

END-OF-LIFE ISSUES FOR NATIVE AMERICAN AND ALASKA NATIVES:

A CRITICAL LITERATURE REVIEW

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End-of-Life Issues for Native American and Alaska Natives:
A Critical Literature Review

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ABSTRACT

This paper conducts a critical literature review on end of life issues relating to Native Americans and Alaska Natives. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) framework was used to guide this literature review. In particular, a PRISMA flow diagram which outlines the various steps of the critical literature review is given. The review identified 18 papers. Although all of these papers fit the inclusion criteria, there was very little uniformity among them. Six common themes emerged; namely, communications, program development, spirituality, rituals, advance planning, and guidelines. A detailed discussion of these six themes along with nursing implications is presented. While work is being done to develop cultural competence, it is apparent nurses must continue to develop their skills related to these six areas of concentration in order to improve end of life care in Native American and Alaska Native populations.

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CHAPTER 1. INTRODUCTION

Nursing Issue

Literature suggests people of minority descent have continually been at a disadvantage when it comes to health and health care. Benz, Espinosa, Welsh, and Fontes indicated health imbalances among diverse populations of people exist in several categories and they include specific diseases such as hypertension and diabetes along with access to health care (2011). The Institute of Medicine's report of "*Unequal Treatment Confronting Racial and Ethnic Disparities in Health Care*" statement indicated health care for minorities such as African Americans, Hispanics, American Indians, and Alaska Natives was less optimal than whites in access, insurance, and with health care choices (Smedley, Stith, and Nelson, 2003). Among approved recipients for renal transplants, whites have a higher percentage of transplantation than those who are African American 52% versus 17% respectively (Rohack, 2005).

Of particular concern is health care among Native Americans and Alaska Natives (NA/AN). Reasons restricting health care with this population of people include finances, geographic location, and mistrust relating to spiritual beliefs (Centers for Disease Control and Prevention [CDC], 2013). Additionally, in 2009 compared to those of white descent more Native Americans and Alaska Natives lived in poverty and had poor housing (CDC, 2013) which can negatively affect one's well being. Furthermore, the constituents in these populations are associated with negative health outcomes and higher mortality rates from chronic diseases. According to the Centers for Disease Control and Prevention in 2009 the five leading causes of death for Native Americans was as follows: heart disease, cancer, unintentional injuries, diabetes, chronic liver disease and cirrhosis (2013).

The Indian Health Services website indicates Native Americans and Alaska Natives in the IHS area still experience health disparities. The years of 2005-2007 showed life expectancy of Native Americans and Alaska Natives was less than all races in the United States by 4.1 years and death rates among Native Americans and Alaska Natives were higher as a result of alcohol, diabetes, and accidents (Indian Health Service [IHS], 2013).

It is important to understand even though Native Americans as a whole endure poorer health and have a life expectancy lower than the general population they represent a relatively small segment in society, yet it is expected that Native Americans' numbers will increase in years to come. The United States census bureau indicated that as of 2010 there were 5.2 million Native American and Alaska Natives (Norris, Vines, Hoeffel, 2012). The Center for Disease Control website indicated as of 2010, 1.7% of the population was Native American and Alaska Native and it is expected the Native American and Alaska Native populations will increase to 8.6 million by the year 2050 (CDC, 2013).

In spite of the small population and lower life expectancy with indigenous people, without doubt, health practitioners at some point in their careers will encounter people who are Native American and/or Alaska Native. This could be due in part to increased life expectancy, living with chronic diseases, moving to various areas, and limited access to Indian Health Service. As a result, health care practitioners should become familiar with the health care services and needs of Native Americans and Alaska Natives.

The Indian Health Service is a federally recognized program established to provide health care for Native Americans and Alaska Natives who are enrolled members of federally recognized tribes (IHS, n.d.). This health service is well intended but there are shortcomings. For instance, the majority of health services offered are to Native American and Alaska Natives

who live in Indian country meaning those who live on or close to reservation land (IHS, 2013). As of the year 2010 a large portion of Native Americans and Alaska Natives (78%) did not live in Indian country (Norris, Vines, and Hoeffel, 2012), consequently, millions of Native Americans and Alaska Natives are left searching for health care services not provided by IHS. Finally, the IHS program funding is less than optimal as it is often treated as discretionary opposed to mandatory funding (Westmoreland and Watson, 2006).

Knowing Native Americans and Alaska Natives are living longer with chronic diseases and possibly using health care services outside of the IHS serve area, it is likely health care practitioners will need to provide care when the person becomes terminally ill and cure is no longer an option. According to Kitzes and Domer the dying process with Native Americans and Alaska Natives has changed because of living longer and with high occurrence of chronic diseases (2003). As a result, health care providers should have an understanding of Native American health, culture, preferences, and communication style when addressing such a delicate subject.

Although, research and statistics generated in the literature have documented health disparities and health diseases acquired by Native Americans and Alaska Natives, it is less known how this group of people address or approach end of life issues. As the Native American and Alaska Native population continues to grow, and chronic diseases and high death rates associated with certain diseases persist, it is imperative for health care providers to understand their unique needs when life is short. Keeping in mind there are approximately 565 federally recognized tribes in the United States each with their own unique life style and cultural identity it is important for health care providers to understand and become culturally aware of end of life issues such as spirituality, communication styles, and rituals when providing end of life care.

One important factor to consider is that research generated from tribal affiliations may or may not be relevant for individuals or individual tribes. With that identified, we must determine ways to provide culturally sensitive care for each person when end of life is drawing near.

The original intent for this critical literature review was to determine the usage of hospice care among Native Americans. However, during the investigation process there was very little information available in the literature, related to Native Americans and Alaska Natives use of hospice care. Therefore, the scope and range of the critical literature review was increased in breadth to encompass end of life issues as it relates to Native Americans and Alaska Natives. The author anticipated that by expanding the topic more literature would be available for analysis.

The aim of the critical literature review was to identify the needs of Native Americans and Alaska Native when providing end of life care. The author focused on answering the following questions:

- What is known about end of life as it relates to Native Americans and Alaska Natives?
- Are there barriers in the ability to provide culturally competent end of life care with Native Americans and Alaska Natives?
- Are Native Americans and Alaska Natives aware of palliative and hospice care services and if so, are they receptive of these services?

There are at least three areas in which this critical literature review may assist health care providers. First, information obtained from the critical literature review will ultimately help nurses and physicians provide culturally acceptable care as it relates to the death and dying experience of Native Americans and Alaska Natives and their respective families. Second, information obtained in the review will help guide future research endeavors related to end of

life care. Third, the critical literature review may help nurse educators determine what information to include in their curriculum regarding diversity and end of life care.

The need to provide holistic and culturally sensitive care for each individual and his or her family is necessary especially for the individual who is near the end of life. The nursing profession promotes the concept of holistic health and includes such views in nursing courses and nursing practice. Nurses utilize holistic care when providing alternative therapies such as massage, prayer, and meditation. Some Native Americans concept of health includes the notion of holism. For example, Portman and Garret pointed out that health care for Native Americans is associated with both the spiritual and physical world (2006). Horowitz (2012, p.25) outlined the concept of holism, within Native American culture as interconnectedness with the “mind, body, spirit and the environment”. Finally and best stated, Lowe (2002, p.6) writes, “Within the Native American worldview, the individual does not view self as a being independent from others. A person is viewed as an extension to and is integrated with a family, community, tribe, and the creation/universe.”

Similarities exist between Native American culture and the nursing profession such as recognizing health and healing is best achieved when the mind, body, and spirit work together for better health outcomes. Having this commonality can create an environment, which can and should result in providing holistic and culturally acceptable care at the end of life. The nursing profession has identified the importance of diversified health care and education. As a profession we can be a leader in developing programs addressing end of life care with Native Americans and Alaska Natives.

As the United States population continues to become more diversified nurse educators must adapt their nursing curriculum to reflect changes in demographics and become more

vigilant in providing education as it pertains to diversity and end of life issues. Increased awareness about the concepts of diversity and end of life issues can be accomplished through advanced education and research. Additionally, The American Nurses (ANA) position on end of life care states nursing education should prepare nurses with the needed knowledge to provide compassionate care at the end of life (June, 2010). Furthermore, the American Association of Colleges of Nursing Essentials for Baccalaureate Programs advocate for students to be prepared to care for at risk populations along with having the knowledge related to end of life and palliative care (October, 2008). Therefore, the nursing profession must continue to research and advocate for specialized training related to diversity and end of life care. Not only is it essential for nurses to research and disseminate information related to Native Americans/Alaska Natives and end of life, we have an obligation to also educate health consumers about programs such as palliative care and hospice programs. Nurses having adequate knowledge about end of life care with Native Americans and Alaskan Native can help the dying individual and family members during this transitional time.

Some communities are in the process of developing palliative care programs for Native American and Alaska Natives. For instance, the “Elder Care Task Group” which is a group of people from the Indian Health Service, Navajo tribe, Bureau of Indian Affairs, and Arizona Long Term Care are working together to address palliative care and end of life issues at Fort Defiance Navajo reservation (Kitzes & Domer, 2003). Programs such as palliative and hospice care are necessary and should be available for all people regardless of a person’s race, culture, or ethnicity. Unfortunately, such programs are not fully meeting the needs of Native Americans and Alaska Natives as evident by the lack of programs available on or near tribal reservations. All health care workers but particularly nurses, nursing educators, and practitioners who work

closely with Native Americans and Alaska Natives should have an understanding of end of life preferences and cultural norms within this group of people. The more educated nurses and practitioners become surrounding this issue, the more likely end of life care can be addressed and implemented within Indian country. As an example, the National Cancer Institute (NCI) and Indian Health Service (IHS) developed a “palliative care curriculum” (Arnella, Finke, Domer, Kaur, Merriman, & Ousley, 2010). The program was implemented to improve health care workers’ knowledge of palliative care with Native Americans and Alaska Natives. Evaluations of the program were favorable with participants having a better understanding of palliative care, and 65% indicating they would change the way they practice (Arnella, et al., 2010). NCI and IHS demonstrated with both collaboration and cooperation that education about end of life care can be obtainable in Indian country. The palliative care curriculum demonstrated the benefits of establishing a working relationship with tribal communities through education and research. Nurse researchers and educators can also build working relationships with tribal communities and a starting point is gaining understanding how the dynamics of culture affects both end of life care and acceptance of end of life programs such as palliative and hospice care. In the following chapter the author will highlight or define palliative and hospice care.

Background Information

Palliative care is a program within the health care field, which focuses on alleviating and relieving symptoms associated with life limiting illnesses as opposed to a curative model. The World Health Organization (2002) identified palliative care as a way to provide holistic care using a multidisciplinary team approach to enhance the lives of individuals and families during the course of a terminal illness. Some people may have the misconception palliative care means curative treatments are no longer accessible. However, within the palliative care framework is

the notion that individuals can participate in the program while still seeking and receiving curative medicine. The World Health Organization (2002) recognized individuals can opt into a palliative care program earlier into the course of the illness and if feasible can still utilize other forms of health care such as chemotherapy or radiation. Additionally, the National Hospice and Palliative Care Organization's website identified that palliative care utilizes the concepts of hospice care however; a person can enter into the program earlier than those entering into a hospice program (2011). Palliative care's definition essentially broadens the population served. Given the previously stated definition of palliative care, it could be possible for Native Americans/Alaska Native to receive palliative care while still seeking and utilizing traditional medicine. Although, palliative care's philosophy is similar to hospice they are two different health care entities.

Within the nursing profession is the specialty of hospice care. Hospice care is a form of health care, which provides end of life care for those who are terminally ill, and curative treatment is no longer applicable. According to the National Hospice and Palliative Organization (2011) hospice is geared toward "caring" as opposed to curing. Within the hospice philosophy is the notion that individuals have the right to die with dignity (Miller, 2012) and free of pain. One of the unique aspects of hospice care is that it is multidisciplinary by providing many services other than nursing care, examples include music and art therapies (Miller, 2012) massage therapy, and pet therapy. Additionally, chaplaincy services are available upon request. From this author's experience, the goal of hospice care is to provide holistic nursing care addressing physical, mental, social, and spiritual needs of clients and their families so each day is lived to its fullest potential free of pain. Hospice's holistic approach to end of life care certainly can be introduced into the Native American and Alaska Native culture. For instance, many Native

Americans still seek the guidance of medicine men (Horowitz, 2012) which could be integrated into the plan of care. Marr, Neale, Wolfe, and Kitzes (2012) worked with Native American clients and families in a palliative care consultation program and “traditional healers” are not only consulted but also appreciated. With meticulous thought and care, Native American and Alaska Native traditions and preferences can be integrated into a person’s plan of care, while still being admitted into a hospice program.

Native Americans and Alaska Natives have unique beliefs related to death and dying. Communication style also can differ from mainstream culture. For example, some Native American’s communication style tends to be more indirect and could conflict with the frankness seen in American culture (Limb & Hodge, 2008). When speaking about death some Native Americans use storytelling and images to communicate (Cacciatore, 2009). In addition, some Navajos Indians do not like to talk about death and mentioning the deceased person’s name is avoided (Walker & Balk, 2006). Such beliefs and convictions could discourage a person from entering into palliative or hospice care due to the openness and willingness of health care providers to discuss death and dying. The communication differences could have negative connotations with end of life care. In other cases, there are Native Americans and Alaska Natives who would like to learn about palliative and hospice care programs. For example, DeCourtney, Branch, and Morgan, met with aboriginal peoples in Alaska and formed focus groups, which discussed death and dying in their culture (2010). The diversity among Native Americans and Alaska Natives needs to be recognized, and end of life care such as palliative and hospice care should be available to those who desire such services.

Although, hospice has been around for over 25 years and admissions have continually grown through the years, the increase is not necessarily representative of all cultures. The

National Hospice and Palliative Care Organization (2012) reported in 2011 that greater than 17.2% of hospice patients were of minority descent or non-Caucasian. Only 0.2% of the patients were American Indian or Alaska Native as compared to 82.8% being Caucasian. Interestingly, these statistics have not changed much in the last few years. For example, in 2009 the National Hospice and Palliative Care Organization reported 0.2 % of hospice patients were Native American or Alaska Native compared to 80.2% Caucasian. Although, there was an increase in hospice patients it did not reflect an increase in Native Americans and Alaska Natives utilization. Underutilization of hospice and palliative care by minorities may be the result of culture, access, and knowledge. DeCourtney, Jones, Merriman, Heavener, and Branch (2003) described distance as a barrier in providing health care for Alaska Natives residing in the isolated Bristol Bay area, as the tertiary hospice was located “329 air miles southwest of Anchorage.”(p.502). Additionally, DeCourtney, Branch, and Morgan (2010) identified that access to remote villages in Alaska made it difficult to provide palliative care in a culturally sensitive manner for Alaska Natives. While, accessibility is one determinate in end of life programs, culture may also play a role as it relates to palliative care. Kitzes and Domer (2003) recognized that end of life issues were not fully addressed as the result of cultural aspects related to death and lack of resources within the health care system and communities. A study by Schrader, Nelson, and Eidsness (2009, p.75) indicated more Native Americans had less knowledge and had never “heard of hospice” compared to non-Natives. Continued research will be needed in order to fully understand the logistics of death and dying among Native Americans and Alaska Natives.

Definitions

The goal of this paper was to perform a critical literature review addressing end of life issues related to Native Americans and Alaska Natives. The author searched for sufficient

literature to determine factors, which inhibit or promote end of life care for Native Americans and Alaska Natives. The following definitions are used for the terms: Native American, Alaska Native, end of life, spirituality, death, dying, bereavement, terminally ill, and palliative/hospice care.

The Merriam Webster's collegiate dictionary defines American Indians as people who are members of the "aboriginal peoples of the western hemisphere" (2000, p. 37). Barnes, Adams, Powell-Griner (2010) indicate Native Americans and Alaska Natives are people who originated from North, South, or Central Americas and have either community or tribal affiliation. For the purpose of this paper the terms Native American, American Indian and Alaska Natives will be those people who reside in the United States affiliated with federally recognized tribes or connected with tribal communities. All people who are identified as Native American, American Indian, and Alaskan Native were included in this critical literature review and may reside either in rural, urban, or on Indian reservations.

With an aging population, at some point in a nurse's career he or she will most likely care for a client with a terminal illness. According to the Taber's Cyclopedic Medical Dictionary terminally illness refers to an incurable disease (2001). Likewise, end of life occurs when therapy is ineffective, comfort becomes the focus of care, and cure is not likely (Wilke & TNEEL Investigators, 2003 as cited in Miller, 2012). Terminal illnesses will eventually progress and death and dying is the consequence.

Death and dying are often used simultaneously, however practically speaking they are different. Death is irreversible and happens when all physiological functions cease (Miller, 2012). On the other hand according to Gulanick, Myers, Klopp, Gradishar, Galanes and Puzas (2003p. 1047) dying "is an active process". From this author's nursing experience, dying is the

act or process of the body systems shutting down and ultimately ends in death. Signs and symptoms associated with dying include fatigue, constipation, difficult breathing, dehydration, and malnutrition (Miller, 2012). As a person begins to actively die, signs and symptoms become more prominent and include mottling of skin, cool extremities, decrease and irregular respiration rate, decreased blood pressure, and decreased level of consciousness (Miller, 2012).

The dying process is very much individualistic, varies from person to person and can be very stressful for the client and his or her family. Nursing care during the dying process is pivotal and requires thoroughness in order to meet the needs of the client and family. Due to the individualistic nature of death and dying nurses must be conscientious of diverse beliefs relating to end of life and include cultural preferences when providing care (Miller, 2012). Along with providing physical care to dying individuals and families, a nurse may need to address and implement care surrounding bereavement and spirituality.

Bereavement is an emotional reaction seen when loss is experienced (Tabers, 2001). Like the death and dying process, bereavement varies from person to person and can occur before the actual loss occurs. During this delicate time spirituality may help ease, motivate, and soothe a person's mental and physical health. Part of the Hospice and Palliative Nurses Association's position statement implies spiritual care may be comforting and encouraging as death draws near (HPNA, 2010). Spiritual beliefs or spirituality is often associated with religion; however, this is not always the case. According to Potter and Perry a person's spiritual beliefs are influenced by culture, life events, and perceptions of life (2013). Spirituality within Native American culture is the driving force that ties everything in the world together (Lowe, 2002). Realizing the meaning, how it maybe all encompassing, and the importance associated with spirituality, spirituality is vital in providing holistic care. Therefore, nurses should inquire about

a person's spiritual beliefs and include such beliefs into the plan of care. Having a more complete understanding of a person's spirituality can help the nurse implement appropriate therapeutic nursing interventions for each person and family to achieve physical and inner peace.

The underlying premise of hospice care is to assist and help individuals die with dignity (Miller, 2012) which can be accomplished by promoting comfort and providing palliative care. People of all nationalities and cultures should have access to reliable and quality end of life care; in particular hospice services should be available for all. However, it is not always the case as described earlier in the paper. The result of under utilization of hospice services could be due in part to barriers.

Barriers can be described as anything which obstructs, inhibits, or prevents something from happening. The Webster's collegiate dictionary defines barrier as "a natural formation or structure that prevents or hinders movement or action" (2000, p. 10). Within Native American and Alaska Native communities, geographical location, decreased education, lack of availability of formal end of life care such as palliative and hospice care could potentially be considered barriers and thus might explain the under usage of these health services amongst the Native population. This critical literature review focused on discovery of any barriers and how end of life issues affect Native Americans and Alaska Natives.

CHAPTER 2. METHODOLOGY

PRISMA Framework

Health care has and continues to be very fast paced which necessitates the need for current research and health literature to be accessible with relative ease. However, health research can be time consuming and burdensome when trying to find the exact and most appropriate literature when needed. Practitioners in health care need to be current with health standards and guidelines in order to provide the best and most optimal levels of services. The increased demand for evidence-based practice in health care has become a staple in providing care. The nursing profession dictates that each nurse is required to stay active and up to date with current health trends. Often times, this is accomplished through reading professional journal articles. In particular, many clinicians read and rely on critical literature reviews as a way to stay current with health research (Moher, Liberati, Tetzlaff & Altman, 2009). For instance, Jones and Evans (2000, p.66) stated that “nursing has now begun to utilize the systematic review process as a reliable method of summarizing the best available evidence in order to guide clinical decision making and practice.” Furthermore, in an article describing a literature review, Wood (2003) identified the need for nurse researchers to conduct more systematic reviews to endorse evidence-based practice for clinicians.

While clinicians become reliant on critical literature reviews, it is imperative that the literature review process is completed with a systematic and non-bias approach. Nightingale (2009) recognized that a systematic literature review can balance and generate research in an objective manner. When carrying out rigorous research, guiding principles along with a standard set of rules can assist authors to potentially lessen the inclination toward biases. An initial attempt at providing such guidance pertained to Quality of Reporting of Meta-analyses

(QUOROM) statement (Moher, Cook, Eastwood, Olkin, Rennie, and Stroup, 1999). This statement was primarily used for guiding and reporting randomized trials. However, as research evolved and systematic reviews started to cover more topics, it was deemed necessary to update and revise the QUOROM statement (Liberati, Altman, Tetzlaff, Mulrow, Gotzsche, Loannidis, et al., 2009).

To date, the Preferred Reporting Items for Systematic Reviews and Meta-Analysis statement, known simply as PRISMA (Liberati, et al., 2009), is typically used for such guidance. In fact, according to Nightingale (2009), many journals are now requiring PRISMA statements to be utilized and included in literature reviews. Briefly, the PRISMA statement can be viewed as a prescription to help researchers develop the skills necessary to properly carry out a systematic literature review. The statement basically includes two components. That is, an inventory of items to include in the literature review and the so-called PRISMA flow diagram (Moher et al., 2009). The idea is that by utilizing the PRISMA statement, authors will be able to uncover all pertinent articles as it relates to the research topic.

As previously noted, some researchers in the nursing profession are calling for more critical literature reviews to be completed and disseminated. Moreover, they are also advocating the use of the PRISMA statement. Fredericks, Lapum and Lo (2012) are three nurse researchers who are answering this call. For example, their literature review on anxiety, depression, and self-management used the PRISMA flow chart to map out their literature review. Happel and Gaskin (2012) also used the PRISMA statement in guiding their systematic literature review. An article by Brereton, Gardiner, Gott, Ingleton, Barnes, and Carroll (2011) about end of life care is yet another example of a systematic review that used the PRISMA flow diagram to summarize their search process. It should be noted that the PRISMA flow diagram found in Liberati et al.

(2009) grants an author permission to use the flow diagram in their own research provided it is properly credited. Likewise, the PRISMA statement was used to guide the critical literature review presented in this paper.

Review Protocol

In accord with the need identified by Wood (2003), Nightingale (2009), and Liberati et al. (2009), this author performed a critical literature review designed to critically analyze the topic of end of life as it relates to Native American and Alaska Native cultures. Once more, the framework for the project is rooted in the recommendations given by Wood (2003) and Burns and Grove (2009) and the PRISMA statement discussed by Nightingale (2009), Liberati et al. (2009), and Moher et al. (2009). The following is a brief description of the various components used in the current critical literature review.

Databases

The search strategy for the critical literature review was limited to on-line data bases and included Scopus (SciVerse Scopus), ERIC (Educational Resource Information Center), PsychINFO (Psychological Information Database), CINAHL (Cumulative Index of Nursing and Allied Health Literature), and Medline. Through September, 2013 these data bases were searched for journal articles that addressed at least one of the search terms used in the critical literature review.

Search Terms

This critical literature review focuses on end of life issues as they relate to Native Americans and Alaska Natives. Thus, search terms were derived based on two constructs; the population description name and the end of life issue. For the population description the following names were used: “Native American”, “American Indian”, “Alaska Native”, and

“indigenous people”. For the end of life issues, the following words and phrases were used: “palliative care”, “end of life”, “hospice”, “terminally ill”, “death”, “dying”, “barriers”, “bereavement”, and “spirituality”. Combining the two constructs yielded $4 \times 9 = 36$ different search terms that were employed in the critical literature review. For example, "indigenous people" and "palliative care" is one such search term. For convenience, all 36 search terms used in the review are listed in the Appendix. Of course, this process only identified potential articles to be included in the study. Inclusion and exclusion criteria were used to help determine which articles ultimately became a part of the literature review.

Inclusion Criteria

To begin, it should be noted that preliminary searches suggested that the existing body of literature on end of life issues as they relate to Native Americans and Alaska Natives was limited. Thus, it was deemed necessary that the inclusion criteria be somewhat liberal. With that in mind, the inclusion criteria included all types of studies (e.g. descriptive study designs, qualitative/quantitative studies, case studies, and explanatory papers). Also, there were no restrictions on sample sizes. Naturally, the populations being researched needed to be predominately Native American and/or Alaska Native. The specific criteria to be addressed within the cultural groups were limited to hospice care, palliative care, and end of life preferences as determined by each respective cultural group. In addition, only journal articles were included in the literature review.

Exclusion Criteria

On the other hand, a somewhat conservative exclusion criterion was utilized. For example, articles that addressed only a disease process, unintentional deaths (e.g. suicide or accidents) and did not discuss end of life, palliative care, or hospice care among the chosen

population were discarded. Also, articles were eliminated if the title or abstract did not speak to at least one of the search terms given in the Appendix.

PRISMA Flow Diagram

As outlined in Burns and Grove (2009), it is important to report the number of articles found and the number of relevant articles. In accord with Nightingale (2009), this information should be summarized in the form of a PRISMA flow diagram. To this end, Figure 1 gives a PRISMA flow diagram (adapted from Liberati, et al., 2009) for the present critical literature review.

To summarize, it can be seen from Figure 1 that the total number of articles found by utilizing the five data bases and the 36 search terms was 4,473. The actual number of articles for Scopus, Medline, ERIC, PsychINFO, and CINAHL were 2,046, 790, 683, 568, and 386, respectively. Indeed, many of the same articles appeared in more than one data base. In fact, there were 1,375 duplications. This left 3,098 unique articles for consideration based on the inclusion and exclusion criteria. From Figure 1 it can be seen that 1,592 articles were excluded because the title did not address at least one of the 36 search terms. This left 1,506 articles to be screened based on the article abstract; of which, 1,437 were discarded. Sixty-nine articles remained to be assessed for eligibility after reading the entire article. At the conclusion of the process, 18 articles satisfied all of the inclusion criteria. In the subsequent chapters, an overview and synthesis of these 18 articles is presented. Additionally, a general discussion and some nursing implications are also presented.

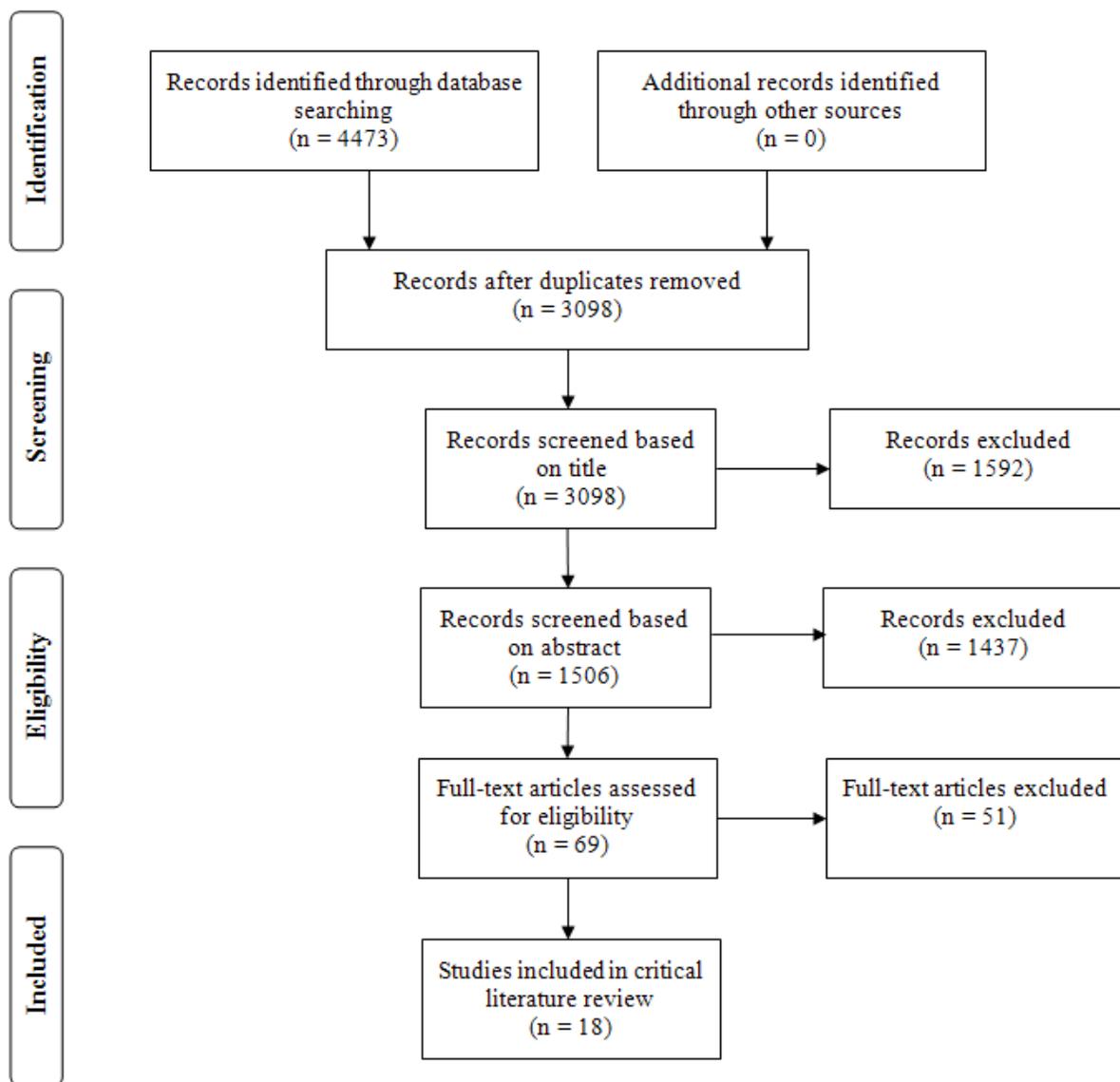


Figure 1. A PRISMA flow diagram for the critical literature review; adapted from Liberati et al. (2009).

CHAPTER 3. RESULTS

Overview of Selected Studies

Table 1 outlines and gives a brief overview of the selected articles in alphabetical order for this critical literature review. The information in the table contains the lead author, year, type of paper, geographic location, participants, and outcomes.

Table 1. Summarization of Studies Included in Critical Literature Review

Lead Author	Year	Type of Paper	Geographic Location	Participants	Outcome
Arnella	2010	Descriptive Article	Indian Health system specific geographic location unknown.	Interdisciplinary health care providers	A curriculum for palliative and end of life care was developed to enhance the knowledge of health care workers who worked with Native Americans. The program was beneficial with participants gaining knowledge and increased awareness with palliative and end of life care.
Cacciatore	2009	Case Study	Reservation of unknown origin	Native American Family (a young and middle aged couple), Social Worker, and Medical examiner	The author gave an example of her account with a Native American family after the death of a Native American Infant.

Table 1. Summarization of Studies Included in Critical Literature Review (continued)

Lead Author	Year	Type of Paper	Geographic Location	Participants	Outcome
Colclough	2013	Qualitative	Reservation of unknown origin	A total of 58 participants including Native Americans and Health care providers with or without Native American heritage.	Interviews were obtained from participants with the intent on gathering information about cultural values and aspects related to decision making at the end of life with this particular tribe with the goal in establishing hospice care. End of life decision making was viewed differently among Native Americans and health care providers with Native Americans having unawareness they had choices and could make autonomous decisions as some viewed the physician as being in authority. The themes of misunderstanding of illnesses and barriers that affected the misunderstanding were acknowledged. Hospice care was established however currently is not functioning due to organizational problems and lack of funding.

Table 1. Summarization of Studies Included in Critical Literature Review (continued)

Lead Author	Year	Type of Paper	Geographic Location	Participants	Outcome
DeCourtney	2010	Qualitative	SW Alaska	84 Alaska aboriginal elders from six aboriginal Alaska communities	The authors gathered information about Alaska Native preferences and customs as it related to death and dying. A common theme emerged from all the communities in the study which was the desire to stay at home during the dying process.
DeCourtney	2003	Descriptive Article	Bristol Bay Area SW Alaska	Health care workers, Alaska Native villagers	A helping hands program was designed and developed to provide palliative care and pain management to Alaska villagers.
Domer	2008	Descriptive Article			This paper described existing palliative care and hospice programs for the Native American population. Common themes included the ideas of building trust, distinct and unique tribal customs, and family participation.

Table 1. Summarization of Studies Included in Critical Literature Review (continued)

Lead Author	Year	Type of Paper	Geographic Location	Participants	Outcome
Finke	2004	Descriptive Article	New Mexico	Pueblo of Zuni, Healthcare Representatives from Pueblo Of Zuni's Home Health Care Agency, Zuni Comprehensive community Health Center, and the University of New Mexico Health Science Center	Three distinct health institutes worked together to form end of life and palliative care services in the Pueblo of Zuni, serving both Navajo and Pueblo nations.
Gorospe	2006	Descriptive Article			The author depicted the need for palliative care among Native Americans and described how this phenomenon needed to be addressed by public health.

Table 1. Summarization of Studies Included in Critical Literature Review (continued)

Lead Author	Year	Type of Paper	Geographic Location	Participants	Outcome
Grossman	1993	Qualitative	Salish American Indian Community	Seven Elders and 21 adolescents from the Pacific Northwest American Indian Community	Most all participants in the study had been affected by unintentional deaths. A number of participants mentioned drug and alcohol being a contributor to the deaths. Among some of the participants was the belief in “spirit sickness” an illness mimicking depression and rooted in the belief that ghosts cause the illness. Healing was associated with traditional ceremonies, Christianity, and counseling.
Hampton	2005	Commentary	Oklahoma City		This paper described the inception of a hospice care program in Oklahoma and identified the need for more research as it related to Native Americans and end of life.

Table 1. Summarization of Studies Included in Critical Literature Review (continued)

Lead Author	Year	Type of Paper	Geographic Location	Participants	Outcome
Hepburn	1995	Qualitative		Physicians, nurses, social workers, and administrators	The authors interviewed twelve health care workers known to work with Native Americans (Navaho, Mountain and Southern Ute, Chippewa, Pueblo, and Apache) The author inquired about information related to autonomy, advance directives, competence, and surrogate decision makers The information obtained was then structured into guide lines for clinicians who worked with Native Americans.
Kitzes	2004	Retrospective study & Interviews	New Mexico	Health care workers, cultural advisors	The study identified there were inadequate palliative care programs in Indian country. Yet, programs were beginning to address the need.
Kitzes	2003	Descriptive Article			Kitzes described palliative care and hospice programs which worked with Native Americans, and outlined elements to include when developing future end of life programs for Native Americans.

Table 1. Summarization of Studies Included in Critical Literature Review (continued)

Lead Author	Year	Type of Paper	Geographic Location	Participants	Outcome
Marr	2012	Quantitative	New Mexico University of New Mexico Hospital	Health care workers & Native American patients and their families in the southwest	This paper discussed an empirical study relating to a newly created palliative care consultation service. The primary focus was on comparing non-Native Americans and Native Americans with regard to prevalence of “family meetings” and do not resuscitate(DNR) status before and after palliative care consultation. With regard to primary outcomes, there were significant increases in the prevalence of family meetings and DNR code status from pre-to-post consultation. As a byproduct of this study, the authors included a table of techniques that could be used to help facilitate Native American end of life discussions. The information presented provides practitioners with valuable information that may enhance communication of palliative care issues with Native Americans.

Table 1. Summarization of Studies Included in Critical Literature Review (continued)

Lead Author	Year	Type of Paper	Geographic Location	Participants	Outcome
Mazur-Bullis	1984	Case Study	North West North Dakota	Native American community members from the Fort Berthold Indian Reservation	A case study addressing four ceremonies of public grieving as it pertained to a Native American family in North West North Dakota and included the wake, the funeral, the commitment service, and feast and give away.
Schrader	2009	Quantitative	South Dakota	Native Americans and non-Natives.	Schrader's study compared attitudes about end of life issues in South Dakota among Native Americans and non-Natives. The authors looked into four areas including spirituality, family, health care, and self. With regards to spirituality a large percent identified being at peace was important. Family was valued and the fear of being alone at the time of death was expressed. Health care was examined and looked at both the environment and participants' views of healthcare providers. Finally, the area of "self" addressed how individuals felt about death and dying.

Table 1. Summarization of Studies Included in Critical Literature Review (continued)

Lead Author	Year	Type of Paper	Geographic Location	Participants	Outcome
Walker & Balk	2006	Qualitative	Several sites non-named specifically	27 members of from the Muscogee Creek Tribe	The authors conducted interviews with members of the Muscogee Creek Tribe to find information about bereavement rituals. Rituals varied among tribal members but a few common themes emerged such as; never leaving the body alone, giving a final hand shake, and having a wake service the night before burial.
Walker & Thompson	2009	Qualitative	Oklahoma	27 members from the Muscogee Creek Tribe	A study that identified spirituality as it related to death with members from the Muscogee Creek Tribe. Information revealed many of the participants believed in supernatural spirits and relationships which existed with the deceased.

For the most part articles were published in year 2000 and beyond with the exception of three which were published in 1984, 1993, and 1995. Although, the three articles were somewhat dated, this author felt it necessary to include them as they presented valuable information and gave rise to end of life issues with Native Americans. In particular Grossman's study was the only one from the critical literature review identifying views of adolescents on end of life, and thus was included. As can be seen from the above table, the types of articles were a mixture including quantitative, qualitative, and explanatory. The Participants and outcomes were

related to Native American and/or Alaska Natives. The following section summarizes and brings together components of the selected articles.

Synthesis of Selected Studies

The articles obtained in the critical literature review contained some similarities and differences as each article was not constructed in the same fashion. For instance, included articles were qualitative, quantitative, or descriptive. Nonetheless, the articles all identified end of life issues with Native American and Alaska Natives. This author identified the need to include all types of articles as there were sparse numbers of literature pertaining to the identified topic. Also, inclusion of various types of articles provides a more comprehensive view of end of life issues for Native Americans and Alaska Natives.

The geographical settings identified in the articles were diverse and spanned several locations throughout the United States and Alaska however, not every article divulged its locale. The primary location included several Indian reservations or regions where a number of Native Americans and Alaska Natives reside. For instance, New Mexico is home to several Native American tribes and three of the studies in this literature review took place in New Mexico. Two of the studies took place in SW Alaska covering several communities. These communities provided the participants for the articles.

The participants of the articles consisted of Native Americans, Alaska Natives, and health care providers who had a vested interest in Native American and Alaska Native health care. The number of participants ranged from as few as a single Native American family consisting of five members to as many as 84 Alaska aboriginals representing six Alaskan communities. Some of the participants were enlisted and obtained for the studies only after a known member in the research group had gained access into the tribal communities or a key informant had helped with

recruitment. Health care participants were multidisciplinary in nature and ranged from local native villagers to nurses, clinicians, a pastor, and social workers. Health care entities included the University of New Mexico, hospitals, clinics, a home health agency, and selected Indian Health Service sites.

The eligible articles for this critical literature review were quite varied and none followed the same research approach. In fact some of the articles were not research articles but rather articles describing the phenomena of end of life issues among Native American or Alaska Natives. Consequently, the 18 articles obtained from the literature review were eclectic in nature. By illustration, ten of the articles in this literature review addressed palliative care. Within the ten articles five address program development, two identified palliative programs already in existence, one was a commentary about end of life issues for Native Americans, one described how palliative care was a public health concern, and one study examined palliative care issues at particular Indian Health Service facilities. The other seven articles discussed end of life issues with Native Americans and did not necessarily describe palliative or hospice care among the population. In this critical literature review there were only a few “true research studies” meaning qualitative or quantitative research articles. Four articles were quantitative, six were qualitative, two were case studies, and six were non-research articles. The characteristics of the selected articles made it difficult to analyze, nonetheless after careful synthesis six themes emerged as follows; communication, spirituality, rituals, program development, advance planning, and guidelines.

The process of analysis for determining the themes which emerged included reading each article in its entirety and highlighting or taking notes while reading the articles. After completely reading the articles this author then determined the topic that each paper addressed. For instance,

articles discussing palliative or hospice care was then grouped together, and so on. Once the articles were categorized, this author then reread the paper looking for commonalities and or differences among the articles. From the analysis, six themes became the focus of the synthesis.

Communication

Although not always directly written, a commonality identified in most of the articles was the need for adequate communication among practitioners, patients, families, and tribal communities. A total of 16 out of the 18 articles in some form or fashion described or declared information about communication. Good communication was an essential part of health care and became of utmost importance when working with patients, families, and communities in which culture was different from the practitioners. Aspects identified in relation to communication included: death and dying conversations were not acceptable in some Native American/Alaska Native communities, trusting relationships, active listening, patience, flexibility, silence, and knowing family involvement/family decision maker.

Discussions about end of life were sensitive and difficult to address for some patients, families, and practitioners, and often times the topic was not addressed until death was apparent. Although, some Native American and tribal communities may adhere to cultural traditions and may not desire or believe in discussing death and/or the deceased, the articles in this literature review identified that with much cultural consideration, the topic can be discussed with some Native Americans and Alaska Natives. Part of the communication process, when working with Native Americans and Alaska Natives, is to know tribal beliefs and customs and whether or not a person subscribes to these customs. The articles acknowledged that each person and tribal community had their own beliefs and traditions; therefore practitioners needed to identify and recognize each person's unique stance related to end of life.

At the core of every nursing encounter is the necessity to build a trusting relationship with clients , which is true when working with Native Americans and Alaska Natives as well. However, establishing a relationship with Native Americans and Alaska Natives may take longer than with general population members. Among the articles in this literature review, eight identified the phenomena of mistrust, one pointed out the value in building a trusting relationship, and one article identified the need to build the relationships slowly when working with Native Americans and Alaska Natives.

Part of communication is the ability to listen attentively and understand another person's view points and perceptions via direct dialect or by nonverbal communication. Active listening surfaced during this literature review and three of the articles directly identified active listening as a way of communicating with Native Americans and Alaska Natives. Another communication method identified was the ability to be flexible as some Native Americans and Alaska Natives do not adhere to time in the same manner as non-Indians. That is, Native Americans are more focused on what is currently going on as opposed to a more linear view (Lowe, 2002). Three articles addressed the necessity for flexibility. Patience which goes along with being flexible interestingly was only mentioned in one article. However, four of the articles stressed the importance of allowing the patient to control the dialogue pace, which at times meant having long pauses during the conversation. Two of the articles mentioned silence as a form of communication with Native Americans. When a person is unable to communicate verbally due to a health condition, a family member may emerge and become the person's decision maker or advocate. Although not mentioned in every article was the need to allow for a patient representative, often times a family member, to surface on its own. The patient representative might appear early on in the discussion or it may take time, emphasizing the importance of

patience among health care providers. End of life discussions often included family members and four articles mentioned family meetings. For practitioners it was important when working with Native Americans and Alaska Natives to understand family dynamics and determine who the family decision maker was or who the head of the family was. With the exception of six articles, the concept of family was revealed to be an important element when communicating with Native Americans and Alaska Natives.

Many Native American and Alaska Natives adhere to their own spoken language and tribal language can differ according to the tribal affiliation. Language was another theme brought up in six of the articles. The articles addressed the necessity to assess and determine a person's primary language and when necessary a translator should be offered and awarded.

Program Development

End of life issues with Native Americans and Alaska Natives, until recently, had not been part of mainstream studies. In particular, palliative and hospice care are now surfacing and becoming an area for growth with his population of people. A promising number of hospice and palliative care programs have materialized such as the Helping Hands Program in Alaska (DeCourtney et.al, 2003) and the Palliative Care Consultation Service in New Mexico (Marr, et. al., 2012). The different palliative care programs generally focused on education for health care workers such as the "Palliative Care Curriculum for the Indian Health System" (Arnella, Finke, Domer, Kaur, Merriman, & Ousley, 2010) or were patient focused as demonstrated in the "Palliative Care Consultation Program" at the University of New Mexico Hospital (Marr, Neale, Wolfe, & Kitzes, 2012), and the "Palliative care program in the Pueblo of Zuni" (Finke, Bowannie, & Kitzes, 2004). The palliative care program developed in Alaska focused on patients and health care workers (DeCourtney, Jones, Merriman, Heavener, & Branch 2003).

The programs in this critical literature review ranged anywhere from early beginning stages of development to more established programs. For instance, the University of New Mexico's palliative care consultation program came into existence in 2009, while palliative care in Pueblo of Zuni and the Helping Hands Program in Alaska were developed in 1997 and 1999 respectively. The Indian Health Service (IHS) is a federal program established to provide health care for Native Americans and Alaska Natives and has recently acknowledged the importance of end of life care. As a result, in 2006, they collaborated with the National Cancer Institute and developed a palliative care curriculum for health care providers (Arnella, et al., 2010).

An overarching element common to the palliative care programs was the need and desire to help Native American and Alaska Natives with health concerns at the end of life and establish palliative care services not routinely available for this population of people. According to McKenzie, Neiger, and Smeltzer (2005) having community input and assessing the need was a critical point when developing programs. Each of the programs in the current literature review sought input from the community they served either by surveys, focus groups, or from healthcare workers working with Native Americans and Alaska Natives. Although, the literature review programs contained promise, they were not developed without significant difficulty.

During the program development phase, two of the programs indicated staffing was a concern. The concern revolved around inadequate staffing and high turnover rates among staff. The staffing issues indirectly affected the amount of time needed to develop the programs, signifying the need to allow for extra time for program development. Moreover, the concept of time was not only an issue resulting from poor staffing but also in general terms. For instance, sudden events such as bad weather, tragedies in communities, acquiring written contracts from participating organizations, and travel issues all influenced the length of time needed for program

inception. DeCourtney, Branch, and Morgan (2010) exemplified the time element taking eight years to accumulate the needed information to develop a palliative care program in Alaskan communities. Another concern when working with and developing programs for Native Americans and Alaska Natives was the language spoken among individuals and tribes.

A number of Native Americans and Alaska Natives spoke little or no English but instead conversed in their own native language. Four of the studies mentioned language as a concern. The need for translation was warranted when working with some Native American and Alaska Native tribes and as a result translators/translation was available for non-English speaking natives. In addition to using interpreters', health care assessment tools such as pain scales needed to be adapted so the population using the tools could understand them. The "Helping Hands Program" did modify a faces pain scale to reflect the patient population using it (DeCourtney, et al, 2010). Kitzes and Berger (2004) identified in their chart review study that there was a lack of pain assessment scales. This finding was critical as pain and pain management should be assessed and documented in all patient charts.

Within the selected end of life programs in the critical literature review was the awareness that some Native Americans and Alaska Natives desired to remain at or close to home when death was near. The Schrader, Nelson, and Eidsness (2009) study indicated Native Americans would prefer end of life services, that is, hospice care at home. Although the desire to stay at or near home at the time of death seems desirable among some Native American and Alaska communities, in reality it may not always happen as one would like. Kitzes and Berger (2010) identified from their chart review in selected IHS facilities a large number of deaths occurred in the hospital setting. Nonetheless, positive attributes have occurred since the inception of some of these end of life programs and included; an increase in admittance into the

palliative care programs, increase in do not resuscitate orders, discussions about end of life, and increased education about palliative care for health care workers within selected IHS facilities. Although, these programs were successful, a bewildering phenomenon was the realization there were very few end of life programs available along with the lack of literature addressing the issue.

Two of the articles in the literature review outlined palliative care programs in the making or currently in operation. A total of seven programs were outlined in these two articles. Of the seven programs identified only three came up in the critical literature review, indicating a deficit in published literature. Kitzes and Domer (2002) indicated it is difficult to quantify the number of end of life programs within the IHS as “there is no central reporting for these programs” (p. 205). Having no formal reporting system in place makes it difficult to understand or determine the exact number of functioning programs and if these programs are successful. As a result further research and protocols are needed which could be addressed in future nursing research.

Health care has increasingly become more interdisciplinary in nature as is also true for palliative care and hospice care programs. A notable concept within the critical literature review was the recognition that programs need to work with multiple individuals and agencies in order to be sustainable and successful. The vast majority of the studies within the critical literature review, in particular the program development articles, stated that health care professionals worked cooperatively together with the goal of providing end of life services for Native American and Alaska Natives.

This critical literature review has highlighted the emergence of recent published articles addressing end of life issues with Native American and Alaska Natives. Although, end of life

programs are beginning to materialize and become more known to tribal communities, health care facilities, and educational institutions must not become complacent with the quest to provide end of life care to meet the needs of Native Americans and Alaska Natives. Nurses can be the leaders in advocating for such services, conducting research, and participating in educational opportunities to better serve Native Americans and Alaska Natives.

Spirituality

As nurses, it is our obligation to incorporate and include all aspects of a person's belief system when providing care including spirituality. Therefore, it is important to assess and know how a person and family cope during stressful times such as death and dying. These coping strategies can then be implemented in the plan of care. For example, some Native Americans believe in both traditional and western medicine (Andrews and Boyle, 2012), as a result certain rituals and natural remedies maybe requested and utilized. This critical literature review highlighted several spirituality factors associated with Native Americans and Alaska Natives that are quite varied among tribes and individuals.

Van Winkle (2000) described death and dying as both natural and accepted by a number of Native Americans and Alaska Natives. In accord with Van Winkle (2000), six of the articles in the literature review identified death and dying as naturalistic and an important part of the life cycle. As an example, within the Creek tribe death and dying is considered natural and not a misfortune or celebration (Walker and Thompson, 2009). Kitzes and Berger (2004, p. 836) point out "death is a natural and accepted part of the life cycle". Additionally, Alaska Natives also believe death is part of the life cycle (DeCourtney, Branch, and Morgan, 2010). Schrader, Nelson, and Eidsness (2009) identified 87% of American Indians in their study believed "dying is an important part of life" (p.72). Related to the thought that death is considered a natural

occurrence is the theory of life being cyclical in nature meaning there is no end or beginning. Native Americans and Alaska Natives generally see death and dying as circular in nature (Van Winkle, 2000). Consequently, death and dying may be considered a transition or journey from this life to the next with life existing beyond death. A significant and diversified concept in six of the articles was the belief in spirits. The spirit beliefs varied in meaning; however, the concept of existence in life beyond this world was evident. For instance, within the six articles some believed spirits were either good or bad in nature; caused illness and or harm, and were able to help a dying person converge from the present world to the next. Among the six articles three declared that a person's spirit remained in this world for a total of four days post death and thus funerals were conducted after the fourth day of death.

A person's belief in spirits may or may not be determined by the amount of acculturation. Van Winkle (2000) described that Native American and Alaska Native faith systems as possibly routed in Christianity, traditional beliefs, or both. According to Walker and Thompson's study "the more traditional the belief system held by the participant, the more interactive they were with the spirits they encountered" (2009, p. 137). Within the selected articles for the critical literature review, five of the articles mentioned how culture could influence a person's spirituality and belief system. Many of the Native Americans and Alaska Natives had been exposed to Christianity and hence had an effect on their spirituality. The majority of the articles discussed how Native Americans and Alaska Natives believed and practiced both Christianity and traditional Native religion, indicating a duality in spiritual beliefs. While, duality existed among some Native Americans and Alaska Natives, several articles, eight in all, pointed out that traditional medicine was still present and utilized by some Native Americans and Alaska Natives. Although, some of these articles mentioned traditional medicine, only a few of the

articles included “types” of traditional medicine or ceremonies utilized. For example, one article described the healing practice of “spirit dancing” (Grossman et al., 1993), one article described how purification was used after being exposed to or around a deceased person (Walker and Balk, 2007), one article talked about the use of sage to ward off evil (Mazur-Bullis, 1984), and one article described Indian healers as those with “gifted hands” (DeCourtney et al., 2010).

Spirituality and traditional medicine are two very important concepts to understand and address when encountering Native Americans and Alaska Natives during times of wellness, illness, and at the end of life. Having a genuine respect and awareness of traditional medicine and spirituality can facilitate a healing environment and build a working relationship with clients, families, and communities. Also, important for a practitioner is to know how certain rituals can be a significant and vital component during end of life situations.

Rituals

Seven of the articles described an assortment of rituals prescribed during death and dying. The rituals varied among tribal affiliation and individuals, making it clear each person and tribe was unique in their own right. Within the seven articles three mentioned the ritual of having a wake ceremony one day prior to a funeral. Although, three of these articles commented on observing or participating in a wake service, five of the articles stated a funeral ceremony was also conducted for the family and deceased. Only one of the articles described vivid details about the funeral service which involved elements of Christianity such as a sermon, scripture reading, and prayer (Mazur-Bullis, 1984). During the burial service rituals were also observed and the rituals varied according to one’s tribe. The rituals, although varying among tribes, included hand digging the grave, family/friends filling in the grave site, forming a cross on the casket using dirt, giving a “farewell handshake” which is placing a handful of dirt over the casket, use of the herb

sage, and burying the deceased with personal items. Two of the articles mentioned a celebration after the funeral service although the celebrations had different titles, one being a “potlatch” and the other “Giveaway”. Despite the different names, the celebration was a time for honor and thanksgiving.

Advance Directives

Advance planning documents such as living wills and do not resuscitate orders are completed by some clients. However, within some Native American and Alaska Natives tribes these documents may be considered culturally inappropriate. Van Winkle (2000) indicated some Native Americans did not wish to discuss death or dying. Therefore advanced planning documents may go unresolved until death is imminent. Two of the articles indicated this was in fact the case. Nonetheless, the articles also showed that with much consideration and care these documents and discussions about end of life can be accepted and completed. The Marr et al. (2012) study indicated an increase in do not resuscitate orders post palliative care consultation. DeCourtney et al. (2003) indicated advance directives were discussed once trust was acquired and they also saw an increase in do not resuscitate orders for certain diseases after the palliative care program was initiated. Finke et al. (2004) described the enrollment into palliative care could take place without bluntly stating the illness. DeCourtney, et al. (2010) indicated that during program development, discussions about death and dying became easier for both team members and tribal members involved in the process. Finally, Schrader et al. (2009) indicated 25% of Native Americans in their study had completed advance directive documents. Clearly, from the above examples it is possible to obtain end of life documents and discuss end of life issues with some Native American and Alaska Natives which is a significant finding. However, we must not forget the heterogeneous nature of Native American and Alaska Natives and proceed with

caution when trying to elicit advance directive information. Some of the articles in the critical literature review offered advice or guidance when working with Native American and Alaska Natives during end of life and are discussed in the following paragraphs.

Guidelines

Cacciatore (2009); DeCourtney et al.,(2003); DeCourtney et. al (2010); Finke et al., (2004); Gorospe (2006); Hepburn (1995); Hampton (2005); Kitzes et al. (2003); Kitzes and Berger (2004); and Marr et al. (2012) in their respective articles offered guidelines or strategies when communicating or developing hospice and palliative care programs. Although the content contained in the articles varied, the intended message was to convey that palliative care and end of life communication can be accomplished when working with Native American and Alaska Natives. Among some of the ideas included, although not listed in each of the identified papers were the following components: being fully committed; inquiring about culture/affiliation with tribe; adjusting communication style; having translators available; family and community involvement; use of contemporary and traditional customs; adapting programs to fit tribal/personal norms; interdisciplinary working conditions; state, local, and federal assistance; and education surrounding end of life care.

Nurses can use the guidelines offered in the previously cited articles when working with Native American and Alaska Natives. However, the advice not only fits well within the Native American and Alaska Native culture but also could be used when working with all clients and families. Being prudent when assessing the client and family will inherently give rise to the above guidelines such as being devoted to the person, involving family, adapting communication styles to fit the situation, and inquiring about spirituality and traditions. The following chapter will identify implications for nursing.

CHAPTER 4. DISCUSSION AND CONCLUSION

Discussion

The intent or purpose of the critical literature review was to investigate the phenomena of end of life issues among Native American and Alaska Natives. Specifically, the purpose was to find out what is known about end of life care with Native Americans and Alaska Natives, to determine if there are barriers that inhibit care at the end of life, and how well palliative and hospice care services are known among Native Americans and Alaska Natives; and how receptive they are of these services.

End of Life Knowledge

The question “what is known about end of life as it relates to Native Americans and Alaska Natives” remains elusive. There are more than 500 federally recognized tribes throughout the United States and Alaska, each having their own set of beliefs and traditions surrounding end of life, making it difficult to truly know a specific answer to the above question. This critical literature review identified eighteen articles related to the issue with only a handful of tribes acknowledged in the papers. Nonetheless, generally speaking one can conceptualize important elements such as communication, family involvement, spirituality, and rituals can play a significant role at the end of life for Native Americans and Alaska Natives. As with all patient care, practitioners should identify the needs of each individual and family and implement care accordingly. It cannot be over emphasized that each person, family, and tribal community hold their own set of values and traditions making it imperative to approach end of life care with great consideration and caution. Furthermore, additional research is necessary and deeply needed. From this author’s research it can be implied there are very few known programs available. The current research project generated nine known health care agencies administering end of life care

with Native Americans and Alaska Natives. The service areas included communities in New Mexico, Alaska, Arizona, South Dakota, North Carolina, and Oklahoma (Hampton, 2005, Domer and Kaur, 2008, Marr et. al., 2012, and Kitzes and Domer, 2003).

The current literature review implied palliative and hospice care is a relatively new health care entity within Indian country as a result there were few published studies related to palliative and hospice care for Native American and Alaska Natives. Kitzes and Domer (2003) indicated that there was no single or central data reporting system to determine the number of palliative care programs existing in tribal communities or within the Indian Health Services, making it difficult to definitely answer how many programs exist and whether or not Native Americans or Alaska Natives are familiar or aware of such services. There are promising programs evolving indicating that with much cultural considerations palliative and hospice care can be implemented with this population of people.

Although, little is written in the form of end of life care for Native Americans and Alaska Natives, it is becoming clearer that health care agencies are recognizing the need for education surrounding palliative and hospice care in Indian country. First, The National Cancer Institute(NCI) developed educational material addressing palliative and end of life care for oncology known as (EPEC-O), subsequently the NCI and the Indian Health Services teamed up and an additional component was added to the education program to include material relevant to Native American and Alaska Native cultures (Arnella, et.al., 2010). The new selection of the curriculum included information such as family structures within the tribe and traditional healers (Arnella, et. al., 2010). The efforts between NCI and IHS to educate and provide end of life services for Native Americans and Alaska Natives hopefully will increase both awareness and usage of palliative and hospice care services.

Hospice Awareness

The degree of awareness about end of life care among some Native Americans and Alaska Natives was notable as some of the articles in the critical literature review demonstrated an understanding, need, and receptiveness of palliative and hospice care services. Schrader et al (2009) indicated only 14% of their study participants “have never heard of hospice” (p.77). Interviews by Finke et al (2004) determined that hospice services would have been appreciated by some group members. Developed by DeCourtney et al the “Helping Hands Program was recognized as important and welcomed by the people of Bristol Bay” (2003, p. 504). Arnella, Finke, Domer, Kaur, Merriman and Ousley (2010) reported over 50% of respondents from the Quality of Cancer Care Committee of the National Cancer Institute’s “palliative care needs assessment” indicated palliative and hospice care services within the IHS were needed (p.16). According to Domer and Kaur traditional healers associated with the “Dine’ Medicineman’s Association” from the Fort Defiance area all agreed a home care program with end of life services was desirable and acceptable (2008). Finally, Marr et al (2012) palliative care consultation program identified that Native Americans decided upon hospice services comparably to non-native Americans.

Integrating and educating Native Americans and Alaska Natives about end of life care is feasible when completed in a respectful manner. The critical literature review provided a glimpse into the awareness and acceptability of palliative and hospice care in a number of Native American and Alaska Native communities. As with all sensitive topics the method or manner in which health care providers approach the subject can have an effect on the overall acceptance or rejection of end of life services. While acknowledging cultural norms with Native American and Alaska Natives health care providers have the ability to promote and support end of life care for

individuals and tribal communities. Every individual and family has a basic right to be aware of and receive palliative and hospice care services when life is short. Additionally, health care providers need to grant these services within a culturally acceptable manner. Native Americans and Alaska Natives like most people want their wishes respected, especially at the end of life. Marr et al stated it best “common values include celebrating life, respect for traditional ways, hope for a peaceful death, and access to comfort-focused care while surrounded by family on or near tribal land” (2012, p. 72). In this author’s professional opinion Marr expressed the epitome of palliative and hospice care.

Barriers

Although not explicatively written, barriers do persist when it comes to providing culturally competent end of life care for Native American and Alaska Natives. These barriers include distance/availability, inadequate staffing/limited resources, and misconceived myths. It is important to recognize these barriers to help improve, eliminate or reduce health care disparities related to end of life care with Native Americans and Alaska Natives.

Misconceptions surrounding end of life care with Native Americans and Alaska Natives exist and may be due in part by the lack of research and education dealing with the subject. On the other hand these misconceptions or myths may come from misguided or misunderstandings about Native American and Alaska Native culture. Ultimately, these misconceived notions can become a barrier in providing quality end of life care. Marr et al., (2012) acknowledged the following myths linked with Native Americans; Native Americans prefer not to divulge end of life preferences, talk about death and dying, or recognize do not resuscitate status. Although, there may be individuals and tribal members who tend to not want to discuss death and dying, this does not mean all people and tribes adhere to the same belief system. The critical literature

review exemplified that some Native American and Alaska Natives are willing to discuss end of life care and perhaps even appreciate the value of palliative and hospice care services. Myths or misconceptions are not the only barrier in providing culturally congruent end of life care, education and adequate staffing can also be an obstruction to end of life care.

Another significant issue, insufficient staffing was an issue addressed in a few of the studies. Finke et al (2004) describe hiring of staff members a difficult process as a result of the rural environment and inadequate resources available at the tribal agency. DeCourtney et al (2003) also encountered issues with medical workers such as high attrition rates among nursing coordinators related to high travel demands and limited resources. Additional staffing concerns revolve around the limited medical visits by the physicians in the Bristol Bay area and the fact health care for villagers is provided by “community health aides” albeit the care is given under the direction of a physician (DeCourtney et al., 2003). Adding complexity to the matter, often times the aide is a relative of the patient, making care giving complicated (DeCourtney et al. 2003). Staffing is not only of concern, education also is of importance. DeCourtney et al. (2010) describes participants in their focus groups as wanting both medical help and education when providing end of life care. Insufficient staffing and end of life education or training in Native American and Alaska Natives communities should be focused upon and recognized as a serious health barrier. Future grant writing among health professionals in government agencies and academic settings could potentially influence and help reduce insufficient staffing and aid in educational efforts related to end of life care. Long term goals should be geared toward recruitment and retention of health care workers in tribal communities. While staffing and education are important components affecting end of life care, distance can also be problematic.

Distance and availability of palliative and hospice care work in combination with each other and becomes a barrier in providing end of life care with Native Americans and Alaska Natives. According to Marr et al., end of life services such as palliative and hospice care was not as available to Native Americans as to the rest of the nation (2012). Either the lack of or availability of end of life services could be associated with distance as many Indian reservations are located in rural areas.

Rural and remote areas certainly can attribute to inadequate health care. A few of the articles declared distance and geographical location problematic when providing end of life care. Finke et, al. (2004) described distance as an issue for staff training as the training took place over a hundred miles from the tribal area. The availability and remote living arrangements of Native Americans and Alaska Natives has made receiving local health care difficult resulting in health care taking place miles from their home and family (DeCourtney, et al., 2003 and Marr, et al., 2012). Consequently, the distance and isolation from family members can affect an individual's mental and physical health status. According to DeCourtney et al., older adults who are transported via plane to strange environments often times die shortly after leaving their homes and families are then left without proper closure, leading to complications in grief (2003). Thus, this isolation and separation contributes to and inhibits end of life care in tribal communities. Although, this author's research did not inquire about long term care availability, it is worth noting as it is not uncommon for long term care facilities to provide end of life services.

In main stream society, nursing home care is available in most communities, yet there are a limited number of nursing homes available in Indian country. According to Smyer and Stenvig, only a small number of nursing homes are available in Native American communities and finances from the Indian Health Service are not sufficient in meeting long term care needs

(2013). Gorospe also, reported a lack in nursing homes for Indians (2006). Finally, according to Baldrige there were only 12 tribal nursing homes in the country (2001). For end of life care to be fully met within the Native American and Alaska Native communities, it will be necessary for tribal agencies and the Indian Health Service to advocate for appropriations to be allocated for end of life and long term care.

Implications

End of life issues affecting nursing care with Native Americans and Alaska Natives include the following elements; spirituality, communication, and cultural competence. Spirituality is difficult to define as each person has his or her own spiritual beliefs. Nurses are called to provide holistic care by assessing and providing nursing interventions affecting one's spirituality. According to Polzer, Casarez, and Engebretson (2012) the basis of nursing is to provide holistic care including the dimension of spirituality. For some Native Americans, spirituality is connected to health. For instance, Walker and Thompson explained (2012, p. 131) "spirituality embodies and is ultimately responsible for all aspects of health as seen through the supreme natural balance of mind, body, and spirit". It is important for health care professionals working with all clients, and especially Native American and Alaska Natives, to assess and incorporate spirituality when providing care, as this group of people have strong spiritual beliefs. Native Americans and Alaska Natives may express spirituality differently, again it is important to individualize care. The critical literature review revealed that family, rituals, and communication are expressions of spirituality among some Native Americans and Alaska Natives; thus spiritual assessment should include inquiring about family, rituals, and adapt communication accordingly. Polzer, Casarez, and Engebretson, listed nursing interventions involving spiritual needs of a person to include respect, listening, building trust and adhering to a

person's wishes (2012). These nursing interventions would certainly fit well when caring for or working with Native Americans and Alaska Natives as trust and communication techniques were identified and deemed important in this critical literature review. Having the ability to address spirituality requires approaching health care holistically and not just looking at the disease process. Assessment of spirituality can be accomplished by having good communication skills and being culturally competent when providing care.

Communication

Nurses need to acknowledge and understand how each individual and cultural group may subscribe to communication techniques quite different from their own. Nurses must use effective communication skills to accommodate cultural differences. Additionally, health care is increasingly becoming more multidisciplinary in nature and thus necessitates competent communication skills. According to the American Association of Colleges of Nursing, nurses must have the ability to communicate effectively with other health disciplines (AACN, 2009). Hospice programs integrate health care across disciplines (Miller, 2012) in order to provide comprehensive care for dying individuals and families. Several of the articles in this critical literature review identified the concept of a multidisciplinary or multiagency approach (DeCourtney et al., 2003; Finke et al., 2004; Marr et al., 2012; and Arnella, et al., 2010). Nurses often times provide both direct and indirect care which entails hands on care along with coordinating and managing care among and across disciplines (Stanhope and Lancaster, 2008); therefore, nurses must be proficient and skilled in communicating with both health professionals and the people for whom they give care, as they are an integral part of the health care team. Douglas et al., developed nursing standards delineating competencies to be used in providing culturally competent care (2011). One of the standards was the concept of "cross-cultural

communication” which indicated “Nurses shall use culturally competent verbal and nonverbal communication skills to identify client values, beliefs, practices, perceptions, and unique health care needs” (Douglas et al., 2011 p.326). This statement echoes and reiterates communication techniques to be included when working with Native American and Alaska Natives. For example, Marr et al., 2012 and Cacciatore, 2009 pointed out that in Native American culture, silence is a form of communication and therefore should be respected. Marr et al, 2012; Cacciatore, 2009; and Hampton, 2005 suggested allowing the client and or family to control the conversation pace, requiring nurses to adjust their communication techniques accordingly and provide adequate time when working with Native Americans and Alaska Natives. Communicating with different cultures such as Native Americans and Alaska Natives will involve becoming culturally competent.

Cultural Competence

It is each nurse’s responsibility to the profession and for the people they serve to strive for cultural competence and increase their awareness of diversified care. Although, there seems to be no definitive definition for cultural competence (Barnes, Craig, and Chambers, 2000), it is this author’s professional opinion that cultural competence is a behavior that creates an atmosphere of tolerance and mutual respect allowing for interactions to occur without bias. According to Purnell “cultural competence in health care is having the knowledge, abilities, and skills to deliver care congruent with the patient’s cultural beliefs and practices” (2013, p. 7). It may not be possible to be fully competent in every culture but it is crucial nurses make every effort to become culturally sensitive. Campinha-Bacote developed a model that helps facilitate health practitioners in their journey in becoming culturally competent. In the model there are five components; cultural awareness, cultural knowledge, cultural skills, cultural encounters, and

cultural desire. The five constructs work together to help facilitate the process of becoming culturally competent (Camphina-Bocote, 2002). Nurses and all health care professionals can utilize Camphina-Bocote’s model in practice when working with Native Americans and Alaska Natives to help create an environment conducive to those for whom they are caring for and can especially be helpful during end of life care. Additionally, Madeline Leininger’s cultural care diversity and universality theory and sunrise enabler can be used with both research and providing culturally congruent care.

Sunrise Model

The sunrise model includes the following topics; “technological, religious and philosophical, kinship and social, cultural values and lifeways, political and legal, economic and educational” (Sagar, 2012, pp.1-2). The sunrise model illustrates how each of the above topics is influenced by the environment, language, and ethno history of a person, family, and community (Sagar, 2012). The sunrise model displays nursing care in the middle of and interwoven between generic and professional care, permitting the nurse to work cooperatively within the two entities (Nelson, 2006), allowing for culturally congruent care. The following synthesized topics generated from this literature review fits into several of the sunrise model categories and is demonstrated in Table 2 and the following paragraphs.

Table 2. Relationship of Synthesized Topics to Sunrise Model

Common Themes	Corresponding Sunrise Theme
Communication	Kinship and social factors
Spirituality	Religion and Philosophical factors
Rituals	Cultural Values Beliefs and lifeways
Program Development	Economic factors
Advanced Planning	Political and legal factors
Guidelines	Nursing action modes

Communication within Native American and Alaska Native groups takes on many forms including verbal and nonverbal communication styles and often times involve communicating

with the family. When decisions need to be made Native American elders may consult with family members (Hepburn and Reed, 1995) emphasizing the influence of kinship and social factors amongst this group of people.

Religion and philosophical factors can be connected to a person's spirituality which is true for Native Americans and Alaska Natives. For instance, some Native Americans and Alaska Natives view death as a natural occurrence (Van Winkle, 2000) which represents a person's philosophical belief regarding death. Spirituality can relate to a person's religion which may be expressed in Christianity or traditional Native American and Alaska Native ways of life.

Cultural values, beliefs, and lifeways correspond with a person's rituals. Each tribe and tribal member has his or her own distinctive values, beliefs, and lifeways associated with death and dying which are expressed in rituals. Death and dying rituals also vary among tribes but common to many tribes is the observance of wakes and funerals.

Economic factors affect palliative care program development and are associated with fears for some Native American and Alaska Natives. According to Schrader, Nelson, and Eidsness (2009), in the event of a terminal illness 68% of their respondents indicated they feared their family finances would not last. Fink et al., (2004) indicated underfunding among the Indian Health System could contribute to the fact end of life care is just now becoming apparent in Native American communities. Furthermore, a number of Native Americans and Alaska Natives live on reservations and have to travel great distances to receive health care, which can be burdensome and financially straining. Finally, technology and staffing can be economically challenging during program development (Finke, et al., 2004).

With the enactment of the Patient Self-Determination Act of 1991, physicians who receive Medicare and Medicaid reimbursements are required to provide health information to

clients about their medical rights and choices (Stanhope & Lancaster, 2008). Additionally the Patient Self Determination Act of 1991 signifies the significance of advance directives (Stanhope & Lancaster, 2008). These documents include living wills and durable power of attorney for health care and could be considered culturally inappropriate for some people. According to Kitzes and Berger, advance directive documents are “intrusive and insensitive” for many Native Americans (2004, p836).

Leininger’s model also identifies nursing actions and includes “cultural care preservation and or maintenance”, “culture care accommodation and or negotiation”, and “culture care repatterning and or restructuring” (Leininger & McFarland, 2006). Cultural care preservation/maintenance includes nursing actions associated with supporting and maintaining values and beliefs (Leininger & McFarland, 2006). Cultural care accommodation/negotiation involves actions to help facilitate culturally acceptable care by adjusting and negotiating health care (Leininger & McFarland, 2006). Finally, repatterning and restructuring entails mutual decision making and modifying health care so optimal health is achieved (Leininger & McFarland, 2006). These nursing actions most certainly can be utilized when working with clients at the end of life.

Guidelines promoted in this critical literature review can be implemented using Leininger’s action modes. For instance, family and extended family are valued in Native American and Alaska Native culture and by including family in a person’s care is utilizing the action mode of “preservation and /or maintenance”. Depending on a person’s language preference, it may be necessary to provide a translator when working with Native Americans or Alaska Natives. Also, Native American and Alaska Natives may want to have a medicine man or medicine women involved in his or her care, therefore, providing or consulting such services

would be accommodating and adapting care to fit the person's beliefs. Finally, when a nurse modifies or changes a care plan to include traditional Native American and Alaska native traditions, such as allowing sage by the bedside, the action mode of repatterning and restructuring is being implemented.

Future Research

Research surrounding end of life care within Native American and Alaska Native communities is a relatively new phenomenon. Very few empirical or qualitative studies have been published addressing this area in health care. Although, this critical literature review highlighted some end of life issues surrounding Native Americans and Alaska Natives much knowledge and research is still warranted.

Marr et al. indicated their palliative care consultation program did not conduct evaluations with patient and family recipients of care (2012). Within the palliative and hospice care programs acknowledged in this paper, only two had any type of evaluation of the program and included DeCourtney et al. (2003) and Arnella et al., (2010). Future research could include evaluating already established programs for approval and usage.

Schrader et al. indicated Native Americans "were much less likely to be aware of hospice services" (2009, p. 83). Their study could be replicated in different Native American and Alaska Native communities. Walker and Thompson (2009) and Walker and Balk (2007), studied spirituality and bereavement rituals within the Muscogee creek tribe and the same concepts could be explored with other Native American and Alaska Native tribes. Accordingly, Grossman et al (1993) investigated meaning of death to Native adolescents. More research is definitely needed regarding the meaning of death by adolescence. The study by Grossman and associates was the only one identifying end of life issues with adolescents.

Native American and Alaska Native beliefs and values are heterogeneous; therefore, it would be beneficial for researchers to investigate end of life issues with a variety of Native American and Alaska Natives and look for similarities and differences amongst tribes. Additionally, research could be conducted with Native American and Alaska Native tribes to determine if end of life issues are of concern or priority for them and if so how do they provide end of life services for their members. Another area for future research would be to compare and contrast end of life services among those residing on or near reservation versus urban residing Native American and Alaska Natives. Finally, Finke et al (2004) alluded to the difficulties acquired when working with multiple health/educational agencies, future research should be conducted to determine ways to improve working conditions among tribes, health care facilities, and educational systems.

Closing Remarks

Up until recently Native American and Alaska Native end of life care has been stagnate, however, currently we are seeing a revolutionary change in healthcare for this population of people. The current critical literature review demonstrated how health care professionals, educational systems, tribal agencies, and most importantly Native American and Alaska Native people are willing to discuss, provide, and accept end of life care. Native American and Alaska Native knowledge about end of life care is perplexing resulting from the sheer number of tribes. However, some Native Americans and Alaska Natives are aware of palliative and hospice care and are accepting of these services. Nonetheless, these services are not fully being implemented in Native American and Alaska Native communities and this could be the result of geographical location, insufficient staffing, and education. On the other hand several palliative and hospice care programs have been initiated with success. Several studies documented the expression of

spirituality and meaning of death within certain tribes. Some Native Americans and Alaska Natives show a willingness or openness to disclose end of life care preferences. The syntheses of this critical literature review illustrates how the following end of life principles affect Native Americans and Alaska Natives and include; palliative and hospice care programs, communication, spirituality, advance directives, rituals, and guidelines. Although nursing implications include communication, spirituality, and cultural competence, it is necessary for education and research to continue in all three areas. With an aging population living longer with chronic diseases end of life care including palliative and hospice care will become even more prominent. Nursing programs could integrate end of life care throughout their curricula, requiring clinical rotations in palliative and hospice care settings. Academia could establish relationships with nearby tribal communities to inquire and build mutual respect revolving around end of life care. Finally, barriers or obstacles affecting end of life care in Native American and Alaska Native communities needs to become a primary focus in order to effectively meet the needs of Native Americans and Alaska Natives.

REFERENCES

- American Association of Colleges of Nursing. (2008). *The essentials of baccalaureate education for professional nursing practice*. Retrieved September 21, 2011, from <http://www.aacn.nche.edu/Education/pdf/BaccEssentials08.pdf>
- American Association of Colleges of Nursing. (2009). *The essentials of baccalaureate education for professional nursing practice*. Retrieved August 6, 2013, from <http://www.aacn.nche.edu/education-resources/BacEssToolkit.pdf>
- Andrews, M. M., & Boyle, J. S. (2012). *Transcultural concepts in nursing care* (6th ed.). Philadelphia, PA: Lippincott Williams & Williams.
- Arenella, C., Finke, B., Domer, T., Kaur, J. S., Merriman, M. P., & Ousley, A. (2010). Adaptation, dissemination, and evaluation of a cancer palliative care curriculum for the Indian health system. *Journal of Palliative Care*, 26(1), 15-21.
- Baldrige, D. (2001). Indian elders: Family traditions in crisis. *American Behavioral Scientist* 44(9), 1515-1527.
- Barnes, D. M., Craig, K. K., & Chambers, K. B. (2000). A review of the concept of culture in holistic nursing literature. *Journal of Holistic Nursing*, 18(3), 207-221.
- Barnes, P. M., Adams, P. F., & Powell-Griner, E. P. (2010). Health characteristics of the American Indian or Alaska Native adult population: United States, 2004-2008. *National Health Statistics Reports*, 20, 1-23. Retrieved March 28, 2013, from <http://cdc.gov/nchs/data/nhsr/nhsr020.pdf>
- Benz, J. K., Espinosa, O., Welsch, V., & Fontes, A. (2011). Awareness of racial and ethnic health disparities has improved only modestly over a decade. *Health Affairs*, 30(10), 1860-1867.

- Brereton, L., Gardiner, C., Gott, M., Ingleton, C., Barnes, S., & Carroll, C. (2011). The hospital environment for end of life care of older adults and their families: An integrative review. *Journal of Advanced Nursing* 65(5), 981-993.
- Burns, N., Grove, S.G. (2009). *The practice of nursing research, appraisal, synthesis, and generation of evidence* (6th ed.). St. Louis, MO: Elsevier Saunders.
- Cacciatore, J. (2009). Appropriate bereavement practices after the death of a Native American child. *Families in Society: The Journal of Contemporary Social Services* 90(1), 46-50.
- Colclough, Y.Y. & Brown, G.M. (2013). End of life treatment decision making: American Indians' perspective. *American Journal of Hospice & Palliative Medicine* 00(0), 1-10.
- Campina-Bocote, J. (2002). The process of cultural competence in the delivery of healthcare services: A model of care. *Journal of Transcultural Nursing* 13(3), 181-184.
- Centers for Disease Control and Prevention. (2013). *American Indian & Alaska Native populations*. Retrieved August 27, 2013 from <http://www.cdc.gov/minorityhealth/populations/REMP/aian.html>
- 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), 501-508.
- 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.
- Domer, T., & Kaur, J. S. (2008). Palliative practice in Indian health. *South Dakota medicine : the journal of the South Dakota State Medical Association, Spec No.*, 36-40.

- Douglas, M. K., Pierce, J. U., Rosenkoetter, M., Pacquiao, D., Callister, L. C., Pollara-Haatar, M., et al. (2011). Standards of practice for culturally competent nursing care: 2011 update. *Journal of Transcultural Nursing*, 22(4), 317-333.
- Finke, B., Bowannie, T., & Kitzes, J. (2004). Palliative Care in the Pueblo of Zuni. *Journal of Palliative Medicine*, 7(1), 135-143.
- Fredericks, S., Lapum, J., & Lo, J. (2012). Anxiety, depression, and self-management: A systematic review. *Clinical Nurse Research*, 21(4), 411-430.
- Gorospe, E. C. (2006). Establishing palliative care for American Indians as a public health agenda. *Internet Journal of Pain, Symptom Control and Palliative Care*, 4(2), XVII-XVIII.
- Grossman, D. C., Putsch, R. W., & Inui, T. S. (1993). The meaning of death to adolescents in an American Indian community. *Family Medicine*, 25(9), 593-597.
- Gulanic, M., Myers, J. L., Klopp, A., Gradishar, D., Galanes, S., & Puzas, M. K. (2003). *Nursing care plans and nursing diagnosis and intervention* (5th ed.). St. Louis, MO: Mosby, Inc.
- Hampton, J. W., & Castro, L. (2005). End-of-life issues for American Indians: A commentary. *Journal of Cancer Education*, 20(SUPPL. 1), 37-40.
- Happel, B., & Gaskin, C. J. (2012). The attitudes of undergraduate nursing students towards mental health nursing: A systematic review. *Journal of Clinical Nursing*, 22, 148-158.
- Hepburn, K., & Reed, R. (1995). Ethical and clinical issues with Native-American elders: End-of-life decision making. *Clinics in Geriatric Medicine*, 11(1), 97-111.
- Horowitz, S. (2012). American Indian health integrating traditional native healing practices and western medicine. *Alternative and Complementary Therapies*, 18(1), 24-30.

- Hospice and Palliative Nurses Association. (2013). *HPNA position statement spiritual care*. Retrieved August 30, 2013, from <http://www.hpna.org/PicView.aspx?ID=385>
- Indian Health Service. (2013). Disparities. Retrieved August 27, 2013, from <http://www.ihs.gov/newsroom/factsheets/disparities/>
- Indian Health Service. (2013). IHS 2013 profile. Retrieved August 28, 2013, from <http://www.ihs.gov/newsroom/factsheets/ihsyear2013profile/>
- Indian Health Service. (n.d.). About IHS. Retrieved August 28, 2013, from <http://www.ihs.gov/aboutihs/>
- Jones, T., & Evans, D. (2000). Conducting a systematic review. *Australian Critical Care, 13*(2), 66-71.
- 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), 830-838.
- Kitzes, J. A., & Domer, T. (2003). Palliative care: An emerging issue for American Indians and Alaska Natives. *Journal of Palliative Care Pharmacotherapy, 3-4*(17), 201-210.
- Limb, G. E., & Hodge, D. R. (2008). Developing spiritual competency with Native Americans: Promoting wellness through balance and harmony. *Families in Society: The Journal of Contemporary Social Services, 89*(4), 615-622.
- Leininger, M.M. & McFarland, M.R. (2006). *Culture care diversity and universality a worldwide nursing theory* (2nd ed.). Sudbury, MA: Jones and Bartlett Publishers, Inc.
- Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gotzsche, P. C., Loannidis, J. P. A., et al. (2009). The PRISMA statement for reporting systematic reviews and meta-analysis of studies that evaluate health care interventions: Explanation and elaboration. *PLOS*

- Medicine*, 6(7), Article e1000100. Retrieved April 1, 2012, from <http://www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.1000100>
- Lowe, J. (2002). Balance and harmony through connectedness: The intentionality of Native American nurses. *Holistic Nursing Practice*, 16(4), 4-11.
- Marr, L., Neale, D., Wolfe, V., & Kitzes, J. (2012). Confronting myths: The native american experience in an academic inpatient palliative care consultation program. *Journal of Palliative Medicine*, 15(1), 71-76.
- Mazur-Bullis, R. (1984). Pastoral care in a Native American context. *Journal of Pastoral Care*, 38(4), 306-309.
- McKenzie, J. F., Neiger, B. L., & Smeltzer, J. L. (2005). *Planning, implementing & evaluating health promotion programs* (4th ed.). San Francisco, CA: Pearson Education, Inc.
- Merriam-Webster's collegiate dictionary (10th ed.). (2000). Springfield, MA: Merriam-Webster, Incorporated.
- Miller, C. A. (2012). *Nursing for wellness in older adults* (6th ed.). Philadelphia, PA: Lippincott Williams and Wilkins.
- Moher, D., Cook, D. J., Eastwood, S., Olkin, I., Rennie, D., & Stroup, D. F. (1999). Improving the quality of reports of meta-analyses of randomised controlled trials: The QUOROM statement. *Lancet*, 354, 1896-1900.
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Methods of systematic reviews and meta-analysis preferred reporting items for systematic reviews and meta-analysis: The PRISMA statement. *Journal of Clinical Epidemiology*, 62, 1006-1012.
- National Hospice and Palliative Care Organization. (2012). *Facts and figures hospice care in America*. Retrieved October, 2012 from

http://www.nhpco.org/sites/default/files/public/Statistics_Research/2012_Facts_Figures.pdf

National Hospice and Palliative Care Organization (2009). Facts and figures hospice care in America. Retrieved September 21, 2011 from http://www.nhpco.org/files/public/Statistics_Research/Hospice_Facts_Figures_Oct-2010.pdf

National Hospice and Palliative Care Organization. (2011). *What is hospice and palliative care?* Retrieved October 31, 2011, from <http://www.nhpco.org/i4a/pages/index.cfm?pageid=4648>

Nelson, J. (2006). Madeleine Leininger's culture care theory: The theory of culture care diversity and universality. *International Journal for Human Caring*, 10(4), 51-54.

Nightingale, A. (2009). A guide to systematic literature reviews. *Surgery*, 27(9), 381-384.

Norris, T., Vines, P. L., & Hoeffel, E. M. (2012). The American Indian and Alaska Native population: 2010. *U.S. Census Bureau*. Retrieved August 27, 2013, from <http://www.census.gov/prod/cen2010/briefs/c2010br-10.pdf>

Polzer Casarez, R. L., & Engebretson, J. C. (2012). Ethical issues of incorporating spiritual care into clinical practice. *Journal of Clinical Nursing*, 21, 2099-2107.

Portman, T.A.A., & Garrett, M.T. (2006). Native American healing traditions. *International Journal of Disability Development and Education*, 53(4), 453-469.

Position statement: Registered nurses' roles and responsibilities in providing expert care and counseling at the end of life. (2010). Retrieved March 21, 2012, from <http://www.nursingworld.org/MainMenuCategories/EthicsStandards/Ethics-Position-Statements/etpain14426.pdf>

- Potter, P. A., Perry, A. G., Stockert, P.A., & Hall, A.M. (2013). *Fundamentals of nursing* (8th ed.). St. Louis, MO: Mosby, Inc.
- Purnell, L.D. (2013). *Transcultural health care a culturally competent approach* (4th ed.). Philadelphia, PA: F.A. Davis Company.
- Rohack, J. (2005). Demographics can mean health care disparities. *American Medical News*, 48(9), 30.
- Sagar, P. L. (2012). *Transcultural nursing theory and models application in nursing education, practice, and administration*. New York, NY: Springer Publishing Company.
- Schrader, S. L., Nelson, M. L., & Eidsness, L. M. (2009). Reflections on End of Life: Comparison of American Indian and Non-Indian Peoples in South Dakota. *American Indian Culture and Research Journal*, 33(2), 67-87.
- Smedley, B. D., Stith, A. Y., & Nelson, A. R. (2003). *Unequal treatment: Confronting racial and ethnic disparities in health care*. Washington, D. C.: The National Academies Press.
- Smyer, T., & Stenvig, T. E. (2007). Health care for American Indian elders: An overview of cultural influences and policy issues. *Home Health Care Management and Practice*, 20(1), 27-33.
- Stanhope, M., & Lancaster, J. (2008). *Public health nursing population-centered health care in the community* (7th ed.). St. Louis, MO: Mosby, Inc.
- Van Winkle, N. W. (2000). End of life decision making in American Indian and Alaska Native cultures. In K. L. Braun, J. H. Pietsch, & P. L. Blanchette (Eds.), *Cultural issues in end of life decision making*. Thousand Oaks, CA: Sage Publications, Inc.
- Venes, D. (Ed.). (2001). *Taber's cyclopedic medical dictionary* (19th ed.). Philadelphia, PA: F. A. Davis Company.

- Walker, A. C., & Balk, D. E. (2006). Bereavement rituals in the Muscogee Creek Tribe. *Death Studies, 31*, 633-652.
- Walker, A., & Thompson, T. (2009). Muscogee creek spirituality and meaning of death. *Omega: Journal of Death and Dying, 59*(2), 129-146.
- Westmoreland, T. M., & Watson, K. R. (2006). Redeeming hollow promises: The case for mandatory spending on health care for American Indians and Alaska Natives. *American Journal of Public Health, 96*(4), 600-605.
- Wilke, D., & TNEEL Investigators (2003). Toolkit for nurturing excellence at end of life transition (TNEEL). University of Washington School of Nursing. As cited in Miller, C. A. (2012). *Nursing for wellness in older adults* (6th ed.). Philadelphia, PA: Lippincott Williams and Wilkins.
- Wood, M. J. (2003). Systematic literature review. *Clinical Nursing Research, 12*(1), 3-7.
- World Health Organization. (2002). National cancer control programs: Policies and managerial guidelines (2nd ed.). New York, NY: World Health Organization.

APPENDIX. SEARCH TERMS

The following is a list of the search terms that was used in the critical literature review.

- "Native American" and "palliative care"
- "Native American" and "end of life"
- "Native American" and "hospice"
- "Native American" and "terminally ill"
- "Native American" and "death"
- "Native American" and "dying"
- "Native American" and "barriers"
- "Native American" and "bereavement"
- "Native American" and "spirituality"
- "American Indian" and "palliative care"
- "American Indian" and "end of life"
- "American Indian" and "hospice"
- "American Indian" and "terminally ill"
- "American Indian" and "death"
- "American Indian" and "dying"
- "American Indian" and "barriers"
- "American Indian" and "bereavement"
- "American Indian" and "spirituality"
- "Alaska Native" and "palliative care"
- "Alaska Native" and "end of life"
- "Alaska Native" and "hospice"

- "Alaska Native" and "terminally ill"
- "Alaska Native" and "death"
- "Alaska Native" and "dying"
- "Alaska Native" and "barriers"
- "Alaska Native" and "bereavement"
- "Alaska Native" and "spirituality"
- "indigenous people" and "palliative care"
- "indigenous people" and "end of life"
- "indigenous people" and "hospice"
- "indigenous people" and "terminally ill"
- "indigenous people" and "death"
- "indigenous people" and "dying"
- "indigenous people" and "barriers"
- "indigenous people" and "bereavement"
- "indigenous people" and "spirituality"