# A Comparison of Quality of Life Between Native and Non-Native Cancer Survivors

Native and Non-Native Cancer Survivors' QOL

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Abstract This paper compares quality of life (QOL) outcomes between Native American and non-Native cancer survivors. Native Patient Navigators helped Native cancer patients complete a 114-item QOL survey and access survivorship information available on the NACES website. The survey was modified from Ferrell et. al's QOL measure and assessed the four domains of cancer survivorship: physical, psychological, social, and spiritual [1]. Findings from Native survivors were compared to Ferrell's findings. This is the first time that QOL outcomes have been compared between Native and Non-Native cancer survivors. Natives scored lower for physical and social QOL, the same for psychological QOL, and higher for spiritual QOL in comparison to non-Natives. Overall QOL scores were the same.

Although this is the largest sample of Native cancer survivors reported in peer-reviewed manuscripts, these Native survivorship data are based on a self-selected group and it is unknown if the findings are generalizable to others.

**Keywords** American Indian · Native American · Cancer · Survivors · Psychosocial · Quality of life

# Introduction/Background

This paper compares quality of life (QOL) outcomes between Native American cancer survivors and non-Native survivors. It summarizes QOL findings from almost 600

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Native American cancer patients (all sites) and compares those data with Grant, Padilla, and Ferrell (of the City of Hope (COH), Duarte, CA) QOL measures. Their data are from 600 non-Native cancer survivors from the latter 1990s. Assessing QOL is essential as methods to improve both the length and quality of cancer survivorship advance. In particular, understanding the effects of cancer and cancer treatment over time play a role in helping patients cope with diagnosis, treatment, and short- and long-term follow-up.

During 1997-2006, short-term trends in death rates for all cancers combined decreased for all racial/ethnic groups for both men and women, except for AIAN women [2]. According to the 2008 Indian Health Service (IHS) data [3], there are regional differences for most cancer sites with Alaska and the Northern Plains and Southern Plains having elevated mortality in comparison to other AIs living in the 48 contiguous states. Native Americans continue to have the poorest 5-year relative survival in comparison to all other ethnic and minority groups in the USA [4–7]. The same pattern is observed when relative risks are estimated for all cancers combined (adjusted RRs, 1.7 for males and 1.8 for females) [4]. In many geographic regions, there are no accurate survival data available, and quality of life (QOL) information specific to Native American cancer survivorship issues have not been collected, thus the true extent is unknown [8–10].

The cancer burden continues to escalate among Natives [11, 12]. Burden includes multiple ways cancer impacts the whole family such as loss of income from the patient who cannot maintain a job, family members moving home to serve as the caregiver to the patient, increased demands (time and money) for transportation to and from the cancer care facility, child care costs, and so on.

The "Native American Cancer Education for Survivors" (NACES) study and findings specific to breast survivors were described in *Cancer*, March 2010 [10]. The purpose of NACES is to improve the QOL of cancer patients by increasing knowledge and informed choice using innovative, tailored web-based technology (http://www.NatAmCancer.org). Native Patient Navigators help patients complete the QOL survey and access the survivorship information available on the website. The NACES is organized as a QOL Tree with information that is interactive, culturally appropriate, written at reading grade levels 5–7 for most pages, and based on Native survivors sharing their stories throughout the education materials. The education content is both culturally appropriate and scientifically accurate.

## Measuring Quality of Life

The four domains of survivorship (physical, psychological, social, and spiritual) described by Ferrell et al. in 1997 continue to be essential measures of QOL [13]. Each domain encompasses qualities valuable to a person diagnosed

with cancer. Both newly diagnosed (1 year or less since diagnosis with cancer) and long-term survivors (diagnosed with cancer five or more years ago) need continued assessments of physical symptoms, particularly pain, fatigue, and sleep concerns, to address their well-being [14].

Psychological educational interventions also are effective in improving QOL during the first year of treatment ("newly diagnosed") such as by helping the patient improve emotional coping skills and reactions to the disease, having feelings of hope and for recovery. Psychological education about long-term treatment effects over time continues to be important [15]. Thus, such interventions are also beneficial to more long-term survivors.

Social supportive care services, satisfaction with social support, network size, and reliance on formal and informal social ties affect for long-term cancer survivors are also significant factors affecting QOL. Social QOL includes the impact of cancer on family and work life. This domain also varies by ethnic and demographic characteristics [16]. Therefore, enhancing the social networks of cancer survivors' should improve their QOL [17].

Spirituality, religion, and personal beliefs are relevant to health-related QOL and health care assessments [18]. The inclusion of spirituality within QOL allows for a more holistic assessment and improves the case for a bio–psycho–social–spiritual model of health [19]. Long-term survivors frequently report that cancer either positively or negatively influenced their lives, but others felt the cancer had little long-term impact. Those who expressed more negative feelings reported that pain, physical deformities, and social isolation significantly reduced their QOL [20]. Thus, perceptions on how cancer has affected survivors' lives may influence, or be influenced by, their functional abilities and QOL [21].

Ashing-Gwim et al. adjusted for demographic and medical variables within cancer survivors, and found that health-related QOL was significantly correlated to socioeconomic status (SES): a higher SES was related to a higher QOL [22]. Thus, SES plays a significant role in quality of life which may impact a cancer patient's ability to return to "normal life" following the completion of treatment. In addition, ethnic variations existed in QOL according to SES, with sociologic stress being one of the most important influencing factors.

Additional data are needed to understand the needs of long-term survivors, especially those in groups underrepresented in published QOL studies, such as Native Americans. These data may help identify the kinds of support services survivors want and need [23]. Much more work and long-term tracking of Native American patients is needed to document if or how the severity of physical symptoms changes over time and if their experiences are significantly different from non-Native Americans [10]. This publication



begins to address this gap in research regarding Native Americans diagnosed with cancer.

Native Cultures and Cancer: Concepts from the Past to Those of the Present

Native American Cancer Research staff has worked with Native cancer survivors since the latter 1980s [8–10, 24-29]. Many cultural changes have evolved since that time, but Native cultures continue to be very different one from another. The concept of a "cancer diagnosis" within Native communities is met with feelings of fatalism, fear, anxiety, and depression by most patients. The concept of fatalism is not superstition, but was based on the realities that many Natives saw in their family or neighbors diagnosed with cancer that did pass on from the disease. In the 1980s and first half of the 1990s, "cancer" as a word, much less as a diagnosis, was rarely uttered. Notable Native leaders, such as Mary P. Lovato (Santo Domingo Pueblo, bone and kidney cancer survivor; passed 2008) were ostracized by their communities in the 1980s and 1990s because of their cancer diagnoses. This ostracism often was extended to spouses and children of the person with cancer. Although there are still Native subsets that will not use the word "cancer," such avoidance is no longer the norm. In fact, today, most cancer survivors receive proactive support from their communities and few are ostracized. This paper provides scientific documentation that there is a much more hopeful outcome for most Native cancer patients and that overall, Natives are doing as well as non-Native cancer patients.

### Methods

The NACES QOL survey was primarily administered with the assistance of a trained Native Patient Navigator. In 2005, the research team from COH gave permission to NACR to use their QOL instruments in the creation of a QOL survey specific for Native Americans. Fourteen other QOL survivorship instruments also were reviewed, but the COH QOL items were the primary foundation for the NACES QOL survey [30]. All items were modified for cultural appropriateness with Native American communities. The NACES Advisory Committee, comprised of ten Native cancer survivors living in geographically diverse regions of the USA and Canada, and two Panels of Experts recommended modifications for use with Native communities. One of the more consistent modifications was to reduce the number of choices from ten in the COH tools to five for the NACES survey since Native patients reported they did not want to answer items that had so many choices for responses. The COH collaborators agreed with this change and modifications to the scoring system were made.

#### NACES QOL Scoring Method

The methods of scoring the NACES QOL survey are based on methods developed for the COH Survey that used ordinal scale questions to measure QOL. Possible responses ranged from 0 to 10, where a value of 0 represents the worst outcome and a value of 10 represents the best outcome, with some reversals necessary [30]. The 41 items of the COH instrument represent the four domains of quality of life including physical, psychological, social, and spiritual well-being.

The NACES QOL survey was adapted from the COH instrument and included 24 items. The 24 items assessed the four domains as follows: physical (6 items), psychological (6 items), social (7 items), and spiritual (5 items). Scoring of the NACES instrument mirrored the COH protocol. Reliability of the NACES instrument was calculated using Cronbach's alpha and compared with data from Ferrell et al. (see Table 1). As Table 1 shows, the reliability coefficients from the NACES data using the adapted instrument compare favorably with reliability reported by Ferrell.

#### **Findings**

As of June 2010, the NACES website has QOL survey data from 596 Native cancer survivors (all cancer sites) (Table 2). Almost half of the survivors are from the southwest region of the USA and the majority is female. Because NACES was originally focused only on breast patients, almost half (n=264; 46.4%) are breast survivors. More than half have a high school or less education (n=310; 56.5%). More than half (n=354; 58%) of the survivors are long-term survivors (diagnosed more than 5 years previously).

Table 3 summarizes the Native cancer survivors' dimensions of QOL ranging from "extremely poor" to "excellent." Almost half of the Native cancer survivors self-reported physical (n=263/585; 44.9%), social (233/515; 45.3%), and mental/emotional (n=245/559; 44.0%) QOL as "good" or "excellent." At least half (n=256/493; 51.9%) of the

**Table 1** Reliability coefficients (Cronbach's Alpha) for the NACES and Ferrel et al. instruments

QOL dimension	NACES	Ferrell
Physical	0.87	0.77
Psychological	0.81	0.89
Social	0.77	0.81
Spiritual	0.82	0.71
Overall	0.90	0.93



Table 2 Descriptive characteristics of NACES and COH survivors

	NACES survivors <sup>a</sup>		COH survivors		
	N=596	100%	N=686	100%	
Gender					
Female	486	82.2	556	81.05	
Male	105	17.8	130	18.95	
Year of birth			Age		
1970-1989	32	5.5	Mean=49.6 year	S	
1950-1969	282	48.5	Median=49 year	S	
1940-1949	173	29.8	SD=12 years		
1910-1939	94	16.2			
Education					
Less than HS	148	27	28% (less than		
High school/GED	162	29.5	college degree)	)	
Technical/some college	152	27.7			
Associates/bachelors/ masters/doctorate	87	15.9	72% (college degree or above)		
Region of the USA					
Alaska/Canada	30	5.2	Not given		
Northern plains	77	13.2			
Southern plains	173	29.7			
Pacific coast	20	3.4			
East	12	2.1			
Southwest	270	46.4			
Cancer types					
Bone	1	0.2			
Brain	7	1.2			
Breast	264	46.2	294	43	
Cervix	72	12.9	30	4	
Colorectal	34	6.1	25 (colon)	4	
Eye	3	0.7			
Gallbladder	4	0.7			
Head and neck	6	1			
(including oral) Hodgkin's lymphoma	1	0.2	59 (lymphoma) 53 (Hodgkin's)	9	
Kidney	1	0.2	33 (Hougkii s)	o	
Leukemia–ALL	1	0.2	25	4	
			23	4	
Lung	36	6.4	52	0	
Ovary	62	11.1	53	8	
Pancreas	1	0.2			
Prostate	22	4			
Skin	6	1			
Stomach	26	4.7			
Testicular	7	1.2			
Thyroid	1	0.2			
Uterine	3	0.5	100		
Other	90	15.1	139	21	

<sup>&</sup>lt;sup>a</sup> Totals vary due to missing data and multiple diagnoses of cancer

Native cancer survivors self-reported their spiritual QOL as "good" or "excellent."

Table 4 asks how well the survivor is able to do what she/he wants to do on a daily basis, physically, spiritually, socially, and mentally/emotionally. More than 70% of the Native cancer survivors reported they could do these functions most or all days: physical (n=403/573; 70.4%); spiritual (n=369/424; 87.0%); social (n=407/537; 75.8%); and mental—emotional (n=142/160; 88.8%). The mental—emotional functionality item was accidentally omitted from the survey until fall 2008 (thus, the fewer responses). Overall, the NACES survivors reported being able to do whatever they wanted to do most days (Table 4); thus, the patients believed they could carry on normal daily living tasks.

Table 5 shows the comparison of QOL ratings of the NACES Native survivors with the COH non-Native cancer survivors. Native cancer patients scored lower than the non-Native cancer patients for both overall (mean of 7.2 as compared to 7.8 for non-Natives; p<0.05) and for specific variables within the physical QOL subscale. Native survivors mean for fatigue was 6.1 in comparison to 6.7 for non-Natives. Natives also had fewer problems with nausea and lack of appetite (8.0 and 7.7 in comparison to 9.4 and 8.3 for non-Natives). However, almost half of the NACES participants were long-term (diagnosed five or more years previously) survivors.

Both groups had the same overall score for the psychological QOL subscale (a mean of 5.9 for both groups). However, components within the psychological QOL differed. The largest difference was for "usefulness" for which the Native survivors rated much lower (mean of 4.3) in comparison to the non-Native survivors (mean of 7.8; p<0.05). Also of note is the Native low mean for "anxiety" (3.0) in comparison to the non-Natives mean of 5.7 (p<0.05).

Native cancer survivors had lower social OOL (4.8 mean compared to 6.6 mean for non-Natives on the subscale). This is observed on every variable (personal relationships, support from others, feelings of isolation). However, while Natives scored lower on the physical and social QOL subscales, they scored higher on the spirituality subscale in comparison with non-Natives. Cultural differences are likely to be the basis for the higher scoring on the spirituality subscale. Most cancer survivors of any race or ethnicity tend to express more religiosity and spirituality once diagnosed with cancer. Native American cultures, although very diverse, are strongly intertwined with spirituality of all living and nonliving structures. This core of spirituality is probably why the Native cancer patients were more inclined to report there was no spiritual change in their QOL following their diagnoses with cancer. Likewise, the importance of spiritual activities has a mean of 7.0 for Natives, in comparison to a 5.6 mean among non-Natives. The Native cancer patients are also very



**Table 3** Perceived quality of life for four dimensions

Quality of life						
	Extremely poor	Poor	Okay	Good	Excellent	Total
Physical	10 (1.7%)	77 (13.2)	235 (40.2)	226 (38.6)	37 (6.3)	585
Spiritual	3 (0.6)	34 (6.9)	200 (40.6)	155 (31.4)	101 (20.5)	493
Social	8 (1.6)	78 (15.2)	196 (38.1)	175 (34.0)	58 (11.3)	515
Mental/emotional	9 (1.6)	89 (15.9)	216 (38.6)	199 (35.6)	46 (8.2)	559

Global\_QOL=physical QOL+social QOL+mental/ emotional QOL+spiritual QOL Range from 4 to 20, mean 13.85, SD 2.8

hopeful (mean of 8.6 as compared to 7.9 for non-Natives) and have a strong sense of a life purpose (mean of 8.2 as compared to 7.4 for non-Natives).

#### Discussion

When working with Native cancer patients and their families, the research team is typically met with fears, hopelessness, and helplessness based on previous generations' experiences with cancer. However, great advances have significantly changed outcomes to many types of cancer. These advances are clear by the steadily increasing number of healthy, long-term cancer survivors. Natives sometimes still make comments that the improvements are only in non-Natives and not in our communities because of our poorer Indian health care systems, we do not have the same benefits. The latter is a valid concern: the data continue to support that Native cancer patients must overcome more barriers to obtain timely, quality cancer care. Likewise, the data also support that such efforts to overcome barriers are working. The Native American cancer survivors taking part in the NACES show comparable QOL with non-Native cancer survivors. There are variations in QOL domains, probably related to health care issues, cultural practices, and lifestyle influences within the Native communities.

A major question in evaluating these data is whether this group of Native cancer patients is similar or different from US populations. When compared to the COH data, overall, they appear to be very similar. When differences are noted, they are likely due to cultural differences between Natives and non-Natives (e.g., spirituality). In general, Natives had either the

same or similar QOL subscale scores for overall QOL and psychological well-being. They scored poorer on physical and social well-being subscales but higher on the spiritual well-being subscale. Stories shared by the Native survivors help explain these variables. The investigators do not yet understand some of the poorer physical QOL scores among the long-term survivors (fatigue, weakness, pain). They conducted logistical regression with variables (diabetes, age, arthritis) but none of the variables yet explain why the patients would continue to have such issues when they were diagnosed and completed cancer treatment five or more years previously.

Although the overall comparison of psychological items was equivalent for NACES and COH, the investigators ran logistical regression on psychological measures (concentration, depression, feelings of usefulness) with several other variables (diabetes, age, fatigue). They do not yet have an explanation for specific lower scores for the NACES sample. Survivors' stories help reflect possible influences. Patients discuss returning to their homes or villages in the midst of subsistence hunting season. Everyone, including the patient recovering from surgery is expected to help out. More than one such patient ripped out her surgical stitches from cleaning the fish. Other family and community members working on the subsistence food preparation had no idea the women had just had cancer surgery. The focus was on preparing food for the winter. The women (two separate villages) went to their local health aid (there are no physicians living and working in their villages) to have the stitches re-sewn. With the patient's permission, the Native Navigators were allowed to talk to one or more family members to explain about the cancer (the disease itself), the family member's recent cancer diagnosis, the need to

Table 4 Functional ability

Able to					
	Never able	Not able most days	Able most days	Able all days	Total
Physical	32 (5.6)	138 (24.1)	295 (51.5)	108 (18.9)	573
Psychological	1 (0.6)	17 (10.6)	114 (71.3)	28 (17.5)	160
Social	24 (4.5)	106 (19.7)	247 (46.0)	160 (29.8)	537
Spiritual	12 (2.8)	43 (10.1)	209 (49.3)	160 (37.7)	424



Table 5 Comparison of NACES and COH patients' QOL for four domains

Items (by subscales)	QOL in 596 Native American cancer survivors (2010)			QOL in 687 cancer survivors (COH; Ferrell and Dow 1997)			
	Mean	Std Dev	95% CI	Mean	Std Dev	95% CI	Difference
Physical well-being							
Nausea	8	2.6	7.8-8.2	9.4	1.6	9.3-9.5	-1.4*
Appetite	7.7	2.9	7.5–7.9	8.3	2.5	8.1-8.5	-0.6*
Menstrual change/fertility	7.5	2.9	7.3–7.7	7.4	3.8	7.1 - 7.7	-0.1
Overall physical well-being	5.9	2	5.7-6.1	7.2	2.1	7.0 - 7.4	-1.3*
Aches/pain	7.1	2.9	6.9-7.3	7.1	2.8	6.9-7.3	0.0
Fatigue	6.1	3.1	5.9-6.4	6.7	2.8	6.5-6.9	-0.6*
Total physical subscale	7.2	2	7.0-7.4	7.8	1.7	7.7–7.9	-0.6*
Psychological well-being							
QOL single item	5.8	2.1	5.6-6.0	7.8	2.1	7.6-8.0	-2.0*
Usefulness	4.3	2.7	4.1-4.5	7.8	2.1	7.6-8.0	-3.5*
Happiness	7.4	2.4	7.2–7.6	7.7	2	7.6-7.9	-0.3
Satisfaction	7.4	2.2	7.2–7.6	7.5	1.9	7.4-7.6	-0.1
Concentration/memory	7.5	2.6	7.3-7.7	6.9	2.2	6.7-7.1	+0.6*
Anxiety	3	3.1	2.8-3.3	5.7	2.5	5.5-5.9	-2.7*
Total psychological subscale	5.9	5.8	5.8-6.0	5.9	1.6	5.8-6.0	0.0
Social well-being							
Personal relationships	5.8	7	5.5-6.1	7.9	2.8	7.7-8.1	-0.9*
Support/others	5.1	5	4.9-5.3	7.8	2.4	7.6-8.0	-2.8*
Feel isolated	5.7	5	5.5-5.9	7.6	2.9	7.6-8.0	-1.9*
Home activities	3.2	3	3.0-3.5	7.5	2.8	7.3-7.7	-4.3*
Employment	5.3	7.5	5.0-5.6	6.9	3.5	6.6-7.2	-1.6*
Financial burden	5.4	5	5.2-5.6	6.2	3.4	6.0 - 7.2	-1.2*
Family distress	1.6	0.5	1.5-1.7	3.3	2.6	3.1-3.5	-1.7*
Total social subscale	4.8	4.7	4.7-4.9	6.6	2	6.5-6.8	-1.8*
Spiritual well-being							
Hopefulness	8.6	9.5	8.5-8.7	7.9	2.1	7.7-8.1	+0.5*
Life purpose	8.2	9.5	8.1-8.4	7.4	2.6	7.2-7.6	+0.8*
Positive change	6.3	7.5	6.1-6.5	7.2	2.7	7.0-7.4	+0.9*
Spiritual change	5.5	5	5.3-5.7	6.9	2.8	6.7-7.1	-1.9*
Importance of spiritual activities	7	7.5	6.8-7.2	5.6	3.5	5.3-5.9	+1.5-1.3
Total spiritual subscale	7.2	7.4	7.1–7.3	6.6	1.8	6.5-6.7	-0.6*
Overall QOL	6.5	6.6	6.4–6.6	6.5	1.3	6.4-6.6	0.0

<sup>\*</sup>statistically significant at p < .05

have her work on tasks less strenuous to avoid ripping out the stitches again, and other ways the family could help support her throughout her recovery. The family and community members immediately reassigned the women to less vigorous roles throughout the subsistence preparations.

Social support was lower among the Native participants. For many tribal nations, it is still difficult to acknowledge a cancer diagnosis. An example is a Native man who returned home following colorectal cancer surgery. He is a "hot shot" firefighter and attempted travel with his team to another state to fight forest fires within a few days of his surgery.

However, during the outgoing flight he experienced postsurgical difficulties and his colleagues discovered he had just completed cancer surgery. They reassigned him a job in the firefighters' coordination center to help protect him from climbing the high mountains with a full backpack to fight the forest fire. Another firefighter drove him home to avoid the changing air pressure causing pain from his healing surgery. This reticence to share information about a cancer diagnosis is also evident within the immediate and extended family. Several cancer patients explained that they did not want to worry their families and waited until they were

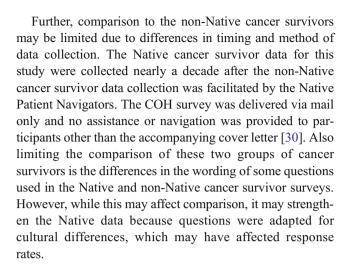


through with their treatment before they shared information with them ... waiting as long as 2 years (to never) after completing treatment for some patients. Ten percent never shared information about their disease with extended family members (aunts, uncles) and 10.9% of the NACES survivors never informed their co-workers about their disease.

In general, Native cancer survivors were more likely to not answer spirituality questions than they were for questions about physical, social, or mental-emotional items. This is primarily due to retaining the privacy of spiritual beliefs to avoid others (New-Agers) from misusing Native spiritual practices. Some tribal Nations prohibit the sharing of spiritual information because of the abuse or misleading information shared in publications and elsewhere. Thus, the NACES spirituality QOL items are not intended to collect details about private ceremonies. Regardless, some spiritual issues arise that non-Natives would not initially associate with spirituality. For example, almost all cancer patients who lose hair (not all patients do lose hair) during chemotherapy are unhappy or upset about the large clumps of hair falling out. One of the NACES patients was a member of a tribe for which males retain long hair as a sign of spiritual power, traditional respect for ancestors, and decision-making roles. When the tribal leader lost his hair, he stepped down as pipe-holder and spiritual leader for his community until his hair grew in again (had to cover his ears before he retained his spiritual and leadership role). Thus, some situations are misinterpreted by non-Natives working with our communities, but the issues are actually spiritual OOL or similar factors that are unique to individual tribal Nations.

#### Limitations

Although this is the largest sample of Native cancer survivors reported in peer-reviewed manuscripts, these Native survivorship data are based on a self-selected group. It is not known how well these findings represent the entire population of Natives diagnosed with cancer. Almost half of the NACES participants are from the Southwest; however, cancer incidence is significantly higher among Alaska Natives and Northern and Southern Plains Natives than those who are from the southwest. More than half of the NACES participants are long-term survivors (diagnosed with cancer five or more years ago). Medical records, commonly referred to as the "gold standard" for confirming self-reported patient data, were not used for the NACES based on excessive missing data and errors within the survivors' health records. This is partially due to Native cancer patients having to use Contract Health Services for cancer treatment and care; health services may be based several hundred miles from the survivors' home locations.



#### Conclusion

The survivors who completed the NACES QOL survey appear to have comparable QOL in comparison to the COH non-Native cancer survivors. This can be viewed as a message of hope for Native cancer survivors since as recently as the 1980s and 1990s, Native cancer patients expressed feelings of hopelessness, depression, and an overall sense of doom. However, since taking part in this educational program, the NACES cancer survivors are reflecting high QOL in physical, psychological, and spiritual well-being. Clearly, Natives need more and expanded social support programs within their local communities, but social networks and extended families play an important role in QOL and survivorship.

The overall QOL is the same for the NACES Native cancer survivors as it was for the 1997 COH non-Native cancer survivors. Cancer is a disease that knows no prejudice and affects everyone equally.

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**Conflict of Interest** The authors declare that they do not have a conflict of interest.



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