

CULTURAL CONSIDERATIONS AT THE END OF LIFE:
COMMUNICATION OF HEALTHCARE PROVIDERS
WITH NATIVE AMERICAN PATIENTS

by

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Heidi Lynn Hunsucker

April 2012

DEDICATION

This project is dedicated to my family. First, to my husband, for all the encouragement he has given me through this process and all the times he handled the rest of the responsibilities in the household so I could work on school. Second, to my girls for being understanding when Mommy had to go do school.

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ABSTRACT

The purpose of this project was to provide information to non-Native-American healthcare providers to help enhance their communication with Native-American patients at the end of life. The end of life can be a distressing time for patients, families, and healthcare providers alike. Cultural differences which may exist among these groups can make the transition even more difficult. Communication may be hindered due to misunderstandings or unclear expectations.

This project was an extension of a study focusing on an Indian reservation in north central Montana which identified several areas to focus on for improving end-of-life care including educating the patients and families about palliative care options, helping healthcare providers become more culturally sensitive, and creating a culturally appropriate and sensitive end-of-life program. A pamphlet was developed based on the findings of a literature review and information from a cultural expert to help healthcare providers identify and address communication issues at the end of life. The pamphlet addressed communication issues between non-Native-American healthcare providers and Native-American patients. Madeleine Leininger's Theory of Culture Care Diversity and Universality was used to guide the project, and a modified Delphi method was used to help create a culturally appropriate pamphlet for non-Native-American healthcare providers.

By understanding their own cultural influences and taking the time to understand and respect the cultural influences of their patients, healthcare providers can provide quality end-of-life care. Communication at the end of life can be enhanced by recognizing that culture may confound understandings and expectations, and addressing that factor can help remove barriers from quality care.

This pamphlet will serve as a device to help prepare APNs for the barriers they may encounter when working with patients from not only the individual tribe in north central Montana, but also to make them aware of the fact that cultural barriers exist among different cultures. Perhaps making APNs aware of the cultural differences will open the way for increasing research about different cultures in the future. APNs should enter into every patient encounter with the knowledge that there are things they can learn from their patient to better provide effective care.

CHAPTER 1

INTRODUCTION

Purpose of the Project

The purpose of this project was to provide information to non-Native-American healthcare providers to help enhance their communication with Native-American patients at the end of life. This project was developed in support of research conducted on an Indian reservation in north central Montana. The project involved developing a pamphlet to distribute to non-Native-American healthcare providers working with Native-American patients and families in end-of-life circumstances. This was intended to provide a quick reference tool for healthcare providers to better understand how to effectively and respectfully communicate with Native Americans when providing end-of-life care.

Background and Significance of the Project

Dealing with End-of-life Issues

Advances in medical management of diseases and safety procedures have helped to increase the lifespan of individuals around the world. “Death is no longer predominately likely to be the sudden result of infection or injury, but is now more likely to occur slowly, in old age, and at the end of a period of life-limiting or chronic illness” (National Institutes of Health [NIH], 2004). This leaves patients, families, and healthcare

providers with time to evaluate their health conditions and work through stages of grieving regarding the inevitable loss of a loved one and a patient.

Nationally, hospice programs are available in many areas to help coordinate end-of-life care for patients and families and to provide a vital link between healthcare providers and patients (*About Hospice*, 2010). Nurses and support personnel from hospice programs help patients and their families with the physical, emotional, social, and spiritual aspects of the dying process (*About Hospice*, 2010).

No matter what beliefs or cultural values a person or family holds, death is a difficult transition. Often patients present to their healthcare providers with the struggles of this transition and the difficult decisions related to the end of life. This gives healthcare providers the opportunity to work with families through the time of transition at the end of life. However, practitioners then face the challenge of meeting both the physical and cultural needs of their patients at this transition.

Cultural differences are an important part of end-of-life care that must be taken into consideration by healthcare providers who may be caring for a patient from a different cultural background. Hallenbeck and Goldstein (1999, p. 27) point out that in palliative care situations, “people with differing backgrounds and values are thrown into a situation in which the proper course of action is debated and from which neither side can easily withdraw.” It is vitally important to consider a patient’s cultural background as well as their position within that culture (Colclough & Young, 2007; Hepburn & Reed, 1995; Kitzes & Berger, 2004). Healthcare providers must find a way to support their patients throughout the transition from health, to disease, through the end of life.

Patient and Family End-of-Life Experiences

Patients, as well as families, may experience fear, loneliness, anxiety, pain or discomfort throughout the course of a terminal illness (*About Hospice*, 2010). Healthcare providers must be prepared for these multifaceted reactions when working with patients and their families at the end of life. Communication among all three entities becomes of utmost importance and many factors must be considered when addressing patients and families (Emanuel, Ferris, von Gunten, & Von Roenn, 2007; Ferrell, 2005; Royak-Schaler et al., 2006; NIH, 2004). Native American or Alaska Native patients may or may not be open to discussing their diagnosis with family members, which may lead to confusion and frustration between both parties according to DeCourtney, Jones, Merriman, Heavener, & Branch (2003). Healthcare providers are yet another participant in the discussion of end-of-life decisions, and if cultural considerations are not taken into account, they may contribute additional stress to the situation (Hallenbeck & Goldstein, 1999).

End-of-Life in Montana

The state of Montana has 29 hospice programs available to residents (Kaiser State Health Facts, 2009). Medicare beneficiaries numbered 3,219 people served by these programs and an average of 62 days were covered for each participant in 2009 (Kaiser State Health Facts, 2009). However, the majority of the Indian reservation considered in this project is located in a county in north central Montana that is not served by a hospice program (Peace Hospice of Montana, n.d.). This creates a barrier for residents of both the county and the reservation with regards to obtaining quality end-of-life care.

Residents throughout Montana and around the country are faced with choices regarding end-of-life care. This includes decisions to pursue care close to home or to opt for services available in another area of the state (Shreffler-Grant, 2010). Often patients nearing the end of life choose to seek care close to home so they can be near family and support systems through that time of transition (DeCourtney et al., 2003). This choice may force Native Americans in particular to enter a relationship with a healthcare provider with hesitance and perhaps even mistrust depending on their past experience with non-Native Americans (Holkup et al., 2010).

Native American Considerations

Nationally, there are 5.2 million Native American and Alaska Native peoples in the United States, or 0.9% of the population (U.S. Census Bureau, 2012). Native Americans comprise 6.3% of Montana's state population (U.S. Census Bureau, 2012). Specifically considering the reservation in north central Montana which this project focuses on, 34.4% of residents work in educational, health, and social services; 74.4% have a high school degree or higher, however, only 13.5% have a bachelor's degree or higher (U.S. Census Bureau, 2000). Nationally, 83.9% of the population attains a high school degree or higher and 27.0% attains a bachelor's degree or higher (U.S. Census Bureau, 2000). 6% of the tribe in north central Montana is age 65 or older, placing much of the burden of healthcare provision and costs on the younger generation (U.S. Census Bureau, 2000). These facts are important for healthcare providers to consider when addressing Native-American patients and their families in this particular geographic area of Montana. Providers must consider the educational level of the patients and families as

well as the occupational background in order to provide clear and understandable information regarding the patient's diagnosis and treatment options.

Healthcare providers on the Indian reservation in north central Montana chosen for this project are responsible for providing end-of-life care for their patients as there is no hospice program available to residents. Care at the end of life often falls to the families as the home health program does not deal with end-of-life care (Y. Colclough, personal communication, n.d.B.). The hospital on the reservation has a room double the size of the other rooms that is set aside for patients and their families at the end of life, however, this room is seen as a "death room" since only terminal patients are placed there. This leads to patients who must be hospitalized at the end of life being forced to use this room despite the perceived stigma, a sense of "giving up", and fear that the rooms are occupied by the spirits of others who have died there (Y. Colclough, personal communication, n.d.A.). There is also a dedicated palliative care room available at the nursing home called the "comfort room", however, this was only used twice when it was labeled a hospice room, and four or five times since it was renamed a "comfort room" (Y. Colclough, personal communication, n.d.A.).

Initially, members of the tribal community were resistant to the idea of a hospice or palliative care program. A committee that looked into the barriers to end-of-life care on the reservation found that many people do not understand the benefits of a hospice program and felt that the community would benefit from education regarding end-of-life care. After providing education about how end-of-life programs are operated and what the goals of care are, there was increasing support among the tribe. They also believed

that helping Indian Health Service personnel and non-Native-American healthcare providers understand the cultural specifics of the tribe could help improve communication at the end of life (Y. Colclough, personal communication, 2011).

Description of the Project

The project design involved developing a pamphlet intended for non-Native-American healthcare providers to reference regarding communication with Native-American patients and families at the end of life. Healthcare providers face challenges when dealing with patients of a different cultural background and since “Native Americans are a very diverse group about which few helpful generalizations can be made” (Hepburn & Reed, 1995, p. 99), it can be difficult to determine appropriate cultural interventions. Madeleine Leininger’s Theory of Culture Care Diversity and Universality (1997) was used to guide the project, and a modified Delphi method was used to help create a culturally appropriate pamphlet for non-Native-American healthcare providers.

CHAPTER 2

REVIEW OF THE LITERATURE

The purpose of the literature review was to identify what research had been conducted regarding Native Americans and end-of-life care, what barriers exist for providing quality end-of-life care, what programs have been developed for culturally diverse populations with regard to end-of-life care, and to identify areas for improvement of end-of-life care in culturally diverse communities. Three databases were used: CINAHL, Cochrane Library, and Medline. Keywords included “end-of-life care”, “Native American”, “communication at end of life”, “palliative care”, and “healthcare provider communication”. Systematic review and primary research studies were chosen. Reference list reviews also yielded articles with more specific information.

End-of-Life Experiences and Concerns

End-of-Life Experiences

Reaching the end of life is inevitable for every person regardless of age, health status, cultural background, or spiritual beliefs. However, there is no clear distinction of when the “end of life” begins (NIH, 2004). “Terms such as palliative care, end-of-life care, and hospice care” are considered “key terms” with regard to care provided when a patient is nearing death (NIH, 2004, p. 3). There is insufficient evidence to determine what differences exist in the definitions of the end-of-life experience based upon gender, race, region, or ethnicity” (NIH, 2004, p. 3).

Effective care at the end of life can certainly honor the desires of patients, address problems before or as soon as they arise, and support effective communication between patients, families, and caregivers (Royak-Schaler et al., 2006). Other factors to consider when striving to improve the quality of end-of-life care include: “pain management, symptom control, ... and the death event” (Ferrell, Virani, & Grant, 1998).

All of these objectives could be better met by using hospice programs whenever appropriate and available and incorporating hospice principles such as meeting patients’ physical, emotional, social and spiritual needs into home health care agencies (*About Hospice*, 2010; Ferrell et al, 1998). The population continues to age and the number of programs offering end-of-life and/or hospice care have continued to grow throughout recent years (Ferrell, 2005). However, when clear and accurate information is not provided or perceived either by the patient, family, or healthcare provider, there is often resistance to hospice care (Byock, Twohig, Merriman, & Collins, 2006).

Emanuel, Ferris, von Gunten, and Von Roenn (2007, p. “Introduction to the Last Hours of Living,” para. 1) point out that “clinical competence, willingness to educate, and calm and empathic reassurance are critical to helping patients and families in the last hours of living.” Practitioners may not be comfortable with the changes that occur throughout the dying process and may therefore be hesitant to openly discuss these changes with the family and caregivers (Emanuel et al., 2007). Clinicians can therefore increase confidence in end-of-life care for patients and families by becoming educated themselves on the clinical course of the last hours and be open to communicate this information with patients and families (Byock et al., 2006).

Native American and Minority Experiences

Practitioners are faced with addressing the health needs of patients from different cultures due to the diversity of America, many of which may be different from the practitioners' own background. Even when serving in a home community, healthcare providers may encounter different cultural identities. "Communities of identity may be centered on a defined geographic neighborhood or a geographically dispersed ethnic group with a sense of common identity and shared fate" (Israel, Schulz, Parker, & Becker, 1998, p. 178). End-of-life care can be improved by taking into consideration the cultural values and communication styles of both the patient and the family (Colclough & Young, 2007).

Colclough and Young state that "studies about families' experiences of end-of-life decision making reflect a majority population, White Americans' view. Minorities' viewpoints for end-of-life care decisions ... clearly differed from those of the majority population" (2007, p. 206). Healthcare providers must then be aware, particularly if they received their training in the United States focused on Western medicine, that they may be caring for patients with different values, beliefs, and healthcare preferences (Hallenbeck & Goldstein, 1999). Also, practitioners may find that if they relocate to a culturally different area, that palliative care resources may not be available, particularly in Indian Health Service areas (Arenella et al., 2010). Native Americans may then be forced to seek care outside of their own cultural community, increasing the probability that they will encounter cultural barriers (Hallenbeck & Goldstein, 1999).

Advances in medical diagnostics and treatment options have made great improvements in healthcare, which has increased life expectancy, leading to a change in the dying process. Rather than dying suddenly at younger ages, many people now live longer and suffer from chronic diseases (Kitzes & Berger, 2004). Native Americans are not exempt from this shift. Other implications of this change in age and disease progression include the change in the location of death and the support system's involvement both before and after the passing. People are more likely to spend their last days in a hospital or nursing home, rather than at home, and support resources may be called upon for a lengthy disease process rather than solely for support of the family after a death (DeCourtney et al., 2003; Kitzes & Berger, 2004).

Healthcare providers should strive for acceptance of both the disease and process when working with Native-American patients at the end of life (Hepburn & Reed, 1995). The patient's own wishes should be respected by the practitioner, rather than the wishes of the family (Kitzes & Berger, 2004). It is important to recognize the significance of the elder within the family structure when striving to understand the course of decision making (Hepburn & Reed, 1995). Autonomy is respected in Native American cultures, as another family member cannot know what the spiritual significance of an illness or healthcare decision means for another individual (Hepburn & Reed, 1995).

Communication Issues at the End-of-Life

The National Consensus Project (NCP) has developed clinical practice guidelines for quality palliative care which includes key elements and "eight domains [...] focus[ed]

on promoting both the philosophy of palliative care and raising awareness of the necessity of quality palliative care with recommended practices” (NCP, 2009, p. 4). These guidelines and domains help create a foundation upon which to build or evaluate palliative care programs.

One of the key elements outlined by the NCP is communication skills. Communication at the end of life is important, not only between practitioner and patient, but also among healthcare providers, families of dying patients, and other disciplines such as social workers, chaplains, and case managers (NIH, 2004). Important components of communication skills “include developmentally appropriate and effective sharing of information, active listening, determination of goals and preferences, assistance with medical decision-making, and effective communication with all individuals involved in the care of patients and their families” (NCP, 2009, p. 9). Since active listening is one of the cultural considerations with regard to the oral tradition of Native Americans, it is an important cultural aspect to consider. These components guided the focus of the literature review.

Developmentally Appropriate Information

Patients and their families are faced with many difficult challenges at the end of life. Not only are they faced with the unknown of the disease process and the dying process, they are often thrust into the unfamiliar realm of healthcare with its medical jargon and constant requests for care decisions (Byock et al., 2006). Frustrations for patients and families included trouble understanding the medical language that was often

used by healthcare providers and not being able to reach a healthcare provider with questions when they would arise (Royak-Schaler et al., 2006).

Information regarding treatment options and care decisions must be clearly understandable when discussing diseases and treatment options with patients and families (Byock et al., 2006; Nelson, Schrader, & Eidsness, 2009). Patient and family characteristics that must be considered include developmental and education level as well as communication style preferences (Colclough & Young, 2007; Ferrell, 2005).

Effective Sharing of Information

Provision of essential information is an important component of creating a positive experience for the patient, family, and caregivers involved in the care of the dying person (Duggleby et al., 2010). Patients and families are faced with the unknown of both the disease and the dying process (Byock et al., 2006; Royak-Schaler et al., 2006). Families have reported that they depend on the knowledge and experience of healthcare providers, and that they rely upon the healthcare provider for timely information on such topics as timing of interventions, treatments, and when to come and be at their loved one's side (Colclough & Young, 2007). Easily understandable information regarding the possibility of survival was also requested (Bakitas et al., 2008).

Research has shown that "clear, open, and frequent communication with clients may help to decrease frustration and uncertainty" (Winters & Sullivan, 2010, p. 189). Providers must assess the patient and family's readiness and comprehension of intervention discussions and must evaluate the timeliness of their conversations with patients and families regarding end-of-life care (Duggleby et al., 2010). Providers should

be encouraged to discuss end-of-life wishes and options before the imminent need arises in order to allow patients and families the time to research their options and establish their preferences (Nelson et al., 2009). Families also perceive that effective communication at the end of life helps improve the quality of that time for patients and families, as well as reducing aggressive treatments (Bakitas et al., 2009; Wright et al., 2008).

Determination of Goals and Preferences and Assistance with Medical Decision-Making

Patients and families face many decisions when dealing with chronic illnesses and the end of life. For example, constant requests for care decisions (Byock et al., 2006) and treatment choices (Bakitas et al., 2008; Royak-Schaler et al., 2006) overwhelmed them. Healthcare providers may focus on making decisions about treatment and advanced directives (Royak-Schaler et al., 2006). Therefore, introduction to palliative care options may be delayed due to fear of failure for cure or lack of understanding or a misunderstanding about palliative care (Byock et al., 2006; Emanuel et al., 2007). Education on the palliative care process could help reduce this deterrent for quality end-of-life care for not only patients and families, but also for healthcare providers (Byock et al., 2006).

Healthcare providers will inevitably experience a transition to the end of life with their patients; however, their perspective of the experience and the important aspects of the process may differ from those of their patients, especially if they are from different cultural backgrounds. The patient should be able to anticipate that this time will not add

undue distress or suffering to themselves, the family, or the caregivers and that the patient's wishes should be respected as much as possible within "clinical, cultural, and ethical standards" (Institute of Medicine [IOM], 1997). Patients must take the step to make their preferences for the end of life known to both family members and healthcare providers to create a smooth transition as death nears (Nelson et al., 2009). Patients who already have advanced directives in place should be encouraged to share that information with their healthcare providers and healthcare facilities to create a smooth transition at the end of life (Nelson et al., 2009). Effective communication skills for healthcare providers could help improve the end-of-life process for both patients and their families (Ferrell et al., 1998; Ferrell, 2005).

Effective Communication with All Individuals Involved in the Care of Patients and their Families

When patient autonomy in decision making is respected, open discussion about life threatening illness and its prognosis among the family members may not occur (DeCourtney et al., 2003; Hallenbeck & Goldstein, 1999). Patients may want privacy and confidentiality regarding their own illness (Nelson et al., 2009), and patients and families may have different treatment preferences (Kitzes & Berger, 2004; Royak-Schaler et al., 2006). Practitioners must respect the wishes of the patient in end-of-life decision making (Kitzes & Berger, 2004).

Healthcare providers must ensure that timely and accurate information is provided to the patient and family. There are various options for ensuring effective communication. Suggestions for healthcare providers included: "developing strategies to

facilitate the sharing of critical information about the patient's condition such as identifying a family contact person who would be available at all times to receive and communicate to others information from the hospital staff" (Royak-Schaler et al., 2006, p. 758).

Cultural Considerations

Communication at the end of life is strongly influenced by preference and cultural background of both the family and the healthcare provider (Royak-Schaler et al., 2006). Some providers report holding conversations with patients and families of different cultural backgrounds and walking away from the interchange unaware of the actual discussion that had taken place due to differing cultural communication styles (Hepburn & Reed, 1995). Healthcare providers can avoid this confusion by "develop[ing] an understanding of the authentic wishes of the patient concerning treatment" (Hepburn & Reed, 1995, p. 107). Clear communication between involved persons can help create a positive experience for those involved with end-of-life care (Royak-Schaler et al., 2006). The use of a cultural translator may need to be considered (Hepburn & Reed, 1995).

Some patients and their families may be confronted with challenges such as the patient not wanting communication with the family regarding the diagnosis or a fear of discussing the dying process (Colclough & Young, 2007). Cultural backgrounds and beliefs often factor into this process, affecting the patients' and families' views of medical care choices, the dying process, as well as treatment options (Coehlo & Manoogian, 2010).

Native American Considerations

There are 565 federally-recognized Indian tribes in the United States, each holding diverse and unique beliefs (Hepburn & Reed, 1995; U.S. Census Bureau, 2007). “One culture’s value framework on a given clinical issue could be very different from that of another culture on the same value issue” (Hepburn & Reed, 1995, p. 99). Family is very important to Native Americans and is often defined in a broader sense than for most White Americans (Colclough & Young, 2007; Hepburn & Reed, 1995). Within the broad definition of “Native American culture” is the concept of a subculture, wherein a specific family forms its own values, beliefs, traditions, and practices (Cohelo & Manoogian, 2010). It is important to recognize those patients who are considered “elders” within their culture and to recognize that those elders are dependent on support from their subculture (Cohelo & Manoogian, 2010; Hallenbeck & Goldstein, 1999; Hepburn & Reed, 1995).

Native Americans hold a perspective that “time is circular, rather than linear, native peoples understand that a cycle of birth, life, and death is fundamental in nature and requires no manipulation or anticipation” (Hepburn & Reed, 1995, p. 100). Often there may be a hesitancy to deal with authority, be that healthcare providers, government programs, or home health care, due to historical trauma (Hepburn & Reed, 1995; Holkup et al., 2010). Practitioners must recognize that there may be differences in the way “other ethnic and cultural groups approach such decisions and in the framework of beliefs within which such decisions are made” regarding end-of-life care decisions (Hepburn & Reed, 1995, p. 102). Often an individual’s wishes are respected because autonomy is

highly valued in Native American culture (Hepburn & Reed, 1995). Therefore, it is important for the healthcare provider to understand the patient's wishes with regard to care at the end of life (Hepburn & Reed, 1995; Kitzes & Burger, 2004).

When addressing end-of-life preferences with a patient of any cultural background, there are some general concepts that apply to all patients. “[D]eath is a natural and accepted part of the life cycle, great diversity among communities and individuals exists in values, beliefs and proscribed behavior, and the principle of patient autonomy is respected coupled with consensus and cooperation” (Kitzes & Berger, 2004, p. 836). Other research projects related to the end-of-life experience of both Native Americans and Alaska Natives have found tailored techniques that are suitable for those specific cultures.

Native Americans may be resistant to discussing end-of-life choices and preferences prior to a life-threatening illness (Hepburn & Reed, 1995). However, with carefully chosen communication techniques, the practitioner may be able to have successful conversations about end-of-life preferences with patients (Hepburn & Reed, 1995). “Establish[ing] trust with the elder and the family and ... be[ing] open in communication with them” (Hepburn & Reed, 1995, p. 106) is important when working with Native-American cultures.

A research project focusing on Native Americans in the Southwest found that educating patients and families about changes, interventions, and roles during the end of life using a Medicine Wheel model was effective in relating to patients and families through their own culture (Burhansstipanov, Castro, Harjo, Lee, & Rattler, n.d.). An end-

of-life program specifically developed for use with Alaska Natives found that “decentralized services with central technical support and home health nurse visits were effective program components” (DeCourtney et al., 2003, p. 505). Other important components include taking the goals and lifestyle choices of patients into consideration when developing a care plan and including traditional customs and activities into the care plan (DeCourtney et al., 2003). Incorporating both healthcare services and social services created a more culturally sensitive and quality end-of-life experience (DeCourtney et al., 2003).

Perhaps one of the key elements within the healthcare provider-patient relationship is trust. “Physicians can actively develop rapport with ethnically diverse patients simply by demonstrating an interest in their cultural heritage” (Searight & Gafford, 2005, p. 521). Practitioners must recognize that they enter into any conversation with a patient carrying their own cultural biases and opinions, which play a role in the way each addresses the topic (Ngo-Metzger, August, Srinivasan, Liao, & Meyskens, 2008).

Healthcare providers must be aware of their own cultural influences before they can begin to concern themselves with their patients’ cultural values. Performing a cultural self-assessment can help practitioners understand what influences affect the way they view health and illness (Kleinman, 1980). Simple questions can help determine the way patients view their healthcare. Primary care providers are uniquely positioned to develop the trusting relationship needed to begin to understand the importance a patient’s culture plays in healthcare decisions (Ngo-Metzger et al., 2008; Searight & Gafford,

2005). “The physician’s partnership with his or her patients and their families provides unique insight into their values, spirituality, and relationship dynamics, and may be especially helpful at the end of life” (Searight & Gafford, 2005, p. 521).

Summary and Conclusion

The review of the literature highlighted several areas where healthcare providers and patients often encounter difficulties due to misunderstandings. One particular challenge facing the providers and patients in a culturally diverse community is the potential cultural difference between practitioner and patient. This cultural incongruence can create unique challenges in providing effective and quality care at the end of life. Communication style differences are perhaps the most difficult to overcome. The author chose to focus on this issue in the development of an intervention.

CHAPTER 3

PROJECT DEVELOPMENT AND IMPLEMENTATION

Project Location

This project was developed through collaboration between the author, a cultural expert familiar with the healthcare system on the reservation, and a research committee focused on improving end-of-life care on a north central Montana Indian reservation. This project was an extension of a study focusing on an Indian reservation in north central Montana which identified several areas to focus on for improving end-of-life care including educating the patients and families about palliative care options, helping healthcare providers become more culturally sensitive, and creating a culturally appropriate and sensitive end-of-life program (Y. Colclough, personal communication, n.d.D). Input to the project was considered from a nearby Hospice program that serves Cascade, Choteau, Pondera, Toole, and Teton counties. Unfortunately, most of the Indian reservation is outside these counties, and so is unable to receive services from them.

Theoretical Framework

Leininger's Theory of Culture Care Diversity and Universality was a driving force behind the development of this project. Dr. Leininger developed her theory to help facilitate the understanding of "transcultural nursing knowledge" (Leininger, 1997, p. 19). Her theory "provid[es] an appropriate and useful theoretical framework/conceptual

model of nursing for nurse practitioners that informs advanced practice nursing, particularly the nurse practitioner role, to provide culturally congruent care to diverse and similar clients in primary care practice contexts” (McFarland & Eipperle, 2008, p. 48).

Healthcare providers continue to encounter new and different cultures and must work to provide quality care to the people they serve (Hubbert, 2008). Leininger’s theory is easy to understand and applicable to any culture and therefore is able to be utilized by any healthcare provider interested in improving cultural awareness and sensitivity (Nelson, 2006). The Sunrise Enabler paradigm depicts Leininger’s theoretical concepts, and is similar to the ‘circle of life’ known to many Native Americans (Tom-Orme, 2002). See Appendix A, Leininger’s Sunrise Enabler for the Theory of Culture Care Diversity and Universality, for a copy of the paradigm.

Leininger’s theory emphasizes the importance of delivering culturally congruent and sensitive care (Hubert, 2008; McFarland & Eipperle, 2008). Her Sunrise Enabler paradigm creates a visual representation of the myriad components of any given patient’s cultural makeup. One way healthcare providers can work to become familiar with the cultures they serve is by attending “culturally-based community or education programs or events and community based culture care research projects” (McFarland & Eipperle, 2008, p. 59).

Project Development

After completing the general literature review, the development of the project began with a discussion between the author and a mentor from the Montana State

University College of Nursing who was already involved with research regarding end-of-life care for Native Americans. The author then attended a meeting among healthcare providers and researchers who had been working on evaluating the unique end-of-life healthcare needs of the reservation community. The Montana State University researcher gave a presentation summarizing the findings of the research which indicated that there were areas that would benefit from education of community members and healthcare providers regarding end-of-life care and cultural awareness and sensitivity. A second conversation between the author and the Montana State University researcher helped determine the specific issue to be addressed by the project. It was decided that the project would address communication issues between non-Native-American healthcare providers and Native-American patients. This would be accomplished by developing a pamphlet tailored for non-Native-American healthcare providers working with Native-American patients at the end of life.

Healthcare providers on the Indian reservation are not all Native American and therefore face a barrier when working to meet the cultural needs of their patients. After a thorough review of the literature available regarding the cultural challenges of providing end-of-life care in general, as well as to Native Americans specifically, a pamphlet was developed to provide a general guide for practitioners working with clients of a different culture at the end of life. The focus of the pamphlet was on providing culturally appropriate end-of-life care for Native Americans.

Research has shown that there is no clinically significant difference between providing educational materials via video, written materials or the internet (Egberts,

Green, Ilic, McKenzie, & Risbridger, 2008). While oral tradition is highly valued in Native-American culture, this project was designed for non-Native-American healthcare providers, so a written method was chosen (Morgan, 2009; Wilson, 1996). A short, tri-fold pamphlet was designed to create an accessible written guide for communicating with culturally diverse clients, focusing on end-of-life care.

A modified Delphi method was used for the revision and completion of the pamphlet (Polit & Beck, 2008). Input was sought from both the principle investigator of the research project on the north central Montana Indian reservation, as well as from a cultural expert familiar with the healthcare system on the reservation. Based on their recommendations, the pamphlet was adapted to meet the specific needs of the healthcare providers in the community of interest.

The pamphlet contained guidelines for conducting a cultural assessment (Kleinman, 1980), as well as helpful communication tips for healthcare providers (Y. Colclough, personal communication, n.d.B.; Burhansstipanov et al., n.d.). Pamphlet content was developed based on the information identified through a review of the literature which revealed several areas for improvement in communication at the end of life. The NCP's recommendations for effective communication skills guided the topics presented within the pamphlet.

Culturally sensitive training has been indicated as a helpful step for improving communication between non-Native-American healthcare providers and Native-American patients and families (Community Healthcare and Cultural Expert, personal communication, October, 28, 2011). Cultural sensitivity is important in creating an

environment where healing and/or acceptance can take place (Coehlo & Manoogian, 2010). Therefore, cultural sensitivity was the first component of the pamphlet.

Some practitioners may not even consider the way they view a culture's beliefs, values, or traditions. It is important for healthcare providers to evaluate their own understandings of culture, illness, and health before attempting to understand their patient's point of view. A cultural self-assessment may be helpful in identifying incongruences. It may also be helpful to ask questions of the patient and family to gain a better understanding of their values and beliefs.

Kleinman developed an eight question cultural self-assessment that can assist healthcare providers to better understand their own cultural beliefs as well as the beliefs of their patients (Kleinman, 1980). "The Kleinman questions, developed out of medical anthropology research, are designed to elicit the patient's health beliefs and expectations or concerns about the disorder and the treatment" (Department of Health and Human Services, 2004, p. 11). Kleinman's cultural self-assessment was chosen for its succinct nature, lending to its ease of use in the clinical setting. It is also suitable for any culture with which the practitioner may be working. For these reasons, it was included as the second component of the pamphlet. Permission was obtained from University of California Press Books for the use of the assessment questions.

Personal communication with the Montana State University researcher and a cultural expert was utilized to create a pamphlet specific to the chosen community, which is the final component of the pamphlet (see Appendix B, Pamphlet). Research within the north central Montana community showed that healthcare providers report that at times it

is most useful to openly ask the patient and family if they prefer to have all the information up front, or if they would prefer to hear a little bit at a time or have other family members present for the conversations (Y. Colclough, personal communication, n.d.B, n.d.C). Some patients may feel that discussing such situations may “jinx them” (Y. Colclough, personal communication, n.d.B).

While communication between the practitioner and the patient is important, encouraging the continued communication between the patient and their family is equally important. The elder can be an example and a teacher to younger family members even in death (Y. Colclough, personal communication, n.d.C). Healthcare providers may encounter situations where they can encourage their patient to be a leader and teacher even in illness and death.

Healthcare providers should recognize cultural differences in communication beyond the speaking of a different language. Native Americans may utilize a more indirect form of communication, and a non-Native-American healthcare provider may not even realize what was discussed during a conversation or what the outcome of that conversation was. For this reason, it is important for healthcare providers to consider the need for a cultural interpreter when working with Native American clients.

Self-Trial of Pamphlet

Cultural awareness is paramount in providing culturally appropriate care to patients. For this reason, the author’s own answers to Kleinman’s eight questions (1980) are included here. “What do you think caused your illness?” (Kleinman, 1980): the author believes that illness is caused by identifiable culprits such as bacteria, viruses, stress, or harmful substances such as

mold, carcinogens, or pollutants. “Why do you think your illness started when it did?”

(Kleinman, 1980): the author believes that illness may begin due to exposure to a toxin or other causal agent, particularly during times of decreased immune function. “What do you think your illness does to you?” (Kleinman, 1980): the author believes that illness may have many different physical and psychological effects, depending on the type of illness. The author does not believe that illness has spiritual ramifications. “How severe is your illness?” (Kleinman, 1980): the author believes that illness severity varies, and is usually correlated with objective findings, as well as subjective feelings. “What are the chief problems your illness has caused you?”

(Kleinman, 1980): this answer would vary depending on the physical and social components affected by the illness. “What do you fear most about your illness?” (Kleinman, 1980): the author would typically fear long-term health effects from a given illness, as well as the inability to treat the illness. “What kind of treatment do you think you should receive?” (Kleinman, 1980): the author would hope to receive traditional Western medical treatments that are proven to be appropriate treatment for the diagnosed illness. She would not likely pursue homeopathic or unproven treatments. “How do you hope to benefit from treatment?” (Kleinman, 1980): the author would hope first for cure, if not cure, then for comfort through the duration of the illness.

CHAPTER 4

DISCUSSION

Purpose of the Project

The purpose of this project was to identify a clinical nursing problem in the area of end-of-life care, perform an in-depth analysis of the research done, and develop a solution for the identified problem. The problem identified through a review of the literature was communication issues between healthcare providers and patients, particularly when different cultural backgrounds are involved, when addressing end-of-life care. A pamphlet was developed to help healthcare providers understand potential barriers and how to address them. The hope is that by clearly outlining potential barriers and identifying ways for healthcare providers to deal with them, end-of-life care will be improved for all participants.

Cultural Considerations

Practitioners must seek out ways to learn more about the culture they serve. Working with a cultural mentor may be helpful, as would attending various cultural activities available in the culture where they live and work. Exposure to different cultures may help enhance understanding, or at least sensitize practitioners to the cultural differences around them.

Through the development of this pamphlet, the author learned that cultural sensitivity is important in providing all care for patients, including end-of-life care. This

does not mean becoming fully immersed in the culture of the patient, but rather respecting that there are differences, and seeking to better understand the circumstances from the patient's perspective. This may mean utilizing Kleinman's eight questions (1980) when presenting a new diagnosis to a patient and family. It may also be cultivated by developing a trusting relationship with patients and asking them to teach the provider about important cultural components of healthcare and life. Practitioners will be limited in their ability to learn about the different cultures of their patients if they do not understand their own beliefs about health, illness, and death, as well as their feelings about other cultures.

Throughout this process of cultivating cultural sensitivity, communication is a key component. Without open, trusting communication, neither the practitioner nor the patient can hope to learn about the other party, or respect their wisdom. Practitioners may become frustrated with the patient and family for not understanding the importance of making choices with regard to treatment options and end-of-life care if they do not understand the cultural impact of these decisions. Both the literature review and the discussions with the Montana State University researcher and the cultural expert helped the author begin to understand some of the cultural differences that exist between Native Americans view of healthcare and the author's own view.

The end of life can be a challenging time for patients, families, and healthcare providers alike. Frustration about care choices and treatment preferences rooted in cultural misunderstandings only serves to magnify the challenges. Death may have spiritual significance for a patient unique to their own culture. Through this project, the

author learned that it is important to develop a trusting relationship with patient in order to better understand and meet the specific end-of-life needs relative to their culture.

Limitations and Challenges

The main limitation of this project was that it was not actually used. In order to further develop the use of this pamphlet, it should be tested in the healthcare setting, evaluated for clarity and usefulness, revised, and reintroduced. It should then be presented to practitioners who work with culturally diverse patient populations and support should be provided to answer any questions the healthcare providers might have.

A second potential limitation is the specificity of this pamphlet to the north central Montana Indian tribe. Because of the differences not only between Native-American tribes, but also between the many different cultures around the world, the pamphlet would need to be adjusted to be specific to each culture in order to be most beneficial to healthcare providers. This would require the aid of a cultural expert in each culture the pamphlet was to be adapted for.

One challenge encountered by the author was that she is not Native American. It was difficult to understand the Native-American culture due to lack of experience and exposure to the culture. Very little research has been done on Native American culture, and specifically on the tribe in north central Montana which was the focus of this project. Therefore, it was difficult to fully understand the differences and barriers unique to that population.

This challenge also presented itself in communication efforts with the cultural expert. The author contacted the cultural expert via e-mail with questions and seeking input, and received only very short and non-specific replies. Native-American cultural historically relies on verbal communication rather than written, and perhaps contacting the cultural expert via telephone or in-person would have facilitated better communication.

A second challenge the author experienced was in working with her project advisor. The project advisor was also not Native American, nor was she of the same cultural background as the author. This led to different understandings and interpretations of expressions, research findings, and even what constituted a barrier. This challenge, however, also helped the author broaden her scope and look at barriers and information from a different perspective.

This second challenge was also a sort of “double difficulty” in that the project advisor was also not a native English speaker. This presented communication difficulties between the author and the project advisor. E-mail communication helped this barrier, however, verbal communication was also necessary at times, and required a focused effort on the part of both entities to understand each other.

Implications for Advanced Practice Nursing

All healthcare providers, including Advanced Practice Nurses (APNs), will work with patients of different cultural backgrounds. These cultural differences may present barriers to effective care, whether they are in end-of-life communication, treatment

decisions, or the simple explanation of a disease process. APNs must be watchful for potential miscommunications with their patients, and take steps to help address these differences before they create a problem in the relationship.

Kleinman's eight questions (1980) are very helpful in taking the first step toward addressing cultural barriers. The APN must understand his or her own cultural beliefs and values before attempting to overcome the barriers of patients. Performing a cultural self-assessment will prepare the APN to recognize and address cultural barriers as they present themselves in the care of patients.

This pamphlet will serve as a device to help prepare APNs for the barriers they may encounter when working with patients from not only the individual tribe in north central Montana, but also with other cultures. It will help make them aware of the fact that cultural barriers may exist among different cultures. Making APNs aware of the cultural differences may open the way for increasing research about different cultures in the future. APNs should enter into every patient encounter with the knowledge that there are things they can learn from their patient to better provide effective care.

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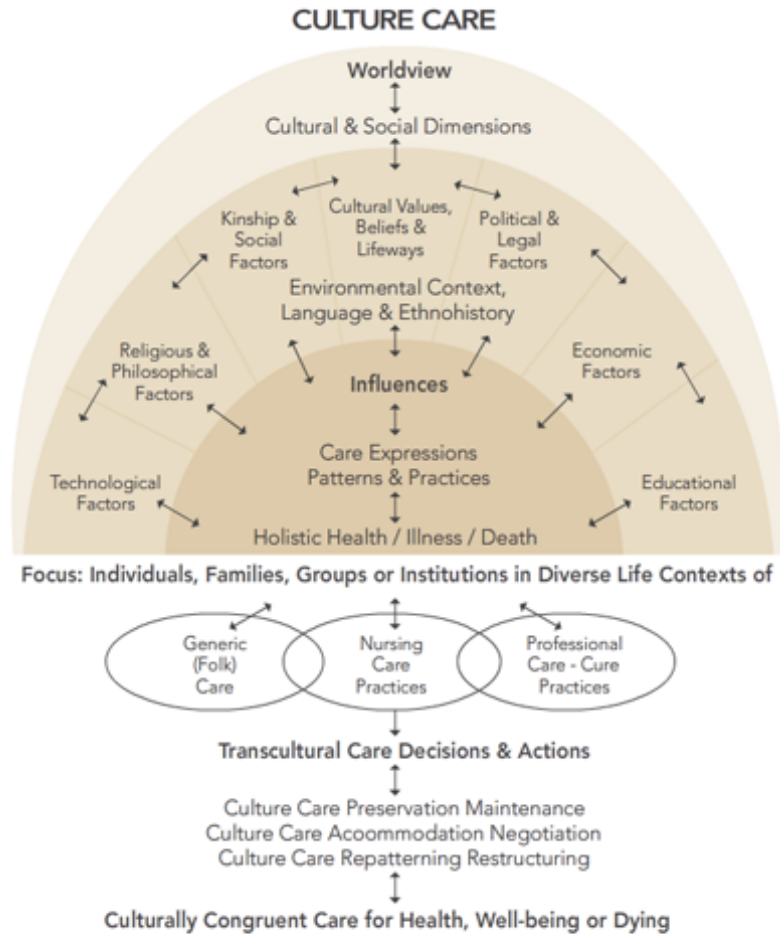
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APPENDICES

APPENDIX A

LEININGER'S SUNRISE ENABLER FOR THE THEORY OF CULTURE
CARE DIVERSITY AND UNIVERSALITY

Leininger's Sunrise Enabler for the
Theory of Culture Care Diversity and Universality



Code: ↔ (Influences)

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APPENDIX B

PAMPHLET

Communication at the End of Life

It can be difficult to discuss end-of-life issues with patients and their families. Cultural differences can magnify this difficulty. Healthcare providers can take steps to create an environment where communication is fostered between themselves and their patients. Recognizing cultural differences and taking steps to address these differences can improve the quality of communication between providers, patients, and their families.

Considerations when Working with Native Americans

- ∞ Healthcare providers must recognize the patient's role within the family.
- ∞ Family meetings have been strongly recommended for communicating important information and requesting healthcare decisions at the end of life.
- ∞ Providers must establish a trusting relationship with both the patient and the family to provide optimal care.
- ∞ Healthcare providers must understand the importance of spiritual beliefs in the process of healing and death.

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Cultural Considerations at the End of Life for Healthcare Providers:

Tools for providing culturally sensitive care at the end of life to Native American patients



Cultural Sensitivity

Understand yourself, then your patient



Healthcare providers need to understand their own feelings toward different cultures they may be working with. This includes differences in communications, perceptions of disease, and expectations of treatment. Native American cultures value and respect elders and healthcare providers must recognize who is the elder and leader within the family, as well as the impact the death of an elder may have on a family. Allowing traditional treatments and rituals will create a more fulfilling end-of-life experience. Providers can learn about cultures they serve by attending public cultural events such as powwows or tribal college events within the community.

Here are eight questions to ask yourself as a provider, and also to ask your patients

Questions to Include in a Cultural Assessment:

1. What do you think caused your illness?
2. Why do you think your illness started when it did?
3. What do you think your illness does to you?
4. How severe is your illness?
5. What are the chief problems your illness has caused you?
6. What do you fear most about your illness?
7. What kind of treatment do you think you should receive?
8. How do you hope to benefit from treatment?

Source: From Kleinman, A. (1980).

Patients and healers in the context of culture. Berkley, CA: University of California Press, by permission.

Cultural Communication Differences



Differing communication styles may complicate conversations with patients. Some cultures utilize indirect communication, which may confound the clinicians' understanding of the conversation. The need for a cultural interpreter should always be evaluated. Providers working with Native American patients and their families need to ascertain the patient and family's understanding of the illness and its likely progression. By understanding cultural differences, healthcare providers can provide a positive and culturally appropriate end-of-life experience.