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Review Article

End-of-Life Care and Advanced Directives in Hispanic/Latinx Patients: Challenges and Solutions for the Practicing Oncologist

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Abstract

Advanced end-of-life care (EOL) comprises a group of strategies to provide comfort to patients at the end of life. These are associated with better quality of life, better satisfaction, and a lower rate of hospitalizations and aggressive medical treatment. Advanced EOL care, including advanced directives completion and hospice enrollment, is suboptimal among Hispanic/Latinx patients with cancer due to personal, socio-cultural, financial, and health system-related barriers, as well as due to a lack of studies specifically designed for this population. In addition, the extrapolation of programs that increase participation in EOL for non-white Hispanics may not work appropriately for Hispanic/Latinx patients and lead to overall lower satisfaction and enrollment in EOL care. This review will provide the practicing oncologist with the tools to address EOL in the Hispanic/Latinx population. Some promising strategies to address the EOL care disparities in Latinx/Hispanic patients have been culturally tailored patient navigation programs, geriatric assessment-guided multidisciplinary interventions, counseling sessions, and educational interventions. Through these strategies, we encourage oncologists to take advantage of every clinical setting to discuss EOL care. Treating physicians can engage family members in caring for their loved ones while practicing cultural humility and respecting cultural preferences, incorporating policies to foster treatment for the underserved migrant population, and providing patients with validated Spanish language tools.

Key words: disparities; neoplasm; Hispanic Americans; palliative care; advanced directive.

Implications for Practice

Advanced end-of-life (EOL) care practices are associated with better quality of life and satisfaction, a lower rate of hospitalizations, and unnecessary aggressive medical treatment. However, advanced EOL care is suboptimal among Hispanic/Latinx patients with cancer due to different barriers and a lack of studies aimed at this population. The extrapolation of programs that increase participation in EOL for non-white Hispanics may not work appropriately for Hispanic/Latinx patients. This review will provide the practicing oncologist with the tools to address EOL in the Hispanic/Latinx population. Through these strategies, we encourage oncologists to take advantage to discuss EOL care and engage family members while practicing cultural humility.

Introduction

As of 2020, 18.5% (60.6 million) of the United States (US) population identified as Hispanic/Latinx. Between 2010 and 2020, more than half (51.1%) of the total increase in the US population came from this community's growth.[1] Cancer is the most frequent cause of death among them, accounting for 20% (46 500) of total deaths.[2] An essential component of the cancer-care continuum is the early provision of high-quality palliative and supportive care, as studies have shown improved overall survival with the early incorporation of palliative care.[3] In addition, patients with advanced cancer are in need of end-of-life (EOL) care, which aims to provide person-centered and family-oriented care, providing comfort, and improving quality of life.[4] Nevertheless, despite the increased representation of Latinx individuals within the US population, there is a lack of research addressing the experiences faced by Hispanic/Latinx who are receiving palliative and supportive care, hospice, and EOL services. Until January 2021, through the systematic review of 4 databases, only 6 trials aimed at palliative and end-of-life care for the Latinx/Hispanic population were identified, which compelled clinicians to continue extrapolating data obtained

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from a majority white population to treat Hispanic/Latinx patients.[5]

In the US, Hispanics/Latinx disproportionately underutilize EOL services compared to the general population.[6,7] Hispanics/Latinx are the least studied population regarding EOL care preferences and decision making, and traditional delivery of healthcare services and advanced care planning may not be as effective in reaching Hispanic/Latinx patients.[4,5]

In this review, we provide the practicing oncologist with a toolkit on how to address EOL in the Hispanic/Latinx population. Furthermore, we overview the status of EOL care, hospice enrollment, and completion of advanced directives (AD) among the Hispanic/Latinx population.

Hispanic and Latinx are not synonyms even though they are used interchangeably; Hispanic refers to descendants from Spanish-speaking populations, while Latinx encompasses people who are from or descended from Latin America. Throughout the text, we will use both terms to refer to the group of individuals of Latin American origin or descent and serve as a form of gender-neutral or nonbinary identity.

Disparities in Enrollment in EOL Care

Many theories have been proposed to explain disparities in the Hispanic/Latinx community. A key factor associated with underutilization of EOL care within the Hispanic/Latinx population is the reduced access to medical services due to economic constraints since 20% of Latinx immigrants experience poverty.[8,9] Language barriers pose a further challenge for receiving appropriate and culturally sensitive EOL care. Furthermore, patients' immigration status can hinder timely enrollment in EOL care, including hospice care, out of fear of deportation.

Another consideration of the origin of these disparities stems from the fact that the US Hispanic population is relatively young. Based on hospice utilization rates by The National Hospice and Palliative Care Organization, the hospice enrollment rate for Latinx/Hispanic deaths is 38%, contrasting to an enrollment rate of 82% among NHW.[10] While this inequity in healthcare delivery may be secondary to the issues outlined previously, it might also reflect the so-called salmon bias, or "statistical immortality," where migrants desire to spend their last days and die in their country of origin.[9]

Finally, insurance coverage could play a role in EOL care access. Latinx Americans represent one-third of the Medicaid-covered population, and during the COVID-19 pandemic, Medicaid users were more like to die at home without hospice care compared to a commercially insured population (33 vs. 19%, $P = .04$).[11]

Latinx/Hispanic Patients' Perceptions Regarding Death and EOL Care

Culture, healthcare beliefs, and ethnicity impact how patients experience illness and make decisions regarding their medical care near the EOL. Generally, Hispanic cultures value a collective decision-making process; thus, family members have a strong presence at the EOL for Hispanic/Latinx patients.[12,13]

It is important to avoid stereotyping Hispanic/Latinx patients about their perceptions and beliefs about EOL, and physicians should actively inquire about preferred strategies for decision-making, including family involvement. One approach is to practice cultural humility, a strategy that focuses on lifelong learning about other's cultures and beliefs; coming with an open mind and understanding our own unconscious bias is essential when addressing EOL with Hispanic/Latinx patients.[14]

Barriers to Active Participation of Hispanic/Latinx Patients in EOL Care

Barriers to active participation in EOL, including hospice enrollment, among Hispanic/Latinx patients with cancer are complex and differ from those found among NHW. Table 1 provides a structured summary of the most common barriers identified in the literature.

Communication Barriers and Mistrust

Historically, ethnic minorities in the US have reported lower satisfaction regarding communication with physicians about EOL goals than NHW.[15] Healthcare providers might provide only limited information on EOL to Latinx/Hispanic patients, as some have reported difficulty discussing EOL practices with minority groups, including Hispanics/Latinx. A survey examining perceptions of barriers to advanced care practices among clinicians reported that 24.3% of healthcare workers expressed difficulties discussing advanced care practices with non-English speakers. On the other hand, most providers (62.2%) attributed such difficulties to the patients, and not to providers themselves or to the health care system.[16] While a direct language barrier may cause this, it can also be partially explained by limited previous clinical interactions with Latinx/Hispanic patients, perpetuating healthcare disparities.[17]

Mistrust among underserved populations has been previously described, which could hinder communication with minorities. Two strategies to overcome this are to recruit community leaders that the Hispanic/Latinx community trusts to aid in communication and actively involve local and on-site allies to solidify networks with the community.[18]

Migration Status

Patients' migratory status also plays a role in the underutilization of EOL care. Services provided to undocumented immigrants are limited compared to those offered to other patients.[19] There is a knowledge gap regarding undocumented immigrants' hospice use, and current literature is limited to case reports.[20] Oncologists should seek to incorporate policies

Table 1. Barriers to advanced EOL care in Latinx/Hispanic patients with cancer.

Personal	Limited knowledge about advanced EOL care Care-givers bias Language barriers Fear of deportation Economic restraints
Socio-cultural	Family is central to decision-making and EOL planning Religious beliefs tend to focus on a better life will lead you to a better death
Healthcare	Preference for a more paternalistic approach Mistrust in healthcare providers Physician bias

and procedures that foster appropriate treatment of the underserved migrant Latinx population.

Limited Knowledge About Palliative Care and Hospice

Limited knowledge and misconceptions about EOL care from patients and caregivers represent a barrier to patient involvement. A large cross-sectional study in California sought to outline the variation in insight regarding EOL care among a racially and ethnically diverse patient community. Being Hispanic was an independent risk factor for being unaware of hospice care, palliative care, and advanced directives (AD).[21] A significant proportion (76.7%) of Hispanic caregivers reported being unaware of the availability of hospice care, and more than half (59.3%) agreed that hospice is offered when "nothing else can be done." Despite a general lack of understanding, most (76.6%) disagreed that receiving hospice care meant giving up on life.[22] This leads to an area of opportunity for healthcare providers to engage in meaningful conversations with patients and their families regarding EOL care.[23,24]

Clinicians should inquire more when patients from Hispanic/Latinx backgrounds refuse hospice enrollment, as it might be based on limited knowledge and address concerns regarding negative misconceptions about hospice care.

Linguistic Barriers

Non-English prolific Latinx caregivers and patients may misunderstand the term hospice given that its literal definition in Spanish ("*hospicio*") refers to an orphanage, or mental health institution, which might imply suboptimal or stigmatized treatment.[23] Language barriers can hinder the ability of native Spanish speakers to access culturally sensitive and comprehensive information regarding hospice care. Caregivers whose primary language is English are about four times more likely to elect hospice care for a loved one than Spanish-speaking caregivers.[22] This suggests that English speakers may have better access to high-quality information regarding the relevance of hospice care and other forms of EOL care.

A relevant project aimed at improving advanced care planning engagement in underserved rural communities, including Hispanic/Latinx, was implemented statewide across Colorado.[25] Bilingual patient navigators (PN) facilitated conversations between patients and caregivers. Patients and caregivers also received bilingual information materials and completed an engagement survey after each session. Findings from this project revealed patients generally preferred bilingual providers, describing an increased sense of comfort and trust when communicating directly in their native tongue.[6] Such data can aid in the development of culturally sensitive and effective communication strategies regarding AD and EOL planning for Hispanic/Latinx patients with cancer.

A strategy that oncologists can adopt in their daily practice is to have available printed materials in Spanish. Reputable online sources of information in Spanish include the American Cancer Society (https://www.cancer.org/cancer-information-in-other-languages/spanish.html) and Cancer.net, the patient portal of the American Society of Clinical Oncology (ASCO) (https://www.cancer.net/cancer-net-en-espa%C3%B1ol). Another solution, which has been implemented in some cancer centers, is obtaining support from language interpreters. A recently published qualitative study exploring the experiences of Spanish medical interpreters conducting EOL discussions found that interpreters focused intensively on communication accuracy, even when discussions caused distress.[26] When addressing patients and families through the assistance of an interpreter, it is essential to speak directly to the patients using the first person while keeping sentences concise and paying attention to non-verbal communication. Unfortunately, interpreters are not available in many sites, particularly in the community, or cannot always be present, particularly during brief one-on-one encounters with the healthcare team or after hours.[20] Furthermore, having these conversations take time and 15-min consultations with the oncologist make this challenging and potentially worsening the current gaps in healthcare.

Influence of Family Values

Broadly speaking, Latinx families tend to play a more central role in EOL decision-making, whereas non-Hispanic white families largely value personal autonomy.[27] Hispanic families often congregate to discuss healthcare-related options in greater detail before any decisions are made. It is not uncommon for some Hispanic/Latinx caregivers to shield their loved ones from being informed of their terminal diagnosis due to fear of a worse outcome.[28,29] Instead, they may consider providing hope and encouragement to the patient as an especially meaningful intervention in medical care. While this family-centered decision-making style has been shown to be common among Hispanics, physicians should not assume this will be the case for every patient and should engage in conversations regarding patient preferences for decision-making. We encourage providers to discuss with patients and their families their religious beliefs and practices and ask if they would be interested in getting support from a religious figure, for example a priest or chaplain.

Paternalism

Hispanic individuals have often been characterized as invested in building relationships based on personal connections and trust. Paternalistic approaches to healthcare decision-making are quite common in Latin American societies and, it may be more common for some Hispanic patients to prefer physician-directed decision making.[24]

When trust is earned, much can be gained in the patient–physician relationship. Studies have shown that caregivers who trust that their physicians will make the best EOL decisions for their loved ones and are four times more likely to use hospice services compared to those who do not.[30] This can be especially powerful if the message is delivered from a provider whom the family trusts. We recommend that oncologists take advantage of every clinical setting to inform patients about EOL and hospice care while seeking conversations with patients regarding the role they would like their families to play in their care.

An important limitation of the available literature on EOL among racial/ethnic groups is the grouping of the many diverse Latinx/Hispanic communities into a single block, without addressing the differences stemming from their differing geographic, ethnic and cultural, origins. Such an approach can foster stereotypes and lead to the loss of important components which could be essential for a particular patient.

AD Completion and Hospice Care Among Hispanic/Latinx Patients

An essential component of EOL care is the completion of AD. Unfortunately, is considerably lower among Hispanic/Latinx individuals than among other racial/ethnic groups. AD provide patients with a standardized written form in which they may outline their wishes in the case of life-threatening situations.[31] AD completion is consistently associated with higher patient and family satisfaction with EOL care.[32] However, the decision-making process behind completing an AD is often influenced by complex factors, including cultural and socially mediated beliefs.

Several studies have documented racial/ethnic disparities in AD completion, with lower rates described in minorities. Hispanics/Latinx, for instance, have as much as 70% lower odds of AD completion than NHW.[33] Additionally, compared with 54% of NHW, only 29% of Hispanics/Latinx have ever discussed AD with a healthcare provider, thus leading to a decreased discussion about EOL planning and participation in hospice care.[32] These findings suggest that the lower completion in AD in the Hispanics/Latinx population could be related to a lesser attachment from the medical team to engage in these talks.

Benefits of hospice care include enhancement of life satisfaction, reduced caregiver burden, as well as improvement of self-care. Additionally, lowers healthcare costs through the reduction of hospital visits and medical interventions that may not add to the length or quality of life.[34,35] Disparities in hospice utilization between NHW patients and other racial/ethnic groups in the US are common. According to the National Hospice and Palliative Care Organization, only 6.7% of hospice care users self-identified as Hispanic/Latinx,[10] and Hispanics are far less likely to have heard about hospice care than their non-Hispanic white counterparts.[36]

Various strategies have been studied to fill the gaps in AD completion and hospice enrollment in the Hispanic population, with most including the participation of other individuals in the healthcare team, such as social workers and case managers.

Strategies to Improve Hispanic/Latinx Participation in EOL Care

Patient Navigation

The Colorado PN, a statewide initiative where bilingual PN partnered with healthcare staff to host AD sessions reported a 47% rate of AD form completion, which was numerally higher than historical reports. In addition, 98% of participants expressed high satisfaction and engagement with the sessions.[6]

Another culturally tailored patient navigation program, Apoyo con Cariño, was tested in a randomized clinical trial that included 223 Latinx adults with advanced cancer in the state of Colorado. The main outcome of this trial was the documentation of advanced care planning in the patient's medical record, with secondary outcomes including changes in pain and hospice use. Patient navigation led to an increase in the documentation of AD when compared with patients receiving usual physician-directed care (65.2% vs. 36.0%).[6,37] The trial could not show clear evidence that a culturally tailored patient navigation program improved other palliative care outcomes such as hospice enrollment and pain control. While hospice use was high in both the control and intervention groups (79.7% vs. 83.6%, respectively), there were no statistically significant differences noted. When comparing the hospice enrollment in Apoyo con Cariño to previous reports, the enrollment rate is considerably higher than what has been reported in the US in the Hispanic/Latinx population of 40%. The authors describe contamination of the intervention as a possible explanation for the lack of benefit of the intervention regarding hospice use, as many sites in Colorado only had one practicing oncologist. One option to determine the effect of culturally tailored patients' navigation interventions, is to implement similar models in multiple sites across the US which could lead to a more representative sample.

A similar randomized trial conducted among Hispanic/Latinx patients with advanced cancer in Mexico showed that a patient navigation intervention increased the completion of AD from 0% to 48%.[36] Although this study highlights the potential benefits of patient navigation among Latinx patients, it is important to mention that, in contrast with the US, AD are not part of usual cancer care in most Latin American countries.[38]

Currently available evidence arising from the US and Mexico in the Latinx/Hispanic population has proven that a culturally tailored navigation programs can lead to a higher rate of AD completion. Nevertheless, the benefit of the intervention on hospice enrollment has not been proven to this date and needs to be further explored in a more significant patient sample.

Geriatric Assessment-Guided Multidisciplinary Interventions

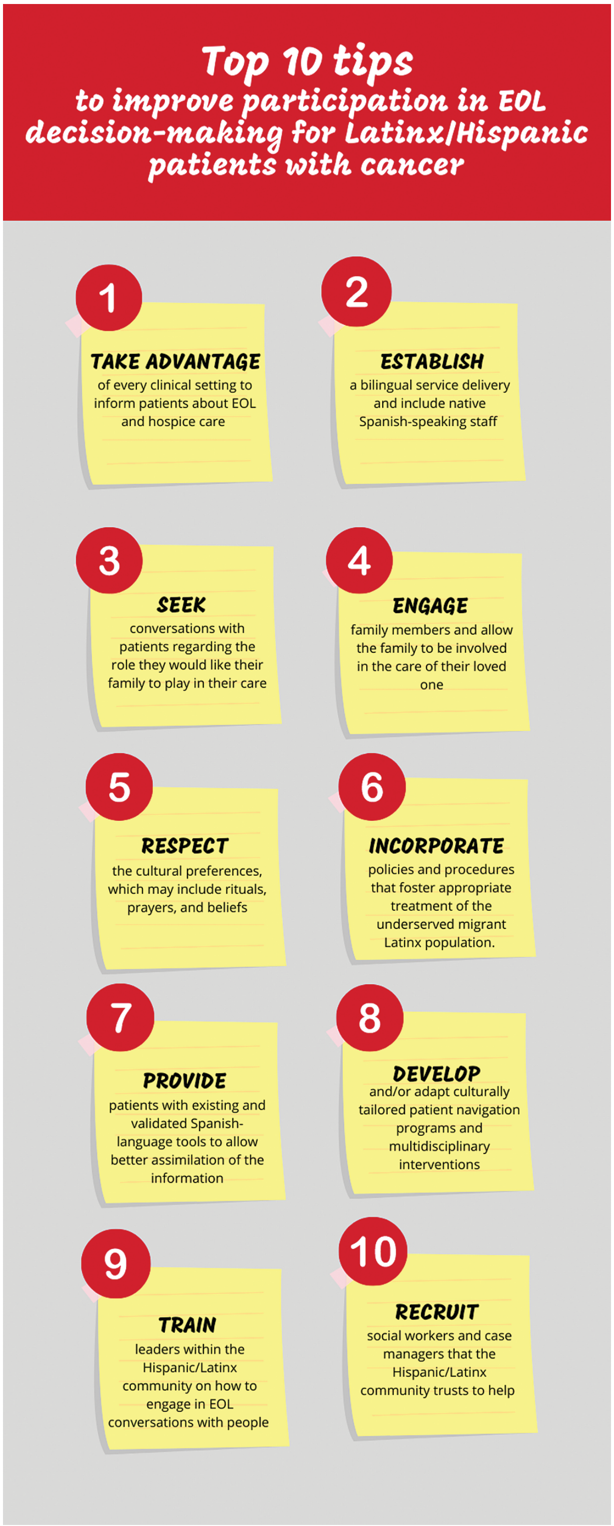
Interventions other than patient navigation have also shown an improvement in the rate of completion of AD Specific geriatric assessment–driven interventions, such as those tested in the GAIN randomized controlled trials have proven to be effective for increasing AD completion among older adults with cancer, increasing AD documentation from 46.3% to 74.6%. While this intervention was not tailored exclusively for a Hispanic population, the proportion of Hispanic/Latinx individuals included in the GAIN trial was 19.3%, which reflects the actual proportion of Hispanics in the US.[39]

Counseling Sessions

A recent meta-analysis showed that patients with cancer who identify as Hispanic/Latinx are more likely to be depressed and to have a worse health-related quality of life.[40] "*Puente para cuidar* (Bridge to caring)" is an integrated care program developed to combine counseling sessions based on interpersonal and behavioral psychotherapies with culturally tailored educational interventions and PN to assist with EOL care in Latinx patients. A pilot study of this intervention provided insights into its feasibility as well as its limitations. Notably, it provided several teaching moments regarding difficulties faced by Latinx patients during their cancer care, such as limited transportation preventing access to oncology or infusion appointments. These lessons serve as future areas that PN, as well as medical providers, can help address to engage Latinx patients in EOL care in a more equitable fashion.[41]

Educational Interventions

Prior studies examining EOL discussions between healthcare providers and Latinx patients have identified the patient's educational level as an independent predictor influencing



Top 10 tips to improve participation in EOL decision-making for Latinx/Hispanic patients with cancer

1 TAKE ADVANTAGE of every clinical setting to inform patients about EOL and hospice care

2 ESTABLISH a bilingual service delivery and include native Spanish-speaking staff

3 SEEK conversations with patients regarding the role they would like their family to play in their care

4 ENGAGE family members and allow the family to be involved in the care of their loved one

5 RESPECT the cultural preferences, which may include rituals, prayers, and beliefs

6 INCORPORATE policies and procedures that foster appropriate treatment of the underserved migrant Latinx population.

7 PROVIDE patients with existing and validated Spanish-language tools to allow better assimilation of the information

8 DEVELOP and/or adapt culturally tailored patient navigation programs and multidisciplinary interventions

9 TRAIN leaders within the Hispanic/Latinx community on how to engage in EOL conversations with people

10 RECRUIT social workers and case managers that the Hispanic/Latinx community trusts to help

Figure 1. Strategies to improve participation in EOL decision-making for Latinx/Hispanic patients with cancer.

EOL decisions. Among patients with lower educational levels, detailed verbal descriptions of medical conditions and of the various components of EOL care do not seem to be associated with an increasing understanding.[23] A potentially useful alternative strategy for communicating about EOL preferences is the utilization of short educational videos, for example, “*PREPARE su cuidado Médico*” aimed at the caregivers of terminally ill patients. In a study conducted in a primary care setting, there was a significant increase in the proportion of Latinx patients (from 40% to 75%) who chose comfort care as an option.[42] Clinicians can educate their patients with existing and validated Spanish-language tools, to allow better assimilation of the information and address misconceptions that patients and their families might have regarded EOL care.

Based on the analyzed data, we provide an infographic (Fig. 1) that highlights the 10 strategies to approach Latinx/Hispanic patients regarding EOL care, to increase AD completion and hospice enrollment.

It is noteworthy to highlight the need for educational interventions aimed at health-care providers to improve timely communication with patients and caregivers on EOL practiced in an effective manner. Although the inclusion of content-oriented training in cultural competence may increase provider knowledge, attitudes and skill, there is limited data supporting an improvement in patient satisfaction, outcomes, or access to healthcare. Therefore, inclusion of process-oriented training in cultural humility may be a better strategy to increase not only knowledge but also a recognition of bias, privilege, and limits of expertise.[43]

Conclusions

Advanced EOL care, including AD completion and hospice enrollment, is suboptimal among Hispanic/Latinx patients with cancer due to personal, socio-cultural, financial, and health system-related barriers, as well as due to a lack of studies specifically designed for this population. An extrapolation of programs and initiatives that are successful for increasing participation in EOL for NHW populations may not work for Hispanic/Latinx patients and their families and lead to overall lower enrollment in EOL care. Finally, we encourage practicing oncologists to take advantage of every clinical setting, for example during inpatients visits, outpatient consultations, or treatment infusions, to inform their Latinx/Hispanic patients and their families about EOL and hospice care while practicing cultural humility and to develop programs and initiatives which are truly culturally sensitive for our patients.

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Conflict of Interest

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Data Availability

No new data were generated or analyzed in support of this research.

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