

Nursing's role in advance care planning for hispanic / latino individuals

El papel de enfermería en la planificación anticipada de la atención de las personas hispanas / latinas

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Abstract

End-of-life care decisions are challenging for most people and cultural beliefs may facilitate or hinder such decisions. Advance care planning provides a venue to interact with and communicate to healthcare professionals a person's documented health and medical treatment wishes at end of life. Open communication, cultural accommodation, and mutual understanding among the healthcare provider, patient, and family are key to effective advance care planning. This article discusses how Hispanic / Latino people address end-of-life care and what cultural aspects are especially relevant for this population. The nurse's role in assisting Hispanics / Latinos with advanced care planning is presented at various levels of the nursing professional spectrum.

Key words: End of life, decision making, Hispanic-Latinos, nursing, advance care planning

Resumen

Las decisiones relacionadas con las fases terminales de la vida son difíciles para la mayoría de las personas. Las creencias culturales pueden facilitar o dificultar dichas decisiones. La planeación adelantada del cuidado provee el mecanismo para interactuar y comunicarse con los profesionales de la salud sobre los deseos de la persona para el final de su vida. La comunicación abierta, la adaptación cultural y el entendimiento mutuo entre el proveedor de la salud, el paciente y la familia son la clave para una planeación adelantada efectiva. Este artículo analiza cómo la gente hispano/latina enfrenta las fases terminales de la vida y qué aspectos culturales tienen una relevancia especial para esta población. El papel del personal de enfermería que trabaja con los hispano/latinos en la planeación de las fases terminales de la vida es presentado en los varios niveles profesionales de enfermería.

Palabras clave: Final de la vida, toma de decisiones, hispano-latinos, enfermería, planificación anticipada de la atención.

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INTRODUCTION

Healthcare professionals grapple with decisions regarding end-of-life care for individuals. Assessing and understanding end-of-life care preferences through ongoing discussions with the competent person or a designated surrogate decision maker is an important component of this care. Advance care planning provides the venue to interact with and communicate to healthcare professionals a person's health and medical treatment wishes. Knowing an individual's preferences in advance could contribute to patient and family satisfaction with appropriate resource allocation for care at end of life.

As the United States population ages and becomes more ethnically diverse, nurses need to be culturally sensitive when working with individuals during advance care planning. By 2030, 1 in 5 individuals will be 65 and older. While trends suggest that by the year 2050, ethnic minorities will make up approximately 50% of the population. The Hispanic / Latino population will triple from 46.7 million (15%) to 132.8 million (30%) (1) This article explores end-of-life care preferences and the nursing role in advanced care planning for Hispanic / Latino individuals.

Death and Dying

Although dying and death are universal human experiences (2) as medicine and health care evolved, death changed from a sudden event due to infection or injury, to an event in old age or at the end of a life-limiting or chronic illness. The average life expectancy in the United States is 77.7 years of age and the leading causes of death are heart disease, cancer, and stroke(3).

In the American society, as Dr. Rachel N. Remen (4) states, "we have made death into a technological and management issue and robbed it of its holy significance and dignity." Of the 2.4 million people in the United States who die each year, 133,004 are Hispanic / Latino and a majority of those individuals die in health institutions rather than at home (3). Death can be a stressful experience for individuals and families if they are unable to communicate the end-of-life care they desire or their expressed wishes are ignored.

A landmark study, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) (5) reported the following findings. Communication between physicians and patients addressing the individuals' end-of-life wishes was limited. Greater than one third of the patients who died spent their last days in an intensive care unit. Forty-six percent of the individuals received mechanical ventilation within 3 days of their death. At least 50% of the time, dying patients were in moderate to severe pain.

The Mularski, Heine, Osborne, Ganzini, and Curtis(6) study revealed that terminal pain and symptom management had not improved during the ten years following the SUPPORT study. Family interviews addressing symptoms their loved ones experienced prior to death revealed that only 47% of family members believed that the pain experienced by their loved one was controlled most or all of the time, and only 3% of family members felt that their loved one was able to breathe comfortably.

Hispanic / Latino Culture

The Hispanic / Latino group, the largest and fastest growing minority in the United States, encompasses the subgroups of Mexican, Puerto Rican, Cuban, Central and South American(7). An estimated 46.9 million Hispanics / Latinos , 15% of the nation's population, live in the United States and are expected to increase to 132.8 million by the year 2050 (1).

According to Livingston of the Pew Hispanic Center, six out of ten Hispanic / Latino adults in the United States have undocumented status and lack health insurance. Undocumented status decreases access to health care, increases the risk of not having a regular healthcare provider, and diminishes the chance of adopting preventive behaviors (8). No studies have explored the relationship between Hispanic/Latino documented status and having a completed advanced care directive.

While individual uniqueness is recognized, being aware of the following cultural generalities may facilitate the healthcare professional's understanding of the Hispanic / Latino perspective of health, illness and death. The importance of family, familismo, is characterized by strong family ties and support within and across generations (9-11).

Cuellar (10) describes four additional cultural themes that influence Hispanic / Latino beliefs and practices: espiritismo, jerarquismo, personalismo, and presentismo. Espiritismo refers to the belief in good and evil spirits and their influence on health and well-being. Jerarquismo is the respect for hierarchy and authority. Personalismo

is described as trust building based on mutual respect. Presentismo emphasizes the present since there is no sense of control of the future.

Another cultural value of special relevance for end-of-life care is machismo, decision making centered around the male figure. When a relevant decision is to be made, there is the expectation that a male figure is consulted and male consent is given before the decision is made.

Authority is another core element in the Hispanic culture. Respect for authority is valued and promoted through the use of formal titles such as señor, señora and decision-making issues are contextualized within authority recognition. Those having authority, either by age, experience, or formal title are expected to intervene actively in health-related decision making.

Predestination, the belief that events happen because they are meant to happen and because they have a purpose, is important for end-of-life decisions as some Hispanic/Latino groups feel disempowered in decision making related to life and death. Other authors refer to predestination in terms of fatalism, the belief that "the course of events cannot be changed and life events are beyond one's control" (12).

To advocate culturally appropriate care, the nurse needs to view the individual's perspectives of health, illness, and death through the individual's cultural lens. Leininger (13-15) and Leininger and McFarland (16) view culture as the learned and shared values, beliefs, norms, and practices of a specific group that guide thinking, decisions, and actions. While cultural behavior develops

over time and is unique to a specified group, Giger and Davidhizar (17) recognize culture as a dynamic process facilitating self-worth and self-expression.

Culture influences decision making. By asking how decisions are made and whether the individual wishes to participate in decision making, an individual's autonomy is respected as well as honoring cultural beliefs and values (18).

End of Life Care

A person encounters illness and functional limitations as the individual moves across the life continuum toward the end of life. While the literature does not present a clear definition of end of life, National Institutes of Health (19) points out that evidence supports the following as components of end of life. A chronic disease(s) or persistent symptoms or functional impairments are present. Symptoms or impairments resulting from the underlying irreversible disease require formal or informal care and can lead to death.

In the United States, end-of-life care is rooted in Western values(20). As a person transitions toward end of life, the individual should be made aware of end-of-life care possibilities such as hydration, artificial nutrition, antibiotics, and symptom control so the person is able to make and communicate educated decisions about the care they desire. The goal of end-of-life care is to provide care and comfort so a person has a good death. The Institute of Medicine (21, p.4) describes a good death as "free from avoidable distress and suffering for patients and families, and caregivers; in general accord with the patient's and family's

wishes; and reasonably consistent with clinical, cultural, and ethical standards."

End-of-Life Nursing Education Consortium (22) emphasizes that the goal of end-of-life care, to have a good death, can be accomplished by addressing the dimensions of quality of life. The Quality of Life Model (23) supports the idea that dying impacts the individual's physical, psychological, social, and spiritual dimensions. The physical well-being focuses on not only physical symptoms related to the disease progression, but also functional ability, sleep, rest, and appetite. The psychological well-being focuses on expressed emotions, psychological issues and concerns. Social well-being involves structure, relationships, and roles within the family. The spiritual dimension addresses the individual's capacity to connect with others, surroundings, and powers outside of self(24). Recognizing that these broad dimensions are applied universally, the individual and family define the quality of life for themselves according to their life experiences, culture and values.

Duffy, Jackson, Schim, Ronis, and Fowler (20) recognize comfort, physician communication, addressing responsibilities, hope and optimism, and honoring spiritual beliefs as end-of-life concepts important to most individuals. Providing appropriate end-of-life care includes understanding and respecting an individual's values and preferences related to these concepts.

Born, Greiner, Eldonna, Butler, and Ahluwalia (25) found Latino families to be open to end-of-life care that reduced caregiver burden and emphasized spirituality and family consensus is valued. Duffy, Jackson, Schim, Ronis, and Fowler (20) re-

ported that Hispanic / Latino men and women desired to die with dignity and have good end-of-life care. While Hispanic women requested more extensive medical interventions, Hispanic men desired few medical interventions, but would request assistance in ending their life. Hispanic women favored alternative medicine.

Advance Care Planning

Advance care planning is a dynamic process of discussing, reflecting upon and understanding future medical decisions and end-of-life care preferences (26). Through this process, the individual, family members and health professionals learn not about how the person wants to die, but how the individual wants to live their final stage of life.

Teno, Lindmann, Nelson, and Lynn (27) convey that advance care planning focuses on four goals. The decision-making process improves through shared decision-making, flexibility, and education. Care is consistent with the individual's preferences when capacity is lost. A person's well-being improves by reducing over or under treatment occurrences. An individual's concern about possible family burden is decreased.

Educating and discussing with the person, at various times, the natural course of a chronic or life limiting disease and the changes the person experiences should be part of advance care planning. Since an individual's goals and preferences for end-of-life care may change over time, decisions about care should be reviewed periodically. The Quality of Life model (23) can be used as a guide to facilitate discussions dealing with perceptions, decision making,

communication, and values in relation to a person's physical, psychological, spiritual, and social well-being.

In the United States, the Patient Self-Determination Act, 1990 acknowledges a person's right to either refuse or accept medical treatment (28). This federal legislation mandates the following for an individual being admitted to a hospital, skilled nursing facility, home health agency, or hospice program:

- provide written information about an individual's right under state law to make medical care decisions, including the right to accept or refuse medical interventions;
- the right to create an advance directive;
- document in an individual's medical record whether or not the person executed an advance directive;
- provide education about advance directives.

All fifty states and the District of Columbia have state legislation legalizing some form of advance directive.

While the Patient Self-Determination Act provides a person the legal right to express their end-of-life wishes, the advance directive (AD) and Physician Order for Life Sustaining Treatment (POLST) are tools for effective communication and documentation of end-of-life care decisions. Brown (29) identifies two common AD forms, the living will and health care power of attorney. The living will facilitates documenting wishes about accepting or refusing specific

life-sustaining medical interventions. A health care power of attorney documents who the person has designated to make healthcare decisions in the event the individual is unable to. More often, a combined AD, a living will and a health care power of attorney, is used.

The POLST Paradigm is "designed to convert patient preferences for life-sustaining treatments into immediately actionable medical orders" (30, p.119) that are transferable across healthcare settings. This program, originating in Oregon, has been implemented in several states and a majority of states are considering POLST legislation.

After collaboration among healthcare professionals, the patient or proxy decision maker and family in conjunction with any existing AD, the POLST document is completed and signed by the physician and the patient or proxy decision maker. Cardiopulmonary resuscitation, medical interventions such as mechanical ventilation, comfort measures only, antibiotics and artificially administered nutrition are addressed. This paradigm is recommended for an individual who has an advanced life-limiting condition or who desires to further define their treatment preferences.

Cultural Considerations

A healthcare professional's acknowledgment of a person's cultural background fosters respect and dignity. Having general starting points assists the healthcare professional in understanding and anticipating behavior. As suggested by Bastida (11), Cuellar (12), Sotomayor and Applewhite (13) and Perkins, Supik and Hazuda (31) cultural considerations should be considered when ha-

ving advance care planning discussions with Hispanic / Latino patients.

Religion and family are central to Hispanic/Latino life. Values such as *espiritismo* may influence personal decision making on topics such as organ donation and end-of-life care. Religious figures such as priests and pastors are respected and often consulted about issues of death and dying, hence indicating the importance of involving them in nursing educational endeavors related to advance care planning.

Familismo understood as placing the well-being of the family over the individual, reflects strong family ties and support within and across generations. Family members should be included in discussions addressing the person's wishes about end-of-life care and advance care planning. Decision making in the Hispanic / Latino family often involves extended family and figures such as uncles, aunts, cousins, along with the members of the nuclear unit. This is an important consideration when talking to families about advance healthcare planning. Nurses need to identify who are the members of the family who need to be involved in the decision-making process, so they can be educated on the various options regarding advance care planning.

Jerarquismo, respect for hierarchy, reflects the importance of showing respect to healthcare professionals. Discussing the individual's expectations of Western medicine and desires for care acknowledges the individual's perspective and may minimize the person's tendency to agree with or defer to the physician when they are not in agreement with the physician.

Authority figures not only involve those in the healthcare field but also those who are worthy of respect and admiration in a given family unit. Nurses should identify those who are authority figures and have a hierarchical relevance in the family to involve them in the decision-making process and related educational efforts.

Personalismo, trust building based on mutual respect, demonstrates the value of personal interaction. Opportunity for the Hispanic / Latino individual to discuss their values of life and desires for end-of-care, displays respect while valuing personal interaction. Recognizing the importance of addressing members of Hispanic / Latino family units with respect, particularly those who are elderly and by the virtue of their age, are recognized as authority figures is essential. For instance, using señor or señora, instead of the first name, when interacting with the elderly, is an important element in building mutual respect and trust.

Presentismo places emphasis on the “now” with little consideration of the “past” or “future.” Although death is recognized by Hispanics / Latinos as a natural part of life, it is still viewed as undesirable. Nurses should recognize that for many in the Hispanic/Latino culture, talking about death, or making arrangements related to the death process may bring about misfortune. To address this belief, nurses should involve religious figures recognized by the family in the education of possible alternatives related to advance care planning.

Other values such as machismo, fatalism, and predestination are also important. Nurses may need to initially consult male figures in decisions related to advance

care planning, and then extend that consultation to other members of the family unit. Fatalism and predestination can be construed in a positive manner if nursing educational efforts involve a dialogue with the family members about religious values and expectations.

Nursing’s Role in Advance Care Planning

Quill(32)notes that introducing advance care planning conversations early in the disease process promotes better outcomes such as more informed choices, better symptom management and more opportunity for resolution of important issues. The nurse is an important advocate for facilitating advance care planning. Individuals are comfortable with the nurse inquiring about an AD (33), and the nurse spends more time with the patient and family than the physician (34). The supportive figure that Hispanics / Latinos may see in nurses can be an asset in the dialogue about advance care planning.

While laws protect an individual’s right to determine and communicate how the person wants to live the final stage of life, a healthcare professional’s duty is to facilitate advance care planning and documentation. A majority of the time, the healthcare professional, a nurse or physician, rather than the patient or a family member initiates the process. Often, the nurse faces the challenge of understanding the individual’s cultural beliefs on end of life, advance care planning, and the use of tools to document advance care decisions.

As a starting point, querying the individual and family about their understanding of the disease provides opportunity to clarify and

reinforce information the physician may have provided about the course of illness, prognosis, treatment options, potential burdens and benefits, and alternatives. This contributes to understanding the disease impact on physical, psychological, social, and spiritual dimensions of quality of life within the cultural context. Exploring the cultural themes of *espiritismo*, *familismo*, *jerarquismo*, *personalismo*, and *presentismo* provides information on how these cultural themes influence the Hispanic / Latino individual's beliefs and practices relating to advance care planning.

Attention to a person's values is critical for clear communication and patient education (35). Using understandable information with clear and ongoing communication contributes to an individual's understanding that goals of care change as the person's disease progresses and quality of life is impacted.

Simple steps such as providing education and educational materials, time for conversation, and listening to the person's hopes, concerns and wishes facilitate the healthcare professional's understanding of the individual's desires for care. The nurse should be aware of how decisions are made and by whom within the family system.

Since individuals 65 years and older have a greater incidence of chronic disease and account for most deaths, they may be more interested in advanced care planning and completing an AD. An adult is more likely to complete an AD if there is assistance from a nurse or social worker (36). With guidance, individuals are able to document their expressed preferences about specific treatments and expectations of Western medicine.

There is a great importance of having expressed preferences documented. If an individual understands the structure, content, and purpose of AD and POLST forms, the person may be more receptive to documenting their care preferences. An effective AD documents the person's designated surrogate decision maker, expressed health care preferences and goals, is detailed, and easy to use (37).

When addressing issues related to advance care planning with Hispanics / Latinos, nurses need to recognize the value of the family. Although individual decision making should be acknowledged and respected, family-based decision making and education ought to be the cornerstone of nursing care for this cultural group.

Nurses should remember that "family" for Hispanics / Latinos encompasses nuclear, extended, and community members. Trusted friends, religious figures, *compadres* and *comadres* can be important motivators and educators in moments of crisis. Their contribution should be used not only in moments of crisis, but also during the educational process.

McLean and Graham (38) found in the study, *End-of-Life Issues Personally and Spiritually (ELIPSE)*, conducted with 66 Latino adults, that receiving "bad" news was easier when the news was delivered by a trusted family member or a religious figure. This is important from a nursing perspective because it implies that information related to life and death issues can be delivered effectively through a family member or a trusted religious figure, rather than through a healthcare professional.

Although more Hispanics / Latinos are learning the value of the “right to know,” many still believe in the relevance of the right of “not to know” (38). When faced with news such as a terminal disease stage, some Hispanic / Latino individuals believe that it is better not to inform the person since such knowledge may increase stress levels and contribute to depression. In these situations, nurses may rely on respected figures such as religious leaders, comadres, compadres, and family members to participate in the discussion with the family and patient about her/his condition.

A study conducted by Eleazer et al.(39) suggested that Hispanics are becoming more willing to complete an AD. This willingness represents an important opportunity for nurses to educate this population on the logistic and procedural aspects of an AD. Wissow et al. (40) added that physicians face time barriers and are conflicted about bringing up AD discussions with their patients. This is another reason for nurses to be prepared to discuss and facilitate advance care planning with the patient and family.

Although nurses may have good intentions of providing culturally-sensitive care, their efforts can be harmful if they do not have the proper education and understanding of the cultural values of Hispanic / Latino families. This premise implies that nurses need to receive culturally-sensitive education at all levels, undergraduate and graduate, and actively seek opportunities to further their understanding of Hispanic/Latino cultural values. Being equipped with the knowledge and understanding of their limitations and cultural biases contributes to nurses being effective facilitators of advance care planning.

CONCLUSION

Advance care planning should be regarded as a covenant, with the healthcare professional bringing knowledge of possible courses of illness and treatment options while the person brings stated wishes, values, and beliefs, in order to determine the best course of action for the individual. This requires open communication, cultural accommodation, and mutual understanding among the healthcare professional, patient, and family.

By using documentation tools such as an AD and POLST, future end-of - life care decisions are documented. The documented preferences should be discussed among the healthcare professional, patient, and family and reviewed periodically.

Cultural values are important in the process of educating families about advance care planning. When addressing life and death issues with Hispanic / Latino clients, it is important to involve recognized authority, as well as family and religious figures who understand the dynamics of individual families.

The nurse’s role in working with Hispanics/ Latinos in advanced care planning is vital. Nurses need to be educated on how to begin the process of advance care planning with Hispanic / Latino families in a culturally-respectful and sensitive way. The process should start at the diagnosis of a chronic or life-limiting illness and involve the individual, nuclear and extended family, as well as religious figures and other respected members of the community.

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