End of Life Issues and the Use of Hospice/Palliative Care among Latinos

The Ethical Concerns

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Abstract

This paper talks about the different barriers that prevent Latinos/Mexicans to use hospice services when dealing with a terminal illness in the United States. Major barriers like the lack of legal documentation, medical coverage, and lack of money may keep the patients from receiving end of life services, hospice or palliative care. In addition to that, patient’s differences in language, culture, health care expectations and religious/spiritual beliefs can influence the end of life decisions and the use of Palliative care from Latino families. Providers share some of these linguistic and cultural barriers as well. The article explains some ethical concerns related to disparities when using the end of life services and share some recommendations to provide culturally appropriate services to the Latino/Mexican community.
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Latinos are less likely than whites to use hospice. (Kreling n.d.). Lack of Medical coverage and legal status are major barriers that prevent Latinos to have access to hospice services, but these are not the only barriers. Other cultural and social factors have a big influence in the end of life decisions as well. For instance Smith, Sudore and Perez (2009) explained how Latino families have a support network with strong ties of solidarity, interdependence and loyalty. Based on this family foundation they make end of life care decisions. Lack of knowledge of what hospice is about and what the services consist of, can be other reasons that prevent Latinos from using hospice services. (Fernandez 2013). I also mentioned some ethical concerns in the article, related to the lack of legal status and how this prevents the individual from qualifying for hospice services, and the lack of cultural sensitivity from the clinicians and how this interfere when the Latino is making end of life decisions..

Literature Review

Overall, Latinos are less likely than whites to use hospice. Even though there is evidence that their needs for services are greater. (Kreling n.d.). For instance Latino patients maybe undertreated for cancer pain, and Latino caregivers have more depression in bereavement. (Kreling n.d.). According to the National Hospice and Palliative Care Organization, of the 885,000 patients admitted to hospice programs in 2002, 82% were white, less than 10% black and less than 5% were Hispanic or Latino. (Fleming 2004). According to the Census Bureau (2014) Hispanics or Latinos represent 17.4 percent of the population of United States and it is estimated to be the largest minority by 2015. (Kreling n.d.). While there has been increased
effort in hospices to reach out non-white populations, hospice care is still underutilized by Latino families. (Kreling n.d.). The question is why? - Why? a persistent ethnic disparity exists in a society where civil rights are a core value and where supportive programs, like Medicare and Medicaid have been designed to assist underserved and physically disadvantaged populations to obtain health care and end of life services?

Fleming 2004 explained that ensuring reimbursement resolves only part of the problem. Besides financial reasons there is a conglomeration of different factors that influence the Latino families when making end of life decisions. Smith et al 2009 explained that it is a strong influence of the Latin American culture:

“Latin American today is a product of 500 years of population and cultural admixture of the indigenous peoples, the European colonialists and immigrants, and forced migrations of Africans. Within the Latino community, there is a considerable variation in health care access and utilization patterns by country of origin.” (Fleming 2004)

According to the Census Bureau although there is a tremendous diversity within the Latino community - Mexicans are by far the largest Hispanic origin population in the United States (U.S.), accounting for nearly two thirds (64%) of the U.S Hispanic population in 2012. (Gonzalez and Lopez 2013).

The act of dying and death has been a more naturally accepted process culturally in the Latino communities than others. Religion and spiritual beliefs have an important role in the acceptance of death (Stanford School of Medicine). Mexicans believe in the eternal life in which souls continued to live in afterworld. (UNC School of Education n. d.). The cross is a sacred sign and it symbolized the cardinal points of direction. The day of the dead is a celebration where
Mexican demonstrates a strong sense of love and respect for their ancestors; they celebrate the continuance of life, family relationships and community solidarity. The day of the dead celebration, allows people to talk about and even find humor in death. In this way death losses some of its sadness and horror. (UNC School of Education n.d.).

In contrast, although death seems to be more accepted by Hispanic/Latino elders, there is no doubt that the use of Hospice tends to be significantly lower in this group. (Stanford School of Medicine). According to Smith et al., (2009) there are other particular issues that may affect the end of life decisions in Latinos. These are:

- **Familismo**: Latinos place a great value on the family; direct family: father, mother children. And extended family: aunts, uncles, grandparents, cousin, nephews, sisters, sisters in law. Etc. Extended family forms a collective support network with strong ties of solidarity, interdependence and loyalty. (Smith et al., 2009). When a terminal illness affects a member of the family, it affects the entire family. If the illness affects the oldest in the family (parents or grandparents) families say, “they took care of us when we were little, now it is our turn, we need to take care of them.” Leaving the parents in a hospice care means lack of love and respect, lack of responsibility from the family, it means abandoning the parents with strangers in a much more fragile state of their life.

- **Machismo**: although machismo can have a negative connotation of male oppression, this can also refer to the need men feel to serve as the family provider and protector. Machismo can also have an overwhelming influence on decision making for Latina women, especially in less privileged social classes. (Smith et al., 2009).
• Fatalismo: May manifest a pessimist attitude about the future, leading terminal ill patients to delay seeking treatment and potentially suffer alone. (Smith et al., 2009).

• Religious and Spiritual Considerations: some Latinos may believe that suffering was to be born as part of a test of faith, this concept has also been noted in literature attitudes of African Americans toward end of life care, and may represent a common expression of perseverance and struggle in the face of discrimination and subjugation. (Smith et al., 2009).

• Discrimination: Latino immigrants have qualitatively described negative patient-provided interaction; including feeling the doctors did not take enough time to educate or examine them, and did not care about them personally. Perceived discrimination can have detrimental consequences for health related behavior, for instance patient who perceive medical discrimination are less likely to take recommended screenings for early detection of cancer and in the case of hospice, patients who experience discrimination may deny hospice care, isolating themselves and suffering in silence. (Smith et al., 2009).

Different research mentioned other important factors that interfere with the use of the hospice from the Latino/Mexican community in this country:

• Lack of knowledge about hospice programs: According to Fernandez, the definition of hospice is different in this country than the definition of the word “hospicio” in Spanish, in many Latin American countries the word “hospicio” is a place destined to aid orphan children. According to Kreling many Latinos have a misconceptions that hospice is a place for poor, old people or for people with disabilities. Fernandez
argues that one of the main barriers that prevent Latinos to use hospice is not knowing what the services consist of. (Fernandez 2013).

- Lack of cultural awareness from the providers, when discussing the issue. (Fernandez 2013). Providers don’t take the time in analyzing how to present hospice services to the Latino community and there is an ineffective and inappropriate communication barrier between provider and patient. (Fleming 2004).

- Fleming 2004 highlight that distrust from patient toward the provider may exist because the patient believes he will be treated differently cared for less or marginalized. (Fleming 2004).

- According to Flemming 2014 the use of Hospice services would indicate “giving up hope and faith” in the life of the dying patient. (A study and Kansas City that explored end of life preferences and barriers among low income urban African American and Latinos found that they preferred having families provide for loved ones at the end of life, but emphasized a desire to have services available to reduce caregiver burden.).

- Lack of insurance; Overall 37% of all Hispanics do not have health insurance (Medicare, Medicaid). More than 57% of Mexican immigrants are uninsured, compared with 20% of those born in U.S. (Stanford School of Medicine). The lack of legal status is directly related to the lack of medical coverage and lack of access to other social services. There was 11.1 million of Latino immigrant in lack of legal status in 2011. (Pew Research Center 2013)
• Limited English Proficiency (LEP): According to Smith et al., 2009, thirty-two million of the estimated 44 million Latinos residing in the United States, speak Spanish at home. English proficiency varies by generational status: in a study from the Pew Hispanic Center of 14,057 Latino adults, 23% of first generation immigrants reported being able to speak English very well, compared to 88% among second generation and 94% among later generations. Errors in understanding are very common when clinicians communicate in English with a Spanish speaker patient with LEP, even when Latinos don’t understand they may signal understanding to appear cooperative and not defy the authority figure (Smith et al., 2009). Some hospice services don’t even have a Spanish phone line where monolingual, undocumented patients or their caregiver can call for information about palliative care. (Martinez 2004). Unfortunately many LEP patients are not aware of their legal right to trained medical interpreter.

• Health Literacy Considerations. Patients with limited health literacy are more likely to have difficulty processing writing and oral health information and to have difficulty navigating the health care system and less likely to engage in shared decision making. (Smith et al., 2009).

Ethical considerations

According to V.J. Periyakoil, MD director of Palliative Care Education and Training at Stanford University School of Medicine, there are no specific hospice agencies that provide information in other languages. “For undocumented immigrants everything is harder, they are not covered by Medicaid, therefore they don’t get access services at all,” she stated, “I have seen tragic cases where the patient is isolated from their social network, has limited English
proficiency and is dying.” She said. (Martinez 2014). According to my analysis, a case like this is against article number 25 of the human rights declaration that stated that “Everyone has the right to a standard of living adequate for the health and wellbeing of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.” (Universal Declaration of Human Rights) If this country promotes that ‘everyone has the right to medical care and necessary social services in the event of sickness and old age” how come the health care system denies hospice care to sick and old people just because of the lack of legal status?

In 2012 in the article “Home: Palliation for Dying Undocumented Immigrants” from the New England Journal of Medicine Dr. Ricardo Nuila, of the Baylor College of Medicine in Houston, Texas wrote that “for many undocumented immigrants, terminal illness is a revolving door”, because many times the undocumented patients suffer as much mentally from this process as they do physically. He stated. “Sometimes providers send patients to their home countries, patients may pay for their final journey home, but often funding comes through the patient’s home government, such a Mexico protection Department. If arranged properly, sending a dying patient home can be a win solution: it provides dying patients a means for palliation without using County or emergency Medicaid funding” Dr. Nuila noted. (Martinez 2014). Carlos Sada, the consul general of Mexico in Los Angeles, said that in the past two years, they have sent five terminally ill immigrants to Mexico at a total cost of $24,000. (Martinez 2014). In my opinion denying palliative care to a patient and sending him/her back to their native country in such a fragile health condition just because of the lack of legal documentation in against human rights. Again article 25 of the declaration of human rights says that “everyone has the right to security
in the event of sickness or old age.” Traveling causes more stress on the ill person and chances are that families in the native country won’t have money to buy medication and/or other necessary things to assist the dying person.

According to Searight and Gafford (2005) Principalism a well establish ethical framework for medical decisions in the United States and Western Europe, highlights cross-cultural differences that occur along four dimensions: Autonomy, beneficence, nonmaleficence and justice. Although many patients in United States value autonomy, other cultures emphasize beneficence, in this country legal documents such as advance directives and durable power of attorney are strategies to prolong autonomy, in situation where the patient can no longer represent themselves, other cultures however; de-emphasize autonomy, perceiving it as isolating rather than empowering, this cultures believed that communities and families, not individuals alone, are affected by the life threatening illnesses, and the accompanying medical decisions. Cultures valuing nonmaleficence (doing no harm) protect patients from emotional and physical harm caused by directly addressing death and end of life care.

Overall Mexican families don’t talk about the advanced directive documents, some of them believe that by talking about death they are calling and/or wishing their own death. Besides that the vision of many Mexicans is focused in the present, because they are not sure if they will be here tomorrow.
Recommendations

- Clinicians and other providers must increase their cultural awareness/sensitivity to cultural diversity, there are cultural proficiency guidelines developed by the American Academy of Family Physicians that clinicians can review to increase their cultural awareness. (Searight & Gafford 2005)

- Latinos may feel that truth – telling about prognosis, is harmful for the patient and cruel to the family. The patient is often protected from information and from the responsibility of making decision in the Latino families, especially in those families less acculturated. (Smith et al., 2009). Clinicians should be prepared for large families to be present at the bedside and to be involved in care. Clinical decision making and therapeutic options may need to be consider in the collective context of the family unit. (Smith et al., 2009). Ask the patient: “Would you be more comfortable if I spoke with your brother, son, wife or daughter alone or would you like to be present? Let me know if you change your mind?” (Searight & Gafford 2005)

- Machismo can also have an overwhelming influence on decision making for Latina women, especially in less privileged social classes. A private consultation with the Latina patient is recommended for the clinician in order to truly assess the goals of the Latino patient. (Smith et al., 2009).

- Latino males, may feel shame and disappointment when symptoms or functional decline, limiting their ability to fulfill patriarchal expectations. Clinicians should respectfully inquire about these concerns and find ways to help Latinos contribute to their families at
the end of life. For instance provider can say “this medication will help you be as pain free as possible, so you can continue to care for your family” (Smith et al., 2009).

- The government must ensure special palliative programs for those undocumented individuals young and old, with a terminal illness that are dying in this country.

- Physicians should ask patients or family members about availability of writing advanced directive and durable power of attorney in a culturally and linguistically sensitive way and/or they must train a translator to interpret the end of life topic with the patients—taking in considerations the level of education (literacy level) of the patient as well. (Searight & Gafford 2005)

- Latino patients should be informed about the right to an interpreter at no cost.

- Physician or other clinical staff can actively develop rapport with ethnically diverse patients, by demonstrating an interest in their cultural heritage. Through skillful use of patient-centered questions and including interpreters as necessary - physicians can develop a richer understanding of patient’ health preferences.

**Conclusion**

In summary, some Latino families are in greater need of hospice/palliative care but due to several barriers they underutilized hospice services. Some of these barriers are very complicated including lack of legal status and lack of medical coverage. The Latino/Mexican culture exerts a profound influence on the end of life decision and experiences of patient and their loved ones. In order to increase utilization of hospice and/or end of life services from the Latino/Mexican community, it is essential from the clinicians and other medical staff to learn cultural factors that influence and interfere with the end of life decision making. Providers and other clinical staff,
including interpreters must offer culturally and linguistically appropriate services to the Latino families that are experiencing end of life situations. The government must re-consider providing end of life services to any person when necessary, regardless to their legal status. Patients have to be aware of their human rights when seeking end of life services, this will help to prevent ethical issues. Finally each ethnic group is different, and even more each subculture within the group. Each family and case is different, and it brings a new perspective to hospice services.

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