

# Providing Culturally Sensitive End-of-Life Care for the Latino/a Community

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## ABSTRACT

The Latino population is the fastest-growing population in the United States. This rapid growth has resulted in an increased need for culturally sensitive health and education services, especially at end of life. Terminal illness experiences, beliefs, and expectations are linked to cultural values. Latino culture values end of life and is rich in beliefs, traditions, and rituals related to this important time. This article reflects the author's clinical and personal experiences as a Latina and reviews the literature regarding end-of-life issues and Latinos. It also offers suggestions on how to better serve the Latino community, and examples of important traditions, rituals, and beliefs at the end of life.

## INTRODUCTION

*"The Mexican is familiar with death, jokes about it, caresses it, sleeps with it, celebrates it: it is one of his favorite toys and his most steadfast love... he looks at it face to face, with impatience, disdain of irony."*<sup>1</sup>

The 2000 United States census<sup>2</sup> reported an increase in the Latino population that, while occurring in all states, is particularly high in states not traditionally populated with Latinos. This has created a surge of new Latino communities in places without health services (or any other services) prepared to meet their needs. Latinos often lack culturally-sensitive health services, particularly at end of life.

Terminal illnesses experiences, beliefs, and expectations are linked to cultural values.<sup>3,4</sup> Latino culture values the end of life and is rich in beliefs, traditions, and rituals related to this important stage of life. While Latinos as a group share many cultural values, they come from different countries and therefore don't share a homogenous set of values. Communities now

reflect people from many more diverse educational and socioeconomic backgrounds, varied lengths of time living in the United States (with many newcomers), and greater numbers of older people. Different levels of acculturation occur in different immigrant groups from different countries, which also affect values held by the community and individuals. This shift in Latino demographics poses significant challenges but also enriches the experience of providing health services at end of life for Latinos.

Most of the literature on Latinos and end-of-life issues is written for nursing and palliative care journals, and little is specifically directed to primary care clinicians.

This article reflects the author's clinical and personal experience as a Latina and reviews the literature regarding end-of-life issues for Latinos. Suggestions are offered on how to better serve individuals from this population at the end of life (Table 1) as are a review of traditions, rituals, and beliefs at the end of life (see Appendix 1). As previous articles mention, this information should only serve as a starting point and should not be used to stereotype or to generalize about members from this ethnic group.<sup>5,6</sup>

While traditional medicine is still widely accepted and practiced in most countries in Latin America, and by Latinos in the United States, most Latinos are also familiar with the scientific medicine model.<sup>7,8</sup> I have observed a "circle" pattern in my clinical practice with Latinos that blends the traditional with modern health care. Patients start by treating themselves or their family members with home or traditional remedies and/or providers. If traditional remedies don't work, then they access the medical system. If the medical system fails to work as well, they return to seek the assistance of traditional medicine practitioners and, in the case of the chronic and/or terminal illnesses, religious assistance as well.<sup>9</sup>

Various factors play an important role in the Latino's approach to the end of life including their perspective on family and community, religion and spirituality, re-

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**Table 1.** Latino Health End-of-Life Issues and Recommendations for Health Care Professionals

Issue	Recommendation
Latinos are a very diverse group with diverse cultural values.	Avoid generalizations. Use specific population background information as reference.
May decline medical decision-making, may elect not to know medical diagnosis/prognosis.	Inquire about patient preferences and if needed obtain verbal-/not written consent to talk to appointed family member/s. Understand cultural differences.
Prefer that family members be present for clinic visits, particularly if bad news will be delivered.	Ask patient if family member needs to be present. Understand presence of extra family members in the room.
Decisions made as consensus with family members involvement.	Talk to all pertinent family members. Educate about disease process and assist with reaching consensus.
Preference for in-home care by family members.	Facilitate in-home care, provide family members with support systems.
Underutilization of hospice services. (Poor information, distrust and poor language/cultural access)	Instruct about services, provide language/culture appropriate services, and team up with Latino community organizations.
Increased sense of community.	Involve patient's community and community resources in patient's care.
High sense of spirituality.	Employ faith in God as a source of hope, comfort, and acceptance. Encourage faith system participation.
Decreased use of advanced directives.	Investigate and understand cultural beliefs about end-of-life issues and provide appropriate information.
Late access to health care system due to competing survival needs	Provide social services assistance. Inform about consequences of late diagnosis/treatment.
Very respectful of health care professionals, don't question treatment plan.	Establish a trusting relationship and engage patient in decision-making from the beginning. Verify that information was understood.
Terminal illnesses considered a punishment, inspiring great guilty feelings.	Explore beliefs and fears; comfort, educate, and reassure about the dying process.
"Fatalism" belief system based on "God's will" originated	Educate about disease course, choices, and resources as a survival skill.
Increase pain threshold, "stoicism," perception of pain multidimensional (family roles/protection, sign of strength, continue fulfilling family needs)	Acknowledge cultural differences, inform of available choices/positive results and reach a balanced treatment plan.

spect and dignity, time and space, and their concept of health.

## **FAMILY AND COMMUNITY**

Latinos' lives revolve around family, both the immediate and extended family. All family members are involved in every aspect of life, from birth to death. Most important decisions are made by consensus rather than individually, and decisions about terminal care are no exception. In most instances, patients prefer to be given bad news in the presence of their family.<sup>10</sup> In other instances, families prefer that health professionals not inform the patient about the diagnosis and prognosis of the terminal illness. In many of these cases, the patient agrees with this approach. In some cases, even if patients are aware of the diagnosis, they prefer not to be involved in the decision-making. What may appear

to the medical community as denial may in fact be resilience on the patient's part. Patients and families want to keep hope, and many think the final decision is in the hands of God, not the doctors. Some of these behaviors may conflict with the current American health system, which promotes individuality and patient confidentiality.<sup>11,12</sup>

Family also plays a very important role in the care of the terminal patient. Latinos take care of their family members out of love rather than obligation. To care for their loved one is a privilege. The majority of Latinos with a terminal illness prefer to die at home in the company of ALL of their family members. Therefore, clinical services should aim to support not only the patient but also the family, and, if possible, to provide in-home services. Hospice and other facilities should make accommodations for family traditions and fami-

lies' decision-making as a priority in end-of-life care for Latinos.<sup>13,14</sup>

Similar to their family values, Latinos' sense of community is very high. This is particularly true when it comes to helping each other when someone in the community faces a terminal disease. It is a great source of support not only for the patient but particularly for the families. In some communities everybody is part of the dying process, before, during, and after the death. Many of the community members contribute money for the burial expenses.<sup>15</sup>

## RELIGION AND SPIRITUALITY

Catholicism is still the most common religion observed by Latinos, yet many other religious associations are growing among this community, especially among Latinos in the United States.<sup>16</sup> Regardless of religious association, without question, Latinos have a strong faith in God.<sup>7,13,17</sup> Religious faith plays an important role in understanding health and disease<sup>18,19</sup> and is a key source for the acceptance of dying and the grieving process. In many cases, religious faith may become stronger when a family member faces a terminal illness. Patients and families turn to God for hope and/or comfort believing that whatever happens will be meaningful. Several traditional practices are based on this: group praying; religious mass offerings (masses are dedicated to God or a specific Saint to ask for health and well being); cleansings (traditional practices conducted by "curanderos,"—traditional healers—to "clean" the body and the spirit from disease and/or bad spirits/spells using praying, various plants, animals, and eggs); and "mandas," which are saint's offerings (people offer material things, praying, actions requiring a sacrifice, to a specific saint in exchange for health, favors, and/or miracles).<sup>8,9</sup>

## RESPECT AND DIGNITY

Latinos place great emphasis on individual dignity and are reluctant to have personal care given by anyone other than an assigned family member. Life-sustaining measures are less acceptable. Patients and families perceive those as futile, prolonging the inevitable, undignifying and causing suffering. Family members want to assure that the dying person is pain free and treated with respect.<sup>13,20,21</sup>

Respect is an important concept in Latino life. There are well-established hierarchies and roles among members of the family that play an important part in decision-making. In the majority of the cases, the head of the household, usually a man, will make the main decisions. With older adults, the oldest child is usually appointed

to assist with the decision-making. If the hierarchy is not well defined, consensus must be reached among all of the children and other family members.

Latinos have a high regard and respect for expert knowledge, and expect highly directive providers. Because of this, they rarely overtly question or challenge providers.<sup>7</sup> Yet in the case of terminal illnesses, very often "second opinions" are sought either from other health care professionals or from traditional healers.

Trust is also very important in the patient–doctor relationship. Latinos give respect to health professionals but also expect respect in return. Many Latinos do not share their personal cultural beliefs with clinicians, fearing their beliefs would not be respected and addressed in their care. There is also an historical distrust of institutions and fear related to immigration status and discrimination<sup>17,22</sup> that can interfere with their seeking help at the end of life. For instance, Latinos may underutilize hospice services. In 1995, the National Hospice and Palliative Care Organization reported that only 4% of Hospice patients at the national level were Latino. Many reasons have been cited for this, including language access, cultural beliefs, distrust in institutions, and poor information about services.<sup>20,21</sup> Health care facilities need to be aware of this and to form an alliance not only with the patient but with community organizations to inspire trust and dismantle the fears.

## TIME AND SPACE

Due to their spiritual, religious, and cultural values, Latinos perceive death not as the end but rather as a continuum of life. They believe there is a duality: the "spiritual" space and the "physical" space. The relationship between the living and the dead is reflected in the majority of their beliefs and traditions about death (ie "Mom is here taking care of us.")<sup>23</sup> Many have witnessed at least 1 family member or friend die, but the concept of "time" (when this would happen) is a very personal one ("I will decide when I die.") The majority expects it to happen at an advanced age, and therefore planning for death may not be started until the very late stages of illness, if at all. There are also some beliefs around planning, such as "If you planned it then it would happen."<sup>5,24</sup> Latinos are much less likely to have advance directives compared to other racial groups.<sup>17</sup>

Regarding "physical" space, many Latinos have an acquired feeling of "not belonging" to the United States that is most evident when they or someone in the family dies and the family would like for the body to be returned "home." Because of cultural and religious be-

liefs the majority elect burial versus cremation, which can add to the legal and economic aspect of dying, since transporting the body back to the country of origin can be quite costly and complicated.

## CONCEPT OF HEALTH

Latinos believe that “health” is associated with not having pain and being able to work and carry out family responsibilities. They have a very strong work ethic and don’t want to be perceived as lazy or weak. This is particularly true for Latino men. With insurance issues compounding the cultural issues, many men do not seek medical care until diseases are more advanced and harder to cure. While the concept of prevention is understood, it is not a priority in light of survival issues. This community continues to bear a disproportionate high mortality rate of preventable diseases.<sup>25</sup>

Many Latinos consider terminal illness a punishment for something they did or didn’t do, and it inspires in them a deep feeling of guilt. This is particularly true when it comes to the death of a child or when death is unexpected.<sup>26</sup> This feeling poses a challenge to health care professionals, but is also an opportunity for intervention in the grieving process by maintaining good communication with the patient, exploring their beliefs and fears, and comforting, educating, and reassuring patients about the dying process.

Many articles cited a “tendency toward fatalism” in this community. This concept has deeper roots and is often overly simplified by health care professionals unfamiliar with the culture. In many cases, without other choices due to lack of resources, Latinos are more accepting of death, developing a belief system based on “God’s wishes.” Education about disease processes, resources, and choices will make a patient more likely to participate in their medical care.

One of the most important medical issues at the end of life that is closely related to cultural experiences is the patient’s perception of pain. For Latinos, the perception of pain is multidimensional, not only physical.<sup>14</sup> Latinos are often characterized as “stoic,” but not many people are aware of the roots of this stoicism. To be able to endure pain is part of the role of family members, both men and women. This is meant to protect other family members from suffering and worrying about them, and also to be able to continue fulfilling their roles as providers for the family. This is closely related to believing that everything is shared among the family and pain is not an exception. To be able to endure pain is also a sign of strength, which is especially valued in men.<sup>14</sup> Therefore, when working with a patient from

the Latino community, it is important to be aware of this fact, acknowledge it, educate patients and families about resources, and to try to reach a balanced treatment plan.

Other important medical issues include the cultural perception about autopsy and organ donation. Largely due to religious and spiritual values and, to a lesser degree, because of distrust of the system, many Latinos do not allow either of these procedures. Although we hope this will change in the near future in the face of religious changes, more education about the importance of these procedures and the assurance of equal treatment by the medical system are needed.

## CONCLUSION

Latinos have very rich values about death and the dying process. Some of these values could conflict with some of the values and medical ethics of our health care system. When providing care at the end of life for Latino individuals, it is important to learn about the basic concepts of this population’s culture, acknowledge cultural differences and similarities, educate them about the US health system and disease processes. It is important to keep an open communication channel, explore our patients’ beliefs and values, explore our own beliefs and values, and, if possible, compromise to try to reach the most balanced consensus on decision making to provide the best possible care for this population. In summary, humility and an open mind are needed to reach and best serve the Latino community, especially in end-of-life care.

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## APPENDIX I

### *Mexican Traditions*

#### The Funeral

Many Mexicans, particularly in the rural areas, celebrate funerals with an open casket at their own homes. Everybody in the community is invited and contributes to the funeral and to the burial. The casket is decorated with flowers and candles. Food is offered for everyone and many times the deceased's favorite music is played. In some towns, a group of women (las pleñideras) especially dedicated to crying at the funeral are hired, and they accompany the body until the burial. Praying is done at the funeral and then at the burial. In some cases, the funeral continues for several days, sometimes waiting for everybody in the family to arrive before the burial.

#### La Novena

The majority of Latinos are Catholic and observe the Catholic traditions. "La novena" is a religious tradition observed for 9 days after the burial. A group of people—men and women—from the community get together at the deceased's house and pray the rosary in his or her name. It is thought that by doing this, the deceased's soul gets to Heaven faster. Food is offered to the participants every night.

#### Dia de Muertos (Day of the Dead)

The Day of the Dead is celebrated in Mexico on November 1st ("Dia de los angelitos" [Children]) and 2nd ("Dia de todos los santos" [Adults]). This is a pagan-religious celebration (a clear example of the Mexicans' cultural duality) to honor and to show respect to the loved ones who have passed away. It is one of the most ancient traditions practiced by this community. People believe that on this day the spirits of the deceased come back to share with the living. At home people show their respect by setting an "altar," which consists of a decorated table with a nice table cloth, flowers, candles, and the main items: the pictures of the person(s) who have died and their favorite food for them to enjoy again. At church, services are offered to the dead and praying groups are organized. At the cemeteries, all tombs are decorated with special flowers, "Zempazuchitl" (marigold)—used only for this occasion—and candles. To complete the celebration, music is played and food and drinks are brought to share with deceased loved ones. All of this is done in a respectful and spiritual way. At the street market sugar skulls (candy with people's names) are sold as a friendly reminder of humans' mortality.

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