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Native American Breast Cancer Survivors' Physical Conditions and Quality Of Life

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Introduction/Background

Breast cancer associated morbidity issues for Native American patients have never been reported. To our knowledge, this paper is the first report of these experiences. Because this is the first of several papers on findings from the “Native American Cancer Education for Survivors” study, in-depth background information is provided about both the population and the study. Working with Native patients over the past few decades, the authors have generally encountered the message that ‘once you have cancer, you should begin to select a grave site.’ This paper documents a message of hope for Native American breast cancer survivors.

According to the National Cancer Institute, approximately 63 percent of all American Indian (AI) and Alaska Native (AN) breast cancer patients are alive five years after diagnosis. This is the poorest five year relative survival of any ethnic and minority group in the US.¹⁻³ In many geographic regions, no accurate survival data are available and quality of life (QOL) information specific to Native American cancer survivorship issues has not been reported,⁶⁻⁷ thus the true impact of cancer in this population is unknown.

The cancer burden continues to escalate among AIANs,⁸⁻⁹ and importantly, Native Americans are *not* experiencing the decreases in cancer incidence that is occurring among other racial groups.¹⁰⁻¹¹ In November 2007, the federal government (specifically NIH, CDC, IHS) released a *Report to the Nation*⁸ that emphasized AIAN cancer incidence data. Breast cancer incidence is particularly elevated within Northern and Southern Plains tribal nations, with the highest rates in Alaska Natives. According to the 2008 Indian Health Service (IHS) mortality data (Figure 1), age-adjusted breast cancer deaths continue to be elevated for AIANs living in Alaska, the Northern Plains and the Southern Plains, in comparison to Natives living in other regions.¹²

Although age-adjusted rates are elevated among Alaska, Northern and Southern Plains AIANs, the actual number of cancer patients and the related cancer burden may be higher among those who live in the southwest and Southern Plains. According to the US Census 2000³⁸, the 48 contiguous states that are west of the Mississippi have 43% of all AIs in comparison with other regions of the US. The five states with the highest numbers of AIs are California, Oklahoma, Arizona, Texas and New Mexico, of which AZ and NM are within the Southwest and OK (Southern Plains). Of the ten most populated reservations and off-

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reservation trust lands, Navajo Nation (AZ, NM, UT with 175,228 AIs) is the largest and no other reservation is close to this elevated number of Native residents. Of the nine remaining largest reservations, Fort Apache, Gila River, Tohono O'odham, and San Carlos are all located in AZ/ the Southwest (respectively 11,854, 10,578, 9,794 and 9,065 AIs). In comparison, only two of the largest reservations are based in the Northern Plains: Pine Ridge and Rosebud (respectively 14,484 and 9,165 AIs living in SD/ Northern Plains). Osage (9,209 AIs living in OK) is within the ten largest reservations and is within the Southern Plains region.

Many breast cancer survivors experience co-existing physical conditions, co-morbidities and side effects from treatment. However, there has not been any documentation of the prevalence of such conditions specifically within Native American breast cancer survivors. Likewise, there is a dearth of information about how co-existing conditions differ among newly diagnosed Native breast cancer (within one year), patients diagnosed one to four years ago, and those who are long-term survivors (five or more years from diagnosis). This paper provides the first descriptive summaries for such prevalence specific to Native breast survivors.

NACR's work with Native Cancer Patients leading to the Survivorship Program

Native American Cancer Research (NACR) staff has worked with Native cancer survivors since the latter 1980s to help minimize the effects of cancer and cancer treatment and improve the Native patient's quality of life (QOL). 7·13· 14· 15· 16· 17· 18· 19· 20· 21 In the 1990s, the "National Native American Cancer Survivors' Support Network" was created and NACR initiated and continues to support gatherings specifically for Native cancer survivors. NACR also creates programs specifically designed to meet the needs of Native cancer survivors and makes cancer information available to survivors, families and healthcare providers free of charge from its website at <http://NatAmCancer.org>.

Native Americans and the Internet

During the 1990s, NACR developed culturally specific survivor education materials that were provided in print at meetings or through one-on-one or small group contact. The choice to move from print-only materials to the web was based on emerging technology and skills within Native Communities. While face-to-face is generally the preferred mode of AIAN communication, AIANs are gradually obtaining access to computers and the Internet with some elders reporting that their grandchildren often help them find information. Data collected by the authors while implementing cancer education programs with Native communities throughout the US, shows that use of the Internet within Native Communities has increased greatly over the past six years. In 2002, only 15% of respondents reported they could download information from the Internet themselves. By 2006, the percentage more than doubled to 35% and in 2007 this increased to 65.2%. The trend for increased access is consistent across all sites queried by the authors, but does not appear to be universal. Community centers and individual home access is improving but access to high speed services, finances and equipment failure limit consistent access in many regions where AIANs live.

"Native American Cancer Education for Survivors" (NACES) [Susan G. Komen for the CureR [#POP0202135] and [#POP0503920] and NCI [R25 CA 101938 and U01 CA 114609]

Overview—NACES is a community-driven education intervention based on the Social Cognitive Theoretical Model.^{22· 23· 24} The "community" for this project is Native cancer patients. NACES focuses on cancer survivorship as a continuum that begins with diagnosis

and continues for the remainder of a survivor's life. NACES is based on the belief that educating cancer survivors about survivorship issues at all stages of their illness and recovery is crucial to increasing their access to information and services that may enhance their quality of life. NACES' overall purpose is to improve the quality of life for Native Americans who are breast cancer survivors by (1) developing and testing culturally specific cancer education materials; (2) making the materials easily available through the internet and (3) helping survivors find resources to help them with their cancer issues. Included in this program are interactive educational modules, resources and a survey to assess participants' QOL. An advisory committee of Native cancer survivors who were diagnosed with different types of cancer and from geographically diverse regions of the country provides guidance on key components of the intervention and critique the content for cultural acceptability, layout, and priorities. Native Patient Advocates help patients complete the QOL survey and access the survivorship information available on the website.

NACES Web Layout: NACES utilizes a tree to symbolically represent QOL (see figure 2). The roots include family and friends' support; personal beliefs and practices; personal knowledge; and traditional cultural beliefs and practices. The trunk includes survey questions related to the patient's cancer diagnosis and QOL. The limbs identify the major content areas (e.g., side effects), while the branches are the major topics (e.g., fatigue) and the leaves represent specific content (e.g. fatigue causes). Most content is organized using the Native Medicine Wheel that includes the body, mind, emotions and spirit.²⁵ The site also includes (1) Video vignettes of more than 88 Native cancer patients each talking about aspects of their cancer journeys; (2) Storytellers (caricatures who relate experiences compiled from at least three patients); (3) Sample Questions to ask the provider; (4) Visitors Questions (responses to questions posed by website users); (5) Definitions; and (6) a Site Map, all located on the web page side bar which is visible on all pages. The average literacy level for content is grades 5–7.

Use of the NACES Website: Currently there are more than 1200 daily visitors^a to the NACES QOL website. These numbers have been fairly consistent since November 2006. The website records and tracks several user characteristics based on IP address including the search engine used, the web access site, pages visited, files downloaded, and so on. From these data, a variety of reports can be generated. Users are primarily from North America. However, about 10% of the monthly users are from China, Africa, or the former republics of the USSR.

Beginning in mid-April 2007, NACES invited users to post comments/questions and NACR staff and consultants began providing responses to be posted in the side bar under "Visitors' Questions." In the initial 3 months, more than 2,000 comments were received. Most were medical, educational and/or cultural questions about cancer or cancer care, with a focus on physical conditions experienced by Native cancer patients. The NACES site does not provide any specific medical advice and viewers are reminded to contact their medical providers for any question of a personal, medical issue.

NACES QOL Survey: The NACES QOL survey was initially developed in the latter 1990s as part of the "National Native American Cancer Survivors' Support Network." It was based on more than 15 existing instruments such as: FACT-G (version 4) ²⁶⁻²⁷, FACT Spirituality Subscale-version 328 and QOL-CS²⁹. The items underwent multiple

^aMost websites record usage by "hits". The NACR website has more than 8,500 daily *hits*; However, "hits" is an erroneous estimation because it refers to the number of graphics that open on a page resulting in overestimations. The number of "visitors" is a more accurate estimate of website usage.

modifications to make them culturally acceptable and understandable to the proposed audience.

When the Network evolved into NACES in 2002, NACR added many QOL items from Ferrell's cancer survivorship instruments to the survey.^{30, 31, 32, 33} These were revised by a Panel of Experts with special assistance from Drs. Betty Ferrell and Marjorie Kagawa-Singer. The NACES staff was unable to obtain a sample size of Native cancer survivors sufficient to fully validate the refined QOL instrument. However, face validity was through the tool being reviewed during the 2006 National Native American Cancer Survivors' Conference and March 2006 NACES Advisory Board meeting. About fifty Native American cancer patients provided feedback and suggestions for improvement. The Native Advisory Committee served as the Cultural Panel of Experts and reviewed the modified survey and made several revisions to improve cultural acceptability for Native cancer patients. These changes were submitted to Drs. Ferrell and Kagawa-Singer to ascertain that changes in the phrasing did not alter the scientific accuracy of the questions or responses. The QOL survey collects information on demographic characteristics, current disease status, and physical, psychosocial, spiritual and social QOL components.

The survey has four sections for a total of 114 questions: Part 1 is "Cancer patients' demographics and personal history" (31 items); Part 2 is divided into 2A- QOL – Physical and spiritual (27 items); and 2B- QOL – Mental-emotional and Social Issues (34 items); Part 3 is Cancer Patients' and Survivors' Current Health (6 items) and Part 4 has two parts: 4A Survivors Cancer Care Issues (9 items) and 4B for breast cancer patients only (7 items). The survey is divided into parts to allow the survivor to complete sections of the survey rather than having to complete the entire survey at one sitting. Completing the entire survey usually requires more than one hour.

All website visitors have access to the survey and survivorship information. However, NACES also hired eleven Native Patient Advocates as consultants, provided them with a laptop computer and printer, and trained them to provide one-on-one (face-to-face) assistance in finding and using information on the Internet to local patients or their family members. The Native Patient Advocates are Natives who are either cancer survivors or have dealt with cancer personally. Several are also on the NACES Advisory Committee. They are trained via face-to-face meetings and webinars on how to optimize use of the website. Following training, they meet with patients in their respective regions in sites such as a tribal library to access the Internet and help the patient complete the QOL survey and review survivorship information located on the NACES website.

Patients could complete the survey directly online themselves, with the assistance of a family member (usually a grandchild) or with the assistance of a trained Native Patient Advocate. However, almost all (90%) surveys were completed with a Native Patient Advocate helping the survivor. Many of these patients enjoy having the opportunity to explain their situations through stories when completing the survey with a Native Patient Advocate. Thus, these surveys may take ninety minutes to two hours. Those who complete the survey with the Advocate are given a \$25 gift card as partial compensation for their time and efforts.

Data Analysis and Evaluation Methodology

As of April 2009, more than 600 Native Americans completed the QOL survey, of which 266 were Native breast cancer patients. In this paper, survey data collected from October 2006 through April 15, 2009 are reported. The patient always has the option to not answer any item in compliance with the IRB and each survey item allows the survivor to refuse to answer the question. Most of the survivors chose to not answer some items (none on a

consistent level), thus the number of respondents are included with the percentages of the descriptive data. The findings are for these patients and may or may not be relevant to Native cancer survivors in other regions.

Methods

Because of limited sample size, the analysis focused on descriptive, non-parametric statistics. Survey response data were entered online into a Filemaker ProR database and converted to SPSS for analysis. These data are cross-sectional, referring to one time point. These data were examined. As IRB compliance allows the option of not answering a survey item, many survivors chose to not answer some items (none on a consistent level), thus the number of respondents may differ for each question.

Data analysis began with categorization of respondents into three groups based on length of time since diagnosis. Natives who were diagnosed within the previous twelve months were Group A (newly diagnosed; n=40/266; 15% of the survey sample), those diagnosed between one to four years previously were Group B (n=52/266; 19.5% of the survey sample), and those diagnosed more than five years ago were Group C (long-term survivors; n=174/266; 65.4% of the survey sample). These groups represent one data time point for collection and do not track the same patient over time.

Chi-square tests were used to identify statistically significant associations and Eta values were used to assess the strength of significant associations. P-values less than .05 were considered statistically significant and eta values were interpreted as follows: under 0.20 as weak, 0.2–0.4 as medium/moderate and above 0.40 as strong relationships.^{34, 35} Data are presented for each group. No inference can be made that alterations in symptoms, side effects or co-morbidities are related specifically to duration of survival since this is cross-sectional and not cohort data, and solely represents a single point in time for each individual respondent. It is important to note that the findings described here relate solely to the Native breast cancer survivors who took part in answering the survey, and may or may not be relevant or generalizable to Native breast cancer survivors who did not take part nor to Natives diagnosed with a type of cancer other than breast.

Findings: Native American Breast Cancer Patients

Demographics

Of the 266 Native breast cancer survivors who completed the survey, almost all (n=263/266, 98.9%) were female and a majority (n=174/266, 65.4%) were diagnosed five or more years ago. More than half (n=114/214, 53.3%) had less than a high school degree and some self-reported as having no formal education at all. Sixteen (n=16/266, 6%) has a bachelors' degree and only ten percent (n=26/266, 10%) had a graduate degree. More than two-thirds (n=163/234, 69.7%) were full-bloods. Almost half (n=125/266, 47%) currently live on a Reservation; less than one-fifth reported (n=41/266, 15.4%) living in a rural setting, but not on a reservation, and one-fifth (n=58/266, 22%) live in a city, town or village. Fourteen percent (n=39/266, 14%) move back and forth among the city, Reservation or rural area. More than half work for a salary or pay (n=142/266, 53.4%) and of those who work, almost half (n=127/266, 47.7%) work full-time. A large proportion of the survivors are from the Southwest (n=115/266, 43.2%) and almost one-quarter (n=63/266, 23.7%) are from the Southern Plains: these regions are also where the highest numbers of AIs reside in the US.

Accessing cancer care was reported to be difficult for many survivors due to financial and/or healthcare challenges. More than one-third of the survivors had private insurance (n=100/266, 37.6%;) while 6% (n=16/266) had no insurance at all or were able to use some

form of federal coverage (CMS, IHS). The Indian Health Service (IHS) or a tribal program was only used by 6.8% (n=18/266) of the patients. A large proportion (n=117/266, 44.0%) relied on CMS (Medicaid; Medicare, Part A [hospitalization]; Medicare, Part B [out-patient]; or Medicare Parts A and B) for their cancer care. Fifteen percent of those who used CMS are Medicaid users (n=42/266, 15.8%), documenting the young age at the time of diagnosis. Other than CMS, almost none of the patients used any other public care program (n=2/266, 0.8%).

Breast Cancer-Associated Morbidity/Treatment Side Effects

Survivors of all types of cancer are likely to report their physical health as good or excellent. 36-37 This was also true for Native survivors. When asked to rate their physical health, almost half (n=129/261; 49.4%) reported their health as “good” or “excellent”. However, differences were noted among the Groups. Only 28.9% (n=11/38) of Group A reported “good” or “excellent” health, but 57.6% (n=99/172) of Group C reported “good” or “excellent” health (chi-square = 32.959; p = 0.000 and eta = 0.324).

Table 1 provides a summary of self-reported physical QOL based on how well the patient was able to physically do what she wanted. These data for Group C document a message of hope to the newly (within one year) diagnosed breast cancer patient who may be fearful that current side effects and treatment-related symptoms would always remain since those who were long-term survivors were less likely to experience similar side effects or experienced them with less intensity. Less than half (n=17/38, 44.7%) of Group A newly diagnosed patients reported rarely or never being able to do what they physically wanted to do daily. However, for long-term survivors (Group C), only 18.0% (n=30/167) report similar physical limitations. These comparisons across Groups were statistically significant with a Chi-square of 20.611 (p value of .000) and the eta was .218.

Table 2 summarizes the reported physical side effects self-identified by survivors (psychosocial and spiritual QOL issues are presented elsewhere) by Group (i.e., time since diagnosis). Of note is that several of the physical side effects are experienced less often in those who have survived a longer period of time. For example, 41.0% (n=16/39) of Group A, report fatigue being a problem every day or a few days each week, while only 10.4% (n=17/164) of Group C report this level of fatigue. Pain is similar, with 48.7% (n=19/39) of Group A, reporting having pain every day or a few days each week; however this level of pain is reported in only 8.0% (n=12/150) of those in Group C. These findings are of particular importance for those newly diagnosed patients who are fearful that their fatigue or pain will never decrease or resolve.

The physical side effects that are statistically significant include self-reported conditions such as fatigue, weakness, anemia, pain, joint pain, neuropathy, appetite, and infections. As the data on side effects in Table 2 illustrates, the frequency for these side effects differ among the patients in Groups A, B and C. Group C consistently has fewer side effects or side effects with less intensity, as would be expected for long-term survivors without other complications.

The most common side effects that caused a problem every day or a few days each week among Group A were: weakness (52.8%), joint pain (50%), unmanaged cancer pain (48.7%), inability to concentrate (48.7%), weight change (47.4%), fatigue (41.0%), nausea (44.4%), problems with appetite (36.8%), anemia (36.7%), radiation burns (21.6%), neuropathy (19.4%), heart problems (17.2%), infections (15.2%), and lymphedema (12.9%). Obviously, cancer treatments (chemotherapy, radiation, adjuvant therapies) may be responsible for compromised immune systems and for many of these side effects (weakness, pain, anemia, fatigue, nausea, infections, radiation reactions), while some may be elevated

due to lack of access to standard management strategies. In comparison, fewer than 10% of Group C self-reported having any of the side effects summarized in Table 2. The exception was their ability to concentrate with 60.9% (n=103/169) reporting problems with concentration every day or a few days each week.

Health Problems

Native American breast cancer survivors in this study reported several physical health problems that were also confirmed by a healthcare provider. More than one-quarter were told by a provider that she has high blood pressure (n=75/266, 28.2%). Almost one-fifth are overweight or obese (n=52/266; 19.5%) and one-sixth has thyroid problems (n=43/266, 16.2%). Chi-square was conducted to examine if there was a significant difference in the prevalence of health problems across Groups A, B and C. However, there was no statistically significant difference in the prevalence of health problems among these groups,

The survey asked about physical problems that emerged since their breast cancer diagnosis. Table 3 summarizes these findings. The majority of “new” problems were statistically significant and most have an eta value that show a moderate statistical relationship between the problem and the Group (length since diagnosis).

About one third of Group A had “new” problems with pain (42.5%), fatigue (42.5%), weakness (40.0%), depression (37.5%), body weight (37.5%), hair loss (32.5%), moody (30.0%), skin burns (30.0%), and post-surgery problems (30.0%). In comparison, few of Group C identified these symptoms as problems. One-fifth (n=37/174; 21.3%) of Group C survivors had unmanaged pain. Others in Group C identified weakness (n=26/174; 14.9%), dry skin (n=21/174; 12.1%) and fatigue (n=19/174; 10.9%) as problems that were new since diagnosis. For all three groups combined, more than one-quarter experienced unmanaged pain (n=76/266; 28.6%) as the most common “new” health problem identified at some time since their diagnosis with breast cancer. Other elevated “new problems” among all three groups combined was weakness (n=61/266; 22.9%), body weight (n=61/266; 22.9%), fatigue (n=49/266; 18.5%), dry skin (n=45/266; 16.9%), depression (n=43/266; 16.2%); and hair loss (n=41/266; 15.4%).

Discussion

This study documents many health problems and side effects, yet all three groups (A, B and C) self-reported good health. AIANs continue to experience disparities in their daily life, such as access to cancer treatment and healthcare. A large proportion (43.98%) of AI breast cancer patients relied on CMS (Medicaid, Medicare) for their care. Only 6.8% (n=18/266) obtained care through IHS or IHS Contract Health Services. IHS/Tribal/Urban healthcare services are not now and never have been equivalent to health insurance. These services are too underfunded by US Congress to be considered “insurance”. Thus, most of the patients experienced some difficulty accessing cancer care in spite of living on reservations and being eligible for tribal or IHS services. These patients also worked with the Native Patient Advocates and with NACR Headquarters to help them access timely and higher quality cancer treatments. Based on previous studies^{6, 7, 19, 20} and self-reported information from the Native Patient Advocates, the breast cancer survivors continue to have long intervals from initial diagnosis (biopsy) and initiation of cancer care (6 months). However, Native Patient Advocates are only present in few geographic regions and greater access to timely quality care is needed for the patients.

A large percentage of patients collectively self-reported problems with pain, fatigue, weakness, depression and hair loss occurring since diagnosis. Group A patients identified problems such as weakness, joint pain, unmanaged cancer pain, inability to concentrate,

weight change, fatigue, and nausea. Obviously, cancer treatments (chemotherapy, radiation, adjuvant therapies) may be responsible for many of these. However, others may be elevated due to lack of access to standard management strategies. For example, 44% (n=16/36) of Group A respondents had problems with nausea, yet this side effect can be controlled or managed by use of appropriate medications. Based on discussions during survivors' events, many of the Native patients were not offered anti-nausea prior to, during or following their cancer treatments, making side effect management for nausea essentially impossible. Likewise, the NACES website tracking programs consistently documents side effect content areas as among the more commonly accessed pages on the website. The majority of web users' submitted questions from the NACES website also focus on treatment side effects.

Selected self-reported problems, such as unmanaged pain as identified by those in Group C are disconcerting. It is not known why pain is so common in this group or what this symptom is specifically related to (it may be a continuation of pain experienced with initial diagnosis and treatment or it may be pain associated with a more recent and unrelated condition). However, based on qualitative data and transcripts from more than forty Native breast cancer patients, access to appropriate pain medications generally is not feasible for those relying on IHS for their medications. It is not known why pain and other problems appear to be elevated among Groups A, B, and C, nor why a significant number of Group C survivors experience these side effects.

Group A patients reported a lot of problems with joint pain: half (18/36; 50%) had joint pain problems every day or a few days each week. It is not known if this pain is related to cancer treatments, arthritis or some other co-existing condition. Because joint pain can affect the patients' ability for physical activity and such activity may be related to improved QOL and reduction of side effects, more information is needed to understand how to deal with this joint pain. Also of concern was that 43.8% (n=21/48) Group B patients also reported joint pain. Joint pain was not a common problem among Group C survivors (n=11/154; 7.1%). It is not known how to interpret these problems at this time.

Almost half (n=18/38; 47.4%) of the Group A patients reported problems with weight change. Most of this group is likely to be taking part in chemotherapy and have weight loss. However, the survey item needed to be more specific to determine weight gain or weight loss to be able to accurately determine what the data mean.

Some reported problems are accompanied by cultural contexts. Hair loss is traumatic for most cancer survivors regardless of race or ethnicity. However, hair holds unique cultural roles and functions that vary greatly among tribes. For some, hair reflects spiritual strength and balance. To lose one's hair for those from that tribal nation results in isolation within the home to avoid others from seeing the patients' "weakened spiritual being". For others, all hair, even from the hair brush, is saved for use in ceremonies or for inclusion in the pillow or padding of the coffin/death bed. To have hair falling out in bunches as does happen for many people undergoing chemotherapy, implies impending death according to selected tribal nations. Either hair loss cultural explanations would impact depression for most people.

Because diabetes is excessive among southwestern tribes, diabetes and geographic region was examined. About one-fifth (n=24/115; 20.9%) of Southwestern AIs and 11.1% (n=7/63) of Southern Plains (OK, KS, TX) survivors had a new problems with diabetes. Having a new problem with diabetes after one's breast cancer diagnosis was less common for survivors from all other regions of the US. Diabetes was examined based on the percentage who had diabetes prior to breast cancer diagnosis and those diagnosed with diabetes following their breast cancer diagnosis were comparable. Because cancer treatments and

diabetes affect many of the same body systems, the impact of having co-morbidities of breast cancer and diabetes would seem to cause more problems and affect the patients' QOL. The long-term follow-up study currently underway is examining such possibilities.

Among the more disconcerting problems was the patients' ability to concentrate. Collectively more than half of the survivors in Groups A, B and C reported problems with their ability to concentrate on a daily or several days each week. It is not known if this is due to the cancer treatments, growing older or some other reasons.

This study has limitations. These data describe what Native breast cancer patients are experiencing based on self-reported information. The data should be interpreted to be self-reported outcomes for Natives who were newly diagnosed survivors (Group A), between one to four years since their breast cancer diagnosis (Group B) and long-term survivors (Group C). These data were recorded at different stages of disease and measured at one time point. The data do not track the same survivor over time (e.g., the participants were evaluated at one point in time and grouped by time since diagnosis), thus it is unclear what the data would be if the same patients were tracked over time. It is also unclear whether the Native breast cancer patients' experiences are the same as non-Natives in terms of severity and overall outcome.

Other study limitations include: (1) The NACES staff was unable to obtain a sample size of Native cancer survivors sufficient to fully validate the refined QOL instrument but face validation was feasible by the review conducted during the 2006 national Native American cancer survivors' conference and March 2006 Advisory Board meeting. About fifty cancer patients provided feedback and suggestions for improvement. (2) Because there is no national sample of Native cancer survivors to compare the NACES data to, this is a convenience sample. The findings are for these patients and may or may not be relevant to Native cancer survivors in other regions. (3) Not all questions were answered by all participants (i.e., missing data). The patients answered most, but not all of the survey questions. The patient always has the option to not answer any item in compliance with the IRB, thus some patients implemented that choice to refuse to answer, skip some items or quit taking the survey altogether. Some return to the survey to complete it at a later date. A small number (less than five) passed away before completing all sections of the survey. The exact reasons for incomplete data are unknown; however, no question was consistently omitted.

Conclusions

This is the largest known study that documents Native American breast cancer patient's physical quality of life. No other literature was found describing physical conditions in these patients. A total of 266 Native breast cancer survivors completed part or all of the QOL survey of which a large subset was from the Southwest and Southern Plains, where the majority of AIs live within the 48 contiguous states.

Treatment outcomes for people who are diagnosed in 2009 are much better than they were for people who were diagnosed five years or more ago. Those who are newly diagnosed and able to obtain timely access to quality treatments are likely to have at least as good if not better outcomes in terms of problems and side effects than those in Group C of this study. Cancer treatment varies by stage at the time of diagnosis and potential short and long term side effects differ from patient to patient. In no way does this paper claim that patients who are currently undergoing diagnosis will see the same side effect and health problem experiences as those who were in Group C. However, because cancer outcomes have

improved for breast cancer over time, the experiences of those who are five or more years since diagnosis provide a meaningful yet conservative estimate of outcomes.

Most of the QOL surveys were completed with the assistance of the Native Patient Advocates rather than by the patient directly or with the assistance of a family member. The Native Patient Advocates working in Arizona and Oklahoma were very effective in working with cancer patients from those regions. Thus, the largest proportion of AIs who completed the survey from the lower 48 contiguous states is from the Southwest (n=115; 43.2%) and Oklahoma (n=63; 23.7%). Although there are greater numbers of AIs living in those regions of the country in comparison to the Northern Plains and other geographic regions, there appears to be a need for greater training to increase the effectiveness of Native Patient Advocates.

The Native Patient Advocates worked with more than 90% of the patients who completed the QOL surveys. Few of the survivors accessed and completed the QOL survey alone or with their families' assistance. However, based on the NACES website tracking documentation, many of the survivors do access the content information from the NACES website directly or with their family members. They also access the NACES information with the assistance of the Native Patient Advocates. The effectiveness of the trained Native Patient Advocates helping the patient access and complete the NACES QOL survey and find information from the NACES and other (NCI, ACS, Susan G. Komen for the CureR) websites was essential to the success of this study.

AIAN breast cancer patients reported in this manuscript have low education attainment: more than half (53.3%) had less than a high school degree. Less education usually means greater difficulty understanding or accessing timely medical care. The Native Patient Advocates were very helpful in clarifying information for these survivors.

Clearly there is need for much more work and long-term tracking of Native American patients to begin to document if or how the severity of physical symptoms lessen over time and if their experiences are significantly different from non-Natives. NACES is collecting follow-up QOL data from some of the participants of the original survey and those findings may also help generate other study hypotheses and interventions. Several issues about the disparities and physical outcomes may be clarified through the follow-up survey.

What appears to be of most significance in these findings is that symptoms generally appear to be less prevalent among Group C, the long-term survivors. This may be a message of hope to newly diagnosed Native breast cancer patients who may falsely believe that their lives will never improve or that cancer treatment causes long term side effects for which there is no respite or recovery. For most of them, their lives will improve.

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Figure 1.
IHS Age Adjusted Breast Cancer Mortality Rates, 1999–2003

Figure 2.
NACES QOL Tree Layout

Table 1

Physical Quality of Life

Native breast cancer patients		Time since diagnosis			Total (n=255)
		Group A "newly diagnosed" Diagnosed within Last Year	Group B Diagnosed Between 1-4 Years Ago	Group C "long-term survivor" Diagnosed 5 or More Years Ago	
Physical QOL	Extremely Poor or Poor	26.3% (n=10/38)	21.6% (n=11/51)	2.9% (n=5/172)	10% (n=26/261)
	Okay	44.7% (n=17/38)	41.2% (n=21/51)	39.5% (n=68/172)	40.6% (n=106/261)
	Good or Excellent	28.9% (n=11/38)	37.3% (n=19/51)	57.6% (n=99/172)	49.4% (n=129/261)
		Statistics Physical Body QOL: Chi-square 32.959; p=.000 eta=.324			
Physical Ability (to do what want to do)	Not able to physically do most things or everything I want to do	44.7% (n=17/38)	44.0% (n=22/50)	18.0% (n=30/167)	27.1% (n=69/255)
	Able to physically do most things I want to do	39.5% (n=15/38)	42.0% (n=21/50)	63.5% (n=106/167)	55.7% (n=142/255)
	Able to physically do everything I want to do	15.8% (n=6/38)	14.0% (n=7/50)	18.6% (n=31/167)	17.3% (n=44/255)

Statistics Physical Body QOL: Chi-square 20.611; p=.000 eta=.218

Table 2

Physical Side Effects Experienced by Native Breast Cancer Survivors

Side Effect	Measure	Time since diagnosis			Total	Chi-Square	eta
		Group A "newly diagnosed" Last Year	Group B "Diagnosed Between 1-4 Years Ago"	Group C "long-term survivor" Diagnosed 5 or More Years Ago			
Nausea	Not a Problem or only a Problem a Few Days Each Month	44.4% (n=16/36)	76.1% (n=35/46)	95.8% (n=136/142)	83.5% (n=187/224)	$\chi^2 = 61.356$ p=.000	.516
	A Problem At Least Once a Week	11.1% (n=4/36)	2.2% (n=1/46)	2.8% (n=4/142)	4.0% (n=9/224)		
	A Problem a Few Days Each Week or Every Day	44.4% (n=16/36)	21.7% (n=10/46)	1.4% (n=2/142)	12.5% (n=28/224)		
Weakness	Not a Problem or only a Problem a Few Days Each Month	25.0% (n=9/36)	58.3% (n=28/48)	90.3% (n=140/155)	74.1% (n=177/239)	$\chi^2 = 75.914$ p=.000	.516
	A Problem At Least Once a Week	22.2% (n=8/36)	6.2% (n=3/48)	1.9% (n=3/155)	5.9% (n=14/239)		
	A Problem a Few Days Each Week or Every Day	52.8% (n=19/36)	35.4% (n=17/48)	7.7% (n=12/155)	20.1% (n=48/239)		
Joints	Not a Problem or only a Problem a Few Days Each Month	36.1% (n=13/36)	50.0% (n=24/48)	88.3% (n=136/154)	72.7% (N=173/238)	$\chi^2 = 59.551$ P=.000	.493
	A Problem At Least Once a Week	13.9% (n=5/36)	6.2% (n=3/48)	4.5% (n=7/154)	6.3% (N=15/238)		
	A Problem a Few Days Each Week or Every Day	50.0% (n=18/36)	43.8% (n=21/48)	7.1% (N=11/154)	21.0% (N=50/238)		
Anemia	Not a Problem or only a Problem a Few Days Each Month	50.0% (n=15/30)	81.0% (n=34/42)	95.6% (n=131/137)	86.1% (n=180/209)	$\chi^2 = 47.406$ p=.000	.467
	A Problem At Least Once a Week	13.3% (n=4/30)	2.4% (n=1/42)	2.9% (n=4/137)	4.3% (n=9/209)		
	A Problem a Few Days Each Week or Every Day	36.7% (n=11/30)	16.7% (n=7/42)	1.5% (n=2/137)	9.6% (n=20/209)		
Appetite	Not a Problem or only a Problem a Few Days Each Month	47.4% (n=18/38)	76.0% (n=38/50)	94.0% (n=141/150)	82.8% (n=197/238)	$\chi^2 = 49.684$ p=.000	.448
	A Problem At Least Once a Week	15.8% (n=6/38)	10.0% (n=5/50)	2.7% (n=4/150)	6.3% (n=15/238)		
	A Problem a Few Days Each Week or Every Day	36.8% (n=14/38)	14.0% (n=7/50)	3.3% (n=5/150)	10.9% (n=26/238)		
Pain	Not a Problem or only a Problem a Few Days Each Month	35.9% (n=14/39)	58.0% (n=29/50)	87.6% (n=141/161)	73.6% (n=184/250)	$\chi^2 = 52.678$ p=.000	.445
	A Problem At Least Once a Week	15.4% (n=6/39)	6.0% (n=3/50)	3.7% (n=6/161)	6.0% (n=15/250)		
	A Problem a Few Days Each Week or Every Day	48.7% (n=19/39)	36.0% (n=18/50)	8.7% (n=14/161)	20.4% (n=51/250)		

Side Effect	Measure	Time since diagnosis			Total	Chi-Square	eta
		Group A "newly diagnosed" Diagnosed within Last Year	Group B "Diagnosed Between 1-4 Years Ago"	Group C "long-term survivor" Diagnosed 5 or More Years Ago			
Weight Change	Not a Problem or only a Problem a Few Days Each Month	42.1% (n=16/38)	66.0% (n=31/47)	90.7% (n=136/150)	77.9% (n=183/235)	$\chi^2 = 46.995$ p=.000	.428
	A Problem At Least Once a Week	10.5% (n=4/38)	8.5% (n=4/47)	1.3% (n=2/150)	4.3% (n=10/235)		
	A Problem a Few Days Each Week or Every Day	47.4% (n=18/38)	25.5% (n=12/47)	8.0% (n=12/150)	17.9% (n=42/235)		
Fatigue	Not a Problem or only a Problem a Few Days Each Month	35.9% (n=14/39)	61.2% (n=30/49)	82.3% (n=135/164)	71.0% (n=170/252)	$\chi^2 = 36.326$ p=.000	.366
	A Problem At Least Once a Week	23.1% (n=9/39)	12.2% (n=6/49)	7.3% (n=12/164)	10.7% (n=27/252)		
	A Problem a Few Days Each Week or Every Day	41.0% (n=16/39)	26.5% (n=13/49)	10.4% (n=17/164)	18.3% (n=46/252)		
Radiation Burns	Not a Problem or only a Problem a Few Days Each Month	62.2% (n=23/37)	83.0% (n=39/47)	94.4% (n=136/144)	86.8% (n=198/228)	$\chi^2 = 31.731$ p=.000	.341
	A Problem At Least Once a Week	16.2% (n=6/37)	2.1% (n=1/47)	3.5% (n=5/144)	5.3% (n=12/228)		
	A Problem a Few Days Each Week or Every Day	21.6% (n=8/37)	14.9% (n=7/47)	2.1% (n=3/144)	7.9% (n=18/228)		
Infections	Not a Problem or only a Problem a Few Days Each Month	66.7% (n=22/33)	82.2% (n=37/45)	95.8% (n=137/143)	88.7% (n=196/221)	$\chi^2 = 28.576$ p=.000	.324
	A Problem At Least Once a Week	18.2% (n=6/33)	4.4% (n=2/45)	2.8% (n=4/143)	5.4% (n=12/221)		
	A Problem a Few Days Each Week or Every Day	15.2% (n=5/33)	13.3% (n=6/45)	1.4% (n=2/143)	5.9% (n=13/221)		
Neuropathy	Not a Problem or only a Problem a Few Days Each Month	41.7% (n=15/36)	68.8% (n=33/48)	84.6% (n=132/156)	75.0% (n=180/240)	$\chi^2 = 31.094$ p=.000	.304
	A Problem At Least Once a Week	38.9% (n=14/36)	20.8% (n=10/48)	8.3% (n=13/156)	15.4% (n=37/240)		
	A Problem a Few Days Each Week or Every Day	19.4% (n=7/36)	10.4% (n=5/48)	7.1% (n=11/156)	9.6% (n=23/240)		
Menopause ^b	Not a Problem or only a Problem a Few Days Each Month	57.1% (n=16/28)	59.5% (n=25/42)	85.3% (n=93/109)	74.9% (n=134/179)	$\chi^2 = 16.649$ p=.002	.301
	A Problem At Least Once a Week	7.1% (n=2/28)	4.8% (n=2/42)	2.8% (n=3/109)	3.9% (n=7/179)		
	A Problem a Few Days Each Week or Every Day	35.7% (n=10/28)	35.7% (n=15/42)	11.9% (n=13/109)	21.2% (n=38/179)		
Lymphedema	Not a Problem or only a Problem a Few Days Each Month	83.9% (n=26/31)	81.4% (n=35/43)	96.2% (n=127/132)	91.3% (n=188/206)	$\chi^2 = 14.470$ p=.006	.243
	A Problem At Least Once a Week	3.2% (n=1/31)	.0% (n=0/43)	.8% (n=1/132)	1.0% (n=2/206)		

Side Effect	Measure	Time since diagnosis			Total	Chi-Square	eta
		Group A "newly diagnosed" Diagnosed within Last Year	Group B "Diagnosed Between 1-4 Years Ago"	Group C "long-term survivor," Diagnosed 5 or More Years Ago			
	A Problem a Few Days Each Week or Every Day	12.9% (n=4/31)	18.6% (n=8/43)	3.0% (n=4/132)	7.8% (16/206)		
Heart	Not a Problem or only a Problem a Few Days Each Month	79.3% (n=23/29)	88.4% (n=38/43)	95.7% (n=134/140)	92.0% (n=195/212)	$\chi^2=12.443$ p=.014	.234
	A Problem At Least Once a Week	3.4% (n=1/29)	4.7% (n=2/43)	2.1% (n=3/140)	2.8% (n=6/212)		
	A Problem a Few Days Each Week or Every Day	17.2% (n=5/29)	7.0% (n=3/43)	2.1% (n=3/140)	5.2% (n=11/212)		
Ability to Concentrate	Not a Problem or only a Problem a Few Days Each Month	5.1% (n=2/39)	24.0% (n=12/50)	11.2% (n=19/169)	12.8% (n=33/258)	$\chi^2=13.341$ p=.010	.173
	A Problem At Least Once a Week	46.2% (n=18/39)	34.0% (n=17/50)	27.8% (n=47/169)	31.8% (n=82/258)		
	A Problem a Few Days Each Week or Every Day	48.7% (n=19/39)	42.0% (n=21/50)	60.9% (n=103/169)	55.4% (n=143/258)		

^b Many of the survivors are too young to experience menopause, or experienced it long ago. Increased problems due to advancing age.

Table 3

Since the breast cancer diagnosis, have you had any NEW health problems

Problem	Time since diagnosis			Total	Chi-Square	eta
	Group A "newly diagnosed" Diagnosed within Last Year	Group B Diagnosed Between 1-4 Years Ago	Group C "long-term survivor" Diagnosed 5 or More Years Ago			
Depressed	37.5% (n=15/40)	30.8% (n=16/52)	6.9% (n=12/174)	16.2% (n=43/266)	$\chi^2 = 32.648$ p=.000	.350
Skin Burns	30.0% (n=12/40)	26.9% (n=14/52)	4.6% (n=8/174)	12.8% (n=34/266)	$\chi^2 = 30.419$ p=.000	.338
Post-Surgery	30.0% (n=12/40)	28.8% (n=15/52)	5.7% (n=10/174)	13.9% (n=37/266)	$\chi^2 = 28.017$ p=.000	.325
Moody	30.0% (n=12/40)	19.2% (n=10/52)	4.6% (n=8/174)	11.3% (n=30/266)	$\chi^2 = 25.059$ p=.000	.307
Hair	32.5% (n=13/40)	28.8% (n=15/52)	7.5% (n=13/174)	15.4% (n=41/266)	$\chi^2 = 24.572$ p=.000	.304
Body Weight	37.5% (n=15/40)	42.3% (n=22/52)	13.8% (n=24/174)	22.9% (n=61/266)	$\chi^2 = 24.072$ p=.000	.301
Fatigue	42.5% (n=17/40)	25.0% (n=13/52)	10.9% (n=19/174)	18.4% (n=49/266)	$\chi^2 = 23.446$ p=.000	.297
Weakness	40.0% (n=16/40)	36.5% (n=19/52)	14.9% (n=26/174)	22.9% (n=61/266)	$\chi^2 = 18.325$ p=.000	.262
Insomnia	27.5% (n=11/40)	15.4% (n=8/52)	5.7% (n=10/174)	10.9% (n=29/266)	$\chi^2 = 17.180$ p=.000	.254
Pain	42.5% (n=17/40)	42.3% (n=22/52)	21.3% (n=37/174)	28.6% (n=76/266)	$\chi^2 = 13.162$ p=.001	.222
Ability to Concentrate	12.5% (n=5/40)	17.3% (n=9/52)	3.4% (n=6/174)	7.5% (n=20/266)	$\chi^2 = 12.739$ p=.002	.219
Anxiety	25.0% (n=10/40)	13.5% (n=7/52)	6.3% (n=11/174)	10.5% (n=28/266)	$\chi^2 = 12.639$ p=.002	.218
Infections	20.0% (n=8/40)	5.8% (n=3/52)	5.2% (n=9/174)	7.5% (n=20/266)	$\chi^2 = 10.568$ p=.005	.199
Memory	17.5% (n=7/40)	25.0% (n=13/52)	8.0% (n=15/174)	13.2% (n=35/266)	$\chi^2 = 10.177$ p=.006	.196
Dry Skin	25.0% (n=10/40)	26.9% (n=14/52)	12.1% (n=21/174)	16.9% (n=45/266)	$\chi^2 = 8.473$ p=.014	.178

Self-reported "new" problems since diagnosis that were not significant:

Headaches, illnesses, high blood pressure, newly diagnosed diabetes, arthritis, heart problems, lymphedema, allergies, body aches, and problems with new medications