

Quality of life among Native American cancer survivors:  
Approaching harmony and balance after cancer

A Dissertation  
SUBMITTED TO THE FACULTY OF THE  
UNIVERSITY OF MINNESOTA  
BY

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IN PARTIAL FULFILLMENT OF THE REQUIREMENTS  
FOR THE DEGREE OF  
DOCTOR OF PHILOSOPHY

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May 2019

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## ACKNOWLEDGMENTS

This work would not have been possible without the “village” of people that encouraged, loved, and supported me through the doctoral journey. I want to thank my primary advisor Dr. Eileen Harwood for believing in me from the beginning and for her steady mentorship over the years. Thank you for your guidance, friendship, and for always supporting me to do me. I also want to thank my committee members Drs. Darin Erickson, DeAnn Lazovich, and Kathleen Call for their thoughtful feedback, advice, and support throughout the years.

I want to express my sincere gratitude to Dr. Linda Burhansstipanov for trusting me to work with data collected by her organization, Native American Cancer Research Corp., and for her enthusiastic mentorship. While your schedule pulled you in multiple directions all over the world, you always made time for me and made me feel like I was the only person with whom you were working. Thank you for welcoming me into your home, for sharing your passion for research with me, and for your careful review of and thoughtful feedback on my work. You taught me what true mentorship looks like.

Thank you to Kris Rhodes at American Indian Cancer Foundation for welcoming me into the AICAF family during my graduate studies. I learned a lot from you and have you to thank for the origin of this research study. I also want to thank Harlan Luxenberg at Professional Data Analysts for his patience and for investing in my career and training.

Thank you to my friends and their families who literally opened up their doors to me for extended writing retreats – the Neiman family (Patti and Devi), Allison Zaccardi and Grandma Sue – thank you! My gratitude also goes out to friends who were always there to provide a listening ear, critical feedback, or a shoulder to cry on depending on the day – Maurine Neiman, Rachel Osband, Elizabeth Goldsmith, Eli Williamson, Kate Noble, Sandy Newton, and Melissa Chapman Haynes – you are deeply appreciated. Lizzy, thank you for accompanying me on multiple extended writing retreats. In addition to being extremely productive, you made them enjoyable. I would also like to extend a special thanks to other friends who supported my learning and dissertation progress – Amy Cyr, Charles Rogers, Sarah Sevcik, and my Book Club.

Finally, I want to thank my family. I have no words that can adequately capture my gratitude for your unconditional love and support. Avery, Aria, and Elijah, your mom is finally done with her dissertation.

## ABSTRACT

**Introduction:** Studies centered on understanding quality of life (QoL) among Native American cancer survivors are underrepresented in the literature. This knowledge gap presents a risk of underestimating and failing to adequately address the true burden of cancer in this population.

**Purpose:** The purpose of this study was to gain a person-centered, comprehensive understanding of factors that influence QoL among Native American cancer survivors and how they manifest in survivors daily lives.

**Methods:** We used a convergent mixed methods design to analyze data from 831 QoL surveys and 52 interviews with geographically and clinically diverse samples of Native cancer survivors. We employed latent class analysis (LCA) to identify “classes” of survivors with similar response patterns across physical, mental/emotional, social, and spiritual QoL domains (quantitative) and thematic analysis to identify themes of advice survivors’ had for other Native survivors and how that advice reflected survivors’ experiences and QoL after diagnosis (qualitative). Findings from the quantitative and qualitative studies were integrated to identify “meta-themes” of factors that influence QoL after cancer and how those factors operate in the context of survivors’ daily lives.

**Results:** LCA identified four classes of survivors with unique QoL profiles: *Positive QoL* (42%); *Well, overwhelmed* (30%); *Mildly burdened* (17%); and *Poor QoL* (12%). We identified four meta-themes from our integrated analysis: 1) Culture: Value systems and spirituality are benchmarks for evaluating the cancer experience; 2) Years since diagnosis: Treatment and non-treatment related mechanisms influence healing over time; 3) Geographical context impacts access to medical and cultural resources for healing; and 4) Perceived control over cancer: Gaining control through self-advocacy and support.

**Discussion:** Ignoring heterogeneity and contextual influences on QoL underestimates and misspecifies needs of many Native survivors.

**Conclusion:** Interventions to support Native cancer survivors must support the whole person on their path to establishing harmony and balance after cancer.

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## DEFINITIONS

**Cancer survivor** – An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life (National Cancer Institute. *Survivorship Definitions*).

**Quality of life** – An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (World Health Organization. *WHOQOL: Measuring Quality of Life*)

**Native American** – All Native peoples of the U.S. and its trust territories (i.e., American Indians, Alaska Natives, Native Hawaiians, Chamorros, and American Samoans), as well as persons from Canadian First Nations and Indigenous communities in Mexico and Central and South America who are U.S. residents (National Congress of American Indians, 2017). Note that where literature cited uses different terminology (e.g. American Indian/Alaska Native), we use the terminology of those authors when citing their work.

**Convergent mixed methods study design** – In this research design, the researcher uses concurrent timing to implement the quantitative and qualitative strands during the same phase of the research process, prioritizes the methods equally, and keeps the strands independent during analysis and then mixes results during the overall interpretation (Creswell & Clark, 2011, p. 70)

**Latent class analysis** – A method of grouping individuals into unique categories or “classes” based on their *pattern* of responses to a set of categorical variables. It is a method used to identify unobservable subgroups within a population.

## ABBREVIATIONS

QoL – Quality of life

HRQoL – Health related quality of life

WHO – World Health Organization

NACES – Native American Cancer Education for Survivors

NACR – Native American Cancer Research Corporation

IHS – Indian Health Service

LCA – Latent class analysis

PRCSDA – Purchased/Referred Care Service Delivery Area (formerly Contract Health Service Delivery Area (CHSDA))

## CHAPTER 1. BACKGROUND

### Introduction

The American Cancer Society estimates that by the year 2026, 20 million people in the United States will be living with a history of cancer (American Cancer Society, 2016). Of the 16.9 million cancer survivors alive today, two-thirds are considered long-term survivors having been diagnosed five or more years ago (National Cancer Institute. *Statistics*). Given increasing recognition of the physical, psychological, emotional, social, spiritual, and financial problems cancer survivors may face long after treatment ends (Hewitt, Greenfield, & Stovall, 2005), researchers and health care providers are increasingly interested in understanding not just *how long*, but *how well* people are living after cancer (Jacobsen & Jim, 2011). Existing research to identify and better understand how quality of life (QoL) is affected after cancer diagnosis and treatment has contributed greatly to our knowledge of the experiences and unique needs of cancer survivors (Mayer, Nasso, & Earp, 2017). However, only a small portion of that research is centered on understanding the experiences and needs of under-resourced populations including Native Americans. Native Americans experience some of the worst cancer health outcomes of any ethnic group in the U.S. including lower 5-year survival and higher mortality-to-incidence ratios than White patients for the most common cancers though mortality rates vary greatly by region (Espey et al., 2014; White et al., 2014). Much less is known about how *well* Native Americans are living after cancer (Yabroff, Lawrence, Clauser, Davis, & Brown, 2004). Making up less than 2% of the U.S. population, Native Americans are often not represented in national QoL studies or small numbers preclude disaggregation of their data to examine outcomes within diverse Native populations or disparities in QoL between Native Americans and other racial and ethnic groups. Without this information, we risk underestimating the true burden of cancer in this population and designing support services that misalign with Native survivors' needs and priorities.

Of the studies that have examined QoL among Native American cancer survivors, the vast majority have been qualitative (Becker, Affonso, & Beard, 2006; Braun, Mokuau, Hunt, Kaanoi, & Gotay, 2002; Cavanagh, Wakefield, McLoone, Garvey, & Cohn, 2015; Craft, Patchell, Friedman, Stephens, & Dwyer, 2017; Eide, 2007; Haozous, Knobf, & Brant, 2011; Hodge, Itty, Cadogan, & Martinez, 2012; Hodge, Itty, Cadogan, Martinez, & Pham, 2016b; Ka 'opua,

Mitschke, & Kloezeman, 2008; Krebs, 1997; Pelusi & Krebs, 2005). Strengths of those studies are that they provide a nuanced understanding of how Native Americans in diverse regions in the U.S. experience life in light of their cancer journey by eliciting personal stories of survivorship. Their narratives provide rich descriptions of their lived experience as cancer survivors that gets missed in studies that rely on a priori theories and standardized surveys. However, the small sample sizes and exploratory nature of those qualitative studies limit our ability to gain insight into the distribution or determinants of QoL on a population level. The even fewer quantitative studies published on this topic provide a baseline understanding of the unmet needs of Native cancer survivors and the prevalence and determinants of QoL outcomes, but provide limited understanding of how findings fit into the context of survivors' lives (Burhansstipanov et al., 2012; Burhansstipanov et al., 2010; Doorenbos et al., 2010; Goodwin, Burhansstipanov, Dignan, Jones, & Kaur, 2016; Hodge et al., 2012). This is particularly problematic for investigating a subjective, dynamic, multidimensional outcome like QoL. Additionally, existing quantitative studies reported on average QoL scores across physical, psychological, social, and spiritual domains of QoL – an approach that misaligns with the holistic way many Natives conceptualize health as *balance* between these domains (Anderson & Olson, 2013; Hodge, Limb, & Cross, 2009). A critical need exists for a more complete, person-centered understanding of how QoL is affected among Native Americans after cancer diagnosis and treatment. To address that need, this dissertation used a convergent mixed methods study design in which findings from quantitative analysis of QoL survey data were integrated with findings from qualitative analysis of interview data to generate a comprehensive understanding of QoL among Native American cancer survivors. This mixed methods design combines the strengths of quantitative and qualitative methods while overcoming their weaknesses to provide a more complete understanding of QoL than either method can provide alone.

The purpose of this study was to gain a comprehensive understanding of QoL among Native American cancer survivors by using a mixed methods research approach to identify factors that influence QoL and describe how those factors manifest in survivors' daily lives. Findings from this study can be used to inform development and implementation of programs and policies to support optimal QoL among Native Americans after diagnosis and treatment of cancer. Pursuant to that goal, the objectives of this research were to 1) examine heterogeneity of QoL among Native American cancer survivors (quantitative), 2) gain insight into survivors' experiences navigating life after cancer including resources and strategies survivors found most useful for coping and living well after diagnosis (qualitative), and 3) integrate and interpret

quantitative and qualitative findings to generate a more complete understanding of factors that influence QoL among Native American cancer survivors and how (mixed methods objective). By achieving these objectives, this study generates new knowledge that can be used to tailor policies and programs to best meet the needs of Native American cancer survivors in the U.S.

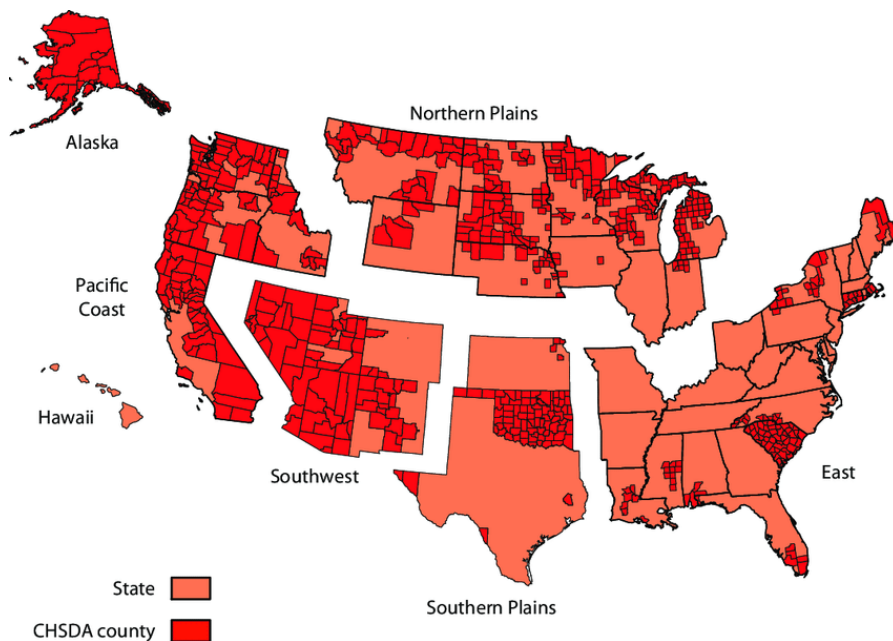
## Background

### *Cancer burden among Native Americans in the United States*

#### *Cancer incidence and mortality rates*

Despite advances in understanding about cancer prevention, screening, and treatment, Native Americans continue to die from cancer at a higher rate than Whites and have the poorest 5-year survival rates of all racial or ethnic groups for all cancers combined (60% in American Indians/Alaska Natives compared to 68% in Non-Hispanic Whites) (Jemal, 2017). However, cancer-related morbidity and mortality among Native Americans varies considerably by region of the U.S. (See Figure 1 for a map of Purchased/Referred Care Service Delivery Areas used for reporting geographic differences in cancer outcomes among Native populations in the U.S.). Natives living in the Northern Plains, Alaska, and the Southern Plains have the highest mortality rates, while those living in Southwest and East have the lowest (Espey et al., 2014; White et al., 2014). Death rates are two times higher for American Indian/Alaska Native men living in the Northern Plains (338.1 per 100,000) compared to those in the Southwest (163.8 per 100,000) for all cancers combined.

**Figure 1. Map of Purchased/Referred Care Service Delivery Areas (formerly Contract Health Service Delivery Areas (CHSDA)) (Purdue et al., 2014).**



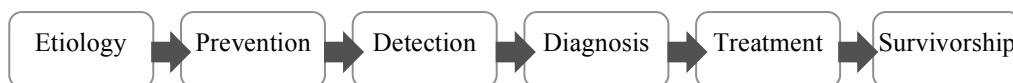
Mortality rates are highest for lung, colon, breast, and prostate cancers among both White and American Indian/Alaska Native patients (White et al., 2014). However death rates for liver and kidney cancer are over two times greater among American Indians/Alaska Natives in most regions compared to that of Whites. Other cancers for which death rates are consistently higher for American Indians/Alaska Natives include gallbladder, stomach, and kidney cancer. While cancer mortality rates have decreased over the past couple decades among Whites, they have not changed and in some cases increased among Native Americans (White et al., 2014). Interestingly, the marked regional variation in cancer death rates among Native populations is not evident in Whites for whom regional variation in death rates is minimal (Perdue et al., 2008). Furthermore, disparities in mortality to incidence ratios between American Indians/Alaska Natives and Whites are most evident for breast (female), cervix, colorectal, and prostate cancers – cancers most responsive to screening and treatment (White et al., 2014).

Cancer incidence rates follow similar patterns as death rates (White et al., 2014). Incidence rates for all cancers combined range from 316.6 per 100,000 in the Southwest to 655.4 per 100,000 in the Southern Plains. Incidence of colorectal cancer is nearly five times greater among American Indians/Alaska Natives in Alaska compared to Natives in the Southwest (42 vs. 7 per 100,000, respectively) (Perdue et al., 2008).

#### *Inequities across the cancer control continuum*

The cancer control continuum is a framework often used in public health to describe stages of cancer progression from etiology to prevention, detection, diagnosis, treatment, and survivorship (Figure 2) (National Cancer Institute. *Cancer Control Continuum*).

**Figure 2. The cancer control continuum.**



Applying a social ecological perspective to the cancer control continuum is a useful framework for understanding cancer inequities among Native Americans. Social ecological theories of health posit that cancer health outcomes are the result of multiple influences interacting at the individual, community, organizational, and social/political levels of society over an individual's lifetime (Krieger, 2001; Stokols, 1996). Applying this theory to the cancer control

continuum reveals how inequities at any stage of the continuum and across all levels of influence generate disparities in cancer health outcomes among Native American communities.

**Etiology.** Exposure to traumatic events in childhood has been linked to increased risk for chronic diseases later in life (Felitti et al., 1998). For many diseases including cancer, risk increases with increasing number of traumatic events to which a child is exposed. Notably, these genetic changes may even occur in utero increasing genetic risk factors for disease among unborn children of mothers exposed to trauma during pregnancy (Entringer et al., 2011). The significance of these findings is especially relevant among Native Americans, a population that has experienced persistent exposure to physical and social trauma and chronic poverty. Disparities in exposure to adverse childhood events are postulated to contribute to health disparities among Native Americans today (Brockie, Heinzlmann, & Gill, 2013; Warne & Lajimodiere, 2015).

**Prevention.** One explanation for the high cancer mortality rates and regional disparities in cancer mortality among Native Americans in the U.S. is high prevalence of commercial tobacco use (Cobb, Espey, & King, 2014). Native Americans have some of the highest rates of commercial tobacco use in the U.S. and smoking is a well-established risk factor for many cancers (Centers for Disease Control and Prevention, 2012). In Minnesota, a Tribal Tobacco Use survey conducted in 2010-2012 revealed that 59% of self-identified Native Americans reported being a current smoker, which was more than three times the state-wide prevalence of 16% (American Indian Community Tobacco Projects, 2013). In addition to commercial tobacco use, other risk factors for cancer including obesity, physical activity, alcohol consumption, and diet also vary in prevalence by region of the U.S. and by race, which might also help to explain regional variation in cancer incidence and death rates among Native American populations (Espey et al., 2007).

**Detection.** Another factor that may contribute to poor cancer outcomes among Native Americans is low rates of cancer screening and early detection. Compared to White women, American Indian women are less likely to have had a Pap smear in the last three years (79.2% versus 83.8%) and less likely to have had a mammogram in the past 2 years (67.8% vs. 76.0%) (Cobb et al., 2014). Low screening rates may result in late-stage cancer diagnoses and disparities in cancer survival (Espey et al., 2007; Guadagnolo et al., 2009). One study of colorectal cancer found that 66.5% of American Indian/Alaska Native patients were diagnosed with late-stage disease versus 59.6% of White patients (Perdue et al., 2008).

Geographic isolation limits access to health care for some Natives, especially those living on reservations, thereby limiting access to cancer screenings, treatment, and support (Burhansstipanov & Hollow, 2001; Doorenbos et al., 2010). One study reported that after adjustment for income, education, state of residence, population 65 and older and rurality, individuals living in counties with higher percentages of American Indians/Alaska Natives had reduced access, availability, and utilization of health care services including longer distance to and lower screening rates for mammograms and colonoscopies (Towne Jr., Smith, & Ory, 2014).

**Treatment.** Even after diagnosis, Native Americans may experience inequities in cancer treatment (Javid et al., 2014; Simianu et al., 2016). One study found that American Indians/Alaska Natives were significantly less likely than White patients to receive optimal guideline-concordant cancer care after diagnosis (Javid et al., 2014). American Indian/Alaska Native patients had 37% to 58% lower odds of undergoing surgery for all cancer types, 53% lower odds of receiving adjuvant therapy for breast cancer, and 64% lower odds of receiving adjuvant therapy for colon cancer compared to White patients. Most notably, treatment disparities were significantly associated with likelihood of survival such that overall likelihood of survival was 38%, 26%, 48%, and 64% lower among the patients who did not receive guideline concordant surgery therapy for breast, colon, prostate, and lung cancer, respectively, compared with those who did undergo surgery.

The Native American health care delivery system (Indian Health Service (IHS), tribal programs, and Urban Indian Health Centers) does not typically provide oncology care (Warne et al., 2012). Therefore, most oncology services are provided through Purchased/Referred Care (formerly called “Contract Health Services”), which are often located far away from a patient’s home. Under-resourcing of tribal infrastructure and IHS means that sometimes IHS runs out of money to pay for Purchased/Referred Care for some Native Americans resulting in late cancer diagnoses, treatment, and ultimately poor health outcomes (Burhansstipanov & Hollow, 2001; Warne, Kaur, & Perdue, 2012).

**Survivorship.** While research to describe and understand patterns of cancer prevention, detection and treatment among Native Americans is fairly well represented in the literature, substantially less is known about health outcomes of Natives in the cancer survivorship period after treatment completion. This study was designed to help fill that gap.



### ***Cancer inequities in the context of history and injustice***

*“To understand the root causes of health inequities among American Indians, it is important to understand the historical context in which this population has lived.”*

*– Warne and Lajimodiere, 2015, p. 567*

The inequities evident among Native Americans today did not occur by accident, but rather reflect systems and policies designed to exploit and undermine Natives’ ability to maintain the cultures, lifestyles, land, and traditions that had sustained them for hundreds of years. While the government promised to provide health care, food, housing, and education in exchange for Native lands, those promises have yet to be adequately fulfilled (National Congress of American Indians, 2017; U.S. Commission on Civil Rights, 2018). Many Native American health disparities can be linked to chronic poverty and trauma resulting from colonization and government sanctioned attempts at genocide of Native people in the U.S. (Warne & Lajimodiere, 2015).

Warfare, genocide and infectious diseases including the intentional spread of smallpox nearly decimated the Native population such that by the late 19<sup>th</sup> century, fewer than 250,000 Natives remained (National Congress of American Indians, 2017; Warne & Lajimodiere, 2015). After Natives were forced off their lands and relocated to reservations, the government pushed to assimilate Natives into mainstream life. One strategy the government used to accomplish this goal was to forcibly remove Native children from their families to attend off-reservation boarding schools designed to strip Natives of their culture and language. In addition to the devastating effects of breaking apart families, many children suffered physical, sexual, and emotional abuse during their time at the boarding schools (Lajimodiere, 2014).

Some scholars use the term *historical trauma* to describe the “long-term impact of colonization, cultural suppression, and historical oppression of many indigenous peoples including Native Americans in the U.S. and Aboriginal peoples” (Kirmayer, Gone, & Moses, 2014, p. 300). Historical trauma is thought to have intergenerational effects such that trauma of previous generations affects the health and well-being of subsequent generations through a variety of proposed mechanisms at multiple levels including “interpersonally, through altered parenting; within families, which may be disrupted by loss of members or exposure to stressors like domestic violence; at the level of the community, when many individuals and families are impacted by disturbances of social networks and experiences of safety and solidarity that affect

health; and at the level of nation, where the suppression of culture and the disruption of family and community threaten the continuity of whole peoples” (Kirmayer et al., 2014, pp. 308-309).

In addition to historical trauma, ongoing structural violence against indigenous populations disrupted traditional ways of life, failed to respect sovereignty, exploited indigenous lands and resources, and created economic inequalities, all of which contribute to poor health and health disparities among Native Americans (Farmer, Nizeye, Stulac, & Keshavjee, 2006a; Kirmayer et al., 2014). Structural violence refers to “social structures – economic, political, legal, religious, and cultural that stop individuals, groups, and societies from reaching their full potential” (Farmer et al., 2006a, p. 1686). Because it is deeply embedded in our societal structures, recognizing the occurrence of structural violence can be difficult. Farmer et al. (2006a) describe examples of structural violence to include unequal access to resources, political power, education, health care, and legal standing. One example of structural violence as it relates to cancer disparities is underfunding of the Indian Health Service (IHS). The federal government spends less per capita on Native American health care than on Medicaid recipients, prisoners, veterans, and military personnel (U.S. Commission on Civil Rights, 2003). Notably, over two-thirds of Natives in the U.S. live in urban areas, but funding for Urban Indian Health programs represent only about 1% of the overall IHS budget (U.S. Commission on Civil Rights, 2018).

A report by the U.S. Commission on Civil Rights in 2003 concluded, “The anorexic budget of IHS can only lead one to deduce that less value is placed on Indian health than that of other populations. If funding levels continue to stagnate, the health status of Native Americans will continue to decline, resulting in even greater needs in the future” (U.S. Commission on Civil Rights, 2003, pp. 49-50). Authors of the report recommended immediate funding for “infrastructure development, without which tribal governments cannot properly deliver services; tribal courts, which preserve order in tribal communities, provide for restitution of wrongs, and lend strength and validity to other tribal institutions; and tribal priority allocations, which permit tribes to pursue their own priorities and allow tribal governments to respond to the needs of their citizens” (p. iii). Under-resourcing of tribal infrastructure and Indian health services means that sometimes IHS runs out of money to pay for Purchased/Referred Care for Natives who need it resulting in late cancer diagnoses, treatment, and ultimately poor health outcomes (Burhansstipanov & Hollow, 2001; Warne et al., 2012). Recently, scholars and advocates have questioned whether the underfunding of IHS constitutes a treaty violation (Urken, 2016).

### ***Cancer survivorship as a unique stage of the cancer control continuum***

Based on model projections of Bluethmann et al. (2016), the National Cancer Institute estimates that 16.9 million cancer survivors were alive in the U.S. as of January 2019 (National Cancer Institute. *Statistics*). The projected increase in the prevalence of cancer survivors is expected to result in cancer care costs totaling \$157.77 billion in the year 2020 (Mariotto, Yabroff, Shao, Feuer, & Brown, 2011). Proportionate with the increase in 5-year survival rates from 50% in 1970 to 68% in 2013 is an increase in understanding of the unique needs of cancer survivors (American Cancer Society, 2016; Siegel, Miller, & Jemal, 2016).

In 2005, the Institute of Medicine (IOM) published a landmark report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, that called attention to the lasting effects of cancer and cancer treatment that may affect survivors and their families for many years after treatment completion (Hewitt, Greenfield, & Stovall, 2005). The report concluded that monitoring and coordinating care for survivors and their families post-treatment is critical to long-term health and urged the health care community and other stakeholders to raise awareness of cancer survivorship as a distinct phase of cancer care, engage in research to identify and increase understanding about late effects of cancer, develop guidelines for survivorship care, develop systems of comprehensive and coordinated care for survivors, and to take a public health approach to survivorship care.

The lasting effects of cancer may be positive and negative. Many survivors experience positive outcomes after cancer including spiritual growth, increased self-esteem, a deeper appreciation for life, and a renewed life purpose (Aspinwall & MacNamara, 2005; Peltier, 2015). Other survivors experience long-term challenges including financial toxicity (Pisu et al., 2015), higher risk of secondary cancers (Curtis et al., 1973), late effects of cancer treatment (Den Oudsten et al., 2012; Irvine, Vincent, Graydon, Bubela, & Thompson, 1994), fatigue, psychological distress, limitations in cognition, sexual dysfunction, infertility (Nieman et al., 2006), comorbidities (Piccirillo, Tierney, Costas, Grove, & Spitznagel Jr, 2004), fear of recurrence, changes in employment (de Boer, Taskila, Ojajarvi, van Dijk, & Verbeek, 2009), and change in family roles (Hodge, Cadogan, Itty, Williams, & Finney, 2016). Challenges may ebb and flow depending on where a survivor is in their “season of survivorship” – a term that has been used to describe different phases of cancer survivorship including acute survivorship, transition at the end of treatment, extended survivorship, and permanent survivorship (Miller,

Merry, & Miller, 2008). Some evidence suggests that these challenges may be exacerbated in historically marginalized populations (Aziz & Rowland, 2002; Pisu et al., 2015).

Cancer survivorship interventions are designed to accomplish one or more of the essential components of survivorship care including 1) prevention of recurrent and new cancers, and other late effects; 2) surveillance for cancer spread, recurrence, or second cancers; 3) assessment of medical and psychosocial late effects; 4) intervention for consequences of cancer and its treatment; and 4) coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met (Hewitt et al., 2005). Strategies to prevent recurrent and new cancers include interventions to promote physical activity, healthy eating, and smoking cessation. At the community level, cancer support groups, community education, and survivor celebrations provide psychosocial support to survivors and caregivers. Support groups can be delivered online (Klemm et al., 2003), in-person (Ussher, Kirsten, Butow, & Sandoval, 2006), or through telehealth (Doorenbos et al., 2010). Benefits of cancer support groups include sense of empowerment, sense of community versus isolation, increased education, and improved ability to cope with disease (Ussher et al., 2006).

Interventions at the health system level are designed to assess and address medical and psychosocial late effects of cancer and improve coordination of care for survivors. Some health centers have developed specialized survivorship clinics staffed by multidisciplinary teams of providers that provide comprehensive support to address long-term medical and psychosocial needs of cancer survivors (Klemp, 2015). One intervention that has gained traction and is now required by the American College of Surgeon's Commission on Cancer for accreditation is survivorship care plans. Survivorship care plans are comprehensive documents including a patient's treatment summary and follow-up plan that can be used by patients, caregivers and providers to share information with each other and improve coordination of care as a patient transitions out of active treatment (Klemanski, Browning, & Kue, 2015). Patient navigation programs are another strategy for improving care of cancer survivors while also holding promise as a strategy for eliminating cancer health disparities (Burhansstipanov, Harjo, Krebs, Marshall, & Lindstrom, 2015; Freeman, 2006). Patient navigators help cancer patients identify barriers to care and provide resources and support to help patients overcome those barriers thereby improving adherence to care and cancer outcomes (Braun et al., 2012; Freund et al., 2014). More recently, enough research has accumulated to create survivorship care guidelines for survivors of colorectal cancer (El-Shami et al., 2015) and breast cancer (Runowicz et al., 2016).

Implementing and evaluating interventions to address the needs of cancer survivors and translating survivorship research into practice has been challenging for a number of reasons. One is that cancer is a heterogeneous disease with diverse treatments of varying toxicities and survivors often transition between different phases of care over their lifetime experiencing different needs in each phase (Alfano et al., 2014; Miller et al., 2008). Other challenges are that survivorship care spans multiple stages of the cancer control continuum; treatments for cancer are constantly evolving; and lack of consensus on the most effective survivorship interventions or models of survivorship care (Alfano et al., 2014). Despite these challenges, one area of agreement is that a survivor's QoL should be a key outcome of any survivorship intervention (Jacobsen & Jim, 2011).

### ***Quality of life as an important outcome of cancer survivorship***

The World Health Organization (WHO) defines QoL as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organization. *WHOQOL: Measuring Quality of Life*, para. 2). Researchers, clinicians, and survivors agree that measuring how *well* cancer patients are surviving is equally important as measuring how *long* they are surviving (Jacobsen & Jim, 2011). QoL measures have been used in descriptive epidemiologic studies to understand the nature and burden of problems experienced over time by survivors of diverse cancers and treatments (Carrillo, Carrillo, Ramirez-Ortega, Ochoa-Carrillo, & Oñate-Ocaña, 2016); as an outcome measure in clinical trials (Hussain et al., 2013); as an endpoint of cancer survivorship programs (Wolin & Colditz, 2011); and as an outcome of public health initiatives including Healthy People 2020 (Healthy People 2020. *Cancer objective C-14*).

### *Defining and measuring QoL*

QoL is subjective, dynamic, and multidimensional construct making it difficult to measure with standardized instruments (Carr & Higginson, 2001). Some argue that because QoL is unique to individuals, patients should be allowed to define their QoL in relation to their unique experiences, goals, and expectations versus clinicians or researchers defining it for them through predetermined domains (Carr & Higginson, 2001). The subjectivity of QoL is illustrated by the “disability paradox” – the finding that people with serious and persistent disabilities still report experiencing excellent QoL (Albrecht & Devlieger, 1999). Furthermore, because QoL is evaluated as the difference between expectations and experience, changes in experience over time result in changes in expectations and subsequent evaluation of QoL illustrating the dynamic nature of QoL (Carr, Gibson, & Robinson, 2001). Researchers interested in measuring QoL over time have to be particularly mindful of this recalibration or “response shift” when interpreting QoL outcomes (Hamidou et al., 2014). Finally, researchers generally agree that QoL is a multidimensional construct that broadly encompasses four domains including physical, psychological, social, and spiritual well-being (Ferrell, Dow, & Grant, 1995; Muzzatti & Annunziata, 2013). Furthermore, patient self-report is thought to be the best way to collect data on QoL so if providers and patients have conflicting evaluations of a patient’s QoL, “the patient should have the final word” (Addington-Hall & Kalra, 2001, p. 1420). In summary, the nuance and challenges of measuring and conducting research on QoL are so great that the International Society of Quality of Life Research has devoted an entire peer-reviewed journal, *Quality of Life Research*, to disseminating multidisciplinary research on QoL.

With these limitations in mind, a recent literature review identified eight assessment tools designed to evaluate QoL specifically in long-term cancer survivors defined by the authors as “people who have experienced cancer, are not being treated, and are almost certainly facing symptoms and problems different from those experienced by cancer patients under treatment and the general population” (Muzzatti & Annunziata, 2013, p. 3143). The authors note that many generic QoL tools and disease-specific QoL tools designed for cancer patients have limited utility for assessing long-term survivorship. The review only included instruments designed to measure QoL as a general construct, but many domain specific instruments to measure fear of recurrence (Koch-Gallenkamp et al., 2016) or psychosocial distress (Vodermaier, Linden, & Siu, 2009) for example, also exist and have been used by researchers to investigate QoL issues of cancer survivors. Sometimes, QoL is distinguished in the literature as “health related quality of life

(HRQoL),” which describes the impact that health status has on one’s QoL or “global QoL,” which is a more general measure of overall life satisfaction and well-being. Both measures have been useful for understanding QoL of cancer survivors (Ganesh et al., 2016).

Decisions about how to assess QoL in cancer survivors in terms of type of instrument to use or population to study depend on intended use of the data (Osborne et al., 2012). For example, many instruments designed to measure QoL ask questions about health *status* (i.e. the presence or severity of a problem), while fewer instruments ask health *evaluation* questions in which survivors are asked to evaluate the impact of health problems on their life (Osborne et al., 2012). Because the current U.S. health care system is structured such that cancer patients are often treated by cancer specific oncologists, much of the research on QoL of cancer survivors is presented by cancer type or by treatment received though some population based studies to investigate QoL of cancer survivors of any cancer also exist (Stein et al., 2006; Yabroff et al., 2004).

Inductive, qualitative research with cancer survivors has revealed many QoL issues faced by cancer survivors (Burg et al., 2015; Dow, Ferrell, Haberman, & Eaton, 1999; Ferrell et al., 1995). Dow et al. (1999) describe eleven themes that illustrate how cancer survivors of varying cancer types described the meaning of QoL. The eleven overarching themes include struggle between independence-dependence, balance, wholeness, life purpose, reclaiming life, multiple losses, having control, altered meaning of health, and surviving cancer from a family perspective.

One prospective, population-based study of older adults living in England found that compared to adults without a cancer diagnosis, adults with a cancer diagnosis reported poorer self-rated health, QoL, and life satisfaction 0-2 and 2-4 years post diagnosis (Williams, Jackson, Beeken, Steptoe, & Wardle, 2015). Cancer survivors were also more likely than those without a cancer diagnosis to report depressive symptoms, and impairments in mobility and activities of daily living. One study estimated that 25% of all cancer survivors in the U.S. report poor physical QoL and 10% of survivors report poor mental QoL compared to compared with only 10% and 6% of adults without cancer respectively (Weaver et al., 2012). However, QoL in survivorship appears to depend on clinical characteristics including cancer type, time since diagnosis, presence of co-morbidities, treatment received, and age at diagnosis and social characteristics including race or ethnicity, socioeconomic status, and employment (Bours et al., 2016; Rodriguez, Hawkins, Berkowitz, & Li, 2015; Westby, Berg, & Leach, 2016). In general, QoL is more favorable among survivors of breast, prostate and melanoma cancers (Weaver et al., 2012) and tends to improve with length of time since diagnosis such that longer-term survivors report better

QoL than shorter term survivors (<5 years post-treatment) (Burhansstipanov et al., 2010). Additionally, survivors with comorbidities tend to report lower QoL than those without comorbidities (Weaver et al., 2012) and survivors diagnosed at an early age tend to report worse QoL than survivors diagnosed at later age (Boyes, Girgis, D'Este, & Zucca, 2012). Social characteristics are also associated with QoL such that survivors with low SES (e.g. low educational attainment, low income) report poorer QoL; survivors who are unemployed report poorer QoL compared to those who are employed; and racial or ethnic minority survivors tend to report poorer QoL than non-Hispanic Whites (Westby et al., 2016).



## **CHAPTER 2. LITERATURE REVIEW AND RESEARCH CONTRIBUTION**

Most of what is known about QoL among Native American cancer survivors has been derived from qualitative research studies that describe the experience of living with and beyond cancer or the meaning of cancer from the perspective of Native survivors or family members/caregivers. A recent literature review to document the experiences of and interventions developed for indigenous cancer survivors identified only 17 peer-reviewed articles that fit the authors' inclusion criteria [(i) participants had completed cancer treatment with curative intent or were family members or treating clinicians of indigenous cancer survivors; (ii) cancer survivors were indigenous; and (iii) articles either described interventions targeted at survivors and/or investigated what the indigenous cancer survivor needed to improve their health care/QoL during their survivorship period] (Cavanagh et al., 2015). Of the 17 articles identified, 12 were qualitative studies and only five them provided quantitative data. Of the five studies that reported quantitative data, one examined the effect of complementary and alternative medicine use on the risk of breast cancer-specific death among multi-ethnic cancer survivors including 229 Native Hawaiians (Matsuno, Pagano, Maskarinec, Issell, & Gotay, 2012), one surveyed primary care providers within the Alaska Tribal Health System (n=268) to understand how to better optimize care for prostate cancer survivors (Tilburt et al., 2014), and one was a program evaluation of a telehealth support group for Native cancer survivors from rural areas in Washington and Alaska (n=32) (Doorenbos et al., 2010). Only two of the quantitative studies reported on the prevalence of QoL outcomes among Native survivors – one reported on QoL (physical, social, spiritual, psychological) of Native breast cancer survivors (n=266) and the other compared QoL between Native (n=596) and non-Native cancer survivors from a large, geographically diverse sample of Native survivors in the U.S. (Burhansstipanov et al., 2012; Burhansstipanov et al., 2010). Both studies examined data from the Native American Cancer Education for Survivors (NACES) program. While findings from the limited amount of published research on QoL of Native cancer survivors varied by population, what follows are descriptions of a number of common themes that ran through nearly all of the articles.

### **Native American orientations to cancer, health, and QoL**

Understanding orientations to health and QoL among Native communities provides context for understanding how a diagnosis of cancer and cancer treatment may affect QoL among

Native survivors. Many Native cancer survivors report that having cancer means being out of balance between self, spiritual forces, community, and land (Colclough & Brown, 2014; Hodge et al., 2016b). For some survivors, feeling out of balance is what triggered them to seek out medical care in search of a diagnosis (Peltier, 2015).

One theme that emerged in all of the qualitative studies with Native cancer survivors was the value placed on family and community (Ka 'opua et al., 2008). Family was often defined as including a broad group of relatives including first-degree and extended relatives (Burhansstipanov & Hollow, 2001; Craft et al., 2017; Ka 'opua et al., 2008). Responsibility to and respect for family and community meant that sometimes survivors placed family and community needs over their own. Some survivors reported that they do not talk about their cancer or related symptoms with others so as not to burden or place additional hardship on family or other members of the community (Hodge, Cadogan, Itty, Williams, & Finney, 2016a; Hodge et al., 2016b). Stoicism, or hiding one's suffering from the public so as not to appear physically vulnerable was another value cited by survivors as reason for not talking about their cancer (Haozous et al., 2011). Other reasons for not talking about their cancer with family or community included a desire to honor the cultural value of humility (Becker et al., 2006); a belief that talking about cancer would bring cancer upon oneself (Hodge et al., 2016a), and the fact that in some Native languages, a word for cancer does not even exist (Csordas, 1989).

Because of the value placed on family and community, many Native cancer survivors report feeling a responsibility to help other survivors by sharing their own personal stories of survival and hope and raising awareness of cancer in their communities (Becker et al., 2006; Braun et al., 2002; Pelusi & Krebs, 2005). Responsibility to help others was often cited as the reason survivors were able to find the strength and motivation to care for one's self (Becker et al., 2006; Pelusi & Krebs, 2005).

One fairly common belief about cancer was that it was universally fatal. In Navajo language, a language in which terms to denote cancer existed, it translated to "a sore that does not heal" or "keeps on rotting" (Csordas, 1989). Frequent personal experiences of watching members of the community die from cancer served to justify the belief that cancer was fatal (Becker et al., 2006; Hodge et al., 2012). When diagnosed with cancer, some survivors report passive acceptance of the diagnosis noting that it is "meant to be" or that fate cannot be altered (Eide, 2007; Hodge et al., 2016a). Kramer (1995) explains that this attitude of acceptance is not fatalism, but represents another cultural value of living fully in the present. On the other hand,

survivors also describe a strong will to live and to do whatever it takes to survive illustrating that passive acceptance of cancer is not universal (Braun et al., 2002).

Many Native American cancer survivors frame their experience with cancer as a journey (Pelusi & Krebs, 2005). Some survivors emphasize that cancer is only one small part of their life journey, thus not a dominant aspect of their life (Pelusi & Krebs, 2005). Survivors have also described their cancer as a gift or as necessary for learning a life lesson (Braun et al., 2002; Haozous et al., 2011).

For nearly all survivors, spirituality lies at the core of their cancer experience. Pelusi and Krebs (2005) noted that among survivors in her research, "...spirituality was part of who participants were and not a separate issue, apart from one's self, in terms of themes. Spirituality was seen as the essence of life, with participants choosing their own paths in how they would live and express their spiritual being" (p. 15). Spirituality influences Native survivors' beliefs and understandings about cancer, reactions to their cancer diagnosis and cancer experience, strategies for treating and healing from cancer, and approach to end of life. Despite differences in beliefs about what happens to one's spirit at the end of life, a general consensus among many Native Americans is that death is not final, but part of the life continuum where upon death "the spirit does not die, but lives on or transitions" (Duggleby et al., 2015, p. 7).

In summary, Native American cultural orientations to life, health, and disease including spirituality as the essence of life, respect for and responsibility to family and community, living fully in the present, and respecting that one's life on earth is only one "stop" on the spirit's life continuum, influence perceptions of and experiences with cancer. It is in this context that Native cancer survivors evaluate their QoL.

## **Literature review**

One reported consequence of adhering to cultural values of not bringing one's burdens home and "not talking about it" is that some Native survivors suffer from their cancer and its after effects in silence and isolation (Hodge et al., 2016a; Hodge et al., 2012; Itty, Hodge, & Martinez, 2014). Survivors report hiding painful symptoms or neglecting care in order to spare their family members from additional worry or hardship (Hodge et al., 2016a). In some communities, survivors experience social isolation due to stigma or shame stemming from a belief that cancer was contagious or that cancer was a "payback" disease for past wrongdoings (Hodge et al., 2012; Peltier, 2015). Social isolation is particularly distressing in the context of a culture that places high value on family and community connectedness (Haozous et al., 2011). In addition to the

psychosocial consequences of social isolation, other consequences of “not talking about it” included poor management of physical symptoms including pain and fatigue, ignorance of one’s family history of cancer, and incomplete or inadequate knowledge about cancer (e.g. causes, symptoms, treatment and treatment side effects, late effects, etc.) (Eide, 2007; Haozous et al., 2011).

One QoL concern voiced by Native survivors in previous research was that of unmanaged pain. Pain was described by survivors as “more than a physical symptom; it is spiritual and social as well. It affects how one functions” (Pelusi & Krebs, 2005, p. 15). Many survivors did not speak of their pain with others, but when they did, they only told close family and only if they believed that family member could do something to ease their suffering (Haozous et al., 2011). Pain was attributed to cancer related fatigue (Hodge et al., 2016b), under-treatment by providers because of culturally inappropriate pain scales used to assess pain (Burhansstipanov, 2005), misinterpreting Native patients’ stoicism as absence of pain (Haozous, Doorenbos, Alvord, Flum, & Morris, 2016), and financial and geographic barriers to accessing pain medications (Burhansstipanov, 2005).

Communication barriers resulting from cultural restrictions on talking openly about cancer and illness meant that survivors often had little or no knowledge of their family history of cancer (Hodge et al., 2012). Uncertainty around cancer and its causes made some survivors fearful and anxious about risk to their family members (Burhansstipanov, 2005). Other gaps in knowledge reported by survivors included knowledge about cancer treatment, symptoms, long-term side-effects of treatment, and nutrition after cancer (Doorenbos et al., 2010; Hodge et al., 2016a; Hodge et al., 2012). Survivors expressed concerns that their health care providers did not provide them with sufficient information about cancer (Hodge et al., 2016b), yet some survivors preferred to defer treatment decisions to their health care providers without asking for further explanation (Hodge et al., 2012). Lack of knowledge around end-of-life care also contributed to feelings of helplessness, hopelessness, anxiety, panic, and frustration (Colclough & Brown, 2014).

Cancer and the effects of treatment often resulted in survivors and caregivers taking on new or different roles in their families or in the larger community, which sometimes had negative effects on survivors, family members and caregivers (Hodge et al., 2016b). One challenge faced by survivors experiencing cancer related fatigue was concern of being perceived as useless to the community or lazy if their fatigue prevented them from engaging in social events (Hodge et al., 2016b). For some survivors, having to rely so heavily on others to help with everyday tasks

because of cancer related fatigue or weakness challenged their self-identity as a “strong” Indian (Craft et al., 2017). In an effort to maintain a sense of dignity and respect as strong Indians, some survivors elected not to seek help when needed or share needs with their health care providers (Craft et al., 2017).

Access to culturally appropriate health care including traditional Indian and Western medicine is another challenge reported by Native survivors (Burhansstipanov, 2005). Geographical barriers to care means that tribal members may need to travel hundreds of miles for care, which places a heavy financial and emotional burden on survivors, their families, and caregivers (Hodge et al., 2016a).

A consistent finding in the literature is that a majority of survivors choose to pursue Western medical treatment for their cancer and report good rapport, trust and satisfaction with Western medical providers (Braun et al., 2002; Eide, 2007; Pelusi & Krebs, 2005). However, trust in medical providers was not universal. Some survivors who elected to combine traditional healing and Western biomedical treatment reported feeling judged by health care providers who did not understand or support traditional healing methods (Pelusi & Krebs, 2005). Other survivors attributed their late diagnosis and delayed treatment to providers who disregarded their concerns (Braun et al., 2002). While the majority of Native cancer survivors pursued Western medical treatment for their cancer, the mind-body disconnect and individualized nature of Western medicine sometimes conflicted with the holistic and collectivist approach to health desired by many Native Americans (Kramer, 1995).

Despite challenges faced by survivors and their families after cancer, many Native survivors report experiencing positive outcomes from their cancer journey and not just surviving, but thriving (Pelusi & Krebs, 2005). Some cancer survivors report that cancer helped to bring their families geographically and emotionally closer together (Braun et al., 2002; Craft et al., 2017). Other survivors report that their cancer taught them to be more grateful for gifts in life and to live life more fully in the moment (Pelusi & Krebs, 2005). Having cancer led survivors to consider what was most important in life and reprioritize where necessary.

The qualitative findings from the research cited above provide in-depth understanding of issues Native Americans face after a diagnosis of and treatment for cancer. However, what these studies do not provide is an indication of how prevalent the identified issues are in Native communities. The two largest quantitative studies to specifically investigate QoL of Native cancer survivors both examined data from the Native American Cancer Education for Survivors (NACES) dataset, which contains cross-sectional QoL survey data from a large, geographically

diverse sample of Native cancer survivors in the U.S. (Burhansstipanov et al., 2012; Burhansstipanov et al., 2010). Findings from those studies support many of the themes identified in the qualitative research described above. For example, one study compared QoL of Native (n=596) to non-Native (n=687) cancer survivors and found that Native survivors reported similar global QoL as non-Natives, but higher positive outcomes (i.e. hopefulness, life purpose, positive change after cancer), and worse social and psychological QoL outcomes (Burhansstipanov et al., 2012). More specifically, compared to non-Native survivors, Native survivors were more likely to respond that cancer significantly interfered with daily activities at home, that their cancer made them feel isolated from others, that they received inadequate support from others, and that they did not feel useful. Native survivors also scored significantly worse than non-Native survivors on feelings of usefulness and measures of anxiety. The other quantitative study was a cross-sectional investigation to describe physical conditions of Native breast cancer survivors and explore changes in reported physical health with increasing time since diagnosis (Burhansstipanov et al., 2010). Results indicated that 60% of individuals surviving  $\geq 5$  years versus only 29% of patients diagnosed within the last year reported their health as “good or excellent” suggesting that QoL may increase with increasing time since diagnosis. The proportion of survivors that reported experiencing physical symptoms steadily decreased with increasing time since diagnosis such that newly diagnosed survivors (diagnosed within the past year) reported experiencing more physical symptoms than survivors who were diagnosed 1-4 and  $\geq 5$  years prior. However, one unsettling finding was that just over 20% of long-term survivors (diagnosed  $\geq 5$  years prior) reported experiencing unmanaged pain and 15% reported experiencing weakness. The authors were unable to identify any factors to help explain this finding using traditional regression analyses, but hypothesized that access to pain treatment may be a contributing factor. Qualitative studies found that some Native survivors describe pain as more than a physical symptom, which may affect the way they experience pain and report their pain to others (Pelusi & Krebs, 2005).

## **Limitations of existing research**

### *Methodological limitations*

The majority of the aforementioned studies are qualitative studies that provide rich description of how Native American cancer survivors experience cancer and evaluate life after treatment. However, the extent to which themes generalize to the larger Native population is unclear. The absence of this information makes it difficult to know where to prioritize resources

to support survivors on a population level. Furthermore, qualitative studies are not well suited for investigating patterns and interactions between themes or how those interactions define or influence QoL. In contrast, quantitative studies provide estimates of the prevalence of QoL outcomes and insight into associations between survivor characteristics and QoL, but exclude survivor voices to put those data into context. In the absence of contextual data we risk assuming homogeneity of experiences and lose specificity critical for designing equitable and effective interventions. Consequently, existing single method studies (quantitative or qualitative) provide only a partial picture of QoL among Native survivors.

*Limited representation of Native American cancer survivors in existing population-based studies*

While a relative abundance of population-based studies exist to describe QoL issues among cancer survivors in the general population, the extent to which those findings generalize to Native American populations is uncertain for multiple reasons. One reason described in the previous chapter is the unique historical context in which Natives have lived in the U.S. – a context that has shaped patterns of health and disease among Native populations. Additional reasons include the following.

**Cultural influences on health and QoL.** Culture is not a “static, monolithic body of tradition unresponsive to time and circumstance,” but rather is heterogeneous and constantly evolving (Kirmayer et al., 2014, p. 305). The federal government currently recognizes 573 tribes in the U.S., all of which have unique cultures and histories. Culture provides the lens through which one views, understands, and interacts with the world (Singer et al., 2016). While heterogeneous, some cultural beliefs are shared by multiple Native communities including the view that health is a balance between the physical, emotional, mental, and spiritual components of health (King, Smith, & Gracey, 2009; Wilson, 2003). Another belief shared among many indigenous communities is that spirituality is paramount to life and health of individuals and community (Hodge et al., 2009). The conceptualization of health as a balance of individual, community, and spiritual influences may not always align with dominant Western approaches to cancer prevention and control that often treat the physical, social, psychological, and spiritual domains of QoL in isolation. For example, the dominant narrative around cancer being something to “fight” or something to be at “war” with may lead to prioritizing physical health to the detriment of maintaining balance in all other domains, which conflicts with the belief system of many indigenous populations (Peltier, 2015). Finally, in contrast to the individualized orientation to

health and disease that characterizes the dominant approach to health care in the U.S, the collectivist culture of many Native Americans means that some cancer patients may feel a strong responsibility to ease the burden of family and community sometimes at the expense of their own individual, social, and mental health (Ka 'opua et al., 2008). In summary, culture influences how individuals and communities understand cancer and its causes, how people engage in cancer care activities across the cancer care continuum, preferences for treatment and healing, and coping strategies after diagnosis and treatment.

**Geographic barriers to care.** Because IHS does not provide cancer care (with few exceptions), reservation dwelling Natives must obtain cancer care at health care facilities off-reservation through Purchased/Referred Care (Warne et al., 2012). In one survey of 269 Native American cancer survivors, 48% of survivors reported having to travel more than 100 miles one-way to obtain cancer care (Goodwin et al., 2016). Some Native Hawaiians must travel by air to obtain cancer services not available on their island. Having to commute long distances to receive cancer care can create tremendous burdens on families including financial burden, struggles maintaining employment, securing transportation and lodging, finding childcare, and anxiety surrounding uncertainty about the length of time they'll need to be away (Braun et al., 2002; Burhansstipanov & Hollow, 2001). Geographical barriers to care make it difficult for some Natives to attend medical appointments or obtain needed medication (Burhansstipanov, 2005; Burhansstipanov & Hollow, 2001).

Notably, 78% of Native Americans live outside of American Indian and Alaska Native areas (U.S. Census Bureau, 2012). However, even Natives living in urban areas in closer proximity to health care face barriers to care due to lack of reliable or affordable transportation and lack of access to IHS clinics and hospitals for routine or follow-up care, which are typically provided by clinics located on or near tribal lands (Itty et al., 2014).

**Complexity of the Indian health care delivery system.** The Indian health care delivery system is composed of three main components including programs operated directly by IHS, tribally-operated programs, and urban Indian health programs. Collectively, these programs are referred to as the IHS/Tribal/Urban or the I/T/U system. In contrast to other populations in the U.S., Native Americans have a legal right to health care services as a result of treaties, court decisions, acts of Congress, Executive orders, and other legal bases (Warne et al., 2012). The I/T/U programs are supported by different funding streams and are not insurance or entitlement



programs. IHS is primarily funded through Congressional appropriation; tribal programs are funded through programs that fall under the Indian Self-Determination and Education Assistance Act (PL 93- 638); and urban programs are funded through Title V of the Indian Health Care Improvement Act (PL 94-437) (Warne et al., 2012).

The complexity of the I/T/U health delivery system affects access to, delivery, and quality of care for many Native Americans. Availability of health care services generally depends on whether a Native patient is eligible for IHS direct care only (services provided in IHS facilities), Purchased/Referred Care, Medicaid, or private insurance (Warne et al., 2012). Services provided by IHS are restricted to members of federally recognized tribes, which excludes thousands of Natives from un-enrolled or non-federally recognized tribes (Tribal Epidemiology, 2013). All federally enrolled tribal members can receive direct care services from IHS, but only those who can demonstrate that they resided on a reservation for at least one year are eligible for referrals for contract services including oncology. Thus, urban Natives will sometimes travel back to tribal lands to receive some of their health services or to quality for referral services (Burhansstipanov & Hollow, 2001). Currently 41 Urban Indian Health Organizations operate in 41 sites throughout the U.S. and typically provide outreach and referral services related to primary care, mental health and social services, but not oncology care (Indian Health Service). Patients eligible for direct care, but not eligible for Purchased/Referred Care would be responsible for the entire cost of diagnostic testing, chemotherapy, radiation and/or adjuvant therapy received in the private sector. However, even patients who are eligible for Purchased/Referred Care, are not guaranteed coverage for oncology services because IHS will only pay for referrals if funds are available. If IHS runs out of funds to pay for Purchased/Referred Care before the end of the fiscal year, which does happen, the consequence is that patients may delay or neglect to receive needed medical care including oncology care (Warne et al., 2012).

**Data limitations in Native American communities.** Racial misclassification, small numbers, lack of disaggregated data and lack of integration across data systems makes it difficult to document needs, identify disparities, monitor progress, and use data to secure resources to address disparities across the cancer care continuum among Native populations (Tribal Epidemiology, 2013). Making up only 1.7% of the U.S. population, Native Americans are often not represented or grouped into the “other” category of ethnicity/race in population-based epidemiologic studies of cancer survivorship (Burg et al., 2015; Smith et al., 2007; Yabroff et al., 2004). Because of the relative small population of Natives in the U.S., their contribution to

aggregate national data is imperceptible rendering them invisible or statistically insignificant (Tribal Epidemiology, 2013). However, disaggregating data of Native populations from other racial and ethnic groups and by tribe or region, is essential to identify disparities in cancer-related health outcomes (Nguyen, Chawla, Noone, & Srinivasan, 2014). A related issue is that of missing data, particularly data that may be useful in identifying inequities and heterogeneity in risk among Native populations that may be important for evaluating tribal specific protective or risk factors of cancer or the extent to which the federal government is upholding treaty obligations (Tribal Epidemiology, 2013). Currently, members of all 573 federally recognized tribes in the U.S. are lumped together as one homogenous Native American population, which precludes the ability to identify ways in which their unique histories and cultures may contribute to differential health outcomes (Tribal Epidemiology, 2013). Furthermore, most cancer statistics for Native Americans only include data from Natives living in IHS Purchased/Referred Care Delivery Areas, which excludes all Natives living in the many urban and rural non-reservation areas or villages for which I/T/U services are unavailable (Jim et al., 2014; Kaur, Burhansstipanov, & Krebs, 2013).

Racial misclassification of Native Americans in national cancer registries and other state or national datasets may underestimate the cancer burden among Native populations. One study found that 45% of the cases/records in the Oklahoma Central Cancer Registry were misclassified as some other race rather than Native American. Another study that compared IHS data to the Washington State Cancer Registry found that more than 25% of American Indians identified as having 100% blood quantum (full-heritage) were misclassified as non-American Indian in the tumor registry (Sugarman, Holliday, Ross, Castorina, & Hui, 1996). Correcting for racial misclassification revealed an age-adjusted cancer incidence among American Indians of 267.5 per 100,000 – substantially higher than the 153.5 per 100,000 reported prior to correcting for misclassification (Sugarman et al., 1996). Data linkage projects to link existing databases in Tribal Epidemiology Centers, state departments of health, IHS, Centers for Medicare & Medicaid Services, Behavioral Risk Factor Factors Surveillance System (BRFSS), and national cancer registries have substantially improved our current understanding of cancer trends and disparities among Natives living in the U.S. (Espey et al., 2014; Roen, Copeland, Pinagto, Meza, & Soliman, 2014).

In summary, uncertainties exist about the extent to which conclusions can be drawn about the QoL of Native American cancer survivors from research studies that use national data or data in which Native Americans are excluded, unidentified, or subsumed in the “other” category of race or ethnicity. Social determinants of health including historical trauma and ongoing structural

violence against Native communities likely influence the way Native Americans experience and engage in cancer prevention, detection, treatment, and survivorship activities. While data linkage projects have improved understanding of cancer incidence and mortality among Native communities, limited data exists to demonstrate prevalence and distribution of QoL related outcomes among Natives who survive cancer. In the absence of these data, a danger exists of underestimating the burdens facing Native cancer survivors and falsely assuming that surviving cancer is equivalent to living well after cancer. A critical need exists for more research to understand how QoL is affected among cancer survivors underrepresented in survivorship research including Native Americans.

### **Contributions of this study**

This study addresses the aforementioned research gaps in the following specific ways.

#### *Addresses the unique needs of underserved cancer survivors*

While much has been learned about the QoL of cancer survivors from existing research, Native Americans are underrepresented in the literature. Furthermore, many existing studies report extensively on the experiences of survivors in the early stages of their cancer journey and fewer report on experiences of survivors many years after treatment completion or specifically on QoL.

This study addresses these gaps by centering the research in a population of Native American cancer survivors and assessing QoL as a primary outcome. Additionally, this study supports the national Healthy People 2020 goal of improving QoL of cancer survivors and responds to recommendations from the cancer research community to identify and address the unique needs of underserved cancer survivors by strategically focusing research among Native Americans and exploring heterogeneity within this population (Lee Smith & Hall, 2015). Our research responds to calls from patients, health care providers, and the cancer research community to focus on QoL as an important endpoint of survivorship programs (Jacobsen & Jim, 2011; Rowland, 2008).

#### *Uses person-centered methodologies*

In many Native cultures, health is conceptualized as a *balance* between the physical, emotional, mental, and spiritual components of health (Wilson, 2003). However, previous

quantitative studies to investigate QoL in Native American cancer survivors have reported average scores *within* QoL domains in contrast to interactions or balance *between* domains – an analytic approach that misaligns with a holistic, balanced, conceptualization of health (Burhansstipanov et al., 2012; Burhansstipanov et al., 2010). Our study uses person-centered methodologies to understand QoL as a balance between physical, social, psychological, and spiritual components of health. Study design and methods are grounded in a conceptual model inspired by the Medicine Wheel reflecting the way many Native traditions conceptualize health as balance within and between physical, emotional, mental, and spiritual well-being. Implied in the definition of health as balance is the notion that QoL cannot be understood by measuring any component in isolation. Therefore, the quantitative strand of this study uses a novel methodological approach to assess QoL as a latent variable to better capture the essence of QoL as interactions within and between the physical, emotional, mental, and spiritual domains of health.

Because QoL is subjective and multi-dimensional, what QoL “looks like” is expected to vary from person to person. However, previous quantitative studies to examine QoL among Native American cancer survivors examined QoL by measuring average scores in each QoL domain. In addition to conceptual misalignment with Native understandings of health, these variable-centered analyses may mask potentially important differences *between* individual survivors for example by over- or underestimating QoL in survivors who report poor or excellent QoL in all domains of QoL. By taking a person-centered approach to our quantitative analysis, we allow for identification of classes of survivors who report similar *patterns* in QoL across QoL domains. We expect this approach to 1) provide new information on how QoL manifests as an interaction between QoL domains and 2) identify classes of Native American cancer survivors who may have different support needs based on different patterns in QoL outcomes. Qualitative analyses provide context to quantitative results and provide a means for interpreting results in the context of survivors’ daily lives.

*Overcomes methodological limitations by using a mixed methods research approach*

Our study addresses limitations of previous research by using a mixed methods research design that leverages strengths of quantitative and qualitative methods while overcoming their weaknesses to provide a more complete picture of QoL among Native survivors than either method could achieve alone. To our knowledge, this is the first mixed methods study to investigate QoL of Native American cancer survivors. We are aware of one study that published findings from the qualitative component of a mixed methods study, but a follow-up publication describing results of the integrated analysis are currently unavailable (Craft et al., 2017). Another study collected quantitative data on pain and qualitative data on experiences of pain among Native survivors, but data were not “mixed” by combining, merging, or embedding one within another to characterize it as mixed methods research as defined by Creswell and Clark (2011) (Haozous et al., 2011).

*Promotes research to advance health equity in Native American communities*

The impetus for this research arose from a need to fill gaps in the literature described above, but also from an urgency to address an expressed community need for more support services for Native cancer survivors (K. Rhodes, personal communication, October 6, 2015). This research study was conceived after consulting with the American Indian Cancer Foundation (AICAF) and Native American Cancer Research Corp (NACR), both Native-led, community-based nonprofit organizations dedicated to reducing the burden of cancer and optimizing QoL among Native Americans diagnosed with cancer and their caregivers. NACR played an important role in this research by consulting with and advising Ms. Bastian throughout the project. Community-engaged approaches to research, particularly with Native American communities who have been harmed by research in the past, increase the likelihood that research will be translated into action, ensures that the research is culturally appropriate, that the community benefits from the research, and that tribal sovereignty is respected (Burhansstipanov, Christopher, & Schumacher, 2005).

## **Purpose of this study**

The purpose of this descriptive mixed methods research study was to gain a person-centered, comprehensive understanding of factors that influence QoL among Native American cancer survivors and how those factors manifest in survivors' daily lives. More specifically, this study was designed to answer the following quantitative, qualitative, and mixed methods research questions.

### *Quantitative study research questions*

1. What patterns of heterogeneity in QoL exist among Native American cancer survivors as identified through latent class analysis?
  - 1a. What is the distribution of survivors in each QoL class identified?
  - 1b. What survivor characteristics are associated with class membership?

### *Qualitative study research questions*

2. What advice and words of wisdom do Native American cancer survivors prioritize in messages to other survivors?
  - 2a. What do those messages reveal about how survivors interpret and experience QoL after cancer?

### *Mixed methods research question*

3. What factors influence QoL among Native American cancer survivors and how?

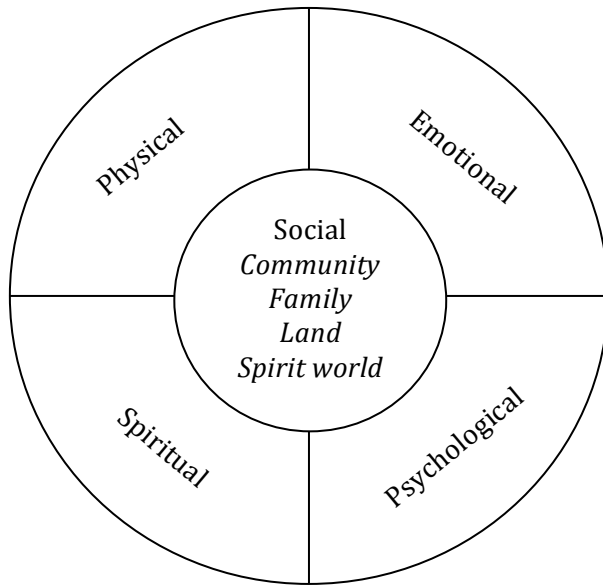
By using a mixed methods research approach, this study generates knowledge about patterns and prevalence of QoL outcomes useful for prioritizing future research and identifying survivors in greatest need, but also generates specific and contextual information required to inform intervention design. Both types of information may be used by policy makers, health care providers, caregivers, and community organizations to tailor policies and programs to meet the heterogeneous needs and optimize QoL of Native American cancer survivors.

## **CHAPTER 3. STUDY DESIGN**

### **Conceptual model**

The conceptual model guiding the design and analysis of this mixed methods research study is the Medicine Wheel, which represents the way many Native cultures conceptualize health – as a balance within and between the physical, emotional, mental, and spiritual components of health (Figure 2) (Wilson, 2003). At the center of the wheel is a circle for community, which represents the belief that balance extends beyond the individual and includes balance with the land, community, family, and the spirit worlds (Wilson, 2003). Conceptualizing health as a biological embodiment of complex interactions between individuals, families, communities, the environment, and macro-level societal influences over one’s life course is also consistent with an ecosocial theory of health (Krieger, 2011). The notion that QoL is a balance between physical, emotional, mental, and spiritual well-being implies that QoL cannot be understood by measuring any component in isolation. Consequently, in the quantitative phase of this study, we measure QoL as a latent variable, which cannot be measured directly, but manifests as interactions between various components of health represented in the Medicine Wheel. Our conceptual model served as a guide for variable selection for the quantitative study and in the qualitative phase of this study, provided a framework for interpreting survivor narratives. Finally, the community-engaged approach to this research keeps community at the center to ensure that the research process was respectful of culture, traditional knowledge and practices, and designed to benefit Native communities.

**Figure 3. Conceptual model for the research study inspired by the Medicine Wheel.**

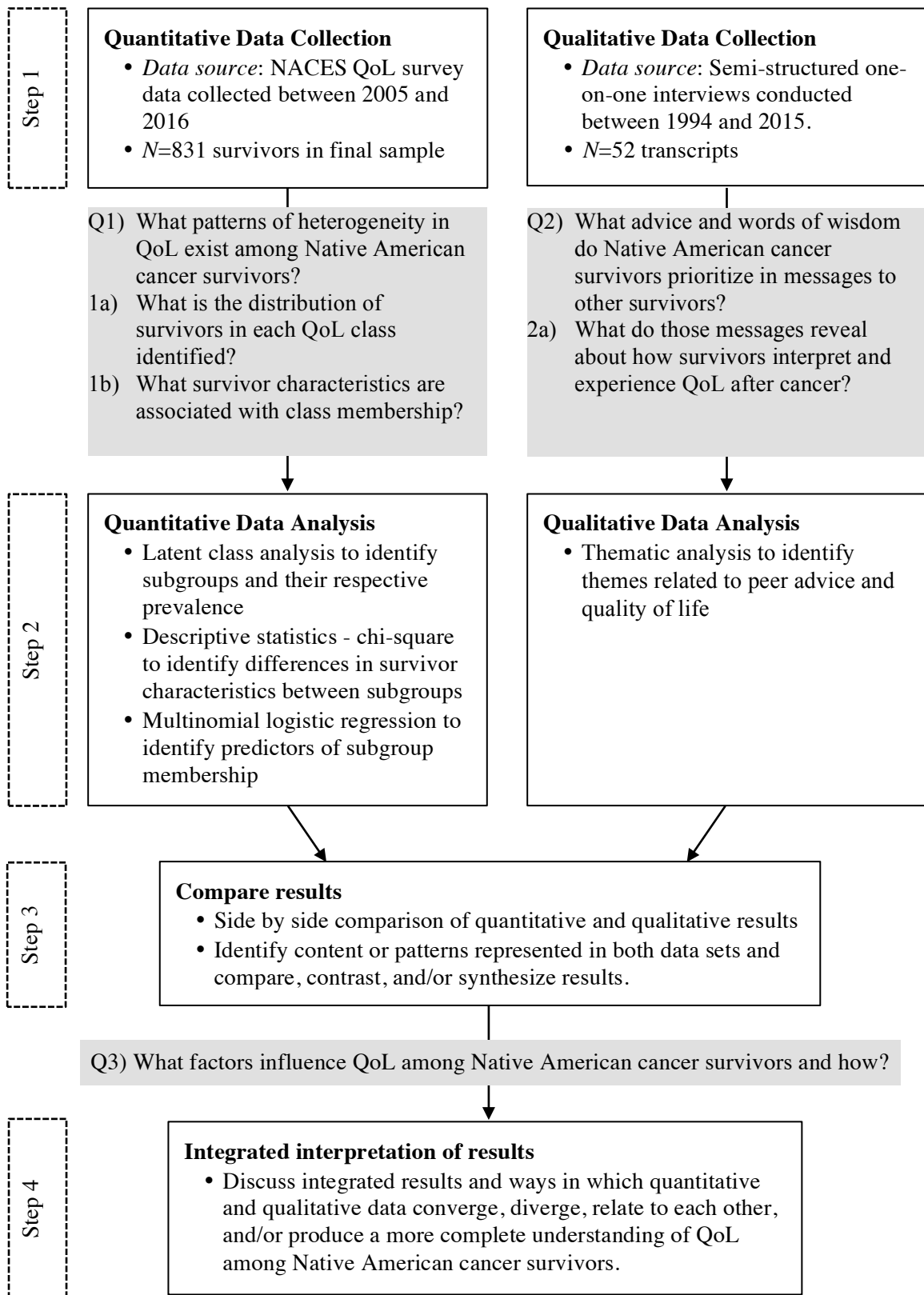


### **Study design**

In this descriptive cross-sectional study, we used a convergent mixed methods design to leverage strengths of quantitative data from a large-scale survey and qualitative data from in-depth interviews to attain comprehensive understanding of QoL among Native American cancer survivors. Merging these different, yet complimentary, data allows us to identify patterns and associations between variables related to QoL and incorporate survivors' voices in our results. Consistent with a convergent mixed methods design, quantitative and qualitative data were collected in parallel (though data were collected prior to the conception of this study) and analyzed separately. "Mixing" occurred at the final step of interpretation where quantitative and qualitative data were integrated to determine how they compared or related to each other (See Figure 4) (Creswell & Clark, 2011). From the integrated interpretation, we drew inferences and made conclusions about what was learned from combining quantitative and qualitative data to answer our mixed methods research question.



**Figure 4. Overview of the concurrent parallel mixed methods research design.**



## **Philosophical assumptions**

Our decision to use mixed methods for this research was informed by a pragmatic philosophy that collecting the two types of data was the best way to answer our research question. As a multi-dimensional construct, we are interested in understanding interactions between QoL dimensions and factors associated with QoL outcomes, which are best achieved through quantitative methods. However, QoL is subjective and dynamic so we are also interested in understanding complexity and range of individual perspectives about what QoL means, which is best achieved through qualitative methods. A mixed methods approach leverages the strengths while overcoming weaknesses of each method to provide a more complete understanding of QoL than either method could provide alone.

The quantitative phase of this study allowed for the possibility of generalizing findings to a large group and will provide information to decision makers on patterns, prevalence, and magnitude of QoL issues facing cancer survivors. However, quantitative survey data are insufficient for understanding the context or meaning behind participant responses to closed-ended survey questions. In the absence of participant voices, the researcher, subject to his/her own biases, is left to interpret meaning behind quantitative findings. Historically, this has been especially problematic in research conducted in Native communities where researchers have caused harm to communities by misinterpreting or misrepresenting research results (Harmon, 2010). To overcome weaknesses of quantitative research, the qualitative phase of this study strives to honor participant voices and allow cancer survivors to express their beliefs and attitudes about how cancer influenced their daily lives in their own words. By combining methods, our study takes advantage of the strengths of quantitative and qualitative research while overcoming their weaknesses to provide a more comprehensive and holistic understanding of QoL among Native cancer survivors.

## **Data sources and study population**

### *Quantitative study*

Quantitative data for this study are secondary QoL survey data collected by Native American Cancer Research Corporation (NACR) between the years 2005 and 2016. Survey data were collected online from Native American cancer survivors through the Native American Cancer Education for Survivors (NACES) QoL survey. The survey collected responses to items related to QoL, cancer-specific clinical factors (e.g. cancer type, treatment received, years since

diagnosis, etc.), and respondent demographics. All data were self-reported. Survivors completed the NACES QoL survey online by requesting a code name and then creating a password that allowed them to login and complete the survey at their leisure. The survey takes about 90 minutes to complete and is divided into four sections (health and personal health history, QoL, current health, and care issues). Survivors completed the survey on their own or with the assistance of a Native patient advocate. The survey underwent adaptations over the years so only those QoL survey items that remained consistent between the years 2005 and 2016 were considered for analysis. Reliability testing conducted in 2012 with a sample of Native survivors found Chronbach's alpha reliability coefficients comparable to those from prior studies ranging from 0.77 for the social QoL scale to 0.90 for the measure of overall QoL (Burhansstipanov et al., 2012). The instrument has not been fully validated in a sample of Native American cancer survivors though face validity was deemed acceptable after a thorough review of the instrument by NACES Advisory Board members and by Drs. Ferrell and Kagawa-Singer to ensure adaptations made to items from the original QoL instrument did not change scientific relevance of the questions or responses (Burhansstipanov et al., 2010).

NACR established NACES in 2002 as a community-driven education intervention to improve QoL of Native breast cancer survivors by providing survivors and their caregivers with culturally specific cancer education materials and connecting them with resources to help them with their needs (Burhansstipanov et al., 2010). The NACES program includes a web-based survey to assess QoL, which visitors to the website may voluntarily complete independently or with the help of a Native patient advocate. While originally designed to support breast cancer survivors, NACES was expanded to Natives diagnosed with any type of cancer beginning in 2007. The NACES QoL dataset currently contains QoL survey data from over 1,000 Native American cancer survivors from the Southern Plains (34%), Southwest (32%), Northern Plains (19%), Southeast (3%), and Northwest (2%). Ten percent of respondents were from other geographic regions including the Northeast, Alaska, Canada, and Hawaii. Because of small sample sizes, data for the current study were limited to Natives living in Northern Plains, Southern Plains and Southwest, which collectively represent 90% of participants in the NACES QoL dataset.

### *Qualitative study*

Qualitative data for this study come from de-identified transcripts of one-on-one interviews with Native American cancer survivors who volunteered to share their cancer stories with NACR at various cancer education and awareness events around the U.S. between the years 1994 and 2015. Participants consented to the videotaped interviews and to NACR using their interviews for research purposes by signing a release form at the time of their interview. In cases where survivors asked interviewers not to share specific portions of their interview with others, NACR deleted the text from transcripts prior to sharing them with us for this study. Interviews followed a semi-structured format in which survivors were encouraged to share the story of their cancer journey starting with how they found out they had cancer, how they and their family reacted to the news, what their treatment experience was like, what helped them along their cancer journey, and messages of advice for other Native Americans. All interviews were conducted and transcribed by NACR staff. Some transcripts included demographic and self-reported clinical information including region of residence, age at diagnosis, type of cancer, cancer recurrence, and years since diagnosis, however, collection of this data was inconsistent. Where data were missing for one of our inclusion criteria (region of residence), we contacted NACR and they provided us with the missing information. Only interviews conducted with survivors living inside the contiguous U.S. were considered for inclusion in analysis to remain consistent with data collection for the quantitative phase of the study.

### **Overview of analytic methods**

#### *Quantitative study*

Quantitative data were analyzed using latent class analysis (LCA) to identify unique classes of cancer survivors who reported similar responses to QoL survey items across physical, mental/emotional, social, and spiritual domains of QoL. Traditional “variable-centered” approaches to quantitative analysis of QoL that report mean QoL scores are insufficient for differentiating survivors who report poor or positive health outcomes across all QoL domains or any combination in between. However, differentiating survivors on their unique QoL experiences may be useful for tailoring survivor support services. LCA overcomes limitations of traditional analyses by analyzing *interactions* between QoL measures. In this study, QoL was measured as a latent variable, which cannot be measured directly, but can be measured indirectly by analyzing

interactions between variables that have been measured and can be observed (i.e. indicator variables) (Collins & Lanza, 2010). After running the LCA, we assigned survivors to the class for which they had the highest probability of membership and performed multinomial logistic regression to identify survivor characteristics associated with class membership.

### *Qualitative study*

We used a descriptive phenomenological method of inquiry to explore QoL from the perspective of Native American cancer survivors' lived experiences navigating life with cancer (Starks & Brown Trinidad, 2007). As a methodology, phenomenology is concerned with understanding common features of a lived experience, in this case, what it means to live well after cancer. This method of inquiry aligns well with our goal of understanding QoL from a holistic, person-centered point of view. We used thematic analysis as our analytic approach for identifying, analyzing, and reporting patterns (themes) within the data related to peer advice and QoL (Braun & Clarke, 2006). Research suggests that within cancer support groups, the advice survivors provide to others most often reflects their personal experiences navigating issues along their cancer journey (Sillence, 2013). Themes were identified through an inductive process, which allows the data to drive the themes though our analysis was designed to answer a research question rather than follow a purely inductive, data-driven approach (i.e. grounded theory) of simply seeing what comes out of the data (Braun & Clarke, 2006). Themes were identified at the semantic level such that themes were based on their surface meaning without attempting to identify and interpret any underlying or latent ideas from participant narratives. Interviews were analyzed following the six-step process for conducting thematic analyses outlined in Braun and Clarke (2006). However, analysis was a recursive process of moving back and forth between steps as analysis progressed.

### *Integrated interpretation*

We used a process of data triangulation to integrate and interpret quantitative and qualitative data at the interpretation level (Farmer, Robinson, Elliott, & Eyles, 2006b). We first listed all findings from the quantitative and qualitative analyses and sorted them into similar categories that addressed our research question. These "meta themes" served as the dimensions by which we compared quantitative and qualitative results to evaluate whether the two types of data confirmed results of the other, diverged from each other, or expanded on the other by providing insights that would have been missed had we examined QoL from a single perspective

(Creswell & Clark, 2011). We report findings through weaving in which results are connected to each other thematically (Fetters, Curry, & Creswell, 2013).

## CHAPTER 4. QUANTITATIVE STUDY

### Introduction

The National Cancer Institute estimates that there are 16.9 million cancer survivors alive in the U.S. today and that two-thirds of those survivors were diagnosed five or more years ago (Bluthmann et al., 2016; National Cancer Institute. *Statistics*). Cancer survivors may face multiple challenges after treatment completion that affect their quality of life (QoL) including financial toxicity (Pisu et al., 2015), higher risk of secondary cancers (Curtis et al., 1973), late effects of cancer treatment (Den Ouden et al., 2012; Irvine, Vincent, Graydon, Bubela, & Thompson, 1994), fatigue, psychological distress, limitations in cognition, sexual dysfunction, infertility (Nieman et al., 2006), comorbidities (Piccirillo, Tierney, Costas, Grove, & Spitznagel Jr, 2004), fear of recurrence, changes in employment (de Boer, Taskila, Ojajärvi, van Dijk, & Verbeek, 2009), and changes in family roles (Hodge et al., 2016a). Understanding the short- and long-term effects of cancer and related treatment on survivors' QoL is important for informing interventions to support survivors in achieving and maintaining optimal QoL after cancer.

While much research exists to describe QoL concerns of cancer survivors, only a small fraction of that research centers on understanding QoL among under-resourced populations such as Native Americans for whom QoL challenges may be exacerbated due to consequences of historical and ongoing injustices (Cavanagh et al., 2015; U.S. Commission on Civil Rights, 2003). Furthermore, existing studies often report *average* QoL scores that often mask important differences in QoL between individuals. This strategy is particularly problematic for understanding QoL among Native populations because of pronounced regional variation in cancer rates among this population and diverse customs and cultures of the 573 federally recognized tribes in the U.S. To our knowledge, this is the first study to examine QoL of Native American cancer survivors from a holistic, *individual* level perspective using methods of latent class analysis as part of a mixed methods research study.

Any examination of QoL in Native American populations must consider the strength of this population to survive and thrive in light of a history of near genocide from government-sanctioned exploitation of their people, land, and resources (Warne & Lajimodiere, 2015). Atrocities included forced removal of tribes from their land, removal of children from families to attend boarding schools designed to “Kill the Indian, Save the Man,” attempts at genocide, and numerous broken treaties (Whitbeck, Adams, Hoyt, & Chen, 2004). The ongoing trauma and

poverty experienced by many Native communities today are lasting consequences of these injustices (Warne & Lajimodiere, 2015). Injustices continue today through ongoing structural violence against Native Americans, which Farmer et al. (2006a) defines as “economic, political, legal, religious, and cultural structures that stop individuals, groups, and societies from reaching their full potential” (p. 1686). Violence against Native Americans disrupted traditional ways of life, stripped communities of their land and resources and created economic inequalities that create and maintain cancer health disparities we see today (Farmer et al., 2006a; Galtung, 1969; Kirmayer et al., 2014).

Advances in early detection and cancer treatment over the past four decades have contributed to an increase in five-year survival rates in the U.S. for all cancer types from 50% in 1970 to 68% today (Siegel, Miller, & Jemal, 2018). However, five-year all cancer survival rates for Native Americans remain the lowest of all racial and ethnic groups at 60.5% (Jemal et al., 2017). Because cancer-related morbidity and mortality rates among Natives vary considerably by region of the U.S., reports of overall cancer rates for this population may be misleading. However imperfect, aggregated cancer data for Native Americans reveal disturbing patterns in cancer outcomes including higher mortality to incidence ratios for the most common cancers compared to Whites (Espey et al., 2014; Siegel, Ma, Zou, & Jemal, 2014; White et al., 2014) and stagnating or increasing mortality rates compared to a steady decrease among Non-Hispanic Whites (White et al., 2014). Factors contributing to these disparities may also influence survivors’ QoL after cancer. Thus, understanding the QoL of Native American cancer survivors is an important component of addressing cancer burden in Native communities.

Much of what is known about the QoL of Native American cancer survivors comes from qualitative research studies that provide insight into ways in which Natives experience QoL along their cancer journey. Those studies reveal themes of social isolation and psychosocial distress (Hodge et al., 2012; Peltier, 2015), stigma and shame (Braun et al., 2002; Eide, 2007), unwanted role changes (Hodge et al., 2016b), unmanaged pain (Haozous et al., 2011), fear and anxiety stemming from uncertainty of cancer and its causes (Burhansstipanov, 2005), and positive outcomes when survivors reprioritized their lives to focus on what is most important (Pelusi & Krebs, 2005). However, few quantitative studies exist to provide insight into the prevalence of those outcomes.

One study found that Native cancer survivors report more positive QoL outcomes (i.e. hopefulness, life purpose, positive changes after cancer) compared to non-Native survivors, but worse social and psychological outcomes (Burhansstipanov et al., 2012). Another study surveyed



Native breast cancer survivors and found that 30% of long-term survivors (diagnosed  $\geq 5$  years prior) reported experiencing unmanaged pain (Burhansstipanov et al., 2010). One limitation of these studies is that QoL was reported as an average score within each QoL domain (physical, social, psychological, spiritual), which fails to identify meaningful differences between individual survivors. Because QoL is multidimensional and subjective, we expect variation in what QoL means from person to person and in the weight that survivors attach to various domains of QoL (Carr & Higginson, 2001). Finally, Native conceptualizations of health and wellness are holistic and centered around balance and harmony (Wilson, 2003). Thus, QoL cannot be fully understood by measuring its components in isolation, but rather by considering interactions within and between QoL domains.

One strategy for overcoming this limitation is to use novel methodologies like latent class or latent profile analyses that can drill down to the individual level to identify “hidden” groups of individuals who respond similarly to a series of QoL measures. For example, in one study among a national sample of lung cancer survivors, researchers used latent class analysis to identify four classes of survivors with similar health related quality of life (HRQoL) including a class with “good HRQoL” (42%) who reported few limitations across all measures; a “poor HRQoL” class (19%) who reported experiencing limitations on nearly all measures; a group with “pain dominant” impairments to HRQoL (31%); and a group of survivors with “mobility/usual activity” impairments (9%) (Kenzik, Martin, Fouad, & Pisu, 2015). The authors also found associations between class membership and survival emphasizing the value of identifying heterogeneity in QoL and tailoring support strategies to support survivors’ needs. One limitation of the study is that it was limited to indicators of health status (i.e. presence and severity of problems in mobility, self-care, usual activities, pain/discomfort, and anxiety/depression). It did not include measures of patient perceptions of the impact those problems had on their daily lives— a critical component for understanding QoL (Osborne et al., 2012).

The purpose of this study was to examine heterogeneity of QoL among Native American cancer survivors. More specifically, we used latent class analysis (LCA) followed by multinomial logistic regression to answer the research questions: 1) What patterns of heterogeneity in QoL exist among Native American cancer survivors? 2) What is the distribution of survivors in identified classes? and 3) What survivor characteristics are associated with class membership? These analyses comprise the quantitative component of a convergent parallel mixed methods study to gain a more complete understanding of factors that influence QoL among Native American cancer survivors and how those factors manifest in the context of survivors daily lives.

Understanding how QoL outcomes cluster within classes of cancer survivors may inform tailored approaches for supporting survivors that more closely align with individual needs.

## **Methods**

Traditional “variable-centered” approaches to quantitative analysis that examine mean QoL scores of cancer survivors are insufficient for differentiating survivors who report poor or positive health outcomes across all QoL domains or any combination in between. However, differentiating survivors on their unique QoL experiences may be useful for tailoring survivor support services. LCA overcomes limitations of traditional analyses by analyzing *interactions* between QoL measures. In this study, QoL is measured as a latent variable, which cannot be measured directly, but can be measured indirectly by analyzing interactions between variables that have been measured and can be observed (i.e. indicator variables) (Collins & Lanza, 2010). In this study, we included 12 indicator variables to measure QoL in four domains: physical, mental/emotional, social, and spiritual. LCA uses information on how individual survivors responded to each indicator variable to organize survivors into “classes” or groupings of survivors with similar response patterns. After assigning survivors to the class with which they had the highest probability of membership, we used multinomial logistic regression to identify survivor characteristics associated with class membership.

## ***Data source***

This study analyzed secondary data from the Native American Cancer Education for Survivors (NACES) QoL survey, which was adapted from the City of Hope QoL instruments developed by Ferrell et al. (1995) and includes 24 items to measure four domains of QoL relevant to cancer survivorship (physical, mental/emotional, social, spiritual) (Ferrell, Hassey-Dow, & Grant, 2012). The survey was adapted for Native Americans through a participatory process to ensure items were culturally acceptable and understandable. Chronbach’s alpha reliability coefficients were comparable to those from prior studies ranging from 0.77 for the social QoL scale to 0.90 for the measure of overall QoL and face validity was deemed acceptable by the original authors of the instrument (Burhansstipanov et al., 2012). Survivors volunteered to complete the 90-minute survey online and nearly all survivors completed the survey with the assistance of a Native patient advocate. Because the survey underwent adaptations over the years, only those items that remained consistent between the years 2006 and 2016 were considered for

analysis. A total of 1,184 individuals completed the survey between 2006 and 2016. More information about the NACES QoL survey is provided in Chapter 3.

### ***Study Sample***

The analytic sample was restricted to survivors who completed the NACES QoL survey between January 1, 2006 and December 31, 2016; self-identified as Native American; were  $\geq 18$  years of age at the time of their cancer diagnosis; and resided in the Northern Plains, Southwest or Southern Plains regions of the U.S. (survivors from outside of these regions were excluded because of small sample sizes). Survivors were excluded if they were missing data for all indicator variables included in the LCA. After applying inclusion and exclusion criteria, a total of 831 (70%) survivors were included in the final study sample.

### ***Measures***

#### *Quality of life*

QoL was assessed across four domains: physical, mental/emotional, social, and spiritual. Most survey items were measured on a 5-point likert scale with a few exceptions including three items measured dichotomously (“yes/no” to having experienced problems with fertility, anxiety, or financial burden) and one item measured on a 4-point scale (interference in daily life). While we could have modeled indicator variables as continuous, we believed that doing so was inappropriate because of the ordinal nature of the variables, which are not truly continuous in the sense of there being equal intervals between each response option. Modeling indicator variables as continuous would also result in loss of information about how survivors responded to specific questions – specificity necessary for informing action and targeting interventions. Finally, dichotomizing indicator variables to identify survivors experiencing poor outcomes identifies survivors who may benefit from additional support services.

We anticipated a priori that including all 24 survey items in the LCA may result in sparse data in some cells and in models that fail to converge. Therefore, we limited the number of indicator variables to 12 as recommended in the literature (Wurpts & Geiser, 2014). First, we eliminated variables that were missing  $>10\%$  of data. Next, we identified variables that were highly correlated within QoL domains ( $>0.50$ ) and eliminated the variable with the least variance in responses. We also eliminated variables that were not endorsed by at least 10% of the sample and eliminated the four variables that were measured on a dichotomous versus ordinal scale to

maintain measurement consistency. Finally, we consulted with collaborators at Native American Cancer Research Corporation to identify variables that were most conceptually relevant to the research questions and would be useful for illuminating areas for intervention.

The final 12 indicator variables included two measures of physical QoL (overall physical QoL and physical ability to do everything one wants); five measures of mental/emotional QoL (overall mental and emotional QoL, ability to concentrate, life satisfaction, life stress since diagnosis, feelings of usefulness); four measures of social QoL (overall social QoL, social support, social isolation, interference with daily activities); and one measure of spiritual QoL (positive changes in one's life since diagnosis) (Table 1).

### *Survivor characteristics*

Survivor characteristics included in analysis were selected based on consistency with the conceptual model and previous literature in cancer survivorship, health disparities, and social determinants of health (Braveman, Egerter, & Williams, 2011; Warne & Lajimodiere, 2015). Measures included gender, year of birth, residence, region, insurance type, employment status, and education. We also included self-reported measures of years since diagnosis, cancer type, continuation of cancer care (treatment, support, follow-up appointments), and perceived degree of control over cancer. Cancers were classified by body location/system aligning with the National Cancer Institute classification system (National Cancer Institute. *Cancers by Body Location/System*). If a survivor reported a diagnosis of cancer, but did not report cancer type, their cancer type was classified as "unknown."

**Table 1. Description of the 12 QoL indicator variables included in the latent class analysis.**

<b>QoL Domain</b>	<b>Survey Question</b>	<b>Definition of indicator</b>
<i><b>Physical</b></i>	How good is your physical QoL (strength, feeling tired, sleep, pain, appetite) today?	0 = Excellent; Good; Okay 1 = Poor; Extremely Poor
	Overall, do you currently feel you are physically able to do everything that you want to do on a daily basis?	0 = Do everything; Do most things 1 = Not able to do most things; Never able to do what I want
<i><b>Mental / Emotional</b></i>	How good is your mental and emotional quality of life (control, anxiety, depression, happiness, distress)?	0 = Excellent; Good; Okay 1 = Poor; Extremely Poor
	How is your present ability to concentrate or to remember things?	0 = Excellent; Good; No better or worse 1 = Poor; Extremely Poor
	How satisfying is your life today?	0 = Totally satisfying; Satisfying 1 = Okay; Somewhat satisfying; Not at all satisfying
	How stressful or overwhelmed do you feel your life has been since your diagnosis?	0 = Not stressful at all; Occasionally stressful; Okay 1 = Fairly stressful; Very stressful
	How useful do you feel?	0 = Extremely useful; Very useful; Useful 1 = A little useful; Not at all useful
<i><b>Social</b></i>	How good is your social quality of life (family distress, family relationships, affection, isolation, employment, finances)?	0 = Excellent; Good; Okay 1 = Poor; Extremely Poor
	How much support do/did you receive from others?	0 = Very good support; Good support 1 = Some, not enough; No support; Too much support
	How much has your cancer made you feel isolated (alone) or separated from others?	0 = Feel well supported; Feel okay; Rarely feel isolated 1 = Occasionally feel isolated; Feel very isolated
	How much has your cancer interfered with your daily activities at home (e.g. cook, clean, fish, or game, care for livestock)?	0 = Not at all; Very little; Somewhat 1 = A lot
<i><b>Spiritual</b></i>	To what extent has your illness made positive changes in your life?	0 = Great deal of positive change; A lot of good changes; Good changes 1 = A few good changes; Not at all

## *Analysis*

Descriptive analyses were conducted to describe study population characteristics, covariates, and survivor characteristics in QoL classes. We used chi-square tests of independence to examine differences in survivor characteristics between survivors with complete and missing data and between survivors in QoL classes. After applying a Bonferroni correction to account for multiple comparisons (n=40 comparisons), estimates were considered to be statistically significant if  $p < 0.0013$ .

### *Latent class analysis*

We used LCA to identify meaningful classes of cancer survivors who reported similar responses to the 12 QoL survey items included in the LCA (Table 1). After running a series of LCA models ranging from 1 to 6 class solutions, we compared all models using model fit criteria and interpretability of classes to identify the best fitting solution. The best model will have high homogeneity within classes such that response patterns of survivors within each class are as similar as possible to each other, and a high degree of separation such that a given response pattern is characteristic of one class only (Collins & Lanza, 2010). Criteria used to determine best fit included: *Parsimony* – all else being equal, a simpler model estimating fewer classes is preferred; relative model fit indices including *Bayesian Information Criteria (BIC)* and *Akaike Information Criteria (AIC)* – smaller values are optimal; *entropy* – values closest to 1 are optimal; and *interpretability* – the degree to which the classes are conceptually meaningful (Collins & Lanza, 2010). To test for solution stability, we ran LCA models with multiple sets of starting values to determine whether models converge to the same solution. Finally, we assigned individuals to the class for which they had the highest probability of membership for use in subsequent regression analyses. All latent class analyses were performed in Stata 13 (StataCorp. 2013. College Station, TX: StataCorp LP) using the LCA Plugin developed by the Methodology Center at Penn State (LCA Stata Plugin (Version 1.2) [Software]. (2015). University Park: The Methodology Center, Penn State. Retrieved from methodology.psu.edu).

### *Multinomial logistic regression*

We conducted multinomial logistic regression to explore associations between QoL class membership and survivor characteristics. Regression models estimated associations between

survivor characteristics and class membership controlling for all other variables in the model. Results are reported as relative risk ratios (RRR) and 95% confidence intervals of class membership compared to a referent group of survivors identified through LCA as having the most positive QoL outcomes. RRRs are obtained by exponentiating coefficients from the multinomial logit model (which are in log-odds units) and may be interpreted like odds ratios. For example, if an  $RRR > 1$ , it indicates that the risk of membership in a particular class relative to the risk of the membership in the reference group increases as the variable increases given variables in the model are held constant. Regression analyses were performed in Stata 13 (StataCorp. 2013. College Station, TX: StataCorp LP).

### *Missing data*

When completing the NACES QoL survey, survivors could refuse to answer or to skip questions so reasons for missingness are unknown. Overall, 95% of the study sample had complete data for at least 10 of the 12 indicator variables included in the LCA. An examination of associations between missing data and survivor characteristics revealed that region and area of residence were significantly associated with missingness suggesting that data is missing at random, which is considered ignorable and accommodated in LCA by employing full-information maximum likelihood (FIML) data procedures.

Of the 831 survivors included in the LCA,  $n=147$  (17.7%) were missing data for at least one covariate. Survivors born prior to 1949, living on a reservation, living in the Southwest, not working for pay, and with a high school education or less were most likely to be missing data for covariates. These findings suggest that data are missing at random so we employed multiple imputation by chained equations techniques to account for missing data in logistic analyses. For the imputation, we used multinomial logistic imputation models including all variables in the final analytic model as covariates. No auxiliary variables were included. Imputations were run until Monte Carlo estimates for all p-values were  $\leq 0.02$  (White, Royston, & Wood, 2011).

### *Sample size*

In a LCA, having too small of a sample may lead to “underextraction” or failing to identify a small, but meaningful class in the data (Collins & Lanza, 2010). Only recently has work been done to try to understand how large of a sample size is needed to avoid underextraction in LCA (Dziak, Lanza, & Tan, 2014). Currently, a formula for predicting power in LCA is not available. Sample size requirements depend on relative class sizes (prevalence of

classes in the data) and measurement quality (high quality indicator variables are those that are strongly associated with the latent class variable and have probabilities of endorsement close to 1 or 0). Some authors suggest that a sample size of at least 500 is desirable when doing LCA, which we comfortably exceed with a sample size of 831 (Finch & Bronk, 2011).

## **Results**

### ***Sample characteristics***

The final study sample was primarily female (79%) and most survivors lived in the Southern Plains (43%) (Table 2). The proportion of survivors who lived in urban areas (39%) was similar to the proportion of survivors who lived on the reservation (35%). Just over half of survivors had some technical training or some college or higher (54%). The majority (55%) of survivors were long-term cancer survivors (diagnosed 5 or more years prior) and just under one-third (31%) were breast cancer survivors. At the time they completed the survey, nearly two-thirds of survivors reported that they continue to receive cancer care including treatment, support, or follow-up appointments.



**Table 2. Descriptive characteristics of survivors included in the final study sample (n=831).**

<b>Characteristic</b>	<b>N (%)</b>	<b>Characteristic</b>	<b>N (%)</b>
<b>Gender</b>		<b>Insurance</b>	
Female	648 (79%)	IHS/Tribal/Uninsured	176 (22%)
<b>Year of birth</b>		Medicaid/Other public	157 (19%)
1949 or earlier	333 (41%)	Medicare/VA/Tricare	212 (26%)
1950-1959	292 (36%)	Private	270 (33%)
1960 or later	191 (23%)	<b>Years since diagnosis</b>	
<b>Residence</b>		<1 year	147 (18%)
City/town/village	320 (39%)	1-4 years	218 (27%)
Move back and forth	79 (10%)	5 + years	450 (55%)
On the reservation	286 (35%)	<b>Cancer type</b>	
Rural not reservation	143 (17%)	Breast	260 (31%)
<b>Region</b>		Gynecologic	117 (14%)
Northern Plains	187 (23%)	Gastrointestinal	78 (9%)
Southern Plains	356 (43%)	Genitourinary	62 (7%)
Southwest	288 (35%)	Lung	29 (3%)
<b>Native blood quantum</b>		Other	33 (4%)
Full (100%)	451 (55%)	Multiple	120 (14%)
3/4 (75-99%)	126 (16%)	Unknown	132 (16%)
1/2 (50-74%)	153 (19%)	<b>Continue to receive care</b>	
1/4 (25-49%)	50 (6%)	Yes	494 (62%)
<25%	35 (4%)	<b>Degree of control over cancer</b>	
<b>Work for pay</b>		Good/complete	628 (78%)
Yes	401 (50%)	Fair	93 (12%)
<b>Education</b>		Little control	28 (3%)
High school or less	364 (46%)	Not at all	53 (7%)
Tech/apprentice/some college	248 (32%)		
College grad or higher	174 (22%)		

***Latent class analysis***

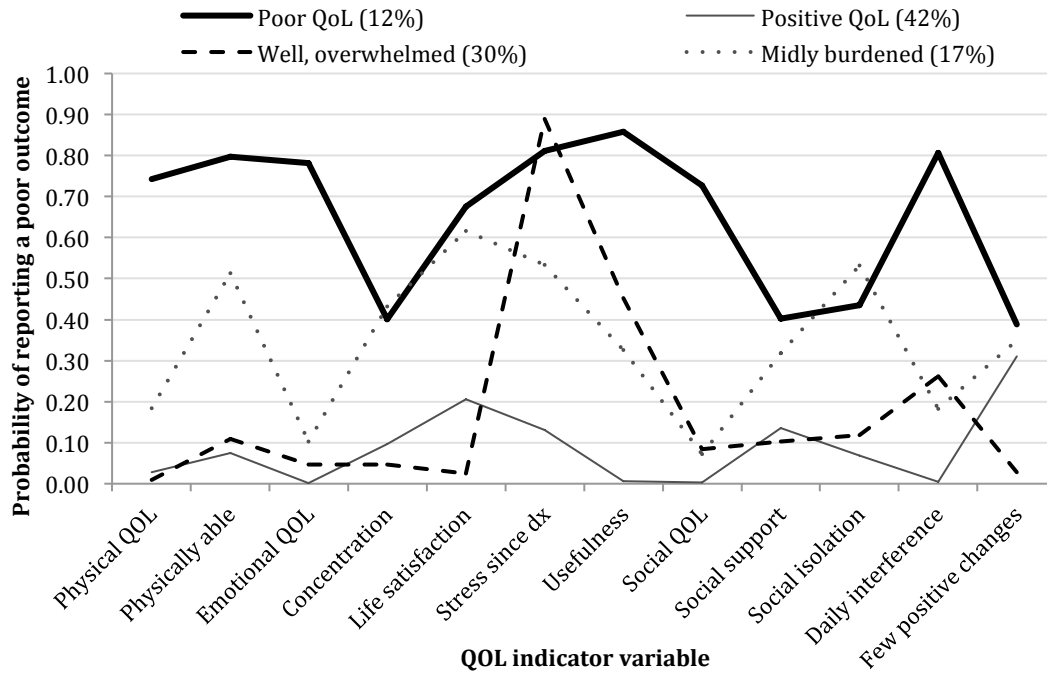
We identified four classes of cancer survivors with unique response patterns to physical, mental/emotional, social, and spiritual QoL measures (Figure 5). Item response probabilities for the four classes are presented in (Table 3). Overall endorsement of indicator variables among the entire sample ranged from a low of 12% (poor overall social QoL) to a high of 50% (life has been fairly or very stressful since one's cancer diagnosis). Model fit statistics for 1-class through 6-class LCA model solutions are presented in (Table 4). Based on fit statistics alone, the 5-class solution provided the best fit to the data having lower  $G^2$ , AIC, and log-likelihood values than the 4-class solution and a BIC lower than the 6-class solution. However, interpretability of the 5-class

solution was tenuous because one class had response probabilities near 0.5 for nearly half of the indicators signifying low homogeneity within classes. Furthermore, two classes in the 5-class solution had prevalences of less than 10%. Thus, the more parsimonious 4-class solution was selected as the best model based on interpretability, model fit statistics indicating that the 4-class solution was better than the 3-class solution, and separation such that classes are meaningfully distinguishable from each other based on unique patterns of item response probabilities.

Using the 4-class model solution, survivors were assigned to the class for which their posterior probability of membership was highest after 20 simulations. Mean class specific entropy, calculated as the average mean posterior probability of membership by most likely class, was 86%. Mean posterior probabilities by most likely latent class are presented in Table 5. We report prevalence based on class assignment versus strict probabilities to stay consistent with our decision to assign survivors to their most likely class in subsequent analyses. The four classes in order of prevalence include:

1. **Positive QoL** (n=345, 42%). Survivors in this class reported positive outcomes across all QoL measures and all domains (i.e. low endorsement of negative outcomes).
2. **Well, overwhelmed** (n=247, 30%). This class is characterized by survivors who reported that life has been “Fairly” or “Very” stressful since their cancer diagnosis, but reported positive outcomes across all other QoL measures.
3. **Mildly burdened** (n=142, 17%). Response patterns of survivors in this class resembled those of survivors in the *Poor QoL* class, but diverged in their more positive assessment of overall physical, mental/emotional, and social QoL and feelings of usefulness.
4. **Poor QoL** (n=97, 12%). Survivors in this class had high probability of endorsing multiple limitations across multiple QoL domains including poor physical, mental, and social QoL, and interference with daily life.

**Figure 5. Plot of item-response probabilities for reporting a poor outcome on QoL indicators among members of each latent class.**



**Table 3. Item response probabilities for QoL indicator variables included in the latent class analysis.**

QoL Indicator variables	Overall* n=831	Positive QoL n=345 (42%)	Well, overwhelmed n=247 (30%)	Mildly burdened n=142 (17%)	Poor QoL n=97 (12%)
<b>Physical</b>					
Physical QoL	<b>0.14</b>	0.03	0.01	0.18	0.74
Physically able	<b>0.26</b>	0.07	0.11	0.51	0.80
<b>Mental Emotional</b>					
Emotional QoL	<b>0.13</b>	0.00	0.05	0.10	0.78
Able to concentrate	<b>0.18</b>	0.10	0.05	0.43	0.40
Life satisfaction	<b>0.29</b>	0.21	0.03	0.62	0.68
Stress since diagnosis	<b>0.50</b>	0.13	0.89	0.53	0.81
Usefulness	<b>0.29</b>	0.01	0.45	0.33	0.86
<b>Social</b>					
Social QoL	<b>0.12</b>	0.00	0.08	0.07	0.73
Social support	<b>0.19</b>	0.14	0.10	0.32	0.40
Social isolation	<b>0.22</b>	0.07	0.12	0.53	0.44
Daily interference	<b>0.21</b>	0.00	0.26	0.18	0.81
<b>Spiritual</b>					
Positive changes	<b>0.25</b>	0.31	0.03	0.35	0.39

\*Proportion of all survivors who endorsed each indicator variable.

**Table 4. Model fit statistics for latent class analysis models of 1 to 6 solutions.**

No. classes	G <sup>2</sup>	AIC	BIC	log-likelihood
1	2572.9	2596.9	2653.5	-4940.6
2	1513.3	1563.3	1681.4	-4410.8
3	1281.5	1357.5	1537.0	-4294.9
<b>4</b>	<b>1160.3</b>	<b>1262.3</b>	<b>1503.1</b>	<b>-4234.3</b>
5	1057.3	1185.3	1487.6	-4182.8
6	994.5	1148.5	1512.2	-4151.4

**Table 5. Mean posterior probabilities of class membership by most likely class.**

Most likely class	n	Positive QoL	Well, overwhelmed	Mildly burdened	Poor QoL
Positive QoL	345	<b>0.88</b>	0.05	0.07	0.00
Well, overwhelmed	247	0.12	<b>0.81</b>	0.06	0.01
Mildly burdened	142	0.08	0.05	<b>0.80</b>	0.06
Poor QoL	97	0.00	0.01	0.06	<b>0.93</b>

### *Descriptive characteristics of survivors in QoL classes*

Survivors in QoL classes differed significantly by year of birth, area of residence, region, insurance, education, years since diagnosis, and cancer type ( $p < 0.0001$ ) (Table 6). Most survivors in the *Positive QoL* and *Mildly burdened* classes lived in a city/town/village (56% and 44% respectively) whereas most survivors in the *Poor QoL* and *Well, overwhelmed* classes lived on the reservation (45% and 61% respectively). Regional differences between survivors in QoL classes also existed. The majority of survivors in the *Well, overwhelmed* class lived in the Southwest (71%) whereas the majority of survivors in the *Positive QoL* class lived in the Southern Plains (67%).

In addition to geographical differences, more survivors in the *Positive QoL* class had higher than a high school education (69%) and private health insurance (40%) compared to survivors in other classes. In contrast, survivors in the *Poor QoL* class were most likely to be unemployed (67%), to have been diagnosed with multiple or unknown cancers (52%), and to report continued cancer care (86%) compared to survivors in other classes. Notably, the vast majority of survivors in the *Well, overwhelmed* class are long-term cancer survivors (80%), which is over one and a half times more than in any other class.

### ***Multinomial logistic regression***

Eleven covariates were included in the final logistic regression model including gender, year of birth, area of residence, region, insurance type, work for pay, education, years since diagnosis, continue care, cancer type, and degree of control over cancer. A comparison between complete case and imputation models revealed similar results so we report results from the imputation model in order to preserve all survivors in the sample and reduce potential bias from systematic differences between survivors with complete and missing data.

After adjustment for all covariates in the model, significant sociodemographic predictors of class membership included area of residence and region of the U.S. (Table 7). Survivors living in the Southwest were 10.5 (3.7 – 30.0) times more likely to be in the *Poor QoL* class and 4.8 (2.4 – 9.9) times as likely to be in the *Well, overwhelmed* class versus the *Positive QoL* class compared to survivors living in the Southern Plains. Survivors in the Northern Plains also had 4.2 (1.7 – 10.7) times the risk of being in the *Poor QoL* class versus the *Positive QoL* class compared to survivors in the Southern Plains. Survivors who lived on a reservation or moved back and forth among the city, reservation, and/or rural areas were over 2.6 times more likely to be in the *Well, overwhelmed* and *Poor QoL* classes than the *Positive QoL* class compared to survivors who lived in a town or city.

Other characteristics associated with class membership included years since diagnosis and perceived degree of control of cancer (Table 7). Compared to recent cancer survivors (<1 year since diagnosis), long-term survivors had 2.3 (1.1 – 5.0) times the risk of being in the *Well, overwhelmed* class versus the *Positive QoL* class. Risk of being in the *Poor QoL* class decreased with increasing length of survivorship. Long-term survivors had an 80% (50% – 90%) lower risk of being in the *Poor QoL* class compared to recent survivors. Survivors' who perceived having fair to no control of their cancer were at higher risk of being in the *Poor QoL* and *Mildly burdened QoL* classes compared to survivors who perceived having good or complete control of their cancer. Perceived sense of control of one's cancer was the only variable significantly associated with membership in the *Mildly burdened QoL* class ( $p < 0.0001$ ). Survivors who perceived having little control of their cancer were 5.2 (1.7 – 16.4) times more likely to be in the *Mildly burdened* class versus the *Positive QoL* class compared to survivors who perceived good or complete control of their cancer. While not meeting our threshold for statistical significance, cancer type was the only other variable that appeared to be associated with membership in the *Mildly burdened* class ( $p = 0.0187$ ). Survivors diagnosed with lung cancer had 4.4 (1.4 – 14.2)

times the risk and survivors diagnosed with multiple cancers had 2.3 (1.2 – 4.6) times the risk of being in the *Mildly burdened* class versus the *Positive QoL* class compared to breast cancer survivors.

**Table 6. Descriptive characteristics of survivors in each latent class.**

Characteristic	Latent class			
	Positive QoL N=345 (42%)	Well, overwhelmed N=247 (30%)	Mildly burdened N=142 (17%)	Poor QoL N=97 (12%)
<b>Gender</b>				<i>p</i> =0.176
Female	260 (76%)	204 (83%)	107 (75%)	77 (79%)
<b>Year of Birth</b>				<i>p</i> <0.0001
1949 or earlier	130 (38%)	114 (47%)	56 (41%)	33 (35%)
1950-1959	127 (37%)	94 (39%)	43 (31%)	28 (29%)
1960 or later	85 (25%)	33 (14%)	39 (28%)	34 (36%)
<b>Residence</b>				<i>p</i> <0.0001
City/town/village	193 (56%)	40 (16%)	63 (44%)	24 (25%)
Move back and forth	11 (3%)	37 (15%)	10 (7%)	21 (22%)
On the reservation	51 (15%)	150 (61%)	41 (29%)	44 (45%)
Rural not reservation	88 (26%)	19 (8%)	28 (20%)	8 (8%)
<b>Region</b>				<i>p</i> <0.0001
Northern Plains	77 (22%)	29 (12%)	53 (37%)	28 (29%)
Southern Plains	232 (67%)	44 (18%)	63 (44%)	17 (18%)
Southwest	36 (10%)	174 (70%)	26 (18%)	52 (54%)
<b>Insurance</b>				<i>p</i> <0.0001
IHS/Tribal/Uninsured	89 (26%)	26 (11%)	51 (37%)	10 (11%)
Medicaid/Other public	49 (15%)	54 (22%)	22 (16%)	32 (34%)
Medicare/VA/Tricare	63 (19%)	87 (36%)	34 (24%)	28 (30%)
Private	135 (40%)	76 (31%)	32 (23%)	23 (25%)
<b>Work for pay</b>				<i>p</i> =0.002
Yes	176 (52%)	132 (55%)	63 (45%)	30 (33%)
<b>Education</b>				<i>p</i> <0.0001
High school or less	104 (31%)	145 (65%)	58 (42%)	57 (66%)
Tech/apprentice/some college	132 (39%)	43 (19%)	51 (37%)	22 (26%)
College grad or higher	103 (30%)	35 (16%)	29 (21%)	7 (8%)
<b>Years since diagnosis</b>				<i>p</i> <0.0001
<1 year	58 (17%)	17 (7%)	38 (28%)	34 (36%)
1-4 years	117 (35%)	32 (13%)	39 (28%)	30 (32%)
5 + years	161 (48%)	197 (80%)	61 (44%)	31 (33%)
<b>Cancer type</b>				<i>p</i> <0.0001
Breast	104 (30%)	99 (40%)	30 (21%)	27 (28%)
Gynecologic	71 (21%)	29 (12%)	13 (9%)	4 (4%)
Gastrointestinal	42 (12%)	12 (5%)	18 (13%)	6 (6%)
Genitourinary	34 (10%)	13 (5%)	12 (8%)	3 (3%)
Lung	8 (2%)	6 (2%)	12 (8%)	3 (3%)
Other	15 (4%)	6 (2%)	8 (6%)	4 (4%)
Multiple	45 (13%)	25 (10%)	31 (22%)	19 (20%)
Unknown	26 (8%)	57 (23%)	18 (13%)	31 (32%)
<b>Continue cancer care*</b>				<i>p</i> <0.0001
Yes	176 (54%)	130 (54%)	105 (77%)	83 (86%)
<b>Degree control cancer</b>				<i>p</i> <0.0001
Good/complete	274 (84%)	220 (91%)	80 (58%)	54 (56%)
Fair	24 (7%)	18 (7%)	31 (23%)	20 (21%)
Little control	5 (2%)	1 (0%)	13 (9%)	9 (9%)
Not at all	23 (7%)	4 (2%)	13 (9%)	13 (14%)

\* Includes treatment, support, and/or follow-up appointments.

**Table 7. Multinomial logistic regression results (RRR and 95% CI).**

Characteristic	Positive QoL	Latent class			p-value (overall)
		Well, overwhelmed	Mildly burdened	Poor QoL	
<b>Gender</b>					0.6478
Female		Ref	Ref	Ref	
Male		0.9 (0.4-1.9)	0.7 (0.4-1.4)	0.7 (0.3-1.5)	
	<i>p-value</i>	<i>0.8488</i>	<i>0.2970</i>	<i>0.3382</i>	
<b>Year of Birth</b>					0.2886
1949 or earlier		Ref	Ref	Ref	
1950-1959		1.5 (0.9-2.5)	1.0 (0.6-1.7)	1.3 (0.6-2.7)	
1960 or later		0.8 (0.4-1.6)	1.1 (0.6-2.2)	1.6 (0.7-3.8)	
	<i>p-value</i>	<i>0.1232</i>	<i>0.8970</i>	<i>0.5156</i>	
<b>Residence</b>					0.0001
City/town/village		Ref	Ref	Ref	
Move back and forth		3.9 (1.6-9.7)	2.7 (1.0-7.4)	8.8 (2.9-26.3)	
On the reservation		3.9 (2.0-7.4)	1.5 (0.8-2.9)	2.6 (1.1-5.8)	
Rural not reservation		1.0 (0.5-2.0)	0.9 (0.5-1.7)	1.0 (0.4-2.8)	
	<i>p-value</i>	<i>0.0001</i>	<i>0.2182</i>	<i>0.0011</i>	
<b>Region</b>	Reference Class				<0.0001
Southern Plains		Ref	Ref	Ref	
Northern Plains		1.0 (0.5-2.0)	1.7 (1.0 -3.1)	4.2 (1.7-10.7)	
Southwest		4.8 (2.4-9.9)	1.8 (0.8-4.0)	10.5 (3.7-30.0)	
	<i>p-value</i>	<i>&lt;0.0001</i>	<i>0.1473</i>	<i>0.0001</i>	
<b>Insurance</b>					0.0745
Private		Ref	Ref	Ref	
IHS/Tribal/Uninsured		0.7 (0.3-1.3)	1.9 (1.0-3.5)	0.5 (0.2-1.3)	
Medicaid/Other public		1.1 (0.6-2.2)	1.2 (0.6-2.7)	1.1 (0.4-2.6)	
Medicare/VA/Tricare		1.6 (0.8-3.2)	1.7 (0.8-3.4)	1.5 (0.6-3.6)	
	<i>p-value</i>	<i>0.1464</i>	<i>0.2442</i>	<i>0.1931</i>	
<b>Work for pay</b>					0.0082
No		Ref	Ref	Ref	
Yes		1.9 (1.1-3.2)	1.0 (0.6-1.6)	0.6 (0.3-1.2)	
	<i>p-value</i>	<i>0.0251</i>	<i>0.8826</i>	<i>0.1180</i>	
<b>Education</b>					0.2362
College grad or higher		Ref	Ref	Ref	
High school or less		2.2 (1.2-4.2)	1.5 (0.8-3.0)	4.5 (1.6-12.7)	
Tech/apprentice/some college		0.9 (0.5-1.6)	1.4 (0.7-2.5)	2.5 (0.9-6.9)	
	<i>p-value</i>	<i>0.0028</i>	<i>0.4152</i>	<i>0.0133</i>	



**Table 7. Multinomial logistic regression results (RRR and 95% CI) (continued).**

Characteristics	Positive QoL	Latent class			p-value (overall)
		Well, overwhelmed	Mildly burdened	Poor QoL	
<b>Years since diagnosis</b>					<0.0001
<1 year		Ref	Ref	Ref	
1-4 years		1.1 (0.5-2.4)	0.7 (0.4-1.3)	0.4 (0.2-0.9)	
5 + years		2.3 (1.1-5.0)	0.8 (0.4-1.6)	0.2 (0.1 -0.5)	
<i>p</i>		<i>0.0170</i>	<i>0.5154</i>	<i>0.0034</i>	
<b>Continue care</b>					0.1068
Yes		1.0 (0.6-1.6)	1.7 (1.0-3.1)	1.8 (0.8-3.9)	
<i>p</i>		<i>0.8801</i>	<i>0.0531</i>	<i>0.1620</i>	
<b>Cancer type</b>					0.0187
Breast		Ref	Ref	Ref	
Gastrointestinal	Reference Class	0.4 (0.17-1.10)	1.8 (0.8-4.0)	0.8 (0.2-2.7)	
Genitourinary		0.5 (0.16-1.61)	2.1 (0.7-5.9)	0.8 (0.2-4.1)	
Gynecologic		0.8 (0.42-1.61)	0.7 (0.3-1.5)	0.4 (0.1-1.5)	
Other		0.4 (0.1-1.6)	1.8 (0.6-5.3)	1.0 (0.2-4.5)	
Lung		1.3 (0.3-5.3)	4.4 (1.4-14.2)	1.5 (0.3-8.1)	
Multiple		0.5 (0.3-1.1)	2.3 (1.2-4.6)	2.1 (0.9-4.8)	
Unknown		1.5 (0.7-3.0)	2.1 (0.9-4.6)	2.7 (1.1-6.4)	
<i>p</i>		<i>0.3770</i>	<i>0.0240</i>	<i>0.3350</i>	
<b>Degree control cancer</b>					<0.0001
Good/complete control		Ref	Ref	Ref	
Not at all		0.9 (0.3-3.0)	2.0 (0.9-4.4)	7.4 (2.6-21.1)	
Little control		0.4 (0.0-3.8)	5.2 (1.7-16.4)	10.2 (2.6-39.4)	
Fair control		1.6 (0.7-3.5)	3.8 (2.0 -7.3)	4.0 (1.7-9.3)	
<i>p</i>		<i>0.5018</i>	<i>0.0001</i>	<i>&lt;0.0001</i>	

## Discussion

The quantitative strand of our mixed methods study sought to explore heterogeneity in QoL among Native American cancer survivors. We identified four classes of survivors with unique QoL profiles including a class of survivors with consistently positive QoL outcomes (*Positive QoL*, 42%), a class of survivors with consistently poor QoL outcomes (*Poor QoL*, 12%), a class of survivors experiencing high stress (*Well, overwhelmed*, 30%), and a class of survivors experiencing moderate limitations, but positive overall QoL (*Mildly burdened*, 17%). Survivor characteristics significantly associated with class membership included geographic area of residence, region of the U.S., years since diagnosis, and perceived control over cancer.

We were encouraged to find that the most prevalent latent class was the *Positive QoL* class and that the *Poor QoL* class was least prevalent. Our findings align with previous research with a subset of survivors from the current study where authors found a similar proportion of survivors reported “good” or “excellent” physical QoL (45%), social QoL (45%), mental/emotional QoL (44%), and spiritual QoL (52%) (Burhansstipanov et al., 2012). Our study expands upon those findings by demonstrating that most survivors report those positive domain specific outcomes simultaneously. Juxtaposing our findings with those of Burhansstipanov et al. (2012) our study exposes important differences between survivors that are masked by limiting investigation of QoL to individual domains.

While we expected to identify classes of survivors at the positive and negative extremes of QoL as found in previous studies among non-Native survivors (Kenzik et al., 2015; Reese et al., 2015), we were surprised to find a relative large class (30% prevalence) of survivors characterized by QoL outcomes nearly identical to the *Positive QoL* class except for near unanimous reports of feeling stressed or overwhelmed since their cancer diagnosis. That nearly all survivors in the *Well, overwhelmed* group are experiencing considerable stress in the absence of other obvious QoL limitations is quite striking. Another 17% of survivors had a moderate probability of reporting poor outcomes across QoL domains, but uniformly reported positive overall physical, mental/emotional, and social QoL (*Mildly burdened* class). Despite survivors in three of the latent classes (*Positive QoL*, *Well, overwhelmed*, and *Mildly burdened*) reporting positive overall QoL in each domain, their unique response patterns on other QoL indicators suggest they have very different support needs. More specifically, interventions to support survivors in the *Positive QoL* class may focus on maintaining positive QoL interventions to support survivors in the *Well, overwhelmed* class could be tailored to focus on alleviating stress

and interventions for survivors in the *Mildly burdened* could be tailored to focus on managing overlapping physical, emotional, and social challenges. What our findings demonstrate is that ignoring individual differences by averaging QoL scores may underestimate support needs of survivors in the *Poor QoL* class and misspecify needs of survivors in the *Well, overwhelmed, Mildly burdened*, and *Positive QoL* classes. We caution health care providers against assuming that survivors who report similar health limitations have similar needs or that the impact of those health limitations on QoL is similar between survivors. When assessing QoL, providers should ask patients questions about health status and health evaluation and get a sense for how those outcomes hang together (Osborne et al., 2012). Additionally, encouraging storytelling among Native patients aligns with cultural modes of communication and may be an effective way for survivors to educate providers about how QoL issues interact across domains to influence QoL and lend providers a more holistic assessment of QoL from the patient's perspective (Hodge, Pasqua, Marquez, & Geishirt-Cantrell, 2002).

Just as cancer incidence and mortality rates vary by geographical region, we also found that where a survivor lived was associated with QoL class membership (White et al., 2014). More specifically, living in the Southwest, on a reservation, or moving back and forth between the reservation and a city/rural area were positively associated with membership in the *Poor QoL* and *Well, overwhelmed* classes holding all other variables constant. One potential explanation for geographical influences on QoL is that geography influences access to cancer care and support (Towne Jr, Smith, & Ory, 2014). Previous research found that some Native cancer patients living in rural areas or on reservations have to travel great distances (over 100 miles one-way) to obtain cancer care (Burhansstipanov, 2005; Burhansstipanov & Hollow, 2001; Doorenbos et al., 2010). A study among Native breast cancer survivors found that experiencing multiple access barriers to care negatively impacted social QoL (Goodwin et al., 2016). We were unable to thoroughly explore associations between distance to care and QoL class membership in our study because of high prevalence of missing data (22% missing data for "travel distance to care"). However, an exploratory analysis using available data (n=654) found near complete overlap between living in the Southwest and having to travel 100+ miles one-way for cancer care among survivors in our study sample (90% of survivors who lived in the Southwest reported having to travel over 100 miles one-way to receive cancer care compared 39% of survivors from the Northern Plains and 18% of survivors from the Southern Plains). Having to travel long distances for care or to obtain needed medication can pose heavy burdens on families who need to secure transportation and lodging, arrange for childcare, or take time off of work to attend health care appointments (Braun

et al., 2002; Burhansstipanov & Hollow, 2001; Doorenbos et al., 2010). It may be that the associations we see between living in the Southwest and membership in the *Poor QoL* and *Well, overwhelmed* classes are confounded by distance to care, which may be the mechanism by which living in the Southwest contributes to poor QoL outcomes including sustained stress. Future research is needed to explore this hypothesis further. One implication of this hypothesis, if it does hold, is that addressing access barriers in ways that maintain survivors' access to social support may be one way to improve the QoL of cancer survivors, including long-term survivors who may continue to travel for follow-up appointments or medications and whose needs may be overlooked.

Consistent with previous research, we found that shorter time since diagnosis was associated with poor QoL (Bours et al., 2016; Burhansstipanov et al., 2010; Weaver et al., 2012). We found evidence of a negative dose-response relationship between time since diagnosis and membership in the *Poor QoL* class. Long-term survivors (5+ years since diagnosis) were 82% less likely to be in the *Poor QoL* class compared to recent survivors (>1 year since diagnosis). In contrast, long-term survivors were two times more likely to be in the *Well, overwhelmed* class compared to recent survivors. One explanation for these findings is that newly diagnosed survivors are more likely to be in active treatment compared to longer-term survivors, which is an especially challenging time in a survivor's cancer journey (Miller, Merry, & Miller, 2008). However, even after adjusting for continuing to receive cancer care, years since diagnosis remained independently associated with membership in the *Poor* and *Well, overwhelmed* classes suggesting that years since diagnosis influences QoL through mechanisms outside of treatment. One proposed explanation is a phenomenon known as "response shift" in which survivors' ratings of QoL increase over time due to changes in the internal standards they use as a reference for evaluating QoL (Carr et al., 2001; Hamidou et al., 2014). Essentially, survivors' perspectives and expectations change over time, thereby moving the baseline for evaluating QoL. Because we only have QoL data from one point in time, our study could not characterize the influence of response shift on our findings, but it is plausible that response shift may partially explain why long-term survivors were least likely to be in the *Poor QoL* class.

We found that perceived degree of control over cancer was strongly associated with class membership. Survivors who perceived having little to no control over their cancer were more likely to be in the *Poor QoL* or *Mildly burdened* classes compared to survivors who reported good to complete control over their cancer. Our findings align with previous research among non-Native cancer survivors demonstrating that perceived control protects against psychological

distress and supports adaptation to illness (Bárez, Blasco, Fernández-Castro, & Viladrich, 2009). While our study reveals an important association between perceived control and QoL class membership, the direction of the association is unclear because of the cross-sectional nature of our data. In other words, we cannot say with certainty whether perceived control is a cause or consequence of being in the *Poor QoL* or *Mildly burdened* classes. The exploratory and quantitative nature of this study precludes us from elucidating mechanisms behind these associations further. However, understanding mechanisms behind these associations are necessary for tailoring interventions to support survivors. Future research studies to qualitatively assess the meaning of control among Native cancer survivors may reveal specific points of intervention to improve survivors' sense of control and thus QoL.

Our study addresses multiple gaps in the literature by adding to the relatively few studies of QoL that are centered in Native cancer experiences and by identifying four previously undescribed classes of survivors with heterogeneous QoL profiles. We demonstrate the feasibility of using LCA to model QoL from a holistic perspective that aligns more closely with Native conceptions of health than traditional methods. Our study also contributes to the literature by identifying multiple avenues for future research. One finding requiring further investigation is why 30% of survivors in our study, specifically long-term survivors living on a reservation and in the Southwest, reported feeling stressed and overwhelmed since their cancer diagnosis, despite reporting no other QoL issues. We propose geographical barriers to care may account for survivors' enduring stress, but stress may also be related to fear or recurrence, which is fairly common among long-term cancer survivors, but for which data were unavailable in the current study (Koch-Gallenkamp et al., 2016; Simard et al., 2013). Reasons for stress may also be entirely unrelated to survivors' cancer diagnosis. For example, a survey among a random sample of enrolled men and women of the Hopi tribe in Arizona found that 20% of those surveyed self-identified as a caregiver and 21% of those caregivers reported difficulty with stress (Cordova et al., 2016). Future studies should include an assessment of fear of recurrence to examine its association with class membership. Researchers could also interview a subset of survivors from the *Well, overwhelmed* class, and for comparison, the other QoL classes, to better understand reasons behind survivors' enduring stress. Qualitative data may be especially helpful for identifying sources of stress that we have not considered in our research.

Another finding requiring further investigation is why survivors in the *Mildly burdened* class reported positive overall physical, mental/emotional, and social QoL, yet had a relatively high probability of reporting poor life satisfaction. These findings raise questions about what life

satisfaction means to survivors in this class. Future qualitative studies might explore how survivors interpret life satisfaction and how that differs from their interpretation of overall measures of QoL. In the absence of qualitative data, our ability to interpret the meaning of our quantitative findings in the context of survivors' very day lives is limited. An explanatory mixed methods study that randomly samples and interviews survivors from each class may be an especially useful approach for gaining contextual understanding of strengths and needs of survivors in each class. The qualitative strand of our mixed methods study begins to fill that gap by generating contextual knowledge about how survivors experience cancer and interpret their experiences to make judgments about their QoL.

### ***Strengths and limitations***

Findings of our research must be interpreted in the context of its strengths and limitations. One limitation is that our data included cross-sectional data from a convenience sample of cancer survivors. Self-selection bias may have resulted in over-estimates of positive QoL outcomes if survivors with poor QoL were less likely to take the survey. We cannot conclude the extent to which results generalize to the broader Native American population. Furthermore, the cross-sectional nature of our data limits interpretation of directionality of associations. As noted above, whether perceived degree of control is a cause of or consequence of membership in the *Poor* or *Mildly burdened* classes is unclear. Understanding directionality is important for intervention design and timing.

Another limitation is that the “classify-analyze” approach we used to characterize associations between descriptive characteristics and class membership ignores uncertainty in classification of individuals to classes. We found that a small number of survivors (n=23, 2.7%) in our analytic sample had posterior probabilities <0.50 for all classes, which indicates high uncertainty in class assignment. Further, Lanza and Rhoades (2013) warn, “In any latent class model, the issue of reification is of great importance. More than with traditional analytic approaches such as regression analysis, with LCA it can be easy to conclude that the set of latent classes identified in an analysis represent the actual types of individuals in the population. Instead, the latent classes provide a useful heuristic for representing heterogeneity across the dimensions included in the model” (p. 166). We believe our use of the classify-analyze approach is acceptable in the context of this descriptive, exploratory study, which was designed to contribute new knowledge to an under-researched field and generate hypotheses for future research, which we achieved.

Our study was an analysis of secondary data that were not collected specifically to answer our research questions. This is relevant to our study because LCA is not designed for use with ordinal data, which is how QoL items were measured in the NACES QoL survey. We dichotomized indicator variables to ease interpretability of results, but in doing so, we may have lost potentially useful information. Additionally, survey items were measured using inconsistent scales (e.g. dichotomous, 4-point, and 5-point scales) that often included a neutral response option that we had to force into a positive or negative outcome for the LCA. We recognize that using different cut points may result in the identification of a different number of latent classes that may be qualitatively different than those we identified in this study. Relatedly, our analysis excluded potential confounders such as age at diagnosis, fear of recurrence, and comorbidities that are known to be associated with QoL (Boyes et al., 2012; Syrowatka et al., 2017; Wu & Harden, 2015). We cannot know for certain what effect their exclusion had on our findings, but readers should take these omissions into consideration when interpreting our results.

It is possible that quantitative differences (i.e. class prevalences) and/or qualitative differences (i.e. number of unique classes) exist between classes defined by age at diagnosis or years since diagnosis for example that we did not explore in our analysis. Future research might run multiple-group LCA and LCA with covariates if sample sizes allow (Collins & Lanza, 2010). Despite limitations of secondary data, our study includes data from the largest data set on QoL among Native Americans that we are aware of and included analysis of the four domains most relevant to understanding QoL among cancer survivors (Ferrell et al., 1995) to uncover meaningful heterogeneity in QoL among Native cancer survivors previously unreported in the literature.

## **Conclusions**

Our study demonstrates the existence of heterogeneity in QoL among Native American cancer survivors by identifying four classes of survivors with unique QoL profiles. We also identify demographic and self-reported clinical factors associated with class membership including geographic area of residence (e.g. urban/rural/reservation), region of the U.S., years since diagnosis, and perceived control over cancer. Our research has important implications for measuring QoL and tailoring interventions to support QoL among Native cancer survivors. One encouraging finding is that the majority (42%) of survivors in our sample reported experiencing positive outcomes across all QoL domains. However, we also identified a relatively large group (30% prevalence) of primarily long-term survivors who reported feeling stressed or overwhelmed

since their cancer diagnosis despite no reports of other QoL issues. Results of our study suggest that it may be of benefit to tailor interventions to unique needs of survivors in different QoL classes. More specifically, ignoring heterogeneity may underestimate needs of survivors experiencing poor outcomes across multiple QoL domains and misspecify needs of survivors in other classes. We demonstrate the value of using LCA to identify meaningful differences in support needs of Native American cancer survivors that honors cultural perspectives of QoL as balance between mind, body, spirit, and environment. As the health care and public health community strive to ameliorate cancer related inequities among diverse Native communities, understanding how needs may differ between individuals will be critical to designing support services that adequately meet those unique needs.



## CHAPTER 5. QUALITATIVE STUDY

### Introduction

Understanding quality of life among Native Americans with a history of cancer is essential to understanding the true burden of cancer in Native communities. Descriptive statistics about cancer incidence, mortality, and survival provide estimates of the number of individuals diagnosed with cancer and length of survival, but are uninformative for estimating the impact of diagnosis on survivors' daily lives, their families, and communities. In 2005, the Institute of Medicine published a report, *From Cancer Patient to Cancer Survivor: Lost in Transition* that elevated awareness of the complex and pervasive ways that cancer and related treatment can impact a person's life even long after treatment ends (Hewitt et al., 2005). Research to investigate quality of life among cancer survivors increased steeply after the year 2000, but few of those studies center on understanding quality of life among under-resourced populations such as Native American populations whose cancer experiences are inextricably linked to the unique historical context in which this population lives (Harrop, Dean, & Paskett, 2011; Warne & Lajimodiere, 2015).

Compared to other racial and ethnic groups in the U.S., Native Americans have the poorest 5-year survival rates for all cancers combined (60%) and are more likely to die from their cancer than patients who identify as White (White et al., 2014). Cancer incidence and death rates vary considerably by cancer type and by Contract Health Service Delivery Area (CHSDA) region. However, incidence and death rates for some cancers such as liver, stomach, kidney, and gallbladder cancer, are consistently higher among Natives compared to White populations across multiple regions (White et al., 2014). Conditions that gave rise to present day cancer disparities including poverty, poor access to cancer care (Goodwin et al., 2016), high rates of obesity and commercial tobacco use, are byproducts of historical injustices enacted against Native Americans by Europeans in the 18<sup>th</sup> Century and the U.S. government in the late 1800s to mid-1900s (Cobb, Espey, & King, 2014; Goodwin et al., 2016; Warne & Lajimodiere, 2015). This includes attempts at genocide and forced removal of Native children from their families to attend boarding schools designed to "Kill the Indian, Save the Man," where many children experienced physical, sexual, and emotional abuse (Warne & Lajimodiere, 2015). A more recent example includes severe underfunding of the Indian Health Service (IHS). A report by the U.S. Commission on Civil Rights (2003) concluded, "The anorexic budget of IHS can only lead one to deduce that less

value is placed on Indian health than that of other populations. If funding levels continue to stagnate, the health status of Native Americans will continue to decline, resulting in even greater needs in the future (p. 49-50).” Any inquiry into the quality of life of Native cancer survivors must be interpreted in the context of this historical backdrop. For more information on how colonialism and structural violence against Natives has shaped present day health disparities and how this context makes it inappropriate to generalize research findings from non-Native communities to Native populations, see Chapter 2.

As a construct, quality of life is determined by an individual’s perception of their experiences and position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (World Health Organization. *WHOQOL: Measuring Quality of Life*). As such, the only person qualified to judge a survivor’s quality of life is the survivor themselves. While health care providers can collect objective information on the presence or absence of treatment side effects or health conditions, they are unqualified to speak to the impact of those conditions on survivors’ daily lives. For these reasons, eliciting Native survivors’ stories about their cancer experiences and their interpretation of those experiences is critical for designing support services that align with survivors’ culture, values, and priorities. Qualitative research methods are uniquely suited for studying quality of life because they capture details and complexity of survivors’ experiences from a patient-centered contextual perspective (Vaismoradi, Turunen, & Bondas, 2013).

Previous qualitative studies to investigate Native survivors’ lived experiences with cancer provide insight into the ways in which culture, values, and context influence survivors cancer experiences and perceptions of quality of life. Findings suggest that contextual factors including reluctance of families to talk about family history of cancer and fatalistic attitudes about cancer in the community and may lead survivors to underestimate their own cancer risk or to suffer from their cancer in isolation (Braun et al., 2002; Eide, 2007). Spirituality, centrality of family and community, Native identity and sense of belonging, connectedness, reciprocity, and harmony describe some of the cultural values and beliefs upon which many Native survivors evaluate their life in the context of their cancer journey (Haozous et al., 2016; Pelusi & Krebs, 2005). When resources and supports do not align with survivors’ culture, values, priorities, or lived realities, it can lead to negative outcomes. Existing research documents multiple quality of life concerns among Native survivors including social isolation (Hodge et al., 2012), unmanaged pain (Burhansstipanov et al., 2010), fear and anxiety around cancer risk to family members (Burhansstipanov, 2005), cancer related fatigue (Hodge et al., 2016b), psychological distress

including depression and feelings of guilt (Hodge et al., 2016b), and financial burdens (Guadagnolo et al., 2011). However, survivors also report positive outcomes from their cancer experience including increased geographical and emotional closeness with family (Braun et al., 2002; Craft et al., 2017), increased gratitude for life, living more fully in the moment (Pelusi & Krebs, 2005), and a refocusing of life priorities (Eide, 2007). One study that compared quality of life between Native and non-Native cancer survivors found that Native survivors had higher scores on measures of spiritual well-being (i.e. hopefulness, life purpose, and positive change after cancer) than non-Native survivors (Burhansstipanov et al., 2012).

A strength of existing qualitative studies is that they contribute to the literature by describing, in detail, a wide range of survivor experiences including those of men (St. Clair, 2005; Tilburt et al., 2014), Native Hawaiians (Braun et al., 2002; Eide, 2007), Natives living in Oklahoma (Craft et al., 2017) and the Pacific Northwest (Haozous et al., 2016), and Native breast cancer survivors (Krebs, 1997). While small sample sizes limit generalizability of findings to the larger population of Native survivors, collectively, the incremental contributions of each study contribute to a deeper understanding of how Natives navigate life after a diagnosis of cancer and how well they are living after diagnosis. The current study adds to existing research by describing Native cancer survivors' experiences navigating life after cancer through the specific lens of advice giving. Research suggests that within cancer support networks, advice giving commonly reflects survivors' personal experiences (Sillence, 2013). This study composes the qualitative strand of a larger convergent parallel mixed methods study to generate a holistic understanding of factors that influence quality of life among Native cancer survivors and how those factors manifest in survivors' daily lives. While the quantitative strand of the mixed methods study (described in Chapter 4) offers insight into patterns and prevalence of quality of life outcomes among a large sample of Native survivors, the current study provides complementary contextual information to deepen understanding of survivors' lived experiences establishing and maintaining a high quality of life after diagnosis.

The purpose of the current study is twofold. Firstly, it is to honor study participants' intentions to help other Native survivors by sharing their cancer stories. By publishing survivors' stories and messages of advice, we hope this paper passes their wisdom forward for the benefit of Native communities. The second purpose is to gain insight into cancer survivors' experiences navigating life after cancer and the resources and strategies survivors found useful for coping and living well after diagnosis. More specifically, this study answers the research questions: 1) What advice and words of wisdom do Native American cancer survivors prioritize in messages to other

survivors? and 2) What do those messages reveal about how survivors interpret and experience QoL after cancer? To our knowledge, this is the first study to explore survivors' experiences through the lens of advice giving. Our study examines messages survivors prioritize when providing advice to other Native survivors as a way of understanding survivors cancer experiences and quality of life. Knowing what matters most to survivors for living well after cancer will help caregivers align supports with survivors' preferences and needs. Finally, results of this study will be integrated with results from the quantitative study to generate a more comprehensive understanding of quality of life among Native American cancer survivors than either method could achieve alone.

## **Methods**

### ***Study design and research approach***

This study uses a qualitative descriptive study design with phenomenological overtones to explore ways in which Native cancer survivors experience quality of life in light of their cancer (Sandelowski, 2000). Phenomenological approaches to research aim to describe the lived experience of individuals and “capture meaning and common features, or essences, of an experience or event” (Starks & Brown Trinidad, 2007, p. 1374). In this study, we are interested in understanding common features of how cancer survivors experience quality of life in light of their cancer diagnosis and how those experiences influence their messages of peer advice. From an epistemological perspective, our analysis follows a realist/essentialist approach that assumes a direct correlation between what survivors say and what they mean in contrast to a constructivist approach that views language as socially constructed and assumes latent meaning behind a participant's words (Braun & Clarke, 2006).

We expect the advice survivors' give to their peers reflects their personal experiences living with and beyond cancer, thus provides a window for exploring what it means to live well after cancer. In this study, we analyze transcripts from semi-structured interviews with a geographically and clinically diverse convenience sample of 52 Native cancer survivors to describe themes of peer-advice and explore ways in which that advice reflects survivors' experiences living a life of quality after diagnosis. Data for this study are secondary data collected by Native American Cancer Research Corporation (NACR) for purposes of informing research and educational programs to support Native cancer survivors (<http://natamcancer.org/>).

### *Data source*

Data for this study are de-identified transcripts from one-on-one semi-structured videotaped interviews conducted by staff at NACR with a convenience sample of Native cancer survivors who volunteered to share their cancer stories with NACR at various cancer education and awareness events around the U.S. between the years 1994 and 2015. Transcripts of interviews with caregivers or survivors who lived outside of the contiguous U.S. were excluded from analysis. Fifty-two interview transcripts were included in analysis. Demographics of interviewees are provided in Table 8. Most survivors in our study sample lived in the Northern Plains (40%), followed by the Southern Plains (27%), Southwest (25%) and Northeast or Northwest (8%) (See Chapter 1, Figure 1 for map of the regions). Just over half (55%) of survivors in our sample were breast cancer survivors, primarily because NACES began as a program for breast cancer survivors only opening up to other cancer types in 1999.

Participants consented to the videotaped interviews and consented to NACR using their interviews for research purposes by signing a release form at the time of their interview. In cases where survivors asked interviewers not to share specific portions of their interview with others, NACR deleted that text from transcripts prior to sharing transcripts with us for this study. Interviews followed a semi-structured format in which survivors were encouraged to share the story of their cancer journey starting with how they found out they had cancer, how they and their family reacted to the news, what their treatment experience was like, what helped them along their cancer journey, and messages of advice for other Native Americans. All interviews were transcribed by NACR staff. Some transcripts included demographic and self-reported clinical information including region of residence, age at diagnosis, type of cancer, cancer recurrence, and years since diagnosis, but collection of this data was inconsistent. Where data were missing for inclusion criteria (region of residence), we contacted NACR and they were able to provide us with the missing information. This research was approved by the Institutional Review Board at the University of Minnesota.

**Table 8. Demographic characteristics of interviewees included in the final study sample (n=52).**

<b>Demographic characteristics</b>	<b>N (%)</b>
<b>Gender</b>	
Female	37 (71%)
Male	15 (29%)
<b>Region</b>	
Northern Plains	21 (40%)
Southern Plains	14 (27%)
Southwest	13 (25%)
Other (Northwest, Northeast)	4 (8%)
<b>Cancer type</b>	
Breast	29 (56%)
Genitourinary	8 (15%)
Gastrointestinal	5 (10%)
Gynecologic	3 (6%)
Hematologic	3 (6%)
Head and Neck	2 (4%)
Lung	2 (4%)

### ***Analysis***

We used thematic analysis strategies to identify themes in survivor interview transcripts related to peer advice and quality of life. Thematic analysis is a method for identifying, analyzing, and reporting patterns (themes) within the data (Braun & Clarke, 2006). We followed an inductive process that allowed the data to drive the themes to answer our research questions. Themes were identified at the semantic level such that themes were based on their surface meaning without attempting to identify and interpret underlying or latent ideas from participant narratives. While we followed the Braun and Clarke (2006) six-step process for conducting thematic analysis, our process was recursive and we moved back and forth between steps as analysis progressed. 1) First, we first familiarized ourselves with the data by actively reading through all transcripts to get a sense for the content and dataset as a whole. During this initial read through, we started noting potential themes and patterns. 2) After reading through all transcripts in their entirety, we assigned initial codes to all sections of text that provided meaningful information related to peer advice and quality of life. 3) Next, we refined those initial codes by combining those that represented similar ideas. 4) We then organized the higher order codes further into themes and created a thematic map to look for relationships between them and combined or split codes where necessary. 5) After identifying tentative themes, we reviewed all codes within a theme to ensure they made sense and fit the theme and then reviewed the entire dataset to determine whether the themes fit together and formed a logical story in the context of

the entire dataset. 6) Final themes were reviewed to ensure internal homogeneity such that codes within a theme hung together in a meaningful way and to ensure external heterogeneity such that themes were distinguishable from each other.

NVivo software for Mac was used to organize, code, and analyze the data (QSR International Pty Ltd. Version 12). To assure research quality, draft interpretations of the data were routinely shared with NACR to verify that our interpretation of themes had face validity based on NACR's knowledge and understanding of cancer in the context of Native communities from their 20+ years of experience working with Native American cancer survivors. After analysis was completed, we also compared our findings with those from a previous qualitative study that analyzed a subset of breast cancer survivors from our same dataset to assess comparability of themes (Krebs, 1997). These processes functioned to ensure findings authentically reflected the meaning and experiences of survivors in the study (Whittemore, Chase, & Mandle, 2001).

## **Findings**

A central theme of navigating life after cancer is balancing multiple responsibilities, which at times may conflict with one another. Upon diagnosis, some survivors struggled to take care of themselves while simultaneously taking care of their family and community. Survivors' stories of what worked well and didn't work well at various stages of their cancer journey illuminate survivors' views of what it means to live a life of quality after a diagnosis of cancer. Survivors' experiences directly informed their messages of advice to other Natives, which are characterized by four overarching themes and two subthemes: Listen to your body, Advocate for yourself (subthemes: Advocate for your personal needs, Advocate for your health care needs), Embrace your culture and spirituality, and Share your story (subthemes: Share to cope, Share for hope).

### ***Listen to your body***

*"We know our bodies better than anybody else, so I guess that's the message. Listen to your body and trust it. Trust what it's telling you...you're out of harmony, out of balance, and it's telling you that you've got to get back into it, so listen to it."*

For many survivors, their first suspicion that something was wrong came from a general feeling of being out of harmony and balance. The body was described as a critical messenger for

alerting survivors of illness including cancer. One survivor described feeling changes in her body “on all levels, not just physically” saying, “there were indicators from me spiritually that I needed a change.” Another survivor knew she was unwell because “my body had just been telling me. It was sending messages to me.” Some survivors described knowing that they had cancer before they were even diagnosed:

*“I knew there was something wrong. The feelings I was getting were like a big void, a void over my heart. And there was no pain, there was no life, it was nothing. It was something that was consuming my entire being. Um, this was what the scary part was, that’s why I knew it was cancer before I was diagnosed.”*

Recognizing the power of their bodies to signal illness, one key message survivors had for other Natives was to listen to your body and trust what it is telling you because it is “going to tell us if something is wrong.” Survivors explained, “we know our bodies better than anybody else” and “know when things aren’t right.” In addition to emphasizing the importance of focusing inward and listening to the body’s messages, survivors stressed listening alone isn’t enough. The second part of this message is to trust your body’s messages enough to act on what it tells you.

Behind survivors’ advice to listen to and trust your body were stories of regret from survivors who did not heed this advice; they then faced challenges from delayed diagnosis and treatment. One survivor reflected, “I don’t pretend nowadays, I brought the cancer on, I knew all the symptoms, I ignored them so completely that when it came full circle my ignorance is what almost killed me.” Another survivor shared,

*“...if we don’t listen to those seven warning signs and by God... I knew they were all there, then we end up with problems that most people don’t recover from, and then recovery has got its price. I lost half of my tongue, all my cheek, a good portion of my neck and shoulder but I survived.”*

Among survivors who neglected to act on their body’s message that something was wrong, many did so out of fear and avoidance. One survivor explained, “many times, Native Americans like myself wait, and wait, thinking, ‘well if I don’t go, it might go away.’” One survivor told a story of finding a lump in her breast when showering, which worried her, but she didn’t want to see a doctor right away “because way, deep down inside I knew, I had a feeling that what they were going to find, so it took like a year to finally go to see a doctor about it.”



In addition to being able to communicate messages of illness, survivors also described the body as a powerful source of healing. One survivor described our bodies as having “a lot of inner strength that we don’t know where it comes from and we probably don’t even think it’s there, but it’s there.” Because the body is a powerful source of healing, survivors encouraged other survivors to “have that inner faith in yourself, let your body help you heal yourself.”

### *Advocate for yourself*

*“Don’t be ashamed to do anything that would help yourself”*

*“There is nothing wrong with asking for help no matter how proud you are.”*

Once diagnosed with cancer, survivors were faced with “now what?” Survivors often described the time period between diagnosis and treatment as overwhelming and stressful. In addition to coping with their own shock, fear, and anxiety from their cancer diagnosis, they also felt responsible for assuaging their family’s concerns and fears. Simultaneous with these social and emotional stressors, survivors were faced with having to make high stakes decisions about treatment under pressures of time and urgency. Survivors relied upon a multitude of resources to help them through these tough times. However, their narratives reveal challenges to accessing resources needed for support and healing. Some challenges were internal struggles between asking for help while wanting to avoid burdening others, at the same time trying to always be “the strong one.” Other challenges revolved around accessing appropriate and timely medical care. Whether it was insisting on further diagnostic testing, following-up with health care providers, asking family for help, or getting second opinions, one consistent message from survivors to other Natives was to be a fierce advocate for yourself in your personal life and in the health care setting. Emphasizing this point, one survivor commented, “The family is your foundation...[but] you have to do your part too. You can’t sit there and wait for somebody to hold your hand the whole time.”

### *Advocate for your personal needs*

Female survivors in particular described tensions between taking care of themselves while simultaneously fulfilling their responsibilities to care for others. One survivor attributed her felt responsibility to care for others to the cultural value of selflessness. She shared, “as a mother and as a woman... somewhere along the line I got the message that my life was for other people, not me. And it's taken me a long time to accept that I need to reverse that a little bit. Because,

culturally, our value system dictates that message of selflessness.” The following excerpt from a female survivor illustrates the importance of taking time to take care of oneself.

*... if I could talk about anything to other cancer survivor[s] that is really important is the importance of grieving. Of taking time to really acknowledge what you've been through. A lot of times people say you have to keep a positive attitude and you have to do all this and you know. Keep a positive outlook and keep championing on. And as Indian women we have tendency to do that...to make sure that everyone is doing well and we're not interfering with them and they're not worrying too much about us. So what happens is we don't process the sadness because there is a loss... there is a loss of innocence when you've had cancer and you need to go through those feelings and process them. That's the only way to go through it...like putting food in Tupperware and you go back in October and you're going, what is this fuzzy stuff?*

Many survivors described feeling responsible to continue being “the strong one” despite their limited capacity to do so in light of their cancer. One survivor explained, “I've always been the backbone and supporter for my family in a number of ways. It was hard for me to sit back and have someone help me. That was not my role. I was always the one helping others.” Not being able to meet the expectations of others left some survivors feeling helpless or that “it would be a sign of weakness if I didn't look perfect, if I didn't sound perfect.” In the following excerpt, another survivor describes feeling invalidated when she tried to raise awareness of her needs.

*“... it was like, even though you tell them that this was going on, they didn't believe you, you know. Or the natural response would be, 'Oh, everything is going to be fine.' You know, 'Don't worry, everything will be fine, you're strong.' And everybody has always naturally associated me [with] that, you know, me with that strength that I could endure everything. And I didn't know... I didn't know what to do at this point.”*

Trying to take care of themselves in light of expectations to continue caring for others and staying strong made it difficult for survivors to ask for help and allow others to care for them. One survivor described it as being a “very, very uncomfortable position when you have to start taking care of yourself.” Another survivor shared, “The hardest thing for me...that I really needed help with...was letting people support me emotionally.”

Sometimes putting the needs of others first came at a cost to survivors. For example, one survivor delayed pursuing medical care for her cancer for one year so she could attend to the medical needs of her loved one first. She explained,

*“...because of family problems, dealing with my father’s illness and so forth and I had a nephew who was going through cancer that I put my illness on the back burner. I didn’t really do anything about it ‘til I would say the end of 1988, then I went to see a doctor.”*

Many survivors talked about how difficult it was to see family worry about them or to interrupt their lives to support them. Having cancer was described as being “harder on your family than it is on yourself” because “they have to sit and watch you go through all this.” One survivor explained, “it is tough to take when someone breaks down...It kind of makes you feel bad not because you’re hurt or anything.” Another survivor shared, “I felt worse for the people around me. Because I knew I could pass away. I could be gone with all of this and they had to continue to live.”

Some survivors reconciled their dual responsibilities to self and others by reasoning that taking care of themselves was a means of taking care of others. One survivor explained that it was important for him to take care of his emotional health by processing his feelings because, “...your family will see you doing that and then you can help them do that. Because they’re going to have the perception that they need to be there and do things for you, when in essence, you need to be there and do things for them.”

Underneath survivors’ advice to advocate for one’s needs, was an understanding that advocacy begins with believing you will survive. As one survivor stated, “we live on hope.” Survivors stressed that maintaining a positive attitude and determination to fight the cancer is critical because “if you don’t fight you’re not going to win.” One survivor affirmed, “...that is probably the most important thing is never ever give up.” Self-pity was described as something that “weakens you” and to be avoided at all costs. As such, survivors stressed to caregivers not to pity their loved ones. One survivor explained, “you want to be sympathetic with them, but show your respect of what they do for themselves...I have come a long way, and I’m very thankful that I was able to be able to help myself...you’ve got to help these people to help themselves, if they don’t...if they give up, there’s no way they could last too long.”

*Advocate for your health care needs*

All survivors pursued treatment for their cancer. Drawing upon their positive and negative experiences interacting with the health care system, survivors emphasized the importance of taking someone with you to the doctor, asking questions, and getting second opinions.

Survivors had varying levels of knowledge about cancer before their own diagnosis. Especially among survivors who had little previous knowledge about cancer, the time after diagnosis was an overwhelming period of information overload as they learned about their cancer, treatment options, and prognosis. One survivor explained, “There are so many different aspects of your care that are being addressed in an office visit and you are quite distracted emotionally... and really overwhelmed about the amount of information that [you are] getting. And you can't digest all of that in such a short period of time.” The time after diagnosis was described as moving so quickly that survivors sometimes had to make high-stakes decisions with little time and incomplete information. One survivor commented,

*“I think at first there is always this urgency, because once you find out you have cancer it seems like within hours you're into something else I mean the doctors don't wait; they don't say think about it for two weeks. I mean it's a matter of hours or days. I think that's one thing that I found unusual...I had to make these decisions fairly quick...”*

Knowledge was seen as a resource for communicating effectively with health care providers, calming fears about treatment, and easing stress of decision-making. One survivor described,

*“I realize what I needed to do was educate myself and figure out exactly... what exactly I was up against so I could formulate my battle plan. I armed myself with as much knowledge as I could find on the Internet [and] talked with cancer survivors. I really tried to get a hold on it and look at it from all different angles and aspects. And once I realized what I was up against it was much easier for me to tackle it.”*

Recognizing the challenges of digesting and processing the onslaught of information many survivors received after diagnosis, one recommendation survivors had for other survivors was to take someone with you to the doctor. Some survivors took family members with them to

the doctor and found that to be a valuable way for their families to support them. One survivor shared her experience taking her niece with her to doctor appointments saying,

*“...she could listen to everything [the doctor] had to say and then I didn't have to think about it all and I think that does help, to have someone with you when you're going in and the doctors talking to you because you're not always cognizant of everything that's going on and they can ask questions and they can remember, especially if they're a lot younger than you are. So that really did help.”*

Another survivor shared,

*“I was lucky I had family that... mainly a younger brother...that stood right next to me. And questions that I was too shy to ask or maybe afraid to ask, he'd come right out and ask the doctor, 'Why does my brother have to do this?' So...bring that relative and friend or whoever with you. Because they can get a lot of answers [to questions] that you might be unsure of asking.”*

Many survivors emphasized the importance of asking questions and encouraged other survivors “don't be afraid” to ask questions and to “go ahead and complain! It's okay to complain.” Behind some survivors' advice to ask questions was gratitude for having had positive experiences communicating with health care providers who were patient, empathetic, and open to requests for information. One survivor appreciated that her doctors included her whole family in her medical consult and “explained everything to us to the point where we could understand everything.” However, for other survivors, their advice to ask questions stemmed from regret for not having advocated more strongly for care they needed. One survivor shared a story of going in for a mammogram “and the next thing I knew was... I had an appointment with the surgeon and nobody told me why.” She had a consult with a surgeon about doing a biopsy, but the surgeon wasn't available to do the biopsy for another six weeks. The survivor went on to explain, *“I was just very disappointed that I had to wait six weeks for a biopsy, but it was like I had nothing to do but wait. So I went back home and waited and it was a very stressful six weeks for me to wait. I planted lots of flowers on my porch and that was comforting and waited out the six weeks. Well, the day of my scheduled surgery for the biopsy, my two daughters and I went to the hospital where the biopsy was to be done and were told, 'Oh! Didn't anybody tell you that was cancelled?' And I just broke down and cried. I was so upset...”*

At the conclusion of her interview, she shared “my only regret is that I didn’t ask questions. I wished I would have asked questions and insisted that...that I, not wait for six weeks to have [the biopsy].”

Experiences of missed or mis-diagnosis were not common, but when they did happen, were frustrating and disappointing. Survivors who experienced delays in diagnosis or treatment because of mistakes or imperfections of the health care system highly encouraged other survivors to get second opinions. Reflecting on her delayed diagnosis after doctors took a “wait and see” approach” after discovering a small spot on her mammogram, one survivor said,

*“I think if I had been more insistent, saying, well I really think I ought to have a second opinion on this...I'm not sure I would have saved myself a whole lot... I would have probably gone through the same procedures of surgery and this way I did not have to have my breast removed. But if they caught the cancer maybe a little bit earlier, maybe I wouldn't have had the lymph glands removed. I don't know. But I do think that a second opinion would have helped at that time.”*

Another survivor was devastated after hearing from one doctor that his cancer was “cured” only to find multiple tumors on a subsequent MRI. The survivor described, “I did everything I could to keep from blowing up right there on that spot. And I said, ‘Number one, you're fired; number two, I want a second opinion.’” His experience directly influenced his advice to other survivors:

*“I strongly, strongly encourage you to get copies of your paperwork and get to know your family doctor. Ask him to explain it to you if you don't understand it. If you have the Internet look it up. Find out all you can about your own situation and don't take for granted what these doctors tell you. Especially if they tell you you're cured, you know. Maybe they have got you cured...I'm not saying...don't doubt all of them.”*

What is clear from survivors’ narratives is the important role that education played in facilitating survivors’ ability to advocate for their health care needs. In some cases survivors were medical professionals who had ready access to knowledge and people through their jobs. In other cases, survivors relied on their children to do the research or other family or friends who were educated and could more easily navigate insurance and health care issues.

### ***Embrace your culture and spirituality***

*“Be interested in what you do with your people and for your people”*

*“Don’t forget your Creator”*

Feeling connected to Indian people and culture was a source of strength and grounding for many survivors. Survivors described the importance “keep[ing] your roots with your people, to learn who you are and where you come from.” Some survivors, who felt disconnected from Indian people and culture prior to their cancer diagnosis, returned to the reservation or took steps to learn about and participate in cultural ceremonies after their cancer diagnosis. One survivor described reconnecting to her tribe after her cancer diagnosis saying, “I truly got a sense of real understanding...of my not being alone, of being centered and of being able to focus on the power outside of myself, and what that really meant.” Another survivor described his experience reconnecting to culture after his diagnosis where he was sitting in a sweat lodge with other people and how “All of the sudden I didn’t feel so all alone.”

The importance of being connected to and belonging to one’s Indian community was sometimes only recognized in hindsight. For example, one survivor shared,

*“I didn't realize that I made a big mistake moving away from [the tribe]. Now that I'm grown, I understand now, that I made a big mistake. I missed out on a lot of things; I missed out on a lot of things; here in the [tribe].”*

Another survivor reflected on how it took a long time for her to be able to process the feelings she’s had about her cancer, but now, “I’m around other Indian women. And that’s been a very important missing ingredient in my life is being with my own...”

Nearly all survivors reflected on the prominence of spirituality as a source of hope and comfort during all stages of their cancer journey. Having faith that the Creator was in control and had a purpose for everything gave survivors hope, helped to mentally accept their disease, eased their fears and worries, and allowed survivors to enjoy life, have gratitude, and see positive benefits in difficult times. Survivors talked about how no one can tell them how long they will live because “there’s only one person that can tell you and that is your Creator. He’s the one that chooses when you leave.” Furthermore, many survivors described being brought up to believe that there is purpose for everything, “even if it’s the purpose to serve in cancer research with what happens with your body, there is still a purpose.” For one survivor it meant, “I had to celebrate the cancer too, because it was there for a reason, and I had to learn something.”

Another survivor shared, “I was so privileged, I guess it's a bad thing to say, privilege to having cancer. It just helped me a lot to reach out to others and not be centered on myself.” Turning their lives over the Creator and embracing that there was a purpose to their cancer experience, alleviated survivors’ fears and worries. One survivor explained, “If we are really being true to our cultural beliefs and our spirituality, then there's no fear. Because we are being taken care of so it doesn't matter.”

Putting one’s trust in the Creator and embracing life as a precious “one-time gift given to us by a higher power,” allowed survivors to reframe ostensibly negative experiences through a positive lens of gratitude. One survivor shared,

*“I have um a dry mouth from the chemo, and I have diabetes now. And I have always said that I believe it was medically induced from my bone marrow transplant; but it's a small side effect to live with. I am losing my teeth but that is a material thing I can live with. Lucky I am still here and God still has a purpose for me.”*

The following excerpt exemplifies how their trust in the Creator allowed survivors to make meaning of their cancer experience and let go of their worries.

*“If you are at a spot spiritually that you believe that there is a greater power out there that is commanding your life and you give it up to that and say, you know, ‘I let go and let Lord, let God,’ let that take care of you. That's what I found myself doing. I put the pieces of the puzzle together. I didn't go to South Dakota for nothing. I went down there to be instructed that I was getting ready for a big challenge. Then to find that there is this doctor who is an ethnic person, very sensitive to Native cultures, that is fine to me. That was another indication that I was being taken care of and then to have this drug, this miraculous drug, Taxol, coming from the bark of the yew tree coming from the earth. I mean, what could be more solid. You know, I'm being taken care of. I need to sit back here, and let this work.”*

Survivors emphasized the limitations of western medicine, which narrowly focuses on treating the body while neglecting the spirit and brain. This narrow approach to healing does not align with a Native perspective of health, which one survivor described as a “holistic or whole body point of view” and as being in “balance” and “harmony.” Survivors talked about how



healing from cancer meant having to “live both ways” by embracing western medicine and traditional healing strategies. This idea of living both ways is exemplified by the following quote,

*“Personally, I found that what worked for me was to be able to have a foot in both worlds, you know, the dominant society. What do I have access to here? The best of modern technology. What is my foundation on this other side? It's who I am as an Indian person and what I know best. What has taken care of me? My relationship with the earth, with the spirituality, with the Creator. And so, I kind of said I am going to use the best of both in surviving this and that's what kept me sane, kept me motivated, kept me centered, and just kind of, you know, carried me through it.”*

Another survivor shared the following story explaining why western medicine is not enough for healing from cancer.

*“When you walked into the doctor's office and he told you he's going to take something out of you, you can darn well bet he took part of your spirit with you. It was like a gasp of air that rushed out of me, I felt the hole that he shot in me. And then I went to six or seven doctors and they all shot me full of holes, too. The spiritual part of closing those wounds is as important as the physical part.”*

This survivor further explained that without spirit therapy, “You never fully recover because you're always in pain, you always feel that there's part of you life being left out, just like that part that got ripped out of your body or that got killed by the therapies that you have to go to.”

### ***Share your story***

*“...put focus on other people who could use your help and your experience and show them what you went through. And you're living, breathing, and walking proof that you will survive.”*

*“I had something to offer at this point, hope for other people.”*

At the heart of all survivors' interviews was a desire to help other Natives by sharing their cancer stories. Sharing their cancer stories was a way of sharing hope. For some survivors, meeting other Natives who were surviving and thriving after cancer was a turning point in their

cancer journey. Sharing their cancer stories served two primary purposes for coping with their own illness and for inspiring hope among other Natives.

### *Share to cope*

Feeling understood by family and friends was important to survivors' quality of life. When asked about what helped them during their cancer journey, many survivors credited their families for providing the encouragement, strength, and courage they needed to survive their cancer. Feeling included, accepted, and understood by family and their Native community was an important benchmark by which survivors evaluated their quality of life. Talking with others about how they were feeling was one way of getting empathy and social support survivors needed to help cope with their illness.

When survivors felt that their family and friends did not understand what they were going through, they felt unable to open up and talk about how they were feeling. One survivor described the challenge of trying to convey her feelings to her family saying, "I couldn't verbalize it. I couldn't tell them how much this was hurting me. Even though it wasn't any direct pain, it was the pain inside that was hurting my spirit." Another survivor described feeling frustrated that community members did not understand her need to rest because of chemo-related fatigue. She explained, "People in our culture get very offended. 'We went to see [name] and she wouldn't even open up the door to let us in.'"

For many survivors, feeling understood by others opened the door for them to talk about and process their emotions and cope with their illness. One survivor explained, "You cannot do this alone and you have to have someone there that you can talk to and relate to." For many survivors, connecting with other cancer survivors gave them the most solace and support. One survivor explained, "...you can almost cling to another person that's gone through it." Another survivor said that the doctors "can only try to heal the diagnosis. You can only heal your heart."

One survivor described how connecting with another survivor was a turning point for her. She told a story of how she went to talk to someone about her depression and,

*"...when I sat down I noticed this, ah, I can't say that word. This breast form lying on the table and I looked at it. And then she...by that time she seen it and turned around and said, 'oh I'm sorry' ... and she picked it up. And I was happy. I knew...I knew I shouldn't have felt that way because I was happy because there was somebody else besides me. So I told her, I said 'I wear one of those too.' And*

*she looked at me and said 'since when?' So I said, 'February.' So she came around the table and she hugged me and she said, 'I knew there was something wrong' she said 'you weren't yourself.' So we cried and we talked about everything and it was a big help to me. From there, I think, I started to get well."*

Some survivors established friendships with other cancer patients in treatment waiting rooms, which was a source of valuable social support.

*"It was kind of nice having other people in the room, going through a treatment. You would think that you would want to go the route of being alone. But actually, having other people in the treatment room with you, with IV's in their arms, there was kind of a connection there."*

Attending cancer support groups was another valuable source of support for survivors. One survivor described a particular benefit of support groups saying, "It is important that you are aware that you are not alone, that different health issues and different cancers are happening and they are going through the same things." Survivors who held their feelings and stories inside reflected on the negative consequences of doing so. For example, one long-term survivor reflected on her cancer journey saying, "I was going through depression work shops and all of a sudden I didn't feel depressed no more... The cancer was five years in remission at this point and I was so close to being pronounced cured that I needed some aspects for all that pain to be released that I'd been keeping for years."

One survivor lived by the advice she received from her doctor who suggested that "if you become discouraged just encourage somebody." In addition to helping survivors process their own emotions and cope with their own cancer, sharing their cancer stories with others was a way of inspiring hope and inspiration among other Natives.

### *Share for hope*

For many survivors, bearing witness to other Natives surviving and even thriving after cancer was so powerful for inspiring hope that it became imperative for them to talk about their experience with others. One survivor shared, "...my goal [is] to show Native women that you can survive breast cancer...that you can survive a cancer... and that's my whole goal in life." Through their stories of survival, survivors spread the message to other Natives that "you are not beat just because you are diagnosed."

One reason for needing hope is that for many survivors, receiving a diagnosis of cancer felt like “a death sentence.” One survivor shared, “When I first heard I had cancer, the first thing that popped into my mind was dying, and I didn’t want to die because I enjoy life.” The belief that cancer equated to certain death made even the word “cancer” something to be feared or talked around by calling it something else like, “The Big C.” Survivors described the word cancer as “a heavy word...a foreboded word,” and “one of the dirtiest words you can say to each other, especially in a medical setting.” Oftentimes, survivors associated cancer with death because they witnessed someone close to them who had died from cancer. One survivor shared how upon receiving her diagnosis, “[The] only thing I could think about was dying because I had seen two of my aunts pretty much die right in front of me because of cancer.” Another shared, “I’m being told that I’m next to die. Because I [saw] what cancer had done to my stepfather.”

While witnessing others die from cancer served to justify survivors’ fears of cancer being a death sentence, witnessing others survive cancer provided hope for survival and inspiration for living. One survivor reflected on how being introduced to other cancer survivors was a turning point for her. She described how after her diagnosis, her fear was so intense that she couldn’t remember things, couldn’t sleep, and wasn’t herself anymore. A psychiatrist finally prescribed anti-depressants and sleeping pills, which she tried for several months, but saw no improvement in her symptoms. She shared the following story of attending a cancer support group for the first time:

*“When I got there I saw about fifteen to twenty people in the room. I looked around and saw that everybody was sitting in a circle. When the meeting started, each one introduced themselves, [shared] what they had gone through with the cancer, and how long they had been survivors. It was anywhere from one to forty years. I looked around and said, ‘They’re all survivors? If they can do it, I can do it!’ And from that time on, my life has changed. I thank [name] and her support group for that. My life has turned around. It’s going up-hill, not down-hill.”*

The power of survivors’ stories to provide hope to others was validated by survivors’ own experiences of being inspired by other survivors and by witnessing the effect that their survival stories had on others. Survivors encouraged everyone to share their stories because, “it may seem like it doesn’t help a lot of people, but it does.” Some survivors viewed it as their responsibility to share their cancer story and that “as Indian people, we need to let each other

know that it's there, and that we can offer them so many more things than our relatives and our ancestors had." Another survivor described the importance of staying strong for her daughters saying, "When I was diagnosed with [cancer] rather than curl up into the fetal position that I really wanted to curl up into, I didn't. I remained strong for my daughters. I had to kind of give them a blueprint so to speak to go by if they should ever face breast cancer in their life."

Some survivors drew a connection between their cancer experiences and their life purpose. One survivor shared, "You know, one of my greatest things is I survived for a reason...I have a purpose and I want to say it is for my grandbabies to watch them grow, but I think it's also to spread that Native people can survive." Another survivor concluded, "The sooner we get used to the fact that there are survivors, there are ways to get through it and that you don't give up hope, there will be more hope for other individuals."

Notably, not all survivors found value in talking about their cancer experience with others. Some survivors chose not to talk about their cancer because they did not want to be pitied or they perceived their cancer as something in the past and just wanted to move on. Describing her decision not to talk about her cancer with family, one survivor said, "I mean we live together and we ate together and everything but we just never talked about it, it just happened to us and we just went on with our lives. We just never talked about it." When asked whether her avoidance of topic with family was due to family or cultural reasons, she explained, "It's probably just our family...cause we didn't pity each other or anything. We just expected each other to get through with what we we're going through..."

### ***Summary of themes***

All survivors in this study volunteered to share their cancer stories with NACR for the purpose of educating and supporting other Natives facing a diagnosis of cancer. Our analysis of their narratives revealed four overarching themes of advice survivors prioritized for their peers. The first theme, *Listen to your body*, encourages Natives to recognize and trust the power of their bodies to alert them when they are out of balance. This advice often reflected survivors' personal experiences of becoming aware of their own illness and the consequences they experienced from having acted or not acted on those messages. The second theme, *Advocate for yourself*, describes the imperative for survivors to take an active role in their care and healing in their personal life and in the health care setting. This advice often stemmed from survivors' experiences trying to balance dual responsibilities of caring for themselves and their families. The third theme, *Embrace your culture and spirituality*, encourages Natives to embrace their cultural strengths and

spirituality as powerful sources of healing. Nearly all survivors in our study drew upon spirituality and strength derived from their Native identity and culture as critical sources of healing. The final theme, *Share your story*, encourages survivors to share their cancer story with others as a strategy for self-healing and inspiring hope among other Natives that cancer is survivable. This advice often arose from survivors' experiences meeting other survivors and the powerful affect those encounters had on motivating survivors to fight and survive. While we have described these four themes independently, it is important to note that they often overlapped and interacted with each other within survivor narratives.

## **Discussion**

This study sought to describe Native cancer survivors' messages of advice to other survivors and to explore ways in which that advice reflected survivors' own cancer experiences and quality of life after diagnosis. Our study reinforces findings from previous research highlighting the central reinforcing roles that spirituality, family, community and survivors themselves play in maintaining a positive quality of life after a diagnosis of cancer. The four overarching themes of advice that survivors prioritized for other survivors included: Listen to your body, Advocate for yourself, Embrace your culture and spirituality, and Share your story. We found that the advice survivors offered to other Native survivors for coping with and healing from cancer was deeply grounded in their personal cancer experiences and quality of life outcomes.

Among survivors in our study, living well after cancer required managing multiple and sometimes competing responsibilities to self, family, and community. Survivors felt a personal responsibility to take care of themselves by being in tune with their body and taking action to address concerns when their body signaled they were out of balance. However, for some survivors, prioritizing self-care conflicted with cultural values of selflessness. The struggle to balance dual responsibilities to self and family has been reported in previous research among Native survivors (Braun et al., 2002; Pelusi & Krebs, 2005). One study of Native women in the Northern Plains found that many women expressed reluctance to put their own needs ahead of their families' (Becker et al., 2006). Our study reinforced this finding by demonstrating that even with a disease like cancer in which early treatment is critical, attending to the needs of family may supersede survivors' personal health needs. However, de-prioritizing their own needs had some real consequences for survivors in our study including delayed diagnosis and personal distress from later regret. In contrast, other survivors did not perceive their responsibility to take

care of themselves to be in conflict with their responsibilities to others. For some survivors, taking care of themselves and staying alive *was* their way of taking care of others, which is a finding echoed in previous research (Becker et al., 2006; Braun et al., 2002). We concur with Braun et al. (2002) that emphasizing this framing may be a useful way to encourage Native survivors to take whatever actions are needed to stay strong and well. Health care providers should be mindful of the influence that family and community may have on patient decision-making, especially among patients from collectivist cultures such as Native American communities. Supporting their patients may include collaborating with community organizations to extend support to family members if necessary.

The theme of listening to your body and trusting it when it tells you that you are unwell corresponds with previous research among Native Hawaiians in which survivors reported the ability to intuit their cancer (Braun et al., 2002). One challenge survivors in our study ran into when acting on those messages is that when follow-up tests failed to identify a problem, it was on survivors to convince their health care providers to continue testing. That survivors emphasized advocacy in their messages of peer advice in our study is not surprising given its prominence as a theme in existing literature among Native survivors. In a study among cancer survivors in the Pacific Northwest, Haozous et al. (2016) survivors reported having to be “aggressive” in their advocacy. In Pelusi and Krebs (2005), survivors emphasize the need to be an active participant and “vigilant” about their health and not wait for someone else to tell them what to do. Our research highlights many ways in which health care systems, community organizations, and caregivers can support Native survivors advocacy efforts including encouraging and supporting second opinions, providing culturally relevant and easy to understand educational materials, attending medical appointments with survivors, and trusting that survivors’ know their bodies best.

Nearly all survivors expressed feelings of deep responsibility to share their cancer stories with others to help Native communities, which is not unexpected given the context in which their interviews were conducted. Responsibility to the collective was described as part of what it means to be Native. Our finding that survivors felt compelled to use their experience to help other survivors is consistent with previous research in which survivors described their cancer experience as a gift they could give to their communities (Braun et al., 2002; Pelusi & Krebs, 2005) committing themselves to using their cancer experience in any way that would positively benefit the Native community (Ka ‘opua et al., 2008). Despite the community benefit of sharing one’s cancer story, some survivors elected not to talk about their cancer experience. Aligning

with previous research, we found that some survivors avoided talking about their cancer experience because they didn't want to burden others with additional hardship (Haozous et al., 2011; Hodge et al., 2016a). Other reasons for "not talking about it" included not wanting to be pitied and not wanting to dwell on cancer because it was a thing of the past. It may be that survivors are more willing to share their cancer stories as they enter long-term survivorship because even survivors in our study who said they didn't talk about their cancer volunteered to participate in a video interview. Moreover, fear of burdening others and fear of being pitied are perhaps more relevant during the difficult period of diagnosis and treatment. However, staying silent unintentionally supports a prevalent narrative in some Native communities that cancer means death and may inhibit screening and early detection when people are ignorant of their cancer risk (Eide, 2007). Our findings suggest that providing opportunities for Native survivors to share their cancer stories may support healing and serve as a powerful way of inspiring hope among Native cancer survivors and their communities. An example of how this could be done is posting videos trusted websites of Natives telling their cancer stories as was done with video interviews included in this study (<http://natamcancer.org/vignettes/vignettes.html>).

In concordance with previous research, finding strength in one's spirituality and Native identity and traditions were critical to survivors' cancer journeys. Native culture and spirituality framed survivors' orientations to illness and healing and helped survivors to cope with their illness. Previous research also reports that culture provides a source of "grounding" among Native survivors and that being Native means being connected to each other no matter where or how you live (Eide, 2007; Pelusi & Krebs, 2005). That connectedness provides survivors with a sense of comfort and makes the cancer journey easier. In our study, some survivors who were disconnected with their Native culture prior to diagnosis, made efforts to reconnect with their culture through learning, attending ceremony, and even moving from the city back to the reservation to reconnect with people and place. Many survivors in our study emphasized the importance of "living both ways" by embracing both traditional modes of healing and western medicine because western medicine alone was insufficient for healing the whole self (physical, mental/emotional, social, spiritual domains of wellness). Implications of these findings are that circumstances that prevent survivors from readily accessing family, community, spiritual, and cultural resources – for example, having to travel long distances to receive cancer care – can have especially devastating effects on a survivors' quality of life (Haozous et al., 2016). Interventions to support Native survivors should integrate spirituality and prioritize activities that maintain survivors connections to family, culture, and community. That might mean broadening the scope



of support services to include family members. Existing interventions that model these practices include spiritual care programs in oncology centers (Witte, Begay, & Coe, 2010) and Native patient navigator programs (Guadagnolo et al., 2011; Harjo, Burhansstipanov, & Lindstrom, 2014).

### ***Strengths and limitations***

Interpreting findings from this research requires careful consideration of study strengths and limitations. One limitation is that data for this study were from a convenience sample of Native cancer survivors who volunteered to share their cancer stories with NACR. This may have biased findings toward positive cancer experiences since we did not hear from survivors who were unmotivated to share their stories or were not well enough to attend community events. However, learning from survivors who are motivated and thriving after cancer provides an opportunity to learn from “positive deviance” and identify contexts and strategies that supported these survivors to thrive despite a difficult diagnosis of cancer (Marsh, Schroeder, Dearden, Sternin, & Sternin, 2004). One of the strengths of this study is its inclusion of a large geographically diverse sample of Native survivors of diverse cancers. The demographic and clinical diversity of our study sample offered an opportunity to capture a wide spectrum of survivor perspectives.

Another limitation of this study is that data were secondary data not collected for the purpose of answering our second research question. While interviews were designed to solicit advice, they were not structured to probe survivors about why they prioritized the advice they did or how following or not following their advice influenced their quality of life. Furthermore, qualitative analysis relies on theoretical sampling and conducting and transcribing interviews is an important part of data analysis. This study did not engage in theoretical sampling and the lead author did not participate in the interview or transcription process, which may have compromised research quality. As an example of how this affected analysis and reporting, where transcripts included participant utterances or the punctuation was unclear, we omitted those utterances and clarified punctuation when we reported direct quotes for the sake of clarity. While we were cautious with these edits, it is possible that they may have changed the meaning or essence of what the participant was trying to communicate. However, results of this study are comparable to a previous study that explored Native breast cancer survivors’ experience surviving cancer that analyzed interview transcripts from a subsample of breast cancer survivors included in the current study (Krebs, 1997). We identified multiple overlapping themes between our study and Krebs

(1997), which validates the quality of our interpretive analysis and study findings. Finally, in qualitative research, the researcher is the instrument for analysis (Starks, 2007), which means analysis is inherently influenced by the researcher's life experience and biases. My experience as a non-Native person of color inevitably influenced my analysis and interpretation of the data for this study. Readers are encouraged to consider my position as an outsider working with, but not of the Native community when reviewing results and my interpretation of those results as presented in this manuscript.

## **Conclusions**

This study contributes to the sparse literature on quality of life among Native American cancer survivors by demonstrating the ways in which cancer survivors integrate lessons learned from their own cancer experience into advice they prioritize for other survivors. Survivors' advice to their peers was distilled into four overarching themes: listen to your body, advocate for yourself, embrace your culture and spirituality, and share your story. A deeper look into the origins of those messages revealed challenges survivors face balancing responsibilities to care for themselves while simultaneously embracing cultural values of selflessness. When survivors were able to frame their need to take care of themselves as a direct means of caring of their families and community, it ameliorated that tension and survivors were able to embrace their close connections to family, culture, and spirituality as resources for healing. Future research might explore barriers and facilitators of adhering to the advice described in this study and ways in which adhering to that advice influences survivors' quality of life. This study exemplifies the strengths of qualitative research in that it generated rich descriptions of how survivors navigated life after cancer and how their values, cultural beliefs, and expectations influenced interpretation of their cancer experience. However, it does not provide information about how themes relate to and interact with each other to influence quality of life outcomes at the population level. Future research might include quantitative studies to investigate how themes from this research influence quality of life outcomes at the population level – information needed by public health officials to prioritize resources and supports.

Our findings have implications for the way caregivers and researchers assess quality of life and support needs of Native cancer patients. When working with Native patients to understand their support needs, providers should ask questions to understand survivors' values and priorities, as this information may be more informative for prioritizing supports than information on health status or symptoms alone. It may be that supporting survivors' spiritual

needs or family needs may take precedence over their physical needs. Interviewing patients or administering quality of life questionnaires that incorporate themes from this study including spirituality, cultural expectations, competing priorities, and advocacy skills will help caregivers prioritize supports most meaningful to survivors.

Our findings also have implications for supporting cancer survivors on their journey to healing. Strategies supported by our research, which align with previous studies, include providing opportunities for survivors to share their cancer story with other Native survivors (Kaur, 1996), attending to spirituality in all aspects of support (Ka 'opua et al., 2008), and supporting self-advocacy by providing survivors and their families with knowledge, tools, and supports to advocate for their personal and health care needs (Haozous et al., 2016; Hodge et al., 2016b). From a public health perspective, our findings demonstrate the need to direct resources to improving social determinants of health including transportation, education, employment, and access to culturally safe institutions. Our research describes multiple strengths and resources that exist in Native communities including a strong sense of identity and belonging, spirituality, family and community connectedness, and collective responsibility to care for each other. Population-level interventions that target social determinants of health, especially those developed as collaborations between Native communities and researchers and practitioners, may foster environments that make it easier for communities to bolster their strengths in ways that support cancer survivors (Burhansstipanov et al., 2005; Hardy, Bohan, & Trotter, 2013). For example, improving education in the community supports patient advocacy, reducing transportation barriers reduces burdens on survivors and families when accessing care out of town, and improving access to culturally congruent institutions ensures that all supports and services align with survivor culture and values and support the whole survivor to optimize quality of life.

## **CHAPTER 6. INTEGRATED INTERPRETATION AND DISCUSSION**

### **Introduction**

This chapter describes findings from integrating and interpreting results from the quantitative (Chapter 4) and qualitative (Chapter 5) strands of this mixed methods study. The purpose of combining methods in this study was to provide a more complete understanding of QoL among Native American cancer survivors than either method could provide alone. More specifically, we integrated findings from the quantitative and qualitative studies to answer our mixed methods research question: What factors influence QoL among Native American cancer survivors and how?

### **Methods**

In a convergent parallel mixed methods design, data integration occurs at the level of interpretation (See Chapter 3, Figure 4). In this study, we followed a process of data triangulation to integrate and interpret quantitative and qualitative data at the interpretation level (Farmer et al., 2006b). First, we created a list of findings from the quantitative study (i.e. latent classes and characteristics significantly associated with QoL) and a list of findings from the qualitative study (themes of survivor advice and contextual factors related to QoL). Next, we combined the two lists of findings and sorted them into similar conceptual categories as they related to addressing our research question. Those conceptual categories became the “meta-themes” by which we compared quantitative and qualitative results to evaluate whether the two types of data confirmed results of the other, diverged from each other, or expanded on the other by providing insights that would have been missed had we examined QoL from a single perspective (Creswell & Clark, 2011). We report findings through a process of weaving in which results are connected to each other thematically (Fetters et al., 2013). Specifically, we closely follow the reporting framework of Classen et al. (2007) in which results are reported by meta-theme following the format presented in Table 10. We followed multiple strategies for minimizing threats to validity when integrating and interpreting data from the quantitative and qualitative studies (Creswell & Clark, 2011). When designing the mixed methods study, quantitative and qualitative study samples were collected by NACR during overlapping time periods and in the context of their typical programmatic activities, which increases the likelihood that participants in both datasets are from the same population and thus comparable for integration. Additionally, quantitative and

qualitative studies both examined QoL as a central construct using the same conceptual model of the medicine wheel to guide analysis (See Chapter 3, Figure 2). Finally, we gave quantitative and qualitative findings equal weight during interpretation and present findings from both sets of results for every meta-theme.

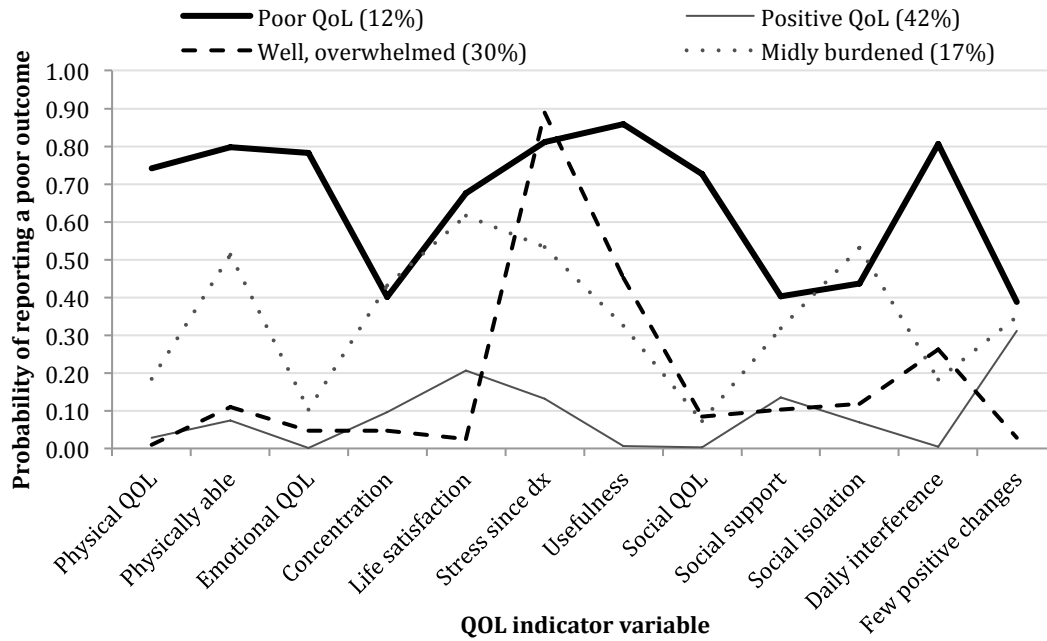
### ***Review of QoL classes identified in the quantitative latent class analysis***

Here we present a quick review of the QoL classes identified through LCA in Chapter 4 to remind readers of what the classes were since we refer frequently to these classes throughout this chapter. The four QoL classes and their respective prevalence include:

5. ***Positive QoL*** (n=345, 42%). Survivors in this class reported positive outcomes across all QoL measures (i.e. low endorsement of negative outcomes).
6. ***Well, overwhelmed*** (n=247, 30%). This class is characterized by survivors who reported that life has been “Fairly” or “Very” stressful since their cancer diagnosis, but reported positive outcomes across all other QoL measures.
7. ***Mildly burdened*** (n=142, 17%). Response patterns of survivors in this class resembled those of survivors in the *Poor QoL* class, but diverged in their more positive assessment of overall physical, mental/emotional, and social QoL and feelings of usefulness.
8. ***Poor QoL*** (n=97, 12%). Survivors in this class had high probability of endorsing multiple limitations across multiple QoL domains including poor physical, mental, and social QoL, and interference with daily life.

A plot of item-response probabilities for each of the twelve indicator variables included in the LCA by latent class is presented in Figure 6. In this figure, higher values mean a higher probability of reporting a poor outcome.

**Figure 6. Plot of item-response probabilities for reporting a poor outcome on QoL indicators among members of each latent class (Copied from Chapter 4, Figure 5).**



## Findings and discussion

By combining significant findings from the quantitative and qualitative analyses we identified four meta-themes to describe factors that influence QoL among Native survivors including 1) Culture: Value systems and spirituality are benchmarks for evaluating the cancer experience; 2) Years since diagnosis: Treatment and non-treatment related mechanisms influence healing over time; 3) Geographical context impacts access to medical and cultural resources for healing; and 4) Perceived control over cancer: Gaining control through self-advocacy and support. See Table 9 for a description of how quantitative and qualitative data were triangulated to arrive at these meta-themes. While these meta-themes served as the basis for integrating and comparing findings from the qualitative and quantitative studies, interpretation was an iterative process of going back and forth between studies to build upon new insights as they emerged from the integrated interpretation (O’Cathain, Murphy, & Nicholl, 2010). We present and discuss findings of our integrated interpretation theme-by-theme in the format described in Table 10.

**Table 9. List of quantitative and qualitative findings and their connection to meta-themes.**

<b>Quantitative and qualitative findings</b>	<b>Meta-themes and corresponding finding</b>
<p><b>Quantitative findings</b></p> <p><i>LCA results</i></p> <p>1. Four QoL classes identified:  <i>Poor QoL class</i> - poor outcomes across all domains  <i>Mildly burdened class</i> - some limitations, but positive overall QoL  <i>Positive QoL class</i> - positive outcomes across all domains  <i>Well, overwhelmed class</i> - only negative outcome is feeling stressed and overwhelmed</p> <p><i>Multinomial regression results (characteristics associated with class membership)</i></p> <p>2. Years since diagnosis  3. Area of residence  4. Region of the U.S.  5. Perceived degree of control over cancer</p> <p><b>Qualitative findings</b></p> <p><i>Themes and subthemes</i></p> <p>6. Listen to your body  7. Advocate for yourself  8. Subtheme: Advocate for your personal needs  9. Subtheme: Advocate for your health care needs  10. Embrace your culture and spirituality  11. Share your story  12. Subtheme: Share to cope  13. Subtheme: Share for hope</p>	<p><b>Culture and spirituality</b></p> <p>(#1) LCA classes support assessment of QoL from cultural perspective of balance  (#10) Embrace your culture and spirituality  (#11) Share your story  (#13) Subtheme: Share for hope</p> <p><b>Geography</b></p> <p>(#3) Area of residence  (#4) Region of the U.S.</p> <p><b>Years since diagnosis</b></p> <p>(#2) Years since diagnosis</p> <p><b>Perceived control and advocacy</b></p> <p>(#5) Perceived degree of control  (#6) Listen to your body  (#7) Advocate for yourself  (#8) Subtheme: Advocate for your personal needs  (#9) Subtheme: Advocate for your health care needs  (#12) Share to cope</p>

**Table 10. Format for reporting findings from the integrated interpretation.**

<b>Organization of findings</b>	<b>Description</b>
Meta-theme	Derived from triangulating findings from the quantitative and qualitative studies (Table 9). Meta-themes answer our mixed methods research question of “What factors influence QoL among Native American cancer survivors and how?”
<i>Quantitative findings</i>	Quantitative findings relevant to the meta-theme
<i>Qualitative findings</i>	Qualitative findings relevant to the meta-theme
<i>Integrated interpretation</i>	Inferences made from comparing findings across methods for each meta-theme.
<i>Discussion</i>	Discussion of findings in the context of existing research

## *Culture: value systems and spirituality are benchmarks for evaluating the cancer experience*

### *Quantitative findings*

#### NACES survey item-response frequencies

Survivor responses to survey questions about spiritual QoL were consistently positive and least variable among all QoL domains. Notably, questions about spirituality also had the highest proportion of missing data. Of survivors who did respond to the spirituality questions, 95% reported positive overall spiritual QoL, 90% reported feeling hopeful about their cancer treatment and their future, and 96% reported a strong purpose for being alive.

#### LCA results

It was fairly uncommon for survivors to report that they did not experience any positive changes in their lives because of their illness (probabilities <0.40), but especially uncommon among survivors in the *Well, overwhelmed* group where nearly all survivors reported that cancer made positive changes in their lives (Figure 6). Compared to all other classes, survivors in the *Poor QoL* class had the highest probability of reporting poor overall social QoL (probability=0.73), not being physically able to do everything they wanted to do (probability=0.80), not feeling useful (probability =0.86), and that cancer interfered in their daily activities at home (probability=0.81). While the probability of reporting concerns about social support and social isolation were highest among survivors in the *Mildly burdened* and *Poor QoL* classes, these variables were only weakly associated with latent classes. In other words, survivors in those two QoL classes had a roughly 50/50 chance of reporting limitations in social support, which is not very meaningful information on its own, but is meaningfully higher than social limitations reported by the *Positive QoL* and *Well, overwhelmed* classes.

### *Qualitative findings*

One prominent theme in the qualitative data was that to be healthy was to be in harmony and balance. Survivors explained, “being well doesn’t necessarily mean that you don’t have difficulty performing some tasks.” Feeling out of balance is how many survivors first knew that something was wrong. One noted limitation of western medicine is that it “cures the body and hopes the brain comes with it.” However, this narrow approach to healing is ineffective because, “the spiritual part of closing those wounds is as important as the physical part.”



Survivors shared that being Native meant being strong and not burdening others with their troubles. Many survivors prided themselves as being “the strong one” and the “backbone and supporter” for their families. As such, it was difficult for survivors to “sit back and have someone help me” because “that was not my role. I was always the one helping others.” Survivors felt that their role was to ensure that “everyone is doing well and we’re not interfering with them and they’re not worrying too much about us.” A stated consequence of trying to maintain one’s role as the “strong one” and avoid burdening others is that, “a lot of times Native people will not express when something is wrong.” Avoiding self-pity was described as an essential part of healing because “self-pity” only “weakens you” and “is not going to accomplish anything.”

Individual and family/community well-being were deeply intertwined among survivors in our study. Many survivors shared that “cancer is hard on [the] individual but it is twice as hard on your family.” Having to tell family members about their diagnosis was distressing. Strong connections to family and community were critical for healing. “Being there for each other and taking care of each other” was described as exemplifying “what it is to be a Native woman.” However, balancing dual responsibilities to self and community could be challenging causing some survivors to question the message that “life was for other people, not me” – a message they felt was “dictated” by their cultural value systems. Recognizing that their survival had power to inspire hope among other Natives with cancer motivated many survivors to persevere and share their cancer story as a “gift” to other Natives.

Lastly, spirituality was central to survivors’ lives and cancer experiences. Nearly all survivors reflected on the prominence of spirituality as a source of hope, healing and comfort during all stages of their cancer journey. Having faith that the Creator was in control and had a purpose for them gave survivors hope, helped them to mentally accept their disease, eased their fears and worries, and allowed survivors to enjoy life, have gratitude, and experience positive benefits in difficult times. Survivors explained, “If we are really being true to our cultural beliefs and our spirituality, then there's no fear. Because we are being taken care of.” Spirituality is why some survivors “celebrated” their cancer “because it was there for a reason,” which was to “learn something.”

### *Integrated interpretation*

The high prevalence of survivors who reported positive spiritual QoL across multiple survey items confirm findings from qualitative data that spirituality plays a prominent role in survivor's lives and cancer experiences.

In interviews, survivors described healing as a process of achieving harmony and balance among mind, body, and spirit. Quantitative LCA results confirm and expand understanding of what "balance" may look like among survivors in our study. Specifically, LCA results confirm qualitative findings that limitations in any one dimension of QoL do not dictate survivors' evaluation of their overall QoL. For example, survivors in the *Well, overwhelmed* class reported high life satisfaction while simultaneously reporting high levels of stress and survivors in the *Mildly burdened* class reported high stress and social isolation, but positive overall emotional and social QoL. The importance of establishing balance and harmony is evident in the strategies survivors used to cope with and heal from cancer including "living both ways" (embracing western medical treatment and traditional healing), prayer, ceremony, reconnecting with land and culture, and embracing family and community.

Survey data did not include a direct measure of the extent to which survivors felt their cancer placed a burden on their family, which was a prominent theme in the qualitative data. However, it did include conceptually similar measures of "usefulness" and the extent to which cancer interfered in survivors' daily activities at home – both of which were included in the LCA. Survivors in the *Poor QoL* class had a high probability of reporting feeling only a "little" or "not at all" useful (probability = 0.86) and that cancer "somewhat" or "greatly interfered" in their daily activities (probability = 0.81). Qualitative findings drove us back to the survey data where we found a significant positive crude association between daily interference from cancer and feelings of usefulness where survivors who reported that cancer greatly interfered in their daily activities were most likely to report feeling "a little" or "not at all" useful [ $\chi^2$  (3df) = 73.8,  $p < 0.0001$ ]. Together, quantitative and qualitative findings confirm the high value survivors placed on upholding expectations of strength and selflessness to maintain their roles as useful, contributing members of their families and communities.

Qualitative findings included a strong theme about interconnectedness between individual and family well-being. In interviews, survivors talked about how difficult it was to see family worry about them or interrupt their lives to support them. Some survivors described cancer as being harder on their family than it was on themselves. These findings drove us back to the

quantitative survey data to explore items related to family distress including responses to the question, “How distressing was it for you to see your family upset about your cancer diagnosis or treatment?” We found that the vast majority (84%) of survivors reported that it was “distressing” or “very distressing” to see their family upset by their cancer diagnosis. We also found a significant association between family distress and QoL class membership where survivors in the *Positive QoL* class were least likely to report experiencing distress from seeing their family upset by their cancer diagnosis (73%) and survivors in the *Well, overwhelmed* class were most likely to report experiencing distress from seeing their family upset about by their cancer diagnosis (96%) [ $\chi^2(3df)=52.4, p<0.0001$ ]. It may be that family distress contributed to survivors’ feelings of being overwhelmed.

In interviews, survivors cited family support as one of the most important components of healing. Families supported survivors’ mental and emotional health, supported decision-making, and motivated survivors to survive. Quantitative data demonstrate that only 19% of survivors endorsed having poor social support across the entire study sample and social support was only weakly associated with the latent variable representing QoL (probabilities  $\leq 0.40$  across all classes). These results suggest that social support was generally strong for all survivors, even among survivors in the *Poor QoL* class. In summary, qualitative and quantitative data confirm that survivors’ QoL is intimately connected to family well-being and support.

### *Discussion*

This meta-theme on cultural value systems and spirituality describes how culture influences QoL by shaping the value systems and expectations survivors use as benchmarks for evaluating their cancer experience. Integrated quantitative and qualitative findings confirm spirituality, achieving balance and harmony, and contributing as useful members of one’s family and community as values survivors strive to uphold to achieve optimal QoL after diagnosis. Integrated findings also confirm that individual QoL is heavily dependent on survivors’ relations with family and community.

Our findings align closely with previous research among Native American cancer survivors in which survivors described spirituality as part of who they were and not something that could be isolated and examined independently (Pelusi & Krebs, 2005). In other words, spirituality is part of the essence of what it means to be Native, which may explain the high prevalence of survivors in our study who reported having a strong sense of life purpose, feeling hopeful about the future, and being able to find something positive in their cancer experience.

Similar to previous research reports, survivors in our study practiced spirituality through prayer, participation in religious services and activities, traditional medicine, and through ceremony (Eide, 2007; Haozous et al., 2011).

Acknowledging QoL as balance and harmony might lead us to conclude that 42% of survivors in our study (survivors in the *Positive QoL* class) were thriving after cancer as evidenced by their reports of positive outcomes across all QoL indicator variables and domains. What is less clear, however, is how to interpret findings from the other classes. For example, we could argue that survivors in the *Well, overwhelmed* class are also thriving since they reported being satisfied with life and experiencing positive overall QoL in all domains. Furthermore, qualitative and quantitative findings suggest that experiencing limitations in any single domain does not dictate overall evaluation of QoL because they are ultimately interpreted in the context of all other domains. From this perspective, we might conclude that the vast majority (72%) of survivors in our study are satisfied with their QoL after diagnosis. This does not suggest that concerns about excess stress among survivors in the *Well, overwhelmed* class be ignored, but rather demonstrates the need to consider the whole person and respect survivors as definitive judges of their own QoL.

Our finding that survivors found it difficult to ask for help because of wanting to maintain their identity as “the strong one” is similar to findings of previous research among Native cancer survivors (Craft et al., 2017). Maintaining their role as strong contributing members of their family and community was a priority of many survivors in our study. Survivors did not want to be pitied or to burden others by asking for help even when needed. For some survivors, a consequence of strict adherence to upholding expectations of strength and selflessness was disappointment and grief when they could not meet those expectations. This may help to explain differences in patterns of QoL outcomes between survivors in the *Mildly burdened* and *Poor QoL* classes. Eighty-four percent of survivors in the *Poor QoL* class reported that cancer interfered “a lot” with daily activities at home, which is over three times that of survivors in all other classes. It may be that severe interference in daily activities among survivors in the *Poor QoL* class limits their ability to contribute in useful ways to family and community and is the driving force behind their reports of high stress, poor overall emotional and social QoL, and poor life satisfaction. In contrast, few (18%) survivors in the *Mildly burdened* class reported “a lot” of interference in their daily activities from cancer and reported uniformly positive overall evaluation of physical, emotional, and social QoL. Our findings are consistent with previous literature that found disruptions in role functioning were an important predictor of depressive

mood among breast cancer survivors in Korea (Lee et al., 2011). Another study among breast, colorectal, and non-small-cell lung cancer survivors in the general population found that when asked to rank the importance of health related quality of life (HRQoL) functional domains and symptoms, survivors listed deterioration in role and social functioning as the most important effects to avoid (Osoba et al., 2006). Being aware of how role changes impact Native survivors and their families, particularly in the context of a collectively oriented culture, is critical for understanding how best to support survivors and their families to cope with and adapt to those changes.

### ***Years since diagnosis: treatment and non-treatment related mechanisms influence healing over time***

#### *Quantitative findings*

##### Multinomial regression results

Years since diagnosis was positively associated with QoL class membership in our adjusted multinomial regression model ( $p < 0.0001$ ). Recent survivors (<1 year since diagnosis) were 4.3 (1.8 – 10.2) times more likely to be in the *Poor QoL* versus *Positive QoL* class compared to long-term survivors (5+ years diagnosis). Furthermore, the relative risk of membership in the *Poor QoL* class versus the *Positive QoL* class decreased in a dose-response manner with increasing time since diagnosis.

Long-term survivorship was positively associated with membership in the *Well, overwhelmed* class. Long-term survivors were 2.3 (1.1 – 5.0) times more likely to be in the *Well, overwhelmed* class versus the *Positive QoL* class compared to recent survivors. Notably, 80% of survivors in the *Well, overwhelmed* class were long-term survivors.

Finally, the only class for which years since diagnosis was not associated with membership was the *Mildly burdened* class. In contrast to the other classes, the *Mildly burdened* class was the only class for which clinical characteristics (i.e. continuing to receive cancer care and cancer type) were marginally associated with class membership. Survivors who reported continuing to receive cancer care were 1.7 (1.0 – 3.1) times more likely to be in the *Mildly burdened* class versus the *Positive QoL* class compared to survivors who were not receiving care. Additionally, the relative risk of being in the *Mildly burdened* versus *Positive QoL* class was higher among survivors with lung cancer and multiple cancers compared to breast cancer

survivors. While these estimates did not reach our threshold for statistical significance, these patterns of association diverge in meaningful ways from the other QoL classes.

### *Qualitative findings*

We did not have complete data on years since diagnosis for survivors in our qualitative data sample so we were unable to examine differences in themes or tone of survivor narratives by years since diagnosis. However, the semi-structured interview protocol led survivors to narrate their cancer story in chronological order from diagnosis, to treatment, to recovery, and finally to advice for other survivors in hindsight of it all. Survivors described the first year after diagnosis as an especially challenging time as they confronted their diagnosis and navigated treatment. Many survivors expressed shock and fear upon diagnosis explaining that cancer had “never been in my family before” and “I never thought it would happen to me.” Fear was intensified by the commonly held perception that cancer was “a death sentence.” Having to tell family members about their diagnosis was distressing for many survivors. Simultaneous with the emotional shock of diagnosis, survivors were pressured to make critical treatment decisions under pressures of time, resource constraints (e.g. geographical barriers to treatment, health insurance), and an unknown prognosis. Survivors often experienced wide ranging physical, emotional, social, and spiritual side effects from treatment that limited their ability to fulfill responsibilities to family and community the way they wanted or was expected of them. For some survivors, cancer was so all consuming in the early period of their cancer journey that they didn’t feel like they were “living life anymore” because they “couldn’t even have a regular conversation with anyone without talking about cancer.”

Over time, as survivors completed and recovered from treatment, many survivors reflected on their cancer experience with gratitude for having survived and for the lessons learned from their experience. In their advice to other Native survivors, survivors in our study stressed the importance of “taking time to acknowledge what you’ve been through” and processing those emotions as “part of the healing process.” Only after processing those emotions could survivors “go on and do the things that you need and want to do.” Many survivors said that because of their cancer, they “enjoy life just a little fuller,” “value things that are important a lot more,” and “live day by day as is comes.” After surviving treatment, many survivors felt compelled to share their cancer story as a way of helping other Natives with cancer. Others regarded their cancer as a thing of the past and preferred not to “dwell” on or talk about it because, “life still goes on.” For some survivors, cancer was described as something that “will always be with you forever and it’s

just learning to deal with it.” Fear of recurrence was a real fear for some survivors who were “always afraid it [would] come back.”

### *Integrated interpretation*

Qualitative data confirm findings from quantitative data that on average, QoL increases with increasing survivorship. Qualitative data revealed that most survivors underwent cancer treatment shortly after diagnosis and that treatment was one of the most challenging times in their cancer journey. Over time, as survivors completed and healed from treatment, many of them grew spiritually, mentally, and emotionally in a way that allowed them to reflect on their cancer experience with feelings of gratitude and appreciation for life. Confirming the qualitative data, quantitative data demonstrated that the relative risk of being in the *Poor QoL* class versus the *Positive QoL* class among recent survivors was 4 times that of long-term survivors. Furthermore, the relative risk of being in the *Well, overwhelmed* class versus *Positive QoL* class was higher among long-term survivors relative to short-term survivors. Both the *Well, overwhelmed* and *Positive QoL* classes were characterized by positive life satisfaction and positive evaluation of overall physical, mental/emotional, and social QoL.

As an explanatory variable for QoL class membership, years since diagnosis is confounded by treatment status and both independently influence QoL. Qualitative data reveal that most survivors receive treatment fairly soon after diagnosis and that treatment and related side effects have a negative impact on survivors’ QoL. Adding a variable for “continuing to receive cancer care” to our quantitative regression model attenuated point estimates for “time since diagnosis” in some cases by more than 20%. Additionally, 86% of survivors in the *Poor QoL* class and 77% of survivors in the *Mildly burdened* class reported that they continued to receive care for their cancer compared to only 54% of survivors in the *Positive QoL* and *Well, overwhelmed* classes. In this case, quantitative and qualitative data confirm the confounding effect of treatment on years since diagnosis. Interestingly, years since diagnosis was not a significant predictor of membership in the *Mildly burdened* class in adjusted models, but continuing to receive cancer care and cancer type appeared to be weakly associated with membership in this class. What these data suggest is that the poor QoL outcomes reported by survivors in the *Mildly burdened* class – mainly physical limitations, stress, and social isolation – may be primarily driven by clinical factors such as treatment and relatively more severe cancers (the relative risk of being in the *Mildly burdened* class versus *Positive QoL* class was higher among lung cancer survivors and survivors with multiple cancers relative to breast cancer

survivors). We suggest caution when interpreting this finding, however, as one limitation of our data is that our measure of whether or not a survivor continued to receive cancer care was broad to include active treatment and follow-up care. Thus, we cannot be certain of the type or intensity of care that survivors who responded affirmatively to receiving care were actually receiving.

The association between years since diagnosis and QoL is not linear, but rather nuanced. Recent and long-term survivors were represented in every QoL class suggesting some recent survivors were experiencing *Positive QoL* and some long-term survivors continued to experience challenges many years after diagnosis. Indeed, one-third of survivors in the *Poor QoL* group were long-term survivors. Additionally, the majority (52%) of survivors in the *Positive QoL* group were diagnosed fewer than 5 years prior. Qualitative data also reveal diversity in trajectories of acceptance and healing among survivors over time. While some survivors were quick to establish balance after diagnosis, for other survivors, that process took many years. Thus, qualitative and quantitative findings confirm heterogeneity in trajectories of healing and restoring balance over time influenced in part by clinical factors and time itself.

### *Discussion*

Key findings related to this meta-theme about the influence of years since diagnosis on QoL are that QoL generally improves with increasing years since diagnosis through two primary mechanisms: 1) completion of and recovery from treatment and 2) mental, emotional, and spiritual growth over time. Additionally, the healing process is not linear, but rather nuanced in which heterogeneity exists among individual survivors. In our research as in that of previous studies, Native survivors describe their cancer experience as a “journey” (Eide, 2007; Pelusi & Krebs, 2005). In a study among Native survivors in the Pacific Northwest, survivors depicted the cancer journey as a waterway likening it to that of the annual canoe journey undertaken by Pacific Northwest tribes (Haozous et al., 2016). They explained, “the cancer journey may include quick and easily navigable routes, but travelers can often be swept into eddies and sandbars or endangered by rocks and other barriers along the way” (Haozous et al., 2016, p. 628). Our finding that survivors’ paths to healing were influenced, but not dictated by the passing of time is congruent with the theoretical model proposed by Krebs (1997) that describes the process Native breast cancer survivors go through to recreate harmony after cancer. The author explains that healing is not linear, but rather “a dynamic picture of evolution and growth” in which there is continuous back and forth movement between gaining strength, managing emotions, maintaining a positive outlook, and moving on with life, throughout a survivor’s life (p. 123).



## ***Geographical context impacts access to medical and cultural resources for healing***

### *Quantitative findings*

#### Multinomial regression results

In adjusted regression models, both measures of geographical context – area of residence (city/town/village, reservation, rural not reservation, move back and forth) and region of the U.S. – were strongly associated with QoL class membership (Chapter 4, Table 7). Specifically, the risk of being in the *Poor QoL* class versus *Positive QoL* class among survivors living on a reservation was 2.6 (1.1 – 5.8) times that of survivors living in a city, town or village. Among survivors who moved back and forth between the city and reservation, the risk of being in the *Poor QoL* versus *Positive QoL* class was 8.8 (2.9 – 26.3) times that of survivors living in a city, town or village.

Survivors who lived in the Southwest had 10.5 (3.7 – 30.0) times the risk of being in the *Poor QoL* versus *Positive QoL* class and 4.8 (2.4 – 9.9) times the risk of being in the *Well, overwhelmed* class versus *Positive QoL* class compared to survivors living in the Southern Plains. The risk of being in the *Poor QoL* class versus *Positive QoL* class was also higher among survivors living in the Northern Plains relative to survivors living in the Southern Plains.

### *Qualitative findings*

For many survivors, living among other Natives and living on tribal land offered opportunities for spiritual healing unavailable at medical centers. Some survivors moved back to their reservations after their cancer diagnosis to gain strength from those cultural and spiritual resources. Many survivors stressed the need to “live both ways,” which was described as taking advantage of the healing powers of culture and spirituality and western medical treatment. Living on the reservation among family and their Native community provided social, spiritual and emotional benefits to survivors’ QoL. Nearly all survivors received the bulk of their support from family and community members.

Living on the reservation afforded survivors important social and emotional support, but it also made it difficult to access cancer care. Provider options were often limited on reservations, which meant survivors had to travel great distances to receive care. Having to travel for care placed a great burden on survivors and their families from having to arrange and pay for transportation and lodging to attend appointments and arrange care for dependents and other family members in their absence. Furthermore, undergoing difficult cancer treatments in an unfamiliar environment was distressing for many survivors. Survivors from rural areas who

traveled to larger cities to receive care felt lost and insignificant in large cancer centers – describing the “complete isolation” they felt as “horrendous.”

### *Integrated interpretation*

Living on reservation affords access to important spiritual and cultural resources for healing, but may create barriers to accessing cancer care that compromise QoL. In our quantitative analysis we found that survivors living on the reservation or who moved back and forth between the reservation and city were more likely to be in the *Poor QoL* class versus the *Positive QoL* class compared to survivors living in urban areas. Additionally, survivors in the *Poor QoL* class were more likely to be recent survivors rather than long-term survivors and 86% reported that they were receiving cancer care at the time they completed the QoL survey. While 21% of survivors in our quantitative sample were missing data for “distance traveled to cancer treatment,” an exploratory analysis of available data (n=654) found that 67% of survivors in the *Poor QoL* class and 78% of survivors in the *Well, overwhelmed* class reported having to travel over 100 miles one-way to receive cancer care compared to only 24% of survivors in the *Positive QoL* class. These quantitative findings confirm qualitative findings that having to travel long-distances to receive cancer care among can negatively influence QoL. In addition to causing financial hardship, traveling long distances for cancer care removes survivors from important social and cultural supports critical to helping survivors cope with and heal from treatment. Consequently, traveling long distances for treatment burdens survivors and their families and may contribute to patterns of social and mental/emotional distress reported by survivors in the *Poor QoL* and *Well, overwhelmed* classes.

In interviews, survivors discussed the importance of “living both ways” to take advantage of what dominant society has to offer – the best of modern technology – while staying grounded in their foundation as an Indian person. For some survivors that meant physically moving back to the reservation after diagnosis. It may be that survivor reports of moving back and forth between the city and reservation in the quantitative data reflect survivors’ efforts to live both ways. Having a “foot in both worlds” kept survivors “sane, motivated, and centered,” but also created logistical challenges to accessing cancer care, which may explain why survivors who moved back and forth between the reservation and city had a higher risk of being in the *Poor QoL* and *Well, overwhelmed* classes compared to survivors who lived in a city, town or village.

Quantitative results suggest that survivors in the *Poor QoL* felt relatively well supported socially, despite limitations in other areas of QoL. Their probability of reporting poor social

support or social isolation was low relative to other QoL limitations (Chapter 4, Table 3). Qualitative data expand understanding of quantitative data by describing the ways in which living on a reservation fosters positive QoL via place-based social and cultural benefits of family and community support and belonging.

Qualitative data were silent on regional influences on QoL so we were unable to provide further insight on associations between region of residence and QoL class membership identified in quantitative analyses. However, an exploratory analysis of survey data revealed a strong and significant association between region of residence and having to travel over 100 miles to receive cancer care [ $\chi^2$  (2df) = 261.9,  $p < 0.0001$ ] where 90% of survivors living in the Southwest traveled over one-hundred miles to receive cancer care compared to 39% of survivors in the Northern Plains and 18% of survivors in the Southern Plains. These data suggest that region of residence may serve as a proxy for geographic barriers to care, which we describe in the preceding paragraphs. Quantitative findings suggest that living in the Northern Plains is associated with a higher risk of membership in the *Poor QoL* versus *Positive QoL* class relative to living in the Southern Plains. Additionally, living in the Southwest region of the U.S. was associated with higher risk of membership in the *Poor QoL* and *Well, overwhelmed* classes relative to living in the Southern Plains.

### *Discussion*

This meta-theme of geographic residence describes how geographic context influences Native survivors' QoL by influencing access to resources for treatment and healing. Where a survivor lives has important implications for accessing health care and social, cultural, and spiritual supports for healing. Quantitative and qualitative data suggest that living among other Natives and on the reservation in particular, positively influenced survivors' QoL by providing survivors with social support, a strong sense of belonging, and grounding survivors in their foundation as an Indian person. Our findings closely resemble those of previous research among Native survivors in which survivors expressed pride in their Native identity and culture as a source of grounding and strength (Craft et al., 2017; Eide, 2007). Living on a reservation provided access to important spiritual and cultural resources for healing including social support, traditional medicines, ceremonies, and other spiritual resources not accessible to survivors in mainstream health systems or non-Native communities. These resources were so critical for healing that survivors who felt disconnected from their Native culture prior to their cancer

diagnosis made efforts to learn about and reconnect with culture by attending ceremonies and in some cases moving back to the reservation. However, survivors emphasized that healing from cancer required “living both ways,” which involved embracing cultural and spiritual resources for healing and western medicine. Unfortunately, enjoying the social and cultural benefits of living on a reservation came with steep tradeoffs when it came to accessing cancer treatment. Our study reinforces findings from previous research that reservation dwelling Natives often face geographical barriers to treatment that require them to travel hundreds of miles to access cancer care and that access barriers to care have a negative impact on QoL (Goodwin et al., 2016; Itty et al., 2014).

While Natives in the Southwest experience the lowest all-cancer incidence and mortality rates relative to Natives living in other regions of the U.S. (White et al., 2014), our study found that survivors living in the Southwest had a higher risk of membership in the *Poor QoL* and *Well, overwhelmed* classes compared to survivors in the Southern Plains. Our convenience sample precludes us from generalizing our findings to the general population of Natives living in the Southwest and Southern Plains, but future research might explore this further to better understand why Natives in the Southwest have the lowest cancer incidence and mortality rates, but some of the poorest QoL outcomes.

### ***Perceived control over cancer: gaining control through self-advocacy and support***

#### *Quantitative findings*

##### Multinomial regression results

Perceived control over cancer was strongly associated with QoL class membership in the overall regression model ( $p < 0.0001$ ). Survivors who reported having “fair” to no control over cancer had over 4 times the risk of being in the *Poor QoL* versus *Positive QoL* class and over 3 times the risk of being in the *Mildly burdened* versus *Positive QoL* class compared to survivors who reported having “good” or “complete” control over cancer (Chapter 4, Table 7). Perceived control over cancer was not associated with membership in the *Well, overwhelmed* class for which 91% of survivors reported good to complete control over their cancer.

The NACES QoL survey did not include direct measures of self-advocacy, but did include a measure of educational attainment. Educational attainment was not significantly associated with class membership in the overall regression model ( $p = 0.2362$ ), but we found some evidence of a trend in which risk of membership in the *Poor QoL* versus *Positive QoL* class

decreased with increasing educational attainment. While not meeting our threshold for statistical significance, we found some evidence that having a high school education or less was associated with membership in the *Well, overwhelmed* class (RRR=2.2, 95% CI: 1.2 - 4.2).

### *Qualitative findings*

Survivors described “not knowing” what was happening or what would happen during or after cancer treatment as “the worst part of everything.” The burden of trying to “prepare for the unknown” was “incredible” and walking into treatment felt like being “an animal going to slaughter.” Feeling “urgency to do something and not having any control” made some survivors “frantic.” Even before treatment, the period between diagnostic testing and receipt of test results was especially distressing as survivors waited for sometimes up to a couple weeks for their “death sentence.” The anticipation during that waiting period was described as “too much to handle.” One key strategy survivors used to gain more control over their cancer experience was self-advocacy. Survivors emphasized, “you can’t sit there and wait for somebody to hold your hand the whole time.” In their advice to other Native survivors, survivors in our study stressed the importance of asking for help when needed and advocating for one’s health care needs by asking questions, getting second opinions, and bringing a support person to doctor appointments. Acknowledging how difficult it can be to ask for help in the context of cultural expectations of selflessness, being strong, and not burdening others, one message survivors had for other survivors was “don’t be ashamed to do anything that would help yourself.”

Multiple factors directly or indirectly supported survivors’ ability and opportunities to self-advocate. First, survivors stressed the importance of listening to and trusting their bodies to tell them when they were out of harmony and balance. Being in tune with one’s body was key to understanding one’s physical, social, emotional, and spiritual needs. Additionally, having knowledge about cancer and treatment positioned survivors to communicate effectively with their health care providers. Survivors talked about how “arming themselves with knowledge” about cancer and “knowing what they were up against” made it “much easier for me to tackle it.” Many survivors stressed the importance of getting second opinions. Trusting their bodies and feeling knowledgeable about their cancer and treatment options helped survivors to ask the right questions, clarify expectations, and make informed decisions – all of which helped survivors feel prepared for the road ahead. Finally, qualitative data revealed how survivors’ educational attainment influenced opportunities to self-advocate by increasing the likelihood of employment with health insurance benefits and paid time off, and equipped survivors with general knowledge

of how to navigate the health care and insurance system. This was especially evident among survivors who held jobs in the health care sector that provided them with knowledge of who to contact, where to go, and what to do in order to get what they needed.

### *Integrated interpretation*

Quantitative and qualitative data confirm that survivors' perceptions of control over cancer are lowest during the treatment period of their cancer journey, which negatively impacts QoL. Qualitative data demonstrate that the time from diagnosis through treatment was a challenging and vulnerable time for many survivors. Survivors had to make critical treatment decisions under pressures of time, geographic constraints, health insurance constraints, and uncertainty about the health or financial outcomes of their decisions. Quantitative data confirm that perceiving to have little control over cancer was positively associated with membership in a sub-optimal QoL class (i.e. *Poor QoL* and *Mildly burdened* class) and that the majority of survivors in the *Poor QoL* and *Mildly burdened* classes were still receiving cancer care at the time they completed the survey (86% of survivors in the *Poor QoL* class and 77% of survivors in the *Mildly burdened* class). Recent survivorship was also positively associated with membership in the *Poor QoL* class.

While survivors could not control the outcomes of their decisions, qualitative data provided many examples of how survivors used self-advocacy as a strategy for gaining control over the things they could. Examples include getting second opinions, bringing someone to doctor appointments, learning everything they could about their cancer, or asking for help when needed. Qualitative data also provide insight into ways in which education – not just of survivors, but of their family and caregivers as well – mediated access to a broad set of resources to facilitate advocacy. Education provides a pathway to employment and technical skills that survivors drew upon to access health insurance, navigate the health system, get second opinions, research their cancer and treatment options, and fight to get appointments when they weren't being heard. While educational attainment was not significant in our overall regression model, we did see a trend in which risk of membership in the *Poor QoL* and *Mildly burdened* classes decreased with increasing level of educational attainment providing some support for qualitative findings that education plays an important role in supporting QoL after cancer. Qualitative data provide insight on how ongoing treatment, physical limitations, and interference in daily life among survivors in the *Poor QoL* class might contribute to feelings of lack of control in addition

to low educational attainment and geographic barriers to care that may limit their ability or opportunities to advocate for their needs.

### *Discussion*

Our integrated analysis related to the meta-theme of perceived control found that when survivors sensed they had little control over their cancer or health care experience, they experienced mental and emotional distress and their QoL suffered. Qualitative and quantitative data concur that survivors in the early period of their cancer journey were most vulnerable to feeling a lack of control and subsequent mental/emotional distress. In interviews, survivors explained that once diagnosed, urgency ensued to make critical decisions about treatment, but in the face of tremendous uncertainty. This caused some survivors to feel “frantic.” Aligning with existing literature, we found that self-advocacy was an important strategy survivors used to maintain or regain control over their cancer experience. In a study among Native survivors in the Pacific Northwest, survivors emphasized the importance of being able to advocate for themselves, but also the importance of having family members and clinicians to advocate on their behalf (Haozous et al., 2016). Authors describe how in some cases, survivors had to be “aggressive” in their advocacy, which surprised the research team. While survivors in our study did not use the term “aggressive” to describe their experiences, survivors described multiple instances in which they had to directly confront office staff, doctors, health insurance companies, and therapists to receive appropriate care.

## CHAPTER 7. CONCLUSIONS AND IMPLICATIONS

### Strengths and limitations

This study has many strengths. Methodologically, our mixed methods study design provided a more comprehensive understanding of how cancer affects QoL among Native American adults than quantitative or qualitative methods could have provided alone. Mixed methods research has also been touted as a strategy for advancing health equity (Thomas, Quinn, Butler, Fryer, & Garza, 2011) and improving translation of research into practice (Glasgow & Emmons, 2007; Wallerstein, Yen, & Syme, 2011). By using person-centered methodologies, we identified previously undescribed heterogeneity in QoL among a geographically diverse sample of Native cancer survivors. These methodological strengths allowed us to generate research findings useful for designing interventions that support the whole person on their path to establishing harmony and balance after cancer.

Another strength of this study is that it contributes to the relative dearth of literature examining QoL outcomes among underserved populations including Native Americans living in the U.S. By centering at the margins and examining QoL from the perspective of Native survivors, this research shifts the baseline of “normal” from dominant western perspectives to a Native perspective (Ford & Airhihenbuwa, 2010; Hardeman, Medina, & Kozhimannil, 2016). This shift in perspective is important for increasing understanding of how to provide culturally congruent care to Native cancer survivors and their families (Schim, Doorenbos, Benkert, & Miller, 2007). Working on this research study with a Native-led community organization that implements interventions to support Native survivors improves the prospect of findings being applied to benefit Native communities.

Readers are encouraged to interpret findings of our study in the context of its limitations. One limitation is that we used different data sources for the quantitative and qualitative strands of the mixed methods study. If the samples are meaningfully different from one another, validity of the integrated analysis may be compromised. However, both study samples were collected by NACR during overlapping time periods and in the context of their typical programmatic activities, which increases the likelihood that participants in both datasets are from the same population and thus comparable. While we would have preferred that qualitative data were a subset of survivors in the quantitative sample, it is not required in concurrent mixed methods study designs where the purpose is to integrate different yet complimentary data to generate a more complete understanding of a phenomenon (Creswell & Clark, 2011). This is in contrast to



explanatory mixed methods designs for example, that use findings from one study to directly explain findings from the other.

Another limitation of this study is that the data are cross-sectional, which limits our ability to interpret the direction of associations in our regression models and provides only a snapshot of QoL – a dynamic construct – at a single point in time. The NACES QoL survey asked survivors to rate their *current* QoL and video interviews were retrospective, thus subject to recall bias and response shift (Hamidou et al., 2014). These limitations may have biased results toward positive outcomes. However, as a descriptive, exploratory study, our research was designed to generate descriptive data and generate new hypotheses for future investigation, which we believe it accomplished.

One limitation of our secondary data analysis is that the data were not collected with the primary intent of answering our research questions. Specifically, LCA is not designed for use with ordinal data, which is how QoL items were measured in the NACES QoL survey. Additionally, we did not conduct or transcribe interviews with survivors, which is an important component of the qualitative analysis process. Using secondary data also prevented us from applying purposive sampling, which is a critical component of qualitative studies (Norman & Yvonna, 2005). However, convenience sampling is considered an appropriate sampling strategy for exploratory studies such as ours (Anderson, 2010). Despite these limitations, this study reports on the largest dataset of QoL outcomes among Native American cancer survivors that we are aware of and a large qualitative sample of 52 Native survivors as well. Comparing our study findings to those of previous studies among subsets of survivors from our study samples revealed close alignment and supports validity of our results (Goodwin et al., 2016; Krebs, 1997).

Finally, in qualitative research, the researcher is the instrument for analysis (Starks, 2007), which means analysis is inherently influenced by the researcher's life experience and biases. My experience as a non-Native person of color inevitably influenced my analysis and interpretation of data for this study. Readers of this study are encouraged to consider my position as an outsider working with, but not of the Native community when reviewing results and my interpretation of those results as presented in this thesis. Conscious of my position as an outsider to this research I regularly consulted with colleagues including those from NACR to have them review aspects of this work and challenge me on my interpretations as appropriate.

## Conclusions

This study sought to gain a holistic understanding of QoL among Native American cancer survivors by using a mixed methods research approach to identify factors that influence QoL and describe how those factors operate in the context of survivors' daily lives to promote or prevent survivors from achieving optimal QoL after cancer. The two most significant contributions of this study are that 1) it is the first study we are aware of to use latent class analysis to operationalize and visualize QoL from a holistic perspective of "balance" among a large population of Native cancer survivors and 2) our mixed methods research approach expands understanding of how previously reported predictors of QoL operate in the context of each other and in survivors' daily lives to influence QoL after cancer.

We identified four latent classes of Native cancer survivors with meaningfully different QoL profiles that would have been missed had we isolated and averaged domain-specific QoL scores as traditionally reported (Burhansstipanov et al., 2012; Westby et al., 2016). One positive finding from our research is that the most prevalent (n=345, 42%) QoL profile was characterized by survivors who reported experiencing positive outcomes across all QoL indicator variables and domains (physical, mental/emotional, social, spiritual). These data suggest that most survivors in our study were thriving and experiencing harmony and balance in their lives after cancer. However, we also identified a relatively large group of survivors who continued to feel stressed and overwhelmed since diagnosis in the context no other QoL concerns and a group of survivors who reported excellent overall QoL in the context of physical, emotional, and social limitations. Understanding these QoL patterns matters because approaches to supporting survivors in each QoL class will likely differ. Survivors in the *Poor QoL* class may need intense support to address multiple health limitations whereas survivors in the *Mildly burdened* and *Well, overwhelmed* classes may need more tailored support to meet their unique needs. Thus, QoL interventions need to be tailored at the individual level.

By integrating and interpreting findings from the qualitative and quantitative components of our study, we identified four meta-themes that directly answered our mixed methods research question of, "What factors influence QoL of Native American cancer survivors and how?" The first meta-theme, *Culture: Value systems and spirituality are benchmarks for evaluating the cancer experience*, describes how spirituality, interconnectedness between individuals and family/community, and achieving harmony and balance among all dimensions of health are critical components to achieving optimal QoL after a cancer diagnosis. The second theme, *Years*

*since diagnosis: Treatment and non-treatment related mechanisms influence healing over time*, highlights the ways in which QoL improves over time as survivors transition out of treatment and experience mental and emotional healing with increasing years of being cancer free. The healing process is heterogeneous and dynamic as survivors move in and out of different phases of their cancer journey over time. The third theme, *Geographical context impacts access to medical and cultural resources for healing*, highlights the ways in which geography may promote or prevent survivors from achieving optimal QoL by structuring access to cancer treatment and psychosocial supports for healing. Living on a reservation provides survivors access to important cultural, spiritual, and social resources for healing, but generates significant distress when survivors have to travel long-distances to access cancer care. The final theme, *Perceived control over cancer: Gaining control through self-advocacy and support*, emphasizes the important roles that self-advocacy and support play in providing survivors with a sense of control over their cancer and how feeling out of control is associated with poor QoL outcomes.

In conclusion, combining methods in this study allowed us to simultaneously zoom in to understand survivors' cancer experiences at the individual level and zoom out to understand patterns in experiences at a population level. This study demonstrates the value of combining those different, yet complimentary perspectives to provide a more complete understanding of QoL among Native survivors than had we limited our investigation to a single method. By combining methods, we identified critical interdependencies and contextual information necessary for informing tailored and culturally congruent interventions to support all Native survivors in achieving optimal QoL after cancer.

## **Implications**

### ***Implications for health care providers***

We reiterate the conclusion of Burhansstipanov et al. (2015) that interventions to prevent, detect, and treat cancer are more likely to be effective if they align with the cultural experiences and beliefs of patients. More specifically, our findings concur with previous research that interventions to support Native American cancer survivors may be most effective if they attend to spirituality, include family, include storytelling, and consider the whole person (Burhansstipanov & Hollow, 2001). This may require designing interventions to directly treat balance and harmony instead of localized problems (Hodge et al., 2009). Interventions that target balance recognize that changing conditions in one QoL domain will affect all other domains (Hodge et al., 2009). We

suggest building on existing interventions that attend to balance, spirituality, and culture that have been received positively by Native survivors and demonstrate promise for improving QoL outcomes including survivor support circles or retreats (Kelley, DeCourtney, & Thorsness, 2015; Weiner, Burhansstipanov, Krebs, & Restivo, 2005), culturally tailored symptom management toolkits (Hodge et al., 2012), spiritual care programs (Witte et al., 2010), and Native patient navigator programs (Harjo et al., 2014; Petereit, Guadagnolo, Wong, & Coleman, 2011). We also suggest building on existing interventions that offer opportunities for storytelling including survivor support groups and the NACES website that includes video vignettes of Native survivors sharing aspects of their cancer stories (<http://natamcancer.org/naces.html>).

When assessing QoL of Native cancer patients, health care providers should use holistic assessment strategies that inquire about all domains of health, but also about perceptions of balance among domains. Understanding how QoL outcomes cluster together within individuals will help health care providers to prioritize and tailor resources in a manner that more closely aligns with the whole person. This holistic approach to assessment may be especially useful among Native populations that conceptualize health as balance and harmony. What “balance” looks like will differ between individuals and shift over time so collecting qualitative data whether through storytelling or open-ended survey questions will reduce the risk of making false assumptions about survivor priorities and the impact cancer-related health limitations have on survivors’ daily lives. Asking survivors about their cultural beliefs, expectations, and socio-ecological context may help health care providers interpret results of QoL assessments in context. Examples include asking survivors about how well they feel they are balancing responsibilities between self and community, the extent to which they feel they are a burden to others, or how well their family is responding to their diagnosis. Seeking to understand survivors’ culture, values, and context may help health care providers prioritize supports they offer to patients to include those that survivors’ perceive will have the greatest positive impact on their daily lives. As other authors have suggested, this may require shifting from a tendency to prioritize and address physical concerns to addressing sociocultural factors, which may play a larger role in influencing QoL (Ashing-Giwa, Tejero, Kim, Padilla, & Hellemann, 2007).

Corroborating findings from previous research, we found that the early period of a survivor’s cancer journey is often one of the most difficult and that survivors may need more intense support from the time of diagnosis through completion of treatment (Miller et al., 2008). However, we demonstrate an equally important need to continue supporting survivors’ physical, mental, emotional, and spiritual QoL beyond the first few years of diagnosis. We echo published

survivorship care guidelines suggesting long-term monitoring of psychosocial late-effects of cancer and caution health care providers against assuming that long-term survivors don't have any support needs just because they completed treatment or don't report physical limitations from their cancer (El-Shami et al., 2015).

Given our findings on the ways in which geography structures survivors' access to critical psychosocial support and medical care, interventions to support Native survivors should include strategies for supporting survivors and their families financially, logistically, and socially when receiving care long-distances from home. Native patient navigator programs may be an effective strategy for addressing survivors' transportation-related barriers to care and their psychosocial, cultural, and spiritual needs. A survey among Native patients at tribal clinics in Idaho and Oregon found that transportation barriers were the number one financial barrier to care and that help with transportation was cited as the second most useful service provided by navigators (Grimes, Dankovchik, Cahn, & Warren-Mears, 2017). Interventions should also include strategies to support survivors' access to social, cultural, and spiritual resources when receiving care far from home. This might involve connecting with community organizations to support accompanying family members with lodging, meals, and transportation. It might even include supporting survivors' family members at home to alleviate distress survivors may feel from burdening family with their absence.

We identify multiple strategies survivors already use to advocate for their needs and gain control over their cancer experience that interventions can build upon to support QoL. Examples include interventions to increase survivor knowledge and understanding about their cancer; supporting access to second opinions; encouraging survivors to ask questions during medical appointments; and providing opportunities for survivors to bring someone with them to appointments. Hodge et al. (2012) describes the development of a survivor "toolkit" designed by and for Native survivors that includes a large focus on improving communication between Native survivors and their health care providers, family, and friends. Survivors involved in developing the toolkit expressed high interest in closing each chapter with skills-building activities to promote self-management of symptoms and care.

Finally, our findings support recent literature calling for more nuanced categorization of cancer survivors that acknowledge differential needs based on phase of illness, clinical factors, and socioeconomic conditions (Park, Peppercorn, & El-Jawahri, 2018; Surbone & Tralongo, 2016). We suggest adding cultural considerations to that list as well. The authors of these articles conclude, "it is time to adopt a more individualized and patient-centered approach to identify and

address the unique experiences of patients with cancer in each phase of illness” (Park et al., 2018, p. 1164). Our study illustrates the potential consequences of ignoring heterogeneity. More specifically isolating and averaging scores in each QoL domain would have underestimated needs of survivors in the *Poor QoL* class who reported limitations in all QoL domains and misspecified needs of survivors in the *Well, overwhelmed* and *Mildly burdened* classes who reported unique patterns of QoL concerns. Using the QoL classes identified in our study as an example, health care providers might support survivors in the *Well, overwhelmed* class by offering interventions to alleviate stress. Public health interventions might identify and address the more upstream sources of stress. Interventions to support survivors in the *Mildly burdened* class might focus on interventions to improve life satisfaction. Finally, interventions to support survivors in the *Poor QoL* class might be of high intensity to support needs in multiple domains and reduce the extent to which cancer interferes with survivors’ daily activities at home.

### ***Implications for researchers***

One priority for future research is to investigate why long-term survivors living on reservations in the Southwest continue to feel stressed and overwhelmed from their cancer so many years after diagnosis. Of particular concern is that their needs may be going unnoticed because they appear to be thriving in other areas of health. We hypothesize that the social and financial burden of having to travel long distances for follow-up cancer care may be a source of excess stress, but it is also possible that the stress is unrelated to cancer. Future studies could interview a random sample of survivors from the *Well, overwhelmed* class to better understand the source(s) of their continued stress and identify strategies to best support them. Future studies might also collect qualitative data from short- and long-term survivors from the *Positive QoL* class to elucidate specific mechanisms of healing that could help inform intervention design. It may be especially informative to learn from survivors who were ostensibly thriving in the early years of survivorship (short-term survivors or survivors undergoing treatment in the *Positive QoL* class) to learn what was working well for them. Findings from these studies could be used to inform strategies for supporting other survivors through the often challenging time of diagnosis and treatment.

We support recommendations of Ashing-Giwa (2005) that researchers should include measures of culture and socio-ecological context in studies investigating QoL among diverse and under-resourced populations of cancer survivors including Native Americans in the U.S. The contextual model of HRQoL (Ashing-Giwa, 2005) provides a useful starting point for informing

tool development and study design. We suggest that if using the model to understand QoL among Native American cancer survivors that QoL be measured holistically to align with the way QoL is understood by many Native survivors. Our study demonstrates the feasibility of modeling QoL holistically as a latent variable, which could serve as the outcome variable in future research studies to test the utility of the contextual model of HRQoL for predicting QoL and designing interventions to support QoL among Native cancer survivors. Future research might also explore ways to integrate questions about cultural beliefs and expectations into QoL assessments and determine whether and how the information influences health care providers' decision-making about treatment and support, and QoL outcomes. In the context of our quantitative study, it may be that cultural beliefs and expectations are the missing link to explain anomalies in quantitative findings. Seeking to understand survivors' culture, values, and expectations may help health care providers prioritize supports they offer to patients to include those that survivors' perceive will have the greatest positive impact on their daily lives.

One important question raised by our research is that if we look at QoL holistically as we have done in this study, how do we interpret findings when survivors report limitations in one or more domains, but maintain a positive evaluation of their overall QoL? For example, does the fact that survivors in the *Mildly burdened* class report positive overall QoL in all domains mean that they perceive they are doing well and do not need further intervention? While survivors in this group reported experiencing physical limitations and social isolation, it may be that they aren't interpreting them as negative experiences. Future qualitative research studies could interview a subsample of survivors in the *Mildly burdened* class to better understand what QoL means to them in light of reported limitations. Findings from that research may have implications for providing care that attends to the whole person.

Finally, given advancements in oncology treatment over the past decade, future studies might replicate our latent class analysis among a cohort of Native survivors diagnosed within the past few years to see if the same QoL classes hold and with similar prevalence or if qualitatively different classes emerge. More research is also needed to explore the clinical utility of using person-centered methodologies like LCA to stratify survivors for tailored support services.

### ***Implications for public health***

Our research findings support previous calls from researchers to institute Native patient navigators as permanent paid staff of the health care system. The National Navigation Roundtable Policy Task Group recently released a white paper that reviews existing payment models for

supporting patient navigation and recommendations for establishing sustainable funding streams to support those programs (Osundina, Garfield, & Downer, 2019). Burhansstipanov et al. (2015) argue that while the role of Native patient navigators is similar to that of community health workers it diverges in terms of scope with Native navigators crossing the community boundary to continue providing cultural support within clinic departments. Navigators play a critical role to ensure that cancer services are “understandable, available, accessible, affordable, appropriate, and accountable” across all stages of the cancer continuum (Braun et al., 2012, p. 402). Grimes et al. (2017) found that navigator programs improved survivors’ QoL by providing critical logistical support (e.g. housing, transportation, appointment scheduling and completing paperwork), but also by providing deep emotional support, which was especially valued by survivors who lacked a strong support system. As such, incorporating Native navigators into existing health systems may be one component of a comprehensive strategy for reducing disparities in cancer outcomes and optimizing QoL among Natives with cancer.

Exploring heterogeneity in QoL among survivor populations provides data useful for informing targeted universalist approaches to population health improvement (Powell, 2008). Targeted universalism is an approach “that is inclusive of the needs of both the dominant and the marginal groups, but pays particular attention to the situation of the marginal group” (Powell, 2008, pp. 802-803). A targeted universalist approach would invest resources to improve QoL of all cancer survivors to a specific standard, while investing additional resources to support sub-groups of survivors with higher needs to achieve the same goals. For example, the American College of Surgeon’s Commission on Cancer Standard 3.1 requires cancer centers to implement a patient navigation process for accreditation. This standard is an example of a universal approach to supporting the QoL of all cancer patients. A targeted universal approach would invest additional resources to support Native navigators who specifically work with Native cancer patients – a population experiencing inequities – to address unique challenges of that population. Thus, targeted universalism is a strategy for eliminating health inequities while improving the health of everyone.

Lastly, our research supports continued investment in addressing social determinants of health including education, employment, and transportation infrastructure to support cancer survivors in Native communities. We provide evidence demonstrating the ways in which a healthy and educated community directly supports the QoL of survivors. In addition to relying on family and community for emotional support, survivors also relied on educated and tech savvy family members to research their cancer or advocate for them in the health care setting.



Employment provided access to health insurance and knowledge of how to navigate the health care system. Investing in the macro-level and systemic determinants of QoL that Ashing-Giwa (2005) outlines in the contextual model of HRQoL (livable wages, education, and employment; reducing life burden; reinforcing social support and ethnic identity; and reinforcing the positive aspects of interconnectedness between individuals and community) will create conditions for existing community strengths to flourish and for members to draw strength from each other to optimize QoL after cancer.

### **Recommendations**

Based on our study findings and implications, we recommend multiple directions for future research and interventions to optimize QoL among Native American cancer survivors.

#### ***Overall recommendations and considerations for future research***

- Use conceptual models similar to the contextual model of QoL described by Ashing-Giwa (2005) that incorporate socio-ecological and cultural influences on QoL to inform future research on QoL among Native American cancer survivors.
- Continue exploring the use of individualized, person-centered approaches (e.g. latent class analysis, qualitative methods) to assess QoL holistically and at the individual level. We demonstrated that traditional methods of isolating and averaging domain-specific QoL scores might underestimate needs of survivors who are faring poorly across all domains and miss or misspecify needs of other survivors.
- Future studies should test the feasibility and clinical usefulness of including questions on QoL assessment tools that ask survivors to rate their overall sense of balance between mind, body, emotions, spirit and community; how well they are balancing responsibilities between self and community; the extent to which they feel they are a burden to others; and how well their family is responding to their diagnosis. Survivor ratings of overall balance could be compared to domain-specific responses and enhanced with survivor interviews to understand how domain specific limitations influence perceptions of balance and what that means for designing interventions to support Native survivors.
- To overcome limitations of our study, future studies could replicate our LCA and conduct interviews with a random sample of survivors from each latent class to directly connect

qualitative to quantitative findings. Doing so would strengthen inferences made from integration and interpretation compared to integrating findings from different study samples as done in our study.

- When using LCA in studies of QoL, we recommend that survey items be scaled to prevent a neutral response (e.g. use a 4-point instead of a 5-point scale). Doing so will make it easier to dichotomize responses for analysis and facilitate interpretation of latent classes.
- Future research should investigate why long-term survivors living on reservations in the Southwest continue to feel stressed and overwhelmed from their cancer so many years after diagnosis. Of particular concern is that their needs may be going unnoticed because they appear to be thriving in other areas of health. Centering research studies among survivors who fit this profile may help to identify sources of stress and targets for intervention.
- One question to be answered by future research is how to design interventions to support survivors who simultaneously report domain-specific limitations to QoL and high levels of balance and harmony or overall QoL. Findings from that research may have implications for providing care that attends to the whole person.
- Future research should test the clinical utility of using person-centered methodologies like LCA to stratify survivors for tailored support services.

***Overall recommendations for designing interventions to support QoL of Native American cancer survivors***

- Design interventions that align with survivors' cultural experiences and beliefs. Specific examples include interventions that attend to spirituality, include family, include storytelling, and consider the whole person.
- Interventions should include strategies that center spirituality in approaches to healing.
- Use holistic QoL assessment strategies that assess expectations and perceptions of balance among mind, body, spirit, and community. This information will help to prioritize and tailor supports that meet the wishes and needs of individual patients.
- Be aware that addressing limitations in any one QoL domain will affect all other domains because of their interconnectedness. Thus, ask patients how a specific intervention might affect balance among other domains.

- Consider that supporting the whole survivor may require prioritizing and addressing socio-ecological and cultural factors that may have a greater influence on a survivors' QoL than physical concerns.
- Offer interventions to support survivors' families because survivors' individual QoL is closely tied to that of their families. This is especially important for supporting survivors who need to travel long-distances from home to receive cancer care.
- Provide social, cultural, and spiritual resources to Natives who must travel long distances to receive cancer care to bridge gaps in those resources left behind when they traveled away from home for care.
- Provide opportunities for survivors and members of their support network to advocate for their needs. Specific examples include interventions to increase knowledge and understanding about cancer; provide access to second opinions; encourage questions; and encourage survivors to bring someone with them to appointments.
- Institute Native patient navigators as permanent paid staff of the health care system to provide critical logistical, emotional, and cultural support for Native survivors and their families in clinical and community settings. Refer to the white paper published by The National Navigation Roundtable Policy Task Group for recommendations on establishing sustainable funding streams to support navigator programs.

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