) *lalaga* model for social work practice with Samoans in the New Zealand context. The framework by DiMatteo and DiNicola is ecological in perspective and considers the influence of psychosocial and environmental determinants on adherence, or the process of steady devotion to health-related recommendations in order to reach therapeutic outcomes. In this empirically-derived heuristic, adherence intent and behavior are associated with knowledge relevant to health recommendations and with attitudes about the disease and its treatment, as influenced by cultural norms transmitted through family, church, and other groups with which individual patients identify.

Positive intention facilitates adherence but may not be sufficient by itself to enact adherent behavior. Factors enabling adherence might include emotional, tangible, and informational support from natural and professional networks. Disabling factors might include personal beliefs, cultural norms, and/or structural barriers such as the lack of access to a regular provider or to care coordination. Indicated are interventions capable of addressing individual well-being and social context (DiMatteo & DiNicola, 1982). Such interventions are especially crucial when intended for socioeconomically disadvantaged and culturally-grounded ethnic minorities in seeking care for cancer and other disease conditions (DiMatteo, 2003).

The *lalaga* model posited by Mulitalo-Lauta (2000) is specific to social work intervention with Samoans. In the Samoan language, the word “*lalaga*” means to “weave or plait”, as in the making of a *pandanus* mat. The model suggests that to be effective Western evidence-based practices need to be culturally-tailored on the values and practices of the group for whom the intervention is intended. Indicated are the integration or plaiting of values, practices, and metaphors consistent with *fa'aSamoa*. Mulitalo-Lauta identifies indigenous values and practices that include: *fa'aaloalo* (respect, courtesy, politeness), *gagana* (use of Samoan language), *agamalu* (humility), *osi aiga* (extended family is vital, all opinions are important), and *tausi aiga* (take care of family). While Mulitalo-Lauta's model was developed for use with Samoans living in Aoteroa (New Zealand), these cultural preferences may be relevant for integration in *Tautai Lavea'i*, a breast cancer patient navigation program (PNP) developed for Samoans in the AS context.

## PATIENT NAVIGATION

The Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 or PL 109-18 articulates the key activities of the PNP, including: (a) outreach to patients seeking care for cancer and other chronic diseases or CD, (b) coordination of psychosocial care for individuals seeking prevention or early detection services, or who following a screening or early detection service are found to have a symptom, abnormal finding, or diagnosis of cancer or other CD, (c) assistance in steering a course through healthcare system barriers and provision of patient advocacy, when indicated, (d) provision of social support (e.g., appointment reminders) that ensure patient's prompt adherence to recommended diagnostic and treatment procedures, (e) serves as a source of communication between the patient, patient's family, and members of the healthcare team, and (f) brokers resources on behalf of the patient (Darnell, 2007). Since the establishment of the inaugural PNP in 1990 (Freeman, 2006), more than 200 cancer programs throughout the US have included some form of PNP component (Darnell, 2007). Controlled trials of psychosocial oncology interventions indicate that PNP are

efficacious in assisting medically underserved women complete cancer diagnostic and treatment procedures (Masi et al., 2007). Pilot programs designed by and for Native Americans and Native Hawaiians have met with promising results (Braun, Allison, & Tsark, 2008; Petereit et al., 2008).

Masi and colleagues (2007) conducted a systematic review of intervention studies aimed at enhancing breast cancer screening, diagnosis, and treatment among minority women. Results from the review suggest that non-adherence is associated with women's fear of finding cancer, lack of understanding about recommended tests, concerns about treatment costs and logistics, and language or cultural differences. Interventions which were culturally-responsive and/or addressed financial and logistical barriers were more effective than reminder-based interventions, especially for women with fewer financial resources and/or no consistent history of mammography. Detected were several trials demonstrating the efficacy of psychosocial care management in promoting adherence to diagnostic and treatment procedures. Support was found for navigation programs like the Screening Adherence Follow-Up (SAFe) project (Ell et al., 2007) which used a social work care coordination approach and care plans based on a holistic assessment of patient needs and risk for non-adherence. Masi and colleagues conclude that interventions which assist patients in navigating health systems barriers seem justified and even necessary to reduce breast cancer disparities among medically underserved, ethnic minority women. Given the evidence, a PNP that provides strong coordination and that integrally plait indigenous values and practices into service delivery seems relevant for AS.

## **METHOD**

The paucity of AS-specific tumor registry and psychosocial oncology research led to our conducting developmental research that utilized a family of primarily, qualitative strategies (Creswell, 1994). First, a medical records audit (MRA) was used to obtain a description of treatment recommendations and frequencies of patient non-adherence and lost to follow-up by the health care system. Cases of abnormal/suspicious screening results, clinical symptoms suggestive of breast cancer, and/or tentative or confirmed diagnoses were identified through the LBJ TMC electronic data base (Oncology Site Manager software program). Cases were limited to the period of January 1, 2006 – December 31, 2008, or that period coinciding with electronic archival of patient data and generally, believed to be more complete than earlier “paper” charts. The final sample was comprised of 30 cases. Cases included for MRA were stripped of names and contact information prior to review. The MRA used an audit form derived for this research. Operational definitions of timely adherence and lost to follow-up were based on LBJ TMC practice, as used by hospital medical and pathology staff. Variables were coded as dichotomous (i.e., yes/no to follow-up on diagnostic procedures, yes/no to follow-up on recommended treatments, yes/no to lost to follow-up by the healthcare system).



Second, a breast cancer survivors focus group (FG) was convened to describe barriers and facilitating factors to treatment-seeking from the lived experience of women receiving at least some of their cancer care in AS. Participants were recruited through a network of breast cancer support groups. The final sample included six Samoan women, five of who were long-term survivors ( $\geq 5$  years since initial diagnosis). The participant who was not a long-term survivor reported complying with recommended treatments available at LBJ TMC and was "hoping" to obtain off-shore referral for radiation and chemotherapy. All women were bi-lingual with some variation in English language proficiency. Age ranged from 31-72 years with a mean of 51 years. A content analysis (Krippendorff, 1980) of the FG discussion was performed using a priori categories (influences to treatment seeking: positive or negative, type of influence: person-, family-, culture-, or health systems- related).

Third, key informant interviews (KII) were conducted continuously to ensure accuracy in interpretation of clinical and cultural findings. Importantly, informants deepened understanding of relevant cultural constructs that might be relevant for use in the PNP. Informants were selected on the basis of diverse disciplinary training, direct cancer care practice at LBJ TMC, high proficiency in use of traditional and popular or contemporary Samoan language, and knowledge of indigenous culture. There were three informants; two males and one female.

Strategies were incrementally used, with data from the MRA informing the focus group inquiry. KII were continuously conducted. Figure 1 displays a summary of methodological procedures.

### **FIGURE 1: SUMMARY OF PROCEDURES**

1. Research receives approval from the LBJ TMC Institutional Review Board. Medical record audit (MRA) form is developed in collaboration with LBJ TMC oncologist and pathologist.
2. Cases are identified through the hospital data base (Oncology Site Manager software). Each case is audited by two independent coders from the research team. Providers' observations are noted. Numeric and unstructured text data is entered into Excel software.
3. Frequencies and some chi square testing are calculated. Content analysis is performed on text data. Emerging findings are discussed by research team with final interpretation reached through research team discussion and consensus agreement, in consultation with key informants.
4. Findings from the MRA inform the development of a semi-structured schedule of questions for use with breast cancer survivors' focus group (FG).



5. FG participants are recruited from a breast cancer survivors' support group network. Consistent with *fa'aaloalo* (courtesy), ASCCN staff extends a personal, face-to-face invitation to participate. Study information is provided and written informed consent is obtained prior to conducting FG.
6. FG is convened one week later and held at a community venue. Two female research team members (one of who is indigenous Samoan and bi-lingual) facilitate discussion. Discussion is audio-taped. Dinner is provided to express appreciation for FG participation.
7. Audio-taped FG discussion is transcribed verbatim. Remarks made in Samoan are translated into English. All transcribed material is entered into Excel software for data management and analysis. Responses are classified using a priori categories (e.g., health care system barriers to patient treatment seeking, culturally-based facilitating factors). A content analysis is performed.
8. Emerging themes and issues from FG are discussed by research team members and linked to MRA findings, as appropriate.
9. Key informant interviews are conducted to ensure accuracy in interpretation of clinical and cultural findings from the MRA and FG. Informants provide on-going consultation on development of PN program components and intervention strategies.
10. Final analyses of all data with implications for PNP components and intervention strategies are derived through discussion and consensus agreement of the research team.

## RESULTS

The MRA indicated that breast malignancy was strongly suspected or confirmed in 93.3% of the cases (unduplicated). Of the 28 cases with suspected or confirmed malignancy, about 64.3% did not complete treatment and were lost to follow-up by the healthcare system. While lost to follow-up occurred across the care continuum, the majority (72% or 13 cases) were lost to follow-up after completion of diagnostic testing and prior to or during treatment. Provider notes sometimes indicated possible reasons for non-adherence, including: women's ambivalence about more invasive cancer care procedures such as mastectomy, confusion about appointment times, preference for use of traditional Samoan medicine, and negative perceptions of LBJ TMC care and concomitant preference for treatment in the US. About 40% of those women completing treatment had had a previous breast cancer treatment episode. Their records indicate that treatment had not been completed in the previous episode. Return to care occurred when disease symptoms were advanced (e.g., fungating and malodorous breast lesions, headaches, decreased appetite/unintentional weight loss) and families could no longer manage patient care on their own.

**FIGURE 2: ADHERENCE AND LOST TO FOLLOW-UP.  
MEDICAL RECORDS AUDIT (N=30)**

Variable	N or Percent
Age(at presentation for current treatment episode)	Range = 27–77 years M=55.3, SD= 12.0
Samoan ethnicity	29 (96.6%)
Breast Malignancy, strongly suspected or confirmed	28 (93.3%)
Lost to Follow Up	18 of 28 (64.3%)
*during diagnostic testing	5 of 18 (27.7%)
*prior to/ during treatment	13 of 18(72.2%)
Completed all recommended procedures	10 of 28 (35.7%)
*had prior treatment episode in which treatment not completed	4 of 10 (40%)

Focus group findings suggest influences to treatment seeking of female breast cancer patients. FG participants agreed that negative beliefs about cancer and its treatment, as well as lack of knowledge and differential understanding of medical explanations may contribute to delays in treatment seeking. Decision-making to seek treatment was viewed as a process that involved patient readiness. As described by one participant, a patient needs to “be prepared to find out the worst and still seek care.” Arriving at a stage of readiness might be facilitated by a PNP that addresses women’s fears about “the worst” and offers accurate information. Participants stated that survivors’ support groups had been helpful in reaching a stage of readiness for treatment, but acknowledged that attending support groups was “not for everyone.” Thus, a PNP that provided informational and emotional support could be helpful. Linguistically-appropriate and culturally-respectful communications were emphasized. For example, older women and/or those originating from the independent nation of Samoa (vs. AS) might prefer use of Samoan language consistent with more traditional and formal conventions (i.e., a characteristic feature of Samoan is the existence of specialized terms used when addressing elders, chiefs, and other authority figures). Also, bi-lingual women may prefer to speak Samoan when discussing sensitive issues related to breast cancer. Notably, the FG transcript evidences that participants switched from English to Samoan language when discussing sensitive issues such as fear of death, concern about family members, and uncertainty in procuring off-shore referral for vital advanced treatments. Family support was mentioned by all participants. The lack of family support (e.g., indifference about treatment, lack of accurate information about breast cancer and its treatment, difficulty in discussing treatment-related issues) could delay treatment-seeking. Participants agreed

that provision of informational and emotional support to families, as well as patients might be an important component of the PNP. At the cultural level, it was stressed that most Samoans adhere to Judeo-Christian beliefs. Diversity in beliefs was noted and participants gave examples of how religious beliefs could have either a positive or negative influence on treatment seeking. Traditional Samoan cultural beliefs were seen as potentially facilitative to treatment seeking (e.g., having a heart of understanding or *agaga malamalama*, being patient and persistent in situations involving physical or emotional burden or *'onosa'i*, speaking in ways that encourage strength or *fa'amalosi'au*). Finally, FG participants identified healthcare systems-related factors that disabled treatment seeking. Lack of consistent information was the most commonly cited barrier. While physicians were experienced as helpful, the latter were not always available to answer questions. Women were unsure to who they might turn when communication with the physician was not available. In such situations, they turned to other healthcare personnel or those within their social network. This could result in conflicting or inaccurate information. Also mentioned were the lack of case coordination and long periods of waiting to get test results or authorization for off-shore referral. Long waiting periods could cause women to be anxious. Indicated were needs for a reliable source of informational and emotional support, patient advocacy, and a single point of contact within the healthcare system. Figure 3 provides a summary of FG findings and PNP implications based on participant suggestions.

Figure 4 presents results from key informant interviews specific to the cultural tailoring of the PNP in AS, as informed by the FG and the work of Mulitalo-Lauta (2000). Also all definitions of Samoan terms were checked for accuracy using the Samoan dictionary prepared by Milner (1993). Practice implications for initial approach to patients and families, clarification of PNP roles and services, development of a positive, productive helping relationship, and facilitation of positive coping, notably, might include: (a) appropriate use of the Samoan language (*gagana talafeagai*) which reflects respect (*fa'aaloalo*), (b) clarification of the navigator's role as one who guides the way (*fa'asino ala*) through the healthcare system with the patient's role likened to that of the canoe paddler (*alofoe*), or the one who generates forward movement, and (c) with patient permission, inclusion of the extended family (*aiga*) in treatment-related discussions, as family is vital and all opinions are important (*osi aiga*). A well-known cultural wisdom is "*o le ala i le pule, o le tautua*" which means "it is through service that one is honored and acknowledged." In the *fa'aSamoa* taking action is important and may be more meaningful than what is verbalized. Thus, across the intervention trajectory, it is crucial that PNP personnel follow-through with what they have committed to do on behalf of the patient.

**FIGURE 3: INFLUENCES TO TREATMENT-SEEKING. SURVIVORS FOCUS GROUP (N=6)**

Level of Influence	Disabling Influences	Facilitating Influences	PNP Implications Based on Participant Suggestions
Individual	<ul style="list-style-type: none"> <li>*Beliefs (cancer = death, treatment causes disfigurement, treatment involves suffering, incapacitation, family hardship).</li> <li>*Lack of knowledge about cancer and its treatment</li> <li>*Difficulty understanding medical explanations.</li> </ul>	<ul style="list-style-type: none"> <li>*Readiness for adherence to diagnostic procedures and treatment (i.e., individual patients may feel ambivalent about recommendations, needs to be “prepared to find out worst and still seek care”).</li> </ul>	<ul style="list-style-type: none"> <li>*Informational support and counseling to address patient’s knowledge deficits, disabling beliefs, resource needs.</li> <li>*Bilingual capacity is necessary, including capacity to use “formal” Samoan with those more traditionally-oriented.</li> </ul>
Family and Friends	<ul style="list-style-type: none"> <li>*Family may not readily talk about sensitive issues like breast cancer and its treatment.</li> <li>*Family may not know much about the disease; thus, might not know what to recommend.</li> <li>*Patient’s family-related responsibilities may take precedence over treatment seeking.</li> <li>*Family members may not understand what is involved in treatment and be unsure of how best to support patient.</li> <li>*Family and friends may provide information that is inaccurate.</li> </ul>	<ul style="list-style-type: none"> <li>*Patient and family are able to talk about treatment from an informed perspective</li> <li>*Family able to provide emotional and tangible which facilitates patient adherence.</li> </ul>	<ul style="list-style-type: none"> <li>*Provide informational support and counseling to address family’s knowledge deficits, disabling beliefs about treatment.</li> <li>*Ensure bilingual capacity, including capacity to use “formal” Samoan with those more traditionally-oriented</li> <li>*Provide individual/family counseling and information on how best to support treatment.</li> </ul>
Culture	<ul style="list-style-type: none"> <li>*Religious/spiritual beliefs that health and healing come only from God.</li> <li>*Prefer indigenous Samoan medicine over Western allopathic medicine.</li> </ul>	<ul style="list-style-type: none"> <li>*Indigenous Samoan cultural beliefs (e.g., agaga malamalama or heart of understanding, fa’amalosi ‘au or speak to encourage strength) may be used to facilitate patient adherence, family support, coping with cancer, and acceptance of PNP.</li> </ul>	<ul style="list-style-type: none"> <li>*Assess role of religion/spirituality in acceptance of treatment, as well as patient/family preference for use of Samoan medicine over Western medicine.</li> </ul>
Health Care System	<ul style="list-style-type: none"> <li>*Difficulty getting accurate information</li> <li>*No single point of contact makes treatment stressful</li> <li>*Multiple appointments are confusing—services lack overall coordination</li> <li>*Treatment involves long waiting periods</li> <li>*Not sure of treatments available at hospital and what must be procured through off-shore care</li> </ul>	<ul style="list-style-type: none"> <li>*Some providers, including oncologist are competent in their practice.</li> <li>*Appreciate providers who are sensitive to patient’s needs.</li> <li>*Appreciate providers who make themselves available for additional communications with patient and family.</li> </ul>	<ul style="list-style-type: none"> <li>*Ensure that patient receives accurate information about tests, results, treatments, and services.</li> <li>*Anticipate and discuss patient barriers to treatment-seeking.</li> <li>*Assist in appointment making, provide reminders, outreach promptly when appointment is missed.</li> <li>*Track delays in test results and other patient requests. Advocate, as indicated.</li> <li>*Provide psychosocial case coordination.</li> </ul>

**FIGURE 4: INTERVENTION PHASES, CULTURAL PREFERENCES, STRATEGIES. DISCUSSIONS WITH KEY INFORMANTS (N=3)**

Intervention Phases	Fa'aSamoa: Cultural Preferences & Metaphors	Culturally Responsive, Linguistically Appropriate Strategies
Initial Approach, Culturally Respectful Entry Etiquette	<p>*<i>fa'aaloalo</i> (respect, courtesy, politeness)</p> <p>*<i>agamalu</i> (humility)</p> <p>*<i>gagana talafeagai</i> (appropriate use of language)</p>	PNP staff demonstrates humility, friendliness, and respect. Appropriate use of language reflects <i>fa'aaloalo</i> (respect). Older and more traditionally-oriented women may favor more formal use of language. Sensitivity needed in degree of formality used.
Roles and Services Clarification	<p>*<i>tautai</i> (to steer)</p> <p>*<i>lavea'i</i> (to extricate)</p> <p>*<i>tautai lavea 'i</i> (rescue from harm; navigator provides guidance to avoid harm and reach desired destination)</p> <p>*<i>fa'asino ala</i> (guide and show the way)</p> <p>*<i>ta'ita' i ala</i> (lead by taking hand of other)</p> <p>*<i>alofoe</i> (paddler)</p>	<p>Ocean voyaging metaphors may be useful in explanation of the PNP. Like the canoe navigator, the PN acts as guide through uncertainty, helping the patient through the uncertainties of breast cancer and treatment-seeking.</p> <p>PN provides informational, tangible, and emotional support that facilitates adherence to diagnostic and treatment procedures. Like the canoe paddler, patient efforts are critical to reaching goals. Patient and PN work together.</p>
Engagement in Helping Relationship, Sustaining Positive Relations	<p>*<i>agaga malamalama</i> (spirit or heart of understanding, open mindedness)</p> <p>*<i>loto fesoasoani</i> (helping spirit extended to all)</p> <p>*<i>O le ala i le pule, i le tautua</i> (it is through service that one is honored and acknowledged; "action speaks for itself")</p> <p>*<i>fa' alototele</i> (offer comfort and encouragement, with due respect)</p> <p>*<i>fa' amalosi 'au</i> (speak so as to encourage strength)</p>	<p>Services are provided with a sincere desire to help and offered with openness to diverse patient and family perspectives. Staff follow-through is crucial to service "speaks for itself."</p> <p>Providing comfort and offering encouragement from PN and family members are important, but must be given with sensitivity to patient's situation and social status.</p>
Facilitation of Positive Coping	<p>*<i>osi aiga</i> (extended family is vital, all opinions are important)</p> <p>*<i>ola mo isi</i> (desire to live for the sake of others)</p> <p>*<i>tausi aiga</i> (take care of family)</p> <p>*<i>fa'aleagaga</i> (spirituality)</p>	<i>Fa'aSamoa</i> is collectivist in orientation and places high value on the family system. Health is holistically conceived and includes spirituality. Families and spirituality may be sources for positive coping. Assessment is indicated with patient preferences respected.

## DISCUSSION

### EXTANT LITERATURE, CURRENT RESEARCH

Disparities in breast cancer morbidity and mortality cannot be accomplished without the three interrelated components of routine screening mammograms, prompt diagnostic testing following a suspicious or abnormal result, and timely treatment. Along this care continuum, socioeconomically disadvantaged, ethnic minority/indigenous women have displayed a dismaying pattern of missed procedures and lost to follow-up by the healthcare system (Press et al., 2008). Among underserved women living in the US proper, rates of lost to follow-up are as high as 60% (Ell et al., 2002). The MRA conducted for the current research documents that 64.3% of indigenous Samoan women did not complete recommended diagnostic and/or treatment procedures and were lost to follow-up by the healthcare system. Thus, the rate of Samoan women's lost to follow-up is comparable, albeit higher to rates detected among medically underserved women dwelling in the US. Warranted is the need to address lost to follow-up among indigenous Samoan women.

In the last 15 years, patient navigation programs have proliferated in the US and met with generally promising results, thus offering the hopeful prospect of increased longevity and enhanced quality of life to breast cancer survivors residing in medically underserved communities (Darnell, 2007). In the focus group (FG) convened for the current research, participants agreed that a PNP would be of potential benefit to women's treatment seeking efforts. Participants were asked to describe both facilitating and disabling influences to treatment seeking. Interestingly, in this group of adherent women (i.e., all had initiated and completed recommended procedures offered by LBJ TMC), the number of disabling influences identified was greater than the number of facilitating influences. Specifically identified were difficulties in obtaining accurate information about cancer and its treatment, "long waiting periods" to receive test results, and lack of communication with providers when concerns arose or requests made (e.g., approval for off-shore referral). Speculatively, such challenges might be greater for those women who were not able to comply with recommendations and were lost to follow-up. Research on cancer-related adherence (CRA) indicates that self-efficacy and social support are associated with higher levels of participation in hospital appointments and procedures (Lev, 1997; Victorson & Peterman, 2006). The ways in which healthcare services are organized are known to challenge socioeconomically disadvantaged and culturally diverse female patients who have reported feeling unconfident in mediating their way through multiple medical departments and in communicating with providers, especially, when the latter were perceived to be of higher social status. (Darnell, 2007; Ell et al., 2007; Freeman, 2006; Victorson & Peterman, 2006). Patients without social support may operate out of misinformation, incorrectly follow recommendations, delay treatment seeking, and/or terminate services before therapeutic outcomes are realized

(Victorson & Peterman, 2006). Insights from FG participants observed that CRA involves a process of treatment readiness. That is, women need to be “prepared to find out the worst and still seek care.” Attention to treatment readiness is indicated and might be facilitated by patient navigation that provides support which is informational (e.g., accurate, clear information on treatment), tangible (e.g., assistance in making appointments), and emotional (e.g., providing moral support at women’s appointments, facilitating positive family involvement). Findings from the MRA (i.e., provider progress notes), FG, and key informant interviews (KI) indicate the importance of linguistically appropriate and culturally responsive navigation services. FG and KI elucidated upon cultural preferences that might be important to include in a PNP for indigenous Samoan women. Attention to linguistic and cultural responsiveness also is emphasized in the extant literature on psychosocial oncology interventions in general and breast cancer patient navigation in particular (Ell et al., 2007; Masi et al., 2007). In summary, results from all phases of our research are consistent with the published literature.

#### LIMITATIONS AND STRENGTHS

Methodological limitations restrict use of the research findings. The records reviewed in the MRA were somewhat inconsistent in reporting of socio-demographic information other than patient’s date of birth. This made it difficult to correlate socio-demographic characteristics with clinical conditions and outcomes. The FG was limited by the use of a convenience sample of women recruited through a breast cancer survivors’ network which advantages the perspective of women who participate in medical and psychosocial services. Also, findings are limited by biases in recall and social desirability. Almost all participants were long-term survivors ( $\geq 5$  years since initial diagnosis) and their responses may be compromised by recall bias. Further, all experiences were self-reported in a group setting and may have been influenced by social desirability bias. Findings from KII are also limited by social desirability bias. Limitations notwithstanding, focus group and KII findings provided a rich description of influences to women’s treatment seeking and on cultural preferences. These findings complemented the MRA results.

Although our efforts were modest, we believe that the research had a number of strengths. In seeking to develop the PNP, we were faced with little, if any AS-specific tumor registry data and/or psychosocial oncology research on breast cancer patients and patients lost to follow-up in AS. Thus, we needed to document the need for the PNP, assess the role of culture in PNP development, and as appropriate, describe relevant cultural preferences for tailoring the PNP within the context of AS. To do this, a family of primarily, qualitative strategies was incrementally used, with findings from earlier study phases informing subsequent ones. We believe that this multi-methods strategy strengthened our capacity to address the research questions.



A second strength of the research was its use of community-based participatory approaches (Minkler & Wallerstein, 2003). Our efforts involved a productive collaboration of several entities which ultimately, advantaged the sharing of multiple and diverse disciplinary, organizational, and patient/survivor perspectives, as well as the sharing of diverse knowledge and skill sets. Notably, the collaboration involved those who were indigenous to AS, as well as those who were non-indigenous to AS. Through the research efforts, we developed positive and productive collaborations and a relational foundation important for future inquiries. Finally, the *lalaga* model (Mulitalo-Lauta, 2000), a Samoan cultural strengths perspective was extended to intervention with breast cancer patients and to the AS context. FG participants and key informants offered an indigenous cultural perspective, essential to building a foundation for future cancer care research with and for indigenous Samoans living in the medically under-resourced, *albeit* culturally-rich Territory of American Samoa. Through our work with indigenous Samoan survivors and providers serving as study informants, we were able to meaningfully plait *fa'aSamoa* with patient navigation, a Western evidence-based practice model derived in the US.

#### FUTURE RESEARCH

In the immediate future, research will pilot the feasibility of *Tautai Lavea'i*, a culturally-responsive PNP. If this PNP is feasible for use with breast cancer patients in AS, we will test the efficacy of a culturally-responsive PNP in a broader population of Samoans, including women and men diagnosed with other types of carcinoma and subsequently, with patients diagnosed with other chronic diseases (CD). Other future research might seek to explain how culture and other factors contribute to treatment seeking and adherence behaviors of Samoan health services consumers. Finally, the current research reminds us of the bio-psychosocial/spiritual needs of cancer and CD patients unable to obtain off-shore services for care not provided within AS. Research to develop a culturally-responsive, resource-appropriate palliative care program is indicated; such efforts would be consistent with Institute of Medicine recommendations for cancer control in developing nations (Sloan & Gelbland, 2007).

#### CONCLUSION

The importance of social work involvement in efforts to eliminate cancer and other health disparities is emphasized by Gehlert and colleagues (2008) in their editorial "(Not So) Gently Down the Stream: Choosing Targets to Ameliorate Health Disparities." In this call to action practitioners and researchers are urged to promote distributive justice in health through ecological interventions that address upstream or systemic targets such as healthcare organizations, as well as the downstream needs of individuals, families,

and communities. Use of community-based participatory research principles (Minkler & Wallerstein, 2003) are indicated to develop intervention models that fully articulate the social determinants of specific conditions that affect a particular group, community, or population (Gehlert et al., 2008).

In indigenous communities like that of American Samoa profound, persistent, and growing upstream disparities in health services resources contribute to disparate health outcomes experienced “(not so) gently down the stream.” Indicated are interventions capable of addressing the bio-psychosocial/spiritual needs of culturally-grounded and socioeconomically disadvantaged individuals as they interact with healthcare and other organizational systems. While resource-poor, AS residents reside in a community which remains rich in indigenous cultural and linguistic traditions, with *fa'aSamoa* permeating every aspect of modern life (ASG, Department of Commerce, 2008), including ways of coping with illness, death, and disability. Thus, health interventions for AS necessarily must include attention to culture and language. In this regard, heuristics such as Mulitalo-Lauta's (2000) *lalaga* model may be helpful in the meaningful plaiting of indigenous cultural preferences with evidence-based practice models derived in the West.

Inherent in a perspective on cultural responsiveness is the premise that all cultures carry strengths and preferences for how help is offered. Respectful, appropriate integration of these strengths and preferences into health interventions remains a critical, yet complex challenge. Meeting this challenge behooves ongoing dialogue between researchers, providers, and community stakeholders with continuous attention to the dangers of (neo) colonialism in research. Continuous attention must be paid to issues of power, privilege, leadership, data ownership, and importantly, the ways in which non-natives or community outsiders interact with those who are of indigenous background and/or residing in community. Attention to these issues is crucial to developing productive collaborations and meaningful, empowering experiences for all involved. Involvement of indigenous community stakeholders ensures cultural and linguistic relevance and by extension, increases the likelihood of developing interventions that may influence positive health outcomes. It is through such collaborations that those burdened by disparities may invest themselves in developing solutions that advance the prospect of health equity and an inheritance of health for all.

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