

5-22-2016

Describing the end of life knowledge, beliefs, and preferences of Alaska Native and American Indian Peoples

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DESCRIBING THE END OF LIFE KNOWLEDGE, BELIEFS, AND PREFERENCES
OF ALASKA NATIVE AND AMERICAN INDIAN PEOPLES

Colleen M. Kelley

90 Pages

This dissertation is comprised of three manuscripts that will be submitted for publication, describing the end of life knowledge, beliefs, and preferences of Alaska Native and American Indian Peoples. The first manuscript is a literature review that examines what is known about the understanding about the end of life knowledge, beliefs, and preferences of Alaska Native and American Indian Peoples. The second manuscript offers results of an exploratory descriptive study designed to describe the end of life knowledge of hospice care services, beliefs about dying, and preferences for end of life care of Alaska Native and American Indian Peoples. Finally, the third manuscript shares this author's experiences and suggestions as a non-indigenous researcher conducting research in an indigenous world. The manuscript offers a brief review of literature of Indigenous worldviews on health and aging, an introduction to the Indigenous Research Paradigm, and practice and research implications.

KEYWORDS: Alaska Native, American Indian, End of life care, Hospice, Palliative care

DESCRIBING THE END OF LIFE KNOWLEDGE, BELIEFS, AND PREFERENCES
OF ALASKA NATIVE AND AMERICAN INDIAN PEOPLES

COLLEEN M. KELLEY

A Dissertation Submitted in Partial
Fulfillment of the Requirements
for the Degree of

DOCTOR OF PHILOSOPHY

Mennonite College of Nursing

ILLINOIS STATE UNIVERSITY

2016

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DESCRIBING THE END OF LIFE KNOWLEDGE, BELIEFS, AND PREFERENCE
OF ALASKA NATIVE AND AMERICAN INDIAN PEOPLES

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ACKNOWLEDGMENTS

I dedicate this dissertation to my husband, Bob, who recently passed away. Bob's unconditional love, encouragement, and support throughout this journey kept me going to meet this goal and I am forever grateful. His customary reference to me as "Doc" always gave me that little push to keep my chin up and keep going. Sadly, it was my first husband's death that led me to my interest in end of life research. Pat's death opened my eyes to the needs of those who are dying and the ways in which those needs seem to be swept under the carpet.

My PhD nursing education focusing on aging and vulnerable populations allowed me to set my research trajectory toward end of life research. Bob brought me to Alaska, allowing me to fulfill my dream to conduct research with Alaska Native and American Indian peoples. I thank the leaders of my research site for allowing me to spend time at their site and I thank my participants for their trust and for sharing so much information with me.

The first role model nurse that I knew was my mom, Lillian. She and my father Frank (deceased) were my first advocates to encourage my success in nursing school. From diploma in nursing, to Baccalaureate in nursing, to Master's in nursing, education has been a thread of my life. Once again, I found this level of education humbling; you do not know what you do not know until you face it head on. I now have many more role models in nursing, including my professors, who are incredibly educated and gifted to share their talents. Thank you to Mennonite College of Nursing, your vision to educate

nurses, at all levels, is demonstrated through your faculty and staff. I thank my dissertation committee members, Drs. Mary Dyck, Beth Leonard, Caroline Mallory, and Wendy Woith—your creativity, support and areas of expertise allowed me to grow and see things in a new way. Dr. Woith, my Chair, is an inspiration and words cannot express my gratitude for her guidance and patience with me.

To my children and stepchildren, Sean, Chase, Caitlin and Rachel, thank you for your patience and support as I was pulled away from scheduled activities to study and work on my projects over these many years. I love you all—to the moon and back! Keep pursuing your dreams and be passionate about achieving your goals.

Finally, this research journey allowed me to become friends with the first cohort of PhD nursing students at Illinois State University, Mennonite College of Nursing. Connee Sloman, Christina Garcia, Debbie Jenkins, and Theresa Schwindenhammer - what a ride we had, and I am so glad we did it together!

C. M. K.

CONTENTS

	Page
ACKNOWLEDGMENTS	i
CONTENTS	iii
TABLES	vi
FIGURES	vii
CHAPTER	
I. REVIEW OF LITERATURE OF END OF LIFE KNOWLEDGE, BELIEFS, AND PREFERENCES OF ALASKA NATIVE AND AMERICAN INDIAN PEOPLES	1
Abstract	1
Introduction	3
Concept Definitions	6
Background	7
End of Life	7
Culture and Pluralism	9
Palliative Care and Hospice	11
Peaceful Death	11
Method	13
Review of Literature	13
Research-Based Contributions in Literature	14
Expert Contributions in Literature	17
Summary	18
Conclusion	19
References	21

II. DESCRIBING THE END OF LIFE KNOWLEDGE, BELIEFS, AND PREFERENES OF ALASKA NATIVE AND AMERICAN INDIAN PEOPLES	29
Abstract	29
Introduction	31
Methods	33
Recruitment and Sampling	33
Assessment and Measures	34
Hospice Beliefs and Attitudes scale	34
Beliefs about Dying and Advance Care Planning scale	35
Preferences for End-of-Life scale	35
Demographic Characteristics, Use of Advance Directives	35
Results	36
Sample Characteristics	36
Variables of Interest	37
Knowledge: Self-reported knowledge and beliefs about hospice	37
Beliefs: Self-reported beliefs about dying and advance care planning	38
Preferences: Self-reported preferences for end of life	38
Preferences: Self-reported preference of place of death	39
Discussion	39
Research Question One	40
Research Question Two	41
Research Question Three	43
Limitations	43
Conclusion	45
References	53
III. PREPARING FOR RESEARCH WITH INDIGENOUS PEOPLES: REVIEW OF LITERATURE AND A NURSING PERSPECTIVE	58
Abstract	58
Introduction	60

My Experiences and Lessons Learned	62
Relationality	62
Lessons Learned	63
Communication	63
Indigenous knowledge systems	65
Indigenous Knowledge System Worldviews	66
Review of Literature	66
Native Nurses Caring for Natives	67
Health	68
Alaska Eskimo—Yup'ik/Cup'ik	69
Navajo	71
Sto:lo	72
Review of Literature on Aging	74
Athabaskan	74
Alaska Eskimo-Inupiaq	75
Alaska Aleut, Alaska Indian-Athabaskan, Alaska Eskimo-Inupiaq, Alaska Indian-Tlingit, Alaska Sugpiaq, Alaska Eskimo-Yup'ik	76
Summary of Literature	78
Indigenous Research Paradigm	80
Conclusion	82
Research Implications	83
Clinical Implications	84
References	87

TABLES

Table	Page
1. Demographic Characteristics for Race	47
2. Sample Demographic Characteristics	47
3. Hospice Knowledge Awareness via the Hospice Beliefs and Attitude Scale	48
4. Beliefs About Dying and Advance Care Planning Scale	49
5. Preferences for End-of-Life Care Scale	50
6. Preference for Location of Death	51

FIGURES

Figure	Page
1. Age distribution, n=44	52
2. Indigenous research paradigm	86

CHAPTER I
REVIEW OF LITERATURE OF END OF LIFE KNOWLEDGE, BELIEFS,
AND PREFERENCES OF ALASKA NATIVE
AND AMERICAN INDIAN PEOPLES

Chapter 1 is a manuscript that explores the state of the science about what is known about end of life knowledge, beliefs, and preferences of Alaska Native and American Indian peoples. The manuscript will be submitted to the *American Journal of Nursing* for publication consideration or as a poster presentation.

Abstract

A goal of Healthy People 2020 (2012) is to reduce or eliminate health disparities. One noted disparity exists in the use of hospice services between Alaska Native and American Indian peoples, among whom the utilization rate is 0.3% compared to 81.5% of their white population counterparts (National Hospice Palliative Care Organization [NHPCO], 2015). This literature review explored published articles about Alaska Native and American Indian peoples' experiences with end of life (EOL) to better understand this health disparity. Although a search of CINAHL, PubMed, and Web of Science produced 356 articles, only 5 research studies, 4 expert reports, and 1 palliative care booklet met the inclusion criteria. Few studies reported the Alaska Native or American Indian peoples' knowledge of hospice/palliative care services, their beliefs about death and dying, or their medical preferences when facing a non-curable illness. The reports pointed out the need to educate health care providers, enhance their comfort to provide

palliative care, create palliative care education program for health care providers, develop a rural community-based palliative care program, explore the negative stigma associated with death and lack of use of hospice, and develop a pamphlet about palliative care specific for the Alaska Native and American Indian peoples.

Introduction

The under-use of health care services at EOL by Alaska Native and American Indian peoples has been reported as a health disparity (Guadagnolo, Huo, Buchholz, & Petereit, 2014; Michalek, Mahoney, Gilbert, & Kaur, 2005; Shiovitz, Bansal, Burnett-Hartman, Andrea, et al., 2015). Furthermore, EOL care available to Alaska Native and American Indian peoples has not been provided in a culturally congruent manner (Burhansstipanov & Hollow, 2001). Programs have been initiated to educate healthcare providers about cultural considerations at EOL for Alaska Native and American Indian peoples; however, their effectiveness is unclear (DeCourtney, Jones, & Heavener, 2010; DeCourtney, Jones, Merriman, Heavener, & Branch, 2003; Education in Palliative Care and End-of-Life Care for Oncology Curriculum [EPECTM-O], 2007). The awareness of Alaska Native or American Indian peoples of different palliative care options when facing a non-curable illness is also unknown. This review of literature examines the Alaska Native and American Indian peoples' understanding of EOL knowledge, beliefs, and preferences. Understanding what is known and unknown will allow us to further develop and improve nursing interventions to increase the likelihood that Alaska Native and American Indian peoples will experience a peaceful death.

There are 5.2 million Alaska Native and American Indian peoples in the US, with the State of Alaska having the highest percentage of this population at 19.5% (Center for Disease Control and Prevention [CDC], 2010). Approximately 108,799 Alaska Native and American Indian peoples reside in the State of Alaska (Alaska quick facts, 2014). The total number of Alaska Native and American Indian deaths reported between 2007 and 2009 in Alaska was 10,572 (Alaska Bureau of Vital Statistics, 2011). In Alaska, the

leading 10 causes of death among Alaska Native and American Indian peoples are cancer, heart disease, unintentional injury, suicide, alcohol abuse, chronic obstructive pulmonary disease, cerebral vascular disease, chronic liver disease and cirrhosis, pneumonia and flu, and homicide (Day, Holck, & Provost, 2011). Alaska Native and American Indian peoples have higher rates of death in all categories compared to their white counterparts, with the exception of heart disease (Day, Holck, & Provost, 2011). Cancer continues to be the leading cause of death among Alaska Native peoples (Carmack, Schade, Sallison, Provost, & Kelly, 2015).

Although Alaska Native and American Indian cancer patients receive poorer quality of care compared to their white counterparts (Burhansstipanov, Gilbert, LaMarca, & Krebs, 2001; Burhansstipanov & Hollow, 2001; Gilliland, Hunt, & Key, 1998; Hampton, 1998), few studies have explored palliative or hospice care experiences by Alaska Native and American Indian peoples. Furthermore, only 0.3% of the American Indian/Alaska Natives were reported to use hospice compared to 76.0% of their white counterparts (National Hospice and Palliative Care Organization [NHPCO], 2015). This disproportionate finding among the Alaska Native and American Indian peoples represents a health disparity in hospice use, a form of palliative care at EOL (National Cancer Institute, 2011).

An essential component of EOL care is the ability to provide care within a cultural context (Baldrige, Garrett, Williams, Aldrich, & Benson, 2011; Kagawa-Singer & Blackhall, 2001; Schim, Doorenbos, & Borse, 2003). Culture influences an individual's behavior, attitudes, preferences, and decisions related to EOL care (Coolen, 2012; Tellez-Giron, 2007; Valente & Haley, 2003). These influences guide a patient's

reactions to dying or decisions associated with dying (Giger, Davidhizar, & Fordham, 2006; Kagawa-Singer & Blackwell, 2001; Koenig & Gates-Williams, 1995; Searlight & Gafford, 2005). One decision made at EOL is whether to implement an advance directive (Kwak & Haley, 2005), which specifies the information that the individual wishes to reveal regarding his/her terminal condition and the desire to die at home or use hospice services (Johnson, Kuchibhatla, & Tulsky, 2009). Despite the recognition that culturally competent care is important at EOL, very little research has explored the knowledge of palliative care/hospice, beliefs about death and dying, use of advance directives, and medical care preferences when approaching EOL among Alaska Native/American Indian peoples. DeCourtney, Branch, and Morgan (2010) reported that advance directives are confusing to Alaska's native peoples; furthermore, Alaska's native peoples are not comfortable discussing future events, and advance directives are often not discussed. Contrary to that view, Baldrige et al. (2011) reported that American Indian and Alaska Native peoples might be more willing to discuss EOL issues than previously reported. Earlier research reports (Hepburn & Reed, 1995) suggested that some American Indians do not speak about death out of fear that it may happen or that talking about advance care planning is considered a violation of Navajo values (Carrese & Rhoades, 1995). This led to the assumption that Alaska Native and American Indian peoples may not be comfortable discussing events that occur in the future, thus making it more challenging to discuss advance directives. Baldrige et al. (2011) suggested that this might not be the case because as culture is ever changing, more successful palliative care programs and EOL conversations are being reported among Alaska Native and American Indian peoples in the lower 48 States.

This literature review begins with definitions of major concepts associated with EOL care, allowing the reader to better understand the context in which this care is based. The concepts defined are culture and pluralism, EOL, palliative and hospice care, and peaceful death. Relevant studies will be reviewed following the definitions.

Concept Definitions

Culture is learned from families during the socialization process, and it consists of beliefs, practices, habits, likes, dislikes, norms, customs, and rituals of a person (Spector, 2004). This review of literature focuses on the Alaska Native and American Indian culture. Alaska Native and American Indian peoples, as the indigenous peoples of Alaska, have been living side by side with the dominant society, contributing to a pluralistic society. According to Merriam-Webster (2012), “pluralism is a situation in which people of different social classes, religions, races, etc., are together in a society but continue to have their different traditions and interests” (www.merriam-webster.com). By definition, this concept may explain why the dominant culture may be unaware of how Alaska Native and American Indian peoples understand EOL concepts.

End of life refers to the last 6 months of life. Before the patient can receive hospice services, the hospice benefits provided by Medicare require that two physicians certify a patient is approximately in his/her last 6 months of life, assuming his/her illness runs a normal course (Center for Medicare and Medicaid Services, 2008). Thus, for the purpose of this literature review, EOL will refer to the last 6 months of life.

The World Health Organization (World Health Organization [WHO], 2013) states that, “palliative care improves the quality of life of patients and families who face life-

threatening illness by providing pain and symptom relief, spiritual and psychosocial support to [sic] from diagnosis to the end of life and bereavement” (para 3). Hospice care is a form of palliative care that focuses on comfort, dignity, and quality of life/relationship closure, all under the control of the patient and family (Ferrell& Coyle, 2010). In the US, Medicare and Medicaid offer hospice benefits to those whose life expectancy is six months or less when their illness follows the expected course (MedPac, 2015; Medicaid, 2016).

Finally, peaceful death is an experience during which the dying person’s EOL wishes and directions are followed as he/she nears death. Similarly, the Institute of Medicine (IOM) offers characteristics desired at the time of death, “...one that is free from avoidable distress and suffering for patients, families, and caregivers in general accord with patients and families’ wishes and reasonably consistent with clinical cultural, and ethical standards” (Field & Cassel, 1997, p. 24).

Background

End of Life

Historically, care of the dying was reported as inadequate in the United States (Field & Cassel, 1997; Last Acts, 2001; SUPPORT, 1995). Grassroots efforts to bring hospice to the US have provided much needed care at EOL, yet patients and physicians do not fully understand many aspects of hospice at EOL (Gazelle, 2007). Some feel that once it is determined that medicine has done all it can do to save a life; the quality of care subsides. The Institute of Medicine’s 1997 report, *Approaching Death: Improving Care at End of Life* (Field & Cassel), brought end of life issues to the forefront. This report identified the management of death in the US with suggestions for research to help us

develop a better understanding of individuals' needs at EOL. In the newly released report by the IOM, the Committee on Approaching Death: *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* reported that despite the increased knowledge of health professionals, patient care has not improved (IOM, 2015). Furthermore, Americans lack knowledge about EOL care options, and community leaders do not fully utilize strategies to make EOL knowledge available in culturally meaningful ways (IOM, 2015).

The American Association of Retired Persons (AARP) in North Carolina (NC) and Massachusetts (MA) studied end of life knowledge, preferences, and beliefs in two surveys. In both surveys, 84% (NC) and 86% (MA) of the AARP members reported being at least somewhat comfortable talking about death. Half of the members reported speaking only to family about their EOL wishes; 11% (NC) and 17% (MA) reported they had discussed EOL wishes with their physician; more than 90% of the members had heard of hospice; and 75% would want hospice support at EOL. Although Alaska Natives and American Indian participants were included in the studies, the results from the AARP surveys did not differentiate or include Alaska Native/American Indian separately (Dinger, 2005; Straw & Cumings, 2003). No study examining EOL knowledge, preferences, and beliefs among Alaska Native/American Indian peoples residing in Alaska has been reported.

In Bristol Bay, Alaska, following the recognition of the need for a hospice-style service for chronically and terminally ill patients, the community worked together to create an EOL program that began its formation in 1999 (Healthy Alaskans, 2010). This EOL program focused on the needs of Alaska Native and American Indian peoples living

in one rural area in Alaska. The program and materials were specifically developed to meet the cultural needs of the Alaska Native and American Indian peoples living in the Bristol Bay area. DeCourtney, Jones, Merriman, Heavener and Branch (2003) described the ways in which focus groups contributed to the program design as well as the ways in which elders provided essential information about EOL needs and practices. Many of the program materials were printed in English as well as translated and printed in Yup'ik, a predominant native language in the area. Unfortunately, the materials developed during this initiative are not retrievable.

Culture and Pluralism

Although the U.S. is often referred to as a melting pot of many cultures and ethnic groups, the melting pot theory of assimilation may no longer be accurate (Locke, 1992). A more accurate depiction of society is that of the US as a multicultural or pluralistic society (Braun, Pietsch, & Blanchette, 2000). This reality is represented by many cultures living among each other, maintaining their traditional cultures, yet truly not understanding each other's specific cultural beliefs or habits (Loustaunau & Sabo, 1997). Cultural pluralism is a concept that highlights the unique ways of a minority society and their contribution to the society as a whole within its distinctive cultural traditions (Barnhardt, 1981).

Alaska's native peoples comprise 11 individual cultures with 20 distinct languages and multiple dialects (Alaska Native Language Center, 2014). These eleven cultures are divided into five groupings based on cultural likenesses and geographic location (Alaska Native Heritage Center, 2016). Culture allows social groups to live in harmony by sharing their beliefs, values, and practices (Giessler, 1998). However, these

group characteristics may not be shared or understood across cultures. Current literature offers very little understanding of Alaska Native and American Indian peoples' knowledge of palliative care or hospice or about their beliefs about dying and Advance Care planning. Their preferences for EOL care are not widely known to the dominant culture.

Cultural studies about Alaska Native and American Indian peoples diagnosed with cancer revealed important characteristics. Buhansstipanov and Hollow (2001) found that nurses were culturally competent with regards to respect of culture needs; however, ancillary staff were not. They also noted that the loss of body parts from surgery could cause spiritual distress because an ancestor might not recognize the person without the body part when he/she passes on to the next side. Some tribes would not allow EOL care in the home because evil spirits could linger or ghost sickness could affect others (Buhansstipanov & Hollow, 2001). It was reported that if EOL care were provided at home, the house would be burned after the death. The authors found that there is a female dominance in decision-making and that non-blood relatives could be included in the decision-making process related to EOL care. Burhansstipanov (2005) reported that cancer survivors recounted inadequate pain management and unreliable pain tools being used to measure pain. She also noted communication discrepancies regarding the meaning of words. Specifically, health care providers may use the expression positive or negative when discussing a diagnostic finding. Words have the potential for misinterpretation; for example, positive means good and negative means bad (Burhansstipanov, 2005). However, in health care a positive result indicates something is wrong, and a negative finding suggests nothing wrong was found.

Palliative Care and Hospice

The State of Alaska is vast; it is more than twice the size of Texas. Alaska has 33,900 miles of coastline, which is 50% more than the continental United States (American Local History Network [ALHN] Alaska, 2013). Many Alaskans live in remote areas where palliative care or hospice services are not available. Alternative solutions to hospice services in the traditional form have been explored because geographically, it is not possible to have hospice in every village. Helping Hands was one alternative solution program created to support those in need of palliative care at home in a remote area of Alaska instead of flying to Anchorage. This program will be covered in the next section. Another alternative in Alaska to traditional medical care delivery was telemedicine. Hudson (N.D.) reported that telemedicine in the form of high-frequency radio, satellite, and fiber optic with computer peripheral support has increased the numbers of off-site patients treated with doctor's advice; in fact, about 72% of those seen via telemedicine needed treatment. Outcomes included decreased travel, decreased waiting times, fewer days of lost work and school, resulting in cost savings of 2.8 million Medicaid dollars between the years 2003 and 2009. Hospice, however, was not on the list of clinical specialties available.

Peaceful Death

A peaceful death or good death can be a desired outcome of EOL care, regardless of whether a patient chooses curative or palliative care. Hospice philosophy embraces the characteristics of a peaceful death, as described by IOM (NHPNA, 2015). Kehl (2006) analyzed 42 articles about a good death and found that experiences and perspectives

affect patient perception of a peaceful death; thus, it is different for each person.

Common attributes of a good death include having control, being comfortable, allowing for closure, recognizing value and beliefs, trusting care providers, knowing about impending death, minimizing any burdens, and leaving a legacy.

There are several identified barriers to a peaceful death for Alaska Natives and American Natives. Burhansstipanov (2005) found Alaska Native and American Indian cancer survivor patients were unlikely to have quality EOL experiences because they did not have access to EOL trained healthcare providers. She also found poor integration between traditional spiritual healing and Western medicine and poor communication between cancer doctors and other physicians, leading to poor collaboration of care.

Dying in pain is a fear reported by three-quarters of respondents of both AARP EOL surveys, which included Alaska Native and American Indian peoples (Dinger, 2005; Straw & Cummins, 2003). Burhansstipanov (2005) reported patients thrashing in pain while dying. Their pain was not managed because they were too weak or not able to travel to pick up their own pain medication. Access to pain medications is a problem for Alaska Native peoples who live in remote areas and may have to fly 900 miles or longer each way to have pain medicine refilled, as pain medications are not readily available in the bush. Medications may also be mailed; however, mail delivery times can vary by several days or longer dependent on weather and other factors affecting flying.

DeCourtney et al. (2003) reported that after the Helping Hands Program was implemented, some elders were able to return to their villages and experience EOL care in familiar surroundings. In fact, home deaths rose from 33% to 77% for patients diagnosed with cancer, lung, heart, and renal diseases. There was also an increase of

written advance directives after the program was initiated. The program focused on pain management, training of health care providers, family members and volunteers. The program successfully delivered modern day palliative care concepts integrated with traditional lifestyle of the community.

Method

The initial search began by meeting with an experienced librarian to review relevant search terms and subject headings. The librarian searched CINAHL, PubMed, and Web of Science. Key search terms and subject headings included Indigenous peoples, Alaska Native, American Indian, palliative care, hospice, and end of life. There were 356 articles identified, which were then examined against the inclusion criteria of: (a) including Alaska Native, American Indian, or Indigenous Peoples in their samples; (b) reporting about experiences with EOL, palliative care, or hospice; (c) including participants of 18 years or older; (d) and being conducted between 1990 and 2016. Abstracts were reviewed for knowledge of hospice care, beliefs surrounding EOL care, and preferences surrounding EOL. Five research articles were found in addition to four expert opinion/experiences related background articles providing noteworthy information.

Review of Literature

The identified literature provided nine examples of how palliative care was being addressed by Alaska Native or American Indian peoples. These examples included reports on the use of focus groups to form rural palliative care programs (DeCourtney et al., 2010), delivery of palliative care by health care providers (Arenella et al., 2010; DeCourtney et al., 2003; DeCourtney & Mitchell, 2006), the process used to establish a

rural community-based palliative care program (DeCourtney et al., 2003; DeCourtney, Branch, & Morgan 2010), a pamphlet introducing the concept of palliative care to Alaska Native/American Indian peoples in a culturally sensitive manner (DeCourtney, 2009), a palliative care program called Education in Palliative Care and End-of-Life Care for Oncology (EPEC™-O) to educate health professionals about American Indian and Alaska Native peoples' cultural experiences (Arenella et al., 2010), and American Indian experiences at EOL (Colclough & Brown, 2014).

Research-Based Contributions in Literature

Focus groups were used to gather information about the formation of culturally sensitive palliative care education programs for health care providers in the literature reviewed. DeCourtney et al., 2010 reported on the focus groups' contribution to the Helping Hands Program creation (a remote community-based palliative care program in Alaska). They conducted an Alaska-wide survey with Community Health Aides (CHA), which was completed in 2007, revealing that elders prefer to die in their communities. The survey results indicated that CHA learned to set boundaries with family and encourage family involvement to assist with care, as CHAs were overburdened. Community health aides also reported that pain management was an issue. In addition to pain medication being sent home with the patient (from hospital), there was a need for other medical supplies to be sent home as well. DeCourtney et al. (2010) reported that a series of focus groups produced valuable information, such as traditional care for dying people, the sort of support needed by caregivers, current preferences and beliefs associated with death, and the need for various community programs that are specific to their cultural needs. Authors made recommendations for the development of culturally

sensitive palliative care programs based on the focus group feedback.

Michalek, Mahoney, Gilbert, and Kaur (2005) conducted a national survey with tribal health directors to study palliative care needs. While conducting a review of literature, they only found two articles that addressed palliative care needs in Native American communities (p.119). Their aim was to increase the knowledge of perceived needs and availability of palliative care services in Native American communities. They mailed a 38-item questionnaire to all tribal health directors listed with the Indian Health Services. Their two mailings yielded a 37% response rate. Michalek et al. (2005) reported on tribal health directors' (THD) perceived current trends of diseases, in addition, the THDs' rank-ordered 10 areas of need for palliative care support in terms of their importance. The top five areas of need were pain management services (70%), followed by the need for advance care planning (58%), hospice contracts (54%), care for the dying (53%), and bereavement support (52%). The survey also asked whether the 10 areas were offered inside the reservation, in nearby community, or not at all. Most services were not available or only available outside the community (Michalek et al., 2005).

Guadagnolo, Huo, Bucholz, and Petereit (2014) studied American Indian peoples' use of hospice. Their review of literature found no study that analyzed hospice enrollment among American Indian cancer patients. Guadagnolo et al. (2014) used Medicare linked databases to analyze hospice utilization patterns of 181,316 White and 690 American Indian patients aged 65 or older. Hospice utilization was measured by assessing hospice admissions during the last 6 months of life. They found fewer American Indian peoples (54%) enrolled in hospice compared to their white counterparts (65%), supporting a health disparity in hospice utilization. (Guadagnolo et al., 2014).

In another study, Schrader, Nelson, and Eidsness (2005) reported American Indian peoples' preferences for EOL care. Their literature review found four articles on American Indian perspectives on EOL. Schrader et al. (2005) adapted the South Dakota's Dying to Know [SDD2K] questionnaire to assess attitudes toward death and dying, advance care planning, resident needs living in South Dakota, knowledge of hospice, EOL preferences of American Indian, and difference between American Indian and non-American Indian needs in South Dakota. Overall, 2,533 surveys were returned, and 71 were from American Indians. The authors used a typology of EOL attitudes and actions comprising four areas, spirituality, family, health care, and self. Most of American Indian participants (96%) felt it was important to experience spiritual peace at EOL. Many participants also valued aging, felt dying was an important part of life, and felt comfortable thinking about life after death (89%, 87%, and 82%, respectively). A high percentage (96%) felt it was important to receive comfort from religious/spiritual services in addition to knowing how to say goodbye. Participants wanted to get honest answers from their physician (94%), and they would like a physician to visit them at home when suffering from a terminal illness (84%). Just 7% had talked about EOL wishes with their doctor, and 28% preferred the physician bring up the subject of EOL with them. American Indian and non-American Indian participants differed significantly in their responses to some items. American Indian peoples were more likely to avoid medical checkups (did not want to find out there was something serious wrong), they were more likely to think their physician would not believe they were in pain or treat pain, they were less likely to trust the information given about EOL by their provider, and they were less

likely to want EOL conversations initiated by their physician and less likely to hear about hospice (all $p = .001$). Only 42% had talked to their spouses about preferred EOL actions (yet 71% had discussed with family), 25% had completed an advance directive, and 90% wanted to die at home.

Colclough and Brown (2014) conducted an exploratory study in Montana based on grounded theory to identify the meanings of EOL experiences of 58 American Indian participants. The central theme identified was *struggle*, which was found to be influenced by *knowledge* (and connectedness). *Knowledge* was further divided into two categories, medical knowledge and care knowledge. Most participants reported being unaware of local options for hospice and being unfamiliar with the term hospice or the meaning of hospice (Colclough & Brown, 2014).

Expert Contributions in Literature

Noteworthy expert contributions to the literature include a study by DeCourtney (2009) who compiled stories from Alaska Native and American Indian elders' personal experiences related to peaceful death and developed a culturally specific pamphlet that introduced palliative care (including hospice) to the Alaska Native and American Indian community. This pamphlet defined palliative care, hospice, and the ways in which culture is honored. It also includes information about children and EOL. Arenella et al. (2010) evaluated an Alaska Native and American Indian culture module that was added to the EPEC™-O train-the-trainer program. The program was developed as a 'train the trainer type model' that contained self-study sections. It also contained video examples of interviewing clients in a culturally appropriate manner. Furthermore, the program format was developed using a multi-disciplinary approach. Eighty-nine participants attended

three conferences that presented the culturally adapted curriculum (Arenella et al., 2010). The respondents worked predominantly in rural areas, majority were nurses (44%), followed by physicians (34%), social workers (12%), pharmacists (5%), and others (5%). Conference expectations were met or exceeded by 96%, knowledge of palliative care had increased post-conference, and 65% felt they would change their practice with this new knowledge. DeCourtney and Mitchell (2006) presented a poster presentation reporting results of a questionnaire administered to physicians, mid-level practitioners, nurses, social workers, and pharmacists in the Alaska Tribal Health System. Of the 67% responding, 73% reported they had not had palliative care training. Furthermore, 69% had cared for patients needing palliative care. Topics respondents identified as needing further training included pain and symptom management and culturally appropriate delivery methods (no formal report on study found in literature). DeCourtney, Jones, Merriman, Heavener, and Branch (2003) summarized the development of the Helping Hands Program, which allows residents living in Alaska's remote areas to return home and receive palliative care and EOL services. As the Helping Hands Program evolved, it became part of a home health program to better meet the needs of the patients returning home to their communities.

Summary

In summary, five research studies have explored Alaska Native/American Indian peoples' EOL needs. These studies have described formation of a culturally sensitive palliative care education programs for health care providers (DeCourtney et al., 2010) and perceived needs and availability of palliative care services in Indian Health Services (IHS) regions (Michalek et al., 2005). Guadagnolo et al. (2014) studied American Indian

hospice admissions while Schrader et al. (2005) studied preferences about EOL care. These five studies highlighted the need for the creation of culturally sensitive programs for Alaska Native and American Indian peoples. EPECTM-O and Helping Hands Programs are available health care practitioners have available to them to provide culturally appropriate palliative care. Tribal health care directors identified deficits in service, lack of knowledge related to hospice concepts (Colclough & Brown 2014), hospice use health disparity among American Indian (Guadagnolo et al., 2014), and EOL preferences of American Indian peoples (Schrader et al., 2009).

Many professionals work hard to gather information to explain palliative care for Alaska Natives and American Indian peoples and health care practitioners. For example, DeCourtney (2009) created a pamphlet in a culturally appropriate story-telling format, Arenella (2010) evaluated expert content in a new module that was added to EPECTM-O with health care providers, DeCourtney et al. (2003) offered step-by-step observations of the creation of Helping Hands and the evolution of the program, and finally, DeCourtney and Mitchell offered examples of the needs of health care practitioners.

Conclusion

Only DeCourtney et al. (2010) reported the results of a focus group about palliative care and beliefs about EOL care with Alaska Native and American Indian peoples residing in Alaska. Given the unique cultures of these peoples, research is necessary to understand their EOL needs. The state of the science lacks in this area. Therefore, it is helpful to learn about other indigenous peoples in the lower 48 States. However, further research needs to investigate the current opinions of those living in Alaska. In alignment with the IOM findings, this review of the literature has found

significant references about EOL care, including enhancing health care providers' EOL knowledge through education efforts and developing culturally specific programs.

Despite enhanced education, the population is in need of practitioners who are skilled in palliative care (IOM, 2015). Furthermore, the IOM (2015) reported that patient care has not improved; the public continues to lack knowledge about EOL care options, and community leaders have not efficiently engaged in strategies needed to begin EOL conversations in a culturally appropriate manner. Alaska is unique in terms of location and resources compared to the contiguous United States. The needs of Alaska Native and American Indian peoples who reside in Alaska can be challenging at best. It is crucial for health care professionals and community leaders to work together to measure the Alaska Native and American Indian peoples' understanding and specific needs to increase their EOL knowledge and their engagement in conversations about EOL experiences.

References

- Alaska Bureau of Vital Statistics. (2011). *Top ten leading causes of death for Alaska*. Retrieved from http://www.hss.state.ak.us/dph/bvs/death_statistics/Leading_Causes_Census/frame.html
- Alaska Native Heritage Center. (2016). *Education and Programs*. Retrieved from <http://www.alaskanative.net/en/main%2Dnav/education%2Dand%2Dprograms/cultures%2Dof%2Dalaska/>
- Alaska Native Language Center Museum. (2014). *Languages*. Retrieved from <http://www.uaf.edu/anlc/languages/>
- Alaska quick facts. (2014). *US Census Bureau*. Retrieved from <http://quickfacts.census.gov/qfd/states/02000.html>
- American Local History Network Alaska. (2013). *Alaska's five regions*. Retrieved from <http://www.usgenet.org/usa/ak/state/regionmap.html>
- Arenella, C., Finke, B., Domer, T., Kaur, J. S., Merriman, M. P., & Ousley, A. (2010). Adaptation, dissemination, and evaluation of cancer palliative care curriculum for the Indian health system. *Journal of Palliative Care*, 26(1), 15-21.
- Baldrige, D., Garrett, M., Williams, E., Aldrich, N., & Benson, A. W. (2011). *Moving beyond paradigm paralysis: American Indian end-of-life care*. Retrieved from <https://www.cms.gov/.../EOL-AI-AN-CIB-508-compliant.pdf>
- Barnhardt, R. (1981). *Barnhardt: Culture, community and curriculum*. Center for Cross Cultural Studies, University of Alaska Fairbanks. Retrieved from <http://ankn.uaf.edu/Curriculum/Articles/RayBarnhardt/CCC.html>

- Braun, K., Pietsch, J. H., & Blanchette, P. L. (Eds.). (2000). *Cultural issues in end-of-life decision making*. Thousand Oaks, CA: Sage.
- Burhansstipanov, L. (2005). Community-driven Native American cancer survivors' quality of life research priorities. *Journal of Cancer Education, 20*(Suppl), 7-11.
- Burhansstipanov, L., Gilbert, A., Lamarca, K., & Krubs, L. U. (2001). An innovative path to improving cancer care in Indian country. *Public Health Reports, 116*, 424-433.
- Burhansstipanov, L., & Hollow, W. (2001). Native American cultural aspects of oncology nursing care. *Seminars in Oncology Nursing, 17*(3), 206-219.
- Carmack, A. M., Schade, T. L., Sallison, I., Provost, E. M., & Kelly, J. J. (2015). *Cancer in Alaska Native people: 1969-2013 The 45-year report*. Anchorage, AK: Alaska Native Tumor Registry, Alaska Epidemiology Center, Alaska Native Tribal Health Consortium 2015.
- Carrese, J. A., & Rhodes, L. A. (1995). Western bioethics on the Navajo reservation. Benefit or harm? *Journal of American Medical Association 274*(10), 826-829.
- Center for Disease Control and Prevention. (2010). *Fast stats: Health of American Indian or Alaska Native population*. Retrieved from www.cdc.gov/nchs/faststats/facts.html
- Center for Medicare and Medicaid Services. (2008). Medicare and Medicaid programs: Hospice conditions of participation; Final rule. *Federal Register, 73*: 32088.
- Colclough, Y. Y., & Brown, G. M. (2014). End-of-life treatment decision making: American Indians' perspective. *American Journal of Hospice and Palliative Medicine, 31*(5), 503-512.

- Coolen, P. R. (2012). *Cultural relevance in end-of-life care*. Retrieved from <http://www.euromedinfo.eu/how-culture-influences-health-beliefs.html/>
- Day, G., Holck, P., & Provost, E. M. (2011). *Alaska Native mortality update: 2004-2008*. Alaska Native Epidemiology Center. Retrieved from http://www.anthctoday.org/epicenter/publications/mortality/AlaskaNativeMortalityUpdate2004_2008_17_jan_2012.pdf
- DeCourtney, C. A. (2009). *Palliative care: Easing the journey with care, comfort, and choices*. Anchorage: Alaska Native Tribal Health Consortium.
- DeCourtney, C. A., Branch, P. K., Morgan, K. M. (2010). Gathering information to develop palliative care programs for Alaska's Aboriginal Peoples. *Journal of Palliative Care*, 26(1), 22-31.
- DeCourtney, C. A., Jones, K., Merriman, M. P., Heavener, N., & Branch, P. K. (2003). Establishing a culturally sensitive palliative care program in rural Alaska Native American communities. *Journal of Palliative Medicine*, 6(3), 501-510.
- DeCourtney, C. A., Jones, K., & Heavener, N. (2010). Helping hands: Easing the end of life journey. *Healthy Alaskans 2010*, Volume II. Retrieved from http://dhss.alaska.gov/dph/Documens/HA2010/Volume%202/05_Helping_Hands.pdf
- DeCourtney, C. A., & Mitchell, K. M. (2006). *Measuring palliative care knowledge, attitudes, behaviors, and training needs among healthcare providers of Alaska natives*. Poster Presentation.
- Dinger, E. L. (2005). *AARP Massachusetts End of Life Survey*. Washington DC: Knowledge Management. Retrieved from http://assets.aarp.org/rgcenter/health/ma_eol.pdf.

- Education in Palliative and End-of-life Care for Oncology (EPEC™-O). (2007).
EPEC™-O: The CD-ROM with AI/AN Cultural Considerations.
- Ferrell, B. R., & Coyle, N. (Eds.). (2010). *Oxford textbook of Palliative nursing* (3rd ed.).
 New York, NY: Oxford University Press, Inc.
- Field M. J., & Cassell, C. K. (Eds.). (1997). *Approaching death: Improving care at the
 end of life, Institute of Medicine.* Washington, DC: National Academy Press.
- Gazelle, G. (2007). Understanding hospice: An underutilized option for life's final
 chapter. *New England Journal of Medicine*, (357) 321-324.
- Geissler, E. M. (1998). *Pocket guide to cultural assessment* (2nd ed). St. Louis, MO:
 Mosby.
- Giger, J., Davidhizar, R., & Fordham, P. (2006). Multi-cultural and multi-ethnic
 considerations and advanced directives: Developing cultural competency. *Journal
 of Cultural Diversity*, 13(1), 3-9.
- Gilliland, F. D., Hunt, W. C., & Key C. R. (1998). Trends in the survival of American
 Indian, Hispanic, and Non-Hispanic white cancer patients in New Mexico and
 Arizona, 1969-1994. *Cancer*, 82(9), 1769-83.
- Guadagnolo, B. A., Huo, J., Bucholz, T. A., Petereit, D. G., (2014). Disparities in hospice
 utilization among American Indian Medicare beneficiaries dying of cancer.
Ethnicity and Disease (24)4, 393-8.
- Hampton, J. W. (1998). The disproportionately lower cancer survival rate with increased
 incidence and mortality in minorities and underserved Americans. *Cancer* (83)
 1687-1689.
- Healthy Alaskans 2010. (2010). *Easing the end of life journey: Helping hands in Bristol*

Bay. Alaska Department of Health and Social Services, Division of Public Health. Retrieved from http://dhss.alaska.gov/dph/Documents/HA2010/Volume%202/05_HelpingHands.pdf

Healthy People 2020. (2012). *Disparities*. Retrieved from <http://healthypeople.gov/2020/about/DisparitiesAbout.aspx>

Hepburn, K., Reed, R. (1995). Ethical and clinical issues with Native-American elders. End-of-life decision making. *Clinical Geriatric Medicine*, 11(1), 97-111.

Hudson, H. E. (n.d.). Rural Telemedicine and Telehealth: The Alaskan experience. Retrieved from <http://www.comsoc.org/files/About%20Consoc/DLT/DSP/EMEA/Hudson-DSP-EMEA2011-Presentation.pdf>

IOM (Institute of Medicine). 2015. *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: The National Academies Press.

Johnson, S., Kuchibhatla, M., & Tulskey, J. A. (2008). What explains racial difference in the use of advance directives and attitudes toward hospice care? *Journal of American Geriatric Society*, 56(10), 1953-1958.

Kagawa-Singer, M., & Backhall, L. (2001). Negotiating cross-cultural issues at end of life. *Journal of American Medical Association*, 286(3001), 2993-3001.

Kehl, K. A. (2006). Moving toward peace: An analysis of the concept of a good death. *American Journal of Hospice and Palliative Care*, 23(4), 277-286.

Koenig, B., & Gates-Williams, J. (1995). Understanding cultural differences in caring for dying patients. *The Western Journal of Medicine*, 163(3), 244-249.

Kwak, J., & Haley, W. (2005). Current research findings on end-of-life decision making

- among racially or ethnically diverse groups. *The Gerontologist*, 5(45), 634-641.
- Last Acts. (2002). *Means to a better end: A report on dying in America*. Retrieved from <http://www.rwjf.org/files/publications/other/meansbetterend.pdf>
- Locke, D. C. (1992). *Increasing multicultural understanding: A comprehensive model*. Newbury Park: Sage Publications.
- Loustanau, M. O., & Soho, E. J. (1997). *The cultural context of health, illness, and medicine*. Westport, CT: Bergin & Garvey.
- MedPac. (2015). Report to Congress: Medicare payment policy. Ch 12, *Hospice Services*. Retrieved from [http://medpac.gov/documents/reports/chapter-12-hospice-services-\(march-2015-report\).pdf](http://medpac.gov/documents/reports/chapter-12-hospice-services-(march-2015-report).pdf)
- Medicaid. (2016). *Hospice benefits*. Retrieved from <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/benefits/hospice-benefits.html>
- Michalek, A. M., Mahoney, M. C., Gilbert, A., & Kaur, J. (2005). Palliative care services: A survey of tribal health directors. *The IHS Provider*, May, 118-9.
- National Cancer Institute. (2011). *A Look at End-of-Life Care Issues for Native Americans*. Retrieved from <http://indiancountrytodaymedianetwork.com/2011/11/21/look-end-life-care-issues-native-americans-63942>
- National Hospice and Palliative Care Organization [NHPCO]. (2015). *Facts and Figures on Hospice Care*. Retrieved from <http://www.nhpco.org/hospice-statistics-research-press-room/facts-hospice-and-palliative-care>
- Pluralism. (2016). In *Merriam-Webster.com*. Retrieved from <http://www.merriam->

webster.com/dictionary/pluralism

- Schim, S. M., Doorenbos, A. Z., & Borse, N. N. (2006). Enhancing cultural competence among hospice staff. *American Journal Hospice and Palliative Care*, 23, 404-411.
- Shiovitz, S., Bansal, A., Burnett-Hartman, A. N., et al. (2015). Cancer-directed therapy and hospice care for metastatic cancer in American Indians and Alaska Natives. *Cancer Epidemiology Biomarkers and Prevention*, (24)7, 1138-1143.
- Searlight, H., & Gafford, J. (2005). Cultural diversity at the end of life: Issues and guidelines for family physicians. *American Family Physicians*, 71(3), 515-522.
- Spector, R. E. (2004). *Cultural diversity in health and illness* (6th ed.). Upper Saddle River, NJ: Prentice Hall Health.
- Straw G., & Cummins M. A. (2003). The Carolinas center for hospice and end of life care. *AARP North Carolina End of Life Care Survey*. Retrieved from www.aarp.org/research/reference/memberopinions/aresearch-import-68.html.
- SUPPORT Principal Investigators (1995). A controlled trial to improve care for seriously ill-hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatment. *Journal of the American Medical Association*, 274(20), 1591-1998.
- Tellez-Giron P. (2007). Providing culturally sensitive end-of-Life care for the Latino/a community. *Wisconsin Medical Journal*, 7(106), 402-406.
- Valente, S., & Haley, A. B. (2003). Culturally diverse communities and end-of-life care. *Care Management Journals*, 4(1), 44-45.
- World Health Organization. (2010). *Better palliative care for older people*. Retrieved

from <http://www.euro.who.int/document/E82933.pdf>

World Health Organization. (2013). *Improving the quality of life for patients and families*. Retrieved from <http://www.who.int/cancer/palliative/en/>

CHAPTER II
DESCRIBING THE END OF LIFE KNOWLEDGE, BELIEFS, AND
PREFERENCES OF ALASKA NATIVE AND
AMERICAN INDIAN PEOPLES

Chapter II is a manuscript that describes the methods and results of survey methodology used to measure end of life knowledge, beliefs, and preferences between Alaska Native and American Indian Peoples. This manuscript will be submitted for publication consideration to *Hospice and Palliative Care Nursing*.

Abstract

This study was designed to describe end of life (EOL) knowledge, beliefs, and preferences of Alaska Native and American Indian peoples (AN/AI). Using a convenience sample, the data were collected from 49 adults living on an urban residential campus in Anchorage, Alaska, and a remote Southwest town in Alaska. Three scales were used to measure the knowledge of hospice (Hospice Beliefs and Attitude Scale), preferences for end of life (Preferences for End-of-Life Care Scale), and beliefs about dying and advance care planning (Beliefs about Dying and Advance Care Planning Scale). The results indicated that most had undocumented advance directives, nearly one-quarter had no knowledge of hospice services, only 10% had heard about hospice from their health care provider, many had misconceptions about services hospice offers, a high percentage are comfortable discussing beliefs about dying, however fewer had discussed

those beliefs with their families. We recommend culturally appropriate advance care planning, with health care providers initiating EOL discussions using a holistic approach.

Key Words: Alaska Native, American Indian, indigenous people, end of life, hospice, palliative care, advance directive, end-of-life preferences, end-of-life beliefs, end-of-life knowledge.

Introduction

Alaska Native and American Indian peoples are considered indigenous people to the United States. As their life expectancy grows, so do rates of chronic diseases, adding to the need for EOL discussions (Kelley, 2010; Kitzes & Berger, 2004; Kitzes & Domer, 2004). In the U.S., hospice and palliative care have become mainstream concepts (Institute of Medicine [IOM], 2015) yet they remain a health disparity for Alaska Natives and American Indian peoples (Guadagnolo, Huo, Bucholz, & Petereit, 2014; Michalek, Mahoney, Gilbert, & Kaur, 2005; Shiovitz, Bansal, Burnett-Hartman, Andrea, et al., 2015). Few research studies have reported on end of life (EOL) experiences of Alaska Native or American Indian peoples. It is crucial to explore how the indigenous people of Alaska relate to EOL issues, concerns, and concepts. Knowledge of their understanding of EOL concepts can help health care professionals develop a plan to better meet the needs of indigenous people at end of life and contribute to a peaceful death experience.

Alaska Natives and American Indian peoples are significantly less likely to utilize hospice services compared to other ethnic groups (National Hospice Palliative Care Organization, 2013). Efforts have been made to narrow this health disparity. Studies have described the development of culturally sensitive palliative care education programs for healthcare providers of American Indian and Alaska Native peoples (Arenella et al., 2010). Some studies have explored the needs of Alaska health care providers to determine their palliative care knowledge and comfort in providing palliative care (DeCourtney, Jones, Merriman, Heavener, & Branch 2003; DeCourtney & Mitchell, 2006). These studies led to education efforts specific to the needs of Alaska Native and American Indian peoples (DeCourtney et al., 2003; DeCourtney & Mitchell, 2006). De

Courtney et al. (2003) described a culturally sensitive palliative care program for Alaska Native and American Indian peoples developed by a rural community formed to meet their EOL needs. DeCourtney (2009) also developed a culturally sensitive educational pamphlet about palliative care and hospice care that discussed EOL care, included stories from elders, and included age appropriate information for the pediatric population.

One crucial assessment is missing in the literature; specifically, no documentation exists on the voices or opinions of Alaska Native and American Indian peoples about their EOL knowledge, beliefs, and preferences. Although this seems like a simple concept, the Alaska Native and American Indian peoples are, understandably, very private people (Spector, 2004). Historically, indigenous peoples have faced European imperialism, colonization (Smith, 1999), mistreatment from the dominant society, and misrepresentation of intent from researchers (Drabiak-Syed, 2010). Such experiences have resulted in skepticism about the motives of researchers, and that may be a barrier to conducting research with Alaska Native and American Indian peoples.

The purpose of this study was to explore and describe Alaska Native and American Indian peoples' understanding of EOL knowledge, beliefs, and preferences. The specific aims of this study were to describe Alaska Native and American Indian peoples' knowledge of hospice/palliative care services and their beliefs and preferences surrounding EOL care. The three research questions were: (a) What is the knowledge of hospice/palliative care services among Alaska Native and American Indian peoples, (b) What are the beliefs of Alaska Native and American Indian peoples regarding EOL care? and (c) What are the preferences of Alaska Native and American Indian peoples regarding EOL care?

Methods

This study was a cross-sectional descriptive survey of Alaska Native and American Indian peoples aged 18 and older. The Institutional Review Board of Illinois State University approved the study protocol.

Recruitment and Sampling

A convenience sample was recruited from a predominantly Alaska Native and American Indian residential housing campus located in Anchorage, Alaska. Some participants were also recruited from a remote Southwest town in Alaska using the “snowball” method, and they were able to participate through a mail-in process. Inclusion criteria consisted of being either Alaska Native or American Indian, aged 18 or older, and having the ability to read and write English. On-site recruitment was completed through poster displays, a newsletter announcement, and meetings. Participants were invited to attend an initial information session at the housing campus activity center to meet the researcher, learn about the study, and review a letter entitled “Request to Participate in Research” that explained informed consent. At the conclusion of the information session, attendees were given the option to ask questions and to complete the survey. Those participants who returned a survey were considered as consenting. One option was to take the survey home, complete it, and mail it to the researcher in the provided stamped addressed envelope. Additionally, participants were invited to take a survey packet (containing the request to participate in research letter and the survey) to share with friends or family members. All participants were offered compensation of \$15.00 for their time. Those who submitted surveys by mail were requested to provide a mailing address so the honorarium could be sent.

Assessment and Measures

The three variables of interest, knowledge, beliefs, and preferences were measured using the Beliefs and Preferences about End-of-Life Care Questionnaire (Johnson, Kuchibhatla, & Tulskey, 2008). Three (out of five) subscales of the questionnaire were used in this study: Hospice Beliefs and Attitudes, Beliefs About Dying and Advance Care Planning, and the Preference for Care Scale. Knowledge of hospice care services was measured using the Hospice Beliefs and Attitudes Scale. Beliefs about dying were measured using the Beliefs about Dying and Advance Care Planning Scale. Preferences for end of life care were measured using Preferences for End-of-Life Care Scale. All items were measured on a 5-point Likert-type scale, where 1=strongly agree, 2=agree, 3=neither agree nor disagree, 4=disagree, and 5=strongly disagree. In addition to the 5-point Likert-type scale, the Preference for End-of-Life Scale and Hospice Beliefs Scale had questions checkbox responses.

Hospice Beliefs and Attitudes scale. The Hospice Beliefs and Attitude scale (Johnson et al., 2008; Reese et al., 1999) includes two single questions asking participants about their knowledge of hospice; specifically, whether they have heard of it and how. In addition, the scale consists of 8 items, which are summed, yielding the minimum score of 8 and maximum score of 40. Question one is reverse coded. A higher score indicates a more favorable belief about hospice. The survey was adapted for this study to reflect Alaskan culture based on the feedback of researchers in the Anchorage area. The original Cronbach's alpha for this scale was 0.74, with the current Cronbach's alpha of 0.56.

Beliefs about Dying and Advance Care Planning scale. The Beliefs about Dying and Advance Care Planning scale (Johnson et al., 2008) explores the beliefs about death and comfort with discussing death. An additional question was added per advice from area culture advisors. The question is, “If I were dying, I would not want to be told, but it’s okay to tell my family.” The scale consists of 8 items, which are summed, yielding the minimum score of 8 and maximum score of 40. Two questions, questions five and eight, are reverse coded for this scale. Lower scores indicate more comfort talking about death. The original Cronbach’s alpha for this scale was 0.75, with the current Cronbach’s alpha of 0.582.

Preferences for End-of-Life scale. The Preference for EOL Care scale (Johnson et al., 2008) explores the beliefs about wanting to live as long as possible with a non-curable illness. The scale consists of 8 items, which are summed, yielding the minimum score of 8 and maximum score of 40. Alaska Native/American Indian advisors rephrasing the question, as follows: If you were seriously ill with a disease like cancer that could not be cured and you could choose where to die, where would you prefer to die? Questions one through four and eight are reverse coded. Higher scores indicate a greater desire to be given life-sustaining options. The original Cronbach’s alpha for this scale was 0.71, with the current Cronbach’s alpha of 0.62.

Demographic Characteristics, Use of Advance Directives

The demographic section consisted of 10 questions inquiring about gender, race, age, marital status, education level, health status, use of a living will, zip code, and the location where the participants lived most of their lives (rural [road line], remote area [no road line], urban area [city]).

Results

Fifty surveys were returned. One participant was under the age of 18 and was not included in data analysis, leaving a final sample size of 49. One person declined compensation, and the under-aged participant received compensation. The results of the data analysis are presented here. This section includes the description of sample characteristics and key variables. The data were collected after a recruitment presentation, the aim of which was to explain the study, and four additional sessions were scheduled for those who wanted to complete a survey, but were not available the day of the presentation. Surveys were mailed to participants who requested them, and survey packets were available for participants to share with family and friends. The data were entered twice using separate SPSS files, and the results were compared for accuracy. For each variable, the number of non-missing values was used. Missing values of frequencies were excluded, and the percentages were based on the number of non-missing values. Nominal and ordinal data analyses included frequency distributions, percentages, and the minimum and maximum modes. Interval data were analyzed with frequency distributions, percentages, the minimum and maximum, and the means and standard deviations.

Sample Characteristics

The total number of participants in this study was 49. The response rate was 79%; specifically, out of 62 surveys that were distributed, 50 were returned. One survey was not useable due to the participant being under 18 years of age. Table 1 and Figure 1 illustrate demographic characteristics of the sample. Most participants were women (82%), mean age was 50.2 years (SD 20.42), and more than half were divorced (32.7%)

or single (30%). Most lived in an urban setting (56.3%), followed by remote areas with no road-line (25%), and rural areas with a road-line (18.8%). The most frequent race reported was Alaska Eskimo-Inupiaq (22.4%), followed by Alaska Eskimo-Yup'ik (20.4%) (see Table 1 for sample race characteristics). When two or more races were reported, they were categorized into "more than one race." Most participants were high school graduates or had earned a GED (36.7%), or had some college or were college graduates (32.7%). Most did not have a living will (77.6%), although most had heard of a living will (83.7%). Health status was reported as very good (38.6%), good (36.5%), fair (22.4%), excellent (6.1%), and poor (6.1%). Most participants were high school graduates or had earned a GED (36.7%), or had some college or were college graduates (32.7%). Most did not have a living will (77.6%), although most had heard of a living will (83.7%). Health status was reported as very good (38.6%), good (36.5%), fair (22.4%), excellent (6.1%), and poor (6.1%).

Variables of Interest

Knowledge: Self-reported knowledge and beliefs about hospice. Knowledge about hospice care services was measured using the Hospice Beliefs and Attitudes Scale. Table 3 displays the number and percentages of individuals who had some or no knowledge of services. While nearly 77% of participants had heard of hospice, 23% had not. Sixty-five percent thought they could not afford hospice care. The mean score of the scale was 26.75, with a minimum 8 and maximum of 40. Almost 70% agreed that they would want hospice care, and 65.2% did not think they could afford hospice care. Thirty-one percent felt they would not need hospice because family members would care for them, almost 32% felt their family would not care for them, and 36.4% were not sure if

their family would care for them. Most (49%) felt that hospice was a place to die, 22% did not think so, and 29% were unsure. Almost half of the sample could neither agree nor disagree that hospice treatment is not as good as the treatment in the hospital, and 9.5% agreed that it was not as good as the treatment in the hospital.

Beliefs: Self-reported beliefs about dying and advance care planning. Almost 82% were comfortable talking about death, and nearly 90% wanted doctors to tell them whether they were dying. Eighty-four percent would tell their family they were dying, while 6% would not. A vast majority of participants (95.8%) believed that dying is a normal part of life, yet 28.3% said that death should be avoided at all costs. Fifty-four percent had thought about the type of care they would want when they will be dying, but only one-third had talked with family about this care. Seventy-four percent would want medical care if they were dying, 25% could not agree or disagree with the statement, and 37.5% had not talked with family. In the previous scale about knowledge of hospice, 36.4% could neither disagree nor agree about whether their family would care for them if they were dying. The mean for this scale was 17.11, with a minimum of 8 and maximum of 40. The lower the score, the greater comfort an individual had in discussing death.

Preferences: Self-reported preferences for end of life. Participants were asked a series of questions about their thoughts and feelings related to the types of medical treatment they would prefer when facing EOL or knowing that they have three to six months of life (see Table 5). Most (54.2%) did not want to have life support or a breathing machine; furthermore, if their brain stopped working, a higher percentage (78.7%) affirmed they would not want to live as long as possible. Nearly 61% preferred not to have a feeding tube, and 22% were unsure. If having only 3-6 months to live,

almost 62% would not like to live as long as possible if in severe pain. When asked if they had a disease that could be cured, 87.8% noted being comfortable would be more important than living as long as possible. Not being in pain was reported as more important than living (59.2%) as long as possible; however, 20.4% of participants could neither agree nor disagree and 20.4% disagreed/strongly disagreed with the statement regarding pain. A large percentage (54.2%) of participants preferred to go to the hospital or emergency room to obtain care. Twenty-seven percent could neither agree nor disagree with that statement while 18.8% preferred to be cared for at home. The mean for this scale was 18.54, with a minimum of 8 and maximum of 40, higher scores indicate a greater preference for life sustaining options.

Preferences: Self-reported preference of place of death. Most participants (55.1%) reported preferring to die at home, followed by dying at the hospital. Some written comments under the option of other included: while camping, fishing, fishing at sea, another city to avoid children associating death with their home, vacation, wilderness—where grew up (Table 5). No participant chose a nursing home; however, one participant did write that in under “other.”

Discussion

The results of this survey represent the voice of the Alaska Native and American Indian peoples residing in Alaska. The key findings suggest that most participants have undocumented advance directives, nearly one-quarter of the sample had no knowledge of hospice services, and many had misconceptions about types of services hospice offers. Although a high percentage of participants were comfortable discussing their beliefs about dying, a much lower percentage had discussed their feelings about the type of

medical care they desire when dying, and they have not shared their beliefs or preferences with their family. This study further revealed preferences for life sustaining efforts, pain measures, and preferred place of death. These findings are the first to be reported and will be discussed separately by research question.

Research Question One

What is the knowledge of hospice/palliative care services among Alaska Native and American Indian peoples? While a vast majority of participants had heard of hospice, 23% had not, and 65% thought they could not afford hospice care. In fact, Medicare, Medicaid, and most insurance companies pay for hospice services. Nationally, there is an upward trend in the use of the Medicare hospice benefit, with the latest results indicating increased use of benefits from 18.8% in 2001 to 30.1% in 2007 (NHPCO, 2015). Most participants had knowledge of hospice from someone who had used hospice, but only 10% had heard about hospice from a health care provider. Although it is helpful to hear about hospice from people who have experienced it, it would be more beneficial to hear about hospice from a knowledgeable health care provider. Health care providers tend to wait too long to bring up a discussion about EOL care (Institute of Medicine [IOM], 2015; Jho et al., 2015; Schockett, Teno, Miller, & Stuart (2005); Taylor, 2004). Research tells us that health care providers continue to have difficulty bringing up EOL discussions (Nedjat-Haiem & Carrion, 2015).

Almost half felt that hospice was a place where people went to die, with nearly 30% being unsure. The location of hospice, or where hospice care can be provided, is another area that needs to be considered. Hospice patients can receive care in many places, and most patient care is done at home (35.7%) while roughly 31.8% are treated at

inpatient hospice facilities (NHPCO, 2015). Hospice care can also be provided in the nursing home, hospitals, or other residential-style facilities.

Other results indicated a lack of education about hospice as well. Almost 30% could not answer whether hospice care meant they would get no treatment, and nearly 48% were not sure whether hospice treatment was as good as the treatment they would get in the hospital. Participants who could neither agree nor disagree with statements could have been unfamiliar with what is being asked. It is entirely possible that respondents did not know whether their family would care for them if they were dying because that conversation had been absent in their time together or they had not thought of advance care planning.

Research Question Two

What are the Alaska Native and American Indian peoples' beliefs about EOL care? Although most participants felt comfortable discussing death, an even higher percentage believed that death is a normal part of life. These personal beliefs did not transcend into sharing of those beliefs. Whereas participants felt they would tell their family if they were dying, fewer had discussed the kind of medical care that they would desire if dying and only one third had shared their thoughts about this medical care.

Colclough and Brown (2013) found that when American Indian peoples were faced with treatment decision-making at EOL, their perception of the physician as the authority figure hindered their autonomy. While the physicians thought that their patients were making the decisions about treatment based on what the patients wanted, that was not the case. Deep et al. (2008) found that residents who communicated bad news at EOL without having proper training were themselves dissatisfied with their delivery, and the

family lacked the understanding of EOL decisions. When learning of a life threatening illness, misperception of facts is quite possible. Patients in shock need time to absorb the bad news, and time is not always given. Contributing to this poor communication is the lack of education provided in medical and nursing schools, poor collaboration among health care disciplines, and little training by physicians to adequately discuss EOL care (IOM, 2015; Jacques et al., 2011). If the patient does not initiate the conversation, their concerns may not be addressed until very late into the illness. Inadequate advance care planning may result in more intensive treatment, more pain, and, hence, poorer quality of life when the health care provider seeks no clear direction nor is an advance directive documented by the patient (IOM, 2015; Towsley, Hirschman, & Madden, 2015). Even when documentation does exist, it may not always be followed; or a health care provider may fail to ask if a document exists (Miller, 2015; Towsley, Hirschman, & Madden, 2015). End of life care conversations are often missed for various reasons. Family members need encouragement to have this conversation, and opportunities present themselves at visits to the healthcare provider's office visits, emergency room, and hospital, especially when accompanied by family. A conscious effort on the part of health care practitioners (HCP) may bring advance directives into a much-needed spotlight.

One-third of the participants could not answer the questions about having thought about the kind of medical care they would want when they will be dying. They may have not thought about the types of treatment, cultural beliefs may have prohibited them from thinking about death, or perhaps they may have been unaware of the types of care that they could receive.

Research Question Three

What are Alaska Native and American Indian peoples' preferences regarding EOL care? Knowing what types of medical care a patient wants when faced with an incurable illness is paramount to providing quality care. Noteworthy, between 8-27% of participants chose "neither agree nor disagree" to respond to these questions. It is unknown why they were unable to agree or disagree, and further exploration of this response is warranted.

When confronted with a non-curable disease, for almost all participants (88%), being comfortable was more important than living as long as possible. Practitioners need to explore each patient's definition of comfort and being without pain to understand the individual expectation. Pain continues to be a concerning factor for minorities, as studies have indicated that minorities are medicated with less pain medication (Shavers, Bakos, & Sheppard, 2010).

Most participants wanted to die at home, with the hospital being the second choice. It is important to discuss patients' preferences, assess their understanding of illness progression, understand their emotional and spiritual needs when facing non-curable diseases or EOL approaches. All these factors are essential in striking the balance between hope and preparing for death.

Limitations

The results should be interpreted with caution due to the limitations of the study. Generalizability is limited in the wake of the convenience sample used. This sample was limited to those living in a particular housing campus, those who worked at the housing campus, and others residing in a remote village in Alaska. However, the sample did

include two sites, widening the applicability of the findings. The participants were self-selected, increasing the potential for selection bias. The participants were offered financial compensation out of respect for their time according to market value, considering the Alaska median hourly salary of \$21.32 (Fried, 2015). While some conflicting literature has indicated that this could be a negative factor in recruitment, it is possible that some participants could have provided any answers, truthful or not, to receive the compensation. To compensate for this, participants were told that they did not need to answer every question, and they could end the study at any time and still receive compensation. This was expected to increase the probability that they would respond truthfully.

Language barriers may have limited this study, as surveys were printed only in English, omitting common Native languages that some Alaska Native and American Indian peoples prefer. Future studies should consider translating the survey into Native languages. Furthermore, I was asked to read questions aloud by some participants who preferred to hear the questions posed versus read. The Alaska Native and American Indian cultures are based on oral traditions; thus, talking through these questions might make it easier in the future to gain a clearer understanding of questions.

These findings are also limited due to the low reliability of the instruments in this sample. The low Cronbach's alphas may be due to adjusting some of the questions per advice of cultural advisors. Additionally, this is the first time the instruments have been completed by a sample comprising only Alaska Native and American Indian peoples. Because discussing death in a direct way may be considered as an influence for death to occur, Alaska Natives/Alaska Indians may have selected answers that were indirect, such

as “neither agree nor disagree,” for some of the items.

Conclusion

This survey was the first to ask Alaska Native and American Indian people to specifically share their thoughts and feelings about EOL knowledge, beliefs, and preferences. Although this sample was small, the participant responses demonstrated a desire to be part of the EOL discussion. This has also been found in Baldrige et al. (2011) work, which found that American Indian elders’ willingness to discuss EOL concepts has helped contribute to successful EOL programs in the lower 48 States.

We found a need to educate Alaska Native and American Indian people about types of hospice/palliative care services, reimbursements for these services, and access to these services. Health care providers are the premier spokespeople to initiate conversations about hospice care; however, most of our participants heard about hospice from people who had used it. As Kitzes (2002) suggested, palliative care conversations should begin ahead of time with Alaska Native and American Indian peoples, before they are actually needed. She suggested using a discreet, indirect approach that would respect the culture of these peoples.

Participants in this study were comfortable discussing death, and they wanted their physician to tell them whether they are dying. However, conversations about desired medical care if they were dying were not as frequently reported. A breakdown in communication has been noted, with one breakdown between the patient and the family and second between the patient and the practitioner. Patients should be supported to have conversations with family members about their wishes for end of life care and perhaps those conversations should be facilitated by a health care professional prior to a major

health event.

As an increasing number of nursing and medical schools engage in collaborative practices, perhaps more practitioners will become more proficient in initiating these conversations. Simulation of end of life conversations are being explored in medicine as a means to prepare individuals for real-life experiences (Jacques et al., 2011). Meanwhile, this study, from the nursing perspective, begins to build knowledge about these two unique populations. The Alaska Native and American Indian peoples comprise the smallest population to use hospice services. Education about EOL care options, advance directives, and more exploration are needed to determine barriers to access to hospice/palliative care in Alaska. While communication may be essential, it is entirely possible that other factors can be explored and addressed to increase hospice utilization.

Table 1

Demographic Characteristics for Race

Race	n	%
Alaska Aleut	6	12.2
Alaska Eskimo/other-unspecified	2	4.1
Alaska Eskimo/Inupiaq	11	22.4
Alaska Eskimo/Yupik	10	20.4
Alaska Indian/Tlingit	2	4.1
Alaska Indian/Haida	1	2.0
Alaska Indian/Athabaskan	5	10.2
Alaska Indian/Tsimshian	1	2.0
American Indian/non-Alaska native	3	6.1
More than one race	8	16.0

Table 2

Sample Demographic Characteristics

		n	%
Gender:	Men	9	18.8
	Women	40	81.6
Age (mean and range):	50.20 (SD) 20.42		
Marital status:	Divorced	16	32.7
	Single	15	30.6
	Married	7	14.3
	Long-term partner	5	10.2
	Widowed	5	10.2
	Separated	1	2.0
Education level:	Less than high school	3	6.1
	High school graduate or GED	18	36.7
	Some college or technical school	16	32.7
	College graduate	8	16.3
Has a living will:	No	38	77.6
	Yes	11	22.4
Lived most of life:	Rural area (road-line)	9	18.8
	Remote area (no road-line)	12	25.0
	Urban area (city)	27	56.3
Health rating	Excellent health	3	6.1
	Very good health	14	28.6
	Good health	18	36.7
	Fair health	11	22.4
	Poor health	3	6.1

Table 3

Hospice Knowledge Awareness via the Hospice Beliefs and Attitude Scale

		n	%				
Have you heard of hospice?							
Yes		36	76.6				
No		11	23.4				
How did you learn about hospice?							
I know someone who used hospice services		20	52.6				
I heard about hospice from someone else		7	18.4				
I heard about hospice from radio, television, or newspaper		5	13.2				
I heard about hospice from my health care provider		4	10.5				
I heard about hospice from my pastor or spiritual advisor		2	5.3				
	Mode	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	
1. If I were dying, I would want hospice care. n=43 (missing 6)	agree	14 32.6%	16 37.2%	8 18.6%	2 4.7%	3 7.0%	
2. Even if I wanted hospice care, I could not afford hospice. n=43 (missing 6)	strongly agree, agree	14 32.6%	14 32.6%	8 18.6%	5 11.6%	2 4.7%	
3. I wouldn't need hospice if I were dying because my family would take care of me. n=44 (missing 5)	neither agree nor disagree	7 15.9%	7 15.9%	16 36.4%	8 18.2%	6 13.6%	
4. Hospice is a place where people go to die. n=41 (missing 8)	agree	7 17.1%	13 31.7%	12 29.3%	6 14.6%	3 7.3%	
5. Hospice care means you get no treatment. n=37 (missing 12)	disagree	0	1 2.7%	11 29.7%	13 35.1%	12 32.4%	
6. Hospice treatment is not as good as treatment in the hospital. n=42 (missing 7)	neither agree nor disagree	0	4 9.5%	20 47.6%	13 31.0%	5 11.9%	
7. Hospice care means giving up. n=39 (missing 10)	strongly disagree	1 2.6%	0	12 28.2%	11 33.3%	19 35.9%	
8. Hospice care causes people to die before their time.	strongly disagree	1 2.3%	0	12 27.9%	11 25.6%	19 44.2%	
<i>Knowledge measured with Hospice Beliefs and Attitudes Scale:</i>					M 26.75	SD 3.91	

Table 4

Beliefs About Dying and Advance Care Planning Scale

	Mode	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. I feel comfortable talking about death. n=49	agree	16 32.7%	24 49.0%	4 8.2%	3 6.1%	2 4.1%
2. If I were dying, I would want the doctors to tell me. n=49	strongly agree	32 65.3%	12 24.5%	3 6.1%	2 4.1%	0
3. If I were dying, I would tell my family. n=49	strongly agree	21 42.9%	20 40.8%	5 10.2%	1 2.0%	2 4.1%
4. Dying is a normal part of life. n=48 (missing 1)	strongly agree	30 62.5%	16 33.3%	1 2.1%	1 2.1%	0
5. Death should be avoided at all costs. n=46 (missing 3)	neither agree nor disagree	5 10.9%	8 17.4%	16 34.8%	8 17.4%	9 19.6%
6. I have thought about the kind of medical care that I want when I am dying. n=48 (missing 1)	neither agree nor disagree	11 22.9%	15 31.3%	16 33.3%	4 8.3%	2 4.2%
7. I have talked to my family about the kind of medical care that I want when I am dying. n=48 (missing 1)	neither agree nor disagree	4 8.3%	12 25.0%	1 2.1%	12 25.0%	6 12.5%
8. If I were dying, I would not want to be told, but it's okay to tell my family. n=49 (missing 1)	strongly disagree	5 10.4%	4 8.3%	5 10.4%	12 25.0%	22 45.8%
<i>Beliefs measured with Beliefs About Dying and Advance Care Planning Scale:</i>				Mean 17.11	SD 3.98	

Table 5

Preferences for End-of-Life Care Scale

	Mode	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree		
<i>If I were told that I had 3-6 months to live, I would want to live as long as possible,</i>								
1. even if I had to be on life support or a breathing machine. n=48 (missing 1)	strongly disagree	5 10.4%	8 16.7%	9 18.8%	12 25.0%	14 29.2%		
2. even if my brain had stopped working. n=47 (missing 2)	strongly disagree	1 2.1%	3 6.4%	6 12.8%	9 19.1%	28 59.6%		
3. even if I had to be fed through a tube. n=46 (missing 3)	strongly disagree	2 4.3%	6 13.9%	10 21.7%	8 17.4%	20 43.5%		
4. even if I were in severe pain. n=47 (missing 2)	strongly disagree	4 8.5%	8 17.0%	6 12.8%	11 23.4%	18 38.3%		
<i>If I had a disease that could not be cured,</i>								
5. being comfortable would be more important to me than living as long as possible. n=49	strongly agree	27 55.1%	16 32.7%	4 8.2%	1 2.0%	1 2.0%		
6. being out of pain would be more important to me than living as long as possible. n=49	strongly agree	16 32.7%	13 26.5%	10 20.4%	6 12.2%	4 8.2%		
7. being at home would be more important to me than being in the hospital. n=47 (missing 2)	strongly agree	21 44.7%	6 12.8%	11 23.4%	8 17.0%	1 2.1%		
8. and I could be taken care of at home, I would still want to go to the hospital or the emergency room. N=48 (missing 1)	agree	12 25.0%	14 29.2%	13 27.1%	2 4.2%	7 14.5%		
<i>Preferences measures with Preferences for EOL Care Scale:</i>					Mean	18.54	SD	5.19

Table 6

Preference for Location of Death

	n	%
Home	27	55.1
Hospital	17	34.7
Nursing Home	0	
Other	4	10.2

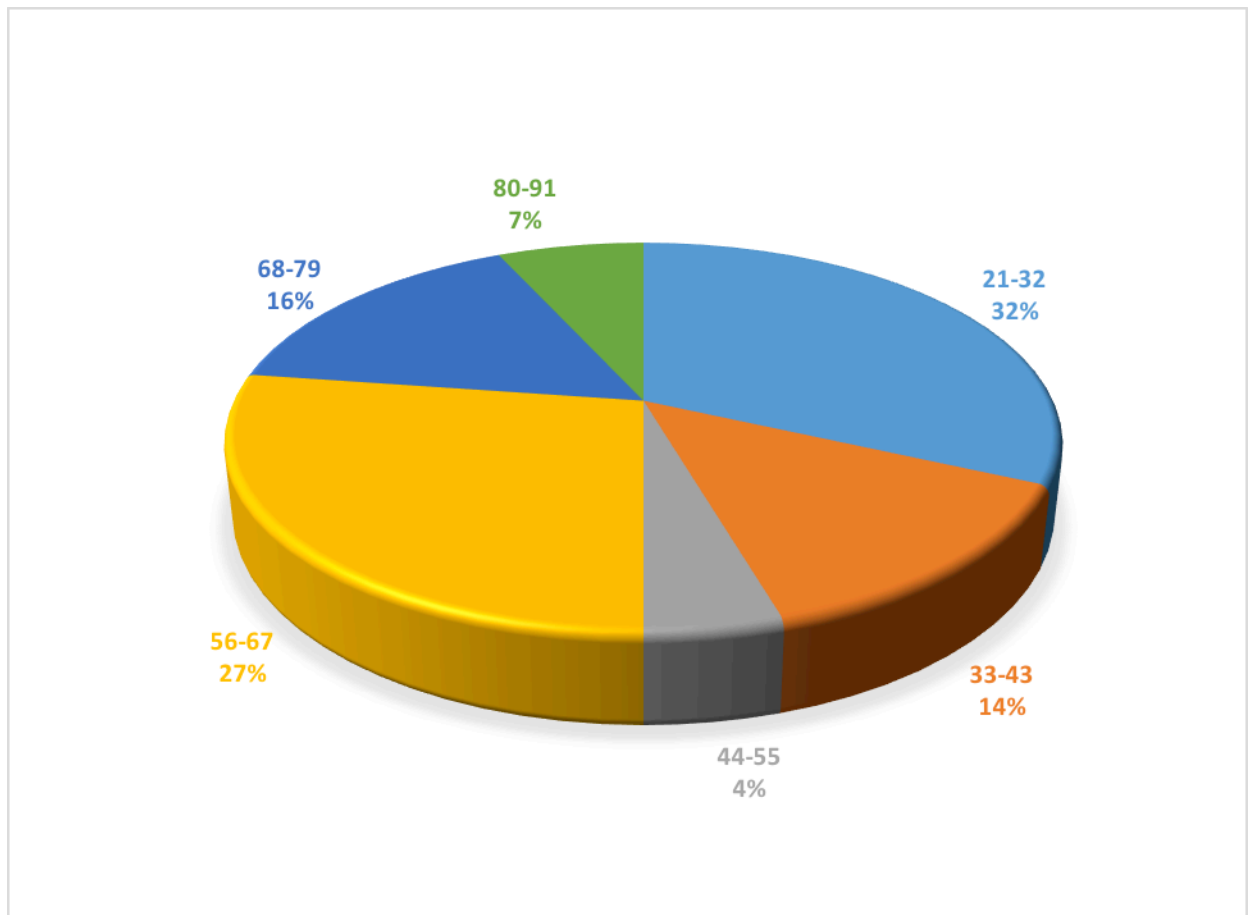


Figure 1. Age distribution, n=44

References

- Arenella, C., Finke, B., Domer, T., Kaur, J. S., Merriman, M. P., & Ousley, A. (2010). Adaptation, dissemination, and evaluation of cancer palliative care curriculum for the Indian health system. *Journal of Palliative Care*, 26(1), 15-21.
- Baldrige, D., Garrett, M., Williams, E., Aldrich, N., & Benson, A. W. (2011). *Moving beyond paradigm paralysis: American Indian end-of-life care*. Retrieved from <https://www.cms.gov/.../EOL-AI-AN-CIB-508-compliant.pdf>
- Colclough, Y. Y., & Brown, G. M. (2014). End-of-life treatment decision making: American Indians' perspective. *American Journal of Hospice and Palliative Medicine*, 31(5), 503-512.
- Deep, K. S., Griffith, C. H., & Wilson, J. F. (2008). Communication and decision making about life-sustaining treatment: Examining the experiences of resident physicians and seriously ill hospitalized patients. *Journal of General Intern Medicine*, 23, 1877-82.
- DeCourtney, C. A. (2009). *Palliative care: Easing the journey with care, comfort and choices*. Anchorage: Alaska Native Tribal Health Consortium.
- DeCourtney, C. A., Jones, K., Merriman, M. P., Heavener, N., & Branch, P. K. (2003). Establishing a culturally sensitive palliative care program in rural Alaska Native American communities. *Journal of Palliative Medicine*, 6(3), 501-510.
- DeCourtney, C. A., & Mitchell, K. M. (2006). *Measuring palliative care knowledge, attitudes, behaviors, and training needs among healthcare providers of Alaska natives*. Poster Presentation.

- Dinger, E. L. (2005). *AARP Massachusetts End of Life Survey*. Washington, DC: Knowledge Management. Retrieved from http://assets.aarp.org/rgcenter/health/ma_eol.pdf.
- Drabiak-Syed, K. (2010). Lessons from Havasupai Tribe vs. Arizona State University board of regents: Recognizing group, cultural, and dignitary harms as legitimate risks warranting integration into research practice. *Journal of Health & Biomedical Law, VI*, 175-225.
- Fried, N. (2015). Alaska's median wage highest in the U.S. *Alaska Economic Trends, February*.
- Guadagnolo, B. A., Huo, J., Bucholz, T. A., Petereit, D. G., (2014). Disparities in hospice utilization among American Indian Medicare beneficiaries dying of cancer. *Ethnicity and Disease (24)4*, 393-8.
- Institute of Medicine (IOM). (2015). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: The National Academies Press.
- Jacques, A. P., Adkins, E. J., Knepel, S., Boulger, C., Miller, J., & Bahner, D. P. (2011). Educating the delivery of bad news in medicine: Preceptorship versus simulation. *Internal Journal of Critical Illness and Injury Science, 1(2)*, 121-124.
- Jho, H. J., Chang, Y. J., Song, H. Y., Choi, J. Y., Kim, Y., Park, E. J.,...Choi, H. J. (2015). Perceived timeliness of referral to hospice palliative care among bereaved family members in Korea. *Supportive Care in Cancer, 23(9)*, 2805-2811.

- Johnson, K. S., Kuchibhatla, M., & Tulsky, J. A. (2008). What explains racial difference in the use of Advance directives and attitudes toward hospice care? *Journal of American Geriatric Society*, 56(10), 1953-1958.
- Kelley, M. L. (2010). An Indigenous problem: Why now? *Journal of Palliative Care*, 26(1), 5.
- Kitzes, J. A. (2002). Guidelines for discussing palliative care and end-of-life planning in American Indian/Alaska Native communities. *IHS Provider*, 27(5), 89-92.
- Kitzes, J., & Berger, L. (2004). End-of-life issues for American Indians/Alaska Natives: Insights from one Indian health service area. *Journal of Palliative Medicine*, 7(6), 830-837.
- Kitzes, J. A., & Domer, T. (2004). Palliative care: An emerging issue for American Indians and Alaska natives. *Journal of Pain & Palliative Care Pharmacotherapy*, 17, 201-210.
- Michalek, A. M., Mahoney, M. C., Gilbert, A., & Kaur, J. (2005). Palliative care services: A survey of tribal health directors. *The IHS Provider*, May, 118-9.
- Miller, S. C. (2015). But, I signed the form. *Journal of Palliative Medicine*, 18(8), 656-657.
- Nadjat-Haiem, F. R., & Carrion, I. V. (2015). Assessing challenges in end-of-life conversations with patients utilizing a public-safety net health care system. *Journal of Palliative Care Medicine*, 32(5), 528-536.
- National Hospice and Palliative Care Organization [NHPCO]. (2013). *Facts and figures on hospice care*. Retrieved from http://www.nhpco.org/sites/default/files/public/Statistics_Research/2013_Faces_Fgures.pdf

- NHPCO. (2015). *Facts and figures on hospice care: Hospice care in America*. Retrieved from <http://www.nhpco.org/hospice-statistics-research-press-room/facts-hospice-and-palliative-care>
- Reese, D. J., Ahern, R. E., Nair, S., O’Faite, J. D., & Warren, C. (1999). Hospice access and use by African Americans: Addressing cultural and institutional barriers through participatory action research. *Social Work, 44*(6), 549-559.
- Shiovitz, S., Bansal, A., Burnett-Hartman, A. N., et al. (2015). Cancer-directed therapy and hospice care for metastatic cancer in American Indians and Alaska Natives. *Cancer Epidemiology Biomarkers and Prevention, (24)*7, 1138-1143.
- Schockett, E. R., Teno, J. M., Miller, S. C., & Stuart, B. (2005). Late referral to hospice and bereaved family member perception of quality of end-of-life care. *Journal of Pain and Symptom Management, 30*(5), 400-407.
- Shavers, V., Bakos, A., & Sheppard, V. (2010). Race, ethnicity, and pain among the U.S. adult population. *Journal of Health Care for the Poor & Underserved, 21*(1), 177-220. doi:10:1353/hpu/0.0255
- Smith, L. T. (1999). *Decolonizing methodologies: Research and indigenous peoples*. London and New York: ZedBooks, Ltd.
- Spector, R. E. (2004). *Cultural diversity in health & illness*. Upper Saddle River, NJ: Pearson Prentice Hall.
- Taylor, C. L. (2004). Improving referral of patients to hospice through community physician outreach. *Journal of Pain and Symptom Management, 28*(3), 294-295.

Towsley, G. L., Hirschman, K. B., & Madden, C. (2015). Conversations about end of life: Perspectives of nursing home residents, family and staff. *Journal of Palliative Medicine, 18*(5), 421-428.

CHAPTER III
PREPARING FOR RESEARCH WITH INDIGENOUS
PEOPLES: REVIEW OF LITERATURE AND
A NURSING PERSPECTIVE

Chapter III is a manuscript that gives new nurse researchers information that is helpful to know how to conduct research with indigenous people, how their knowledge system is learned, and a review of literature demonstrating their unique outlook on life. This manuscript will be submitted to the *Native American and Indigenous Studies Association* for publication consideration.

Abstract

When conducting research with indigenous peoples, the researcher must be considerate to the culture, worldviews, and life experiences of the participants. Many indigenous populations have suffered ridicule, exploitation, oppression, and unfair treatment from the dominant Western society. These aspects are important for a nurse researcher to understand as she or he begins to seek knowledge among indigenous people. The purpose of this article is to share my experiences as a non-indigenous student, discuss the Indigenous Knowledge System, provide a brief review of the literature on indigenous worldviews on health and aging, explain the indigenous research paradigm and its applicability to research, and share my experiences as non-indigenous researcher conducting research with indigenous populations. As I prepared to conduct research with Alaska Native and American Indian peoples, I learned about the Indigenous

Research Paradigm specific to indigenous populations. For scholarship to advance, it is essential to disseminate useful information to other nurses interested in conducting research with indigenous peoples.

Introduction

As part of my doctoral nursing program, my education has centered on nursing of the aged and vulnerable populations. It seemed natural to focus on Alaska Natives when I found out I was relocating to Alaska. As I began exploring literature about Alaska Natives, I noticed that American Indians are often being classified with Alaska Natives into one category due to the U.S. Census category system. I found that while searching for Alaska Native research studies, some articles focused only on American Indians while the title included the Alaska Native/American Indian category name. When exploring end of life (EOL) needs of Alaska Native/American Indian, I discovered a health disparity in hospice usage among Alaska Native/American Indian people. I learned that Alaska Native/American Indian people were the second smallest minority in the country, comprising nearly 15% of the Alaska population (U.S. Census, 2011).

I discovered that I had some gaps in my knowledge base about Alaska Native peoples. Alaska Native and American Indian peoples are indigenous to area now called Alaska. Before my relocation, I did not realize that Indians lived in Alaska; I had thought American Indian peoples originated in the lower 48 States. Alaska Native peoples are a very diverse group, consisting of three ethnic groups (Indian, Eskimo, and Aleut) and 11 cultures (Athabascan, Unangax and Alutiiq, Yup'ik and Cup'ik, Inupiat and St. Lawrence Island Yup'ik, and Eyak, Tlingit, Haida and Tsimshian) spreads out over five geographical locations (far north, interior, southwest, southcentral, and southeast). They speak 28 languages and comprise 229 federally recognized Tribes (National Congress of American Indians, 2016). With so much diversity, there are bound to be differences and similarities among the cultures that nurses will find helpful in planning care. Alaska

Native and American Indian peoples are also the least likely ethnic group to utilize hospice (National Hospice Palliative Organization [NHPCO] NHPCO, 2015). This information inspired me to focus on EOL needs of Alaska Native and American Indian peoples living in Alaska.

To expand my personal knowledge base, I attended two classes at the University of Alaska Fairbanks. One class focused on documenting indigenous knowledge. This classroom experience influenced my worldview of indigenous people. Class sessions included audio and video discussions with Māori classmates residing in, and being indigenous to, New Zealand. The course objectives included learning about the roles of elders, transforming oral knowledge into literate forms, and appreciating indigenous values, beliefs, and life experiences. I learned to look at the world using a different lens—an indigenous lens. I learned about various concepts that were never discussed in my initial schooling.

Upon the completion of this class, I thought it would be beneficial to share with other nurses what I learned, as I had not found articles in the nursing literature on how to conduct research with Alaska Native and American Indian peoples. The purpose of this article is to share my experiences as a non-indigenous student and researcher conducting research with indigenous peoples, discuss the Indigenous Knowledge System (IKS), provide a brief literature review of indigenous worldviews on health and aging, and explain the Indigenous research paradigm and its applicability to research. It is important for me, as a nurse researcher, to understand cultures, cultural viewpoints, and the knowledge system in which these beliefs and practices originate.

My Experiences and Lessons Learned

Relationality

In writing this manuscript, I am striving to develop a relationship with you, the reader, as this is the premise of the development of indigenous knowledge. I will begin this section by introducing the terms that will be discussed in this manuscript. The term *indigenous peoples* refers to people who are known to be the earliest known people to inhabit an area.

Indigenous knowledge systems are the means through which indigenous peoples traditionally develop their knowledge based on their personal experiences in the world (Barnhardt & Kawagley, 2005). Knowledge can be gained in many ways, such as observing, talking, or being, doing, and relating to all things with which we come into contact (Wilson, 2008). The traditional education process includes watching the nature, adapting to environmental changes to survive, watching and demonstrating, and listening to stories while relating them to our surrounding environment (Cajete, 2000; Kawagley, 1995). As Indigenous knowledge framework differs from Western knowledge framework, it is quite possible that Indigenous peoples' perceptions of health and aging could be different as well.

Venes (2001) reported that the World Health Organization defined health "as the state of complete physical, mental, or social well-being, not merely the absence of disease or infirmity" (p. 936). Aging is commonly defined as growing older, and it is often associated with physiological changes of the body systems, which start taking place usually in the 30s. Venes (2001) claimed that for successful aging, "emotional, intellectual, physical and social or spiritual interests are optimally maintained or

developed” (p. 56). When categorizing aged adults using Western definitions, one might say that an older person is an elder. However, in the Indigenous world, Elders, with a capital “E”, does not refer to a chronological age; instead, it is a deserving status given by a community to an adult who is a positive role model, shares wisdom, and is respected (Lewis, 2010).

In an effort to help the non-indigenous nurse researcher learn about the IKS worldview, I provide a brief literature review to discuss research findings related to Indigenous people, Elders, and their views on health and aging in addition to my personal learning experiences. When the data specific to Alaska Natives or America Indian peoples was not available, I sought other indigenous studies to attempt to understand indigenous worldviews.

Lessons Learned

Communication. One of the first lessons I encountered relates to communication. I learned about indigenous people and the importance of sharing a personal history to reflect one’s path in life. Among indigenous people, it is a common practice to introduce yourself by describing your relationship to a geographic location, tribal ancestry, and family. This form of introduction gives context to the community, geography, political views, and heritage (Smith, 1999; Wilson, 2008).

I learned about importance of introductions early in my class, when I was asked to provide a written introduction about myself that was to be posted on the classroom website as an initial course assignment. As I began to read other student introductions, I found my introduction to be very different from those of my new indigenous classmates as well as from my professor, who I thought would be academically focused, like me.

My initial description was a typical academic introduction that included where I went to school, degrees I had earned, work experiences, and so forth. I then noticed that the indigenous students and the professor gave a brief, yet concise detailed history of their parents, heritage, and cultural group, followed by a brief academic introduction. As I read these posts, I was embarrassed that my customary way of introducing myself needed some revision to be similar to other students and my instructor. I had never been in a class where introductions were more personal and included also family ties. In hindsight, introductions were more about creating relationships with others, allowing others to see where you had been, what background you come from, and who you grew to be. I appreciated these examples; for the first time, I was able to take a “professional” as well as a personal perspective. This was a new setting for me. In my first oral presentation to the class, I asked whether it was all right to re-introduce myself in a way that was congruent with the indigenous style. I included what I call my heritage path. This contained details about my parents, location of births, specifics of my career path, the development of my passion for the aging population and end-of-life care, and factors that led me to take a class on IKS. My reintroduction was appreciated and well received from my classmates and professor. I have to confess that I had to call my mother to find out much of the information that I shared. I am thankful for such a simple assignment from this class, not only my classmates learned more about me from my heritage path, but I did as well. As I moved forward after this class and into the research arena with Alaska Native and American Indian peoples, I was sure to introduce myself more in this fashion. One of the critiques (from an Alaska Native) concerned my draft of a consent letter in which I did not introduce myself or the reasons for my interest in end-of-life research

with Alaska Native and American Indian peoples. Subsequently, I included that personal statement about myself in the updated version, making it more culturally appropriate. I initially felt as if I was exposing myself more than I normally would; however, it was important for me to develop a relationship with my potential participants, as evident in the next lesson about how indigenous learning and thinking was different from my learned ways.

Indigenous knowledge systems. The next lesson I learned was about how indigenous knowledge differed from my ways of learning and thinking about the world. Indigenous knowledge systems describe traditional ways of knowing among tribal groups, and this knowledge differs from Eurocentric knowledge systems in that it carries the traditions, values, and culture of a specific tribal community (Barnhardt & Kawagley, 2005). Central to IKS is the concept of relationality. Relationality defines an individual's interaction with others, the environment or land, the cosmos, and ideas about knowledge acquisition (Wilson, 2008). I learned that this knowledge was handed down from generation to generation through story telling or oral tradition. Story telling is a gift shared by Elders with younger generations to disseminate knowledge. The meaning behind stories has many layers; stories can be entertaining, teach lessons, share knowledge, and reveal indirectly how someone feels about a topic of discussion. In my experience with patients, I have listened to stories from Alaska Natives to realize after I left their room, they were not telling me a story about their neighbor, it was about themselves and the way they felt about the topic in which I was interested. Yet, another lesson learned.

Indigenous Knowledge System Worldviews

Review of Literature

What is the worldview of others? For years, we go through school, learning what is told to us, accepting information at face value, and moving forward through life. We typically learn about the world from one viewpoint of the dominant society. As I encountered the indigenous viewpoint – it was an epiphany to me, an “ah ha” moment that taught me a new way to look at life. I had never thought outside the box about worldviews, as ridiculous as that sounds now, but I took things that I had been taught to take for face value. I lived in a very protected world, looking through rose-colored glasses. I never thought about the views of indigenous people (I had not even heard the word indigenous growing up) and the ways in which they perceived and related to their history. I did not know them, I could not ask them when I was growing up, but I began to learn about their history in class, trying to adopt their viewpoint.

Suddenly, “them” became “Other” to me. As I reflected on my philosophy class, I had read Simone de Beauvoir and explored the term “Other” in history. When a dominant society is considered the norm, where and how do “Others” fit? Indigenous peoples have been “Other” since the imperialism conquests. Besides being considered “Other” as a woman, I also saw myself as “Other” in this indigenous world. I was not in-tune with this knowledge system, I had never heard of IKS or the ways in which indigenous peoples acquired knowledge. During my research collection period, an Alaska Native woman told me that I had three things going against me. She told me I might have problems getting people to participate because (a) I was a woman, (b) I was tall, and (c) I had blonde hair. I realized yet again that I was “Other” in my research world.

To help other researchers who want to study with indigenous peoples, I offer this review of literature to discuss a reality that was new to me. For this initial literature search in, I used CINAHL, PubMed, OVID, and EbscoHost search engines. Key words included Alaska Native, Native American, American Indian, Indigenous people, health, successful aging, and wellness. I felt that a nurse researcher should have an in depth understanding of these topics when working with and studying indigenous people. Extrapolation of results focused on Alaska Natives, as this was my initial research population focus. While searching literature, some studies included the word “Alaska Native” in the title, yet these studies pertained little to Alaska Natives. I found this to be related to the fact that the U.S. Census Bureau (2011) combines both American Indian and Alaska Native into one category; therefore, authors sometimes include both Alaska Native/American Indian in the title articles. When literature specific to Alaska Native or American Indian peoples was not available, I sought studies with other Indigenous groups to attempt to understand Indigenous worldviews, as there are commonalities between them, such as how knowledge is gained. Additionally, not all cultures of Alaska Native or American Indian peoples are represented in this review of literature due to lack of studies on specific subcultures. This literature review discusses research findings related to Alaska Native and American Indian peoples, Elders, Indigenous peoples, and their views on health and aging.

Native Nurses Caring for Natives

During my literature search, I found an article about native nurses caring for native peoples. I did not realize there was a conceptual framework of nursing in the Native American culture. I was excited to learn that this research was done, as it is

important for nurses to be aware of all patients' worldviews to provide care that is aligned with the patients' core values and beliefs about health. In a longitudinal study conducted by Lowe and Struthers (2001), Native American, Alaska Native nurses, non-indigenous nurses who cared for Native Americans, and student nurses participated in focus groups focusing on their experiences as a nurse practicing in the Native American culture. These nurses were found to incorporate indigenous worldviews and Western biomedical perspectives into their practice. From their study (conducted over 2 years) of 395 participants in 18 focus groups, Lowe and Struthers developed a conceptual framework of nursing in Native American culture (including Native American, Alaska Native, and American Indian peoples). Dimensions of the framework included spirituality, caring, traditions, respect, connection, holism, and trust. This framework has characteristics of health, relationships, holism, and knowledge based on the medicine wheel, which represents indigenous "oneness" (Lowe & Struthers, 2001). It depicts the various ways in which Native nurses care for Native patients and provides an excellent learning opportunity for any nurse caring for an indigenous person.

Health

No universal definition of health that would represent a worldview has been established. Uys and Smit (1994) mentioned that a worldview is made of a comprehensive structure of beliefs. Many times, these beliefs go "unsaid." According to Edwards (1997), people cannot be without a worldview, which is guided by values, beliefs, and people's understanding of reality. Indigenous peoples have common beliefs about health and healing; yet, their cultural practices and methods have developed according to the environment in which they live and resources available to them in that

environment (Struthers, Eschitit, & Patchell, 2004). Some languages, such as the Cree, have no translation equivalent for health (Adelson, 2000). The understanding of many First Nations' peoples regarding the concept of health has been influenced by colonization, traditional knowledge, and western medical science (Atleo, 1997).

Among the Alaska Native and American Indian peoples, the Traditional Indian Medicine (TIM) model supports the concept of health through the holistic inclusion of mind, body, and spirit, and it teaches healing (Hollow, 1999). In this model, tribal beliefs influence styles of healing techniques (through healers) when an imbalance (spiritual, emotional, mental, or physical health) is present. Cultural practices and methods are present based on the environment of each Nation and available resources of the region in which individuals live (Struthers, Eschiti, & Patchell, 2004). Outside influences may also affect the development of these practices. For example, colonization and western biomedical perspectives in addition to traditional tribal knowledge have influenced the understanding of many people of First Nations' (Aboriginal people of Canada) concerning health (Hopkins, Kwachka, Lardon, & Mohatt, 2007).

Alaska Eskimo—Yup'ik/Cup'ik

Hopkins, Kwachka, Larson, and Mohatt (2007) studied Alaska Eskimo Yup'ik/Cup'ik women's perspective on health and aging. This study offered a cultural perspective of one of the Alaska Native cultural groups regarding health and aging within an Eskimo community. Fifteen Yup'ik/Cup'ik Women from two rural communities participated in an exploratory, descriptive, qualitative study. Hopkins asked participants to identify the environmental, social, and cultural factors that contributed to healthy aging. Participants reported that having a strong, active body and mind were instrumental

to healthy aging.

Furthermore, their activities associated with the subsistence way of life added to their healthy aging. Activities identified with the subsistence way of life included “keeping busy, walking, eating subsistence foods and respect for elders” (Hopkins et al., p. 42). Subsistence-style activities that kept the woman busy included picking berries, preparing fish, collecting plants, sewing, or crafts. Walking was considered a significant component of this way of life. Walking to gather food, for example, was recognized to keep the body and mind active and provide energy. In addition to activities involving subsistence, the women used the school gyms to play sports. As they got older, their activities focused more on traditional style of activities, such as skin sewing or basketry, compared to the gym activity. Ingestion of subsistence food was viewed as vital, as it made the body healthy and strong. Elders of the past were very strong and healthy, which this was attributed to the consumption of subsistence foods. Subsistence foods are natural, organic foods found in the environment in which one resides. In contrast, foods from the markets should be avoided because of their high sugar and fat content. Respect for one’s body was found to be a part of a healthy life. Elders have the knowledge and experiences related to the subsistent way of life, and it is crucial for younger generations to listen to their stories about life and their wisdom regarding a good life. Sharing stories is considered an example of respect and is viewed as contributing to the elder’s well-being. The stories they share, and the knowledge they transmit about subsistent ways of life are important to maintain the community’s well-being. One Elder shared that when she dies, no one will be able to answer questions about the past that she experienced. This oral tradition remains prevalent among Alaska Natives, and it is being revitalized.

Although Yup'ik/Cup'ik women viewed their healthy aging as part of their subsistent way of living, they noted an increase in consumption of prepared foods from grocery stores, which may jeopardize their view of healthy aging. Concerns have arisen due to the higher rates of heart disease and diabetes in this population. Furthermore, physical activity is declining, as 4-wheelers and snow machines represent a newer form of transportation, thus decreasing the level of physical activity among the Yup'ik/Cup'ik people. These women link eating processed foods and having less physically active lifestyles to higher rates of chronic illnesses.

Navajo

The concept of wellness and belief system among the Navajo is called Hózhó (Kahn-John & Koithan, 2015). Kahn-John (2010) examined this very complex concept using Walker and Avant's concept analysis method. She presented her emic (insider view) perspective and interpretation of the Diné (Navajo) wellness philosophy with the premise that American Indian Alaska Native (AIAN) peoples encounter struggles in achieving physical, mental, spiritual, environment, and community wellness. In the literal sense, Hózhó means "path to harmony and old age" (Kahn-John, 2010). Hózhó represents harmony, peace, wellness, and beauty and addresses the person holistically through the body, mind, spirit, environment, and community (Kahn-John, 2010). Hózhó represents a way of living, a way of being that American Indian and Alaska Native peoples, indigenous cultures throughout the world, and nonindigenous people follow (Kahn-John, 2010; Kahn-John & Koithan, 2015).

Kahn-John suggested that the degree to which one conforms to the attributes determines the level of wellness achieved or the level of Hózhó reached. This philosophy

aids in achieving wellness status, and Kahn-John's concept analysis may assist in the future application of health promotion to the Navajo. Kahn-John (2014) further refined the Diné model by adding aspects of the resilience model. Three domains of this model are harmony, respect, and spirituality. If one is ill, there is disharmony associated with a person's Hózhó (Gary, Baker, & Grandbois, 2005). It is believed that increasing the rates of various diseases validates the dangerous effects of Hózhó being out of alignment (Huttlinger & Tanner, 1994).

The Alaska Native and American Indian peoples' worldview stresses order, balance, and harmony. Everything has a meaning in life and nothing is random (O'Brien, Anslow, Percira, & Sullivan, 2002). In nursing practice, it is important to explore and understand each patient's reality. The Hózhó philosophy serves as a framework that health care professionals can use and from which they can learn while culturally exploring specific knowledge, customs, wisdom, and worldviews of Alaska Native or American Indian peoples in practice. In consideration of achieving wellness, nurses caring for the Navajo and other indigenous peoples need to be aware of aspects that lead to Hózhó. Patients' thinking, spirituality, relationships, reciprocity, respect, and discipline are important issues to explore (Kahn-John, 2010). The outcome of Hózhó can be everlasting wellness and a decrease in suffering.

Sto:lo

Labun and Emblen (2007) used grounded theory to explore the concept of health among the Sto:lo people who reside in the lower mainland of British Columbia to provide culturally competent care. Eighteen participants older than 20 years of age participated in this study along with two community leaders. Three themes emerged from these

interviews: health, spirituality, and transitions. To achieve health, the three components must be balanced. An elder explained that everything inside a person must be in balance to be healthy, such as the environment, nature, and people. There may be times that balance is challenged by things that “cannot be helped” (Labun & Emblem, 2010, p. 211), such as hereditary issues or being in the wrong place at the wrong time. Labun and Emblem (2007) explained that a person must learn how to deal with these challenges and make the best of them to create balance. When they are unable to deal with challenges, a family will come to their aid. Second, spirituality is an “ongoing thing” (p. 210) that lives on after the human body dies. A culture advisor with the study explained that if a person takes care of his/her spirit-power, his/her spirit-power would take care of them. Taking “care” means to live in a fashion that connects your human body to your spirit, the Creator, and to Mother Earth. Third, transitions during “those times of change” affect not only a person, but also the community as well. Emotions are an essential element of transitions; it is important to work through emotions. Ceremonies are sometimes used at some transitions (for example, birth, puberty, death) to help individuals adjust to the transition.

The teachings of Elders of the Sto:lo people have played a significant part in knowing how to be healthy. Colonization, residential schools, and assimilation have caused some practices to fall to the wayside. However, the oral tradition of teaching by Elders is making resurgence. The Sto:lo people have a way of living healthy that reflects their environment and spiritual tradition.

Review of Literature on Aging

Athabaskan

The first piece of literature on aging I will discuss is the book *Two Old Women* by Velma Wallis (1993). This book describes a legend passed down to Wallis from her mother. The legend began before Western culture descended into the land, which we now recognize as the United States (possibly Canada as well, as the Gwich'in territory extended beyond the political boundaries of what is now known as Alaska). This story was handed down generation to generation in a story-telling fashion from mother to daughter. The oral tradition of storytelling is viewed as a gift whereby Elders share their wisdom and knowledge (Wallis, 1993).

The story is about two old Athabaskan women who are traveling with their tribe to areas of food sources for survival purposes in the winter months. The story revolves around a particular winter that is very harsh, and the tribe faces starvation. The tribal Chief makes a heart-wrenching decision to leave the two aging women behind, as they are creating hardship for the tribe's ability to move forward to survive. One of the woman's daughter and grandson move forward with the tribe and leave her behind. The women analyze their predicament and decide to survive or die trying. They revert to a former knowledge of hunting and survival skills to ultimately acquire food and shelter and survive the winter. If that is not amazing in itself, the tribe returned near death after finding little food sources, only to be saved by these two old women. The women were betrayed, yet they found forgiveness and inner strength to prove that they had value and deserved to live like the others.

This story teaches many lessons. The reader learned about inner strength and perseverance when found to be “useless” or of no value to society. The aging women had a purpose, and they were found to have been an asset to their tribe by the end of the story. The women reflected and realized that they too were not “pulling their weight” and that they could have tried harder to be of value; however, no one deserves to be left behind as they were. This example of literature is highly regarded by Alaska Natives, as the nature of the oral tradition of transmission allows Elders to teach and share meaningful wisdom with younger generations.

Alaska Eskimo-Inupiaq

Smith, Easton, and Saylor (2009) studied aging among 100 Inupiaq (farthest North Aboriginal people) adults from a health and nutrition viewpoint. They examined whether rural or urban settings would affect self-reported physical/mental health, activities of daily living, body mass index, nutrient intake, and food insecurity. This quantitative comparative study found that villages provided a positive environment for health and aging of older Alaska Natives.

This study suggested that rural elders are more satisfied with their life-style than are their urban counterparts (Smith, Easton, & Saylor, 2009). Rural elders were physically active and participated in community events. They reported fewer problems with activities of daily living (ADL) and independent activities of daily living (IADL), and they had higher levels of physical function. This study used self-reported surveys to collect the data, and as village members reviewed the results, they suggested that under-reporting might have been a factor in declining physical ability of elders in the rural area. As elders increase in age, the community provides more support in the form of food. The

rural community environment was reported to support aging and nutritional needs of elders, and elders reported a preference to remain on their traditional land vs. urban-style communities. Nurses need to assist both rural and urban elders in finding ways to remain active, and have acceptable levels of function.

Alaska Aleut, Alaska Indian-Athabaskan, Alaska Eskimo-Inupiaq,

Alaska Indian-Tlingit, Alaska Sugpiaq, Alaska Eskimo-Yup'ik

Lewis (2010) used interview and survey techniques to explore the concept of successful aging among Alaska Native elders and non-elders. Alaska Native participants represented six Alaska Native tribal groups as well as both urban and rural communities. The ages of the participants ranged from 26-64 years. The interview questions explored their definition of successful aging, the effect of aging on their emotional, spiritual, and cognitive well-being, and their community support through their aging process. Both young and old cited that successful aging is based on whether they make a conscious effort to live a “clean and healthy” life and take on personal responsibility to do so. The major findings of the study indicated the following.

1. Alaska Native's perceptions of aging focus on the status and role of the Elder, their treatment by the community, and expectations of the community that the Elder will share their knowledge and wisdom.
2. Generational differences showed that younger participants focused on physical/mental health and technological advances whereas older participants were more focused on traditional way of living.
3. Geographic location influenced successful aging, in both rural and urban settings. The movement away from subsistent lifestyle effects the Elder roles.

Important themes emerged regarding the holistic view of aging that Alaska Natives reported. First, Elder is not defined by a chronologic age; instead, it is based on wisdom and experiences. As a person ages, he/she may be elderly; however, to be an Elder, one must exhibit sharing their knowledge and experiences and be a role model. It is possible that a young adult is considered an Elder. His/her status is earned and decided by the community. Second, living in a rural versus urban location plays a role in aging. People living in rural communities are more physically active as they are more likely to adopt the traditional way of living. They view their body as having the potential to become weak and lazy in the urban settings, as subsistence-living characteristics were lost. Third, the theme of where one learns about aging successfully emerged. Most participants said they observed their family and relatives and learned from them. It was noted that younger participants cited the Internet and medical practitioners as sources of information about healthy lifestyles. The fourth theme was lifestyle itself. Younger participants felt they might not age successfully because of their employment and physical activity status. Desk-style jobs led them away from the subsistence lifestyle and the activities associated with it. Younger participants acknowledged that the older generation was active, as they had less electronic devices and they relied more on physical activity for survival. Older participants barely mentioned healthcare or access to medical services when discussing successful aging. More pronounced was their ability to share their knowledge about important aspects of aging with the younger generation. The final theme of poor aging shared by both young and old were inactivity, inability to handle alcohol, and giving up when one's health was challenged.

Lewis (2010) found that attributes of successful aging included taking personal responsibility, sharing one's wisdom and knowledge through community involvement, and being active in one's community. Lewis' study is limited due to small number of participants and may not be generalizable; however, it offers much insight into the Alaska Native views and provides a foundation for future research. Many findings from Lewis can inform nurses about how to care for both younger and older adults. The lifestyle of the Alaska Native adult population seems to be transitioning from rural to urban settings, yet tradition and culture are paramount to honor. Lewis also cautioned that defining successful aging is very subjective, yet it is important to consider these various perceptions of successful aging aspects between urban and rural, young and old, as issues of aging arise.

Summary of Literature

Literature reveals that the concepts of health and aging can be unique among elders of indigenous populations. Worldviews about health and aging were influenced by geographical location, natural resources available, culture, tradition, and experiences of the people. An individual's beliefs and practices center on their worldviews.

Some indigenous languages do not have a word that is equivalent to the dominant view of health. The Diné, referring to indigenous and nonindigenous people of Alaska, strive to achieve Hózhó, which encompasses beauty, balance, peace, physical, mental, spiritual, and environmental health. The Diné believe in striving for balance and harmony with everything they encounter. This holistic viewpoint includes being in harmony with one's community. The Yup'ik/Cup'ik Eskimo women follow a subsistence framework of living to achieve health and successful aging. Keeping busy was instrumental to

achieving physical and mental health. The Sto:lo people found that spirituality and balance were a part of achieving health, and balance was sought when encountering people, nature, and the environment. Health can have different meaning for different groups and varying ages. For indigenous populations, health goes far beyond the biomedical model of physical health and incorporates a holistic view of the relationship with the ecosystem. The elder population has similar perceptions of health and it adapts to aging in similar ways.

Velma Wallis wrote about aging in her book *Two Old Women*. The legend talks about the ability to find inner strength, face betrayal, and practice forgiveness as an elder. It is not only a lesson about finding strength from within when challenged, but also to recognize that all people have value, regardless of age. One study by Smith (2009) included Western measures of aging and health by measuring BMI, ADLs, and IADLs along with mental/physical characteristics. This study also differentiated between rural and urban elders and found that rural elders were more satisfied with their lifestyle. Lewis (2010) found that successful aging among Alaska Natives was associated with taking responsibility for their actions and making a conscious effort to live a clean and healthy life, which applies to American Indian cultures as well. Community support was found to be the key to elders feeling valued. It is important for Elder to gain high position in the community, as is the sharing of knowledge and wisdom with others. More research is needed to explore Alaska Native and American Indian peoples' definition of usefulness and its effect on successful aging.

Indigenous Research Paradigm

The concepts of health and aging have been discussed in this literature review. A limited number of studies investigated aging and health among Alaska Native and American Indian peoples. For both indigenous and non-indigenous nurses to fully understand and appropriately diagnose the complex health and aging needs of this population, more research is needed to fill this gap. As nurses begin to close this gap with Alaska Native and American Indian peoples, I recommend using the Indigenous Research Paradigm (IRP). The IRP framework provides an understanding of the distinctive indigenous cultures while allowing for examinations of its differences.

Elements of the IRP include ontology, epistemology, methodology, and axiology. Wilson (2008) explained that these elements are interrelated and that the sum of all the elements is greater than its parts (Figure 2). The foundation of the IRP is that knowledge is relational (Wilson, 2008). Relationships are established among people, animals, cosmos, nature, and the environment. “We could not be without being in relationship with everything that surrounds us and is within us. Our reality, our ontology is the relationships” (Wilson, 2008, p. 76). Wilson explained that the indigenous philosophy has many realities and reality is the connection that a person has with the truth while Western ontology is looking for truth somewhere “out there or external” (Wilson, 2008). According to Wilson (2008), indigenous epistemology is based on the relationships, making both the ontology and epistemology about relationships. The axiology and methodology have a foundation in the concept of relational accountability (Wilson, 2008). Contrary to some Western beliefs of objectivity within the process of research, the researcher in the IRP is inseparable from the subject of the study (Wilson, 2000). This

relationship demonstrates the investigator's accountability for relations in addition to the actual research process itself.

The methodology used in the IRP follows the axiology or ethics/moral principles, which are rooted in respect, reciprocity, and responsibility. I suggest an exploratory research design when conducting research with an indigenous population. Exploratory models have two goals: (a) describe problem, and (b) explore concept in depth (Brink & Wood, 1998). For example, it is appropriate to use this design when examining the effects of urbanization on Alaska Native or American Indian elders who no longer follow the traditional subsistent ways of living or no longer have access or physical abilities to pursue activities of subsistence ways of life.

The IRP methodology requires the researcher to consider how he/she conducts him/herself during the research process. His/her behavior must respect the participants, environment, and community at every level. The researcher must allow the indigenous participants to decide what areas need to be studied (Wilson, 2008). According to the IRP framework, building relationships during every step of research is more important than the research process or the results of the investigation. The indigenous reality or ontology is relationships (Wilson, 2008). Three R's—relationships, respect, and reciprocity—are essential elements of the IRP. The researcher will establish relationships, use respectful behavior, and will reciprocate by giving back to the community. Through strict adherence to the IRP, the researcher demonstrates responsibility throughout the research process by being respectful to the indigenous ontology and epistemology. Allowing the community to have some degree of self-determination regarding negotiating the research agenda is an important component of a successful research process.

Conclusion

When reviewing perspectives on health and aging, diverse worldviews are present within Indigenous systems. A commonality of the Alaska Native and American Indian peoples are the holistic view of knowledge, including mind, body, spirit, cosmos, and the environment. The various views indicate that culture and environment shape how one envisions or believes what health or what aging is. Indigenous views about Elders reflect wisdom and knowledge, rather than chronologic age. Successful aging is earned, and the community supports the attained Elder's status.

Health has no one universal definition; rather, each culture has its own set of beliefs, practices, and ways to understand their reality. Some nurses strive to provide holistic care to their patients; however, not all nursing curricula provide preparation to do so. It is important that nurses understand various cultures and the ways in which a person acquires knowledge without limiting their perceptions to Western points of view.

When conducting research with Indigenous populations, it is important to understand the ontology, epistemology, methodologies, and axiology to understand their worldviews on aging and health. Indigenous philosophy recognizes many realities. The epistemology not only refers to what is known; rather, it refers to the relationships that one shares with reality. Respect, reciprocity, and responsibility are fundamental elements of research conducted among indigenous people. According to the IRP, the research process is considered more important than the results, as relationships are critical with Indigenous people.

Research Implications

Knowledge gained from this literature review enlightened me about Indigenous peoples' views of the world, health, and aging. The cognate classes I took were informational, teaching about indigenous knowledge and education, allowing me to experience what it is like to be the Other in the classroom setting and in the indigenous research world. The experience broadened my viewpoint that enabled me to experience a richer research experience.

When conducting research with Indigenous peoples, I recommend following the guidelines set forth by the Alaska Federation of Natives Guidelines for Research (Alaska Native Knowledge Network, 1993). While following the guidelines, I was respectful by informing potential participants about the purpose of my research study, goals, and period of the survey, the data gathering procedures, and potential effects of the study. I obtained IRB approval, received support of Native leaders at the research site, protected individuals through anonymity, acknowledged their contributions, and reported significant findings. Throughout the research experience, I demonstrated relationality, respect, and I will provide paper copies of my publications.

As I began my contact with potential participants, I carefully designed my introductions; I brought (culturally preferred refreshments) homemade smoked salmon dip, crackers, veggies, snacks, and water for my presentation to offer a casual environment. I made sure I allowed adequate fellowship time to establish new relationships with the potential participants before the start of my research explanation. I was also aware that even though I had a start time for my presentation, it was quite possible that linear time (customary Western-style sequence of events during a meeting)

would not be observed. In fact, I had one person arrive “on time” and others came in during the first hour. I used that hour to meet and greet, introduce myself, and when the room was full, I began my presentation. People arrived during the presentation and I welcomed them and repeated information as needed. As I returned to the site for more sessions, people recognized me and spoke to me about many of their health concerns. I brought refreshments each session that I returned.

As I returned to the site to report the findings and conclusions of our research, I remained focused on respect and reciprocity. The participants in my research study were forthcoming and shared so much with me. I wanted them to have a positive research experience and know that I appreciated their participation. In the evening, I shared the highlights of the findings of our research, I also offered an advance directive information session using the 5 Wishes (*Aging with Dignity*, 2016) education materials, CD, and Advance directive forms. The topic of advance directives had come up several times during my research. I coordinated with area hospice social workers to be present several times that month to assist those who wanted to complete an advance directive. I have now officially begun my research journey with Alaska Native and American Indian peoples regarding EOL care. I attribute my successes to the coursework on Indigenous people knowledge system and ways of learning. I believe the participants had an effect on my life and I on theirs. I am now seen as a nurse researcher who will come back and assist them with health concerns.

Clinical Implications

The knowledge that I gained from this study will be helpful in every clinical situation with Indigenous peoples. The assessments will be more comprehensive knowing

the realm of indigenous worldview. Nursing is already holistic and culturally adept. However, this insight can be helpful in conducting interviews, communicating, and caring for indigenous peoples. Culture and traditions are integral parts of people; thus, honoring and integrating these elements into practice would show respect to our indigenous patients. Culture is also very individual and differs from one person to the next; therefore, it is important to understand patient's specific needs through politely exploring and asking questions.

It is crucial to listen to what your patient is saying. Remember that indirect communication may be the form of communication utilized by your patient to answer your questions. It may also be the means of communication among family members. Silence is also a part of communication. We all learned about silence as a therapeutic tool, albeit it can be uncomfortable, it is essential when speaking with many indigenous peoples. As I learned from the Navajo, periods of silence may represent a gathering of the right words, keeping balance and harmony, not wanting to offend anyone with words that are said (Kahn-John & Koithan, 2015).

My hope is that both Indigenous and non-Indigenous nurses will read this briefing on Indigenous worldviews of health and aging, encouraging them to explore the IRP and choose appropriate methodologies when preparing to conduct research with Indigenous populations. I hope my experiences and lessons learned on this journey increase their awareness of indigenous peoples and enrich their nursing practice.

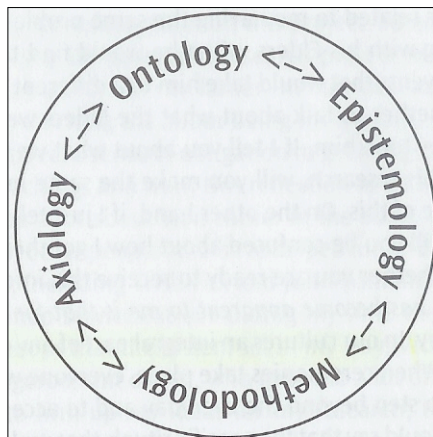


Figure 2. Indigenous research paradigm.
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Publishing from Shawn Wilson's *Research is Ceremony*.

References

- Adelson, N. (2000). *Being alive well: Health and politics of Cree well-being*. Toronto: University of Toronto Press.
- Aging with Dignity. (2016). *5 Wishes advance directive education materials*. Retrieved from <https://www.agingwithdignity.org/fivewishes/about-five-wishes>
- Alaska Native Knowledge Network. (1993). *Alaska Federation of Natives guidelines for Research*. Retrieved from <http://ankn.uaf.edu/IKS/afnguide.html>
- Atleo, M. R. (1997). First Nations healing: Dominance or health. *Canadian Journal for the Study of Adult Education*, 11(2) 63-77.
- Barnhardt, R., & Kawagley, A. O. (2005). Indigenous knowledge systems and Alaska native ways of knowing. *Anthropology and Education Quarterly*, 36(1) 8-23.
- Brink, P. J., & Wood, M. J. (1988). *Advanced design in nursing research*. Thousand Oaks, CA: SAGE Publications.
- Cajete, G. (2000). *Native science: Natural laws of interdependence*. Santa Fe, NM: Clear Light Publishers.
- Edwards, S. D. (1997). What is philosophy of nursing? *Journal of Advanced Nursing*, 25, 1089-1093.
- Gary, F. A., Baker, M., & Grandbois, D. M. (2005). Perspectives on suicide prevention among American Indian and Alaska native children and adolescents: A call for help. *Online Journal of Issues in Nursing*, 10(2), 6.
- Hollow, W. (1999). *Primary care of Native American patients: Diagnosis, therapy, and epidemiology*. In J. M. Galloway, B. W. Goldberg, & J. S. Alpert (Eds.) Boston, MA: Butterworth-Heinemann.

- Hopkins, S. E., Kwachka, P., Lardon, C., & Mohatt, G. V. (2007). Keeping busy: a Yup'ik/Cup'ik perspective on health and aging. *International Journal of Circumpolar Health, 66*(1), 42-50.
- Huttlinger, K. W. & Tanner, D. (1994). The peyote way: Implications for culture care theory. *Journal of Transcultural Nursing, 5*(2), 5-11.
- Kahn-John, M. (2010). Concept analysis of Diné Hózhó: A Diné wellness philosophy. *Advances in Nursing Science, 22*(2), 113-125.
- Kahn-John, M. (2014). *The factor structure of six cultural concepts on psychological distress and health related quality of life in a Southwestern American Indian tribe*. Denver, CO: University of Colorado at Denver.
- Kahn-John, M., & Koithan, M. (2015). Living in health, harmony, and beauty: The Diné (Navajo) hózhó wellness philosophy. *Global Advances in Health and Medicine, 4*(3), 24-30.
- Kawagley, A. O. (1995). *A Yupiaq worldview: A pathway to ecology and spirit*. Prospect Heights, IL: Waveland Press.
- Labun, E. R., & Emblen, J. (2007). Health as balance for the Sto:lo Coast Salish. [Article]. *Journal of Transcultural Nursing, 18*(3), 208-214.
- Lewis, J. P. (2010). Successful Aging through the Eyes of Alaska Natives: Exploring Generational Differences among Alaska Natives. *Journal of Cross Cultural Gerontology, 25*(4), 385-396.
- Lowe, J. & Struthers R. (2001). A Conceptual Framework of Nursing in Native American Culture. *Journal of Nursing Scholarship, 33*(3), 279-283.
- National Congress of American Indians. (2016). *Tribal Nations & the United States: An*

Introduction. Retrieved from <http://www.ncai.org/about-tribes>.

National Hospice and Palliative Care Organization [NHPCO]. (2015). *Facts and figures on Hospice Care*. Retrieved from <http://www.nhpc.org/hospice-statistics-research-press-room/facts-hospice-and-palliative-care>

O'Brien, B. L., Anslow, R. M., Begay, W., Sister Benvinda, A. P., & Sullivan, M. P. (2002). 21st century rural nursing: Navajo traditional and Western medicine. *Nursing Administration Quarterly*, 26(5), 47-57.

Smith, J., Easton, P. S., & Saylor, B. L. (2009). Inupiaq Elders study: Aspects of aging among male and female elders. *International Journal of Circumpolar Health*, 68(2), 182-196.

Smith, Tuhiwai L. (1999). *Decolonizing methodologies: Research and indigenous peoples*. Dunedin, New Zealand: University of Otago Press.

Struthers, R., Eschiti, V. S., & Patchell, B. (2004). Traditional indigenous healing: Part I. *Complementary Therapies in Nursing and Midwifery*, 10(3), 141-149.

U.S. Census Bureau (2011). An overview: Race and Hispanic origin and the 2010 census. Retrieved from <https://www.census.gov/2010census>

Uys, L. R., & Smit, J. H. (1994). Writing a philosophy of nursing? *Journal of Advanced Nursing*, 20(2), 239-244.

Venes, J. (Ed.). (2001). *Tabor's cyclopedic medical dictionary* (20th ed.). Philadelphia, PA: F.A. Davis.

Wallis, V. (1993). *Two old women: An Alaska legend of betrayal, courage and survival*. New York, NY: Harper Collins.

Wilson, J. (2000). *King trapper of the North: An ethnographic life history of a traditional aboriginal sporting king*. University of Alberta.

Wilson, S. (2008). *Research is ceremony: Indigenous research methods*. Nova Scotia, Canada: Fernwood Publishing.