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Promoting Breast Cancer Screening through Storytelling by Chamorro Cancer Survivors

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Abstract

The largest Chamorro population outside of Guam and the Mariana Islands reside in California. Cancer health disparities disproportionately affect Pacific Islander communities, including the Chamorro, and breast cancer is the most common cancer affecting women. To address health concerns such as cancer, Pacific Islander women frequently utilize storytelling to initiate conversations about health and to address sensitive topics such as breast health and cancer. One form of storytelling used in San Diego is a play that conveys the message of breast cancer screening to the community in a culturally and linguistically appropriate way. This play, *Nan Nena's Mammogram*, tells the story of an older woman in the community who learns about breast cancer screening from her young niece. The story builds upon the underpinnings of Chamorro culture - family, community, support, and humor - to portray discussing breast health, getting support for breast screening, and visiting the doctor. The story of *Nan Nena's Mammogram* reflects the willingness of a few pioneering Chamorro women to use their personal experiences of cancer survivorship to promote screening for others. Through the support of a Chamorro community-based organization, these Chamorro breast cancer survivors have used the success of *Nan Nena's Mammogram* to expand their education activities and to form a new cancer survivor organization for Chamorro women in San Diego.

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Introduction

Chamorros are indigenous people from Guam and the Mariana Islands, and California is home to the largest numbers of Chamorros on the continental United States (Tanjasi & Sablan-Santos, 2001). According to the 2000 U.S. census, there were 33,849 Chamorros in California, with 18,471 residing in Southern California (APALC, 2005). Breast cancer is the most common cancer in Chamorro and other Pacific Islander women, yet relatively little is known about their screening behaviors. For instance, from 2000 to 2006 Native Hawaiian

and Samoan women experienced an increase in their age-adjusted breast cancer incidence rates compared to non-Hispanic whites (Cockburn, Liu, & Deapen, 2009). Pacific Islanders also experience later stage of breast cancer diagnosis leading to higher mortality rates in this group (Marshall, Ziogas, & Anton-Culver, 2008). For instance, Tanjasiri and Sablan-Santos (2001) examined the breast cancer risk, knowledge, and screening behaviors in a non-probability sample of Chamorro women age 40 years and older in Los Angeles and Orange Counties (n = 227) and found that 37% of respondents ever performed a breast self-examination (BSE), 93% ever had a

clinical breast examination (CBE), and 77% ever had a mammogram. In terms of screening maintenance, only 27% did BSE monthly, 66% received a CBE in the past year, and 25% received yearly mammograms. This study indicated that BSE and mammography are under-utilized, and emphasized the need for ongoing education and support to promote initiation and maintenance of consistent screening behavior (Tanasiri & Sablan-Santos, 2001).

Possible reasons for low screening rates include persistent myths and misconceptions about breast cancer among Pacific Islanders. Tanasiri and Sablan-Santos (2001) found that many Chamorro women associate breast cancer with death and express the belief that there is nothing much that can be done once the disease is diagnosed (Tanasiri & Sablan-Santos, 2001). The purpose of this case study is to describe the community-based efforts of Chamorro breast cancer survivors to promote breast cancer awareness, early detection and social support through storytelling.

Storytelling as an educational method

Although many definitions for the concept of storytelling exist, it is generally seen as a way of communicating events and experiences using words, imagery, sounds and improvisation to convey or reveal important information and/or aspects of behaviors and consequences, often within a specific cultural context (Haigh & Hardy, 2010). Storytelling as an educational tool has been shown to be successful in promoting cancer screening in multiethnic populations. For instance, Williams-Brown, Baldwin, and Bakos (2002) explored the ways in which storytelling can teach African American women about breast health. The researchers collected stories from 18 women and identified, through content analysis, six main story themes: 1) loss, 2) pain, 3) suffering, 4) fear and worry/stress, 5) death, and 6) faith in God and prayer. They found that through storytelling using these themes, women learned from each other about breast health, dispelled misinformation about breast cancer screening, and supported each other through the sharing and corroboration of each other's stories. In order to test the effectiveness of storytelling

to promote colorectal cancer screening among Latinas, Larkey, Lopez, Minnal, and Gonzalez (2007) conducted a two-group randomized brief intervention pilot study comparing cancer information presented utilizing storytelling vs. a numeric risk tool. Results from this study showed a significant increase in intentions to change positive behaviors (increase in number of servings of vegetables and minutes of physical activity) in the storytelling intervention group compared to the numeric risk tool group. Hence, storytelling can be a rich and powerful method for educating women from many diverse cultures.

Storytelling also has a rich cultural history among Pacific Islanders. Chamorros in Guam have experienced a history of colonialism by the U.S. and other countries (Perez, 2002), and storytelling has helped to strengthen and preserve Chamorro culture through the passing down of historical beliefs and practices. Storytelling also helps people to understand the meanings of complex or challenging events, such as in the case of breast cancer diagnosis and survival. This occurs when people share their personally painful stories with others, gaining understanding and support, which helps them to deal better with this event (Haigh & Hardy, 2010). Both of these strategies are reflected in the development of a storytelling approach to promote breast health among Chamorros in Southern California.

Using storytelling to encourage cancer screening: the development of *Nan Nena's Mammogram*

In 2005, a Chamorro breast cancer survivor living in San Diego wrote a performance piece to encourage women to get mammograms. She wrote this story because there were no stories reflecting Chamorro culture and characters in breast health education at that time. Drawing on the Pacific Islander cultural practice of storytelling, she based the performance piece on her own experience with breast cancer, and targeted older Chamorro women who have never received a mammogram. The survivor named the main character in the play *Nan Nena*, which is used as a term of endearment and respect to elder women in the Chamorro community.

In *Nan Nena's Mammogram*, the audience is introduced to four main characters: Nan Nena is an elderly woman in her 70s, who has never received a mammogram. In the story, Nan Nena has very little knowledge about breast health, self-exams, clinical examination or mammography. She does not realize that there is concern about breast cancer in the Chamorro community, nor does she know anyone who has breast cancer. Thus, she believes it is not something she should be concerned about. She views breast exams as rather personal and that no one but her spouse is to touch her breasts. In addition, she is experiencing no ill health and perceives medical tests as unnecessary. Consequently, she has never considered it a need to get screened. Other characters include the following: Kika is in her late 30s and Nan Nena's niece who tries to convince Nan Nena to go for a mammography screening; Chai is a nurse navigator who meets with Kika and Nan Nena to educate them about breast cancer screening and detection; and Tan Chia is a friend who encourages Nan Nena by easing her trepidations about what it is like to get screened, be diagnosed with breast cancer, get treated, and survive breast cancer.

The story of *Nan Nena's Mammogram* opens in the home of the Chamorro family where Kika has come to visit her aunt. The stage is set with cultural artifacts and images, and all conversation takes place in the Chamorro language. Kika speaks to Nan Nena of her concern for her aunt's wellbeing showing familial support in encouraging health behavior change. The Chamorro nurse navigator Chai provides clinical information in Nan Nena's home using both medical and Chamorro terms to talk about breast health and cancer and to explain mammography. After both the niece and the nurse leave, Nan Nena's friend who is visiting and sharing Chamorro cultural snacks, discloses that during her breast screening a lump was detected and that she had undergone treatment and is going well. Tan Chia is a breast cancer survivor who has not shared her secret with many. Armed with the information from the nurse navigator and with the encouragement and support of her niece and friend, Nan Nena agrees to go for a mammogram and nurse navigator Chai offers to accompany her.

As a storytelling vehicle, *Nan Nena's Mammogram* highlighted the involvement of not only the family but also friends and professionals in promoting breast health, which reflect the diverse social networks common in Pacific Islander communities. To promote social support for breast cancer screening, the performance also used humor to remind women in the audience to have not only their annual clinical breast exams done, but to administer regular self-examinations, and to include their family and female friends in getting screened. For instance, early in the play Nan Nena's friend explains how important examining one's breasts is to detecting cancer early. In response, Nan Nena laughingly states that no one but her husband has ever touched her breasts. This use of humor helps to reduce initial tensions about the subject matter, convey the closeness of the characters, and educate women about key aspects of cancer early detection. The warmth which women discuss and explain breast health and cancer exams gives a family-like atmosphere throughout the scenes, one through which friendship, trust, and support promote the open sharing and discussion of cancer screening. Since 2006, *Nan Nena's Mammogram* has been performed four times and reached approximately 150 Chamorro women and their family members with the message about early breast cancer detection. In 2007, *Nan Nena's Mammogram* was also recorded in an 8 minute digital DVD by a Chamorro production company for dissemination to a larger audience. Using funds obtained through the National Cancer Institute's Community Network Program called WINCART: Weaving an Islander Network for Cancer Awareness, Research and Training, and other funding sources, the video was produced with all original survivor members in their different roles. The DVD is currently used in the health education context by breast cancer survivors during small group education sessions, and by health educators as part of their cancer education workshops in the Chamorro community.

Breast cancer survivors as program champions

After the success of *Nan Nena's Mammogram*, the Chamorro breast cancer survivors expressed an interest in forming their own social support

organization. They reached out to staff at Guam Communications Network (GCN, www.guam.comnet.org), a Chamorro non-profit social service agency in Southern California, to assist them with incorporation as a new organization. GCN saw a growing need for survivorship services in San Diego, where the largest Chamorro population in Southern California reside, and agreed to assist the women. GCN worked with the Chamorro breast cancer survivors in San Diego to form a group called the California Chamorro Breast Cancer Survivor Alliance (CCBCSA). Founded as a nonprofit organization in 2008, the mission of CCBCSA is to support, educate, and encourage Chamorro women to seek screening, and those who diagnosed and/or going through treatment. Through the efforts of GCN, Chamorro survivors in San Diego were encouraged to continue to use storytelling to share their cancer experiences with others throughout not only San Diego but across California and beyond.

Despite these successes there remain limited research on both the breast cancer needs and successful educational approaches for Chamorros in the continental U.S. More research is also needed to promote the community's ability to implement effective breast cancer programs. A future step in the growth CCBCSA's education efforts is to develop and implement an evaluation of the impacts of Nan Nena on Chamorro women's intentions to seek breast cancer screening. In addition, the lack of adequate funding for research and programs is perpetuated by the lack of data in the literature. There is still much that needs to be done in terms of understanding breast cancer risk, knowledge, and screening behaviors within the Chamorro community. For instance, the CCBCSA women have recognized the need to support Chamorros recently-diagnosed with breast cancer, and are thus instituting an informal navigation program despite the lack of Chamorro-specific cancer incidence and mortality data at the county level. In the long term, CCBCSA hopes to promote greater knowledge, skills and support of not only Chamorro women but their family members (including men) to successfully seek and use

cancer screening and support services. Such social support has been shown to be effective in Asian communities (Kagawa-Singer et al., 2009), and CCBCSA hopes such support will help Chamorro family members facilitate their interaction with loved ones, interactions that will motivate and encourage their loved ones to go in and get screened for cancer, to help increase rates of screening and early detection throughout the Chamorro community.

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