

5-2022

## BARRIERS TO THE USE OF PALLIATIVE AND HOSPICE CARE AMONG THE LATINO POPULATION

Diana Ramirez

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BARRIERS TO THE USE OF PALLIATIVE AND HOSPICE CARE  
AMONG THE LATINO POPULATION

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A Project  
Presented to the  
Faculty of  
California State University,  
San Bernardino

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In Partial Fulfillment  
of the Requirements for the Degree  
Master of Social Work

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by  
Diana Ramirez

May 2022

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Approved by:

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## ABSTRACT

Patients suffering from irreversible and terminal illnesses may benefit from the services provided by Palliative and Hospice Care to control any symptom burden and assist in navigating complex medical decisions. Many patients may express hesitation in accepting and enrolling to this service due to misconceptions. Language barriers may add an additional layer of complexity. This study explored the challenges Palliative Care providers encounter when introducing concept of hospice to Spanish-speaking patients and their families for the first time. This study implemented qualitative research methods by using semi-structured one-on-one interviews. Ten members of an In-patient Palliative Care Team at a University Hospital were recruited as participants. Interviews were transcribed into a written form and coded into general themes. The study found that interpretation, use of written materials, misconceptions of the word hospice, religious factors and lack of cultural sensitivity training were some of the barriers identified. Additionally, the findings emphasized the need to increase the number of competent, bilingual providers of palliative care, an increase of cultural sensitivity training, access to high-quality interpreters in delicate complex end-of-life conversations and the need to increase education and community outreach to Spanish-speaking communities. Further research should be conducted to solicit feedback on the barriers affecting access and utilization of palliative and hospice services by the patients and the families receiving the services to obtain a better understanding those barriers.

## ACKNOWLEDGEMENTS

I would like to thank my Advisor, Dr. Armando Barragán for his support and for instilling confidence in me, to follow my instinct and truly believe I was capable of successfully completing the work I have done. I would like to thank my colleagues, the palliative care providers who enthusiastically welcomed this research project and believed in me. Thank you for sharing your experiences and for inspiring me to become a hospice and palliative care provider. Veronica, I want to thank you for believing in me, for supporting and for being my conscience and constantly checking in with me so I can meet all the deadlines. I would also like to acknowledge the patients and families I have heard and learned about. Their journeys have been a blessing and an inspiration to continue my calling and passion that is to serve all patients, especially the Spanish-speaking population.

## DEDICATION

I dedicate this research paper to my daughters Andrea and Fátima for being my drive and motivation. You inspire me to continue and to not give up despite the many sacrifices, limited time, sleepless nights, a pandemic, and many other obstacles. Because of you, I persevered. To my husband Rafael who never doubted I could do this. Thank you for being the rock I could lean on and for all the laughs when I needed them. My sisters Ana and Claudia, and Mike for believing in me and doing whatever it took to make it easier on me, from babysitting to reading my drafts and not letting me give up. To Delia and Dan, not only for providing excellent palliative care to Spanish-speaking patients and their families, advocating on their behalf but for being my inspiration, which ignited the desire and curiosity to investigate this topic even further. To all my friends, co-workers, colleagues within the palliative care team, my supervisor, Chris, and Jeannie for inspiring me to be a good researcher. Lori, thank you for helping me conceptualize, define this project and for your proofreading skills. I dedicate this work to my parents, Arturo and Esther. Papi y mami, les dedico este proyecto a Uds. porque sin su sacrificio de dejarlo todo para darnos un mejor futuro, yo no estaría aquí escribiendo esta dedicatoria. Gracias por sus sacrificios, por enseñarme que la familia es primero y que juntos se pueden vencer muchos obstáculos. Gracias por creer en mí y siempre apoyándome, por cuidar a mis hijas, por todo su amor. A Uds. les dedico este trabajo, lleno de lágrimas, esfuerzo, inspiración y mucho amor.

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## CHAPTER ONE

### INTRODUCTION

#### Problem Formulation

Research has demonstrated that the use of hospice and palliative care significantly improves the quality of life, symptoms, better utilization of health care resources, and increases the likelihood of dying at preferred location of patients suffering from life-threatening illnesses (Worster et al., 2018). The main goals of hospice are to ease suffering during End of Life (EOL) and allow the dying persons to live their lives to the fullest, reducing their suffering and maximizing their comfort during their transition between life and death (Teno et al., 2007). In their study, Kelley et al. (2013) listed a reduction of symptom distress, better caregiver outcomes and increase of patient and family satisfaction as some additional benefits of hospice enrollment.

Unfortunately, despite the added value and benefits of hospice enrollment, it is estimated that only 40% of eligible patients use hospice benefits (Cagle et al., 2016). Kreling et al. (2010) indicated that hospice knowledge is low in the general US population. Most people believe hospice is an institutional setting for EOL care and do not know about home services. Despite many desiring to die at home and free of pain, 60% of patients end up dying in the hospital (Mayeda & Ward, 2019).

Racial and ethnic disparities are observed at EOL care as well. Research has shown that minorities experience more significant barriers to quality of care, lack of access to affordable care, and lack of cultural sensitivity (McCleskey & Cain, 2019). The disparities are also observed at EOL care. Ethnic and cultural minorities are less likely than the Caucasian population to utilize hospice services (Kreling et al., 2010; Mayeda & Ward, 2019). In their study of racial disparities of hospice use, Orstein et al. (2020) found that in general, Black decedents receive more aggressive care and are less likely to use hospice services compared to White decedents.

Furthermore, Orstein et al. (2020) listed mistrust of the health care system, lack of in-home resources, and miscommunication and misunderstanding of treatment options as some of the reasons for these racial disparities. Mack et al. (2010) evaluated differences in patient-physician communication and how this difference contributed to further disparities in EOL care between Black patients and White patients. The study found that EOL discussions and communication goals with White patients seemed to result in less life prolonging EOL care, while Black patients did not experience the same. Many studies have indicated that palliative care and hospice care are underutilized among racial and ethnic minority groups, including African American, Hispanic, and Asian American patients (Worster et al., 2018). In their study, Periyakoil, Neri, and Kraemer (2015) noted that ethnic patients are more likely to agree to ineffective and burdensome high-intensity treatment at EOL,

less likely to utilize hospice care due to poor communication and lack of understanding about treatment options.

EOL discussions are often emotionally charged and difficult for both the patient and the physician or health care professional. Schenker et al. (2012) argued that attitudes towards EOL issues could vary with culture. Some concepts may not translate easily, adding more communication challenges when patient and clinician do not speak the same language. This only increases the disparities Latinos experience when accessing health care and suffering from irreversible illness or at the end of life.

Inequalities in the Latino population are also observed in EOL care and planning. Hong et al. (2017) described Advance Care Planning (ACP) as the health care decision process that involves learning, discussing, and planning treatments for the EOL in the event one is unable to make a reasoned decision. Furthermore, ACP contributes to the quality of care at EOL since it provides clear guidelines for health care professionals regarding patients' preference for EOL treatments while relieving family caregivers' burden for decision-making. Unfortunately, ACP engagement among ethnic minorities is lower both formally and informally when compared to Whites. Only 18% of ethnic minority participants completed advance directives compared to 34% of White respondents (Hong et al., 2017). Possible explanations for low ACP engagement among Latinos are the limited knowledge and inadequate comprehension of medical information and miscommunication related to ACP (Carrion et al., 2013).

Latino cultural values impact access and utilization of hospice care at EOL. For Latinos, when making EOL care decisions, the whole family decision is more important than the individual decision and holds indirect communication preferences (Kreling et al., 2010). In her study, Del Rio (2010) indicated that Latinos use a family-centered decision-making style when making EOL decisions, and Latinos are primarily unfamiliar with advance directives. In their study, Mayeda and Ward (2019) listed lack of health insurance, access to healthcare, suspicion of health care providers, and limited health literacy as barriers to access palliative and hospice care among the Latino population.

Silva et al. (2016) found that language barriers not only lead to misunderstandings between physicians and patients and unnecessary physical, emotional, and spiritual suffering, particularly at the EOL, but it also contributed to worse health care quality for limited English proficiency (LEP) patients. According to Nedjat-Haiem et al. (2018), Latinos have historically experienced barriers to optimal patient-provider communication. Mayeda and Ward (2019) concluded that the lack of effective communication caused by differences in language or culture is one of the barriers that affect palliative and hospice care's receptivity.

In their study, McCleskey and Cain (2019) stressed the importance of the Latino population selecting a provider with whom they share similar characteristics such as race/ethnicity, gender, or religious background. Mayeda and Ward (2019) added that attitudes and comfort levels toward EOL discussions

improved when provided by a trained staff member who uses the patient's preferred language. Their expertise and language skills can help clarify misunderstandings and misconceptions. Hospice translates or sounds very similar to *hospicio* in Spanish, meaning orphanage or place for poor people (Ko et al., 2020; Kreling et al., 2010; Periyakoil, Neri & Kreamer, 2015;). Patients or family members may interpret it as substandard or inadequate treatment (Ko et al., 2016), and it may explain the lower utilization of hospice by the Latino population.

#### Purpose of the Study

The purpose of this study is to examine the challenges the Latino population experiences when facing EOL decisions. More specifically, this study will look at the negative impact language barriers have on Latinos and the disadvantages Limited-English-Proficiency (LEP) patients have when facing EOL care decisions. Research has shown that decision-making and care at EOL among those with LEP differs substantially from the population that speaks English (Barwise et al., 2019). The underutilization of hospice services by the Latino population is very problematic and not fully understood. Racial and ethnic disparities have been noted in the research, but not thoroughly. Cultural and language barriers are primary reasons explaining the low utilization or access, or the lack thereof. Latinos, especially LEP Latinos, are at a disadvantage in accessing hospice care, thus decreasing their quality of care at EOL.

Social workers must be aware of the additional difficulties the Latino population experiences at EOL and advocate for this already marginalized population to access quality EOL care. Social workers play an essential role in facilitating patient and family conversations at EOL, bridging communication gaps, thus preventing misunderstandings and miscommunications (Del Rio, 2010). To study this matter, the researcher utilized an exploratory, qualitative approach. More specifically, the researcher conducted semi-structured interviews of hospice and palliative care providers to gain insight into their experiences, providing care to Spanish-speaking Latino patients and their families.

#### Significance of the Project for Social Work Practice

The implications of social work involvement in EOL care and access to health care are essential. Advocating for culture-sensitive services leads to better outcomes. Nedjat-Haiem et al. (2018) described how social workers are trained to work in an interdisciplinary environment and make sure patients receive culture-sensitive services. Social workers are part of the hospice and palliative care teams treating the patients, and their role may consist of being advocates, educators, or enablers. Social workers' core values of service and social justice drive advocacy for marginalized and under-served populations.

This study's findings will have a significant implication for social work practice on both the micro and macro level. At the micro-level, the results will help understand and clarify the concept of hospice and palliative care in patients. It will also ensure that health care workers understand the importance of being



culture-sensitive when providing EOL care to LEP patients. Furthermore, Del Rio (2010) describes how "Social Workers play a vital role in helping to bridge cultural divide by fostering a greater understanding of cultural differences in decision-making through providing education to Latino patients and families" (p.145). At the macro level, the potential findings from this study would help expand access to health care, increase quality EOL care, and increase the use of professional medical interpreters.

Kreling et al. (2010) recommended using education material tailored to Latino communication preferences, where families could choose translated English materials or the use of interpreters. LEP patients have difficulties understanding and speaking English, but they also face more challenges when interacting with the healthcare system. Thus, it is imperative to develop interventions for EOL care for LEP patients that are linguistically and culturally sensitive (Barwise et al., 2019). According to Norris et al. (2005), the use of professional interpreters in language discordant encounters improves the quality of care. Therefore, this project's research question is as follows: What challenges do providers in hospice and palliative care have in working with Spanish-speaking families?

## CHAPTER TWO

### LITERATURE REVIEW

#### Introduction

This chapter will emphasize the relevant research on the underutilization of hospice and palliative care in the Latino population and the language barriers they encounter when accessing EOL care services. This chapter is divided into four subsections. The first subsection will further define EOL care concepts, such as palliative care, hospice, and Advance Care Planning (ACP). The second subsection will identify the impact of cultural and language barriers Latino, and LEP patients face when making EOL care decisions. The third subsection will explore the use of professional interpreters as a possible solution to diminish language barriers. Finally, this section will include theoretical perspectives that guided this research.

#### Palliative Care, Hospice Care, and Advance Care Planning Definitions

The philosophy of hospice and palliative care may not be fully comprehended, or many times may be misinterpreted. The majority of patients and family members have little or no knowledge of hospice and palliative care, the scope of services, benefits, and limitations. According to Cagle et al. (2016), this lack of knowledge leads to misconceptions, lower acceptance rates, and ultimately low hospice enrollment. Therefore, it is crucial to educate and clarify all aspects of EOL care so patients can make better decisions and increase

patients' matching of preferences and goals. Stajduhar et al. (2019) explained that the purpose of palliative care is to improve quality of life and at the same time relieve any suffering patients with life-threatening illness may experience. Hospice care is a subset of palliative care for those with limited life expectancy who do not pursue curative therapy (Worster et al., 2018). Ko et al. (2020) further differentiate palliative care from hospice care by stating that both hospice care and palliative care provide symptom management to relieve suffering.

Furthermore, hospice care and palliative care both provide medical treatment for symptom management. The difference in enrolling in hospice care versus palliative is that patients in hospice will no longer receive life-prolonging or curative treatments. The lack of understanding and appreciation of palliative care and hospice care may lead to patients and caregivers' refusal of these services when recommended by health care professionals. Furthermore, the knowledge and the clear perception of hospice are crucial and necessary components of EOL decision making. Yet, many patients and family members do not fully understand the purpose of engaging in EOL care planning early enough in their disease trajectory.

The consequences are misinformation and negative attitudes towards hospice or palliative care (Cagle et al., 2016). The adverse effects of not accessing quality EOL care may increase burden and suffering not only to the patient but also to the family members. Stajduhar et al. (2019) explain that while barriers to palliative care exist for the normative population, barriers experienced

by structurally vulnerable people are likely amplified. These barriers can vary from accessing adequate health care to cultural and language barriers that expand the gap between those benefiting and receiving quality EOL care and those who are not. Barwise et al. (2019) argue that decision-making and care at EOL among LEP patients differs from the English-speaking population. This discrepancy can lead to adverse outcomes such as more extended hospital stays, higher readmission rates, and poor understanding of discharge instructions (Barwise et al., 2019).

#### Advance Care Planning Definition

Another aspect of EOL care is Advance Care Planning, or ACP. According to Brown et al. (2018), patients with lower educational attainment levels are less knowledgeable about advance care planning and less likely to engage in advance care planning or to receive palliative care and hospice services than more educated patients. Lack of knowledge regarding advance directives may be associated with low engagement in ACP. Although advance directives (ADs) are a routine in hospital admissions and help communicate patient preferences for care at the end of life, completion rates for adults are between 18 to 36% (Fisher et al., 2012). Barriers to complete ADs are also observed among ethnic minorities. These barriers may include language, lack of knowledge, poor communication, and misconception of not needing ADs if the family is involved in discussions (Fisher et al., 2012).

Low levels of health literacy are associated with preferences for aggressive care at EOL. ACP engagement plays such an essential role in empowering patients to make their wishes known and to creating an EOL plan. LEP patients do not embrace such concepts. Nedjat-Haiem et al. (2018) claimed that ACP does not occur in the medical setting and is missed in outpatient visits for the regular population. Moreover, this gap is amplified when it comes to minorities as this population may receive insufficient and inadequate information to address complex medical decisions due to the lack of cultural and linguistically appropriate patient-provider communication. Carrion et al. (2013) described the importance of meaningfully adapting the concept of ACP for individuals who immigrated to the USA from other countries. Their study found a relationship between the number of years living in the US and the US healthcare system's level of knowledge with the rate of advanced directives completed among Latina women. Hence the importance of being culturally sensitive and open to understanding EOL views in Latinos. Not only do providers need to take into consideration adopting interventions that are culturally sensitive but assess the patient's readiness level to engage in EOL conversations. Among Latinos, ACP is typically not part of their experience since culturally, Latinos do not engage in talking about the possibility of dying and discussing planning for death (Nedjat-Haiem et al., 2018).

#### Cultural and Language Barriers to Quality EOL Care

Many cultural and language barriers contribute to the inequalities the Latino population experiences during illness or at the EOL. More specifically, cultural differences among the Latino population and how they understand and approach disease, suffering, and dying. Maya & Rayeda (2019) identified a lack of effective communication by differences in language or culture as one of the top three main barriers faced by minorities in the health care system. Understanding the Latino community's cultural context is critical in trying to provide and improve the delivery of care at EOL. Del Rio (2010) emphasized the importance for medical providers to understand the Latino decision-making patterns since these often come into contradiction with the values of individualism, self-determination, and autonomy predominant in US culture.

The individualism desired and embraced by US culture contrasts with the family-centered approach displayed by Latinos in their everyday decision-making, including EOL decision-making. Del Rio (2010) further explained that family supersedes that of the individual and defines *Familismo* as emphasizing family loyalty and cohesion. Consequently, this may impact time-sensitive medical decisions due to the delay to allow consultation with the extended family when it comes to EOL decisions. In addition, the family may dismiss the need for ADs because they feel they're irrelevant as long as a patient's family is involved in medical decision making.

An awareness of the Latino family structure is another important aspect when trying to understand Latinos' decision-making process. According to Del

Rio (2010), Latino family structure is traditionally patriarchal and with defined gender roles. This is very important to take into consideration when communicating with Latino families and trying to engage in EOL discussions. Besides, Del Rio (2010) identified another strong value in Latino culture: *Filial duty*. Filial duty considers putting other family members' needs first and puts an obligation to share responsibilities for providing support to the extended family. Being aware of this cultural perspective may help health care professionals understand Latinos' way of thinking and provide improved and tailored care.

Another significant value in Latino culture that describes and influences social interaction is respect. Latinos behave towards others based on a person's authority, age, gender, or economic status. Health care professionals are viewed as authority figures and are shown respect (Del Rio, 2010). Latinos are taught to listen and obey authority figures. These paternalistic views may be reflected in the expectation of physicians making decisions for Latino patients as the opinion of the medical professionals is highly valued and mostly never questioned. Latinos tend to respect their healthcare providers' decisions over their own (Nedjat-Haiem et al., 2018).

Language barriers increase the gap of equal access to the Latino population, in particular, LEP patients. More specifically, communication barriers due to language discordance between patient and clinicians. EOL discussions are already difficult for both the patient and the provider. If a language barrier is added, now these discussions can quickly become more problematic.

Communication between LEP patients and health care professionals is more difficult with negative consequences such as misunderstandings due to interpretation errors, less interaction between patient and provider, and leaving patients less likely to ask questions or make comments or even worse, having their comments ignored (Norris et al., 2005). This lack of understanding may also lead to less patient satisfaction, thus decreasing the physician's trusting relationship.

According to Van Scoy et al. (2017) “when patients and their families discuss their values and beliefs about EOL care, patients are more likely to receive care consistent with their preferences, and satisfaction with that care is improved for both patients and their families” (p.909). Language barriers and communication preferences play an important role in understanding Latino cultural decision making, including EOL decision-making. Kreling et al. (2010) pointed out some cultural preferences among Latinos and their choices of not talking directly about EOL, may be out of a desire to shield and protect the patient, by not sharing information out of caution and to avoid suffering. This indirect communication style clashes very often with the health care professional's desire or ethical obligation to inform the patient and respect transparency and autonomy.

Professional interpreters are not only necessary but recommended to bridge the gap of inequality in accessing health care services. Barwise et al. (2019) argues that “although the use of interpreters to navigate the healthcare



system is mandated for patients with LEP, interpreters are frequently not used, and family members serve as interpreters, further complicating challenging discussions” (p.861). It is very challenging for health care providers to not fall into the practice of not utilizing professional interpreters. Research has proven the benefits of using professional medical interpreters: reducing errors in message delivery, improve patient understanding and comprehension, and improve clinical outcomes and patient satisfaction (Silva et al., 2106).

Health care professionals must be reminded of these benefits and refrain from using family members as interpreters to avoid further miscommunication. Doing so will aid in the communication between the patient and the provider. It will also increase patients' likelihood of being open and genuinely adhere to medical indications or further discuss their preferences. Interpreters facilitate delivering appropriate, compassionate, and supportive communication for LEP (Silva et al., 2016). The outcome of this understanding and supportive communication will also assist in navigating difficult or challenging conversations as those expected during EOL discussions.

Communication with the Latino population may lose meaning through interpreting, as well as in translations. Nedjat-Haiem et al. (2018) noted that an AD document might be translated into Spanish at the same literacy level as the English version, which uses advanced medical language. Therefore, the Spanish version is translated beyond the level of comprehension for some Latinos.

Barwise et al. (2019) recommended a 5<sup>th</sup>-grade reading level is for patients with low health literacy.

### Theories Guiding Conceptualization

Social identity theory is a theoretical framework that guided this research in understanding or explaining how Latino social identity impacts their decisions regarding decision-making at EOL. This framework may help the researcher understand the importance of the family in the Latino identity and how important family is when making decisions collectively, instead of the individualistic approach the non-Latino population might take when making decisions at EOL. A positive social identity for the Latino is of high importance. Social identity theory stipulates that people think of themselves and others as group members rather than as unique individuals in many social situations. The theory also argues that social identity supports intergroup behavior and sees this as qualitatively distinct from interpersonal behavior. This theory has been applied to understand problems in group dynamics and intergroup relations (Ellemers & Haslam, 2012).

Limited English proficient (LEP) patients are at a disadvantage when accessing health care. Effective communication is crucial when providing advance care planning or having family meetings and discussing poor prognosis. The lack of bicultural or bilingual health care providers negatively impacts the Latino population in understanding the benefits of hospice or palliative care during their illness or disease trajectory. Effective communication must be critical. Therefore, communication-related theories might be beneficial in guiding this

research as well. One specific communication theory applicable in this study will be Communication Accommodation Theory (CAT). CAT looks at the patient-provider interaction. This interaction might be even more complicated due to language barriers and the patients' limited English proficiency. EOL decisions are very complex, and if we add the language barrier, the communication between patient and provider negatively suffers. The use of professional medical interpreters aids in reducing this impact. According to Jones et al. (2018) in CAT, interpersonal interactions are based on social identities of the interactants. Therefore, communication becomes influenced by the 'group' memberships that are relevant for each participant.

### Summary

This section discussed some of the factors that may explain the underutilization of palliative care and hospice care among the Latino population. Language and cultural barriers were the main issues cited as explaining the low utilization. Spanish-speaking patients and LEP patients in general are already disadvantaged in accessing health care. Disparities are seen as well when Latinos are making EOL care decisions. Providers of Hospice and Palliative Care are faced with obstacles in providing care in a sensitive way. This study seeks to further understand those challenges providers experience when caring for Spanish-speaking patients and their families.

## CHAPTER THREE

### METHODS

#### Introduction

This study seeks to identify barriers the Latino population faces when accessing and utilizing hospice care and EOL decisions. This chapter is divided into six sections explaining how the study was executed. The sections discussed below are study design, sampling, data collection and instruments, procedures, protection of human subjects, and data analysis.

#### Study Design

The focus of this research project was to understand the underutilization of hospice care services in the Latino community. An exploratory, qualitative approach allowed the researcher to uncover themes or patterns in conversations about Latinos' conversations about hospice care utilization. More specifically, the interview method helped gain a deeper understanding, and gather additional information palliative care team members observe when meeting with families referred to hospice and palliative care services. The researcher conducted semi-structured, one-on-one interviews, face-to-face via Zoom of an interdisciplinary in-patient hospital palliative care team utilizing open-ended questions to collect data.

The interview method allowed participants to share information with greater depth and richness, including context. The interviewer also clarified questions for the interviewees and gathered more insight by probing information

from participants. Non-verbal gestures provided additional information, as well. Finally, the interview also allowed the researcher to collect relevant and unanticipated data. The interview method also enabled participants to share their thoughts and views on the topic of barriers the Latino population experienced when presented with the option to enroll in hospice care.

A few limitations of using the interview method are that they are time-consuming, the limited number of respondents, potential invasiveness with personal questions, and the participant's social-desirability bias. Another significant limitation of using a qualitative design includes having a smaller sample size. Thus, the results may not be generalizable to the entire Latino population.

### Sampling

The sampling technique used for this research study was a non-probability sampling. More specifically, purposive sampling was used. Purposive sampling is a popular method used by researchers since it is extremely time and cost-effective when compared to other sampling methods. The sample was selected from a population conveniently available to the researcher: the in-patient palliative care team at a university hospital. The researcher invited team members to participate in an interview. The researcher recruited 10 participants amongst the palliative care team.

### Data Collection and Instruments

Qualitative data was collected via Zoom, audio-recorded, one-on-one semi-structured interviews between April 2021 and August 2021. For each interview, participants were given the purpose of the study, description, and an informed consent. Demographic information was collected before starting the interview. Demographic information included age, gender, ethnicity, and years of experience.

The researcher created an 8-question instrument to explore palliative care team members' experiences with LEP Latino patients and families making EOL care decisions, the use of professional interpreters, family members as interpreters, family dynamics, the use of written hospice and palliative care materials, cultural sensitivity training and ideas on eliminating barriers within the Latino population.

### Procedures

The researcher attended the monthly palliative care team meeting and invited team members to participate in the researcher's study. The researcher explained the purpose of the research and solicited participation. The researcher explained that participation in the study is voluntary and participants can decline to participate at any point. The researcher scheduled interviews to accommodate the participant's limited availability. The researcher addressed informed consent, confidentiality and reminded participants of the purpose of the study. Each interview lasted between 35 - 55 minutes. The interviews were conducted via Zoom. Before collecting demographic information, confidentiality was explained.

Also, participants were given an informed consent for their participation and verbal consent for recording the interview. Once demographic information was collected, the interview started, and the researcher started recording the zoom meeting. After the interview, the researcher thanked the participant for their participation.

### Protection of Human Subjects

To safeguard participants' confidentiality, the researcher assigned a code number to participants and avoided including any identifying information in transcription of the interview. Interviews were conducted in a private space to maintain the confidentiality of information shared by respondents. Interviews were recorded via Zoom and stored on google drive through the CSUSB student account. After interviews took place, they were transcribed and stored with assigned code. Researcher was the only person transcribing the interviews. No data will be presented in a format that allows for the identification of any participant. Data will be presented without any identifiers. Data will be destroyed by erasing it three years after the project ends.

### Data Analysis

This study utilized thematic analysis techniques. The interviews were recorded digitally via zoom. Then, interviews were transcribed manually. The researcher transcribed all the words spoken by participants, including the nonverbal interactions, such as pauses or other nonverbal expressions. To keep and maintain participants' confidentiality, the researcher will be the only one

transcribing and coding the interviews. Also, to safeguard the confidentiality of participants, no identifying information was used.

The transcriptions were typed in a standard word document, leaving a right margin of 4 inches so notes, codes, and line numbering could be incorporated. According to Grinnell and Unrau (2018), codes can be strings of letters, numbers, or symbols that will help identify text data throughout the transcribed text. The next step was to conduct first-level coding. In this step, data segments or meaning units were identified. The researcher kept in mind throughout the data analysis the research interest: the language barriers Latino population experience when accessing palliative and hospice services. Once meaning units, having similar characteristics were identified, those units were put under one category. Categories and their respective codes were defined. At this point, assigned codes to categories were identified. First-level coding stopped when no more new categories were obtained. Once the first-level coding was done, second-level coding proceeded. In this step, the researcher compared categories and see if there are themes and patterns. Once themes were identified, those themes were also coded. By doing so, the researcher was able to start establishing relationships to develop any conclusions.

### Summary

This study explored Palliative Care Team members' insight on their experiences working and providing care to LEP Latino patients and their families when they are making EOL decisions such as whether or not to enroll in hospice



care. The one-on-one semi-structured interviews allowed Palliative Care Team members to share their perspectives and thoughts of the underutilization of hospice care by the Latino population. Their experiences contributed to understanding the barriers this population experiences. A qualitative approach for this study facilitated the process in the most effective way; it allowed for the Palliative Care Team members to freely express their opinions and capture their insights when providing care to Spanish-speaking patients and families.

## CHAPTER FOUR

### RESULTS

#### Introduction

Chapter four discusses data analysis and data thematic results. For the purpose of this research, an Interdisciplinary Palliative Care Team was interviewed and used as the sole data source. The team was easily accessible to this researcher, so a purposive sampling was utilized. Themes were obtained from the answers for each question that the participants were asked.

#### Analyses

The team included physicians, nurses, social workers, and chaplains. The researcher wanted to capture the experiences of the various disciplines within the team. This sampling yielded ten participants: two male and eight female, years of experience between two years to 15 years and ranged in age from 34 to 62. The racial demographics are as followed: six identified as Caucasian, one as Asian, one as Persian, one Latina and one as multiracial.

#### Data Thematic Results Part I

The research question was: What challenges do providers in hospice and palliative care have in working with Spanish-speaking families? The study utilized a qualitative approach, more specifically used semi-structured one-on-one audio-recorded interviews, which resulted in pages of data. The data collected from these interviews was analyzed for concepts and categories which resulted in themes illustrated with quotes drawn from participants' responses. Five general

themes were observed: interpretation, utilization of written materials, misconception of word hospice, lack of cultural sensitivity training and religious factors. In addition, for more themes were discovered on ideas to eliminate barriers provided by participants.

### Interpretation

The primary finding of this study is that the participants interviewed identified interpretation as a major challenge when providing care to Spanish-speaking patients and families. The first barrier was access to high-quality in-person interpreters. Even before the pandemic, participants shared that they struggled with consistent practice of using a professional interpreter by the treating teams and other health care professionals:

*It's about convenience and time; we don't have time to get an interpreter.*

Limited time and convenience were noted to be a key factor for the limited use of an interpreter with LEP patients. In many instances, for example, health care professionals made assumptions and thought the patient understood the conversation, when in fact they don't:

*I asked why wasn't an interpreter used? Well, we thought he could understand because we asked, and he nodded yes.*

The challenges continued as in-person interpreters were not always used. Phone and video interpretation did not enhance the communication, and actually created more of a barrier. Respondents shared how the nuances of language

and many nonverbal cues do not translate well and the meaning of words were not conveyed correctly:

*When we're able to do it with an in-person interpreter or in the native language, I feel like we're able to do so much more in terms of developing trust and make recommendations about Hospice and get more engagement.*

Another respondent pointed:

*There isn't a filter for the nonverbal communication, the sort of other aspects of communication that are more, that don't really withstand interpretation, like humor, warmth, trust, displays of emotion on the part of the provider.*

With the pandemic, the ability of having the preferred in-person interpreter was very seldom. And the only option was to use phone or video interpreters. The quality of interpretations suffered due to external factors:

*It's hard for a patient who's like, on high flow oxygen, and there's noise going on and they can't talk even if we put a phone on their face.*

Another barrier with interpretation was the actual quality of the interpreter and respondents shared instances where the family members correct the interpreter and saying: “*that's not quite what I meant.*” Spanish-speaking patients come from such a variety of different countries that it adds to the complexity, as one responded pointed:

*There are different types of Spanish, you know it's regional.*

A very common theme mentioned was the strategies used when family members acted as interpreters or when a patient refused to use an interpreter. A recurrent theme in the interviews was the approach utilized by respondents to respond when patients refused interpretation or insisted on having their family members interpret. The overall consensus was if the conversation did not require complex goals of care or end of life discussions, respondents did not oppose to have families interpret:

*If we're doing just a symptom assessment, or just to check in, then I won't push that or fight that and I'll let the family interpret, as long as the family is OK with interpreting.*

Conversely, when a conversation will likely be emotionally charged or contain difficult end of life care decisions, using a professional interpreter is encouraged:

*For any conversation that's kind of, I would say out of scope, more about hospice and end of life care, and trying to really understand wishes, and preferences and values, we then use an interpreter.*

Family members are encouraged to take on the role of family member, not the interpreter:

*We want you to know that you have the right to have an interpreter, but also, I think it's really important to mention that we want you to just be acting as the daughter, not as an interpreter because that's a lot on you. We encourage you to use our interpreters so that you could be here for your father as a daughter. And right now, when you have to be both, it's*

*more difficult.*

One respondent added:

*We emphasize that we want them to be present and support the patient as opposed to having to take on this kind of job or task.*

### Use of written materials

The use of written materials describing palliative and hospice care services was a divided topic among the respondents. For some, they felt that the materials were helpful in explaining to families the concepts of palliative care and hospice care and perhaps prepare the families for the conversation. For others, they did not like the materials or did not have anything to say as they had not used them at all.

For those who found the written materials helpful, they felt the written materials were helpful when accompanied by the explanation of a provider. Respondents felt that the written materials helped answer questions to more timid patients, and patients who are visual learners:

*I think that having unbiased resources available is really important and especially if it can speak to some of the particular concerns or issues or just the normalization of it. So, having these materials, having the resource or something to look at would be very helpful.*

Those respondents that found written materials helpful, expressed the wish of having written materials readily available and wished the documents were available in other languages.

On the contrary, the arguments against the use of written materials:

*What has a larger impact are the conversations; the one-on-one conversations that involve the trust, the rapport, knowing that they may not be accepting of hospice or palliative care in one conversation and it may take more.*

One respondent pointed:

*I don't feel like that gets better with a brochure or literature. It gets better when there's a specific provider who's phrasing things in a way that helps to know that they're not being abandoned by their providers, that they are having their goals met, time at home with symptom control.*

The rest of the respondents declined in commenting if using written materials, like brochures or pamphlets aid in destigmatizing the concept of hospice. Some respondents shared they had never used or provided written materials so they couldn't comment.

#### Misconception of the word hospice

According to the research participants, one of the biggest challenges they encounter with patients and families is the misconceptions and myths around the meaning of the word hospice. Even with English-speaking patients and families, as soon as they hear the word hospice, they think immediate death and no more hope. The word has the stigma associated of a place where you go to die. In addition, some family members may be very reluctant to accept hospice because they might have heard from someone else or they themselves might have faced

an unpleasant experience with hospice providers. Furthermore, many patients and family members have the misconception that they're not going to receive the care they need if they agree to hospice. Or they have a completely wrong idea of what hospice does:

*In some cases, they may think that patients will be shoved in a corner to die, that they are given drugs to make them die which is not what we do, any medications that we give are strictly based on treating symptoms, you know, pain and symptom control.*

Many respondents alluded to the misconception many Spanish-speaking patients and families have of the meaning they associate with the word hospice. The word hospice does not translate, but it's often translated as "hospicio" and this word has a different meaning in Spanish:

*There's often a sense of it being this place that people go where they're sort of abandoned to just die and so it has a very negative connotation in that sense where you're giving up and just sort of neglecting the patient.*

Another example noted by another respondent:

*I learned that hospice was often translated to "hospicio" by other providers and that that was actually a sanitarium where someone would go like for mental illness so I learned to described it as not a place or a building where you go die, I tried to combat the negative connotation.*

Lack of cultural sensitivity training



The question about the kind of cultural sensitivity training the respondents had received was surprising. The lack of such formal training was telling. The majority shared that they did not have much formal training, but they sought out lectures on their own, out of their own interest. Participants emphasized that such training may have been provided in a more general way during their undergraduate education, medical school, or residency training. All respondents agreed that the training they have received is because they actively sought it out and it was more informal. They valued such training and admit it has assisted in providing the care they give to patients:

*I'm interested in classes related to culture and marginalized populations. I really do stuff on my own. I seek out lectures on cultural sensitivity, or I might read articles.*

One respondent shared that difficult conversations with families was not a priority during training, and they received no formal education on how to have culturally appropriate conversations:

*I did not see a lot of demonstration of how to have a culturally sensitive conversation in residency. It wasn't until fellowship in palliative care until I started to have more lectures on how to do these discussions in a culturally sensitive way.*

The trainings received were described as online modules, lectures, grand rounds, symposiums, or tracks at national conferences. A few mentioned having

been exposed to Spanish-speaking communities in their fellowship and training, through travel and studying abroad:

*I took a Spanish course that touched on, not only on the language, but also, the how phrasing and words and understanding kind of the within cultural setting, how some things are different so it's not just a direct translation but understanding the context.*

A respondent specifically shared the importance of understanding cultural aspects, specifically working with Spanish-speaking families:

*Working with Latino families, I was introduced to the concepts of like simpatía, familismo and machismo. The day that someone introduced me to what the real definition of macho, blew my mind.*

Another respondent shared the value of having attended a lecture on how to properly work with interpreters:

*I was talking earlier about the interpreter class that was a very hands-on, logistical one, but very helpful because we work with interpreters all the time. And it was presented by an actual interpreter. I think that most people do not have that training, I mean, they don't know how to work with interpreters.*

### Religious aspects

Another recurring theme in the interviews was the religion factor influencing decisions for many Spanish-speaking patients and their families. Sometimes these religious aspects came up as challenges or barriers as

respondents worked to care for Latino families. Religion can become a challenge for families when presented with the idea of hospice.

*There are not only culture and family dynamics, but there are also faith-based belief system challenges. There is some perception in some families that Catholicism stands in the way of withdrawal of life-prolonging and futile care.*

The question directed to research participants was broader and inquired about family dynamics, but the religious theme was very recurrent in their answers. Many expressed that for families that are very religious, if they don't continue with the current plan of aggressive curative care, they may be interfering in God's plan and not allowing God the opportunity of a miracle.

The miracle theme was a constant when the topic of religion was discussed:

*The religious aspect which often comes up and this desire for a miracle and often the sentiment that I get is that we can't stop treatments or can't stop certain types of aggressive care that would way in the way of a miracle occurring, we think the miracle is gonna happen so we can't stop treating them even if they're very close to the end of their lives.*

Unfortunately, sometimes the use of miracle language is not understood by the medical treating teams and is not dealt with in the most sensitive way. A few of the respondents engaged families who were seen as unrealistic or oppositional. Some patients and families felt that hospice was pushed onto them,

leaving them with feelings of abandonment and hopeless and pressure to sign up for hospice services. One respondent added:

*The way we often approach this is by saying we do hope for a miracle. The miracle may come in many forms. We may say miracles might come as physical healing, may come as spiritual healing or may come as making it to a special day.*

Palliative care practitioners agree that it is beneficial to be aligned, rather than oppositional when it comes to engaging the miracle aspect. Respondents in this study shared how they use the same language, the miracle and religious language, to come together with patients and families. They try to understand where they're coming from and mirror their language and avoid being oppositional.

## Data Thematic Results Part II

### Bilingual providers

When respondents were asked to share their ideas about how to increase access and utilization of hospice and palliative care services, they unanimously stated they needed more bilingual providers. They all realized the importance of having such delicate end of life care discussions in their native language.

Interpretation helps, but it is not the same:

*We will do the entire conversation in Spanish because we find that when we're able to engage with our Latino patients in their native language, then*

*we are able to get much more in depth, in terms of discussing goals of care and planning ahead for the future.*

The ideas of having bilingual providers include having nurses and hospice providers and liaisons. If patients and families receive the information about hospice and what it entails in their own language, and even by someone who looks like them, they might be more inclined to accept the services, to trust those speaking with them:

*I think that there's a sense of trust that can develop between a patient and the provider if they speak the same language. I think it's very valuable for people to trust, to build rapport, to have or to see people like them and to have that sense of familiarity.*

The next best thing would be to expand the in-person interpreter services for all planned goals of care conversations and family meetings:

*Making it easier for the team to speak with their patients with interpreter services so instead of one interpreter on the floor, have three interpreters on the floor. If the patient speaks so silently or can't hear well, use the pocket talkers that amplify the voice.*

#### Community/Religious leaders in outreach and education

Outreach to the community appeared as a recurrent theme when participants provided ideas to eliminate the barriers the Latino population faces when trying to access palliative and hospice care. Almost all respondents agree with the importance of community and church leaders in increasing awareness

and understanding and accepting hospice and palliative care. Moreover, they expressed how crucial it is to normalize hospice discussions in the community:

*Involving community leaders and getting them on board to help understand and demystify death, making death not so scary. The Hispanic population has a really close-knit community, and they have leaders within that community, the father or the pastor. And if they're the ones giving the message to the patients. If you have their buy in, you can normalize hospice, that death is part of life. Then you'll have a lot of people on board.*

Community outreach and education was constantly referred as ways to combat barriers that exist within the Latino community. In addition, it was suggested that this education and outreach is provided by Latino leaders so they can be trusted and easily accepted.

#### Identifying key family members

A key suggestion given in trying to eliminate barriers was the identification of key family members, who may be very oppositional and may not be accepting of their loved one going on hospice. The point of identifying this key family member is to provide further education and clarify any misconceptions. Family is very important within Latino population and is well known that Latino families make decisions as a family:

*There's always one avoidant family member who is having a hard time and doesn't want to have the conversation about mom or grandma dying.*

*So often times, it's about finding that one person that's having all the difficulty and reaching out to them if they're open to it and being able to talk directly to them and include them.*

Family is very important for Latino patients, and it is key to understanding how they make decisions and how they influence one another:

*Latinos, as a whole, are family-oriented and make decisions collectively.*

### Early interventions

Early palliative care consults that introduce palliative care and hospice care to patients are some of the early interventions that respondents felt would assist in eliminating access barriers for Latino patients and families. Early interventions also may increase the normalization of the concepts of hospice and palliative care. It starts by introducing them in routine appointments, with specialists when seeking treatment. The point is to treat this information as a tool and describing them as resources available to patients:

*Opening up that dialogue earlier by normalizing these concepts, introducing them like any other interventions. Information does not negate still pursuing treatment. When someone receives a new diagnosis is saying well part of the package is palliative care and having meet palliative care early and normalize it.*

Early interventions and education are key to helping patients and families plan for their future. Demystifying and normalizing palliative care and hospice care would be a great benefit to patients and families.

## Summary

The results of the thematic analyses showed that there are challenges that Palliative Care Team members encounter when providing care to Spanish-speaking patients and families. The thematic findings were divided in two parts: part one where barriers were described and part two where solutions to these barriers were discussed. The main themes uncovered were interpretation barriers, positive and negative attitudes toward the use of written hospice and palliative care materials, the implications of the misconception of the word hospice, the impact of religious factors in accepting hospice services and the lack of cultural sensitivity training. The major themes uncovered regarding ideas to overcome the barriers were: increase of bilingual providers, community/religious leaders involved in outreach and education, identifying key family members, and early interventions.



## CHAPTER FIVE:

### DISCUSSION

#### Introduction

This chapter will provide a discussion of the findings and a further analysis of the results. In the discussion section, the results will be contrasted with the current literature review. There will be a section that will address the recommendations for Social Work Practice, Policy and Research. At the end, a limitations section will discuss the limitations within this study. The conclusion section will summarize the work done in this study, the findings, and directions for future research and how it impacts social work practice.

#### Discussion

The purpose of this study was to examine the barriers Latinos have accessing palliative and hospice care. More specifically, this study looked at the challenges palliative care providers encounter when providing care to Spanish-speaking patients when they are introduced to hospice care. The results of this study indicated that there are language and cultural barriers that Spanish-speaking patients and their families experience when making decisions about EOL care, and impact whether or not a patient accepts or declines hospice and palliative care services. This finding is consistent with the study by Maya & Rayeda (2019) in which they identified differences in language and culture as one of the main barriers faced by minorities. This study revealed that although interpreters are an excellent tool to assist in EOL conversations with LEP

patients, the use of interpreters is not consistent. Furthermore, the study revealed quality of care of interpretation, external factors such as technology hiccups and the use of family members as interpreters as challenges that providers experience. Using family members as interpreters instead of professional interpreters is a practice that goes against the recommendation by Barwise et al. (2019) of avoiding having family as interpreters. Participants in the study acknowledged that they offer the use of professional interpreters and when patients decline, their strategy is to remind the family member to be a family member and not to take on the task of an interpreter. If patients and families insist, providers manage the situation in a sensitive way as to not sound oppositional and will many times have the interpreter on standby. The study also revealed new insights when having interpreter services. The quality of the interpreter is key to have a meaningful patient interaction and unfortunately, using phone or video interpreters instead of in-person interpreters does not aid in the communication. In-person interpreting was found to be the best thing next to having bilingual providers. The positive aspect of having in-person interpreter is that patients may engage and open up more. The interpreter may be able to capture nonverbal cues and interpret with more accuracy. This coincides with Silva et al. findings (2016) of medical interpreters assisting in message delivery and ensuring there is appropriate, compassionate and supportive communication. Palliative care providers described how the majority of the patient visits go better when they have an in-person interpreter readily available.

According to McCleskey and Cain (2019) and Mayeda and Ward (2019), the Latino population responds better when their provider shares similar characteristics, such as race/ethnicity, and more importantly patients feel more comfortable when their preferred language is used. This was confirmed when the participants shared how, in their interactions with patients and families, patients opened up more and had better EOL discussions with better outcomes.

The study also revealed and agreed with studies that discussed and found the word hospice to be problematic or having a negative connotation. Ko et al., Kreling et al., (2010), and Periyakoil et al (2015) discuss how Spanish-speaking patients negatively react when they hear the word hospice and equate it to abandoning their loved ones to die. In addition, Schenker et al. (2012) argued that attitudes towards EOL issues could vary with culture and some concepts may not translate easily. The word hospice has been erroneously translated to the word *hospicio*, which means orphanage or a place for poor people. The study revealed that palliative care providers are well aware of the negative connotation, they refrain from translating hospice as *hospicio*, and they will make the effort to clarify that they are not talking about a place where their loved ones are going to be taken. Most importantly, palliative care providers will emphasize the true meaning of hospice as a service that can be given to the patient at home or a nursing facility. In addition, the study found that many patients and families believe that enrolling or accepting hospice means to give up hope. This illustrates the lack of education and the myths around hospice. Mayeda and Ward (2019)

emphasize the importance of clarifying misunderstanding and misconceptions around hospice. This study coincides with that and reveals how providers try to eliminate false information or preconceived ideas about hospice by first inquiring with patients what they know or heard about hospice and offer more education and clarification.

The new insights that this study revealed was how little training on cultural sensitivity healthcare providers receive. Furthermore, the training seems to be offered early in their training or the content is very broad. Participants actually seek out training opportunities on their own. This was not found in the literature review. Another insight was the religious aspect as a barrier for the patient or family members accepting or declining hospice services. The study revealed that religion is a key factor in influencing Latino families when making EOL care decisions. Del Rio (2010) discusses cultural aspects of Latinos decision making, *Familismo*, filial duty and respect as highly influential in medical decision-making, but religion was not included. In this research, the religious component influenced the view that patients had in respect to not wanting to intervene in God's plan for a miracle. Patients and families expressed that the reasons they could not consider hospice was because it meant not only giving up, but for blocking a miracle. Involving community and religious leaders was the solution proposed by many participants of the study. They felt that by having the buy-in of the religious leader, hospice and palliative care philosophy could be better received by patients, families and the community at large.

## Recommendations for Social Work Practice, Policy, and Research

### Social Work Practice

Although there is data indicating the barriers LEP and Spanish-speaking- only patients encounter when accessing health care, the racial disparities experienced by this population are evident. The language and cultural barriers increase the already complex EOL care decision making. The social work value of social justice heavily influences the social workers practice when providing services to this marginalized population. The Social Worker role is key to ensure these barriers are first recognized then work with patients and other health care professionals to eliminate them or at least try to minimize them. Social workers play an important role of advocating for the best outcome possible for patients and families. Social workers ensure that interpreting services are utilized and follow best practices when using interpreters. Social workers also play an important role in educating patient and families about palliative care and hospice services, clarifying misconceptions. Social workers provide culturally appropriate services. In addition, social workers collaborate with the other members of the interdisciplinary team and other disciplines to create a care plan that is culturally sensitive to the patient and family. In sum, social workers support patients and family members in difficult situations when making healthcare decisions, and most importantly empower patients and their family members to make decisions that align with their goals and values. By doing so, social workers are ensuring

the self-determination of the patient with providing appropriate information so they make informed decisions.

### Policy

At the macro level, social workers can make sure that there are policies well established and inclusive of LEP patients to ensure patients have access to affordable care. Furthermore, social workers can assist in eliminating barriers at the policy level by ensuring that there are policies that guarantee the appropriate use of interpreters. Education and outreach to the community, including religious or church leaders are within the scope of the social workers. Community education is a key component in trying to eliminate misconceptions and fears around death, dying, hospice and palliative care. If education and outreach increase within the community, then the normalization of words such as hospice can be accomplished.

### Research

Future research in this topic is necessary. It would be interesting to interview hospice providers and gain insight from their perspective, their view on the barriers they encounter as they meet patients and try to introduce the concept of hospice. Another direction for future research would be to interview patients and their families, to gain more insights about the services. In addition, interviewing church leaders and community leaders to help identify areas of confusion around the definitions of hospice and palliative care. Finally, a study with interpreters to see what barriers they perceive. At the macro level, it would

be interesting to look at the effectiveness of policies that mandate the use of professional interpreters.

### Limitations

Limitations of this study include the very small sample of 10 palliative care providers. The participants were part of an inpatient palliative care team. The sampling method used a purposive sample, as the team was conveniently available to the researcher. Therefore, the results may not be very representative as no random sampling was used and the size of the sample was very small. Secondly, there were multiple disciplines: physicians, nurses, chaplains and social workers. A characteristic of a palliative care team is that it is composed of interdisciplinary teams, so the study had perspectives of various disciplines. Thirdly, the study did not include the interpreters, a key health care professional involved and present in many EOL discussions and encounters the palliative care team had with patients and families. The perspective of the interpreters was not included. Finally, the study did not include interviewing patients or family members. The study was not able to get feedback or hear about the experiences of the patients or families when they learned about hospice and how they made healthcare decisions.

### Conclusion

This study discussed how the findings from this research are related to previous studies and demonstrates that Spanish-speaking patients and their families do encounter language and cultural barriers when making EOL care

decisions thus underutilizing palliative and hospice care. Although interpreting service is available to LEP patients, it is not frequently used and there are challenges with using interpreters. Spanish-speaking patients have misconceptions about the word hospice, equating with death, giving up hope and abandoning their loved one. Religion is an important factor influencing EOL care decisions. Even though the study revealed lack of cultural sensitivity training, new insights were revealed as well: strategies to reduce barriers were shared such as increase of bilingual providers and outreach to community and church leaders. Spanish-speaking patients and their families have unique needs and face language and cultural barriers. Social workers not only provide therapeutic interventions when these patients receive a poor prognosis or new diagnosis, social workers fight for social justice and inclusion. Through education, community education and collaborations, language barriers can be reduced.



APPENDIX A  
INFORMED CONSENT

**INFORMED CONSENT**

The study in which you are asked to participate is designed to examine understand the underutilization and challenging accessing hospice care services in the Latino community. The study is being conducted by Diana Ramirez, a graduate student, under the supervision of Dr. Armando Barragán, Assistant Professor in the School of Social Work at California State University, San Bernardino (CSUSB). The study has been approved by the Institutional Review Board at CSUSB.

**PURPOSE:** The purpose of the study is to examine the language barriers Latinos have accessing utilizing palliative care and hospice services.

**DESCRIPTION:** Participants will be asked to participate in an interview to share their experiences when providing care to Spanish-speaking patients and their families and share additional information observed when meeting with families referred to hospice and palliative care services.

**PARTICIPATION:** Your participation in the study is totally voluntary. You can refuse to participate in the study or discontinue your participation at any time without any consequences.

**CONFIDENTIALITY:** Your responses will remain confidential and data will be reported in group form only.

**DURATION:** It will take up to 40 to 60 minutes to complete the interview.

**RISKS:** Although not anticipated, there may be some discomfort in answering some of the questions. You are not required to answer and can skip the question or end your participation.

**BENEFITS:** There will not be any direct benefits to the participants.

**CONTACT:** If you have any questions about this study, please feel free to contact Dr. Barragán at [abarragan@csusb.edu](mailto:abarragan@csusb.edu).

**RESULTS:** Results of the study can be obtained from the Pfau Library ScholarWorks database (<http://scholarworks.lib.csusb.edu/>) at California State University, San Bernardino after July 2022.

\*\*\*\*\*

I agree to have this interview be audio recorded: \_\_\_\_\_ YES \_\_\_\_\_ NO

I understand that I must be 18 years of age or older to participate in your study, have read and understand the consent document and agree to participate in your study.

\_\_\_\_\_ Date

Place an X mark here

APPENDIX B  
DATA COLLECTION INSTRUMENTS  
DEVELOPED BY DIANA RAMIREZ

### **Demographic Questionnaire**

1. What is your age?
2. What is your gender?
3. What is your ethnicity?
4. Years of Experience working with Palliative and Hospice Care Patients

### **Questions during Interview**

5. Can you please share your experiences with Spanish-speaking families hearing about hospice services for the first time?
6. Can you share your experience when using medical interpreters with Spanish-speaking patients and/or families?
7. How do you manage a situation when the patient declines interpreting services and prefers family members to interpret instead?
8. To what extent do you believe that the literature provided on hospice care is useful in destigmatizing the view some families have?
  - a. How were those informational brochures helpful in explaining hospice services to patient and/or family members?
9. How do family dynamics, such as family's acceptance of prognosis or understanding of hospice philosophy affect patient's enrollment in hospice services?
10. What kind of trainings have you received related to cultural sensitivity and language barriers non-English speaking patients may experience in health-care settings?
11. What are your ideas on what can be done to reduce language barriers the Latino population experience accessing hospice services?
12. Do you have any final thoughts to share or add about Latino population access and use of hospice care?

Created by Diana Ramirez

APPENDIX C  
INSTITUTIONAL REVIEW BOARD APPROVAL

February 24, 2021

**CSUSB INSTITUTIONAL REVIEW BOARD**

Administrative/Exempt Review Determination

Status: Determined Exempt

IRB-FY2021-125

Armando Barragan Jr. Diana Ramirez  
CSBS - Social Work  
California State University, San Bernardino  
5500 University Parkway  
San Bernardino, California 92407

Dear Armando Barragan Jr. Diana Ramirez:

Your application to use human subjects, titled “LANGUAGE BARRIERS AND THE USE OF PALLIATIVE AND HOSPICE CARE AMONG THE LATINO POPULATION” has been reviewed and determined exempt by the Chair of the Institutional Review Board (IRB) of CSU, San Bernardino. An exempt determination means your study had met the federal requirements for exempt status under 45 CFR 46.104. The CSUSB IRB has not evaluated your proposal for scientific merit, except to weigh the risk and benefits of the study to ensure the protection of human participants. Important Note: This approval notice does not replace any departmental or additional campus approvals which may be required including access to CSUSB campus facilities and affiliate campuses due to the COVID-19 pandemic. Visit the Office of Academic Research website for more information at <https://www.csusb.edu/academic-research>.

You are required to notify the IRB of the following as mandated by the Office of Human Research Protections (OHRP) federal regulations 45 CFR 46 and CSUSB IRB policy. The forms (modification, renewal, unanticipated/adverse event, study closure) are located in the Cayuse IRB System with instructions provided on the IRB Applications, Forms, and Submission webpage. Failure to notify the IRB of the following requirements may result in disciplinary action. The Cayuse IRB system will notify you when your protocol is due for renewal. Ensure you file your protocol renewal and continuing review form through the Cayuse IRB system to keep your protocol current and active unless you have completed your study.

**Important Notice: For all in-person research following IRB approval all research activities must be approved through the Office of Academic Research by filling out the [Project Restart and Continuity Plan](#).**

- **Ensure your CITI Human Subjects Training is kept up-to-date and current throughout the study.**
- **Submit a protocol modification (change) if any changes (no matter how minor) are proposed in your study for review and approval by the IRB before being implemented in your study.**
- **Notify the IRB within 5 days of any unanticipated or adverse events are experienced by subjects during your research.**
- **Submit a study closure through the Cayuse IRB submission system once your study has ended.**

If you have any questions regarding the IRB decision, please contact Michael Gillespie, the Research Compliance Officer. Mr. Michael Gillespie can be reached by phone at (909) 537-7588, by fax at (909) 537-7028, or by email at [mgillesp@csusb.edu](mailto:mgillesp@csusb.edu). Please include your application approval number IRB-FY2021-125 in all correspondence. Any complaints you receive from participants and/or others related to your research may be directed to Mr. Gillespie.

Best of luck with your research.

Sincerely,

*Nicole Dabbs*

Nicole Dabbs, Ph.D., IRB Chair  
CSUSB Institutional Review Board

ND/MG

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