Hospice Decision-Making in U.S. Mexicans with Terminal Cancer and Their Families

By

Margaret L. Rising, BSN, RN, PhD Candidate

A Dissertation

Presented to

Oregon Health & Science University

School of Nursing

in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

June 3, 2019

Approval Page

APPROVED:

Dena Hassouneh, RN, PhD, FAAN, Dissertation Chair

Patricia H. Berry, RN, PhD, FAAN, Committee Member

Kristin Lutz, RN, PhD, Committee Member

Susan Bakewell-Sachs, Ph.D., R.N., FAAN, Dean, School of Nursing

Acknowledgment of Financial Support

This work was supported, in part, by the Doctoral Degree Scholarship in Cancer Nursing, DSCN-15-077-01, and DSCNR-17-089-03 from the American Cancer Society, and also supported through grants and scholarships from the OHSU Hartford Center of Gerontological Excellence, the Hearst Foundation, and the Oregon Health & Science School of Nursing Alumni Dean's Scholarship, and Sigma Theta Tau Beta Psi Chapter. The content is solely the responsibility of the author and does not necessarily represent official views of supporting agencies.

Acknowledgments

This dissertation would not be possible without the selfless contributions from my dissertation committee. I am infinitely grateful to them for this opportunity. Dena Hassouneh, Committee Chair, tirelessly channeled my passion and guided me toward answers, elusive phrases, and conscientization. Kristin Lutz was my champion of symbolic interactionism, Lenny Schatzman, and Midwestern good sense. Pat Berry brought an entrepreneurial, pragmatic philosophy that led to a critical American Cancer Society grant and a deeper appreciation of hospices and their regulations. Chris Lee served on my committee for a limited time but long enough to make the manuscript option possible and to help me transform Chapter 2A from a literature review into a meta-analysis. To my committee, I humbly and deeply bow in thanks.

Through the years, there were many faculty members and administrative staff that helped me achieve goals or just brightened my day with their unwavering support. I would like to thank Jennifer Dunfield, Hill Taylor, Nathan Dieckmann, Lissi Hansen, Seiko Izumi, MinKyoung Song, Quin Denfield, Frances Lee Lin, Marti Driessnack, Kathryn Wildeck, and Karen Lyons.

For four years, my Dissertation Seminar colleagues tirelessly provided feedback and encouragement in class. I am long-winded and write myself into dense thickets. Captive editors, these dissertation colleagues patiently provided invaluable feedback. Thank you.

Research requires recruitment of research subjects, which proved to be quite a challenge. I logged countless hours networking in healthcare agencies throughout the Pacific Northwest, robbing individuals of their time during the process. My success, in part, rests on those meetings you were generous enough to grant. Thank you.

In a critical grounded theory cross-cultural study, the community advisory board lends tremendous authenticity to the research methodology. So much that the study results are tenuous

without the ability to recall conversations with community advisory board members that support them. You are my mentors, and this study would not be possible without your valuable wisdom and insight.

Along the way, there were particular PhD colleagues who bore the lion's share of my tears, laughter, and dreams. A special thank you to those PhD friends: Nour Alayan, Wafaa Bin Ali, Kiki Fiorno, and Ruth Tadesse.

For several years during the research program, I held part- or full-time positions while chipping away at the PhD. To my fellow RNs at Hopewell House, Radiation Oncology, and Portland Community College, thank you for your unwavering support and patience.

To my friends, neighbors, and book club members with whom I managed to socialize during these last six years. Thank you to you all for your support.

A very special acknowledgement is reserved for Lynn Guerra, a South Texas childhood friend who died during the dissertation. Thank you, Lynn, for sharing your family history and personal hardships and how, seated next to me in junior high, you were forced to reconcile U.S. revisionist history with your family history. Thank you for representing the "Third Space." You are fiercely missed.

Finally, to my family—Jack and Linn, Mom and Dad, my siblings—you know who you are. Thank you for your support and patience.

Abstract

Hospice care is comprehensive patient-centered care that offers improved symptom management and quality of life at end of life (EOL). U.S. Mexicans tend to use hospice at rates lower than their non-Hispanic White counterparts (Whites). Most studies seeking to explain the discrepancy in hospice utilization between U.S. Mexicans and Whites have focused overtly or explicitly on cultural incompatibilities at EOL. This emphasis on differences between cultures has fostered “othering” and has generated a body of EOL and hospice research from the Eurocentric perspective. In contrast, the roles of racism and mistrust in hospice decision-making have been largely ignored. To address this gap in the research literature, this dissertation leverages the strengths of critical grounded theory methodology, which fosters sensitization to the impacts of racism, mistrust, oppression, and exploitation, as well as cultural incompatibilities.

The body of work in this dissertation comprises six chapters, consistent with the 2013–2014 OHSU School of Nursing Doctor of Philosophy Program Guidelines. Chapter 1 is an introduction to the scope of the dissertation, including a brief overview of the literature, purpose, aims, and theoretic framework guiding the research. Chapter 2 is a concept paper exploring the preference for prognostic secrecy in Hispanics. Chapter 3 is a systematic integrative review of the research literature on Hispanics and hospice. Chapter 4 is a systematic integrative review and meta-analysis of the research literature on Hispanic hospice utilization. Chapters 2, 3, and 4 are published. Chapter 5 presents study results, which will be published in the future. Last, Chapter 6 is a discussion and summary of study results as well as implications for nursing practice and future research.

Reflecting the postcolonial theoretical framework of the overall study, the dissertation results re-characterize the existing research literature on this topic and provide strong evidence of the importance of mistrust and marginalization during hospice decision-making to some U.S. Mexicans with cancer and their families. A review of the literature reveals that most work on the topic of Hispanics and hospice is Eurocentric. These studies focus mostly on cultural preferences and treat Hispanics as a monolithic population, fostering generalizations and stereotypes. In contrast, the dissertation research recognizes the heterogeneity among Hispanic subgroups and further teases out heterogeneity within the U.S. Mexican population by virtue of marginalization factors and concomitant mistrust. Postcolonial theory further introduces to the study an awareness of power dynamics in the healthcare encounter that is not found in the research literature. Using critical grounded theory as a methodological approach, a substantive grounded theory is developed that describes the process of hospice decision-making in U.S. Mexicans with cancer and their families. Results show that marginalization, by virtue of low income, low education, lack of citizenship, lack of insurance, and geographic ethnic isolation, leads to mistrust and erosion of the therapeutic relationship, which further leads to resisting hospice enrollment. In contrast, U.S. Mexicans who feel Americanized—a sense of belonging—engage in hospice decision-making in a manner similar to Whites, and there appears to be a trusting and therapeutic relationship with the healthcare provider. Among marginalized U.S. Mexicans, hospice resistance is reflected in the U.S. Mexican practices of “We take care of our own,” returning to Mexico, and reliance on alternative healers, hope, and community palliative care. Opposing hospice resistance factors are hospice acceptance factors, which lead to hospice enrollment even among those U.S. Mexicans who may otherwise resist hospice. Hospice resistance factors include caregiver availability, caregiver exhaustion, need for complex nursing care, need for medical equipment, acceptance of dying, rebuilding trust, and being told they have no choice. In the middle of these hospice resistance and acceptance factors is found a “Third Space,” where U.S. Mexicans with terminal cancer and their families seek an end-of-life experience on their own terms. In this “Third Space,” there is hybridity, ambiguity, and conflicting sentiment, which may or may not lead to hospice enrollment. There, the hospice resistance and acceptance factors negotiate with one another until the terminally ill patient dies. The dissertation research highlights the importance of teaching healthcare providers about mitigating legacies of oppression as much as cultural competence, which is the dominant paradigm. In addition, there is a need for future research with marginalized U.S. Mexican populations on the benefits of community palliative care to this population and on the practice of corralling charity hospital patients with terminal illness into hospice.

Table of Contents

Approval Form ii

Acknowledgment of Financial Support iii

Acknowledgments iv

Abstract vi

List of Tables x

List of Figures xi

Chapters

I. Hospice Decision-Making in U.S. Mexicans with Terminal Cancer and their Families 1

II. Truth-Telling as an Element of Culturally Competent Care at End of Life (EOL) 19

III. Integrative Review of the Literature on Hispanics and Hospice 37

IV. Hispanic Hospice Utilization: Integrative Review and Meta-Analysis 69

V. Hospice Decision-Making in Mexicans with Terminal Cancer and Their Families 105

VI. Summary, Discussion, and Implications of Dissertation Manuscript Findings 143

Cumulative References 196

Appendices 226

List of Tables

Chapter I

Table 1. *Summary of Chapters* 18

Chapter III

Table 1. *Qualitative Articles* 46

Table 2. *Examples of Questions, Themes, and Exemplars from Qualitative Articles* 48

Table 3. *Quantitative Articles* 57

Table 4. *Quantitative Questions and Study Results* 58

Chapter IV

Table 1. *Hispanic Hospice Enrollment* 79

Table 2. *Definitions of Large Databases* 83

Table 3. *Uninsured Individuals by Ethnicity* 102

Chapter V

Table 1. *U.S. Mexican Family Members Living in PNW Relating Family Hospice/EOL Experiences* 120

Table 2. *HCP and HCW Relating Perspectives of Patients' Hospice/EOL Experiences* 121

Chapter VI

Table 1. *Overview of Chapters* 146

List of Figures

Chapter II

Figure 1. The relatively recent development of patient autonomy and its roots in beneficence and non-maleficence. 29

Chapter IV

Figure 1. PRISMA flow diagram. 76

Figure 2. Meta-analysis results on $n = 11$ studies. 95

Figure 3. Meta-analysis results from $n = 3$ palliative care studies. 97

Figure 4. Meta-analysis of $n = 5$ SEER–Medicare database studies. 98

Chapter V

Figure 1. Marginalized U.S. Mexicans seeking the “Third Space” at EOL around hospice decision-making. 117

Chapter VI

Figure 1. Marginalized U.S. Mexicans seeking the “Third Space” at EOL around hospice decision-making. 178

Chapter I

Hospice Decision-Making in U.S. Mexicans with Terminal Cancer and Their Families

Margaret L. Rising, BSN, RN, PhD

Oregon Health & Science University School of Nursing, Portland, OR, U.S.A.

Introduction

As a medical-surgical and hospice nurse, I have personally witnessed tension created by efforts to enroll U.S. Mexican patients in hospice or to keep awareness of hospice secret from dying patients. Because I am proficient in Spanish, my practice as a bedside registered nurse was to create dialogue around this tension with families as part of nursing therapeutic communication. Healthcare professionals generally perceive hospice as ideal end-of-life (EOL) care, and so it was fascinating to listen to the views and feelings of family members as well as alarming to appreciate their level of frustration with their healthcare experiences. Unable to articulate it at the time, I also became vaguely aware of the profound difference between the healthcare–U.S. Mexican interface here in the Pacific Northwest (PNW) compared to my home in South Texas, where U.S. Mexicans are the majority. In an effort to gain insight into families' frustrations and the geographical differences in healthcare experiences, this dissertation explores the process of hospice decision-making in U.S. Mexican families in the PNW. Hospice care is generally considered state of the art EOL care (Christakis & Iwashyna, 2003; Connor, Pyenson, Fitch, Spence, & Iwasaki, 2007; Meier, 2011; Pyenson, Connor, Fitch, & Kinzbrunner, 2004; Teno et al., 2004). In an effort to extend the benefits of hospice care to Hispanics, research has been conducted to understand their care preferences at EOL, including with respect to hospice. Among other culturally oriented topics, research has focused on Hispanic preferences for family decision-making (Blackhall, Murphy, Frank, Michel, & Azen, 1995; Kelley, Wenger, & Sarkisian, 2010; Kreling, Selsky, Perret-Gentil, Huerta, & Mandelblatt, 2010; Selsky et al., 2012), prognostic secrecy (Blackhall et al., 1995; Boucher, Guadalupe, Lara, & Alejandro, 2014; Colon, 2012; Gelfand, et al., 2001, 2004; Gutheil & Heyman, 2006; Kreling, et al., 2010; Selsky et al., 2012), and religiosity (Balboni et al., 2007; Ko & Lee, 2014; A. K. Smith et al., 2008). Although there has been research on the impact of discrimination in healthcare and mistrust in the Hispanic population (Armstrong, Ravenell, McMurphy, & Putt, 2007; Ben, Cormack, Harris, & Paradies, 2017; Galvan, Bogart, Klein, Wagner, & Chen, 2017; López-Cevallos, Harvey, & Warren, 2014; Robert Wood Johnson Foundation, 2017), little is known about the impact of these social forces at EOL and, specifically, on the hospice enrollment process. Consequently, the overwhelming majority of research on Hispanics and hospice focuses on perceived cultural influences rather than discrimination and mistrust. Focusing on cultural differences has furthered "othering," as that concept has been described by postcolonial scholars (Ashcroft, Griffiths, & Tiffin, 2013; Bhabha, 1994). Therefore, research literature on Hispanics and hospice has been racialized in a manner that fosters ethnic stereotypes. Research that promotes "othering" and ethnic stereotypes has failed in its goal of understanding and improving EOL and hospice care in the Hispanic population.

The purpose of this dissertation research is to understand the process of hospice decision-making in U.S. Mexicans with terminal cancer residing in the PNW. Narrowing the scope of the study to U.S. Mexicans acknowledges the considerable heterogeneity within the Hispanic population with respect to current and historical sociopolitical processes (Acuna, 2015; Cordova, 1994; Garcia, 2016; Gonzales-Berry & Mendoza, 2010; Martinez, 1994; Stephen, 2012; Weinick, Jacobs, Stone, Ortega, & Burstin, 2004). Focusing on cancer recognizes that cancer oftentimes exhibits a unique illness trajectory (Murray, Kendall, Boyd, & Sheikh, 2005), that cancer is the leading cause of death in Hispanics (American Cancer Society, 2015), and that cancer is the leading admission diagnosis in hospice (National Hospice and Palliative Care Organization, 2017). Finally, the PNW offers a unique setting in which to conduct research with U.S. Mexicans, owing to the prevalence of Whites (Ennis, Rios-Vargas, & Albert, 2011) and the region’s history of racial intolerance (Garcia, 2016; Gonzales-Berry & Mendoza, 2010; Johnson, 2017; May, 2011; Millner, 2018; Stephen, 2012). Understanding the process of hospice decision-making in U.S. Mexicans with terminal cancer in the PNW furthers the stated goals of the Institute of Medicine (Institute of Medicine, 2014), American Cancer Society (American Cancer Society, 2015), and others (Ward et al., 2004) to improve EOL care for all ethnicities. Implementing critical grounded theory and dimensional analysis, this study will generate a substantive grounded theory and describe the influences of social forces on the process of hospice decision-making in U.S. Mexicans with terminal cancer and their families.

Background and Significance

U.S. Mexicans. In this dissertation, *U.S. Mexicans* are defined as persons of Mexican descent residing in the U.S. This broadly defined category is intended to include U.S. Mexicans who do and do not self-identify as American as well as those with and without documentation to live in the U.S. Sixty-four percent of the U.S. Hispanic population is made up of U.S. Mexicans (Ennis et al., 2011; Gonzalez-Barrera & Lopez, 2013; Motel & Patten, 2012; Pew Research Center, 2011). Oregon’s estimated 404,999 U.S. Mexicans (United States Census Bureau, 2014) comprise 85% of the state’s total Hispanic population (Garcia, 2016; Pew Research Center, 2011). In Washington, the estimated 687,634 U.S. Mexicans (U.S. Census Bureau, 2016) comprise 80% of the state's total Hispanic population (Pew Research Center, 2014a).

Although this dissertation study focuses on U.S. Mexicans, a substantial portion of the research literature and published works employs the words "Hispanic" and "Latino" to refer to the same or similar population. The U.S. Census Bureau defines the words *Hispanic* and *Latino* to include persons of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race (Ennis et al., 2011). Census data describes Hispanics as the largest minority group in the U.S., Oregon, and Washington, comprising 17%, 11.7%, and 11.2% of their total populations, respectively (Ennis et al., 2011; Garcia, 2016; Pew Research Center, 2011). Although useful for purposes of record-keeping, the word "Hispanic" can contribute to misinformation. In reality, the word "Hispanic" is a socio-political construct that artificially joins together culturally and socio-historically distinct Spanish-speaking people (Martinez-Tyson, Barnett, Soler-Vila, & Flores, 2009; Weinick et al., 2004). There is no monolithic Hispanic culture (Weinick et al., 2004), and many so-called Hispanics do not identify as Hispanic. They also may not identify as Latino. Correct use of the words *Hispanic* and *Latino* is debated and a matter of personal preference (Hede, 2013; Retta & Brink, 2007); in practice, they tend to be used interchangeably (Ennis et al., 2011; Humes, Jones, & Ramirez, 2011).

In addition to *Hispanic* and *Latino*, other words are used to refer to persons of Mexican descent. A word that is synonymous with social activism, *Chicano* derives from the 1960s Chicano civil rights movement in the U.S. and emphasizes indigenous Mexican heritage (Acuna, 2015; Cordova, 1994). The phrase *Latin American* refers to romance language–speaking individuals in Latin America, a region extending geographically from Mexico and the Caribbean through South America (Skidmore, Smith, & Green, 2013). A result of the foregoing is that not all Hispanics are Latinos or Chicanos, and not all Latinos are Mexicans. Although this study focuses on U.S. Mexicans, the words *Hispanic* and *Latino* are used where necessary to remain congruent with the research literature.

Whites and non-Hispanic Whites. An abundance of ethnic labels is not limited to U.S. Mexicans. In the research literature on Hispanics and hospice, the vast majority use *non-Hispanic Whites* to refer to persons of European descent, perhaps reflecting the U.S. Census category. Therefore, when reviewing the research literature, the designation *non-Hispanic Whites* is used to remain true to other authors' representations. However, as will be seen, the conceptual framework for this dissertation is critical theory, where the word *Whites* is more commonly found. In addition, dissertation study participants tended to use the word *Whites*. Accordingly, in my original work, I eventually came to use the word *Whites*, but not before publishing Chapters 2, 3, and 4, which are reproduced within this dissertation manuscript as they were published. I feel it is important to recognize the inconsistent terminology. This inconsistent terminology reflects my personal growth through the dissertation process, particularly with respect to my own increased awareness of pervasive Eurocentric bias in research and healthcare. As a consequence, the dissertation as a whole uses both *Whites* and *non-Hispanic Whites* to refer to persons of European descent.

Hospice care. Hospice is defined as patient-centered EOL care provided by an interdisciplinary team comprising physicians, nurses, social workers, chaplains, nurses' aides, volunteers, and others that focus on symptom control, comfort, and quality of life (Meier, 2011; National Hospice and Palliative Care Organization, 2015). It originated in England in the 1960s (Clark, 2007; Pawling-Kaplan & O'Connor, 1989). Evolving and maturing in the context of cancer, hospice filled the void remaining when it was determined that curative care was no longer possible (Clark, 2007; Pawling-Kaplan & O'Connor, 1989). The first hospice in the U.S. was established in 1974, and Medicare published hospice certification regulations in 1983 (Clark, 2007; Pawling-Kaplan & O'Connor, 1989). As of 2016, over 4,382 hospice programs existed in the U.S., providing services through Medicare to an estimated 1.43 million patients and their families (National Hospice and Palliative Care Organization, 2017). Though declining, cancer has been and remains the leading hospice admission diagnosis, comprising 27.2% of terminal hospice admissions (National Hospice and Palliative Care Organization, 2017). Financial reimbursement for hospice care primarily derives from the Medicare Hospice Benefit, which paid for 85.5% of hospice care in 2014, followed by managed care or private insurance (6.9%), Medicaid hospice benefit (5.0%), and charity care (0.7%; National Hospice and Palliative Care Organization, 2015). Statistics reflecting Hispanic hospice use demonstrate considerable variation, with a profound recent reduction. Hispanics comprised 7.1% of hospice patients nationwide in 2014, up from 6.9% in 2012 (National Hospice and Palliative Care Organization, 2013, 2015). However, only 2.1% of hospice patients were Hispanic in 2016 (National Hospice and Palliative Care Organization, 2017).

Hospice offers many advantages to patients with terminal diagnoses and their family members. There is strong research evidence that, relative to traditional EOL care, hospice care offers patients superior pain control (Teno et al., 2004) and quality of life (Meier, 2011), as well as prolonged life in some instances (Connor et al., 2007; Pyenson et al., 2004). Surviving widowed spouses of hospice patients also show improved bereavement outcomes compared to those of non-hospice patients (Christakis & Iwashyna, 2003). In spite of these positive hospice outcomes, home hospice care can also cause harm. It can negatively impact the health of hospice caregivers (Pottie, Burch, Montross, & Irwin, 2014; Wilder, Oliver, Demiris, & Washington, 2008), most of whom are women (Adams, Bader, Horn, & Hernandez, 2008; Adams, Horn, & Bader, 2005; Colón & Lyke, 2003; Colón & Lyke, 2015; Pottie et al., 2014; Wilder et al., 2008). Hospice also has its own culture that is both congruent and incongruent with cultural tendencies in some Hispanics. Hispanic cultural patterns that are congruent with inherent characteristics of hospice care include a preference for care that minimizes suffering (Kelley et al., 2010; Ko, Cho, Perez, Yeo, & Palomino, 2013; Loggers et al., 2013; Perkins, Cortez, & Hazuda, 2009; Sullivan, 2001) and allows the family to provide care or control delivery of care (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004; Gelfand et al., 2001, 2004; Kreling, et al., 2010; Taxis, Keller, & Cruz, 2008). In contrast, a potentially incompatible Hispanic cultural pattern is a preference among some to avoid prognostic discussions, creating potential for discord at EOL (Blackhall, Frank, Murphy, & Michel, 2001; Frank et al., 2002; Gelfand et al., 2001; Gutheil & Heyman, 2006; Kreling, et al., 2010). Moreover, in the home health care setting, there is evidence that Hispanics are disinclined to accept strangers into their homes (Crist, Garcia-Smith, & Phillips, 2006). Because 94% of hospice occurs in the home (National Hospice and Palliative Care Organization, 2017), the preference to keep strangers from entering the home in the home health setting creates another potential for discord when the healthcare team is encouraging hospice enrollment. In summary, just as hospice brings benefits but carries documented hardships, hospice culture is both consistent and inconsistent with documented Hispanic EOL preferences. Hospice's Eurocentric philosophy and bias in the delivery of healthcare may blind U.S. healthcare providers to contradictions between hospice care and U.S. Mexican preferences.

U.S. Mexicans in the PNW. The Mexican and U.S. Mexican populations are remarkably heterogeneous in their socioeconomic and ethnic identities. Ethnically, there remains a large indigenous population, contrasted against lighter-skinned Spanish descendants, although the majority of Mexicans trace ancestry to some combination of the two (Acuna, 2015; Jimenez, 1994). Among U.S. Mexicans, there are differences between foreign-born and U.S.-born individuals. The exact number of foreign-born persons of Mexican descent in the U.S. is not known. One estimate is that, of the 33.7 million persons born in the U.S. and self-identifying as Mexican origin, the ratio of Mexican/U.S.-born Mexican population in the U.S. is 35/65% (Gonzalez-Barrera & Lopez, 2013). In Oregon, Mexican/U.S.-born data could only be found on Hispanics (37/63%; Pew Research Center, 2011). Similarly, Hispanics residing in Washington state are characterized as 38/62% Mexican/U.S.-born (Pew Research Center, 2014a). Not all foreign-born individuals are in the U.S. with appropriate documentation. Of those foreign-born, 18% are unauthorized, 11% are legal permanent residents, and 6% are naturalized citizens. Therefore, 51% of foreign-born Mexicans are described as undocumented, which amounts to an estimated 6.8 million individuals (Gonzalez-Barrera & Lopez, 2013). An estimated 90,000 and 125,000 Mexican individuals are undocumented in Oregon and Washington, respectively (Pew Research Center, 2014b).

Although there is considerable socioeconomic diversity, U.S. Mexicans in aggregate are disproportionately poor, less educated, and uninsured relative to Whites. This socioeconomic disparity exists even though U.S. Mexicans have been described as providing the “labor backbone” of U.S. industries, such as construction, hospitality, and agriculture (Jordan & Perez, 2016). The median individual income for persons of Mexican descent in the U.S. is $20,000 a year (Brown & Patten, 2013; Gonzalez-Barrera & Lopez, 2013). In Oregon and Washington, it is $18,000 (Pew Research Center, 2011) and $22,000 (Pew Research Center, 2014a), respectively, a year (data on Hispanics). A high school diploma is held by 59% of U.S.-born and 21% of foreign-born individuals (Brown & Patten, 2013; Gonzalez-Barrera & Lopez, 2013). Similarly, 21% Mexican-born and 87% U.S.-born in Oregon have a high school diploma (data on Hispanics; Pew Research Center, 2011). As for health insurance, the Centers for Disease Control reports that Mexicans under 65 years of age are the group with the highest rate of uninsured individuals (24.7%) compared to non-Hispanic Whites (NHWs) (7.5%) and other Hispanics, generally (21.9%; Centers for Disease Control and Prevention, 2017). Disposable income, education, and health insurance are among the many factors that are presumed to influence EOL and hospice decision-making. The Medicare Hospice Benefit, which pays for most of hospice in the U.S., is largely unavailable to uninsured and undocumented U.S. Mexicans.

Eurocentric hospice philosophy and enrollment. The Medicare Hospice Benefit is Eurocentric in its hospice enrollment process and underlying philosophy. *Eurocentric* refers to values and beliefs held by persons of European descent, particularly—in the EOL context—the preference for individualism and maintaining control over one’s destiny (Rising, 2017). One example of Eurocentric values in hospice philosophy is that with sufficient support, patients and families can gain satisfaction in preparation for death and even attain emotional growth during the last phase of life (National Hospice and Palliative Care Organization, 2010). Preparing for death assumes awareness of impending death, which is usually, though not always, the case at hospice enrollment. Pursuant to Medicare regulations, hospice enrollment requires informed consent when a patient enrolls in hospice, with an emphasis on the patient or representative fully understanding that hospice care is palliative rather than curative (Code of Federal Regulations, 2017b). To enroll in hospice, patients or their decision makers must decline curative therapy and opt for comfort as the primary goal of care (Code of Federal Regulations, 2017b, 2017c). Physicians must also certify a prognosis of six months or less, assuming the disease runs its normal course (Code of Federal Regulations, 2017a). During hospice enrollment, the degree and explicitness of discussions around informed consent, terminal prognosis, and comfort as the goal of care vary widely, reflecting different attitudes held by individual hospice workers and institutions. Nonetheless, the patient or patient representative must sign consent for hospice enrollment that acknowledges waiver of curative therapy and acceptance of care focused on comfort (Code of Federal Regulations, 2017b, 2017c). In contrast, in collectivist cultures, which includes some Hispanics, open prognostic discussions may be avoided in a beneficent gesture to protect the patient from harm resulting from awareness of a terminal prognosis (Rising, 2017). The Medicare Hospice Benefit is Eurocentric in the inherent assumption that awareness of impending death and preparation for that death would be preferred, but it is not preferred in all cases. Another layer of Eurocentric bias is found in the assumption that the patient or family in question will place full faith or confidence in the provider's determination that a patient's prognosis is terminal. With a significant number of Hispanic individuals reporting discrimination in the healthcare setting (Armstrong et al., 2007; Ben et al., 2017; Galvan et al., 2017; López-Cevallos et al., 2014; Robert Wood Johnson Foundation, 2017), there is a strong possibility that such discrimination would erode the therapeutic relationship necessary to comfortably surrender curative therapy and enroll in hospice. **Colonization of U.S. Mexicans.** The conceptual framework for this dissertation requires an appreciation for the history of colonization of U.S. Mexicans. Mexico was inhabited by indigenous peoples—a combination of the Aztecs and others—when it was colonized by Spain in 1521 (Acuna, 2015). Three hundred years later, in 1820, Mexico won its independence from Spain (Acuna, 2015). By that time, lighter-skinned Spaniards had cohabitated with darker-skinned indigenous peoples, creating a heterogeneous population which is distinctly *mestizo*, or mixed race (Acuna, 2015; Jimenez, 1994). Shortly thereafter, the U.S. set its sights on acquiring Mexico, which was recovering from years of colonization and war (Acuna, 2015). First, Texas won its independence in the Texas Revolution (1836; Acuna, 2015; Martinez, 1994). The U.S.–Mexican War (1845–1848) quickly followed and ended with the Treaty of Guadalupe Hidalgo (1848; Acuna, 2015; Martinez, 1994). The Texas Rangers and the U.S. government brutalized Mexican citizens through murder, scalping, lynching, and land-grabs. Further, the U.S. government effectively colonized the Mexican citizens by ignoring the terms of the Treaty of Guadalupe Hidalgo. Although the U.S. government promised the new U.S.–Mexican citizens they would retain private landholdings, that promise was not enforced. Consequently, the Treaty of Guadalupe Hidalgo effectively ceded *Aztlán* to the U.S. in a manner that left U.S. Mexicans landless (Acuna, 2015; Martinez, 1994). *Aztlán* is the indigenous name in Nahuatl that designates the Southwest U.S., including Texas, New Mexico, Arizona, Nevada, Utah, California, Colorado, and parts of Wyoming, Kansas, and Oklahoma (Acuna, 2015; Martinez, 1994). Chicanos refer to this region as *Aztlán*, a name that references their historical claim to the Southwest U.S. and their indigenous roots (Cordova, 1994). The largest and most dense Mexican populations in the U.S. today are found in the Southwest U.S. (Ennis et al., 2011; United States Census Bureau, 2010).

After losing their land, U.S. Mexicans migrated within the U.S. in search of wage-earning jobs, usually in agriculture and ranching (Acuna, 2015; Garcia, 2016; Gonzales-Berry & Mendoza, 2010; Martinez, 1994; Stephen, 2012). They were accompanied in their search by Mexicans who had recently entered the U.S. from Mexico, some of whom arrived or remained illegally (Acuna, 2015; Garcia, 2016; Gonzales-Berry & Mendoza, 2010; Martinez, 1994; Stephen, 2012). Discrimination, exploitation, and abuse targeted at all U.S. Mexicans, regardless of their migration history, became institutionalized as part of the war effort during World War II (Acuna, 2015; Garcia, 2016; Gonzales-Berry & Mendoza, 2010; Martinez, 1994; Stephen, 2012).

Conflicting government-sponsored efforts became the norm. On the one hand, there was the importation of cheap agricultural labor through joint U.S.–Mexican government efforts, such as the Bracero Program (Acuna, 2015; Garcia, 2016; Gonzales-Berry & Mendoza, 2010; Martinez, 1994; Stephen, 2012). For example, over 15,000 laborers were brought from Mexico to Oregon from 1942–1947 (Garcia, 2016). Early Mexican immigrants settled in isolated rural areas of Oregon where they worked as ranch hands or farmworkers doing “stoop labor” (Garcia, 2016; Gonzales-Berry & Mendoza, 2010; Stephen, 2012). On the other hand, and at the same time, there was a government effort to deport illegal immigrants with programs such as Operation Wetback (Acuna, 2015; Garcia, 2016; Gonzales-Berry & Mendoza, 2010; Martinez, 1994; Stephen, 2012). Many U.S. Mexicans moved to Oregon to escape Jim Crow–like conditions in Texas (Gonzales-Berry & Mendoza, 2010; May, 2011) even though the PNW has its own history of racial intolerance (Garcia, 2016; Gonzales-Berry & Mendoza, 2010; Johnson, 2017; May, 2011; Millner, 2018; Stephen, 2012). These social dynamics and others like them crystallized racism against U.S. Mexicans through the institutionalization of racist government practices (Spanos, 2007). Campaigns like Operation Wetback fueled Oregonians’ perceptions of U.S. Mexicans as inferior and “illegals” (Acuna, 2015; Garcia, 2016; Stephen, 2012).

Through the centuries, the brute force of colonization has given way to the “voluntary” consent of hegemonic control, which is more invisible than colonization and aims to inspire discourse and consent among the formerly colonized (Spanos, 2007). A form of power, hegemony occurs when the ruling class convinces other classes that their interests overlap (Ashcroft, Griffiths, & Tiffin, 2013). The result is covert, but ongoing, discrimination and institutionalized exploitation which results today in extraordinary vulnerability, uncertainty, and suffering for U.S. Mexicans (Acuna, 2015; Gamboa, 2000; Garcia, 2016; Gonzales-Berry &

Mendoza, 2010; Martinez, 1994; Stephen, 2012). For example, today, many media references are found documenting the exploitation of or indifference to the suffering of migrant farmworkers in the context of the U.S. agribusiness complex. Examples of such exploitation include the dangers and indignities of illegal border crossings ("Fields of Tears", 2010; Contro, Davies, Larson, & Sourkes, 2010), discriminatory housing (Holmes, 2006), sexual harassment and rape (Yeung & Rubenstein, 2013), exploitation of children (Schick, 2012), and the high rates of cancer linked to pesticide orsun exposure (Cruz, 2011; Stephen, 2012). Finally, the current political climate has contributed to egregious and inhumane treatment of Mexicans and others arriving at the U.S. border, with little regard for their welfare (Haag, 2019; Jordan, 2018). Exploitation of Mexican laborers represents continued active covert colonialism.

Philosophical Framework and Assumptions

The overarching philosophical framework for this study is postcolonial theory, which asserts that historical forces of oppression, exploitation, and marginalization continue to exist today, oftentimes in more hidden manifestations (Ashcroft et al., 2013; Bhabha, 1994). Critical grounded theory is the methodology that incorporates postcolonial theory into the research, and the type of grounded theory used is dimensional analysis. The philosophical underpinnings of grounded theory include symbolic interactionism and American pragmatism. In this dissertation, these philosophies and research methods dovetail to privilege the experiences and voices of U.S. Mexicans with terminal cancer and their families. The goal of bringing the voices of participants from margins to center further serves to mitigate inherent biases resulting from the cross-cultural nature of this research.

Postcolonial theory. The core assumption of postcolonial theory is that there is an unequal power dynamic between colonizers and the colonized that propagates exploitation, marginalization, oppression, stigmatization, and discrimination (Anderson, 2004; Ashcroft et al., 2013; Bhabha, 1994; Said, 1978). As a type of critical theory, postcolonial theory is concerned with oppressive power dynamics and the quest for justice for the oppressed through enlightenment and emancipation (Kincheloe & McLaren, 2002). One means of wielding such oppressive power is through the strategy of "othering." The colonizer uses a greater position of power to construct an "other" that is both different and inferior; the colonizer then exploits the "other" and remains indifferent to the suffering of the "other" (Anderson, 2004; Ashcroft et al., 2013; Bhabha, 1994; Said, 1978). It is assumed in this dissertation that such exploitation and indifference to suffering occurs within the healthcare setting, even if it remains invisible to healthcare providers. Owing to the Eurocentric bias inherent in U.S. and European research, particularly cross-cultural research (Smith, 2012), it is imperative to employ a research methodology that restores power to the research participants as much as possible within the constraints of feasibility. Critical grounded theory within a postcolonial theoretical framework takes steps toward repairing Eurocentric bias and the unequal power dynamic between researcher and participants. As a research methodology, it sensitizes the investigator to the impact of discrimination, oppression, exploitation, stigmatization, and marginalization on research participants.

There are several consequences to adapting postcolonial theory as a conceptualizing research framework. Importantly, the study design avoids essentialism, which is the tendency to view a group with predetermined, fixed identities, resulting in homogenization and suppression of differences within the group (Narayan, 2000; Sayer, 1997; Wagner, Holtz, & Kashima, 2009). Second, postcolonial theory situates U.S. Mexican participants within a constricting and complicated mosaic of socioeconomic, historical, and political influences beyond their control

(Anderson, 2004; Anderson, 2000; Anderson et al., 2009; Kirkham & Browne, 2006). This complicated mosaic acknowledges that, even though the focus of this study will be on decision-making, actual decisions may not involve free choice (Anderson, 2004). On the other hand, a postcolonial theoretical framework also encourages a reclamation of personal agency through enlightenment and emancipation and an appreciation that hegemonic discourse need not predetermine one's actions (Fanon, 2008; Spanos, 2007). Finally, because it acknowledges social forces, postcolonial theory invites solutions that extend from the individual level to policy and the social foundations of health (Anderson et al., 2009; Kirkham & Anderson, 2002). In sum, postcolonial theory incorporates examination of social forces sometimes overlooked in cross-cultural research and frames the study in such a way to appreciate diversity. However, it will also acknowledge that participants' inner thoughts and feelings ultimately determine actions. Such personal interpretations are consistent with the theoretical assumptions of symbolic interactionism and American pragmatism which underly classical grounded theory (citation).

Symbolic interactionism and American pragmatism. The type of grounded theory (Glaser & Strauss, 1967) used in this study—dimensional analysis—is rooted in symbolic interactionism and American pragmatism (Blumer, 1969; Bowers, 1988; Bowers & Schatzman, 2009; Kools, McCarthy, Durham, & Robrecht, 1996; Robrecht, 1995). Symbolic interactionism, which injects the psychological processing of ideas into understanding behavior, evolved from the social psychology movement in the 1920s that rejected the dominant deductive sociological theory-testing approach (Bowers, 1988). Three main premises form the foundation of symbolic interactionism: (a) human beings act towards things based on the meanings the thing carries for them, (b) those meanings are derived through social interactions, and (c) the meanings are adjusted after persons have interpreted the social interactions (Blumer, 1969). In other words, symbolic interactionism holds that people act in ways that reflect meanings derived through social interaction as well as personal reflection (Blumer, 1969; Bowers, 1988; Bowers & Schatzman, 2009; Kools et al., 1996; Robrecht, 1995). The other philosophy giving rise to grounded theory is American pragmatism. It is a philosophy that assesses scientific truth and meaning through their utility and consequences (Charmaz, 2014; Powers & Knapp, 2011), describes reality as fluid, (Blumer, 1969; Bowers, 1988; Bowers & Schatzman, 2009; Charmaz, 2014; Kools et al., 1996; Robrecht, 1995), and accepts abductive “best-guess” logic (Charmaz, 2014). Together, symbolic interactionism and American pragmatism fostered the paradigm shift from deductive theory-testing to inductive grounded theory construction to describe social processes. For purposes of this dissertation, this distinction between deductive and inductive inquiry is profound. The distinction can be described as the difference between conducting cross-cultural research with surveys created by Whites for Whites versus open-ended interviews in which the U.S. Mexican participants are empowered to identify what is most important to them during hospice decision-making. Grounded theory, therefore, offers flexibility and fluidity necessary to adequately understand the inner decision-making processes of U.S. Mexicans. However, symbolic interactionism and American pragmatism do not include an explicit consideration of unequal power dynamics and oppression. Consequently, it is imperative to employ critical grounded theory and the overarching philosophical postcolonial framework.

In summary, the research methodology used in this dissertation—critical grounded theory—is represented by a combination of the philosophies found in postcolonial theory, symbolic interactionism, and American pragmatism. Critical grounded theory assumes unequal power dynamics that can be mitigated through data collection processes that bring marginalized voices into the open for consideration.

Conclusion

Although there has been considerable research on cultural preferences among Hispanics at EOL, the research literature remains mostly silent on the contributions of mistrust and discrimination to EOL and hospice decision-making. This dissertation aims to address this knowledge gap, specifically through a critical grounded theory study with U.S. Mexicans with terminal cancer and their families. Having acknowledged the Eurocentric bias in the research literature, I decided a goal of this dissertation would be to privilege the voices of marginalized U.S. Mexicans who may have been previously underrepresented in the research literature.

The subsequent chapters in this manuscript dissertation offer evidence toward the ultimate goal of describing the process of hospice decision-making in U.S. Mexicans with terminal cancer and their families. Chapter 2 is a concept paper exploring the preference for prognostic secrecy in Hispanics. Chapter 3 is a systematic integrative review of the research literature on Hispanics and hospice. Chapter 4 is a systematic integrative review and meta-analysis of the research literature on Hispanic hospice utilization. Chapter 5 presents study results. Study interviews occur with guidance and approval from the Oregon Health & Sciences University Institutional Review Board as well as a community advisory board comprised of knowledgeable and experienced U.S. Mexicans professionally engaged with U.S. Mexicans with terminal cancer and their families. Chapter 6 is a discussion and summary of the dissertation and explains the implications for practice.

In compliance with OHSU School of Nursing Doctor of Philosophy Program Guidelines (2013–2014), the purpose and knowledge contribution of each chapter are summarized in Table 1.

Table 1

Summary of Chapters

Chapter	Purpose	Knowledge Contribution
1 Introduction	Introduction to scope of dissertation	Explains significance and need for proposed research
2 Concept	Prognostic secrecy at end-of-life in Hispanic culture	Appreciates different cultural approaches to EOL that bear on hospice decision-making
3 Review	Integrative review of research literature on Hispanics and hospice	Understands current state of the research literature on Hispanics and hospice
4 Meta-analysis	Meta-analysis of database articles on Hispanics and hospice	Understands whether Hispanics are using hospice at rates comparable to Whites
5 Research	Substantive grounded theory of hospice decision-making	Describes the process of hospice decision-making in U.S. Mexicans
6 Final	Interpretation, summary, and implications of all manuscripts	Identifies strengths, weaknesses, and future research suggestions

References

See Cumulative References.

Chapter II

Truth-Telling as an Element of Culturally Competent Care at End of Life (EOL)

Margaret L. Rising, BSN, RN, PhD Candidate

Oregon Health & Science University School of Nursing, Portland, OR, U.S.A.

This manuscript is a concept paper that supplements the literature review because prognostic secrecy is frequently cited in the research literature as a potential explanation for avoidance of hospice in the Hispanic culture. Ms. Rising is the sole author on this paper. She received subsequent editorial advice from Dr. Patricia H. Berry, RN, PhD, FAAN, and Dr. Frances Lee-Lin, RN, PhD and publishing advice from Dr. Janice Crist, RN, PhD, FNGNA, FAAN. This paper was published (Rising, 2017) in the *Journal of Transcultural Nursing*, which is an indexed and peer-reviewed journal with an impact factor of 1.111. The readership for this journal includes nurses, educators, researchers, and practitioners seeking theoretical approaches to the delivery of culturally congruent health care.

Funding Acknowledgments

This work was supported by the Doctoral Degree Scholarship in Cancer Nursing, DSCN-15-077-01 from the American Cancer Society, and also supported through grants and scholarships from the OHSU Hartford Center of Gerontological Excellence, the Hearst Foundation, and the Oregon Health and Science School of Nursing.

Declaration of Conflicts of Interest

None

Abstract

Nondisclosure of terminal prognosis in the context of intercultural interactions can cause moral distress among healthcare providers guided exclusively by informed consent. However, cultural humility can show that revealing and withholding prognostic information are two equally valid paths to the goal of protecting the patient from harm. Assumptions and history giving rise to the preference for truth-telling in the United States are examined. Principles of biomedical ethics are described within the context of United States, Chinese, and Latin American cultures. The Process of Cultural Competence in the Delivery of Healthcare Services is explained and introduces the concept of cultural humility. By focusing more on biases and assumptions brought forth from the dominant culture, healthcare providers may experience less moral distress and convey increased caring in the context of intercultural interactions and nondisclosure of prognosis of a terminal illness.

Key words: prognostic secrecy, truth-telling, prognostic discussion, prognostic withholding, end-of-life care, nursing practice, transcultural care

> Today I bent the truth to be kind, and I have no regret, for I am far surer of what is kind than I am of what is true.
>
> — Robert Brault

Introduction

A Chinese grandmother is in the hospital and dying of cancer. Her daughter serves as medical interpreter for several days. It is thought, but not confirmed, that the daughter is not telling the patient everything the doctor states about the grandmother's poor prognosis. Alone with the patient and the medical interpreter on the phone, the bedside nurse asks, "Do you have any questions for me?" to which the grandmother asks, "Am I going to die?" What is a culturally appropriate and ethical answer that does not cause moral distress for the nurse?

Truth-telling, or revealing a terminal diagnosis or prognosis, is routinely practiced in the United States (U.S.), where informed consent and patient autonomy are dogmatically enforced in the healthcare setting. Yet most U.S. healthcare workers have experienced scenarios involving nondisclosure of terminal prognosis, frequently in the context of caring for patients from non-dominant cultures. Nondisclosure runs contrary to the dominant culture of truth-telling of terminal prognosis in the U.S., which is rooted in the fundamental Western medical ethical tenet of patient autonomy. Although healthcare workers are taught to be tolerant and accommodating of the beliefs and practices of non-dominant cultures, they are not necessarily taught how to resolve any moral distress or personal ethical dilemmas resulting from delivering care inconsistent with their own deeply ingrained beliefs and values. They may be compelled and yet unable to speak the truth in a gesture of care or advocacy for the patient. Reconciling the values underlying nondisclosure and truth-telling may hold the key to minimizing such moral distress and may also improve patient care.

Such a reconciliation of values requires a review of the socio-historical and biomedical ethical roots of disclosure practices in dominant and non-dominant cultures. Only then can one appreciate the value-laden and culturally specific assumptions underlying disclosure preferences. Using examples from two of the fastest growing minority populations and collectivist cultures in the U.S.–Chinese and Latin Americans—this article compares the distinct impact of truth-telling in Western versus collectivist cultures. To mitigate potential moral distress for healthcare workers and enhance culturally competent care, this article promotes the concept of cultural humility introduced in the cultural competence model developed by Campinha-Bacote (2002). With a fresh perspective, recommendations for practice are then suggested.

Truth-Telling in the United States

The current practice of truth-telling of terminal prognosis reflects the relatively recent adoption of informed consent and patient autonomy as guiding biomedical ethical principles in the U.S. clinical setting (Will, 2011a, 2011b). Paternalism, including nondisclosure, had been practiced by physicians since Plato (Plato, trans. 1991) and Hippocrates (Garrett, Baillie, Garrett, & McGeehan, 2009). For 2,400 years, Western medical practitioners practiced medical paternalism through benevolent deception (Will, 2011a). A survey of U.S. physicians in 1961 showed that 88% did not routinely discuss a cancer diagnosis with patients; whereas, in 1979, 98% routinely had such discussion (Novack et al., 1979). This shift occurred as the result of a confluence of world and domestic events, social movements, and philosophical debates.

Advocacy for and dialogue about informed consent evolved over the last 200 years in a variety of settings. Within the medical profession, liberal-minded physicians during the 1700s advocated for truth-telling with patients within the constraints of paternalism (Will, 2011a). Among philosophers in the 1800s, the ideal of self-rule in a liberal society was described by John

Stuart Mills. As an extension of self-rule, Mills proposed that individuals should have the freedom to think and choose rationally and also have guardianship over their minds and bodies, giving rise to the ideal of self-determination (Holstein, Parks, & Waymack, 2010). The first legal reference to the right of informed consent in the medical setting in the U.S. is stated in a New York appellate case in 1914 (Will, 2011b). Subsequently, the Nuremberg trials after World War II heightened the public's awareness of voluntary informed consent in the research setting (Will, 2011b). In the 1960s, within the context of the Civil Rights movement in the U.S., Henry Beecher exposed continued unethical research practices (Beecher, 1966; Will, 2011b) that brought about public outrage (Will, 2011b). Inciting the lay population further, the cases of Karen Quinlan in the 1970s and Nancy Cruzan in the 1980s stirred public debate over the rights of patients to control their own destiny (Brown, 2003). In those cases, Western advances in medical technology had brought physician paternalism into conflict with the philosophical and social movements gripping the U.S. psyche. Western medical advances forced an assessment of whether physician paternalism or individual self-determination should determine the destiny of our minds and bodies in the context of life prolonging medical therapies.

The widely applied four principles of biomedical ethics articulated by Beauchamp and Childress were published in 1979 as a result of biomedical ethical debates of the time (Beauchamp & Childress, 2013). Patient autonomy, facilitated by informed consent, became a controlling guideline in clinical interactions and guidelines from U.S. professional societies and governing agencies. Today, the American Nurses Association's Code of Ethics states specifically that respect for the dignity of individuals requires informed consent in recognition of the rights of self-determination and autonomy (Fowler, 2008). Likewise, The Joint Commission requires informed consent (The Joint Commission, 2015). The ethical principle of patient autonomy is embraced in the U.S. to resolve the tension between our liberal ideals of self-rule and Western advances in medicine. However, not all countries experienced the same advances in medical technology, nor are their philosophies guided by liberal ideals of self-rule.

Truth-Telling in China and Latin America

Approximately one-fourth of the U.S. population is represented by Asians and Hispanics originating from Latin America (Ennis et al., 2011; Hoeffel, Rastogi, Kim, & Shahid, 2012). They experience healthcare encounters in the U.S. without the same collective social history shaping their values and beliefs as individuals raised in the U.S. For illustrative purposes, their cultures provide good exemplars of non-dominant cultural practices to contrast against U.S. practices. Contrary to the U.S. emphasis on self-determination and rugged individualism, Chinese and Latin American families may be more collectivistic, family-centered, and influenced by filial piety, or a duty to respect, care for, and protect older adults (Blackhall et al., 2001; Chen & Fan, 2010; Fan, 2011; Frank et al., 2002; Gutheil & Heyman, 2006; Kreling et al., 2010; Lee, Hinderer, & Kehl, 2014).

Considerable support is found in the literature for the inference that truth-telling in collectivistic and family-centered cultures is perceived as harmful to the patient. Within Latin American cultures, some individuals have expressed the belief that truth-telling can cause psychological harm by extinguishing hope or cause physical harm by expediting death (Blackhall et al., 2001; Frank et al., 2002; Gelfand, et al., 2001; Gutheil & Heyman, 2006; Kreling et al., 2010). A “conspiracy of silence” in Latin America frequently prevails, owing to the family’s wishes to withhold prognosis and the physicians’ lack of specialized end-of-life communication skills (Garcia-Reyes, Lara-Solares, Guevara-Lopez, Flores-Rebollar, & Loaeza Del Castillo, 2008; Ramirez, 2014). This withholding of prognostic information occurs in spite of evidence that Latin American patients would want to know their diagnoses (Wul et al., 2007). As a consequence, patients of Latin American descent residing in the U.S. know very little and inquire very little about their terminal illnesses (Costas-Muniz et al., 2013). Withholding knowledge of a poor prognosis results from the desire to protect the patient from bad news combined with a tradition of physician paternalism similar to that in recent U.S. history. Such an aversion to talking directly about death is not unheard of in any culture, but the aversion is buoyed in the Latin American culture by protective communication styles, which tend to occur in more collectivistic and family-centered cultures. In China, however, withholding knowledge of a poor prognosis has distinctly different cultural roots.

Aversion to truth-telling in China stems from familial paternalism promoted by Confucianism (Fan, 2011). There, paternalistic protection of the terminal patient from delivery of poor prognostic information is in overt deference to the wisdom of the family and the expectation to maintain harmonious family relations, which are consistent with the strong influences of Confucianism (Chen & Fan, 2010). The physician is expected to first reveal the prognosis to the family who, based on their superior knowledge of the patient’s disposition, will decide whether to reveal a terminal prognosis (Chen & Fan, 2010; Fan, 2011). This traditional view has been challenged more recently and there is evidence that a majority of patients in China would want to be told a terminal prognosis (Li et al., 2012).

Collectivistic and family-centered values influencing individuals from China and Latin America are not only associated with a higher tendency toward a preference for nondisclosure (Blackhall et al., 2001; Chen & Fan, 2010; Fan, 2011; Frank et al., 2002; Gelfand et al., 2001; Gutheil & Heyman, 2006). There is also a tendency toward high-context communication styles (Blackhall et al., 2001; Frank et al., 2002). Therefore, perhaps the primary difference is not in what is said but in how it is said. A study by Lipson and Dibble (2005) across 35 cultural groups supports the conclusion that much of the world experiences truth-telling as a more nuanced, complicated, and social phenomenon than does the dominant U.S. culture. A case study by Frank et al. (2002) illustrates how one Hispanic informant told contradictory stories about prognosis awareness to allow anticipation of death while maintaining hope. Therefore, truth-telling and direct communication of a terminal prognosis embraced by a patient-autonomy approach to end-of-life care may be incongruent with collectivistic and family-centered communication styles.

Although these views from Latin America and China may appear paternalistic and contrary to the dominant U.S. culture of patient autonomy, they are based on equally valid medical ethical principles. Introduced in the next section, these ethical principles provide the underlying rationale for nondisclosure of prognosis among individuals influenced by Chinese and Latin American cultures. These principles, as well as patient autonomy, are intended to protect patients from harm.

Biomedical Ethical Principles through a Cultural Lens

Even though healthcare workers in the U.S. protect the patient primarily through the ethical principle of patient autonomy, individuals influenced by Chinese and Latin American cultures may have a preference to protect the patient within the context of a terminal prognosis by giving greater relative merit to the biomedical ethical principles of beneficence (doing good) and non-maleficence (not doing bad; Beauchamp & Childress, 2013; Garrett et al., 2009). Beneficence and non-maleficence are also considered by U.S. bioethicists but were given a more supporting role when policy, law, and public opinion in the 1970s shifted support to patient autonomy and obtaining informed consent. However, moral values are culturally relative, and so provision of culturally appropriate care at EOL should increase consideration of beneficence and non-maleficence where culturally appropriate (Elliott, 2001). In fact, professional organizations and accrediting agencies in the U.S. that have uniformly adopted patient autonomy as a controlling ethical principle still consider beneficence and non-maleficence (Fowler, 2008; The Joint Commission, 2015). The relative priority given to these biomedical ethical principles should be fluid and dynamic in intercultural interactions, acknowledging the relative morals emerging from divergent socio-historical and cultural contexts.

The dominance of the ethical principle of patient autonomy in the U.S. emerged from scholarly debates which were narrowly defined by patriarchal socio-historical and cultural influences of the West and founded on the assumption that acting on one’s own free will is superior to an external locus of control. Collectivism and family-centered cultures such as China and Latin America give rise to different morals and assumptions such that autonomy and truth-telling can be isolating and burdensome (Elliott, 2001). There, duty to family prevails in the form of beneficence and non-maleficence. One explanation for a dominant biomedical ethical principle that does not reflect the morals and cultural values of a large portion of the world’s population is that biomedical ethical debates giving preference to patient autonomy were dominated by white American males whose depictions of ethical dilemmas may not be generalizable to others (Holstein et al., 2010). The self-determination and liberal society espoused by John Stuart Mills was a reflection of the views of white males and not necessarily those of families from collectivist cultures. Understanding the assumption of the superiority of self-determination, individualism, and patient autonomy in U.S. culture is the key to respecting collectivism, beneficence, and non-maleficence in intercultural interactions involving non-dominant cultures. In the clinical setting, awareness of one’s own cultural biases and assumptions introduces empathy into the relationship with individuals from other cultures.

Implications for Practice: Cultural Humility

Cultural Competence Model

Through awareness of self and empathic understanding of others, the cultural competence model (Campinha-Bacote, 2002) is unique in promoting cultural humility in intercultural interactions. The five concepts of the cultural competence model are cultural awareness, knowledge, skill, encounters, and desire. Cultural awareness emphasizes cultural *self*-awareness of biases and assumptions, and it is distinguishable from cultural knowledge about the language, customs, values, and beliefs of other cultures. Cultural *knowledge* is appreciating that individuals influenced by Chinese or Latin American cultures may be inclined to prefer nondisclosure of prognosis; whereas, cultural *awareness* is appreciating that American self-determination and individualism may not be something such a patient values. The other three concepts of the model—cultural skill, cultural encounters, and cultural desire—can be described, respectively, as receptiveness to new cultural information, practicing and engaging in cross-cultural interactions, and experiencing intercultural interactions positively rather than reluctantly. Cultural humility levels the cultural power dynamic, and so it is qualitatively different from cultural sensitivity and tolerance, which retain an inherent assumption that patient autonomy is the ideal means to protect patient rights.

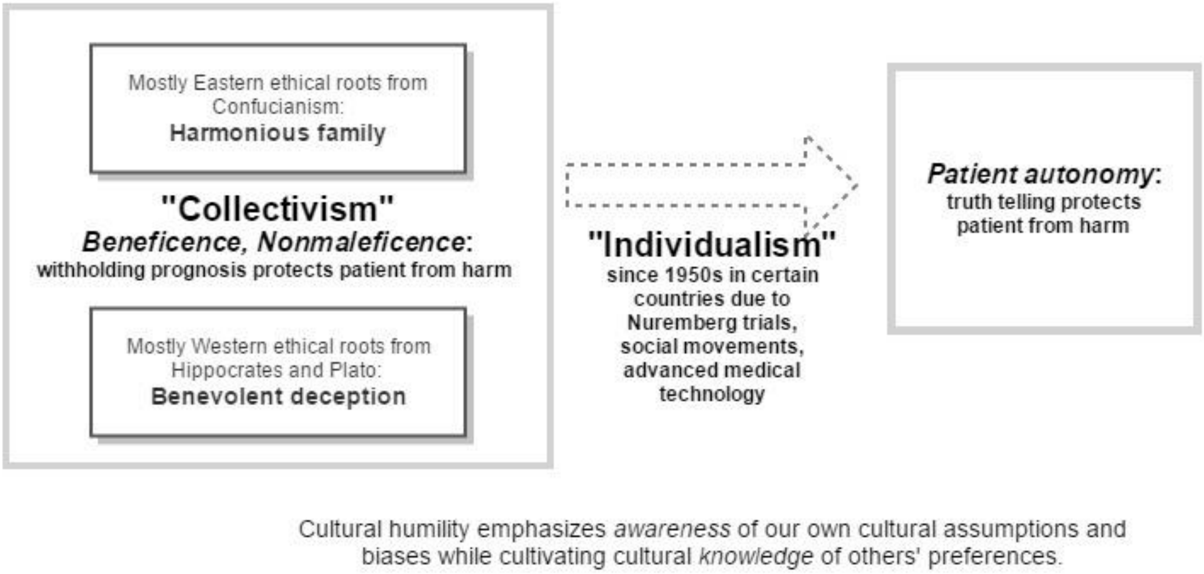

Figure 1. The relatively recent development of patient autonomy and its roots in beneficence and non-maleficence.

The socio-historical framework depicted in Figure 1 facilitates understanding of the self-awareness and cultural knowledge elements of the cultural competence model. It illustrates that, prior to the 1950s and the development of individualism in the dominant culture, Eastern and Western cultures embraced the biomedical ethical principles of beneficence and non-maleficence as a strategy to protect patients from potential harm caused by truth-telling. The biomedical ethical principle of patient autonomy dominated only after recent unique socio-historical events reflecting a preference for individualism in the dominant culture. That this paradigm shift occurred is not generally taught to modern healthcare workers within the dominant culture. Instead of appreciating the shared biomedical ethical histories, modern healthcare workers in the dominant culture are exclusively taught tolerance and accommodation of non-dominant cultural preferences, which tend to highlight differences and promote an uneven power dynamic. Recognizing the historically similar approaches to truth-telling between dominant and non-dominant cultures promotes empathic understanding that supports cultural humility as described in the cultural competence model.

As a result of the shift in the cultural power dynamic inherent in the cultural competence model, intercultural clinical outcomes may improve for patient and healthcare worker. Approaching intercultural encounters with cultural humility conveys caring, which may be more important in relationship-building than knowledge (Campinha-Bacote, 2002). Cultural humility signals mutual positive regard and acknowledges the existence of equally valid alternative means of respecting patient dignity either through autonomy or beneficence and non-maleficence. For the healthcare worker, moral distress may be mitigated by cultural self-awareness because it is no longer a foregone conclusion that the dominant culture's view is necessarily best for the patient. The spirit of the cultural competence model is captured by the Wade Davis quote, "The world in which you were born is just one model of reality. Other cultures are not failed attempts at being you; they are unique manifestations of the human spirit" (Goodreads, 2015). A sincere appreciation that both paths lead to the same value—protecting the patient—may reduce the moral distress experienced when caring for patients from whom the truth about prognosis is being withheld.

The cultural competence model and nondisclosure of prognosis are consistent with professional ethics codes and the legal system. Provision 8.2 of the ANA Code of Ethics states that a "nurse should avoid imposition of the nurse's own cultural values upon others" and should use approaches and care that reflect "awareness and sensitivity" (Fowler, 2008, p.165). To avoid cultural imperialism, as the Code of Ethics suggests, one must be self-aware of one's own culture. In the U.S., the Joint Commission requires in RI.01.03.01 that a hospital allow for exceptions to obtaining informed consent (The Joint Commission, 2015). Outside of the U.S., Joint Commission International more specifically acknowledges in PFR.2.1 that patients can opt out of informed consent and participate in their care by designating another person as their decision maker (Joint Commission International, 2015). Furthermore, the U.S. courts have held that a medical doctor is not obligated to disclose risks when the patient has requested not to be informed (Freedman, 1993). In summary, healthcare workers are not only advised to avoid the imposition of their cultural values on others, they also have legal and ethical permission to permit nondisclosure of terminal prognosis.

Intra-Cultural Variability

Any examination of cultural preferences invites stereotyping unless it is done with the knowledge that individualism is found within all cultures and ultimately dictates choices. In other words, a person from a collectivist culture may make choices in an individualistic or collectivistic manner. In the clinical setting this means that persons from cultures in which nondisclosure is prevalent may, nonetheless, prefer truth-telling. Therefore, an awareness of biases and assumptions of our own and other cultures should be employed to minimize the risk of stereotyping. The general rule is that more variation exists within cultures than among them (Campinha-Bacote, 2002). Rather than seeking the essence of Chinese or Latin American patients based on the research literature or prior encounters, healthcare providers should be flexible and prepared for a spectrum of preferences, known only after an assessment of individual and family.

Illustrative of the importance of individual variation are the results of a recent multiethnic study of 60 older adults in San Francisco (Ahalt et al., 2012). Researchers presented a hypothetical scenario in which doctors believed the patient had less than one year to live. Although this was not a quantitative study, it provided an opportunity to see that, with this small sample, approximately 75% of Chinese adults (15 of 19) and Latino adults (7 of 11) wanted truth-telling. Equally interesting was that approximately 15% of White adults (2 of 14) wanted nondisclosure. Across groups, the participants in the study stressed that preference for prognostic information is a personal choice and doctors should ask before sharing. Accordingly, regardless of culture, best practice is to inquire what the patients know, what they want to know, and who they want to know it (personal communication, M. Smith, October 20, 2014).

Recommendations for Practice: Assessment Matters

Culture, therefore, requires sensitivity and humility, but if individuality trumps culture, then culture can also be irrelevant. Many have written about what *a priori* role culture should play in our patient encounters. One possibility is to consider culture a heuristic device (Turner, 2005) that is as easily discarded as considered, but at least gives notice that previously held assumptions and biases might be inapplicable. Another approach is entirely culture-free, focusing instead on patient cues. A third option is “offering truth,” in which the healthcare professional listens and the patient speaks, allowing the patient to control the pace and content of the conversation (Freedman, 1993). The result is that the patient maintains autonomy by choosing how much information is conveyed. Truth-telling should be tailored to the individual’s needs, and those might change with time (Gold, 2004), which emphasizes the importance of continually assessing patient preferences. Assessing patient preferences by using culture as a heuristic device or waiting for patient cues is consistent with the cultural competence model because neither forces the dominant view on another nor does it presume culture preferences.

A second consideration that spans across cultures is the importance of hope. The fear underlying truth-telling of prognosis in the clinical setting is extinguishing hope and the consequences of extinguishing hope for the patient. Hope, according to the Greek legend of

Prometheus, is what makes the rest of our human experience bearable (Begley & Blackwood, 2000). Latin American informants mention extinguishing hope in the context of the fear of hastening death (Blackhall et al., 2001). Anecdotal accounts and research studies support the inference that extinguishing hope may actually expedite death. In his writings about finding meaning in life, Viktor Frankl observed that hope was an integral component to surviving the concentration camps of World War II (Frankl, 1959/2006). Evidence from a prospective cohort study from Korea, which is a collectivist and family-centered culture, supports the inference that awareness of a terminal prognosis in a palliative care ward decreased survival time and quality of life (Kim et al., 2013). In contrast, among Westerners, it is generally accepted that hope is not lost, and in fact outcomes are better, when patients are fully informed of poor prognoses (Mack & Smith, 2012; Smith et al., 2010). In the West, patients on hospice (Benzein, Norberg, & Saveman, 2001) and with terminal illnesses (Reinke, Shannon, Engelberg, Young, & Curtis, 2010) tend to redefine the meaning of hope as EOL approaches. Research on the effect of prognostic information on hope and survival is evolving. However, its full understanding is not necessary to practice cultural humility and fully respect patient and family preferences.

A final recommendation for practice is to consider whether the prognostic truth we wish to deliver is actually accurate or, alternatively, will be understood in the intended manner. It is unlikely that anyone can be certain of the truth, particularly with regard to prognosis. As the Robert Brault quote at the beginning of this article implies, humans may have a better intuitive sense of what is kind than a scientific certainty of what is true. The layperson’s belief in the fallacy of physicians’ ability to prognosticate with one-hundred percent accuracy is reflected in the study mentioned previously by Ahalt et al. (2011) in which some of the participants who did not want to know prognosis explained that they did not trust the accuracy of the prognosis. A second consideration is not whether physicians are speaking the truth but whether patients and families will hear the truth in such a way as to maintain the fidelity of the intended message. Misunderstandings about prognoses have many explanations, including the lack of cognitive context (Kirklin, 2007) for patients and families to fully understand the impact and significance of what physicians are stating. A modification of what is stated and what is heard also is explained by the tendency of surrogate decision makers to overestimate prognosis based on personal information about the patient (Zier, Sottile, Hong, Weissfield, & White, 2012). Moral distress resulting from nondisclosure of a terminal prognosis assumes the prognosis is correct or will be understood. An appreciation that the prognosis may be wrong or misunderstood may soften the distress caused by nondisclosure.

Returning to the vignette from the beginning of this article, what should the bedside nurse tell the Chinese grandmother who asked through the medical interpreter whether she was going to die? The suspicion that the translating daughter was not conveying prognostic information offered by the physician seems to be borne out by the grandmother's question. Answering her question honestly—truth-telling—would support the grandmother's autonomy and satisfy the dominant culture's preference for informed consent. But, would this be a form of cultural imperialism or honest and empathic communication? Regardless, a truthful and direct response would likely cause family distress and upheaval and loss of trust. Some nurses would not consider prognosis discussions within their scope of practice and would seek collaboration with the physician (Reinke et al., 2010). Another possibility is to call the daughter to inform her that her mother is asking for prognostic information and confirm that it is the daughter's intention to withhold such information and further explore that subject. Regardless of how the grandmother's question is answered, the high-context nature of communication in collectivist cultures had already engendered suspicion on the grandmother's part, and so a lack of reassurance that she is *not* going to die may convey sufficient truth for her to know. As the Japanese film producer Akira Kurosawa portrays in the movie *Ikiru* (Kurosawa, 1952), even when benevolent health providers purposefully withhold a prognosis, a patient has ways of knowing. Without more information, there can be no right or wrong answer. However, cultural humility in this instance would allow the nurse to be *aware* of and resist her bias toward patient autonomy and truth-telling. Moral distress would be mitigated by the *knowledge* that beneficence is a culturally accepted manner in which to protect the patient from harm.

Conclusion

Lack of *self*-awareness about one's own culture can interfere with culturally competent care and contribute to moral distress. When encountering a terminally ill patient from a non-disclosing culture, it is important to resist the tendency toward ethical imperialism and strive, instead, to accept that views from non-dominant cultures are based on the desire to protect the patient from harm. For many in the U.S., individualism, self-determination, and autonomy epitomize what it means to be an American. These values are found at the core of the biomedical ethical principle of autonomy which forms the foundation for U.S. laws and ethics. However, collectivist cultures tend to value the family more than the individual, which can promote a preference for protecting the patient via the ethical principles of beneficence or non-maleficence. In many such cultures, the names Quinlan and Cruzan have not been heard, there has been no civil rights movement, there have been no Nuremberg trials, and there have been no public debates about patient autonomy. Combining cultural *self*-awareness with *knowledge* about other cultures contributes to cultural humility, which allows the possibility that truth-telling and nondisclosure are equal solutions to the same goal of providing dignified patient care.

References

See Cumulative References.

Chapter III

Integrative Review of the Literature on Hispanics and Hospice

Margaret L. Rising, BSN, RN, PhD Candidate

Oregon Health & Science University School of Nursing, Portland, OR, U.S.A.

Dena Hassouneh RN, PhD, FAAN

Oregon Health & Science University School of Nursing, Portland, OR, U.S.A.

Kristin Lutz, RN, PhD

Oregon Health & Science University School of Nursing, Portland, OR, U.S.A.

Chris Lee, RN, PhD

Connell School of Nursing, Boston College, Chestnut Hill, MA, U.S.A.

Patricia H. Berry, RN, PhD, FAAN

Oregon Health & Science University School of Nursing, Portland, OR, U.S.A.

This manuscript is a data-based paper submitted in partial fulfillment of the required literature review with a focus on data reflecting Hispanic patient preferences around hospice. Ms. Rising is the primary author on the paper; Dr. Hassouneh is the senior author on the paper. In memory of Dr. Frances Lee-Lin, this paper was published (Rising, Hassouneh, Lutz, Lee, & Berry, 2018) in the *American Journal of Hospice and Palliative Medicine*, which is an indexed and peer-reviewed journal with an impact factor of 0.969. The readership for this journal reflects the multidisciplinary approach to hospice and palliative medicine by including nurses, social workers, chaplains, and physicians.

Abstract

Effective end-of-life (EOL) and hospice care requires consideration of the specific needs of the individual, including cultural and socioeconomic influences. The purpose of this paper is to review what is represented in the research literature about Hispanic hospice preferences. Using computer research databases and inclusion and exclusion criteria, this integrative review systematically identifies and reviews articles relating to Hispanics and hospice. Twenty-one articles are reviewed. Many are survey and low-inference qualitative designs with limited validity and trustworthiness. Most survey instruments were not validated for Spanish language or Hispanic culture. None of the qualitative studies included theoretical sampling or follow-up interviews. Few study designs considered heterogeneity within the Hispanic population. Interpreting results cautiously, there is evidence that some Hispanics find some satisfaction with hospice care in spite of cultural incongruities and socioeconomic challenges. Future research calls for intervention studies and high-inference qualitative designs to gain insight into hospice experiences and what constitutes quality hospice care from the perspective of Hispanic subgroups. Assessing quality and designing interventions for these EOL cultural and socioeconomic issues will improve EOL care and facilitate the hospice philosophy of promoting emotional growth at EOL.

Key words: Hispanic Americans, Latino/a, Hospice, End of life, Terminal prognosis, Non-disclosure of terminal prognosis

Funding Acknowledgments

This work was supported by the Doctoral Degree Scholarship in Cancer Nursing, DSCN-15-077-01 from the American Cancer Society, and also supported through grants and scholarships from the OHSU Hartford Center of Gerontological Excellence, the Hearst Foundation, and the Oregon Health & Science School of Nursing.

Declaration of Conflicts of Interest

None

Introduction

Enrolling in hospice care can be daunting for Hispanics because of discordant cultural preferences and unique socioeconomic considerations. Open discussions of terminal prognoses and informed decisions to decline curative medical therapies are integral aspects of enrollment in hospice care and the Medicare hospice benefit in the United States (U.S.; National Hospice and Palliative Care Organization, 2015). In stark juxtaposition, some Hispanic individuals prefer more nuanced prognostic discussions; at times, families prefer to withhold prognostic disclosure from the patient entirely (Rising, 2017). Combined with cultural considerations are harsh socioeconomic realities for some Hispanics because of immigrant status, poverty, or lack of healthcare and life insurance. Distinct from most hospice patients, marginalized Hispanic persons may have additional needs, such as for insurance coverage to pay for hospice care (Jaramillo & Hui, 2016) or the desire to return to their home country to die (Selsky et al., 2012). Given the cultural relativity of a “good death” (Field & Cassel, 1997, p. 24), the Institute of Medicine has called for improved culturally competent care at EOL (Institute of Medicine, 2014), including hospice care. General Hispanic cultural healthcare preferences have been described (Carteret, 2011; Del Río, 2010; Juckett, 2013; Talamantes, 2000; Tellez-Giron, 2007; Warda, 2000) but do not include hospice-specific cultural preferences and socioeconomic needs. The purpose of this systematic review is to explore the current state of the science on Hispanic hospice utilization, particularly cultural and socioeconomic barriers.

Cultural Assumptions of U.S. Hospice Care

Hospice philosophy and enrollment reflect its Western individualistic roots. Originating in England in the 1960s (Clark, 2007), hospice care is patient-centered EOL care provided by an interdisciplinary healthcare team, including physicians, nurses, social workers, and chaplains, that focuses on symptom control, comfort, and quality of life (National Hospice and Palliative Care Organization, 2015). An estimated 1.6 to 1.7 million U.S. patients receive hospice care, with 85.5% paid for by the Medicare hospice benefit (National Hospice and Palliative Care Organization, 2015). Philosophically, in acknowledging terminal prognoses, hospice creates an opportunity to prepare for death and experience emotional growth during the last phase of life (National Hospice and Palliative Care Organization, 2010). By extension, the Medicare-driven hospice enrollment process emphasizes open prognostic discussions by requiring (a) an informed decision to accept care focused on comfort rather than cure in light of a terminal prognosis and (b) a physician’s certification that a patient has six months or less to live if the disease runs its usual course (National Hospice and Palliative Care Organization, 2015). Such truth-telling around terminal prognoses is predominantly Eurocentric and is not as prevalent in the Hispanic culture (Rising, 2017). This cultural clash is exacerbated by the negative connotations of the Spanish word “*hospicio*,” which suggests orphanage or poorhouse in Mexico (*hospicio*, 2014).

Characteristics of the Hispanic Ethnic Category

U.S. Hispanics are a mosaic of people and cultures with varying access to healthcare resources. Hispanics are persons of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race (Ennis et al., 2011). At 56.6 million, or 17.6% of the total U.S. population, Hispanics are the largest minority ethnic group in the U.S. today (United States Census Bureau, 2016). The three most populous U.S. Hispanic subgroups trace ancestry to Mexico (63%), Puerto Rico (9.2%), and Cuba (3.5%; Ennis et al., 2011). Socioeconomically, U.S. Hispanics are at a significant disadvantage relative to non-Hispanic Whites (NHWs; Kochhar & Fry, 2014). The collectivist nature of Hispanic cultures promotes *familismo, respeto,* and *fatalismo*, which refer to an emphasis on family, respect for authority, and fatalism, respectively (Carteret, 2011; Del Río, 2010; Juckett, 2013; Talamantes, 2000; Tellez-Giron, 2007; Warda, 2000). Hispanic subgroups are not a culturally or socially homogenous group, which has implications for health care (Del Río, 2010; Talamantes, 2000; Weinick et al., 2004). For instance, the strong indigenous heritage in Mexico may influence folk beliefs and healthcare preferences (Andrews, Ybarra, & Matthews, 2013; Del Río, 2010; Juckett, 2013). In addition, Mexicans are less likely than Puerto Ricans and Cubans to have access to Medicare and Medicaid (Krogstad, 2015; "Persons born in Puerto Rico on or after April 11, 1899," 1952). Federal insurance that would pay for hospice services remains elusive for an undetermined number of undocumented Mexican immigrants in the U.S. (Krogstad & Passel, 2015) and Mexicans with U.S. citizenship in the five-year waiting period for federal insurance (U.S. Centers for Medicare and Medicaid Services, 2016). Homogenizing Hispanics glosses over these diverse Hispanic cultural preferences and socioeconomic needs. In spite of its shortcomings, researchers rely on the Hispanic ethnic label in most of the articles selected for review.

Systematic Article Selection

Articles for this review were systematically selected (McMaster University, 2013; PRISMA, 2015) using computer research databases. The goal was to identify research articles on Hispanic hospice knowledge and attitudes. A combination of the words “Hispanic” and “hospice” were entered into three databases. In OVID Medline (R) 1946 to January week 2, 2017, those words routed to the medical subject heading (MeSH) “Hispanic Americans” (exploded) OR keyword Hispanic AND to the MeSH for “Hospices” (exploded) OR keyword hospice. In PsycInfo 1806 to January week 2, 2017, search words routed to the MeSH for “Latinos/Latinas” (exploded) OR keyword Hispanic AND to MeSH “Hospice” (exploded) OR keyword hospice. In Scopus 1995 to January 14, 2017, the words Hispanic AND hospice were combined as title/abstract/keyword. For example, from PsycInfo:

#1	Latinos/Latinas (subject heading) (explode) OR Hispanic (keyword)	35,006 articles
#2	Hospice (subject heading) (explode) OR Hospice (keyword)	4,319 articles
#3	#1 AND #2	72 articles

Combined OVID Medline, PsycInfo, and Scopus searches resulted in 360 articles. Removing duplicates left 182 articles. Fifty-four records such as reviews, dissertations, commentaries, and pediatric or non-Hispanic focus were removed. The remaining 128 articles were closely evaluated. While acknowledging their utility, exclusion criteria–eliminated articles focused solely on EOL preferences or on hospice caregiving, bereavement, and communications, as well as perceptions of healthcare providers around hospice and hospice length of stay. Database studies were removed and reviewed elsewhere (Rising, Hassouneh, Lutz, Berry, & Lee, 2019). Five articles discovered in citations were added. Case studies were removed to result in a final 21 articles for review, or 10 qualitative (Bade, Murphy, & Sullivan, 1999; Born et al., 2004; Boucher, et al. 2014; Taxis et al., 2008; Carrion, 2010; Duffy, Jackson, Schim, Ronis, & Fowler, 2006; Gelfand, et al., 2001, 2004; Kreling, et al., 2010; Sullivan, 2001) (Tables 1 and 2) and 11 quantitative (Adams, Horn, & Bader, 2007; Carrion, Cagle, Van Dussen, Culler, & Hong, 2015; Colón, 2012; Fischer, Cervantes, Fink, & Kutner, 2015; Jonnalagadda et al., 2012; Kirkendall, Holland, Keene, & Luna, 2015; Pan, Abraham, Giron, Lemarie, & Pollack, 2015; Park, Jang, Ko, & Chiriboga, 2016; Randall & Csikai, 2003; Ruff, Jacobs, Fernandez, Bowen, & Gerber, 2011; Selsky et al., 2012) (Tables 3 and 4). The qualitative and quantitative articles are presented separately, acknowledging the critical research focus of the review.

Qualitative Approach: Study Designs and Methods

Reviewed qualitative studies mostly relied on convenience and purposeful sampling, low-inference focus groups, and no theoretical frameworks. Descriptions of study designs, population samples, and Hispanic subgroups are in Table 1, and example questions with exemplars are in Table 2. Exceptions to predominantly focus group study designs included studies augmenting focus groups with qualitative descriptive interviews (Bade et al., 1999; Kreling et al., 2010; Sullivan, 2001). Others (Carrion, 2010) relied solely on qualitative descriptive interviews or interpretive interviews (Taxis et al., 2008). In addition to purposeful sampling (Born et al., 2004; Boucher, et al., 2014; Carrion, 2010; Duffy et al., 2006; Gelfand et al., 2001, 2004; Kreling et al., 2010; Taxis et al., 2008) and convenience sampling (Bade et al., 1999; Born et al., 2004; Boucher et al., 2014; Carrion, 2010; Gelfand et al., 2001, 2004; Kreling et al., 2010), one study included snowball sampling (Taxis et al., 2008), in which study participants recruit new participants. Future research might include theoretical sampling, follow-up interviews, and high-inference data interpretation to capture the subtleties encountered in cross-cultural and EOL settings. Theoretical frameworks in qualitative research can sensitize to nuances inherent in research across cultures and with death and dying without biasing the investigator’s scope of inquiry. In the reviewed literature, there was only one theoretical framework explicitly identified (Boucher et al., 2014), which was a service-oriented study guided by cultural humility (Albritton & Wagner, 2002; Tervalon & Murray-García, 1998). Without explicitly mentioning a theoretical framework, two studies (Bade et al., 1999; Sullivan, 2001) framed the significance of the study in the ethical tenet of social justice. Future research might find guidance in classic works on death and dying (Kübler-Ross, Wessler, & Avioli, 1972) or early grounded theory work on awareness of dying (Glaser & Strauss, 1966). For a critical theory approach, postcolonialism would sensitize the researcher to historic and current Hispanic oppression (Acuna, 2015; Anderson, 2004; M. M. Martinez, 2018; O. Martinez, 1994; Said, 1978).

Table 1

Qualitative Articles

Authors **Study design** **Conceptual framework**	**Sample size (N) population**	**Population**	**Hispanic Mean Age (yrs)**	**Hispanic subgroup** **Sampling strategy**
Bade et al. (1999) Focus groups and qualitative descriptive interviews; Community-driven bioethics	Group *N* not given Interviews *N* = 7, 9	Diverse community members	Age not given	Subgroup not given; Convenience
Born et al. (2004) Focus groups; No framework mentioned	*N* = 27 Hispanics	Healthy community members	Age not given	Subgroup not given; Convenience
Boucher et al. (2014) Focus groups; Cultural humility/community service	*N* = 21 Hispanics	Senior centers	Mean age = 65	Subgroup not given; Convenience
Carrion (2010) Qualitative descriptive interviews; No framework mentioned	*N* = 20 Hispanics; (10 hospice/10 non-hospice)	Offered hospice in recent past, Mostly paid caregivers	Age = varied	Puerto Rico, Dominican Republic, Peru, Cuba; Convenience, purposeful
Duffy et al. (2006) Focus groups; No framework mentioned	*N* = 16	Healthy community participants	Mean age = 70	Columbians and Mexicans; Purposeful (marketing firm used commercial database)

(continued)

Authors **Study design** **Conceptual framework**	**Sample size (N) population**	**Population**	**Hispanic Mean Age (yrs)**	**Hispanic subgroup; Sampling strategy**
<u>Gelfand et al. (2004)</u> Focus groups; No framework mentioned	*N* = 65 (59 women)	Community organizations, no prior hospice experience	Recruitment ages = 45–64 and > 65	Mexicans (mostly illegal residents); Convenience, purposeful
<u>Gelfand et al. (2001)</u> Focus groups; No framework mentioned	*N* = 65 (59 women)	Community organizations, no prior hospice experience	Ages = 45–64 and > 65	Mexicans (mostly illegal residents); Convenience, purposeful
<u>Kreling et al. (2010)</u> Focus groups with qualitative descriptive interviews	*N* = 30 (*n* = 15 Hispanic)	Caregivers of hospice decedent within last 12 months	Caregiver mean age = 55	Mostly Central or South American; Convenience, purposeful
<u>Sullivan (2001)</u> Focus groups and qualitative descriptive interviews; Bioethics	*N* = 17	Community gatekeepers who serve the community	Age not given	Subgroup not given; Sampling not explained
<u>Taxis et al. (2008)</u> Qualitative interpretive interviews	*N* = 15 (12 women)	Healthy participants with prior hospice experience	Mean age = 46	Mexican (fluent English); Purposeful, snowball

Table 2

Examples of Questions, Themes, and Exemplars from Qualitative Articles

Authors	**Questions**	**Exemplars and themes**
Bade et al. (1999)	Do you know about hospice? Is this a treatment you would like? (No *hospice* explanation.)	"Most" unfamiliar with hospice; but positive attitudes. Hispanics don't use hospice often because of the "cost" and "families tend to take care of their sick" (p. 40). Spontaneous discussion of barriers included insurance, discrimination, negligence, language, cultural insensitivity, personal unfamiliarity with healthcare system.
Born et al. (2004)	No questions on hospice provided; (No explanation of how *hospice* explained)	Minimal hospice knowledge: "Spanish-speaking people don't even know what the hospice concept is" (p. 252). Barriers include prohibitive cost of health care and language. Only one female Hispanic expressed reservations about home hospice: "It seems like Mexican people, if you don't prepare a meal for them, if you go out and get it, it's not the same. So, if you have hospice come in, would the elderly person, or family member view it as you're not doing your job?" (p. 250).
Boucher et al. (2014)	Questions not given; peers explained hospice to group.	A few participants expressed familiarity with hospice. Barriers included power differential in healthcare, perceived healthcare disparities, and ineffectiveness of interpreters since Spanish speakers from different regions speak differently.

(continued)

Authors	**Questions**	**Exemplars and themes**
Carrion (2010)	What do you know about hospice services? Have you considered receiving hospice services? Why or why not? What do you anticipate would be barriers in getting connected with hospice?	Barriers included health literacy, invasion of privacy, slow response time, language, insurance, cultural beliefs, clinical referral, having a paid caregiver, need for Spanish speaking staff and Spanish educational materials. Enabling factors were need for assistance, prior hospice knowledge, and hospital referral. 47-year-old home hospice business owner from Cuba cited dissatisfaction with death being visible to other residents (pp. 201–202) and explained no need for hospice in Cuba because everyone is not working like in U.S. (p. 205). 49-year-old paid caregiver from Cuba about hospice: “I know a little. We consider it shameful. . . . Americans they are prepared to say hospice, yes” (p. 206). 75-year-old Puerto Rican feared loss of privacy, control, language barrier: “I don’t like people in my house” (p. 201). 30-year-old paid caregiver from Puerto Rico rejected disruption: “No, it is too much trouble, when we request hospice it becomes a big problem. They send continuous care, more people coming in all the time” (p. 202).
Duffy et al. (2006)	Rather discharge knowing that your care would be difficult for your family, or go to a nursing home or hospice?	Hispanics want to avoid nursing home but receptive to hospitals and hospice. “Most” were unfamiliar with hospice; no exemplars given.
Gelfand et al. (2004)	What are services participants would want or not want hospice staff to provide?	There is no knowledge about hospice in their community. Hospice worker should not tell patient there is no hope and that they are dying. Skilled-nursing help welcomed for medications and wound care. There are language/culture barriers. Three hospice myths are that it is in-patient, there is no role for family, and it is available 24-hours. Questions from healthcare workers regarding documents, country of origin, and health history scare illegal immigrants.

(continued)

Authors	**Questions**	**Exemplars and themes**
Gelfand et al. (2001)	What are services participants would want or not want hospice staff to provide?	Hospice service may cause embarrassment because signals family caregiving failure. Skilled-nursing help welcomed for medication administration and wound care. Priest visit to the home signals impending death but counseling by priest is okay.
Kreling et al. (2010)	What did you, as a caregiver, know about hospice before the patient's illness? How was the hospice decision made?	Many hospice caregivers had no hospice knowledge or had misconceptions consistent with the Spanish word *hospicio*. Many did not want death discussed openly, even within the family. They wanted the family in charge, including receiving information and making decisions (not the patient). Some believed they could not afford hospice services. Inconsistent with typical hospice teaching, they did not want information about what to expect during the dying process. In spite of cultural mismatches, most were satisfied with hospice care. An example of persistent denial maintained by caregiver: "I had a lot of faith . . . He was already at hospice but I did not think he was going to die" (p. 430). Hispanics did not want to read the death pamphlet (p. 430). "The worst thing about using hospice care? The way they talk to you about death" (p. 431). *Hospicio* misconception: "I didn't know what hospice was. I thought it was a place worse than a hospital" (p. 429).
Sullivan (2001)	No examples of questions given.	Mostly unfamiliar with hospice; once explained, still preferred family to care for the terminally ill.
Taxis et al. (2008)	When you think of hospice, what words or ideas come to mind?	*Familismo:* "We are there for each other" (p. 137). While her family member was receiving hospice care, one participant reported, "I fed him, changed him, bathed him, everything" (p. 138). "I don't want strangers in my home" (p. 138). Positive reception to hospice: Hospice nurses are like "angels, they know what to say and what to do" (p. 138). "Hospice [residential] was wonderful, they let all the family come. We didn't have a certain number and could stay 24/7. The nurses were there if you needed them but they wouldn't butt in" (p. 138). Communication: appreciated specific instructions about stages of dying.

In the reviewed qualitative articles, trustworthiness, which reflects credibility, transferability, dependability, and confirmability, was moderate in quality. When researching in two languages, professional Spanish-language interpreters enhance credibility of translations as long as they are familiar with the local dialect. None of the articles included in this review described using professional interpreters. Instead, Spanish language interviews were conducted by bilingual research assistants (Boucher et al., 2014; Taxis et al., 2008), healthcare professionals (Kreling et al., 2010), facilitators (Gelfand, et al., 2001; Gelfand et al., 2004), or the investigator (Carrion, 2010). Similarly, Spanish-language translation was rarely described, except in three studies (Gelfand et al., 2001, 2004; Taxis et al., 2008). Descriptions of audiotape transcriptions also offer opportunities to demonstrate trustworthiness. However, only five studies described audiotape transcription processes (Boucher et al., 2014; Duffy et al., 2006; Gelfand et al., 2001, 2004; Taxis et al., 2008), and only one researcher reported checking transcription accuracy by comparing to the audiotape (Born et al., 2004). Because coding of transcript data and subsequent conceptual and thematic development transforms participants' words into research findings, explanation of coding and concept-development strategies enhances trustworthiness. Only two researchers linked their coding strategies to the research literature. One (Boucher et al., 2014) cited a source for grounded theory analysis (Thomas, 2006), and another (Carrion, 2010) referenced several sources (Ely, 1991; Kuzel & Like, 1991; Schensul, Schensul, & LeCompte, 1999) for qualitative techniques. Coding software was mentioned in just three studies (Carrion, 2010; Gelfand et al., 2001, 2004). A strength of the reviewed articles for purposes of trustworthiness is that most researchers conducted team coding (Born et al., 2004; Boucher et al., 2014; Gelfand et al., 2001, 2004; Kreling et al., 2010; Taxis et al., 2008); however, one conducted solo coding (Carrion, 2010) and another relied on a professional marketing firm

(Duffy et al., 2006) that may not have been as grounded in the literature as researchers. A similar strength is that most thematic development occurred among teams of researchers (Born et al., 2004; Boucher et al., 2014; Duffy et al., 2006; Gelfand et al., 2001, 2004; Kreling et al., 2010; Taxis et al., 2008), except one study in which the researcher conducted solo thematic development (Carrion, 2010). A small number of articles further enhanced trustworthiness through member checking (Bade et al., 1999; Boucher et al., 2014), external auditing (Boucher et al., 2014), and triangulation of transcript data with responses to brief questionnaires (Duffy et al., 2006; Taxis et al., 2008). In the future, to improve trustworthiness, qualitative researchers might employ on-site professional Spanish-language interpreters and transcriptionists familiar with local dialects during data collection and transcription. In addition, trustworthiness of coding and thematic development might improve when conducted with coding software and in a team setting, including processes for member-checking and external auditing by Hispanic experts. Results from qualitative studies are presented next, organized around the most prevalent and relevant themes.

Qualitative Approach: Study Results

The reviewed qualitative articles showed an overall lack of hospice awareness but general hospice receptiveness in the Hispanic community. In the seven studies that did not purposefully sample participants with hospice experience, participants were largely unaware of hospice (Bade et al., 1999; Born et al., 2004; Boucher et al., 2014; Duffy et al., 2006; Gelfand et al., 2004; Kreling et al., 2010; Sullivan, 2001). One participant stated, "“Spanish-speaking people don’t even know what the hospice concept is” (Born et al., 2004, p. 252). *Familismo*, or an emphasis on family cohesion and obligation, appeared in many ways. A prevalent theme was that Hispanic families take care of their sick (Bade et al., 1999; Born et al., 2004; Carrion, 2010; Taxis et al., 2008). Supporting the *familismo* theme is the suggestion that hospice services were intrusive (Carrion, 2010, p. 201; Taxis et al., 2008, p. 138) or were an embarrassing failure to fulfill filial duties (Born et al., 2004, p. 250; Carrion, 2010, p. 206; Gelfand et al., 2001, p. 394). However, skilled nursing help was welcomed hypothetically in focus groups (Gelfand et al., 2001, p. 394; 2004, p. 10). Also, hospice-experienced participants expressed their belief that maintaining and sharing control of care between families and hospice personnel was acceptable (Taxis et al., 2008, p. 138).

Significant for hospice staff, many participants expressed expectations reflecting Hispanic and hospice cultural differences. For instance, as part of hospice care, chaplains routinely visit patients and families; however, such a visit may have different implications for Hispanics. Focus groups of predominantly Mexican participants did not want home visits from priests, which might symbolize impending death (Gelfand et al., 2001, p. 395). However, family counseling from priests in other contexts was welcomed (Gelfand et al., 2001, p. 395). Significantly, participants indicated discomfort with staff openly discussing death and dying (Gelfand et al., 2004, pp. 10-11; Kreling et al., 2010, p. 431). One caregiver of a hospice decedent stated, “The worst thing about using hospice care? The way they talk to you about death” (Kreling et al., 2010, p. 431). Another stated, “When the doctor says, ‘he’s at the end of his life . . . ’ that’s kind of cruel . . .it made me angry when the doctor told me he was dying” (Kreling et al., 2010, p. 431). In contrast, a participant from a different study stated, “The nurses at hospice are like angels, they know what to say and what to do,” and they appreciated specific instructions about what to expect during the dying process (Taxis et al., 2008, p. 138) (Table 2). These conflicting examples emphasize for healthcare staff the importance of initiating private and tactful discussions regarding prognostic disclosure. The conflicting examples also underscore the importance of anticipating large variations in individual preferences within a cultural group.

In spite of barriers to hospice services, the majority of those receiving hospice services were satisfied with care. Barriers to care included language (Bade et al., 1999; Born et al., 2004; Boucher et al., 2014; Carrion, 2010; Gelfand et al., 2004), discrimination (Bade et al., 1999; Boucher et al., 2014; Gelfand et al., 2004), cultural insensitivity (Bade et al., 1999; Gelfand et al., 2004), and perceived costs (Bade et al., 1999; Born et al., 2004; Kreling et al., 2010). Although the influence of an acute hospital stay on hospice decision-making remains unclear, Hispanic hospice utilization might have been associated with referral during an acute hospital stay (Carrion, 2010; Kreling et al., 2010). In contrast, referrals from clinic were not (Carrion, 2010). Regardless of how they were referred, hospice-experienced participants were mostly satisfied with hospice care in spite of cultural differences (Kreling et al., 2010; Taxis et al., 2008). Dissatisfied hospice-experienced participants were mostly paid caregivers (Carrion, 2010) as opposed to family members, which suggests expectations in those two groups may differ. The quantitative studies are presented next.

Quantitative Approach: Study Designs and Methods

Research strategies in the 11 quantitative studies were mostly descriptive with limited emphasis on validity and reliability or theoretical frameworks. Table 3 describes study populations, and details such as names of scales, example questions, and results are in Table 4. Study designs were mostly descriptive cross-sectional surveys, limiting the ability to infer causation. One exception was a pilot intervention study (Fischer et al., 2015). Researchers used mostly convenience sampling, which introduced an unknown amount of bias and error in their numerical results (Adams et al., 2007; Colon, 2012; Jonnalagadda et al., 2012; Kirkendall et al., 2015; Pan et al., 2015; Randall & Csikai, 2003; Ruff et al., 2011; Selsky et al., 2012). In contrast, three studies introduced randomization through random assignment of participants to control or intervention arms (Fischer et al., 2015) or random selection of phone numbers for telephone-based surveys (Carrion et al., 2015; Park, et al., 2016). Patient-reported measures were used in most reviewed studies. Significant in the quantitative section of this review, many studies used pre-existing English-language scales (Carrion et al., 2015; Kirkendall et al., 2015; Ruff et al., 2011) without evidence of Spanish-language validation or reliability with Hispanic populations. Without evidence of construct validity, there is no assurance that scales are measuring what they are intended to measure. Such ethnic validation of patient-reported measures is not replaced by extensive efforts in reviewed studies to ensure accurate translation (Carrion et al., 2015) or even limiting participants to English-speaking only (Ruff et al., 2011). Similarly, internal consistency of measures, such as reliability, are an important assessment of the strength of measures. Only one study among the 11 quantitative studies reported Cronbach alpha, a measure of reliability, for an exclusively Hispanic sample (Colon, 2012). A final consideration is the inclusion of theoretical frameworks, which provide conceptualizing theories on which to build the knowledge base as well as analytical frameworks. Five articles referenced Eurocentric theoretical frameworks. One (Adams et al., 2007) relied on the 2004 National Health Disparities Report (Agency for Healthcare Research and Quality, 2004), and another (Carrion et al., 2015) relied on the Theory of Planned Behavior (Ajzen, 1991). The Self-regulation Model (Leventhal, Safer, & Panagis, 1983) was used by one research team (Jonnalagadda et al., 2012) and the Andersen Behavioral Health Model (Andersen, 1995) by another (Park et al., 2016). Only one research team (Fischer et al., 2015) acknowledged the cross-cultural nature of research by framing the study with the Patient Navigator Model (Freeman, 1991; Freeman, 2006). In cross-cultural studies involving death, future research might build on theories of acculturative stress (Cervantes, Padilla, & Salgado de Snyder, 1991; Smart & Smart, 1995), uncertainty (Mishel, 1988), transitions (Meleis, 2010), and anticipatory loss (Rolland, 1990). Quantitative study results are presented next, organized around the most commonly measured metrics, namely hospice awareness, knowledge, and attitudes.

Table 3

Quantitative Articles

Authors; **Study design/sampling**	**Sample size**	**Population**	**Hispanic Mean Age (yrs)**	**Hispanic subgroup**
Adams et al. (2007); survey/random, convenience	*N* = 120 (*n* = 60 Hispanic)	Medicare hospice patients	80.8	90% Mexican
Carrion et al. (2015); telephone survey/random, convenience	*N* = 123 (*n* = 16 Hispanic)	General population	47.7	Subgroup not given
Colón (2012); survey/convenience	*N* = 367 (all Hispanic)	Latino cultural event	35.6	46% Puerto Rican
Fischer et al. (2015); intervention/ convenience, randomization	*N* = 64 (all Hispanic)	Safety net hospital	57	Subgroup not given
Jonnalagadda et al. (2012); survey/convenience	*N* = 335 (*n* = 67 Hispanic)	Recent lung cancer diagnosis	64.4	46% Puerto Rican
Kirkendall et al. (2015); survey/convenience	*N* = 2,980 (*n* = 152 Hispanic)	Caregivers of hospice decedents	78.1	Subgroup not given
Pan et al. (2015); survey/convenience	*N* = 604 (*n* = 156 Hispanic)	Community events/centers	45.5	Subgroup not given
Park et al. (2016); telephone survey/random, convenience	*N* = 1,433 (*n* = 569 Hispanic	General population	72.9	58% Cuban American
Randall & Csikai (2003); survey/convenience	*N* = 110 (all Hispanic)	Rural Catholic church attendees	35	84% Mexican
Ruff et al. (2011); survey/convenience	*N* = 329 (*n* = 78 Hispanics)	Community events/centers	44.8 (all ethnicities)	Subgroup not given
Selsky et al. (2012); survey/convenience	*N* = 331 (all Hispanic)	safety net clinic patients	43	C. and S. American, 37% El Salvador

Table 4

Quantitative Questions and Study Results

Authors/ Conceptual Framework	**Questions/Instrument/Intervention**	**Results**
Adams et al. (2007) 2004 National Health Disparities Report	Know Medicare covers hospice? Comfortable discussing hospice with MD?	Yes: Hispanics 43.3%, NHWs 35.0% (p = .35); Very: Hispanics 59.6%, NHWs 78.7% (p = .041).
Carrion et al. (2015) Theory of Planned Behavior	Heard of hospice? Hospice Knowledge Test (23 items) (n = 9): (a) Only individuals over age 65 are eligible for hospice services, (b) Hospice care helps caregivers and family members as well as the dying individual, (c) While receiving hospice care, individuals can also receive treatments, such as chemotherapy, radiation, or surgery to cure the person’s primary illness, (d) Hospice services end when the hospice patient dies [40, p. 650] Hospice Philosophy Scale (a) Death is a normal part of living; (b) Care in the home maximizes a patient’s dignity; and (c) A team approach that includes physicians, nurses, social workers, chaplains and other healthcare professionals is best for a dying patient’’[p.649].	56% (n = 9) Hispanics heard of hospice; no significant difference in hospice knowledge or philosophy
Colón (2012) No framework mentioned	Hospice Knowledge Instrument (a) Familiar with hospice? (b) Hospice is a program that helps persons who are dying and their families (45% know), (c) hospice helps treat cancer (52.7% do not know), (d) hospice services provided in nursing homes (47.1% did not know) [41 p. 237].	57% never heard the word *hospice*

(continued)

Authors/ Conceptual Framework	**Questions/Instrument/Intervention**	**Results**
Colón (2012) No framework mentioned (continued)	Attitudes Toward Hospice Scale (a) Hospice care helps families, (b) If I were dying, I would prefer to be at home with a caregiver and hospice support, (c) If I were dying, I would prefer to be cared for only by family members, (d) I would want hospice services whether or not I had family to care for me, (e) I would prefer to die in the hospital, (f) I would not choose hospice because that would mean that I am not fighting for my life, (g) The spiritual part of hospice would comfort me, (h) If I were dying, I would not want hospice services because I have a lot of family that would take care of me, (i) I would not need hospice services because God would take care of me, (j) Lack of money would prevent my use of hospice services, (k) If I were dying, I would want hospice to help my family take care of me, (l) If I were dying, I would use the services of a folk healer or ‘‘*curandero*’’ instead of hospice services, (m) The patient should be informed that his or her medical condition is terminal, (n) The patient should not be informed that his or her medical condition is terminal, (o) If the patient has a terminal illness the family should decide about patient’s health care and not the patient, (p) If I had a terminal illness I would want to be told, (q) If I had a terminal illness I would not want to be told, but I would want my family to be told $^{p.238}$.	53.7% would use home hospice if terminally ill.

(continued)

Authors/ Conceptual Framework	**Questions/Instrument/Intervention**	**Results**
Fischer et al. (2015) Patient Navigator Model	Culturally appropriate brochure to intervention and control; Intervention = patient navigator home visits	No significant difference between intervention and control group (pilot study).
Jonnalagadda et al. (2012) Self-Regulation Model	Hospice only for imminent death;	Agreed: 71% Hispanics, 53% of NHWs (*p* = .03);
	Hospice not necessary if have family	Agreed: 48% Hispanics, 19% NHWs (*p* = .006), OR 5.5, 1.7–17.7
Kirkendall et al. (2015) No framework mentioned	Family Evaluation of Hospice Care (FEHC) (a) Did you or your family receive any information from the hospice team about what to expect while the patient was dying? (b) At any time while the patient was under the care of hospice, did the doctor or another hospice team member do anything with respect to end-of-life care that was inconsistent with the patient's previously stated wishes, (c) Overall, how would you rate the care the patient received while under the care of hospice?[p.316].	No difference in satisfaction between Hispanics and NHWs (*B* = .02, *P* = .50); Hispanics more likely to feel patient received care against wishes (*B* = .29, *p* = .001)
Pan et al. (2015) No framework mentioned	Heard of hospice?	Hispanic (16%) less familiar with hospice (*P* = .01);
	Recommend hospice to terminally ill friend or family member?	Hispanic (75%) less likely to tell seriously ill family or friend about hospice (*P* = .01)

(continued)

Authors/ Conceptual Framework	Questions/Instrument/Intervention	Results
Park et al. (2016) Andersen Behavioral Health Model	Would use hospice?	Hispanics less likely to use hospice (p = .001)
Randall & Csikai (2003) No framework mentioned	Familiar with hospice? Rate hospice knowledge relative to other services: (a) Hospice, (b) Local county hospital, (c) Medicaid and Medicare benefits, (d) Community health clinic, (e) Rural health clinic, (f) Financial assistance for medications [45 p. 88.] Rate comfort with terminal illness discussion with a variety of persons	85% not familiar with hospice; self-rated hospice knowledge lower than other health services; Uncomfortable having terminal illness discussion with non-Spanish-speaking MD
Ruff et al. (2011) No framework mentioned	Heard of hospice? Beliefs about Hospice Care Scale (24-item) (a) Hospice care means giving up, (b) Hospice care means you get no treatment, (c) Hospice care can be provided in the patient's home if the patient or family wishes it, (d) Those who believe in God do not need hospice [46, p. 178].	70% of mixed ethnic sample had "heard a lot" about hospice; no significant difference by ethnicity in beliefs about hospice care (English-speaking only sample)
Selsky et al. (2012) No framework mentioned	Familiar with hospice? Hospice Knowledge Scale (7 true-false items probing knowledge about aspects of hospice care including eligibility, services available, and location of services); Culturally appropriate, detailed hypothetical scenario	29% heard of hospice; mean hospice knowledge 3.1; recommend: 35% hospice, 38% treatment, 12% leave country/go home

Quantitative Approach: Study Results

Hospice awareness. There is strong evidence in the quantitative research literature that Hispanics are mostly unaware of hospice (Colon, 2012; Pan et al., 2015; Randall & Csikai, 2003; Selsky et al., 2012). Hospice awareness was measured with single yes/no questions. In a rural Catholic church, 49% of a sample composed of almost exclusively Mexicans reported knowing hospice existed (Randall & Csikai, 2003). At an urban safety net clinic, 29% of a sample of Central and South Americans, mostly from El Salvador, had heard of hospice (Selsky et al., 2012). Among attendees at a Hispanic cultural event, 57% of mostly Puerto Rican participants had not heard the word "hospice" before (Colon, 2012). There, stepwise discriminant function analysis showed that household income (.677) was more important than education (.425) and age (.338) in predicting hospice awareness, and nationality did not emerge as a significant predictor of hospice awareness (Colon, 2012).

Hospice knowledge. Hospice *knowledge* is distinguished from hospice *awareness* in that it measures the accuracy of participants' hospice information. To measure hospice knowledge, two previously validated English-language instruments were used. The Hospice Knowledge Test (HKT) consists of 23 true/false questions such as "Only individuals over age 65 are eligible for hospice services" (Carrion et al., 2015, p. 650) (Table 4). In unadjusted chi-squared analysis, the HKT showed no significant difference between Hispanics and NHWs (Carrion et al., 2015). Failure to find significance may have resulted from insufficient power because of a small Hispanic sample size (*n* = 9; Carrion et al., 2015) or heterogeneity of the samples. Table 4 reproduces individual questions that did result in statistically significantly differences between ethnicities. However, given the limitations of sample size it is unclear whether these results are generalizable. The second scale using a previously validated English-language instrument was

The Beliefs about Hospice Scale (BHS). The BHS is a 24-item measure in which the participant agrees or disagrees with statements such as, “Hospice care means you get no treatment” (Ruff et al., 2011, p. 178) (Table 4).The BHS had a Cronbach’s alpha of .88 in the mixed-ethnic sample for this study (Ruff et al., 2011). Logistic regression of predictor variables and results from the BHS showed that ethnicity did not predict hospice beliefs (Ruff et al., 2011, p. 179). Neither the BHS nor the HKT, which were initially developed for NHWs and African Americans (Johnson, Kuchibhatla, & Tulsky, 2008; Webb & Tucker, 2009), were validated for Hispanic samples.

Three studies used scales created for the study at hand, providing mixed results on hospice knowledge from exclusively Hispanic samples. At an urban safety-net clinic, researchers measured knowledge of hospice eligibility and services with seven true/false questions (Selsky et al., 2012). One of the stronger survey-based studies, the true/false questionnaire was developed by the researchers with cognitive testing and back-translation (Selsky et al., 2012) using ideas generated from a previous focus groups study (Kreling et al., 2010). With lower scores indicating poorer knowledge, mean hospice knowledge was 3.1 (S.D. 2.5) out of a possible score of 0–7 (Selsky et al., 2012). In adjusted logistic regression analyses, greater hospice knowledge was reported by women (OR 1.84, 1.02–3.34), those with higher education (OR 2.72, 1.29–5.74), and those affiliated with community social organizations (OR 2.99 1.72–5.22; Selsky et al., 2012). In addition, endorsement of Hispanic cultural values (e.g., collectivism, family-centric values) predicted higher hospice knowledge values (respectively, OR 1.06 per 1-point increase on scale, .001–1.12; OR 1.03 per 1-point increase on scale,1.01–1.04; Selsky et al., 2012).

In another study, conducted with mostly Mexican attendees at a rural Catholic church, self-rated knowledge of six healthcare services on a five-point Likert scale suggested hospice knowledge was lower than knowledge of five other healthcare services (Table 4) (Randall &

Csikai, 2003). Statistical significance was not reported; only that confidence intervals for hospice knowledge (1.32–1.89) and financial assistance for medications (1.77–2.37) were the sole self-rated knowledge of healthcare services scores that overlapped. With an unclear sample size and a high non-response rate, the significance of the results of this study remains unclear.

A final measure of hospice knowledge created for the study at hand occurred at a cultural event with a Hispanic sample (*N* = 367) consisting mostly of Puerto Ricans (Colon, 2012). The instrument consisted of a question asking whether the participant had ever heard of hospice, followed by three true/false questions. Results show limited hospice knowledge (Table 4) and Cronbach's alpha of .77. To compare among nationalities at the Hispanic cultural event, researchers collapsed the 17 identified Hispanic subgroups identified by participants into five groups: Puerto Ricans, Dominicans, Central Americans, South Americans, and ‘‘Other Latino.” Although the “Other Latino” category had the highest hospice knowledge mean score (1.59, *SD* = 1.25, *n* = 59), ANOVA analyses showed no significant differences between Hispanic subgroups (Colon, 2012). Unfortunately, the country of origin of “Other Latino” is unclear. Overall, hospice knowledge in the reviewed studies was variable and predicted not by ethnicity but by other factors such as income, gender, education, and affiliation with community organizations.

Hospice attitudes. Hospice attitudes were conceptualized and measured in a variety of ways. Three studies evaluated hospice patient or family caregiver attitudes. The Family Evaluation of Hospice Care (FEHC) is an established survey routinely sent from hospice facilities to family caregivers after a hospice patient has died (Kirkendall et al., 2015) (Table 4). It is unclear whether the FEHC was available in Spanish, and there was no discussion of instrument validity with Hispanic populations. Moreover, only survey results in which ethnicity was self-reported were included in the analysis, which may have biased results. Significantly, in adjusted analyses, ethnic comparisons showed no difference in overall satisfaction between Hispanics and Whites (*B* = .02, *P* = .5; Kirkendall et al., 2015). Satisfaction with care is noteworthy since Hispanics also were more likely to report that hospice patients received care against their wishes (*B* = -.29, *p* < .001; Kirkendall et al., 2015). In a second study, conducted with mostly Mexican hospice patients, researchers assessed receptiveness to open hospice discussions (Adams et al., 2007). Hispanic patients (59.6%) were significantly less likely to feel "very comfortable" discussing hospice with their doctor than were NHWs (78.7% , *p* = .041; Adams et al., 2007, p. 160). A third study offered insight into hospice attitudes by measuring hospice enrollment after a Hispanic patient navigator intervention (Fischer et al., 2015). Comparing hospice enrollment rates between Hispanics who received patient navigator home visits and those who did not, there was no significant difference between the intervention and control groups (Fischer et al., 2015), suggesting the assistance of a patient navigator does not affect attitudes toward hospice. However, this was a pilot study with a small sample size (*N* = 64) and both groups received a visit from the patient navigator in the hospital as well as a culturally appropriate brochure, which may have duplicated any positive influences from home visits (Fischer et al., 2015). In sum, there is evidence in this limited data from actual hospice users that Hispanics tend to go along with hospice care and find satisfaction with it even if not provided in a culturally appropriate manner.

The following five studies measured hospice attitudes after providing hospice definitions to hospice-naïve participants. Among such hospice-naïve participants, receptiveness to hypothetical hospice was low. A sample of mostly Salvadorians recruited from an urban safety-net clinic were given a hypothetical scenario involving a Salvadorian woman with cancer with less than six months to live and asked what they would recommend (Selsky et al., 2012). In response, 35% of participants recommended hospice and 12% recommended returning to the home country (Selsky et al., 2012). Unfortunately, the definition of hospice given to participants was not reproduced in the article. Participants who preferred maintaining secrecy about prognosis were less likely to recommend hospice care in adjusted analysis (OR 0.81, .67–.99), and increased education and social acculturation were associated with recommending hospice care (Selsky et al., 2012). In contrast, attitudes were more positive toward hospice among a sample of mostly Puerto Ricans at a cultural event (Colon, 2012). In that study, the 17-item Likert-based Attitudes toward Hospice Scale was developed to measure participants' responses to statements such as, "The patient should not be informed that his or her medical condition is terminal" (Table 4) (Colon, 2012, p. 238). A combined 64.8% responded they would want either home or inpatient hospice, and only 3.5% would not use hospice (Colon, 2012, p. 238). Using one-way ANOVA, there were no significant differences in median hospice attitude scores among Hispanic subgroups, but participants with lower income had significantly lower hospice attitudes scores (Colon, 2012). A more positive attitude toward hospice correlated significantly with increased years of education ($r = .30$, $p = .000$; Colon, 2012). In *t*-tests, participants who had prior knowledge of the word "hospice" had significantly higher hospice attitudes scores than those who had not heard of hospice (Colon, 2012).

Unlike the first two studies that did not report hospice definitions, the following three articles reproduced the hospice definitions used in ethnic comparisons of hospice receptiveness. Unfortunately, definitions were markedly different, precluding comparisons between studies (Pan et al., 2015, p. 929; Park et al., 2016, p. 38; Ruff et al., 2011, p. 178). Hispanics (75%, $P < .01$) were less likely than Chinese and Korean participants to tell a seriously ill family member or friend about hospice (Pan et al., 2015) and less likely than NHWs to indicate a willingness to use hospice ($p < .001$; Park et al., 2016). On the other hand, a study in Florida showed no significant difference between ethnicities (Ruff et al., 2011). However, only English-speaking Hispanics were included in that study, there was considerable heterogeneity in samples, and it is unclear whether responses were based on personal knowledge of hospice or the definition provided.

In the final two studies, hospice attitudes were measured with participants with unclear hospice experience, and there was no evidence of hospice definitions. Among recently diagnosed lung cancer patients, more Hispanics (48%) than NHWs (19%; $p = .006$) agreed with the statement, “There is no need for hospice care if a patient has family to care for them (Jonnalagadda et al., 2012, p. 1255).” In contrast, no significant difference between ethnicities was found using the eight-item Hospice Philosophy Scale with responses to statements such as “Death is a normal part of living” (Jonnalagadda et al., 2012) (Table 4). However, results were based on a small Hispanic sample ($n = 16$) with considerable heterogeneity. In summary, Hispanic hospice attitudes toward hospice are difficult to assess because of a variety of approaches.

Conclusion

Much remains to be learned about optimizing hospice care in Hispanics. With few research studies reporting on the quality of hospice care, it is difficult to know first steps to optimize delivery of hospice in a manner consistent with the IOM recommendations. From the limited data available in this review, there seems room for optimism that hospice care can be delivered to Hispanics in a satisfactory manner, particularly if care is taken to be consistent with Hispanic cultural preferences. To improve culturally competent care, future research should explore and explain how, in spite of cultural clashes, Hispanics successfully transition to hospice and find satisfaction with hospice care. In the clinical setting, hospice staff should be mindful of cultural tendencies but always assess for individual preferences. When hospice care and research are grounded in the hospice philosophy of promoting emotional growth at EOL, cultural and socioeconomic considerations flow naturally as a byproduct of patient-centered care.

References

See Cumulative References.

Chapter IV

Hispanic Hospice Utilization: Integrative Review and Meta-Analysis

Margaret L. Rising, BSN, RN, PhD Candidate

Oregon Health & Science University School of Nursing, Portland, OR, U.S.A.

Dena Hassouneh RN, PhD, FAAN

Oregon Health & Science University School of Nursing, Portland, OR, U.S.A.

Kristin Lutz, RN, PhD

Oregon Health & Science University School of Nursing, Portland, OR, U.S.A.

Patricia H. Berry, RN, PhD, FAAN

Oregon Health & Science University School of Nursing, Portland, OR, U.S.A.

Chris Lee, RN, PhD, FAAN

Connell School of Nursing, Boston College, Chestnut Hill, MA, U.S.A.

This manuscript is a data-based paper submitted in partial fulfillment of the required literature review with a focus on articles using data derived from databases to determine frequency of Hispanic hospice utilization. Ms. Rising is the primary author on the paper; Dr. Hassouneh is the senior author on the paper. Dr. Lee provided considerable guidance in the meta-analysis section. This paper is published in the *Journal of Healthcare for the Poor and Underserved* (Rising, et al., 2019), which is the official journal of the Association of Clinicians for the Underserved (ACU) and has an impact factor of 0.860. A peer-reviewed journal, its focus includes health care access and quality in underserved populations.

Abstract

Hospice is patient-centered end-of-life (EOL) care. Hispanics are underrepresented among hospice patients (7.1%) relative to the U.S. population (17%). We conducted a systematic review of the literature and meta-analysis to further understand this underrepresentation. Results show that, in palliative care, Hispanic hospice enrollment is comparable to that of non-Hispanic Whites (NHWs; RR 1.02, 95% CI: 0.93–1.12; $z = 0.49$; $p = 0.627$). However, in heart failure (OR 0.49, 95% CI 0.37–0.66) and stroke (OR 0.77, 95% CI 0.63–0.94), Hispanics are much less likely to use hospice than NHWs. Cancer studies are mixed but in meta-analysis were significant for lower relative hospice use in Hispanics (RR 0.96, 95% CI: 0.94–0.99; $z = 3.01$; $p = 0.003$). It remains unclear whether using census and insurance data in statistical analysis provides valid results since the Hispanic population is younger, healthier, and less likely to be insured. Health equity in hospice may be better represented by hospice quality rather than hospice enrollment rates.

Key words: Hospice, Palliative Care, Health Equity, Hispanic Americans, Mexican Americans, Meta-Analysis, Review, Insurance, Medicare, Database

Funding Acknowledgments

This work was supported by the Doctoral Degree Scholarship in Cancer Nursing, DSCN-15-077-01, DSCNR-17-089-03 from the American Cancer Society, and also supported through grants and scholarships from the OHSU Hartford Center of Gerontological Excellence, the Hearst Foundation, and the Oregon Health & Science School of Nursing.

Declaration of Conflicts of Interest

None

Introduction

Abbreviations

CI = Confidence interval
EMTALA = Emergency Medical Treatment and Labor Act
EOL = End of life
GWTG-Stroke = American Heart Association/American Stroke Association Get with the Guidelines-Stroke Database
ICH = Intracerebral hemorrhage
IOM = Institute of Medicine
MDS = Long-term Care Minimum Data Set
N = Study sample size
n = Hispanic sample size
NHW = Non-Hispanic Whites
NIS = National Inpatient Sample
OR = Odds Ratio
RR = Risk ratio
SEER = Surveillance, Epidemiology, and End Results Program
TCR = Texas Cancer Registry
UCD = University of California Davis
U.S. = United States

Hospice is a patient-centered approach to EOL care that focuses on symptom control, comfort, and quality of life (National Hospice and Palliative Care Organization, 2015). Provided by an interdisciplinary team of healthcare workers, hospice care frequently results in optimal patient and family outcomes such as increased pain control (Teno et al., 2004), improved quality of life (Meier, 2011), and lengthened survival time for widows of hospice patients (Christakis & Iwashyna, 2003). Unlike intensive EOL treatments, hospice care does not aim to prolong patient life but may do so in some illnesses (Connor et al., 2007; Pyenson et al., 2004). Highlighting the importance of care quality, the Institute of Medicine (IOM) has called for the use of patient-centered, family-oriented, and culturally appropriate approaches to care at EOL (Institute of Medicine, 2014). Adopting IOM suggestions would result in increasing cultural sensitivity, including with Hispanics, who are a large and growing segment of the U.S. population. Hispanics have common cultural patterns that are congruent with inherent characteristics of hospice care, specifically, a preference for care that minimizes suffering (Kelley et al., 2010; Ko et al., 2013; Loggers et al., 2013; Perkins et al., 2009; Sullivan, 2001) and allows the family to provide care or control delivery of care (Born et al., 2004; Gelfand, et al., 2001, 2004; Kreling, et al., 2010; Taxis et al., 2008). Despite these consistencies and the positive outcomes associated with hospice care, Hispanics are underrepresented among hospice patients (7.1%) relative to their numbers in the U.S. population (17%; National Hospice and Palliative Care Organization, 2015). It is unknown if the underrepresentation of Hispanics among hospice patients reflects an inequity or if it is because of some other cause. We conducted a systematic review of the literature and meta-analysis on Hispanic hospice utilization in the U.S. to help answer that question.

Hospice enrollment. A variety of sources of hospice enrollment data are used to calculate Hispanic hospice utilization rates. Hospice enrollment is a complex process reflecting Medicare regulations, healthcare staff philosophies, and patient and family preferences. Medicare regulations are an important part of the hospice enrollment process because Medicare pays for 85.5% of the estimated 1.6 million U.S. patients and their families receiving hospice care (National Hospice and Palliative Care Organization, 2015). Pursuant to Medicare regulations, hospice enrollment requires that patients or their decision-makers have declined curative therapy and opted for comfort as the primary goal of care (Code of Federal Regulations, 2017b, 2017c). Physicians must also certify a prognosis of six months or less, assuming the disease runs its normal course (Code of Federal Regulations, 2017a). During hospice enrollment, the degree and explicitness of comfort care and prognostic discussions vary widely, reflecting different attitudes held by individual hospice workers and institutions. Nonetheless, the patient or patient representative must sign consent for hospice enrollment that acknowledges waiver of curative therapy and acceptance of care focused on comfort (Code of Federal Regulations, 2017b, 2017c). Rooted in the biomedical ethical tenet of patient autonomy, such informed consent to hospice enrollment reflects the Eurocentric preferences for individualism (M. L. Rising, 2017). Informed consent also reflects the hospice philosophy that patients' awareness of poor prognoses facilitates closure for the dying patient (National Hospice and Palliative Care

Organization, 2010). This “hospice culture” of individualism and awareness of poor prognoses, however, potentially clashes with cultural patterns around EOL that are common among Hispanics.

Hispanic ethnic category. Hispanics, who are persons of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race, are the largest ethnic minority group in the U.S., numbering 56.6 million (Ennis et al., 2011; United States Census Bureau, 2016). The three largest subgroups of Hispanics are of Mexican (63%), Puerto Rican (9.2%), and Cuban (3.5%) origin (Ennis et al., 2011). An estimated 5.6 million (Krogstad & Passel, 2015) to 6.8 million undocumented Mexicans live in the U.S. (Gonzalez-Barrera & Lopez, 2013). Because of the variety of countries of origin and heterogeneity within those countries, there is no monolithic Hispanic culture. Instead, the Hispanic ethnic category is a sociopolitical construct created by the U.S. Census Bureau (Martinez-Tyson et al., 2009; Weinick et al., 2004).

Nonetheless, specific attributes that may influence hospice enrollment have been identified within the Hispanic ethnic category, usually relating to their cultural tendency toward collectivism. Defining features of collectivist cultures include family cohesion and support such that the needs of the family are considered above the needs of the individual (Del Río, 2010; Talamantes, 2000). In contrast, the predominantly Eurocentric culture in the U.S. is characteristically individualistic. Family may be particularly important among Mexican American immigrants because of their economic vulnerability (Baca Zinn, 1994). Collectivism has the potential to influence hospice enrollment in Hispanics, who are more likely than non-Hispanic Whites (NHWs) to engage in family decision-making at EOL, whether residing outside (Noguera et al., 2014; Yennurajalingam et al., 2013) or inside the U.S. (Bade et al.,, 1999;

Blackhall et al., 1995; Gutheil & Heyman, 2006; Kelley et al., 2010; Kreling et al., 2010; Noguera et al., 2014; Yennurajalingam et al., 2013).

A second example of a Hispanic cultural trait important to the hospice enrollment process relates to open discussions of terminal prognoses. As part of their EOL family decision-making process, Hispanic persons are more likely to prefer prognostic secrecy (Blackhall et al., 2001; Blackhall et al., 1995; Boucher, et al., 2014; Frank et al., 2002; Loggers et al., 2013; M. L. Rising, 2017; Selsky et al., 2012). The rationale behind prognostic secrecy is that sharing such information with the patient or particular family members might be burdensome for them or even hasten the patient’s death (Rising, 2017). Consistent with the biomedical ethical tenet of beneficence, people from collectivist cultures sometimes prefer beneficence to protect their family members from harm (Rising, 2017). Therefore, maintaining prognostic secrecy may require a particularly nuanced and tactful approach when waiving curative therapy during hospice enrollment.

A third example of an Hispanic cultural characteristic relating to hospice is the occurrence of *hospicios*, which are Latin American institutions historically created by the Catholic Church for the poor and destitute ("Hospicio Cabanas, Guadalajara," 2018). The word *hospicio* is also the direct translation of the word *hospice* into Spanish. Therefore, discussions during the hospice enrollment process may be affected by a potentially different and derogatory meaning of hospice previously held by family members. Even with an explanation of the U.S. meaning of the word, enrolling a family member in hospice in the U.S. still might carry stigma in the form of lack of family support. It is unclear, but these cultural clashes may be factors contributing to low Hispanic hospice enrollment rates.

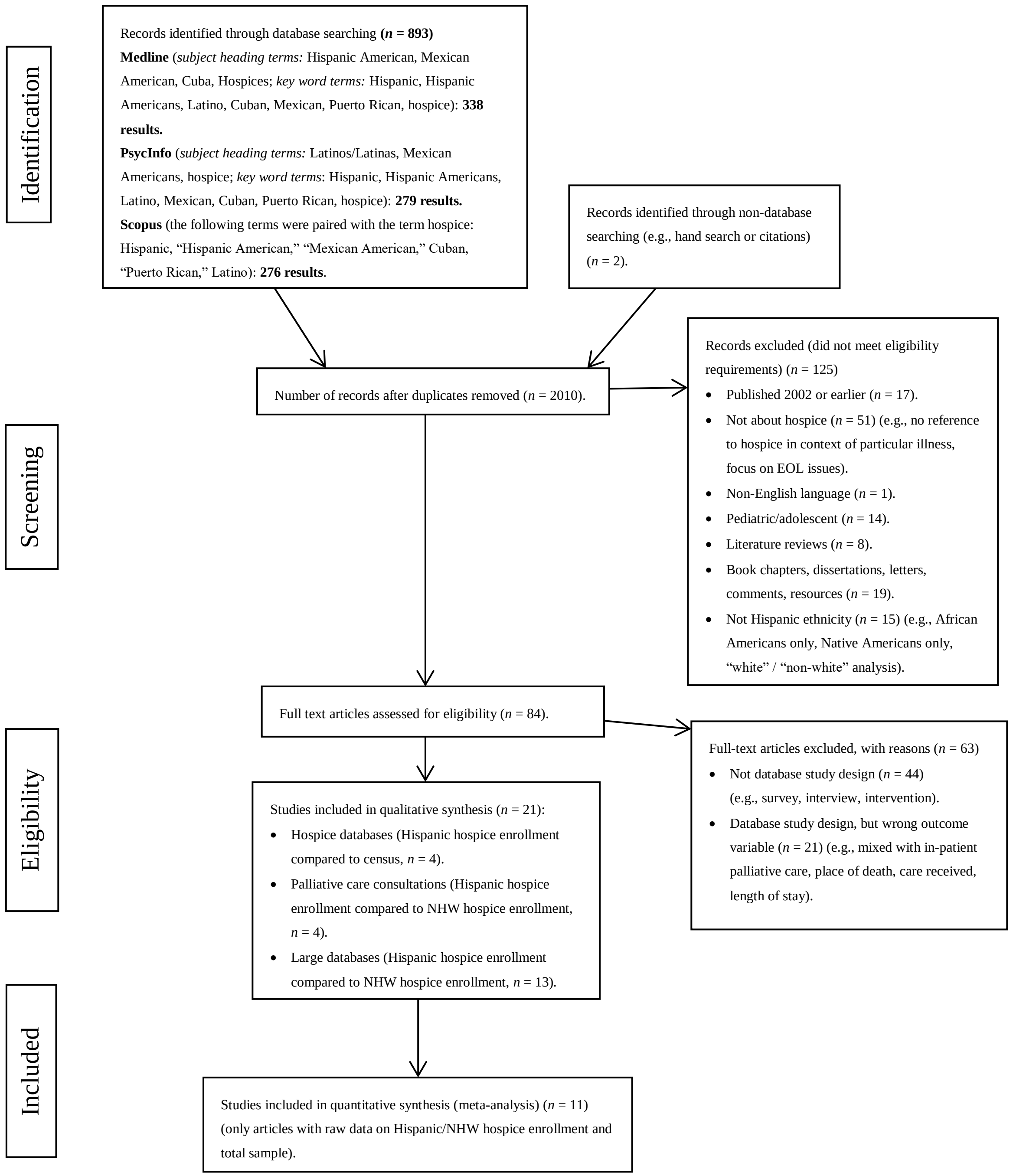

Figure 1. PRISMA (PRISMA, 2015) flow diagram. Adapted from: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic *R*eviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi: 10.1371/journal.pmed1000097. For more information, visit: www.prisma-statement.org.

Methods

The selection of research articles for the descriptive review and meta-analysis (Figure 1) was guided by the PRISMA Transparent Reporting of Systematic Reviews and Meta-Analyses 2009 Checklist (PRISMA, 2015). The goal of the search was to find all articles reporting findings on Hispanic hospice utilization rates using databases. Eligibility criteria included (a) extracted data from a large database, (b) hospice enrollment as an outcome variable, (c) a comparative analysis to report relative Hispanic hospice utilization, and (d) patients 18 years of age and older. Articles published before 2003 were excluded because they were less rigorous. Non–English language articles were also excluded. Search terms, described in Figure 1, were entered into OVID Medline(R) 1946-2nd week April, 2018, PyscInfo 1806-3rd week April 2018, and Scopus April, 2018. The first author screened studies for inclusion in the descriptive review and meta-analysis with guidance from the senior authors. Data were extracted from articles into Excel format then checked for accuracy. The following variables were collected: (a) study authors, (b) date of publication, (c) journal, (d) study design, (e) databases used, (f) disease, (g) age, (h) sample sizes (Hispanic, NHW), (i) analytic approach, (j) outcome variable, and (k) result of statistical test on variables of interest. After the screening and exclusion process described in Figure 1, 21 database studies of Hispanic hospice enrollment remained (Adams, Horn, & Bader, 2006; Colón & Lyke, 2003; Colón & Lyke, 2015; Enguidanos, Vesper, & Goldstein, 2013; Enguidanos, Yip, & Wilber, 2005; Fosler, Staffileno, Fogg, & O'Mahony, 2015; Frahm, Brown, & Hyer, 2012; Givens, Tjia, Zhou, Emanuel, & Ash, 2010; Guadagnolo, Liao, Giordano, Elting, & Shih, 2015; Haas et al., 2007; Hanchate, Kronman, Young-Xu, Ash, & Emanuel, 2009; Hardy et al., 2011; Lackan, Freeman, & Goodwin, 2003; Lackan et al., 2004; Meyers, Lin, Sribney, & Aguilar-Gaxiola, 2008; Rhodes, Xuan, Paulk, Stieglitz, & Halm, 2013; Sammon et al., 2015;

Smith, Earle, & McCarthy, 2009; Taylor et al., 2017; Worster et al., 2018; Xian et al., 2014) (Table 1). The 11 articles chosen for the meta-analysis were the only articles for which raw data on Hispanic/NHW hospice enrollment and total sample sizes were available.

Table 1

Hispanic Hospice Enrollment

Authors	**Disease**	**Age (yr)**	**Date**	**Database**	**Sample (Hisp)**	**Statistics**	**Odds ratio (95% CI) (* = significant # = mixed) (bold = Hispanic rate higher than expected)**
Large Medical and Insurance Databases							
Enguidanos et al. (2005)	various	mean 78.9	1996–2000	dually eligible Medicare-Medicaid	38,519 (5,488)	chi square	Hispanics: 7.5%, Whites: 8.2%
Frahm et al. (2012)	**various**	**mean 86.0**	**2007**	**MDS**	**183,841 (4,228)**	**LR**	***1.214 (1.124–1.311) ($p < .0001$) (adjusted)**
Givens et al. (2010)	heart failure	mean 79.9	2000–2001	Medicare	98,258 (15,903)	LR	*0.49 (0.37–0.66) (adjusted)
Guadagnolo et al. (2015)	6 cancers	> 18	2000–2008	TCR-Medicare-Medicaid	69,572 (9,043)	LR	*0.78 (0.74–0.82) (adjusted)
Haas et al. (2007)	4 cancers	≥ 66	1992–2000	Medicare-SEER	70,669	LR	# > 30% minority tracts 0.51 (0.29–0.91) (adjusted)
Hanchate et al. (2009)	various	mean 81.7	2001	Medicare	158,780 (13,634)	chi square	*Hispanics: 23%, NHWs: 26% ($p < .05$)
Hardy et al. (2011)	Lung cancer	≥ 65	1991–2005	Medicare-SEER	117,894 (1,562)	LR	#overall 0.98 (0.90–1.06); breast cancer 0.73 (0.58–-0.97); LA SEER area 0.87 (0.78–0.97); fee-for-service Medicare 0.90 (0.81–0.99) (adjusted)

(continued)

Authors	**Disease**	**Age (yr)**	**Date**	**Database**	**Sample (Hisp)**	**Statistics**	**Odds ratio (95% CI) (* = significant # = mixed) (bold = Hispanic rate higher than expected)**
Large Medical and Insurance Databases, *continued*							
Lackan et al. (2003)	Breast cancer	≥ 65	1991–1996	Medicare-SEER	25,161 (863)	chi square	Hispanics: 27.2%, Whites: 24.7% (*p* = 0.87)
Lackan et al. (2004)	4 cancers	> 67	1991–1998	Medicare-SEER	34,336 (3,951)	LR	#overall 0.98 (0.90–1.06); breast cancer 0.73 (0.58–0.97); LA SEER area 0.87 (0.78–0.97); fee-for-service Medicare 0.90 (0.81–0.99) (adjusted)
Sammon et al. (2015)	Prostate cancer	median 73	1998–2010	NIS	100,220 (5,712)	LR	*0.65 (0.44–0.95) (*p* = .03)
Smith et al. (2009)	4 cancers	mean 74.7	1992–1999	Medicare-SEER	40,960 (1,520)	LR chi square	1.01 (0.92–1.11) (adjusted) Hispanics: 37.7%, Whites: 42.0% (*p* < .001)
Taylor et al. (2017)	Ovarian cancer	≥ 66	2000–2012	TCR-Medicare	3,666 (553)	LR	*0.78 (0.62–0.97) (*p* = .03) (adjusted)
Xian et al. (2014)	ICH	mean 69.0	2003–2012	GWTG-Stroke	123,623 (10,519)	LR	*0.77 (0.63–0.94) (adjusted)

(continued)

Authors	Disease	Age (yr)	Date	Database	Sample (Hisp)	Statistics	Odds ratio (95% CI) (* = significant # = mixed) (bold = Hispanic rate higher than expected)
Palliative Care Consultations							
Enguidanos et al. (2013)	various	mean 80.1	2007–2009	medical center	364 (93)	LR	1.24 (0.68–2.25) (adjusted)
Fosler et al. (2015)	**various**	**mean 67.0**	**2011**	**medical center**	**198 (30)**	**chi square**	***Hispanics: 77%, Whites: 66% ($p = .007$)**
Rhodes et al. (2013)	various	mean 56.6	2000–2010	Parkland hospital	5,083 (1,225)	LR	1.06 (0.91–1.25) (adjusted)
Worster et al. (2018)	various	Mean 66.1	2006–2015	Thomas Jefferson hospital	2,112 (81)	LR	1.32 (0.74–2.33) (adjusted)
Hospice Database							
Colón & Lyke (2003)	various	mean 74.9	1995–2001	New Jersey, census	1,926 (32)	chi square	*decedents 1.7%, census: 12% ($p < .001$)
Colón & Lyke (2015)	various	mean 76.0	2004–2010	New Jersey, census	2,625 (81)	chi square	*decedents 3.33%, census: 10.8% ($p < .001$)
Adams et al. (2006)	various	mean 80.9	2003	El Paso, census, death statistics	500 (294)	*z*-test	#decedents: 58.8%, deaths: 59.8%, census: 65.5% ($p = .001$)
Meyers et al. (2008)	various	varied	2001–2003	UCD, census, death statistics	932 (93)	not given	**#male non-cancer 19.4%, census: 10.0% ($p < .001$),** female cancer 4.5%, SEER death data: 6.5%

Results

Descriptive analysis: Hispanic hospice enrollment. For presentation of the descriptive analysis, the selected studies are organized into one of three groups according to study design. The first group compared data from hospice databases (Adams et al., 2006; Colón & Lyke, 2003; Colón & Lyke, 2015; Meyers et al., 2008) to census and death data, meaning the proportion of Hispanics enrolled in hospice at a particular hospice facility was compared to the proportion of Hispanics in census and death data served by the hospice. The second group compared data on Hispanic and NHW hospice enrollment rates, but only after palliative care consultations (Enguidanos et al., 2013; Fosler et al., 2015; Rhodes et al., 2013; Worster et al., 2018). The third group compared Hispanic and NHW hospice enrollment rates and sampling was not limited to palliative care consultations (Enguidanos et al., 2005; Frahm et al., 2012; Givens et al., 2010; Guadagnolo et al., 2015; Haas et al., 2007; Hanchate et al., 2009; Hardy et al., 2011; Lackan et al., 2003; Lackan et al., 2004; Sammon et al., 2015; Smith et al., 2009; Taylor et al., 2017; Xian et al., 2014). The large databases used in this third group include the Medicare database, cancer registries, and stroke databases, among others. Table 2 defines each of the larger databases in the third group. As will be seen, conflicting results, limited generalizability, and the variety of databases challenge the construction of a cohesive picture of Hispanic hospice utilization rates.

Table 2

Definitions of Large Databases

Database	Definition
Medicare	Federally funded health insurance mostly for persons 65 years of age and older (U.S. Centers for Medicare and Medicaid Services, 2016d)
Medicaid	Jointly run state and federal health insurance for persons with limited income and resources (U.S. Centers for Medicare and Medicaid Services, 2016c)
Long-term Care Minimum Data Set (MDS)	Health assessment tool required for all residents in a Medicare- or Medicaid-certified long-term care facility (U.S. Centers for Medicare and Medicaid Services, 2016b)
Surveillance, Epidemiology, and End Results Program (SEER)	A population-based National Cancer Institute epidemiological database that has grown to represent 30% of the U.S. population (National Cancer Institute, 2016)
Texas Cancer Registry (TCR)	Statewide population-based cancer registry maintained in collaboration between the Texas Department of State Health Services and the National Program of Cancer Registries – Centers for Disease Control and Prevention (Texas Department of State Health Services, 2016)
National Inpatient Sample (NIS)	The largest publicly available all-payer inpatient database in the U.S. (U.S. Department of Health and Human Services, 2016)
American Heart Association/American Stroke Association Get With The Guidelines-Stroke (GWTG-Stroke)	In-hospital program to improve stroke care with more than two million patient records from 1,656 hospitals (American Heart Association, 2016)

Descriptive group 1: proportions of Hispanics on hospice compared to proportions of Hispanics in census and death statistics. In these studies, researchers compared proportions of Hispanic hospice enrollment to proportions of Hispanics in U.S. Census data (Adams et al., 2006; Colón & Lyke, 2003; Colón & Lyke, 2015; Meyers et al., 2008) or in databases maintaining death statistics (Adams et al., 2006; Meyers et al., 2008) (Table 1). While not universally true, the comparator (i.e., census or death statistics) often dictates whether results are significant, which has been noted elsewhere (von Gunten, 2008). Studies comparing proportions of Hispanics enrolled in hospice to proportions of Hispanics in census data used chi square analysis (Colón & Lyke, 2003; Colón & Lyke, 2015) and *z*-tests,(Adams et al., 2006) unless not reported (Meyers et al., 2008). The results show statistically significantly lower rates of Hispanic hospice enrollment (Adams et al., 2006; Colón & Lyke, 2003; Colón & Lyke, 2015; Meyers et al., 2008), with one exception (Meyers et al., 2008). The exception was found in a population sampled (N = 932; n = 93 Hispanics) in the University of California Davis (UCD) hospice study (Meyers et al., 2008). There, the proportion of Hispanic men (19.4%; non-cancer) enrolled in hospice was actually significantly higher than the proportion of male Hispanics in the Sacramento County census area (10.0%; $p < .001$; Meyers et al., 2008). However, in the same study, significantly lower proportions of female Hispanic hospice cancer enrollees (4.5%) were reported in comparison to Hispanic women in Sacramento County (8.7%; $p < .001$; Meyers et al., 2008).

Consistent with this latter finding, other hospice database studies report statistically lower proportions of Hispanic hospice enrollees. For example, in a study (N = 1,926) conducted between 1995–2001 (Colón & Lyke, 2003), and in a follow-up study (N = 2,625) by the same authors conducted between 2004–2010 (Colón & Lyke, 2015), chi square analysis resulted in significantly lower proportions of Hispanic (n = 32; n = 81) hospice enrollees (1.7% (Colón & Lyke, 2003); 3.3% (Colón & Lyke, 2015)) in comparison to the proportion of Hispanics in New Jersey census data (12% [Colón & Lyke, 2003]; 10.08% [Colón & Lyke, 2015]; $p < .001$). In another study that occurred in El Paso, Texas, (N = 500), *z*-test analyses resulted in significantly lower proportions of elderly Hispanic (n = 294) Medicare hospice enrollees (58.8%) compared to the proportion of elderly Hispanics living in El Paso (65.5%; $p = .001$; Adams et al., 2006). In summary, most comparisons with census data suggest Hispanics are enrolling in hospice at lower than expected rates.

In contrast, results are not statistically significant when death statistics provide the comparator (Adams et al., 2006; Meyers et al., 2008). The same study occurring in El Paso, Texas, (N = 500) found no statistically significant difference in z-test analysis between the proportion of elderly Hispanic (n = 294) Medicare hospice enrollees (58.8%) and the number of Hispanic decedents over 65 years of age dying in El Paso (59.8%; Adams et al., 2006). Continuing the same trend, in the UCD study (N = 932; n = 93 Hispanics), the proportion of female Hispanic hospice enrollees with cancer (4.5%) was not statistically different from the proportion of women who died of cancer in the Sacramento County area based on the Surveillance, Epidemiology, and End Results Program (SEER) cancer registry (6.5%; Meyers et al., 2008). As explained in Table 2, the SEER registry is a population-based National Cancer Institute epidemiological database (National Cancer Institute, 2016) and is used in many of the studies in this review.

There are two plausible explanations for the loss of statistical significance when comparing to death data instead of census data. Both relate to the *Hispanic Paradox*, or the unexpected low mortality rate of the Hispanic population when considering their lower average socioeconomic status (Bostean, 2013; Franzini, Ribble, & Keddie, 2001; Markides & Eschbach, 2005). One explanation stems from the theorized *salmon-bias effect*, which recognizes return migration to Mexico by terminally ill, retiring, or aging Mexicans (Franzini et al., 2001; Markides & Eschbach, 2005; Palloni & Arias, 2004). The salmon-bias effect would predict disproportionately higher census numbers of healthy Mexicans compared to the number of Mexicans dying in the U.S. The result of the salmon-bias effect would be sampling bias that lowers rates of Hispanic hospice utilization, overall, when compared to census data. The second explanation is that proportionately more Hispanics are presumably younger, healthy, and not on hospice. The median age of U.S. Hispanics is lower (27 years) than the median U.S. age (37 years; Pew Research Center, 2012). Using census data as the comparator against the proportion of Hispanics enrolled in hospice may neglect these different population distributions. These explanations suggest hospice database studies comparing hospice enrollment to death data may be more accurate than those comparing to population data. In conclusion, the evidence is mixed in hospice database studies, with census comparators generally giving rise to significant differences and death statistic comparators generally giving rise to non-significant differences.

Descriptive group 2: comparing Hispanic and *NHW* ***hospice enrollment rates after palliative care consultations.*** Study designs in the second group of studies compared Hispanic and NHW hospice enrollment rates following palliative care consultations (Enguidanos et al., 2013; Fosler et al., 2015; Rhodes et al., 2013; Worster et al., 2018) (Table 1). Overall results show Hispanics enrolling in hospice at rates on par with NHWs (Enguidanos et al., 2013; Rhodes et al., 2013; Worster et al., 2018) and even higher (Fosler et al., 2015). In a safety-net hospital in Parkland, Texas, (*N* = 5,083) the odds of Hispanic (*n* = 1,225) hospice enrollment following inpatient and outpatient palliative care consultations were not significantly different from NHWs in adjusted analysis (adjusted OR 1.06, 95% CI: 0.91–1.25; Rhodes et al., 2013). As a safety-net hospital, the sample may reflect a greater representation of under- and uninsured individuals. Other authors have observed that many clinicians at the Parkland Hospital are familiar with the Hispanic culture and speak Spanish fluently (Loggers et al., 2013), which may have contributed to high rates of Hispanic hospice enrollment. In a study at a health maintenance organization medical center in Los Angeles, California, (*N* = 364) also known for its strong palliative care program (Enguidanos et al., 2013), the odds of Hispanic (*n* = 93) hospice enrollment after inpatient palliative care consultations were not significantly different from NHWs in adjusted analysis (adjusted OR 1.24, CI: 0.68–2.25; Enguidanos et al., 2013). Finally, compared to NHWs, a recent study at a university hospital serving the Philadelphia metropolitan area (*N* = 2,112) found comparable odds of Hispanic (*n* = 81) hospice enrollment after palliative care consultation (adjusted OR 1.32, 95% CI: 0.74–2.33; Worster et al., 2018).

In contrast to the foregoing, the fourth palliative care study reported statistically significant higher rates of Hispanic (*n* = 30) hospice enrollment compared to NHWs using chi square analysis (*N* = 198; Fosler et al., 2015). In that study, which occurred at a large Midwestern university medical center, there was a greater proportion of Hispanics (77%) enrolled in hospice than NHWs (66%; *p* = .007; Fosler et al., 2015). Consistently finding expected rates of Hispanic hospice utilization or higher in the context of palliative care consultations suggests mitigation of barriers to hospice care by the psychosocial support provided in palliative care consultations. However, the palliative care consultations studied mostly occurred in the hospital setting, which, alone, may increase Hispanic hospice referrals relative to the clinical setting (Carrion, 2010; Kreling et al., 2010).

Descriptive group 3: comparing Hispanic and NHW hospice enrollment rates. The third group of studies includes 13 articles (Table 1) that compare hospice enrollment rates between Hispanics and NHWs retrieved from large medical-related databases (Enguidanos et al., 2005; Givens et al., 2010; Guadagnolo et al., 2015; Haas et al., 2007; Hanchate et al., 2009; Hardy et al., 2011; Lackan et al., 2003; Lackan et al., 2004; Sammon et al., 2015; Smith et al., 2009; Taylor et al., 2017). Those databases are briefly described in Table 2. These studies stand apart from the other reviewed studies by virtue of their extremely large sample sizes, with an average *N* = 81,962 and range from *N* = 3,666 to *N* = 183,841. The databases also represent a diverse assortment of populations and disease types, from insurance (e.g., Medicare and Medicaid) and hospital (National Inpatient Sample) to disease-specific registries (e.g., cancer and stroke) (Table 2). For clarity, studies are presented in three groups: statistical findings that are (a) non-significant, (b) significant, and (c) mixed.

Descriptive group 3: non-significant results (Hispanic vs. NHW rates). Articles in this section report no statistically significant differences between ethnicities (Enguidanos et al., 2005; Lackan et al., 2003; Smith et al., 2009) (Figure 1). Chi square analyses of proportions of Hispanics (*n* = 863 [Lackan et al., 2003]; *n* =5,488 [Enguidanos et al., 2005]) and NHWs enrolling in hospice showed no significant differences in ethnicity among breast cancer decedents in the SEER–Medicare database (*N* = 25,161; Lackan et al., 2003) and among older decedents with various illnesses in the dually eligible Medicaid/Medicare database (*N* = 38,519; Enguidanos et al., 2005). In contrast, chi square analysis showed significant differences between proportions of Hispanic (37.7%; *n* = 1,520) and NHW (42%; *p* < .001) hospice enrollees in the SEER–Medicare database with breast, colorectal, lung, or prostate cancer (*N* = 40,960; Smith et al., 2009). Significance was lost, however, when sociodemographic and other variables were controlled in logistic regression modelling (adjusted OR 1.01, 95% CI: 0.92–1.11; Smith et al., 2009). Adjusted variables included age, sex, marital status, income, state buy-in status, foreign-born status, site of primary cancer, tumor grade, year of diagnosis, comorbidity score, and SEER registry (Smith et al., 2009). Significance was not lost for African Americans and Asians after the same adjustment (Smith et al., 2009), suggesting statistical covariance of sociodemographic variables is greater in the Hispanic population relative to other minority groups. Another consideration is the possibility of causal connections between controlled variables, such as foreign-born status, income, and ethnicity, which may cast doubt on the assumptions behind statistical modeling (Hebert, Sisk, & Howell, 2008). A strength shared by these studies is their large sample sizes. However, sampling only from the Medicare database may have excluded many uninsured Hispanics (Centers for Disease Control and Prevention, 2017; Krogstad, 2015; Krogstad & Passel, 2015; National Hospice and Palliative Care Organization, 2015; "Persons born in Puerto Rico on or after April 11, 1899," 1952; U.S. Centers for Medicare and Medicaid Services, 2016a, 2016c, 2016d) and so results may be biased toward insured Hispanics and, therefore, limited in their generalizability.

Descriptive group 3: significant results (Hispanic vs. NHW rates). The next seven studies report statistically significant differences between ethnicities (Frahm et al., 2012; Givens et al., 2010; Guadagnolo et al., 2015; Hanchate et al., 2009; Sammon et al., 2015; Taylor et al., 2017; Xian et al., 2014) (Figure 1). Only one study, relying on the MDS database (U.S. Centers for Medicare and Medicaid Services, 2016b) and including nursing home residents, reported a higher likelihood of Hispanics ($n = 4{,}228$) enrolling in hospice compared to NHWs (adjusted OR 1.21, 95% CI: 1.24–1.311; $p < .0001$; Frahm et al., 2012). A strength of this study is its sample size ($N = 183{,}841$). In addition, this study may generate more questions than answers, since multiple studies have suggested that Hispanics, generally, tend to avoid nursing homes as much as possible and prefer family to care for the terminally ill (Duffy et al., 2006; Gelfand et al., 2001). Therefore, it is possible that results from the MDS database are not generalizable to all Hispanics, particularly the uninsured, or those preferring family to care for the terminally ill.

The remaining six studies that reported significant results reported lower odds that Hispanics would enroll in hospice compared to NHWs (Givens et al., 2010; Guadagnolo et al., 2015; Hanchate et al., 2009; Sammon et al., 2015; Taylor et al., 2017; Xian et al., 2014). Four sampled from the Medicare database. The first sampled Medicare decedents without focusing on a specific disease-type (Hanchate et al., 2009). There, the proportion of Hispanic hospice enrollees (23%; n = 13,634) was significantly less than the proportion of NHW hospice enrollees (26%; $p < .05$; Hanchate et al., 2009). A strength of this study is its sample size (N = 158,780; Hanchate et al., 2009). However, because results were reported from chi square analysis and without logistic regression modeling, it is unknown whether confounding variables may have contributed to that significant finding.

A second study sampled Medicare decedents with heart failure diagnoses (Givens et al., 2010). Significantly, Hispanics (n = 15,903) were only half as likely to enroll in hospice as NHWs, even after adjusting for variables such as sociodemographic data, urban/rural residence, comorbidities, use of medical services, and local hospice density (adjusted OR 0.49, 95% CI: 0.37–0.66; Givens et al., 2010). In addition to a large sample size (N = 98,258), a strength of this study includes adjusting for local hospice availability, a novel variable. No other study attempted to account for whether the proximity of hospice may affect utilization. The continued significance of results after adjusting for potentially confounding variables offers strong evidence that Hispanics with heart failure who qualify for Medicare are underutilizing hospice care.

The next two studies extract data from the Texas Cancer Registry as well as Medicare. One extracted data from the linked Texas Cancer Registry–Medicare database (Taylor et al., 2017). Among decedents dying of ovarian cancer from 2000–2012 (N = 2,819), Hispanics (n = 256) were less likely to enroll in hospice than NHWs (n = 553; OR 0.76, 95% CI: 0.61–0.94; p = 0.01; Taylor et al., 2017). The next extracted data from the linked Texas Cancer Registry–Medicare database as well the Texas Cancer Registry–Medicaid database (Guadagnolo et al., 2015). Consequently, the sample included not just elderly cancer patients but also those with limited financial resources (Guadagnolo et al., 2015). There, Hispanics (n = 9,043) dying from breast, colorectal, lung, melanoma, pancreatic, and prostate cancers were less likely to enroll in hospice than NHWs in adjusted analyses (adjusted OR 0.78, 95% CI: 0.74–0.82; Guadagnolo et al., 2015). Controlled variables included sex, income area, education level, and urban or rural residency (Guadagnolo et al., 2015). In addition to a large sample size (N = 69,572), a strength of this study is inclusion of Medicaid-only decedents because it captures younger and financially insolvent cancer patients not necessarily included in Medicare. A weakness of the previous four studies sampling from the Medicare or Medicaid databases is that they may be biased by excluding Hispanics without insurance. In addition, they are not generalizable to Hispanics without citizenship or within the five-year waiting period for federal insurance (Krogstad, 2015; Krogstad & Passel, 2015; "Persons born in Puerto Rico on or after April 11, 1899," 1952; U.S. Centers for Medicare and Medicaid Services, 2016a, 2016c, 2016d).

The remaining two studies reporting significant differences between Hispanics and NHWs are distinguishable from the preceding studies because they do not rely on the Medicare database. Instead, they sampled from the American Heart Association/American Stroke Association Get With The Guidelines–Stroke (GWTG–Stroke) database (Xian et al., 2014) and the National Inpatient Sample (NIS; Sammon et al., 2015), both of which are hospital-driven databases (Table 2). The GWTG–Stroke database maintains records of hospital patients enrolling in hospice after intracerebral hemorrhage (ICH; Xian et al., 2014). Hispanics (n = 10,519) after ICH were significantly less likely to enroll in hospice than NHWs in adjusted analysis (adjusted OR 0.77, 95% CI: 0.63–0.94; N = 123,623; Xian et al., 2014). Significance remained after adjusting for sociodemographic variables, comorbidities, hospital-level neighborhood determinants, and National Institutes of Health Stroke Scale scores (Xian et al., 2014). The results from this study offer strong evidence that Hispanics suffering from ICH underutilize hospice care. In addition to its large sample size, a strength of this study is that it may have included uninsured Hispanics receiving federally funded hospital care under the Emergency Medical Treatment and Labor Act (EMTALA; "Emergency Medical Treatment and Active Labor Act," 1986; U.S. Centers for Medicare and Medicaid Services, 2012) and, by extension, private charity hospice.

The second study relying on a hospital database extracts data from the NIS database (Table 2), which provides a record of hospital discharge data, including to hospice (Sammon et al., 2015). In that study, complex samples logistic regression modeling accounted for hospital clustering and sampling methodology, showing that Hispanics (*n* = 5,712) with prostate cancer were substantially less likely to enroll in hospice compared to NHWs (OR 0.65, 95% CI: 0.44–0.95, *p* = .03; *N* = 100,220; Sammon et al., 2015). Even though these results describe Hispanic hospice utilization in the context of cancer, results from this study are distinguishable from those linked to the SEER and TCR databases because the NIS database is hospital-linked rather than Medicare/Medicaid–linked. Consequently, as with the previous article, a strength of this study is that it may have included uninsured Hispanics receiving federally funded hospital care through EMTALA ("Emergency Medical Treatment and Active Labor Act," 1986; U.S. Centers for Medicare and Medicaid Services, 2012) and private charity hospice. Specifically, the authors report that 5.6% of those sampled in the NIS database were not receiving Medicare, Medicaid, or private insurance reimbursement (Sammon et al., 2015).

Descriptive group 3: mixed results (Hispanics vs. NHWs). Thus far, results from studies offering statistically significant and non-significant results from large databases have been presented. The final three studies report mixed results from the Medicare–SEER database using unique study designs (Haas et al., 2007; Hardy et al., 2011; Lackan et al., 2004). The first study compared ethnic hospice enrollment in census tracts that varied by minority representation (Haas et al., 2007). Logistic regression analysis adjusting for age, income, education, site of cancer, and stage at diagnosis, among others, showed statistically significant results. Specifically, Hispanics who lived in census tracts with “more than 30 percent African Americans and Hispanics” were less likely to use hospice care than Hispanics who lived in “low minority tracts” (adjusted OR 0.51, 95% CI: 0.29–0.91; *N* = 70,669; Haas et al., 2007). The results of this study suggest there may be inadequate hospice resources and services in predominantly minority neighborhoods (Haas et al., 2007).

The second study in this section reporting mixed results compared ethnic hospice enrollment between urban and rural regions (Hardy et al., 2011). There, after adjusting for sex, age, income, comorbid score, and year of diagnosis, among others, Hispanics (*n* = 1,562) with lung cancer residing in urban regions were significantly less likely to enroll in hospice than NHWs in all but one year studied (adjusted OR 0.81, 95% CI: 0.73–0.91; *N* = 117,894; Hardy et al., 2011). In contrast, there were no significant differences by ethnicity in rural regions (adjusted OR 1.17, 95% CI: 0.75–1.84; Hardy et al., 2011). However, the authors of this study observed that the study was underpowered to detect an effect in rural Hispanics, suggesting the possibility of a Type 2 error (Hardy et al., 2011).

The third study with mixed results sampled decedents with breast, colorectal, lung, or prostate cancer (*N* = 34,336, Hispanic *n* = 3,951; Lackan et al., 2004). In that study, there were no significant findings in overall adjusted logistic regression model (Lackan et al., 2004). However, statistical significance was found in subsets of models after adjusting for type of

Medicare (fee-for-service/managed care), sociodemographic variables, cancer type, SEER area, year of diagnosis and year of death. Significantly lower rates of hospice enrollment compared to NHWs were found among Hispanic women with breast cancer (adjusted OR: 0.73, 95% CI: 0.58–0.97), Hispanic residents in the Los Angeles SEER area (adjusted OR 0.87, 95% CI: 0.78–0.97), and Hispanic fee-for-service Medicare beneficiaries (adjusted OR 0.90, 95% CI: 0.81–0.99; Lackan et al., 2004). As with previous Medicare-based studies, these results are limited in generalizability to Hispanics qualifying for federal insurance. The significant differences in Los Angeles and in urban versus rural settings suggest there may be considerable variation in Hispanic hospice utilization by geography and neighborhood. Furthermore, the significant difference in the context of breast cancer but not in the overall study suggests there may be variation in Hispanic hospice utilization by gender.

Meta-analysis. Because of varied study designs and mixed reported results, the descriptive review cannot provide a cohesive answer to the question of whether Hispanics utilize hospice at expected rates. Therefore, we combine the results of several independent studies to conduct a meta-analysis using Stata 15.0. The goal of the meta-analysis is to quantify relative Hispanic hospice utilization rates by combining data from multiple studies.

Meta-analysis methods. Because they provided sufficient raw data, we selected and combined 11 studies for statistical analysis (Enguidanos et al., 2013; Fosler et al., 2015; Givens et al., 2010; Haas et al., 2007; Hanchate et al., 2009; Lackan et al., 2003; Lackan et al., 2004; Rhodes et al., 2013; Smith et al., 2009; Taylor et al., 2017; Xian et al., 2014). Total sample sizes amounted to *N*(NHW) = 308,423 and *N*(Hispanic) = 49,348. We conducted a random-effects meta-analysis, which assumes that study effect sizes—the effect of being Hispanic versus being NHW—are random (instead of fixed). We calculated risk ratios (RR), which reflect the ratio of the probability of Hispanics using hospice to the probability of NHWs using hospice. An RR value less than one signifies a lower risk that Hispanics would use hospice compared to NHWs. Stata 15.0 calculates RR using weighted study results, determined by study sample size and precision of results (i.e., confidence interval width). Each meta-analysis calculation includes a post-hoc $\chi^2$and I^2 calculation to evaluate whether there is homogeneity in effect sizes to merit comparison among the selected studies, or alternatively if there is significant and substantive heterogeneity in results across studies.

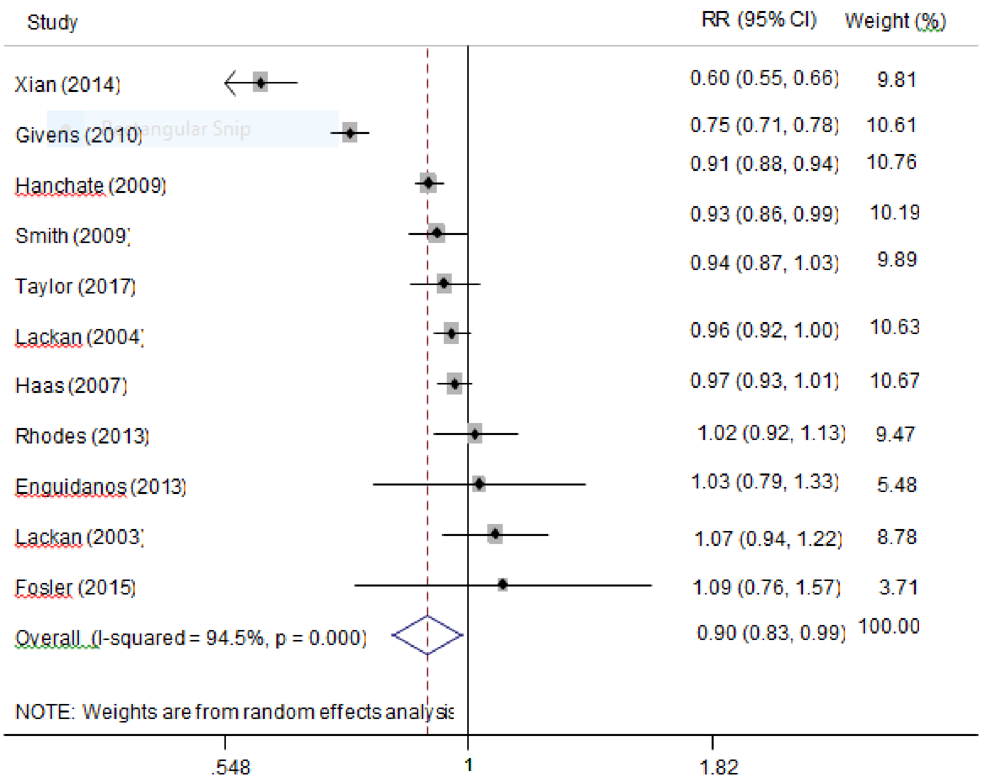

Figure 2. Meta-analysis results on *n* = 11 studies.

Meta-analysis results. The initial meta-analysis conducted on 11 studies (Figure 2) shows Hispanics are 10% less likely to use hospice (RR 0.90, 95% CI: 0.83–0.99; $z = 2.29$; $p = 0.022$). However, post-hoc heterogeneity analyses $\chi^2 = 180.47$; $df = 10$; $p < 0.001$; and $I^2 = 94.5\%$) show significant heterogeneity in effect sizes among the 11 studies. Without sufficient homogeneity in effect size among studies, there is strong evidence that the studies samples are being drawn from are too different to reliably compare in meta-analysis. For example, Hispanics with heart failure and stroke are less likely to use hospice compared to those with cancer. There, Hispanics are 25% less likely to use hospice in the context of heart failure (RR 0.75, 95% CI: 0.71–0.78) and are 40% less likely to use hospice in the context of stroke (RR 0.60, 95% CI: 0.55–0.66). These results suggest underlying disease process may influence hospice utilization, meriting further research. We considered other clinical and methodological differences that may contribute to heterogeneity, regrouped the studies, and then conducted meta-analyses on these smaller study samples.

Specifically, three studies conducted ethnic comparisons among hospital patients who had received palliative care consultations (*n*[NHW] = 1,812, *n*[H] = 1,348; Enguidanos et al., 2013; Fosler et al., 2015; Rhodes et al., 2013). Although an unknown number of patients in the other eight studies selected for meta-analysis may also have received palliative care, we can be certain that all patients in these three studies received palliative care by virtue of study design. Results from the three palliative care studies showed sufficient homogeneity ($\chi^2 = 0.12$; $df = 2$; $p = 0.941$; $I^2 = 0\%$) and that Hispanics and NHWs used hospice at comparable rates (RR 1.02, 95% CI: 0.93–1.12; $z = 0.49$; $p = 0.627$) (Figure 3). A possible explanation for the similarity in rates between Hispanics and NHWs is the well-documented psychosocial support offered by palliative care.

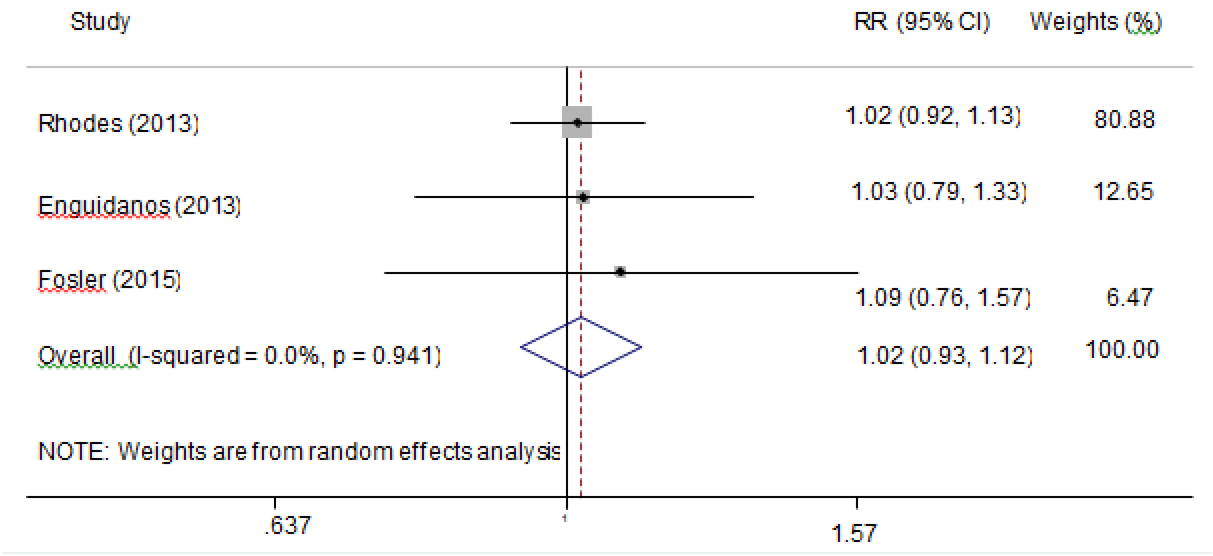

Figure 3. Meta-analysis results from *n* = 3 palliative care studies.

The remaining eight studies combined in meta-analysis continued to show high levels of heterogeneity (χ^2 = 171.63; *df* = 7; $p < 0.001$; and I^2 = 95.9%), and so we selected a subsample of five studies focused on cancer patients from the SEER–Medicare database (*n*[NHW] = 148,203, *n*[H] = 10,440; Haas et al., 2007; Lackan et al., 2003; Lackan et al., 2004; Smith et al., 2009; Taylor et al., 2017). A meta-analysis from these five studies showed sufficient homogeneity in effect size (χ^2 = 4.00; *df* = 4; $p = 0.407$; I^2 = 0%) and that Hispanics are 4% less likely to use hospice than NHWs (RR 0.96, 95% CI: 0.94–0.99; $z = 3.01$; $p = 0.003$) (Figure 4).

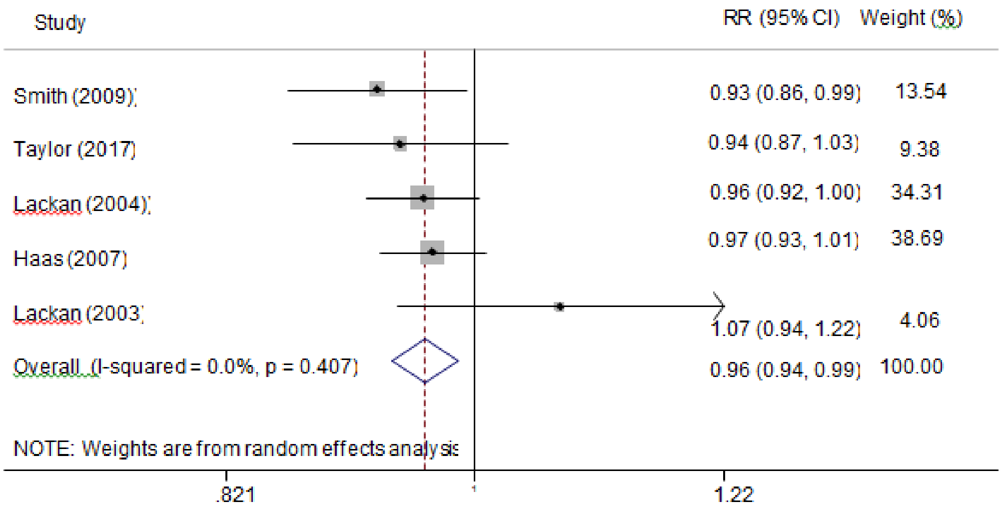

Figure 4. Meta-analysis of *n* = 5 SEER–Medicare database studies.

Discussion

This is the first comprehensive review of articles reporting Hispanic hospice utilization rates and the first to quantify Hispanic hospice utilization rates across combined studies. Consistent with PRISMA guidelines, we will summarize findings, consider their relevance and implications to clinical practice, health policy, and research, and discuss limitations.

As mentioned, varied study designs and research findings prevented a cohesive picture of Hispanic hospice utilization in the descriptive portion of this review. Similarly, because of heterogeneity in effect sizes, we were only able to provide strong statistical findings in subsamples of articles. There were strong findings that consistently stood out throughout the review, however. First, in the context of palliative care consultations, Hispanics tend to use hospice at rates on par with NHWs, or higher. In light of extensive examples in the research literature of palliative care improving outcomes at EOL (Bakitas et al., 2009; El-Jawahri, Greer, & Temel, 2011; Gelfman, Meier, & Morrison, 2008; Higginson & Evans, 2010), it is plausible that the extra social support provided by palliative care providers mitigates any cultural or social barriers to hospice enrollment. Future research should specifically describe the role palliative care consultations play in the hospice enrollment process for Hispanics. In addition, from a clinical perspective, routinely arranging for palliative care consultations with terminally ill Hispanic patients and their families may improve the quality of care received and optimize the hospice enrollment experience. From a policy perspective, valuing palliative care consultations through uniform reimbursements would encourage palliative referrals as well as continued specialization.

Another strong finding is that, in the context of heart failure and stroke, Hispanics tend to use hospice at substantially lower rates than NHWs. Future research is needed in these areas to explain these findings. Moreover, policymakers establishing recommendations pertaining to Hispanic hospice utilization should remain mindful of the possibility of disease-specific influences when generalizing results from findings based on other diseases, such as cancer.

Results from the cancer setting are distinguishable from those pertaining to heart failure and stroke. Many results reported herein suggest that Hispanic hospice utilization in the cancer setting is on par with NHWs. In those studies reporting statistically significant results, the differences are not as strong as in the heart failure and stroke studies. From a clinical perspective, we might ask what social dynamic is occurring in the cancer setting that facilitates hospice enrollment compared with other diagnoses. Further, we might investigate whether we are supporting, through healthcare policy and reimbursement, programs in the non-cancer setting that foster robust healthcare teams and abundance of psychosocial resources.

A fourth study finding that stands out relates to greater rates of Hispanic hospice utilization rates in the nursing home setting (Frahm et al., 2012). This finding begs further investigation, given the current knowledge about Hispanic preference for family caregiving at EOL (Born et al., 2004; Gelfand et al., 2001, 2004; Kreling et al., 2010; Taxis et al., 2008).

A fifth overall finding from this review pertains to calculating Hispanic hospice utilization rates from census data and death data, which tend to provide different results. There is a strong logical argument in favor of death data when considering the Hispanic paradox and the salmon bias effect. However, overall, meta-analysis results showing lower Hispanic hospice utilization rates suggest that census data comparisons may be more accurate. Odds ratios and relative risks in the stroke and heart failure setting provide strong evidence that Hispanics are underutilizing hospice. In addition, the meta-analysis of cancer studies as well as the descriptive review provided strong evidence that Hispanics are underutilizing hospice in that context. Clearly, more research is needed on this subject, and policymakers might cautiously interpret study findings when based on comparisons to census and death data.

Equality in rates of utilization versus equity. Regardless of findings presented in this review, it is important to bear in mind that equality in rates of hospice utilization represent access to healthcare, but do not fully capture equity in hospice utilization. A consideration of policy statements from the IOM (Institute of Medicine, 2014; Nelson, Stith, & Smedley, 2002), the World Health Organization (World Health Organization, 2017), and researchers (Braveman, 2006; Braveman & Gruskin, 2003) leads to the concept that true equity in hospice utilization is derived from equality in quality of care. An emphasis on quality of hospice care, rather than hospice utilization rates, is consistent with the IOM’s emphasis on providing patient-centered and family-oriented care at EOL (Institute of Medicine, 2014). A focus on equity in quality of hospice care also places the equitable distribution of hospice care within the biomedical ethical tenet of social justice (Braveman, 2006; Braveman & Gruskin, 2003; World Health

Organization, 2017) and international (World Health Organization, 2017) and U.S. (Centers for Disease Control and Prevention, 2015; U.S. Department of Health and Human Services, 2014) health policy goals. Unfortunately, few published studies have documented hospice quality outcomes in Hispanics, and available information paints a complex picture. The results of a survey mailed to surviving caregivers found that Nevada Hispanic hospice informal caregivers were significantly more likely to report that hospice patients received care against their wishes, even though they were generally satisfied with hospice compared to NHWs (Kirkendall et al., 2015). The reason for this disconnect is unclear, reflecting the need for more research on Hispanic hospice utilization to improve care quality. Designating hospice utilization rates as the only component of equity in the delivery of quality hospice care has potentially negative consequences for quality of hospice care. Therefore, policymakers and researchers should not rely solely on Hispanic hospice utilization rates as evidence for or against healthcare disparities and health equity.

Access to healthcare: health insurance. A final policy consideration in Hispanic hospice utilization relates to health insurance access—an important social determinant of health ("Healthy People 2020," 2018)—for Hispanics without citizenship or documentation. Studies in this review that relied on Medicare and Medicaid insurance excluded Hispanics without federal healthcare insurance. Such persons may represent the most marginalized and least acculturated Hispanics in the U.S., which may strongly impact their hospice utilization. Among Hispanics, Mexicans suffer the most from lack of insurance. The Centers for Disease Control reports that Mexicans have the highest rate of uninsured individuals compared to NHWs and compared to other Hispanics, generally (Table 3) (Centers for Disease Control and Prevention, 2017).

Table 3

Uninsured Individuals by Ethnicity (Centers for Disease Control and Prevention, 2017)

Ethnicity	**< 65 years old (%)**	**> 65 years old (%)**
Mexicans	24.7	4.2
Hispanics	21.9	3.1
NHWs	7.5	0.3

Access to federal health insurance is important because, across all hospice users, Medicare (85.5%), Medicaid (5.0%), and private insurance (6.9%) pay for a combined 97.4% of hospice, with only 0.7% paid for by charity (National Hospice and Palliative Care Organization, 2015). However, Medicaid and Medicare policies exclude non–U.S. citizens and those who have not been U.S. citizens for five years (Krogstad, 2015; Krogstad & Passel, 2015; "Persons born in Puerto Rico on or after April 11, 1899," 1952; U.S. Centers for Medicare and Medicaid Services, 2016a, 2016c, 2016d). Mexicans, who provide the "labor backbone" of U.S. industries such as construction, hospitality, and agriculture (Jordan & Perez, 2016), are a mix of U.S. citizens and non–U.S. citizens as well as documented and undocumented individuals. The relative Mexican/U.S.-born Mexican population in the U.S. is 33.9%/66% (Gonzalez-Barrera & Lopez, 2013), and there is an estimated 5.6 million (Krogstad & Passel, 2015) to 6.8 million undocumented Mexicans living in the U.S. (comprising 51% of Mexican-born; Gonzalez-Barrera & Lopez, 2013). Inclusion of such individuals may be near impossible in such database studies; this bias should be acknowledged as a study limitation in research reports.

Limitations

There are many limitations to this review. First, expected rates of Hispanic hospice utilization were calculated differently throughout studies, which precludes comparisons of studies. Second, raw data was not available for all studies and so the meta-analysis is only a subsample of the larger descriptive review. Third, the meta-analysis section is limited by considerable heterogeneity in study effect sizes when all studies were considered.

Fourth, even though it is an important assessment tool in Hispanic hospice utilization, there are inherent limitations to database research. Healthcare utilization is a complex process (Aday & Andersen, 1974; Ajzen, 2011; Andersen & Newman, 2005; Andersen, 1995), and even more so in cross-cultural healthcare settings (Campinha-Bacote, 2002; Kim-Godwin, Clarke, & Barton, 2001; Purnell, 2002). Personal and cultural preferences cannot be inferred from database study results because utilization of healthcare is not a proxy for healthcare preferences or delivery of culturally appropriate care.

A fifth limitation relates to the validity of Hispanic ethnicity as a social construct. Hispanics are mostly united by the Spanish language (Martinez-Tyson et al., 2009; Weinick et al., 2004) and are not a culturally and socially homogenous group for purposes of health care (Del Río, 2010; Leininger, 1996; Martinez-Tyson et al., 2009; Talamantes, 2000; Weinick et al., 2004). Reductionist efforts in database studies disregard that ethnic membership is a complex social process (Ford & Harawa, 2010; Kagawa-Singer, 2001; Phillips & Drevdahl, 2003). The resulting sixth limitation of this review is that researchers relied on Hispanic surnames to identify ethnicity (Bach, Guadagnoli, Schrag, Schussler, & Warren, 2002; Kressin, Chang, Hendricks, & Kazis, 2003; Pan, Glynn, Mogun, Choodnovskiy, & Avorn, 1999); this ignores the reality that surnames do not consistently reflect self-identified ethnicity (Ford & Harawa, 2010; Kagawa-Singer, 2001). The seventh and final limitation of this review is the unknown extent to which the healthcare activity of uninsured Hispanics is omitted from databases and research efforts.

References

See Cumulative References.

Chapter V

Hospice Decision-Making in Mexicans with Terminal Cancer and Their Families

Margaret L. Rising, BSN, RN, PhD Candidate

Oregon Health & Science University School of Nursing, Portland, OR, U.S.A.

Dena Hassouneh RN, PhD, FAAN

Oregon Health & Science University School of Nursing, Portland, OR, U.S.A.

Kristin Lutz, RN, PhD

Oregon Health & Science University School of Nursing, Portland, OR, U.S.A.

Pat Berry, RN, PhD, FAAN

Oregon Health & Science University School of Nursing, Portland, OR, U.S.A.

This manuscript is a data-based paper submitted in fulfillment of the traditional methods and results chapters. It is based on data collected from interviews conducted by Ms. Rising. Ms. Rising is the primary author on the paper; Dr. Hassouneh is the senior author. This manuscript will be submitted for publication in *Advances in Nursing Science*, which is a progressive nursing journal with intersectional and social justice views on class, color, and gender as they relate to health. It has an impact factor of 0.882.

Funding Acknowledgments

This work was supported by the Doctoral Degree Scholarship in Cancer Nursing, DSCN-15-077-01 and DSCNR-17-089-03 from the American Cancer Society and also supported through grants and scholarships from the OHSU Hartford Center of Gerontological Excellence, the Hearst Foundation, the Oregon Health and Science School of Nursing, and Sigma Theta Tao, Beta Psi Chapter.

Declaration of Conflicts of Interest

None

Abstract

Hospice care is patient-centered care that offers improved symptom management and quality of life at end of life (EOL). Mexicans tend to use hospice at rates lower than their non-Hispanic White counterparts (Whites). Adopting a Eurocentric perspective, most studies seeking to explain the discrepancy in hospice utilization between Mexicans and Whites have focused on cultural incompatibilities at EOL. Until now, the roles of racism and mistrust in hospice decision-making have been largely ignored. This study adapts a postcolonial framework, which assumes that oppressive and exploitative forces continue today in the healthcare setting and impact healthcare choices made by U.S. Mexicans. Relying on critical grounded theory methodology, this research was sensitized to the impacts of racism, mistrust, oppression, and exploitation, as well as cultural incompatibilities in hospice decision-making in Mexican families with terminal cancer residing in the Pacific Northwest. We found that marginalization, and not ethnicity, is critical to hospice decision-making in Mexicans with terminal cancer. Marginalization triggers mistrust and erosion of the therapeutic relationship, which is a necessary ingredient in choosing hospice care.

Key words: Hospice, Palliative Care, Hispanic Americans, Mexican Americans, postcolonial theory, critical grounded theory, marginalization, mistrust, healthcare, cultural imperialism

Introduction

Hospice care emphasizes symptom control, comfort, and quality of life at EOL for terminally ill patients with a prognosis of six months or less to live (National Hospice and Palliative Care Organization, 2017). Despite the benefits offered by hospice, a recent meta-analysis (Rising et al., 2019) found that Hispanics enroll in hospice less than Whites. The National Hospice and Palliative Care Organization reports that Hispanics make up 2.1% of hospice enrollees, whereas they make up 17% of the U.S. population (Ennis et al., 2011). To date, the literature addressing Hispanic hospice use has largely focused on cultural preferences (Rising, et al., 2018); very little attention has been paid to the influence of societal factors. The goal of this paper is to help address this gap in knowledge by presenting findings related to racism and mistrust from a larger critical grounded theory study of the process of hospice decision-making in U.S. Mexicans with terminal cancer and their families in the Pacific Northwest (PNW). We focus on cancer because it exhibits a predictable illness trajectory (Murray et al., 2005), is the leading diagnosis for hospice enrollment (27.2%; National Hospice and Palliative Care Organization, 2017), and is the leading cause of death in Hispanics (22%; American Cancer Society, 2018).

Background

The U.S. Census Bureau defines Hispanics as persons of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. According to this definition there are 57.5 million Hispanics in the U.S. (Ennis et al., 2011). The U.S. Mexican population (31.8 million; Ennis et al., 2011) comprises 63% of U.S. Hispanics and includes an estimated 6.8 million undocumented persons (Gonzalez-Barrera & Lopez, 2013). Although there has been a recent increase in media coverage of racism directed at U.S. Mexicans, Mexicans have been affected by racism for centuries. During the process of U.S. colonization, Mexicans suffered significant brutalities, including lynching and illegal expulsion from their rightful land (Acuna, 2015); a pattern of dehumanizing structural racism has continued in the postcolonial aftermath (Acuna, 2015; Ayón, Wagaman, & Philbin, 2018; Ortiz & Telles, 2012; Robert Wood Johnson Foundation, 2017; Viruell-Fuentes, 2007). Persistent patterns of racism and discrimination reported in the literature vary and have been linked to increased sensitization to ethnic and racial discrimination (Pérez, Fortuna, & Alegría, 2008), more contact with Whites (Viruell-Fuentes, 2007), higher education (Ortiz & Telles, 2012), and foreign-born status (López-Cevallos & Harvey, 2016). Although U.S. Mexicans experience racism as a group, the approximately 10 million (Ennis et al., 2011) who live in non-ancestral lands experience this oppression differently from those living closer to Mexico. Greater distance from Mexico results in a smaller U.S. Mexican population with concomitant decreases in social and cultural influence and an increased risk for experiencing interpersonal racism in predominantly White areas (Ortiz & Telles, 2012; Viruell-Fuentes, 2007).

Racism and the process of marginalization in healthcare at EOL. Racism and perceived discrimination against U.S. Mexicans are endemic to the healthcare system and contribute to marginalization, as that term was described by Hall, Stevens, and Meleis (1994) and others (Hall, 1999; Vasas, 2005). By pushing persons to the periphery of society based on their identities, associations, and experiences, marginalization creates vulnerability in the health and well-being of such persons, while also fostering resiliency and resourcefulness (Hall, 1999; Hall et al., 1994; Vasas, 2005). Perceived racism by U.S. Mexicans is associated with high mistrust in the healthcare system (Armstrong, et al., 2007; Benet al., 2017; Galvan et al., 2017; López-Cevallos et al., 2014), which in turn interferes with clinicians’ therapeutic relationships with U.S. Mexican patients (Jacobs et al., 2011). These problems are reflected in the choice made by 17% of U.S. Mexicans not to seek medical care specifically to avoid discriminatory experiences (Robert Wood Johnson Foundation, 2017).

Hospice enrollment and insurance coverage. Because EOL is a sensitive time for families, the presence of trust is critical. Yet, high levels of mistrust and the Medicare hospice requirement to relinquish curative therapy (National Hospice and Palliative Care Organization, 2017) pose significant barriers to the provision of quality EOL care for U.S. Mexicans. With limited exceptions (Born et al., 2004; Jaramillo & Hui, 2016; Kelley et al., 2010; Ko & Lee, 2014; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998a; Selsky et al., 2012; Smith, Sudore, & Perez-Stable, 2009; Wright et al., 2013), the occurrence of mistrust in the Hispanic population at EOL has been largely overlooked. Low (Kelley et al., 2010; Ko & Lee, 2014; Wright et al., 2013) and high (Morrison et al., 1998a) mistrust have contributed insignificantly to statistical models, or mistrust was limited to undocumented persons (Jaramillo & Hui, 2016; A. K. Smith et al., 2009) or described only by African American exemplars qualitatively (Born et al., 2004). Institutionalized racism against U.S. Mexicans in the EOL setting is also a concern. Medicare and Medicaid pay for a combined 90% of hospice (National Hospice and Palliative Care Organization, 2015); but Medicare and Medicaid are not available to undocumented U.S. Mexicans, and legal U.S. Mexican residents must wait five years to qualify for coverage (U.S. Centers for Medicare and Medicaid Services, 2016). Differences in social class are reflected in lower rates of insurance coverage among U.S. Mexicans relative to other Hispanic sub-groups (Centers for Disease Control and Prevention, 2017), which results in decreased access and quality of care at EOL.

Uninsured U.S. Mexicans are sometimes admitted to the hospital under the Emergency Medical Treatment and Labor Act (EMTALA), which prohibits hospitals from refusing admission based on ability to pay or citizenship (U.S. Centers for Medicare and Medicaid Services, 2012). In the context of terminal cancer, once patients admitted under EMTALA are medically stable, professional and ethical challenges related to hospital discharge arise when there are no resources available to leave the hospital. In such cases, if patients cannot discharge from the hospital to their homes, then discharge planners may opt for repatriation to Mexico (Young & Lehmann, 2014) or seek local community healthcare resources such as hospice (Jaramillo & Hui, 2016) for persons who cannot afford to pay for their care. When charity hospice is offered, the uninsured person is presented with the "terrible choice" (Casarett et al., 2009) between continuing medical treatment or enrolling in hospice. Other populations—veterans and pediatrics—are spared the "terrible choice" by allowing concurrent therapy (Mor et al., 2016; National Hospice and Palliative Care Organization, 2012). No such option is available for uninsured U.S. Mexicans, whereas, U.S. Mexicans who have insurance retain options such as accessing skilled nursing facilities and home health services. The discrimination, stigmatization, and racism faced by uninsured U.S. Mexicans can result in what Farmer, Nizeye, Stulac, and Keshavjee (2006) called structural violence, which occurs when social structures impinge on health care encounters and impair fundamental human needs. To date, the experiences of uninsured U.S. Mexicans have scarcely been represented in the research literature.

Methods

Research approach. Critical grounded theory makes instrumental use of grounded theory methods while being guided by sensitizing critical theoretical frameworks (Ayón et al., 2018; Freeman et al., 2017; Hassouneh, Akeroyd, Lutz, & Beckett, 2012; Hassouneh & Lutz, 2013). In light of the U.S. colonial encounter with Mexico and its significant aftermath, we chose postcolonial theory (PCT) as our critical framework for this study (Anderson et al., 2009; Ashcroft, et al., 2013; Kirkham & Anderson, 2002). Allaying the risk of stereotyping and *othering* inherent in research with colonized populations (Smith, 2012), PCT heightened our sensitivity to racism, stigma, discrimination, and the power differential between U.S. Mexican families and the healthcare system and providers throughout all stages of the study design. As a result, we could shift the focus of problems and interventions from individuals to larger societal contexts. Postcolonial theory holds that a modernized form of colonization exists today in the form of discrimination, stigma, racism, and marginalization, which can remain largely invisible to members of the dominant culture. Eurocentrism, in which European cultural assumptions are assumed to be normal and natural, contributes to this obliviousness and "othering" found in PCT (Ashcroft et al., 2013). Cultural imperialism is when Eurocentric values, beliefs, and practices are imposed on non-dominant populations. Adding to this body of work, Homi Bhabha, a critical and postcolonial theorist, rejected the binary conceptualization of colonizer and colonized, and described the existence of a hybrid, contradictory, and ambivalent "Third Space," that is a blend rather than a mix of distinct and pure cultures (Ashcroft et al., 2013; Bhabha, 1994).

The type of grounded theory we used in this study was dimensional analysis which, like other forms of grounded theory, is traditionally rooted in symbolic interactionism (Bowers & Schatzman, 2009; Schatzman, 1991). Although symbolic interactionism as a body of theory is cognizant of power and domination it does not center or develop these concepts (Blumer, 1969); our use of PCT helped ameliorate this theoretical gap.

Recruitment and sampling. We obtained approval from the Oregon Health & Sciences University IRB and a Certificate of Confidentiality from the National Institutes of Health before recruiting participants. Participants were recruited throughout the PNW from April through August 2018. For study recruitment, particularly in designing and translating a study brochure and advertisement, we relied on input from a community advisory board (CAB) comprised of U.S. Mexican community members. Initially seeking only the perspectives of family members, we posted study brochures describing the study in public areas frequented by U.S. Mexicans and in medical settings such as hospice programs, hospitals, and Spanish-speaking medical clinics. We also delivered study brochures to community health workers and healthcare professionals who were willing to share brochures with qualified families. In addition, we participated in community events to explain the study to smaller groups and one-on-one. After a low response rate, we advertised the study for two months in two Spanish-language newspapers reaching Spanish-speaking populations throughout the PNW and on Craigslist. We then elected to broaden the study to include healthcare professional (HCP) and community health worker (CHW) perspectives on their U.S. Mexican patients.

We sampled three different groups, all 18 years of age or older. The first group of participants were self-identified U.S. Mexicans with a family member who had received a terminal cancer diagnosis (living or deceased) and qualified for hospice or received a subsequent offer to enroll in hospice. The hospice offer could have been accepted or rejected. The second group of participants were Spanish-speaking community health workers (CHWs) whose clients included U.S. Mexicans with terminal cancer who were hospice eligible. The third group of participants were health care providers (HCPs) who saw U.S. Mexican clients with terminal cancer who were hospice eligible. We included non-Mexican Hispanics and Whites in the second and third groups because there are relatively few U.S. Mexicans in the health care sector working in the PNW.

We used convenience, snowball, and theoretical sampling approaches. The final sample size was *N* = 26, including 11 U.S. Mexican family members, 4 CHWs, and 16 HCPs. Four participants represented both family and HCP sampling groups; one participant represented both CHW and HCP sampling groups. The ethnicity of participants was *n* = 18 U.S. Mexican, *n* = 3 non-Mexican Hispanics, and *n* = 5 Whites. Gender was *n* = 21 female and *n* = 5 male. The categories of HCPs represented include licensed medical social worker, hospital case manager, medical assistant, physician assistant, and Spanish-language interpreter. An honorarium of $50 was offered to HCPs and CWHs, and $100 to U.S. Mexican family members.

Data collection and analysis. Semi-structured interviews were conducted by the first author in person with family members and CHWs, and either in person or by telephone with HCPs. All interviews lasted 60–90 minutes, and there was a total of five brief follow-up interviews by phone. One interview was conducted with a Spanish-language interpreter but other bilingual participants preferred to be interviewed in English. Interviews were recorded and then transcribed verbatim by the first author. To protect the anonymity and confidentiality of participants, all transcriptions were immediately de-identified by removing names, ages, ethnicities, and any descriptions that could identify people and places.

Consistent with a grounded theory approach, the precise questions asked during interviews evolved as topics were introduced by participants themselves. All participants were initially asked what hospice meant to them, as well as how religion, education, insurance, prognostic secrecy, and discrimination affected hospice decision-making. They were also asked to describe stories of hospice decision-making or EOL conversations with providers in which the primary thrust of the conversation was cessation of curative medical treatment. An evolving list of participant-generated topics of importance was verified by members of the CAB and subsequently pursued during interviews. Guided by these topics, the first author conducted initial coding using Atlas.ti 8. Lengthy exemplars supporting coding categories were shared with, and approved by, all authors. Discrepancies in analytic codes were resolved by consensus.

As coding and interviews continued, an iterative process of constant comparative analysis occurred (Bowers & Schatzman, 2009; Schatzman, 1991). The last five interviews involved theory-testing in which more abstract ideas were presented to participants for their responses. Sampling ceased when theoretical saturation occurred, which was declared when no new codes, concepts, or theories had been generated over the course of five interviews. From this iterative process of coding, concept development, and theoretical sampling, a substantive grounded theory was generated through the construction of an explanatory matrix, as described in dimensional analysis (Bowers & Schatzman, 2009; Schatzman, 1991). The influence of racism and concomitant mistrust of health care providers and the health care system were major findings; we present those components of the theory in this paper.

Results

We developed a grounded theory entitled *Seeking the "Third Space" at EOL around hospice decision-making* (Figure 1). The context for the grounded theory was a terminal cancer diagnosis for U.S. Mexicans residing in the PNW, in addition to the social forces of discrimination, paternalism, and the Eurocentric preference for hospice services at EOL. The precipitating event was either cessation of curative medical treatment or hospice offer. Individual subsequent healthcare behavior in the grounded theory was determined by hospice meaning, which was strongly influenced by whether U.S. Mexicans were marginalized. The dimensions of marginalization were influenced by income, education, insurance access, citizenship or residency, or geography. High marginalization led to mistrust and erosion of the therapeutic relationship such that highly marginalized U.S. Mexicans faced the “terrible choice” with little reason to trust their providers, resulting in rejection of hospice. In contrast, those U.S. Mexicans who self-identified as “Americanized” and professed a sense of belonging embraced hospice. There were special cases in which uninsured U.S. Mexicans hospitalized under EMTALA believed they had “no choice,” and so they enrolled in hospice. From the beginning perspective of trust or mistrust, U.S. Mexicans were exposed to, or employed, hospice resistance and hospice acceptance factors. Marginalized U.S. Mexicans who remained in contact with the U.S. medical system gained knowledge by virtue of that exposure as well as the option of negotiating a “Third Space” in which conflicting forces might be reconciled in a manner benefitting patient and family and allowing death on their own terms (Figure 1).

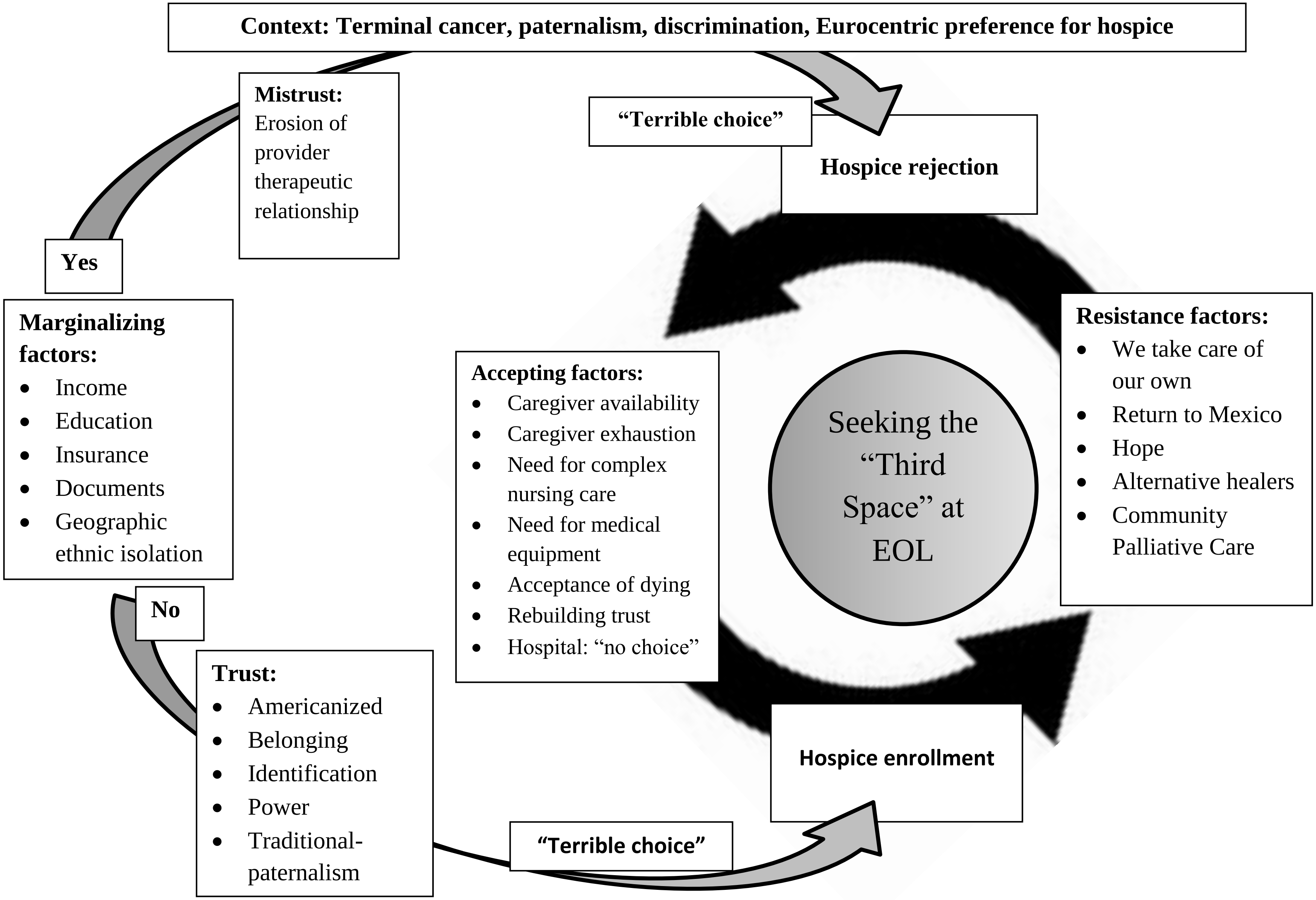

Figure 1. Marginalized U.S. Mexicans seeking the "Third Space" at EOL around hospice decision-making.

Hospice avoidance factors. Themes of mistrust permeated our results, with almost every participant identifying mistrust of the healthcare system as an issue for U.S. Mexicans, even if not personally for them (Tables 1 and 2). That is, participants observed mistrust in *other* U.S. Mexicans, particularly among the undocumented and first- and second-generation U.S. Mexicans. Perceptions held by mistrusting U.S. Mexicans were mostly described by HCPs and CHWs because they routinely had contact with such patients; however, some family members of hospice users also provided such data (Tables 1 and 2). Table 1 depicts U.S. Mexican family members living in the PNW who related family hospice or EOL experiences. Demographic data includes how they were recruited; where they were born and, if born in Mexico, their age at immigration; the geographic location of the EOL encounter; and whether they had experienced or observed mistrust and discrimination within the healthcare system. Table 2 depicts HCPs and HCWs who related the perspectives of patients' hospice and EOL experiences, including whether they reported mistrust and discrimination within the healthcare system.

With respect to hospice enrollment, there were two groups identified: one comprised of hospice enrollers and the other of hospice avoiders. All U.S. Mexicans were exposed in some manner to discrimination, racism, and stigmatization. The defining difference between hospice enrollers and hospice avoiders was the presence or absence of trust in the healthcare system, which reflected the degree of marginalization from the Eurocentric healthcare system. Interactions around EOL and hospice decision-making—including grappling with the "terrible choice"—were influenced by the process of marginalization. Assuming an identity allied with the dominant Eurocentric culture, three family members of hospice enrollers discussed how they were "Americanized." As one family member stated:

> I'm a very Americanized person. My mom . . . always said, "If I decided when I was a young woman and I married your father you know then I came here and I had to learn the language I had to learn how to read and spell it and write it because my children are going to grow up as Americans—they are *here,* we are *here*. . . . " I'm an American, I have to prepare myself as an American, this is what Americans do. . . . It's very important for a Mexican to be an American. To be both.

Another type of trusting U.S. Mexican was described by two HCPs, who described some elderly U.S. Mexicans as "trusting to a fault . . . almost childlike" in their complete deference to the expertise of physicians. Although Spanish-speaking, and not "Americanized," such patients were characterized as preferring a traditionally Mexican paternalistic relationship with physicians. In stark contrast, mistrusting U.S. Mexicans were alienated by Eurocentric and capitalist practices, including healthcare preferences for hospice, by virtue of income, education, insurance access, documentation status, and geographic ethnic isolation.

Table 1

U.S. Mexican Family Members Living in PNW Relating Family Hospice/EOL Experiences

Recruitment method	Born/if born Mexico, age at immigration (years)	Geographic location of reported EOL encounter	# Hospice stories	# EOL/non-hospice/ hospice-rejection stories	Healthcare System Mistrust		Healthcare System Discrim-ination	
					Self or family	Others	Self or family	Others
Adv.	Oklahoma	PNW	1	0	N	N	N	N
Adv.	PNW	PNW	1	0	N	Y	N	Y
Adv.**	Texas	Texas	1	1	N	Y	Y	Y
Adv.	Midwest	Midwest	2	1*	N	N	Y	N
Adv.	California	California	0	1	Y	N	N	N
FTF**	Mexico/ Texas (6)	PNW	2	0	N	Y	N	N
FTF	Texas	Texas	2	1*, 1	N	Y	N	Y
FTF	PNW	PNW, Mexico	0	1	Y	Y	Y	Y
Snowball	Mexico/ PNW (13)	PNW	0	1	Y	N	Y	N
HCP**	Texas	Texas, Mexico	1*	1	N	Y	N	Y
CHW**	Mexico	Mexico	0	1	Y	Y	Y	Y

Note. * denotes non-Cancer story, arising alongside cancer stories; ** denotes family participant was also HCP/HCW offering patient perspectives in Table 2; Adv = advertisement; FTF = face-to-face (at community health events); HCP = healthcare professional; CHW = community health worker.

Table 2

HCP and HCW Relating Perspectives of Patients' Hospice/EOL Experiences

HCP/HCW Ethnicity	# Hospice stories	# EOL/non-hospice/hospice-rejection stories	Healthcare System Mistrust	Healthcare System Discrimination
Mexican**	5	2	Y	Y
Mexican	2	1	Y	N
Mexican**	0	2	Y	N
Mexican	1, 1*	4	Y	N
Mexican, U.S. Born	1	2	Y	N
Mexican, U.S. Born	0	0	Y	Y
Mexican, U.S. Born**	1*	1*	Y	N
Mexican, U.S. Born	2	1	Y	N
Mexican, U.S. Born**	0	0	Y	Y
Mexican, U.S. Born	0	1	Y	N
Mexican, U.S. Born	0	1	Y	Y
White	1*	3	Y	N
White	1*	2	Y	N
White	1	2	Y	N
White	0	1	Y	N
White	0	0	Y	Y
Non-Mexican Hispanic	1	4	Y	Y
Non-Mexican Hispanic	1	3	Y	Y
Non-Mexican Hispanic	0	0	Y	Y

Note. * denotes non-Cancer, arising in context of also telling cancer story; ** denotes HCP/HCW also offered family perspective in Table 1.

Documentation status. The U.S. Mexicans most separated from the Eurocentric healthcare system were those with undocumented status. Observing that undocumented U.S. Mexicans "fear deportation more than death," a U.S. Mexican HCP described the lasting mistrust because of historic abuse of insurance information by the U.S. government to identify and deport undocumented individuals in his community. In describing experiences with uninsured U.S. Mexicans admitted under EMTALA, another HCP who provided case management in the hospital observed, "I read the fear in their eyes when I walk in the room." This fear alienated undocumented U.S. Mexicans even more at EOL; ultimately, they were coerced into using hospice at hospital discharge, even though it meant exposure to the possibility of deportation as hospice workers offered hospice care in the home. A hospital case manager describes a conversation with the mother of a young patient, both of whom were undocumented:

> "Are you scared because you're not a documented citizen?" . . . . "Yeah." She shook her head, "Yeah." Then she started crying. . . . and, I said, "I'm here to take care of him. I'm not here to be the police or anything like that." . . . But, still, you can say as much as you want because as the story goes, she still had fear, right? So we got them all this equipment. They wouldn't open the door! They wouldn't open the door when we had it delivered!

The foregoing exemplar describes the dilemma created at hospital discharge when uninsured U.S. Mexicans are admitted to the hospital under EMTALA and have no means of discharging with medical support except through community healthcare willing to provide care free of charge. All HCPs and HCWs observed that uninsured U.S. Mexicans are pushed toward such charity home hospice because it is the only option available. A significant source of mistrust in the undocumented U.S. Mexican population, specifically with respect to home hospice, was discomfort with having healthcare workers in their home. Because they could live in mixed-status and multi-family homes where undocumented persons also lived, even documented persons feared home hospice, which led to mistrust. A non-Mexican Hispanic HCP described the inherent conflict between home hospice and the need for safety in some U.S. Mexican homes:

> If the goal of hospice is to provide the treatment in the home, imagine having someone hear that, and either you, yourself, are undocumented, or there are folks in your home that are undocumented. You're gonna let people in?! And, now you're gonna expose yourself?! That's pretty tricky right there.

Whereas fear associated with documentation status contributed to marginalization, low levels of education contributed to marginalization because of a lack of awareness of healthcare options and a fear of written contracts in business transactions.

Education. Some U.S. Mexican HCPs were quick to point out the lack of education among many persons emigrating from Mexico. One HCP, who was also a family member of hospice users, observed that her family's higher education levels contributed to them knowing "what was the best for Dad with hospice." Another HCP observed that most of the people he grew up with in Mexico in the 1950s could not read and write, and "It's still true today." The same HCP observed that hospice enrollment paperwork elicits suspicion in U.S. Mexicans who cannot read. He stated, "That's where people become a little suspicious. 'Why are we doing all of this?' You know, 'You're just gonna come and bring me medication. Why do I need all of this?'" Those U.S. Mexicans without an education or the ability to read and write were excluded from, and in a position of inferior power relative to, the Eurocentric capitalist healthcare system, fostering suspicion and mistrust.

A distinct example of the impact of lack of education on hospice enrollment involved U.S. Mexicans' understanding of the Spanish word for hospice, *hospicio*. Some U.S. Mexicans understood *hospicio* to have a derogatory meaning, carrying a strong connotation of abandonment. This U.S. Mexican CHW described how many U.S. Mexicans recoil from the word *hospicio:*

> Hospice has a very derogative meaning for the Spanish-speaking people. . . . *Hospicio* is a place where they take children, older people, homeless, people who do not have any relatives—it doesn't matter the age, the size, the gender—and they find them somewhere else, and they don't have a place to be, or the hospital cannot afford to give them any more service because they don't have medical insurance and they don't have nobody else to be responsible for them.

Several participants described how educated U.S. Mexicans knew from the context that *hospicio* was intended to refer to the American concept of the word hospice; whereas, less educated persons from rural areas of Mexico had never heard the word. The strong reaction against the word *hospicio* was, therefore, found among U.S. Mexicans with limited education. Another marginalizing factor—insurance access—markedly changed options and the power differential at EOL for U.S. Mexicans.

Insurance access. Access to insurance for U.S. Mexicans was complicated by documentation and residency status as well as income. One family member described how her brother-in-law died in the emergency room of a hospital when lack of insurance jeopardized the delivery of urgent healthcare. Her brother-in-law's experience was a negative influence on this participant and her community that fostered mistrust. A situation in which lack of insurance significantly affected the EOL experience of U.S. Mexicans occurred when there was coercive pressure to enroll in a hospice program to facilitate hospital discharge. All hospital HCPs and all CHWs familiar with hospital dynamics agreed that such pressure was commonplace, and, as one HCP asked, “What choice is there?” In her question, she acknowledged the dilemma created when capitalistic, professional, and marginalizing forces collide. In contrast, in the following exemplar, a family member of a hospice enroller described their experience with hospice and how she perceived the pivotal role of insurance:

> I just . . . from what I saw back home [in Texas], I just felt that, as a family, they were completely taken care of through the hospice [enrollment] process, and I don’t know if it’s because she was younger or because they had insurance, you know, that they just got taken care of as a *whole*.

In fact, each hospice enroller in this study had insurance. Many family members described early detection of cancer and long-term relationships with their oncologists, rather than a bewildering first meeting in the hospital during a medical crisis. Hospice discussions were brought up early in the therapeutic relationship, rather than at hospital discharge. Like lack of insurance, low income contributed to the powerlessness reported by marginalized participants.

Income. Insufficient income to pay for healthcare negatively influenced many U.S. Mexicans in this study. For some U.S. Mexicans, lack of money in the context of terminal illness meant powerlessness within the healthcare system. The following exemplar, offered by an HCP who worked in a hospital, describes how she witnessed a mother’s response to her daughter’s healthcare team at cessation of curative therapy:

> We had a pediatric terminal patient. And, we went through a long period of time where the pediatric oncology team was earning that trust from the family. And, they really worked very, very hard to help this child. And, at one point—and I don’t know exactly if

> it was an event that precipitated it or if it was just Mom’s anxiety and fear just overflowing—but, um, she asked the team . . . she kept alluding to “you guys” and “your people” and “our people” and she was drawing the line. But she was kind of dancing around it a little bit. And then, finally, she just went for it, and she said, “Are you treating my daughter differently because her skin is brown?” And then she said, “Are you treating U.S. differently because we have no money. Because we’re nobodies?”

The mother’s use of the phrases “your people” and “our people” demonstrate this mother’s sense of separation and distinctness from the Eurocentric healthcare system, and her internalization of powerlessness is reflected in her self-characterization as “nobodies.” Lack of income appeared to galvanize powerlessness. This internalization was also described by a U.S. Mexican CHW, whose client with terminal cancer perceived her doctor as mean and cruel. In this exemplar, the CHW describes what the client lamented to her:

> I don’t know, I feel like I don’t want to go to the doctor any longer because when I go to him, he just ignore me, he don’t look at me, he doesn’t put any attention [sic], I just feel like what is the purpose of me to go to the doctor? But I understand him, he knows I’m going to die anyways. So why he put any attention on me? It doesn’t matter anymore, he put attention to me or not. . . . I’m invisible, I’m sick, I’m gonna die, I don’t have any money to pay, I cannot hire another doctor, I cannot change doctor, I have to settle with what I’ve got.

The same U.S. Mexican CHW described the added psychic insult when U.S. Mexicans have been admitted to the hospital under EMTALA and then suddenly told they have to be discharged. These terminal patients swing wildly from humbling themselves and accepting charity to facing the end of their lives with no money and no healthcare because they have no sick leave and have been too sick to generate income. In contrast, most hospice enrollers had relatively high income and, if they did not, then they had insurance to pay for hospice.

Geographic ethnic isolation. Participants who had lived in Texas or elsewhere in the Southwest U.S. described significantly different social roles for U.S. Mexicans in the PNW that exacerbated discrimination and mistrust. In the PNW, they reported a lack of established U.S. Mexicans in all professions including healthcare, and a relative abundance of Whites in the general population as well as healthcare. Participants from the Southwest U.S. theorized that the lack of established U.S. Mexican professionals and relative abundance of Whites propagated derogatory stereotypes. As one U.S. Mexican healthcare professional from the Southwest explained, there was little trust among first- and second- generation U.S. Mexicans in the PNW when encountering the healthcare system:

> I mean it comes back down to education, it comes back down to a feeling of trust there, and it just doesn't—it's not established yet here. And, it has to do with the first- and second-generations that are here and it's gonna take them a while to establish that. And discrimination is gonna be there until we have voices that are advocating for everybody else and elevating everybody to help the landscapers, you know . . . the cleaning crew. I mean, that's what it is—they just don't facilitate Latinos as educated individuals. . . . [I]t's just different being here [in the PNW]. . . .

Another participant, who originated from south Texas, described the binary nature of being Mexican in the PNW versus the hybridity in Texas:

> I think that here in Oregon I [don't feel] like a foreigner 100%—but I do get that sense . . . at the hospital, "Do you need it in Spanish?" "No, I don't, I'm speaking *English*.". . . And being Hispanic back home, you meet Mexican doctors, judges, lawyers, DAs, and

> here, I mean, you don't. . . . It's like they make me choose if I want to be White or Mexican and White people think, "Well, you know, you're Mexican," and Mexican people think I'm trying to be White and no, I'm just trying to be me. I was—I am—Mexican but I was born and raised here, and I'm American, like, that's what I am. . . . In Texas I can be both. I can speak English, I can speak Spanish, I can, you know, just be myself.

Even a willingness to participate in the research study fell along geographic lines. All hospice enrollers resided in the PNW; however, a disproportionate share moved to the PNW from geographic regions with larger Mexican populations or used hospice there (Table 1). The relative lack of response to advertising from U.S. Mexicans who originated in the PNW may have been because of the sense of alienation described by study participants.

Mistrust-related resistance factors. Participants who experienced discrimination and stigma resisted hospice enrollment and sought to reclaim their EOL experience by relying on community and family and resources.

"We take care of our own." A frequently reported alternative to the Eurocentric healthcare system at EOL for U.S. Mexicans was represented by the phrase, "We take care of our own." Although reflecting cultural traditions, "We take care of our own" was also rooted in preventing the Eurocentric healthcare system, with its discriminatory and stigmatizing messages, from invading the sanctity of the home. Hence, the corollary of "We take care of our own" was the desire to prevent strangers in the home, or "strangers *en casa.*" There were subtleties to this preference that revealed the degree to which a family was comfortable with the larger Eurocentric healthcare system. Those opposed to having "strangers *en casa*" emphasized mistrust established through discriminatory encounters and erosion of the therapeutic

relationship. One U.S. Mexican HCP described the mistrust her family would feel toward any hypothetical hospice workers entering their home:

> I think our biggest barrier would be, do we have the trust with that person that's gonna come? Yeah, having strangers in our own home would be something *I* wouldn't see, at least as far as, like, my family. I think having a stranger come would be . . . I don't think it would be accepted.

Although college educated, this participant was a first-generation U.S. Mexican who had grown up in predominantly rural and agrarian regions of California, and her advocacy for Spanish-speaking patients sensitized her to the plight of undocumented and lower socioeconomic U.S. Mexicans on a daily basis. Another perspective was provided by a family member of a hospice avoider, also college educated, who volunteered that U.S. Mexicans sometimes felt "racist" against Whites and that this racism fueled the prohibition of "strangers *en casa*." Describing the impact of the intrusiveness of a hypothetical White hospice nurse caring for her mother, this participant shared, "I know for a fact, if my mom ever had help by a White person, and I put her on hospice, and it would be a White woman over a Mexican . . . oh!! She would get pissed to no end!"

In contrast, hospice enrollers and most U.S. Mexican HCPs and CHWs were able to soften their stances against "strangers *en casa*" as well as modify their interpretations of the phrase "We take care of their own." They acknowledged the difficulty of providing EOL care, particularly the personal exhaustion felt by the primary caregivers, who were invariably women. For these women, the impossibility and impracticality of working, managing the home and children, as well as caring for a dying family member, outweighed any mistrust in the healthcare system and intrusiveness of discriminating and stigmatizing messages. Observing that U.S.

Mexicans are not "thinking it through" when they say "we take care of our own," this family member, who was originally from Texas, shared her hypothetical conversation with a US Mexica refusing to enroll in hospice:

> How hard is that gonna be on you guys? How many diapers can you change? How many insulin shots can you give? How many bedspreads can you wash? You gotta turn them. You know, because sometimes, like I said, we have the best intentions but we don't think it through. I mean how can I do all these things if I have to be at work, come home, run to acting class, you know, do whatever else they signed up to do, and yeah, I can stop all those things but I still have to go to work cause I still have to pay the bills.

At a comfortable socioeconomic level, accustomed to navigating the healthcare system, and informed by the confident Texas/Mexican social discourse she brought with her from Texas, allowing the Eurocentric healthcare system into her home was not a threat.

Community palliative care. Community palliative care provided a way in which U.S. Mexican families in the PNW could "take care of their own" at EOL while simultaneously minimizing the discrimination and stigmatization of the Eurocentric healthcare system. Palliative care, like hospice, focuses on holistic care of the patient provided by a multidisciplinary healthcare team (National Hospice and Palliative Care Organization, 2017) There were multiple examples of community palliative care in this study, with varied degrees of healthcare system involvement and concomitant modification of "We take care of our own." None were as culturally imperialistic as home hospice care since palliative care does not require relinquishing curative therapy as a condition of enrollment, and the frequency of home visits are not dictated by Medicare regulations. A significant way in which community palliative care avoids triggering mistrust is the absence of intimidating paperwork associated with hospice enrollment, which is particularly daunting for U.S. Mexicans who cannot read or write. Describing community palliative care, a U.S. Mexican CHW observed that it was a respite from the “Anglo, English-speaking, healthcare system:” She explained why community palliative care provided by U.S. Mexican CHWs was particularly important for the undocumented and lower socioeconomic U.S. Mexican cancer patients:

> . . . it gives them such piece of *mind* and release, because the spirituality portion and the emotional, the mental, take place, then they can reach out to the peaceful moments of *peace*. Now they can *breathe*. Now they can relax. Now they—because they are already with big levels of stress because they’re not working for the longest time, because they don’t have money to cover for their needs, their regular needs that anybody else have in this world. But the difference is that, for them, it’s not just being sick, it’s not being able to *work*, it’s being *undocumented*, it’s not being able to have a job, they don’t have sick-leave benefits, they cannot take a day off. And there are so many barriers that I can talk to you all day long about those barriers. The thing is, when I say palliative care, I want to give you a relief, I want to give you a dose of something that is gonna bring you peace and calm when you understand what palliative care is about. It’s a philosophy, it’s not a treatment, it’s not a medication, it’s not a prescription from the pharmacy. . . . I’m going to help you find out about your options, about what you can choose, about this staying or not staying . . . .

Other manifestations of community palliative care had more health system involvement in the form of more contact with White HCPs; however, they still side-stepped the “terrible choice” presented by hospice enrollment. In one community palliative care model, CHWs worked for hospice and community palliative care agencies, providing advocacy and Spanish-language interpretive services. In another model, hospice and community palliative care agencies prioritized reaching out to the U.S. Mexican community with ethnically concordant HCPs or through contacts with CHWs independent from their agencies. Significantly, regardless of the community palliative care model, all study participants experienced in community palliative care emphasized the trust-building nature of community palliative care as an intermediate step between curative cancer therapy and hospice care in the U.S. Mexican population marginalized by income, education, documentation status, and insurance.

Returning to Mexico at EOL. Another way in which U.S. Mexicans avoided hospice and maintained control of their EOL experiences was to return to Mexico, if they were healthy enough. Oftentimes, they believed they could find the treatment being denied to them in the U.S. Revealing the pervasive belief that U.S. Mexicans were intentionally excluded from the colonial health system, a CHW who had contact with many U.S. Mexicans working for the agricultural industry described a frequent response to discussions about discontinuing cancer treatment:

> I have seen quite a few patients that, when they have been told, “There’s no other treatment here,” they just go to Mexico and see about getting treatment over there. They’re like, “No, there has to be a treatment and I know I will be able to get it in Mexico.”. . . Because, I mean, just the thought that there’s no other treatment. “What do you mean there’s no other treatment?! We’re in the United States, and so I know you’re not wanting to give it to me for some reason. It could be because I don’t have insurance. It could because I don’t have the legal status. You’re just not wanting to give it to me. I know in Mexico—I will find someone in Mexico that will give it to me.” . . . They were illegal. And, they took that risk of, you know, “I’m not gonna be able to come back—if it doesn’t work, or if I don’t get what I’m looking for, I’m not going to be able to come

> back." So they put all of that at stake just to see. That's where I think they don't really believe them because of the ones that have left everything to go somewhere else. . . Mexico. . . and see if that's really true.

In light of the difficulty of U.S.-Mexico illegal border crossings, sacrificing their PNW residence to return to Mexico to seek treatment offers powerful evidence of their conviction that U.S. doctors were withholding treatment. In contrast, the family member of a PNW hospice enroller described how her father and mother travelled all over the world, at great expense, seeking alternative therapies. Their efforts were distinguishable from the lower socioeconomic U.S. Mexicans making illegal border crossings in search of a full array of fundamental cancer treatments. These particular PNW hospice enrollers, who travelled the world seeking alternative therapies, trusted their oncologist, with one participant describing him as a "good friend."

Herbalists and curanderas. A final way U.S. Mexicans regained control of their EOL experiences was though alternative treatments such as herbs and the services of *curanderas.* Participants defined *curanderas* as persons providing a variety of healing services, from massage and herbs to witchcraft, depending on the *curandera*. Significantly, these service providers were from their own community, and so seeking their care was as much a matter of trust and avoidance of discrimination as it was cultural preference. With one exception, none of the U.S. Mexican HCPs and HCWs reported using these alternative therapies themselves. However, many confirmed their use by mistrusting U.S. Mexicans. They described how a sense of mistrust and disenfranchisement experienced in lower socioeconomic U.S. Mexicans, particularly those who are undocumented, moved some to seek alternative therapies and then go to the U.S. doctor as a back-up plan. Demonstrating the difference in perspective between trusting and mistrusting U.S. Mexicans, an HCP who originated from Mexico as a young girl and grew up in Texas described the pursuit of alternative therapies in mistrusting U.S. Mexicans as misinformed and naïve. She revealed that her Mexican family had long ago rejected the services of *curanderas*. Reflecting the complex and subtle nuances of personal relating to the Eurocentric healthcare system, some consumers of alternative therapies had an education and moderate income. One family member, a woman born in the PNW and living modestly in an affluent suburb, described her preference for trying herbs before seeing U.S. doctors. She attributed this preference to an abundance of discriminatory experiences in the U.S. healthcare system that caused her to feel mistreated, as well as knowledge about herbs within her extended family. Reliance on herbs and alternative healers such as *curanderas* typically was kept secret from the healthcare team.

Hospice acceptance factors. U.S. Mexicans who were inclined to reject hospice were sometimes brought around to hospice enrollment when certain events occurred. These acceptance factors included a need for complex nursing care, caregiver unavailability or exhaustion, need for medical equipment, acceptance that the patient was dying, feeling powerless in the hospital setting, and trust-building on the part of HCPs.

Need for complex nursing care. Patients who were hospitalized with terminal cancer sometimes could see the need for hospice by virtue of the complexity of care required. Acknowledging that most U.S. Mexicans are not easily convinced to enroll in hospice, a U.S. Mexican HCP described a family who enrolled in hospice because of the complexity of caring for the patriarch with stomach cancer:

> Well, I think what had happened is they were able to see the need immediately. Because, immediately—when you're diagnosed with stage IV cancer—stomach cancer—you can't do much of anything. You can't hold anything down. You know, I think it's a full-time job and they noticed—at least we talked about what hospice could do for them. They

> went ahead and agreed with it. But that’s one of the many. . . . Others are not so easily convinced hospice can work for them.

In other cases, the U.S. Mexican family initially rejected hospice, but then disease progression created symptoms that necessitated complex nursing care. For example, a U.S. Mexican CHW described a client who initially participated in community palliative care, and then transitioned into hospice when “her lungs started filling up with liquid” and she needed thoracenteses. In these exemplars, the need for complex nursing care overcame mistrust and rejection of the Eurocentric healthcare system. On the other hand, sometimes, the family was overwhelmed and caregiver exhaustion or unavailability was the reason they accepted hospice.

Caregiver unavailability and exhaustion. Dimensions of caregiving served as an acceptance factor in one of two scenarios. Sometimes, a terminally ill cancer patient was living in the U.S. without family or family who could provide care. The following HCP described a U.S. Mexican with terminal cancer who did not have documentation, had no family in the U.S., and refused to return to Mexico.

> He had family down in Mexico but didn’t want to go back. Wasn’t going to entertain the idea of going back . . . . He was always very sweet, really appreciative of support and help, but always—I mean, absolutely wanted treatment. He ended up—he was on our charity care. And so, if somebody is on . . . charity care for treatment, that falls under palliative care, as well. He ended up passing away at [a hospice] in [the city], which is inpatient hospice. They’re incredible. They took him uninsured. I think he stayed there for *weeks,* maybe a month or more.

In other cases, family members simply become exhausted or overwhelmed after having tried to “take care of their own.” There were several stories of exhausted wives or mothers who eventually were unable to continue to provide care, either because of exhaustion or their own health crises. In the following exemplar, a hospital HCP describes their ultimate “success” in enrolling a child in hospice because the child’s mother—who had steadfastly insisted on taking care of her son herself—developed emergent healthcare needs:

> What happened, actually, is Mom got sick. Mom ended up in the ICU and there was no one to take care of him at home because brothers and dad were all working. Really, I don’t think we ever would have been successful [enrolling him in hospice] if Mom hadn’t deteriorated.

This exemplar demonstrates how U.S. Mexican families who initially reject hospice and prefer curative treatment or to take care of their own may eventually enroll in hospice when the presence or health of the caregiver becomes an issue. Because of the availability of medical equipment in hospice, the need for medical equipment sometimes provided the impetus for hospice enrollment.

Need for medical equipment. As long as there remained continued contact with a representative from the healthcare system, a perceived need for medical equipment could be solved through hospice enrollment. Several HCPs and CHWs described situations in which the need for medical equipment tipped the scales toward hospice enrollment. As long as U.S. Mexican families maintained sufficient contact with persons who could inform them of the availability of this equipment, then, when the need arose, hospice was sometimes there to provide the equipment. Contrary to the utility of medical equipment, U.S. Mexicans sometimes were persuaded to enroll in hospice when they could see for themselves that their family members were dying.

Acceptance that the patient was dying. U.S. Mexican families would sometimes enroll in hospice if they were enrolled in community palliative care and could see the dying process themselves. A CHW who worked with U.S. Mexican families on palliative care and hospice explained that it is important that the U.S. Mexican patient understand and internalize that they are dying before a hospice offer is made:

> I wish there was a smoother transition . . . for them to come into palliative care, with the understanding that at the *very end*, when they've got—I don't know—not six months or a year—way *less*. When they—even themselves—feel like, "I think I'm ready to go." . . . Because if they're not ready—just because there's no more treatment—then, "Okay! Here's hospice!" And with this particular patient, she was feeling good, she was feeling okay. "Look at me! I'm good! I don't have no pain. I don't have no this." But there was no treatment, and so hospice was introduced. Like, "What?!" I totally sensed that, "What do you mean, I'm dying? I don't feel like I'm dying! Why am I going to this program where it's for people that are dying?" . . .

If the dying process is not evident, then a hospice offer seems nonsensical to the patient. In contrast, once the dying process was visible, U.S. Mexicans were more inclined to accept hospice. The same CHW described how she sometimes saw clients transition from community palliative care to hospice because the family could see for themselves that the patient was dying.

Perception of powerlessness in the hospital setting. In contrast from the community palliative care setting, terminally ill U.S. Mexicans hospitalized under EMTALA faced hospice enrollment from a position of powerlessness. Without anyone to advocate for them or fully understand their EOL healthcare choices, this exemplar describes how a hospital HCP perceived such powerless patients:

> I think that what I see from most families is that they do what they're told. So, if we tell them, "You have to go on hospice," oftentimes they don't fight. It's upsetting. . . . Usually a passive acceptance. "If we have no other choice, then that's what we will do." And, I think a lot of families feel they don't have a choice.

Although feeling powerless against the Eurocentric healthcare system is not an affirming acceptance, it amounts, nonetheless, to a form of passive acceptance of the process, resulting in hospice enrollment. A final hospice acceptance factor involved trust-building on the part of HCPs and CHWs who were sensitized to the bewildering array of sources of mistrust.

Rebuilding trust. Sometimes HCPs successfully engaged in trust-building with U.S. Mexicans during EOL healthcare encounters. This trust-building could occur at any time and context along the EOL healthcare continuum. Trust-building typically was described as occurring in one of three ways. First, some HCPs excelled in establishing rapport by virtue of their understanding of the Mexican culture. One HCP described how the doctor she worked for would encourage large family meetings at the office as well as in their homes, if invited. A second form of establishing trust was when there was an interpreter who served as an advocate, even if just to a small degree. One family member described how certain Spanish-language interpreters would determine whether the visit to the cancer clinic went well because they could count on them to clarify complex medical concepts for them with the doctor. When CHWs were also interpreters, they were free to advocate for patients; however, licensed interpreters felt bound to varying degrees by a professional obligation to maintain neutrality.

The third form of trust-building was in openly discussing and validating that trust was a legitimate issue. A non-Mexican Hispanic HCP, after gaining trust by virtue of Hispanic heritage and Spanish-language skills, described how she would directly acknowledge issues of race and power and then bring the conversation back to the EOL healthcare decision:

> I learned how to just look at people—a room full of people that really believe the doctor doesn't want to spend another dime on them because they're not worthy, because, you know, fill in those blanks, and just say, "This has absolutely nothing to do with the doctor, with immigration status, with socioeconomic status, with your level of medical literacy, with anything. If you continue to aggressively treat this disease, you are still going to cease and die. Your body cannot sustain life. That's the bottom line." And, it takes, it takes *trust* because if someone who's not of the same culture—or if someone of the same culture but hasn't done the repair work—goes in and does that, they're gonna get thrown out of that room and the service will be fired. Asked not to come back.

Concordant ethnicity, alone, was insufficient to establish trust for U.S. Mexican HCPs, whose superior socioeconomic position and membership in the Eurocentric healthcare system required that they establish trust with some U.S. Mexicans. Building on similar experiences of racism and anti-immigrant bias, the HCP in the following exemplar was able to ease a tense situation by openly discussing his own struggles in the U.S. by virtue of skin color and accent. He stated,

> I, too, have brown skin, I am a foreigner, I have an accent. . . . I hear you. I am like you. . . .You are in an impossible situation. And, we really wish we could do something for your child. Because we've tried everything.

When hospice enrollment was uncertain, the foregoing hospice acceptance factors worked toward persuading U.S. Mexicans with terminal cancer to enroll in hospice. Combined with hospice resistance factors, an informal and continuous negotiation of hospice enrollment at EOL occurred. As depicted in Figure 1, we suggest that U.S. Mexicans during this negotiation process are weighing ambiguous and contradictory values and beliefs, seeking a Third Space at EOL in which they can optimize their dying experience on their own terms.

Discussion

Our results demonstrate the pervasiveness of mistrust at EOL in the U.S. Mexican population, particularly those marginalized by income, education, insurance, documentation status, and geographic ethnic isolation. In contrast, the more Americanized U.S. Mexicans identified with the Eurocentric healthcare system; hospice enrollment manifested their hybridity and internalization of American values. Many of these Americanized participants originated from Texas, where Bhabha's Third Space (Ashcroft et al., 2013; Bhabha, 1994) would represent the hybridization of colonial and non-colonial populations there, owing in part to centuries of cohabitation. Significantly, the relationship of marginalized U.S. Mexicans to the dominant population in the PNW was more binary in the context of hospice and EOL care, although some were more hybridized in other aspects of their lives. From this entrenched perspective, U.S. Mexicans with terminal cancer faced the "terrible choice" whether to enroll in hospice from a position of extreme vulnerability (Hall et al., 1994). However, they also demonstrated resiliency (Hall, 1999; Vasas, 2005) through their language of refusal in "We take care of our own," resourcefulness in alternative healers, hope, and community. For some, community palliative care offered safe and acceptable non-hospice EOL care, particularly when given with the assistance of CHWs. Unlike the imperialistic nature of hospice, community palliative care interfered minimally with EOL preferences informed by mistrust; it also fostered proximity between hospice avoiders and the Eurocentric healthcare system, creating opportunity for hybridization of values, beliefs, and identity around EOL. In this Third Space, U.S. Mexican families were empowered to choose whether to enroll in hospice on their own terms, which sometimes occurred if accepting factors presented themselves. These findings suggest the importance of creating more non-hospice opportunities such as community palliative care to reduce healthcare inequalities at EOL for U.S. Mexicans and their families.

Contrary to previous research on cultural preferences at EOL in U.S. Mexicans, our results support the importance of validating discriminatory pasts and acknowledging mistrust as a form of trust-building. When sensitized HCPs can only partially rehabilitate the therapeutic relationship at EOL, there may be a need to openly discuss what is rarely acknowledged. Openly discussing mistrust requires a shift in our thinking away from a preoccupation with cultural differences toward taking responsibility for the misdeeds of the dominant Eurocentric culture. Many healthcare institutions offer training in cultural competence, but little offer support in developing the empathic and communications skills necessary to discuss mistrust. Our results offer support for the importance of investing in programs that begin larger conversations in the Eurocentric healthcare system about its systematic alienation of minorities. Another important form of trust-building identified by participants was the assistance of interpreters-as-advocates, which has been noted elsewhere.

We also provided evidence that contributes to the larger ethical issue of how to accomplish discharge of U.S. Mexicans admitted to the hospital under EMTALA (Young & Lehmann, 2014). Every HCP and HCW having contact with the hospital system openly acknowledged that uninsured U.S. Mexicans admitted to the hospital under EMTALA are pushed toward hospice as a means of discharge. The patients were hospice-appropriate in that they had terminal cancer; however, they were not inclined to give up curative medical therapy. There is a glaring lack of alternatives for discharging uninsured U.S. Mexicans from the hospital, and it reflects the need for policy change that will continue insurance coverage beyond the hospital doors.

Previous hospice studies with U.S. Mexicans at EOL have occurred in Texas and the Southwest U.S., where there are large U.S. Mexican populations. In contrast, results from this study suggest that geographic ethnic isolation may play a role in separating U.S. Mexicans from the Eurocentric healthcare system. If so, then results from other hospice and EOL studies with U.S. Mexicans may not be generalizable or transferable to regions characterized by geographic ethnic isolation, including the PNW as well as a large part of the U.S. To be as inclusive and representative as possible, future research should attempt to include these isolated U.S. Mexican populations.

A limitation of this study is that the primary investigator was not ethnically or linguistically concordant, which is inconsistent with decolonizing methodologies (Smith, 2012). We also lacked recruitment of marginalized U.S. Mexicans, having to rely, instead, on secondhand stories to represent them. A strength is that our use of PCT allowed us to reject previous Eurocentric approaches to EOL and hospice care with Hispanics. By design, PCT elevates the voices of U.S. Mexicans through qualitative interviews and sensitizes the researcher and participants to discriminatory forces. Using grounded theory allowed U.S. to adjust the focus of our interview questions as participants, in their responses, led U.S. to their central concerns. Finally, we relied on a CAB in the conceptualization of the study design and abstraction of study data.

Conclusion

To address inequities in EOL and hospice care, the voices of the most marginalized U.S. Mexicans need to be included in research. Rather than dwelling on potential cultural differences between Whites and U.S. Mexicans, research should focus on how U.S. Mexicans' experiences differ at the intersections of class, geography, and citizenship. Research that includes consideration of social forces reveal would reveal the degree to which we routinely engage in structural violence (Farmer et al., 2006) against U.S. Mexicans, particularly the marginalized.

References

See Cumulative References.

Chapter VI

Summary, Discussion, and Implications of Dissertation Manuscript Findings

Margaret L. Rising, BSN, RN, PhD Candidate

Oregon Health & Science University School of Nursing, Portland, OR, U.S.A.

Funding Acknowledgments

This work was supported by the Doctoral Degree Scholarship in Cancer Nursing, DSCN-15-077-01, DSCNR-17-089-03 from the American Cancer Society, and also supported through grants and scholarships from the OHSU Hartford Center of Gerontological Excellence, the Hearst Foundation, the Oregon Health & Science School of Nursing, and Sigma Theta Tao, Beta Psi Chapter.

Introduction

There has been an unprecedented increase in research on healthcare at end of life (EOL) in the U.S. in the last three decades. This interest in healthcare at EOL coincides with the importation of hospice care from the UK in the 1960s and Medicare certification of hospice providers in the 1980s (Clark, 2007; Meier, 2011; National Hospice and Palliative Care Organization, 2017; Pawling-Kaplan & O'Connor, 1989). Hospice is EOL care that emphasizes symptom control, comfort, and quality of life for terminally ill patients with a prognosis of six months or less to live (National Hospice and Palliative Care Organization, 2017). Significantly, to enroll in hospice, patients or their decision makers must relinquish curative therapy (National Hospice and Palliative Care Organization, 2017). One area of EOL and hospice research that focuses on Hispanics emphasizes EOL and hospice decision-making and care utilization, with 88 published articles considered at the time of this dissertation (Adams, et al., 2005, 2006, 2007; Badeet al., 1999; Balboni et al., 2007; Barnato, Anthony, Skinner, Gallagher, & Fisher, 2009; Barnato et al., 2006; Blackhall et al., 2001; Blackhall et al., 1999; Blackhall et al., 1995; W. Born et al., 2004; Boucher, et al., 2014; Braun, Beyth, Ford, Espadas, & McCullough, 2014; Braun et al., 2008; Caralis, Davis, Wright, & Marcial, 1993; Carrion, 2010; Carrion et al., 2015; Carrion, Park, & Lee, 2012; Choi et al., 2015; Colón, 2012; Colón & Lyke, 2003; Colón & Lyke, 2015; Cooper, Rivara, Wang, MacKenzie, & Jurkovich, 2012; Del Gaudio et al., 2013; Duffy et al., 2006; Enguidanos et al., 2013; Enguidanos et al., 2005; Espino et al., 2010; Finley et al., 2012; Finley et al., 2013; Fischer et al., 2015; Fischer, Kutner, Sauaia, & Kramer, 2007; Fosler et al., 2015; Frahm et al., 2012; Frank et al., 2002; Gelfand, et al., 2001, 2004; Givens et al., 2010; Gordon, 1996; Guadagnolo et al., 2015; Gutheil & Heyman, 2006; Haas et al., 2007; Hanchate et al., 2009; Hardy et al., 2011, 2012; Hernandez et al., 2015; Jaramillo & Hui, 2016; Johnson et al., 2005; Jonnalagadda et al., 2012; Kelley et al., 2010; Kirkendall et al., 2015; Kirkendall, Shen, & Gan, 2014; Ko, Cho, & Bonilla, 2012; Ko et al., 2013; Ko & Lee, 2014; Kreling, et al., 2010; Kress et al., 2015; Lackan et al., 2003; Lackan et al., 2004; Loggers et al., 2013; Meyers, Lin, Sribney, & Aguilar-Gaxiola, 2008; Mouton, Espino, Esparza, & Miles, 2001; Nedjat-Haiem, Carrion, Lorenz, Ell, & Palinkas, 2013; Noguera et al., 2014; Pan et al., 2015; Park et al., 2012; Park, et al., 2016; Perkins et al., 2009; Phelps et al., 2009; Randall & Csikai, 2003; Rhodes, Lei, Paulk, Stieglitz, & Halm, 2013; Riggs et al., 2016; Rising et al., 2019; Rising et al., 2018; Romero, Lindeman, Koehler, & Allen, 1997; Ruff et al., 2011; Sammon et al., 2015; Selsky et al., 2012; Smith et al., 2009; Smith et al., 2008; Smith et al., 2009; Sullivan, 2001; Taxis et al., 2008; Taylor et al., 2016; Taylor et al., 2017; Thompson, Lawson, Croughan-Minihane, & Cooke, 1999; Volker & Wu, 2011; Wright et al., 2013; Xian et al., 2014; Yennurajalingam et al., 2013; Zahuranec et al., 2009). Hispanics are persons of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race; there are 57.5 million Hispanics in the U.S. (Ennis et al., 2011). The U.S. Mexican population (31.8 million; Ennis et al., 2011) comprises 63% of U.S. Hispanics and an estimated 6.8 million undocumented persons (Gonzalez-Barrera & Lopez, 2013). This dissertation comprises a series of articles and studies with the goal of adding to the knowledge base on Hispanics and hospice decision-making. Manuscripts either reported on *Hispanics* or *U.S. Mexicans*, and so both of those terms are used throughout this chapter. There are six chapters in total as listed below in Table 1. Each chapter furthered the overarching goal of understanding hospice decision-making at EOL in Hispanics and demonstrated different modalities to obtain knowledge.

Table 1

Overview of Chapters

Chapter Number	**Chapter Title**
Chapter 1	*Introduction*: “Hospice Decision-Making in U.S. Mexicans with Terminal Cancer and their Families”
Chapter 2	*Concept Paper*: “Truth-Telling as an Element of Culturally Competent Care at End of Life (EOL)” (Rising, 2017)
Chapter 3	*Literature review*: “Integrative Review of the Literature on Hispanics and Hospice” (Rising et al., 2018)
Chapter 4	*Meta-analysis*: “Hispanic Hospice Utilization: Integrative Review and Meta-Analysis” (Rising et al., 2019)
Chapter 5	*Research study*: “Hospice Decision-Making in U.S. Mexicans with Terminal Cancer and Their Families”
Chapter 6	*Final Chapter*: “Summary, Discussion, and Implications of Dissertation Manuscript Findings”

The purpose of this final chapter was twofold. The first purpose was to succinctly summarize and integrate the entire dissertation, describing the relationship among problems addressed by the study, including the review of the literature, methods, and findings. The second purpose was to discuss interpretations of the results as a whole. Discussions included theoretical, clinical, and policy implications across all manuscripts and the research literature, as well as strengths, weaknesses, and implications for future research and practice.

Summary of Dissertation Chapters

The following is a brief summary of each chapter in the dissertation manuscript:

Chapter 1: “Hospice Decision-Making in U.S. Mexicans with Terminal Cancer and Their Families.” Chapter 1 provided an introduction to, and background on, hospice, cancer, and Hispanics, and explained the importance of these concepts to the overall research study. For example, cancer is the leading admission diagnosis into hospice (27%; National Hospice and Palliative Care Organization, 2017), the leading cause of death in Hispanics (22%; American Cancer Society, 2018), and displays a unique illness trajectory at EOL (Murray et al., 2005). The second concept, hospice enrollment, was chosen because of the high-stakes Medicare requirement to relinquish curative medical therapy that occurs during the hospice enrollment process. Cultural clashes such as prognostic secrecy, religiosity, and family decision-making were described as barriers to hospice enrollment (Rising et al., 2018). The third decision—to focus data collection on the U.S. Mexican population—rejected the characterization of the Hispanic population as a monolithic entity with EOL preferences that could be generalized across Hispanic subgroups (Weinick et al., 2004). Although there still is considerable heterogeneity within the U.S. Mexican population, focusing on U.S. Mexicans distinguished their experiences from those of Puerto Ricans and Cubans, the second and third largest Hispanic subgroups in the U.S., respectively. Initially I chose the phrase *Mexican Americans* to acknowledge the human rights and economic and other contributions of all Mexicans residing in the U.S. However, some research participants rejected that title and preferred *Mexican*. Hence, to refer to persons of Mexican descent who identify as Mexican American and those who identify as Mexican, the results presented in Chapter 5 used the term *U.S. Mexicans*. To gain insight into the U.S. Mexican experience, I read Chicano studies literature, which emphasizes historical oppression and stigmatization. This reading led me on a personal journey of conscientization, whereby I gained awareness of social and political contradictions, which in turn influenced how I chose to design my study. I found it disturbing to compare the version of the Texas-Mexican War presented in my seventh grade Texas history class to the well-documented atrocities committed by the Texas Rangers and their “volunteers” against innocent Mexican civilians.

Similarly, I was amazed to learn that General Santa Anna—a Mexican general we were all taught to vilify—invaded Texas to enforce Mexico’s anti-slavery laws, something we were never taught. Insights of this nature were the impetus for selecting postcolonial and critical theory as sensitizing frameworks for the study and for situating my study in the critical philosophical paradigm. I sought to center voices that have heretofore been marginalized in the EOL literature. This introductory chapter was not published.

Chapter 2: “Truth-Telling as an Element of Culturally Competent Care at End of Life (EOL)” (Rising, 2017). Chapter 2 was a concept paper describing how individuals from Hispanic cultures sometimes withhold news of a terminal prognosis from their terminally ill family members. It demonstrated how EOL preferences reflective of Eurocentric cultures—in which the individual is the unit of concern—sometimes clash with people from collectivist cultures—in which the family is the unit of concern. U.S. clinicians sometimes struggle to accept the practice of prognostic secrecy since it can contradict the strong ethical mandate to obtain informed consent, even though legal exceptions have been described for cultures practicing prognostic secrecy. Withholding news of a terminal prognosis was particularly germane to hospice enrollment, since a patient who is alert will have to be skillfully—and legally—excluded from the healthcare decision-making conversation and the related process of consenting to relinquish curative medial therapy. Chapter 2 reflected the academic literature focusing on barriers to hospice resulting from a cultural preference for prognostic secrecy in Hispanics; it argued for respecting cultural differences around informed consent and truth-telling. Although Chapter 2 reminded the reader of the preponderance of individual variation within cultures, a limitation of this paper was that it may have furthered stereotypes held by some readers. The manuscript was published in the *Journal of Transcultural Nursing.*

Chapter 3: "Integrative Review of the Literature on Hispanics and Hospice"(Rising et al., 2018). Chapter 3 continued to examine the role culture plays in hospice decision-making. It was a review of research studies specifically addressing Hispanics and hospice knowledge and preferences, with the purpose of integrating that literature to produce a cohesive understanding of what was known on the topic. Results show that, overall, Hispanics were largely unaware of hospice unless they had used it previously. Hospice knowledge was predicted by income, gender, education, and affiliation with community organizations. Identified hospice barriers included language, discrimination, cultural sensitivity, and perceived costs. There was endorsement of the obligation to care for sick family members. With regard to prognostic secrecy, some Hispanic participants welcomed open discussions about death and dying, whereas others did not. Because there was so much heterogeneity in study designs and inconsistent study results, there was little additional knowledge gained from integrating these articles. In other words, there was no conclusion regarding what Hispanics prefer with respect to hospice. However, this review set the stage for future research owing to its appreciation of the racializing effect of research on Hispanics and hospice. That is, the research literature fostered a stereotypical view of Hispanics at EOL because of its exclusive focus on cultural differences, such as prognostic secrecy, religiosity, and family decision-making. Most studies focused on differences between Hispanics and non-Hispanic Whites (NHWs) with respect to hospice, seeking to essentialize or stereotype, and to describe the quintessential Hispanic hospice decision maker. These differences served to "other" Hispanics and reinforce NHW preferences and the Eurocentric healthcare system as the norm. For instance, quantitative studies using surveys relied on instruments that were created by NHWs for NHWs. The instruments were translated into Spanish with little consideration as to whether the domains of the scale were relevant to Hispanics at EOL. That is, what was most important to Hispanics at EOL may not have been included in the scales. Although qualitative studies represented more in-depth inquiries, none of them ventured beyond stereotyping cultural topics, and none used standpoint theory or situational knowledge to privilege the voices of participants. Although some studies reported compatibility between Hispanics and hospice, the research literature as a whole suggested Hispanic underutilization of hospice and hypothesized cultural differences as the cause, even if it was not clear how that was so. The strongest implication in Chapter 3 was the need to examine Hispanics and hospice from a perspective that privileges their perspectives as much as possible so as to mitigate the bias resulting from Eurocentric preconceived notions about Hispanics and EOL preferences. Chapter 3 was published in the *American Journal of Hospice and Palliative Medicine*.

Chapter 4: "Hispanic Hospice Utilization: Integrative Review and Meta-Analysis"(Rising et al., 2019). Because it was unclear from the research literature whether Hispanics were actually using hospice at rates lower than NHWs, Chapter 4 reported on a meta-analysis of the database research literature to contribute to the knowledge on this topic. Database articles in Chapter 4 were from a variety of sources, including hospitals and large Medicare databases. Comparisons were mostly between Hispanics and NHWs, although some were between ethnic preponderances in hospices and local census data. As with Chapter 3, there was considerable heterogeneity such that it was difficult to compare studies and offer a consensus. Nonetheless, significant conclusions were drawn. Final results of the meta-analysis show Hispanics significantly underutilized hospice in the context of stroke (RR 0.60, 95% CI: 0.55–0.66) and heart failure (RR 0.75, 95% CI: 0.71–0.78) and only slightly underutilize hospice in the context of cancer (RR 0.96, 95% CI: 0.94–0.99). In the setting of palliative care, Hispanic rates of hospice utilization did not significantly differ from NHWs (RR 1.02, 95% CI: 0.93–

1.12). Lower hospice utilization by Hispanics compared to NHWs was a significant finding because some very strong and widely cited papers in the cancer setting suggested Hispanics use hospice at the same rates as NHWs. In addition, this chapter revealed limitations in efforts thus far to measure hospice utilization rates. Namely, most of the database studies appeared to exclude Hispanics residing in the U.S. without legal documentation, because the studies relied on Medicare or Medicaid databases, which were unavailable to this group. Estimates vary, but almost 20% of the U.S. Mexican population is in the U.S. without proper documentation (Gonzalez-Barrera & Lopez, 2013), and those Mexicans with legal residence must wait five years before qualifying for Medicare or Medicaid (U.S. Centers for Medicare and Medicaid Services, 2016). The next most populous Hispanic subgroups—Puerto Ricans and Cubans—do not have to wait to qualify for federal healthcare insurance. This mandatory five-year waiting period for legal Mexican residents may have contributed to the Centers for Disease Control report that Mexicans have the highest rates of non-insurance among all U.S. Hispanics (Centers for Disease Control and Prevention, 2017). Significantly, Chapter 4 revealed that studies of Hispanic hospice utilization rates by and large excluded undocumented U.S. Mexicans and Mexicans still in their five-year waiting period. The result was to diminish the importance of healthcare behaviors of the most marginalized U.S. Mexicans. Such exclusion of the marginalized in research was an example of what Paul Farmer and others call structural violence (Farmer, Nizeye, Stulac, & Keshavjee, 2006) in the healthcare setting. Disempowering the marginalized also illustrated the Eurocentric nature of research and how it is linked to imperialism and colonialism, as described by Linda Tuhiwai Smith (Smith, 2012). Together, Chapters 3 and 4 also clarified the need to contribute to the knowledge around U.S. Mexican hospice utilization, particularly the most marginalized sub-groups within the larger heterogeneous U.S. Mexican population. Chapter 4 was published in the *Journal of Healthcare for the Poor and Underserved*.

Chapter 5: "Hospice Decision-Making in U.S. Mexicans with Terminal Cancer and their Families." Chapter 5 presented results from a critical grounded theory study of hospice decision-making in U.S. Mexicans. The study relied on postcolonial theory as a sensitizing framework, which brought discrimination, stigmatization, and other social forces into the foreground. The use of a critical grounded theory methodological approach allowed the study questions to evolve in response to participant-articulated priorities. In my research study, I pursued emerging theories as they arose in the data even when findings were unexpected or not included in the original interview guide. Significantly, the original interview guide included questions about cultural issues from the research literature—prognostic secrecy, religiosity, shared decision-making—as well as a question about discrimination; however, participants quickly disavowed the importance of cultural issues in hospice decision-making. At this point in my dissertation studies, I began using *Whites* to refer to persons of European descent in the U.S. rather than *non-Hispanic Whites*, reflecting usage by participants and in critical theory literature focused on Hispanics. From the outset, study results identified mistrust in Whites and the healthcare system overall as a previously overlooked influencing factor in hospice decision-making. Specifically, results strongly suggest considerable mistrust was experienced in the more marginalized U.S. Mexican population, which resulted in erosion of the therapeutic relationship and interference with hospice enrollment. In contrast, U.S. Mexicans who experienced a sense of belonging—who felt like they are Americans—effortlessly enrolled in hospice in a manner similar to Whites. Marginalizing factors included documentation status, income, education, insurance access, and geographic ethnic isolation. Significantly, not a single U.S. Mexican participant confirmed prognostic secrecy, shared decision-making, or religiosity as barriers to hospice enrollment, even though White participants continued to identify them as barriers. U.S. Mexicans identified their own previously unexplored barriers to hospice enrollment, including mistrust resulting from discriminatory forces, illustrating the importance of critical methods to development of the knowledge base

In summary, I began this dissertation with the goal of understanding hospice decision-making at EOL in Hispanics. As my understanding of the subtleties of knowledge generation—epistemology—grew, I developed an appreciation for the racialization of the research literature on this topic and saw the need to privilege the voices of participants. Critical grounded theory provided such a methodology for my primary data collection study, and, using postcolonial theory, I incorporated my newfound knowledge of the historical and contemporary oppression committed against U.S. Mexicans into the study design. The following is a discussion of theoretical, clinical, and policy implications across all manuscripts and the research literature, as well as strengths and weaknesses, and implications for future research.

Discussion and Implications

The findings of this study suggest that, contrary to the considerable proliferation of studies focused on Hispanic cultural preferences at EOL, barriers to hospice enrollment for many U.S. Mexicans do not stem from cultural differences. Instead, significant barriers to hospice are found in the larger social context, particularly the corrosive impact of interpersonal and structural racism on the therapeutic relationship in the EOL encounter. Study results suggest that the root cause of this preoccupation with culture can be found in the pervasiveness of Eurocentrism in the U.S. Specifically, researchers remain oblivious to their Eurocentrism, privilege, and biased perspectives. In addition, hospice care and enrollment regulations are inherently Eurocentric, and there has been no acknowledgment of that bias or attempt to correct it.

Eurocentrism.

Eurocentrism in hospice. Hospice reflects its Eurocentric roots in three primary ways. First, the stated hospice philosophy is to allow time to prepare for death and for personal growth at the end of life (National Hospice and Palliative Care Organization, 2010). Meeting death directly reflects the Eurocentric origin of hospice and its bias toward individualism, patient autonomy, and control of one's destiny (Rising, 2017). The preference for patient autonomy as a predictor of EOL healthcare choices between cultures is explored in some of the research literature reviewed for this study (e.g., Blackhall et al., 1995; Kelley et al., 2010). Hospice's Eurocentric origin is further reflected in the requirement for informed consent. To enroll in hospice care, Medicare requires terminal patients or their decision makers, with guidance from their healthcare providers about their terminal prognosis, to relinquish curative medical therapy (National Hospice and Palliative Care Organization, 2017). Such overt discussions of relinquishing curative medical therapy in the context of terminal prognoses are avoided by some people from collectivist cultures, which includes some Hispanics (Rising, 2017). This potential cultural clash is explored in some of the research literature reviewed for this study (Blackhall et al., 1995; Colon, 2012). The third manner in which hospice is Eurocentric also stems from the Medicare regulatory requirement to relinquish curative therapy, which reflects obliviousness to the existence of discrimination and unfavorable power dynamics for non-Eurocentric populations. Discrimination and unfavorable power dynamics erode the therapeutic relationship necessary to relinquish curative therapy on the advice of a healthcare provider who is a member of the dominant class. The prevalence of mistrust in healthcare providers in the Latino population has been documented in the non-hospice and non-EOL setting (Armstrong, et al., 2007; Ben et al., 2017; Galvan et al. 2017; Jacobs et al., 2011; López-Cevallos et al., 2014; Robert Wood Johnson Foundation, 2017). This dissertation provides evidence of mistrust and the erosion of the therapeutic relationship in the EOL setting. Specifically, mistrust and erosion of the therapeutic relationship occur as a result of discriminatory experiences in healthcare and elsewhere. If persons from non-Eurocentric populations do not have a trusting, therapeutic relationship with the healthcare provider recommending hospice, then healthcare behaviors occur within that mistrusting, unsafe context. In fact, one might argue any assumption around free choice in hospice decision-making for some U.S. Mexicans is impaired or nonexistent. Giving up curative therapy requires trusting that the healthcare institutions and providers do not make hospice recommendations out of indifference or ulterior motives, and some U.S. Mexicans representing non-Eurocentric views may struggle to extend that trust.

Given the Eurocentric nature of hospice care, Centers for Medicaid and Medicare Services (CMS) could acknowledge the flaws inherent in the original design of the Medicare hospice benefit and seek multicultural input into creation of a culturally appropriate EOL service. Unfortunately, the dominant Eurocentric powers controlling policy around EOL healthcare remain indifferent to the commission of “structural violence” (Farmer et al., 2006) against minority populations. Borrowing from liberation theologians, Farmer, Nizeye, Stulac and Keshavjee (2006) describe structural violence as a way that healthcare providers cause injury to people through perpetuation of social forces that are inextricably intertwined in our economic and social worlds. Consistent with structural violence, EOL healthcare providers are not trained to understand or alter its impact. Without reform from within CMS, reform would have to be informed by the research literature. Unfortunately, Eurocentrism permeates the hospice and EOL scientific research, as well.

Eurocentrism in hospice and EOL research methodologies and study designs. Instead of focusing on flaws within the Medicare Hospice Benefit, researchers and policy makers focus on “understanding” and, by extension, “othering” non-European cultures. The stated goals in their research are to improve EOL care, and the implied method of improvement is through accommodation of “otherness” to tailor Eurocentric hospice care to make it more culturally compatible. The result has been to racialize the research literature on Hispanics and hospice, promoting stereotypes. Consequently, the “problem” is portrayed as Hispanics rather than the Eurocentric hospice and EOL healthcare system or the discrimination endured by Hispanics leading up to their EOL encounter. The following is a brief summary of the ways in which the hospice Hispanic literature has been racialized, including post-positivist study designs, Eurocentric statistical analyses, Eurocentric population samples, and Eurocentric constructivist methodologies.

Post-positivist study designs. The foundation for much of the cross-cultural Hispanic hospice research builds on the seminal works by Blackhall et al. (1995) and others that sought to broaden knowledge about advance care planning in other cultures (Blackhall et al., 2001; Blackhall et al., 1999; Blackhall et al., 1995; Frank et al., 2002). The historical interest in advance care planning reflects a significant shift in clinical practice at the time brought about by the SUPPORT study (Murphy & Cluff, 1990a, 1990b) and an interest in promoting patient autonomy at EOL. Many cultural concepts identified in those studies as possible barriers to advance care planning were carried forward into more current hospice studies. For example, research studies exploring Hispanic EOL preferences focus on the preference for prognostic secrecy (Bade et al., 1999; Blackhall et al., 2001; Blackhall et al., 1995; Boucher et al., 2014; Colon, 2012; Del Gaudio et al., 2013; Frank et al., 2002; Gelfand et al., 2001, 2004; Gutheil & Heyman, 2006; Jonnalagadda et al., 2012; Kreling et al., 2010; Loggers et al., 2013; Nedjat-Haiem et al., 2013; Noguera et al., 2014; Randall & Csikai, 2003; Selsky et al., 2012; A. K. Smith et al., 2008; Sullivan, 2001; Wright et al., 2013), family decision-making (Adams et al., 2005, 2006; Bade et al., 1999; Blackhall et al., 2001; Blackhall et al., 1995; Braun et al., 2014; Caralis et al., 1993; Carrion, 2010; Colón & Lyke, 2003; Gutheil & Heyman, 2006; Johnson et al., 2005; Kelley et al., 2010; Kreling et al., 2010; Nedjat-Haiem et al., 2013; Noguera et al., 2014; Selsky et al., 2012; Yennurajalingam et al., 2013), and increased religiosity (Balboni et al., 2007; Born et al., 2004; Finley et al., 2012; Finley et al., 2013; Gelfand et al., 2001; Ko & Lee, 2014; Loggers et al., 2013; Phelps et al., 2009; Ruff et al., 2011; Smith et al., 2008; Smith et al., 2009). Many of these studies are quantitative in design and use translated quantitative instruments originally developed by NHWs for NHWs (Balboni et al., 2007; Barnato et al., 2009; Blackhall et al., 1999; Blackhall et al., 1995; Caralis et al., 1993; Carrion et al., 2015; Colon, 2012; Duffy et al., 2006; Espino et al., 2010; Finley et al., 2012; Finley et al., 2013; Gordon, 1996; Jonnalagadda et al., 2012; Kelley et al., 2010; Kirkendall et al., 2015; Ko et al., 2012; Ko & Lee, 2014; Loggers et al., 2013; Mouton et al., 2001; Noguera et al., 2014; Pan et al., 2015; Park et al., 2015; Phelps et al., 2009; Randall & Csikai, 2003; Rising et al., 2018; Romero et al., 1997; Ruff et al., 2011; Selsky et al., 2012; A. K. Smith et al., 2008; Taxis et al., 2008; Wright et al., 2013; Yennurajalingam et al., 2013). They are rooted in post-positivist and reductionist views that human science is objective and quantifiable. There are qualitative or mixed design studies that avoid use of surveys (Bade et al., 1999; Blackhall et al., 2001; Blackhall et al., 1999; Born et al., 2004; Boucher et al., 2014; Braun et al., 2014; Carrion, 2010; Del Gaudio et al., 2013; Duffy et al., 2006; Frank et al., 2002; Gelfand et al., 2001, 2004; Gutheil & Heyman, 2006; Jaramillo & Hui, 2016; Ko et al., 2013; Kreling et al., 2010; Nedjat-Haiem et al., 2013; Perkins et al., 2009; Smith et al., 2009; Sullivan, 2001; Taxis et al., 2008; Volker & Wu, 2011). Through open-ended interviews, these qualitative and mixed method studies offer constructivist as well as post-positivist worldviews of knowledge production. However, to my knowledge, there have been no critical qualitative studies that explicitly privilege the realities of participants or consider the impact of a Eurocentric healthcare system and other oppressive social forces on Hispanics' EOL care.

Another perspective on Hispanics and EOL healthcare consumption is offered by database studies that seek to determine whether Hispanics are using hospice and intensive EOL therapy at rates similar to NHWs (Adams et al., 2005, 2006; Barnato et al., 2006; Braun et al., 2008; Carrion et al., 2012; Choi et al., 2015; Colón & Lyke, 2003; Colón & Lyke, 2015; Cooper et al., 2012; Enguidanos et al., 2013; Enguidanos et al., 2005; Fischer et al., 2007; Fosler et al., 2015; Givens et al., 2010; Guadagnolo et al., 2015; Haas et al., 2007; Hanchate et al., 2009; Hardy et al., 2011, 2012; Hernandez et al., 2015; Johnson et al., 2005; Kirkendall et al., 2014; Kress et al., 2015; Lackan et al., 2003; Lackan et al., 2004; Meyers et al., 2008; Park et al., 2012; Rhodes et al., 2013; Sammon et al., 2015; Smith, Earle, et al., 2009; Thompson et al., 1999; Zahuranec et al., 2009). Interpretations of these database research findings are contextualized by background and literature review sections informed mostly by the foregoing Eurocentric quantitative and qualitative studies. In other words, there is a strong Eurocentric bias. In these database studies, Hispanic healthcare consumption is used as an implicit proxy for preferences and interpreted through the hegemonic lens of the current research on Hispanics and hospice. Moreover, equal rates of hospice use offer no knowledge about the quality of hospice care for

Hispanics. The end result is the generation of knowledge that is biased by the dominant, Eurocentric worldview and fails to address whether Hispanics are receiving quality of care at EOL.

Eurocentric statistical analyses. Many studies reviewed in Chapters 3 and 4 report income or education as demographic variables and consider them in their analyses, particularly cross-cultural comparative studies between Hispanics and NHWs. Across studies in Chapters 3 and 4, Hispanics have lower income and education compared to NHWs. The outcome variables of interest, such as rates of hospice utilization or EOL preferences, are compared, and income and education variables are treated statistically in a manner that reflects the Eurocentric bias of scientific research. That is, those demographic variables are oftentimes statistically controlled as confounders, or statistical noise, to ensure Hispanics are compared to NHWs of equal income and education. The intent of this reductionist study design is to isolate Hispanic and NHW healthcare behaviors from the “noise” of socioeconomic level. Not all scholars agree with the statistical strategy of separating socioeconomic variables from healthcare behaviors. Hebert, Sisk, and Howell (2008) offer a reconceptualization of the presumptions behind controlling income and education as confounding variables when researching healthcare disparities and making statistical comparisons between ethnic or racial categories. In the usual statistical analysis, the persons representing the ethnic or racial category in question are presumed to have free choice in healthcare behaviors, and education and income are presumed to be causally *un*related to ethnicity or race and healthcare behavior. However, Hebert, Sisk, and Howell (2008) describe a scenario in which education and income could be causally related, which would mean controlling for them statistically would cast doubt on the validity of research results. Such a scenario describes persons as entrapped by their social situation such that they do not have free choice in healthcare behaviors because there is a causal link between socioeconomic variables and healthcare behaviors. The contrasting scenario in which it would be appropriate to statistically control for socioeconomic variables reflects complete free will and free choice, and there is no causal connection between socioeconomic variables and healthcare behaviors. Hebert, Sisk, and Howell (2008) point out that the scenario one chooses—free choice or no free choice—depends on the personal beliefs of the analyst, which is how Eurocentric bias quietly enters into the research study. In the case of healthcare discrepancies, a researcher influenced by social determinants of health (World Health Organization, 2018) and social justice—consistent with the perspectives of Paul Farmer (Farmer, 2004; Farmer et al., 2006) and others (Anderson, 2004; Gregg, Solotaroff, Amann, Michael, & Bowen, 2008; Kirkham & Anderson, 2002)—would opt for less free choice and a causal relation between ethnicity or race and healthcare behavior. This phenomenon was demonstrated statistically by Barnato et al. (2006), who reported higher rates of intensive care use by racial minorities as a hospital effect reflecting neighborhood segregation. Hebert, Sisk, and Howell (2008) explain the importance of a conceptual exercise prior to controlling for demographic variables such as income and education so that researchers can justify their decisions. Throughout the nearly 100 research articles relied upon for this dissertation, the failure of a single study to justify controlling for income and education variables is evidence of Eurocentric bias in scientific research.

Eurocentric research samples and populations: "Hispanics." Another example of Eurocentric post-positivism is the tendency to homogenize Hispanics into a monolithic category of ethnic preferences. Grouping persons from extremely diverse cultures and countries of origin into a single category of Hispanics is a classic example of "othering" that is originally described by Said (1978) as "orientalism." Said (1978) described how so-called scholars from colonial powers combined their new knowledge about the diverse cultures and sociopolitical histories of Asia, North Africa, and the Middle East into one homogenous category, “the Orient.” To some degree, it is understandable that Hispanic database studies rely on the Hispanic category, since most databases collect only information on Hispanics after the creation of that category by the U.S. Census Bureau. However, the objectifying reliance on the Hispanic category continues into survey studies. For example, multiple studies in the well-funded Coping with Cancer Study do not distinguish Hispanic subgroups. In those studies, Wright et al. (2013) validated an acculturation scale used to predict EOL preferences, Phelps et al. (2009) and Balboni et al. (2007) used religiosity to predict EOL preferences, and Barnato et al. (2009) predicted EOL preferences by ethnicity. All of these Coping with Cancer studies engage in face-to-face interviews to complete surveys, and yet the study designs do not inquire about country of origin to acknowledge and address heterogeneity within the Hispanic population.

Homogenization is not limited to surveys of Hispanic EOL and hospice preferences. Even in focus groups, researchers do not verify country of origin. Two such focus groups occur in New York City (Boucher et al., 2014; Gutheil & Heyman, 2006) and report intimate details about EOL preferences. However, researchers report only on “Hispanics,” and so we can only speculate that participants were mostly Puerto Rican based on the prevalence of Puerto Ricans among Hispanics in New York in census data. Who, exactly, is speaking is critical to appropriate generalizing or transferability of study results. Unlike some Mexicans, Puerto Ricans have ready access to federal insurance to pay for hospice, and so there could be significant differences between them based on socioeconomic differences alone. Moreover, as American citizens, Puerto Ricans are familiarized with U.S.-style healthcare. It is derogatory to suggest that results from these New York studies apply to Mexicans, and yet use of the Hispanic category implies just that. In a final demonstration of obliviousness to the heterogeneity within the Hispanic category, some researchers use geographic location to assume country of origin. For example, Braun et al. (2014) and Zahuranec et al. (2009) identify participants as Hispanics, then assumed they were of Mexican origin because the studies occurred in Texas. To demonstrate the fallacy of that assumption, a study by Yennurajalingam et al. (2013) in the same general region of Texas identified 28 Mexican Americans and 51 Puerto Ricans within their Hispanic sample. The tendency to homogenize Hispanics not only brings us further from the authentic voice of the study participant, but also creates so-called research knowledge based on uninformed Eurocentric assumptions. This disrespectful and inaccurate homogenization of diverse people is something I sought to avoid by narrowing the study sample in my dissertation to U.S. Mexicans.

Eurocentric research methodologies: constructivists. Even researchers who study U.S. Mexicans with constructivist methodologies fail to compensate for the Eurocentrism inherent in scientific research. For instance, Taxis et al. (2008) study receptivity to hospice support and teaching among Mexican Americans (their term) living in Austin, Texas, and Las Cruces, New Mexico. Although their methodology is qualitative interpretive, and they explicitly seek to allow "voice and constructed meaning of the participants to emerge from the data" (p. 135) there is no data clearly situating participants and capturing their unique perspectives by virtue of the intersections between ethnicity, socioeconomic status, and sociopolitical history. The researchers describe their participants as bilingual Mexican Americans who read and write in English and who welcome support and teaching about the dying process from hospice nurses. But how their participants navigate the predominantly White healthcare system and understand their experience within the context of discrimination and historical injustices is not explored. In their limitations, Taxis et al (2008) acknowledge the limited transferability of their study results because of the diversity of the U.S. Mexican population and the high prevalence of U.S. Mexicans in their geographic region. However, they do not venture into a description of what diversity looks like in the U.S. Mexican population from their perspectives, including whether there is an oppressed or marginalized U.S. Mexican population alongside the individuals who participated in their study. If so, the oppressed and marginalized U.S. Mexicans may not agree with their findings. One of the major findings of this dissertation study is that more marginalized U.S. Mexicans are mistrustful and tend to reject hospice, whereas "Americanized" U.S. Mexicans—or Mexican Americans such as those in the Taxis et al. (2008) study—embrace hospice. This distinction demonstrates the heterogeneity within the U.S. Mexican population, not by race or ethnicity, but by virtue of marginalizing factors such as income, education, insurance access, documentation status, and geographic isolation. It also illustrates how marginalizing factors contribute to the diversity within the Mexican population and predict healthcare behavior and preferences around hospice. The distinction between a critical approach and a constructivist approach is less marked than it is against post-positivist approaches. However, it is important because the constructivist approach continues to allow for Eurocentric obliviousness and "othering."

Summary: Racialization of colonizing methodologies. In the post-positivist and constructivist methodologies, the research questions posed, and the training provided on EOL, contribute to an essentialized Hispanic or Mexican "Other" in the Eurocentric healthcare system. Researchers and clinicians are taught that they should seek to understand these differences and accommodate them, if needed. As racialized "Others," Hispanics and Mexicans are viewed as culturally inferior and any accommodations made are often implemented with less than subtle condescension. For example, the preference for prognostic secrecy at EOL is viewed negatively, and many clinical healthcare providers struggle with accepting anything less than traditional informed consent even though healthcare education emphasizes acceptance of different views (Rising, 2017). In Chapter 2, I examine the validity of prognostic secrecy as an element of ethical EOL care. From the perspective of the morally distressed healthcare provider, I demonstrate that Hispanic and Mexican "Others" are not the problem and that withholding news of terminal prognoses is an equally valid path to protecting the patient by virtue of beneficence and non-maleficence.

Contrary to cultural differences, Paul Farmer in *Pathologies of Power* (Farmer, 2004; Farmer et al., 2006) and other authors (Anderson, 2004; Gregg et al., 2008; Kirkham & Anderson, 2002) have written about the importance of examining the influence of the social environment, policies, governmental regulations, and other social determinants of health as we consider the underlying factors that shape healthcare behavior in our research and teaching. Shifting the focus of health research to include social forces that are under the control of the dominant, Eurocentric culture has profound implications for the solutions that studies suggest. Rather than pointing to individual and cultural factors as the major drivers of healthcare behavior, the larger social and structural view requires that the dominant culture examine its own behaviors—individual, regulatory, and otherwise—as major contributing factors to health inequities. In the case of hospice, CMS would examine the structural violence it imposes upon "others" by virtue of its Eurocentric regulatory requirements. Without policy changes within CMS, any reform is dependent upon scientific research and professional advocacy at the policy level. However, post-positivist and constructivist methodologies further racialize the issue and do not consider social determinants of health in their investigations. In contrast, critical methodologies seek to understand how the dominant, Eurocentric healthcare system and concomitant social forces impact the EOL healthcare behaviors of Hispanic and Mexican "Others" and also privilege their voices.

Replacing colonizing with critical methodologies. Linda Tuhiwai Smith wrote that research, in and of itself, is "inextricably linked to European imperialism and colonialism" (Smith, 2012, p. 1). Oblivious to their own culture and bias—even convinced of their lack of research bias due to their post-positivist methodologies—Eurocentric researchers have proceeded on the assumption that their beliefs, values, and knowledge are superior. Hence, they skew their findings to support their assumptions through their post-positivist and objectifying research methods. In contrast, Smith calls for the decolonization of research methods with the intention of bringing forth the voices of non-dominant, colonized, and marginalized communities (Smith, 2012). To carry out this directive, research is ideally conducted by and for marginalized communities. Where this is not possible, then a cross-cultural research approach should acknowledge the shortcomings inherent in the assumption that objective, or even constructed, knowledge is attainable. Instead, researchers should privilege the voices of the marginalized through critical research methods that support the creation of situated knowledge, or standpoint, unique to the perspective of the participants. From the decolonizing perspective, surveys of Hispanic EOL preferences constructed by NHWs for NHWs fall far short of this goal, as do qualitative interview studies with limited depth and context of participants. What are needed are methodologies that mitigate the limitations inherent in cross-cultural research and that generate knowledge based on the realities of marginalized participants.

Critical grounded theory using a postcolonial framework. In this dissertation study, I employ several research strategies to investigate hospice family decision-making in U.S. Mexicans in a manner consistent with the decolonizing methodological perspective described above. As a white woman who speaks English as my primary language, I collaborated with members of the U.S. Mexican community in the Pacific Northwest (PNW) through a community advisory board (CAB) comprising professional contacts. I focused on U.S. Mexicans, a Hispanic subgroup, to acknowledge the heterogeneity of the Hispanic population which has previously been treated as a monolithic group by many researchers with respect to preferences and healthcare behaviors. Further, to guard against essentializing U.S. Mexicans, I acknowledged the heterogeneity extant within this population at the outset of the investigation. Moreover, focusing on U.S. Mexicans acknowledges their unique sociopolitical histories and avoids confusing the acquired research data with multiple conflicting population histories. As it turns out, my decision to focus on the U.S. Mexican population has been particularly relevant since the election of President Trump, which has been accompanied by increased anti-Mexican rhetoric, stereotyping, and discrimination.

A sensitizing framework is needed to alert me to the social forces affecting EOL healthcare behaviors in U.S. Mexicans, such as racism, stigmatization, discrimination, and the power differential between U.S. Mexicans and the U.S. healthcare system. Postcolonial theory (PCT; Ashcroft, et al., 2013) is such a theory. Postcolonial theory holds that a modernized form of colonization exists today in the form of continued stigmatization, racism, discrimination, and marginalization, which remain largely invisible to the dominant group. Critical of the binary conceptualization of colonizer and colonized, Homi Bhabha—a key critical and postcolonial theorist—introduces the concepts of hybridity and “Third Space” to the field (Ashcroft et al., 2013; Bhabha, 1994). The concept of the “Third Space” strongly resonates with me, as someone born and raised near the Mexican border, because it introduces the possibility of a hybrid, contradictory, and ambivalent “Third Space” where there is no pure expression of either

Eurocentric or U.S. Mexican healthcare preferences (Ashcroft et al., 2013; Bhabha, 1994). Finally, PCT directly influences the study interview guide by calling for questions about discrimination alongside the oft-repeated cultural themes from the research literature.

Critical grounded theory is a methodological approach that remains responsive to the voices—the "truths"—of U.S. Mexican participants. Unlike quantitative and some qualitative research methods, researchers conducting critical qualitative research adjust their methods in sequential interviews if previously unknown findings emerge and influence the focus of inquiry. Therefore, interview questions not only evolve to reflect theoretical sampling—consistent with grounded theory—their importance also reflects participants' standpoints. For instance, despite the emphasis on prognostic secrecy and religiosity in previous research, U.S. Mexican participants in this study deny the significance of these concepts to EOL and the hospice decision-making process. In contrast, mistrust in the healthcare system permeates the results, particularly with respect to the most marginalized U.S. Mexicans. Using critical grounded theory, the study expands to include questions related to the unanticipated theme of mistrust and captures this previously overlooked phenomenon. As such, it is the most significant finding of this study. Consequently, for the first time, there is evidence in the research literature pointing to the critical importance that discrimination and concomitant mistrust play during EOL decision-making among marginalized U.S. Mexicans in the PNW. The findings across all manuscripts in this dissertation demonstrate the critical role of epistemology in the generation of knowledge in the cross-cultural context. That is, the way that we seek knowledge determines the knowledge that we gain.

The impact of methodology on research findings. A review of dissertation study findings with an appreciation for the impact of research methodologies on the knowledge generated demonstrates the impact of sensitization on research results. Many of the major findings of this study are evident in the research literature but are dismissed through an “othering” cultural lens or statistically controlled out of significance.

Marginalizing factors.

Income and education. In the dissertation study, low income and education are marginalizing factors contributing to mistrust, erosion of the therapeutic relationship, and rejection of hospice. Unlike the studies reviewed in Chapters 3 and 4, in which income and education are statistically neutralized in Eurocentric study designs, low income and education remained central to my analysis. There is supporting evidence in the research literature that low education impacts EOL preferences. For example, Blackhall et al. (1995) report in their seminal work that, after controlling for ethnicity, Mexican Americans (their term) with higher education were significantly more likely to prefer open discussions of terminal prognoses in hypothetical scenarios. Likewise, Kelley et al. (2010) reported that Mexican Americans (their term) with higher education and income were more likely to have completed an advance directive. Similarly, educated and bilingual Mexican American (their term) participants in the study by Taxis et al. (2008) were highly receptive to hospice. The foregoing results likely reflect the hospice decision-making behaviors of the trusting and *non*-marginalized U.S. Mexicans in the dissertation study. The difference between this study and that of Blackhall et al. (1995) and Kelley et al. (2010) is that low income and education in those studies are statistically controlled as separate from the analysis of healthcare behavior. In contrast, participants in this study with low income and education are identified as marginalized and mistrusting with exemplars that revealed the added layer of helplessness and powerlessness at EOL, particularly for those without healthcare insurance. In this study, there is no assumption that low-income and -

education Whites approach hospice enrollment in a manner similar to U.S. Mexicans because Whites do not share the experience of ethnic and racial discrimination. Understanding the polarizing impact of low education and income is critical in this study to understanding their meaning in relation to hospice rejection, which contributes to construction of the substantive grounded theory. From a PCT perspective, low income and education in this population are vestiges of historical and ongoing oppression and discrimination. Having identified the oppressive and discriminatory roots of low income and education, as well as their link to mistrust in the medical system, then the solution is focused on social—not cultural—interventions.

"Hospicio." A special aspect of education level is a critical finding in this study. U.S. Mexicans with low levels of education are inclined to interpret the Spanish word *hospicio* with extremely negative connotations derived from its entirely different use in Mexico. In contrast, more educated U.S. Mexicans understand it to mean the American concept of the word. Mostly *un*educated U.S. Mexicans have never heard the word *hospicio* before, and so there are no preconceptions. In the dissertation study, the word *hospicio* is a polarizing word that invokes strong moral responses along the lines of reactions to use of the word *abortion*. In the research literature reviewed for this study, there were only two studies that noted, in the background (Adams et al., 2006) and discussion sections (Selsky et al., 2012), the potentially negative connotation of the word *hospicio*. This study is the first to provide information about *hospicio* in the findings. Importantly, participants offer evidence that the word *hospicio* is associated with abandonment of loved ones, as well as the near impossibility of overcoming the negative connotations associated with the word. The limited references to the deterring impact of the Spanish word *hospicio* in previous research reflect the preoccupation with particular cultural differences—prognostic secrecy, family decision making, and religiosity. Oblivious to the

polarizing nature of the word *hospicio,* many survey and focus group studies explore hospice awareness and hospice knowledge (Bade et al., 1999; Born et al., 2004; Boucher et al., 2014; Carrion, 2010; Colon, 2012; Gelfand et al., 2001, 2004; Kreling et al., 2010; Randall & Csikai, 2003; Selsky et al., 2012) without acknowledging that there could be confusion between the American and Mexican concepts of hospice. Because this is a grounded theory study which pivoted on the meaning of the word *hospice*, all participants were asked what hospice means to them and their community. In contrast, post-positivist surveys ask simply whether persons had heard of hospice or ask true/false questions to measure hospice knowledge. The clear practice implication for this finding is that health providers should cautiously enter conversations about hospice and consider abandoning use of the word *hospicio*. Moreover, at the policy level, the polarizing nature of *hospicio* should be recognized and a consensus reached on the diplomatic approach to this topic. An intersection point occurs with Spanish-language interpreters, most of whom appear well aware of this potential for miscommunication. Although there are exceptions (Butow et al., 2011; Hsieh, Pitaloka, & Johnson, 2013), many interpreters remain reluctant to step outside of their professionally mandated neutral interpreter roles and advocate for non-violent communication.

Documentation status and insurance access. Of the 31.8 million (Ennis et al., 2011) persons of Mexican descent residing in the U.S., an estimated 20%, or 6.8 million (Gonzalez-Barrera & Lopez, 2013), do not have legal documentation to remain in the U.S. A combination of documented and undocumented U.S. Mexicans provide the “labor backbone” of U.S. industries such as construction, hospitality, and agriculture (Jordan & Perez, 2016). In the dissertation study, documentation status predicts marginalization and mistrust. Not only do those without documentation have cause to mistrust, several participants explain that “mixed status” households extend mistrust in the community. “Mixed status” households occur when many family members live together, or unrelated families combine resources and live together, and there is at least one person among them without legal documentation. Hence, even a U.S. citizen would feel reluctant to accept home hospice for fear of exposing undocumented persons residing in the home. Although this may seem farfetched to those who do not have to worry about these things, their community is rife with stories about the U.S. government using the medical system to identify those without legal documentation and then deporting them. Strongly related to documentation status is lack of insurance, since Medicare and Medicaid are unavailable to persons without documentation or within the five-year waiting period for legal residents (U.S. Centers for Medicare and Medicaid Services, 2016). In other words, those with a green card must wait five years to qualify for Medicare and Medicaid. Lack of access to Medicare and Medicaid is significant, since Medicare and Medicaid pay for a combined 90% of hospice (National Hospice and Palliative Care Organization, 2015). It is noteworthy that all hospice users in this study had insurance, and most of the hospice avoiders did not.

In spite of this direct link between hospice, insurance, and documentation status, few studies on Hispanics and hospice (Gelfand et al., 2001, 2004; Jaramillo & Hui, 2016; Smith et al., 2009) acknowledge the existence of undocumented U.S. Mexicans. In a case study describing the difficulty transitioning an uninsured undocumented cancer patient into hospice, Jaramillo and Hui (2016) explain the challenges of finding charity hospice. However, Jaramillo and Hui (2016) only brought up trust in relation to initial help-seeking for cancer treatment and did not address whether the EOL healthcare team could be trusted to speak the truth or enter their home. In two publications derived from the same focus group studies, Gelfand et al. (2001, 2004) explained that many of their participants were presumptively undocumented. There, mistrust was not identified as a factor in hospice decision-making, and no link was made between undocumented status and mistrust. In another case study, Smith et al. (2009) suggested strategies for bringing up documentation status within the context of an EOL setting. Although trust was identified as a factor with respect to revealing documentation status, trust was not identified as a factor in the therapeutic relationship insofar as EOL healthcare behaviors were concerned. In contrast, this dissertation study identified documentation status as a significant marginalizing factor, directly relating to mistrust and erosion of the therapeutic relationship. Many dissertation study participants described how, because of mistrust, undocumented individuals sought help from alternative healers and used U.S. medicine as a back-up plan. Other participants described how undocumented individuals would return home to Mexico because they did not believe the determination by the U.S. medical system that curative therapy was unavailable.

Probably the most vulnerable undocumented persons described by study participants are those in the hospital who have been admitted under the Emergency Medical Treatment and Labor Act (EMTALA; U.S. Centers for Medicare and Medicaid Services, 2012). Those individuals needing continued medical help upon hospital discharge are corralled into hospice care if they are hospice-eligible. All healthcare providers interviewed agree that the medical system tends to push hospice on these individuals because there is no other choice available for responsible hospital discharge that includes continuity of medical care. From a Eurocentric perspective, healthcare providers see themselves as advocating for the patient when they work hard to find charity hospice and provide continuity of care. However, hospice may be a poor fit for undocumented persons for many reasons, including the following: enrolling in *hospicio* can be terrifying for reasons explained elsewhere, they have no reason to trust that the medical system will not be complicit with the U.S. government, they do not want to risk deportation of other members in their household, they are uncomfortable with strangers in the home, and they are not yet ready to surrender to death. Except for Jaramillo and Hui (2016), who discuss charity hospice in the context of a family that sought to escape the hospital and the associated mounting medical bills, there are no other studies that bring forth this difficult ethical situation at EOL. However, there are publications relating to “repatriation” (Young & Lehmann, 2014) of undocumented individuals and legal residents who are admitted to the hospital under EMTALA, and these publications acknowledge the ethical dilemma driven by business and financial considerations. The policy and ethical implications of the difficulties around discharge of terminally ill undocumented and uninsured patients admitted to the hospital under EMTALA are profound. Pressuring anyone into hospice because charity hospice is the only “exit door” that can be found is contrary to social justice and ethical norms, and it is driven by capitalistic pressures and patient throughput to create empty beds for more hospital admissions. What is needed is a modicum of insurance coverage that follows EMTALA patients back out into the community so that they can be discharged from the hospital in the manner of their choosing and with sufficient healthcare support to satisfy professional duties to the patient. Although this dissertation research further revealed that community palliative care is the obvious solution for the marginalized U.S. Mexican population, including EMTALA patients, this treatment approach has received little recognition.

Geographic ethnic isolation. Another concept that was mostly untouched throughout the preexisting Hispanic hospice literature is geographic ethnic isolation. In the dissertation study, geographic ethnic isolation was reported by participants residing in the PNW who had previously lived in Texas or the Southwest U.S. They described “culture shock” upon moving to the PNW due to the pervasive whiteness of the population and associated lack of cultural and social cohesion. The research literature supports the inference that U.S. Mexicans living in White-prevalent neighborhoods are more likely to experience discrimination (Viruell-Fuentes, 2007). Discrimination then leads to mistrust and erosion of the therapeutic relationship in the healthcare setting (Armstrong et al., 2007; Ben et al., 2017; Galvan et al., 2017; Jacobs et al., 2011; López-Cevallos et al., 2014; Robert Wood Johnson Foundation, 2017). In addition to increased discrimination, participants described the increased “othering” they experience in the PNW by virtue of their ethnicity in that they are perceived as the other part of a binary, separate from Whites. One participant described how people in the PNW make her choose whether she is going to be Mexican or White, whereas in Texas she can be both. With her observation, she effectively described the essence of Bhabha’s conceptualization of PCT. Rather than a binary comprised of the colonizers and the colonized, this participant is accustomed to a “Third Space” that allows for hybridity, contradiction, and ambivalence (Ashcroft et al., 2013; Bhabha, 1994). An example of such a Third Space is Texas, where Tex-Mex culture has developed over centuries of cohabitation. The extreme “othering” in the PNW may play a critical role in the mistrust that erodes the necessary therapeutic relationship at EOL. Therefore, geographic ethnic isolation is an important factor in understanding the research literature on Hispanics and hospice. Except for the Gelfand (2001, 2004) focus groups, which occurred in Michigan, the predominance of research explicitly conducted with U.S. Mexican participants occurs in Texas or the Southwest U.S. Taxis et al. (2008) acknowledge in their discussion that the receptiveness to hospice in their Mexican American (their words) sample from Austin, Texas (30% Hispanic) and Las Cruces, New Mexico (52% Hispanic) may not occur in regions with lower prevalence of Mexican Americans. And it is implicit in publications by Adams (2006, 2007) that other regions of the U.S. will not likely have a population that is 80% Hispanic like El Paso, Texas. To my knowledge, no publication has explicitly discussed the impact on hospice receptivity for U.S. Mexicans living in Whiter regions of the country. The results from this dissertation study suggest that the increased binary-relating and discriminatory experiences increase mistrust and erosion of the therapeutic relationship, which may lead to a higher likelihood of hospice rejection. The policy and research implications of an entirely different relational baseline in predominantly white regions of the country are that funding should support research in more isolated U.S. Mexican communities to better understand their unique needs.

Mistrust. The presence or absence of mistrust in U.S. Mexicans played a critical role in hospice enrollment in this dissertation study. Although mistrust has been described in the Hispanic research literature in the general healthcare setting (Armstrong et al., 2007; Bustillo et al., 2017; Jacobs et al., 2011; López-Cevallos et al., 2014; Thompson, Valdimarsdottir, Winkel, Jandorf, & Redd, 2004), the predominance of research is with African American populations (Born et al., 2004; Cort, 2004; Krakauer, Crenner, & Fox, 2002; Smith, Davis, & Krakauer, 2007; Winston, Leshner, Kramer, & Allen, 2005). In the EOL setting, there is limited inquiry into the role of mistrust in the Hispanic population. Ten articles mention mistrust in some manner in the Hispanic population at EOL and will be briefly discussed here because of the centrality of mistrust to dissertation findings. One article, in the discussion, speculated about an association between healthcare utilization and mistrust (Hanchate et al., 2009). Four report no significant statistical relationships between EOL healthcare preferences and low (Kelley et al., 2010; Ko & Lee, 2014; Wright et al., 2013) and high (Morrison et al., 1998a) mistrust. Two discuss mistrust in the limited context of undocumented patients without offering evidence of mistrust around EOL decisions from their studies (Jaramillo & Hui, 2016; Smith et al., 2009). One focus group study specifically exploring attitudes about hospice reported mistrust in Latinos but only supported the finding with African American exemplars (Born, K. Greiner, E. Sylvia, J. Butler, & Ahluwalia, 2004).

In the quantitative research articles, it is interesting to note the wide variation in reported mistrust levels and that the mistrust variables have not significantly predicted EOL healthcare behavior. Using the 10-item health Care System Distrust Scale, Ko and Lee (2014) reported low-income Hispanics residing in California had lower mistrust (23.32) than Blacks (29.31) and Whites (25.59; Ko & Lee, 2014). The researchers did not follow up or comment on the potentially significant finding that Hispanics reported lower mistrust than Whites. In another article, and based on a stereotype unsupported by the background research literature, Kelley et al. (2010) hypothesized that presumed high trust in their sample population predicted preferences for advance care planning. Using the five-item Likert-style Trust in Healthcare Providers scale, they report 53% of elderly U.S. Mexicans residing in California trusted their providers “completely” or “mostly,” and 47% trusted “somewhat,” “a little,” or “not at all” (Kelley et al., 2010). The third quantitative article to report high trust reported nearly uniformly affirmative answers to the yes/no question of whether they trusted their healthcare provider (Wright et al., 2013). The exact location of that sample was spread over five recruitment sites, but related articles suggest that most of the Hispanics were recruited in Dallas, Texas. At the other end of the trust spectrum, Morrison et al. (1998a) reported high levels of mistrust in their Hispanic sample. They measured mistrust using four statements on a four-point Likert scale, including “I trust the doctors to make the right decisions about my medical care if I were to be very ill or in a coma,” and “I worry that I won’t be treated as well as other people in the hospital if I were to be very sick or dying.” In their results, they described half as many Hispanic patients (40%), compared to African Americans (81.5%) and Whites (84%), reported trust in physicians.

Because they conducted their research in New York City, there is a presumed high prevalence of Puerto Ricans and low prevalence of U.S. Mexicans. In spite of the high mistrust levels reported in Hispanics by Morrison et al. (1998a), their qualitative companion study (Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998b) did not report mistrust in study findings. In the foregoing studies, results about trust have not significantly predicted EOL healthcare behavior. The heterogeneity in trust values across these studies is striking and suggests ethnicity is not necessarily causally linked. In other words, ethnicity does not predict mistrust. Findings from the dissertation study suggest that mistrust is precipitated by marginalizing factors. Acknowledging the heterogeneity within the U.S. Mexican population, healthcare delivery would benefit from research that offers insight into the various mistrust-precipitating factors with the goal of mitigating them.

In summary, critical grounded theory allows the development of themes of mistrust and marginalization, which dominate the dissertation research findings with respect to what influences hospice decision-making in U.S. Mexicans with terminal cancer and their families. The next paragraphs briefly summarize the diametrically opposed mistrust-related resistance factors and accepting factors and also explain the theoretical, clinical, and policy implications of those factors. The grounded theory model is reproduced here (Figure 1).

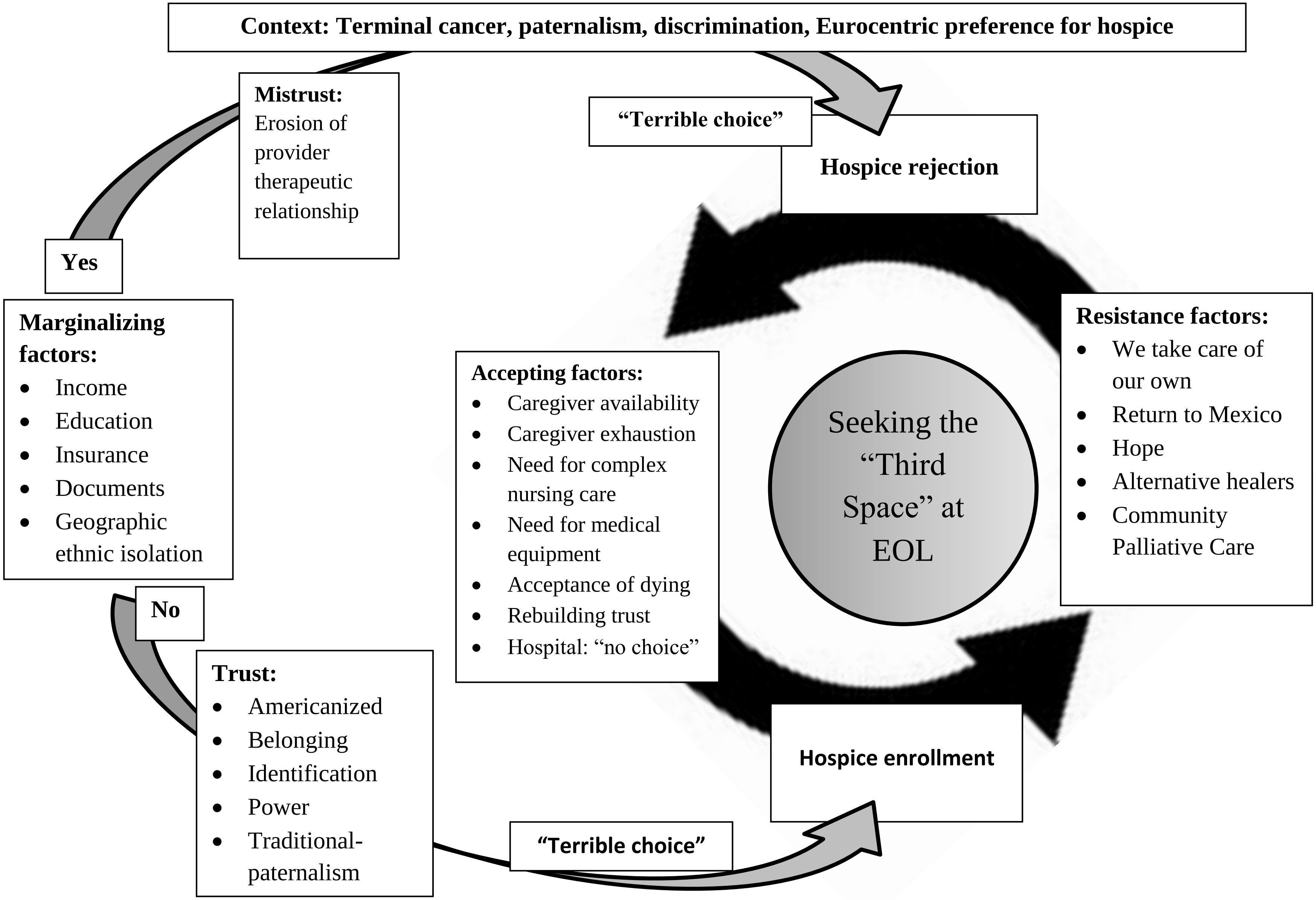

Figure 1. Marginalized U.S. Mexicans seeking the "Third Space" at EOL around hospice decision-making.

Mistrust-related resistance factors. The dissertation findings describe mistrust-related resistance factors among marginalized U.S. Mexicans. These factors allow U.S. Mexicans who mistrust the healthcare system to resist hospice enrollment. Identified factors include practicing "We take care of our own," returning to Mexico for healthcare, seeking alternative healers, and relying on community palliative care.

"We take care of our own." "We take care of our own" is an oft-cited Mexican figure of speech encountered in this study. Such family caregiving is explored in studies reviewed in Chapter 3. However, in those works, cultural themes around "we take care of our own" are given precedence by the researchers rather than the theme of mistrust. Many study designs, findings, or discussions imply a preponderance of family caregiving (Adams et al., 2006; Carrion, 2010; Carrion et al., 2012; Colon, 2012; Del Gaudio et al., 2013; Duffy et al., 2006; Gelfand et al., 2001; Gutheil & Heyman, 2006; Jonnalagadda et al., 2012; Lackan et al., 2004; Selsky et al., 2012) that stems from cultural preferences. Such views are supported by considerable literature describing cultural characteristics of Mexicans, such as the importance of family (*familismo*), respect (*respeto*), and personal warmth (*personalismo*; Carteret, 2011; Del Río, 2010; Juckett, 2013; Talamantes, 2000; Tellez-Giron, 2007). Mistrust is never considered as a rationale for preferring family caregiving in the *hospice* literature, even though there is evidence of Hispanics mistrusting strangers in their home in the *home health* literature (Crist, Garcia-Smith, & Phillips, 2006). Instead of exploring alternative reasons for preferring family caregiving, researchers attribute family caregiving to *familismo* and the Mexican *cultural* preference for family caregiving. Ignoring discriminatory causes and attributing behavior to "other" cultural characteristics is an example of Eurocentrism on the part of researchers.

In contrast, dissertation study findings offer considerable evidence for mistrust of the Eurocentric healthcare system—born of discriminatory experiences—as the rationale for family caregiving. The flexibility of critical grounded theory and the sensitization to discriminatory forces offered by the postcolonial framework allow exploration of what “we take care of our own” means to participants. On its surface, it appears cultural; but upon further inquiry, there is explicit rejection of members of the mostly White, non-Spanish-speaking, hospice health care workforce entering their homes. The clinical implications of this finding are that healthcare providers should not only examine ways in which their behavior furthers mistrust; they should also consider validating that mistrust by empathetically and overtly acknowledging its existence due to discriminatory and racist social practices. Although, anecdotally, many healthcare providers have expressed to the contrary, U.S. Mexican families do not have limitless family members to provide care at EOL. Further, they are negatively affected by the financial and emotional tolls of caregiver burden at EOL. If mistrust were mitigated, then these families may be more willing to accept hospice help and reap the oft-cited benefits of hospice care.

Returning to Mexico. For many U.S. Mexicans in this study, returning home to Mexico at EOL, sometimes for treatment, was seriously considered. Only two previous studies mention returning to Mexico, one in the discussion to make sense of their statistical results (Adams et al., 2006) and another in a survey response to a hypothetical terminal cancer scenario (Selsky et al., 2012). Neither study explores the rationale behind the desire to return home. It would be a logical assumption to conclude that U.S. Mexicans want to return home to be with family. However, in this study, the desire to return to Mexico is related to the perception that U.S. Mexicans with terminal cancer are not being offered available treatments, or their health providers are not advocating for them. Similar to what is learned about the practice of “we take care of our own," understanding the rationale behind the desire to return home offers great insight into motivations behind healthcare-related behaviors. The decision to return home to Mexico to seek curative cancer therapy may be the boldest condemnation and rejection of the Eurocentric healthcare system and sequela of colonialism by U.S. Mexicans. From a clinical perspective, understanding that the desire to return to Mexico is oftentimes a reflection of mistrust in the diagnosis or the parity of care would signal to healthcare providers that they may have failed in establishing a trustworthy therapeutic relationship.

Alternative healers. Alternative healing is explored in one quantitative study at a Hispanic community event (Colon, 2012) and is known to me as treatment that might be considered when facing any healthcare questions. In this study, there is strong evidence of the use of alterative folk healers, particularly herbalists. Not all participants report using alternative healers; however, their use is found across socioeconomic and documentation status. For participants, use of folk healers is a clear rejection of the healthcare system they do not trust. Just as the practices of "we take care of our own" and returning to Mexico are found in this study to have roots in mistrust and not just in culture, study participants who rely on folk healers do so out of mistrust of the healthcare system or because of previous discriminatory experiences in the healthcare system. The implications of the significance of using alternative healers in the clinical setting suggest that, rather than dismissing the seeking of alternative healers as cultural preferences, healthcare providers should examine the underlying motivations behind this healthcare behavior. Understanding motivations is particularly important when U.S. Mexican patients are facing terminal cancer and may greatly jeopardize their survival by postponing chemotherapy, surgery, or radiation. Like returning home to Mexico, seeking alternative healers should not be dismissed as a cultural preference and, instead, should trigger concern that the healthcare provider has failed to establish a trusting therapeutic relationship. Therapeutic dialogue should not focus on the lack of efficacy of herbs so much as on validating mistrust and acknowledging the underlying discrimination that led to mistrust.

Community palliative care. The importance of community palliative care is a significant finding in this study. Community palliative care offers an alternative to hospice that is culturally compatible and, more importantly, allows U.S. Mexicans to delay the uncomfortable decisions to relinquish curative therapy and permit Whites into their homes. Palliative care has been growing as a movement in the U.S., particularly in the hospital setting. Many have not heard of palliative care provided in the community, and it has not received as much support at the local and national levels. Payment structures are such that community palliative care does not reward its provider with cost savings, whereas, hospital palliative care saves hospitals money. However, community palliative care saves the healthcare *system* money, and so national policies should reward its use with generous reimbursement practices and limited bureaucratic hurdles. For marginalized U.S. Mexicans whose healthcare behaviors are influenced by mistrust, community palliative care approaches the embodiment of Bhabha’s “Third Space” in that families maintain control over decision-making and caregiving, and yet they also maintain proximity to the Eurocentric healthcare system, if needed.

Hope. A final form of hospice resistance is found in the prevalence of hope in coping mechanisms and belief systems. Hope is a form of resiliency that sometimes develops in the context of marginalization (Hall, 1999; Vasas, 2005). Where mistrust permeates healthcare decisions to resist hospice, hope permeates the hospice resistance strategies and fuels them. This is a complex topic, and it is not strongly developed in the dissertation due to time and financial constraints of the research study. However, hope manifests in many participants’ descriptions of

U.S. Mexicans at EOL. One frequent statement is “*Si Dios quiere*” (If God is willing). Another way of stating hope more directly combines spiritual faith with hope: “*Ni lo quiera Dios*” (Hopefully, God doesn’t want it). Stories about marginalized participants include references to this generic prayer which also reflects cautious optimism rooted in a power beyond their reach. A third example more explicitly references the importance of hope. A participant refers to the pervasive belief that “L*a esperanza se muere al ultimo*” (Hope is the last to die). One participant who advocates strongly for community palliative care provided by ethnically concordant workers feverishly explains that hope metamorphoses in the end to a hope to die a good death, at last safe from Eurocentric forces and Whites. The reliance on hope, and these expressions that turned their fate over to God, are also characterized as “waiting for a miracle.” Anglo participants who are culturally discordant misunderstand “waiting on a miracle” as unreasonable reliance on religious faith in the face of a terminal diagnosis. The palliative care research literature acknowledges this tension between a faith-based belief in a miracle versus the provider’s statement of terminal prognosis (Widera, Rosenfeld, Fromme, Sulmasy, & Arnold, 2011). However, Hispanic participants and one ethnically concordant Anglo community health worker understand that this emphasis on hope and miracles does not reflect religious beliefs and that the two are distinguishable. The former is a habit of thinking or coping—to maintain resilience—whereas the latter is doctrine from their church. Religion, in fact, is consistently rejected as a barrier to hospice enrollment by U.S. Mexicans. When asked about the importance of religion in hospice decision-making, U.S. Mexican participants are oftentimes perplexed by the relevance of the question. The flexibility inherent in critical grounded theory fosters the emergence of this distinction in spite of Hispanic hospice research literature that is overwhelmingly biased in favor of the importance of religion to Hispanics when engaged in EOL decision-making.

In summary, the substantive grounded theory developed from dissertation research findings illustrates how mistrustful U.S. Mexicans, influenced by marginalization, demonstrate behaviors aimed at hospice resistance. An important conclusion in this study is that healthcare providers should abandon the accepted practices of “Othering” and focusing on cultural differences. Instead, mitigation of hospice avoidance by healthcare providers should prioritize validation of feelings of mistrust and acknowledgment of systematic social discrimination. The next section examines hospice accepting factors in marginalized and mistrustful U.S. Mexicans.

Hospice-accepting factors. Hospice-accepting factors emerge in the dissertation study as influences that promote hospice enrollment in marginalized and mistrustful U.S. Mexicans with terminal cancer in spite of their tendency to resist hospice enrollment. Identified hospice-accepting factors do not reflect the healthcare behaviors of all U.S. Mexicans who choose hospice. Descriptions of *non*-marginalized and *trusting* U.S. Mexicans’ hospice enrollment resemble those of Whites, based on my personal observations around hospice enrollment, since there was no specific data generated in this study about hospice enrollment in Whites. Such Americanized U.S. Mexicans choose hospice because they are comfortable with it, not because of any of the hospice-accepting factors described below, which are not described in the research literature. Accepting factors identified in the dissertation study include caregiver availability, caregiver exhaustion, need for complex nursing care, need for medical equipment, acceptance of the dying process, lack of choice given to EMTALA-admitted hospital patients, and rebuilding trust.

Caregiver availability and caregiver exhaustion. Many marginalized U.S. Mexican families discussed in this study are separated by the U.S.-Mexican border such that extended family is not available to provide care. This phenomenon is particularly evident with migrant workers who embark upon a solo journey from Mexico and with few ties to the community in the U.S. For migrant workers, options for healthcare at EOL are frequently complicated by poverty, documentation status, and lack of healthcare insurance. An example is a young Mexican male who, without sick pay, became homeless and lived out of his car after complications from his cancer prevented him from working. Without family to care for him, the palliative care provider was able to negotiate charity care at an in-patient hospice. However, the young man seemed to be confused by the cessation of life-sustaining blood transfusions at the hospice, suggesting he may not fully understand the consequences of hospice enrollment on his healthcare treatment. Nonetheless, with no one to care for him and no other healthcare alternatives except hospitalization, the in-patient hospice was one of his few options.

In situations in which family is available to provide EOL caregiving, this responsibility oftentimes fells on the shoulders of one person—usually a woman—who eventually becomes exhausted and unable to provide care. Other family members were unavailable to help for many reasons. Sometimes, help was limited because the extended family remained in Mexico. In other situations, the extended family included children who did not choose to contribute to caregiving efforts. In addition, caregiving assistance was limited by financial pressures on family members to continue working jobs that did not offer family medical leave or sick time. In the case of caregiver exhaustion, the designated caregiver at home and providing EOL care to a terminal cancer patient eventually becames too exhausted, and then the family accepted hospice even though it had not previously been welcomed. One participant told the story of a man with terminal cancer who enrolled in inpatient hospice after recognizing the toll his EOL care was having on his wife. The first-generation children, who were not willing to help with the EOL care, were agitated by the decision and complained vociferously. However, support from an ethnically concordant community palliative care provider allowed the patient’s wishes to be honored. Another situation involving caregiver exhaustion described a mother and son remaining in the U.S. illegally. The mother steadfastly resisted enrolling her son in hospice over the course of a year, in one instance refusing to allow hospice workers into the home to deliver medical equipment. Eventually, her health deteriorated to the point that she had to be hospitalized, leaving no one at home to care for the boy, because his father and siblings all worked. Without the mother to provide care and resist against hospice, the young patient was enrolled in hospice.

In summary, whether caregiving was initially unavailable or became unavailable because of caregiver exhaustion, the unavailability of caregiving can lead to hospice enrollment in marginalized U.S. Mexicans who have previously resisted enrollment. In marginalized U.S. Mexicans—frequently poor and uninsured—paid caregiving is not an option, as it is among many Whites. Even among more Americanized U.S. Mexicans receiving hospice through the Medicare Hospice Benefit, the research literature supports a preponderance of extended family caregiving in Hispanics versus paid caregiving in Whites (Adams et al., 2005). The inability to hire paid caregivers leaves exhausted or isolated U.S. Mexicans with little option but to accept hospice services. Enrollment, however, sometimes represents defeat and fosters family discord. The Eurocentric views expressed by White healthcare providers in this study overwhelmingly reflect hospice enrollment as a “success” and fail to appreciate the need for follow-up regarding emotional repercussions of giving up on hospice resistance. From a critical theory perspective, this research exposed the potential for inflicting harm on U.S. Mexican terminal cancer patients and their families when Eurocentric healthcare providers “succeeded” in hospice enrollment. The clinical repercussions of this study are that healthcare providers need to assess for the occurrence of such emotional turmoil, which can lead to complicated grief and other lingering emotional issues with survivors. Similarly, there was a need for investigation into what it means to receive hospice care against personal preferences because, to my knowledge, the research literature is silent on this topic.

Need for complex nursing care and need for medical equipment. In some instances, U.S. Mexicans inclined to resist hospice enrollment see that the Eurocentric healthcare system offers something that warrants overriding hospice aversion. An example of complex nursing care encountered in data collection is managing a medical device to drain fluid from the lungs as needed. A second example is a patient with advanced stomach cancer and constant emesis who needs maintenance of a nasogastric tube. According to the participant, the family members could “see for themselves” that they were going to need help, and the Eurocentric healthcare team was there to provide it. The provision of medical equipment also contributes to overriding hospice aversion. Equipment such as hospital beds, walkers, and bedside commodes are routinely provided as part of hospice care. Probably the most commonly cited medical equipment in this study was the “free” home-delivery of a hospital bed.

Marginalized U.S. Mexicans accepted this medical equipment or complex nursing care in spite of their hospice aversion when they understood it was needed. However, healthcare providers whose agendas include persuading U.S. Mexicans with terminal cancer to enroll in hospice oftentimes cited the availability of complex nursing care and sophisticated medical equipment as enticements before the family sees the need. If complex nursing care or medical equipment are not overtly needed from the perspective of the U.S. Mexican decision maker, then “we take care of our own” prevails. However, some patients can experience a time in which healthcare needs become overwhelming, at which point complex nursing care or medical equipment was received in the context of reluctant hospice enrollment. In such cases, maintaining a connection to the Eurocentric healthcare system, even while resisting hospice, was important to expedite hospice enrollment, once it was desired. Community palliative care represents such a connection, further underscoring its important role in marginalized communities and the need to support it at the level of national healthcare policy.

Acceptance of the dying process. As discussed in the hospice resistance sections, some U.S. Mexicans choose to return to Mexico or seek alternative healers. Such hospice resistance occurs because those marginalized U.S. Mexicans do not trust healthcare providers—who represented discriminatory and oppressive forces—to speak the truth about their cancer diagnosis or to advocate for them. In contrast, when terminally ill cancer patients and family members could see for themselves that a patient was dying, they were more willing to accept hospice. As one community health worker described, patients' and families' self-perceptions of health were too optimistic at the time when healthcare providers attempted to have hospice discussions, which she perceived as prematurely timed. Attempts at such conversations were met with incredulity on the part of patients, who did not see themselves as dying, and their families. Among such patients and families, the attitude was that if they were still walking, breathing, and talking, then they were nowhere near death. An abstract discussion about the inevitability of death with the healthcare provider was not welcomed and strongly rejected, particularly when they did not trust the healthcare provider to provide accurate information or advocate for them. However, once they could see for themselves that death was imminent, they were receptive to hospice. A community health worker deeply involved with palliative care and hospice in her community articulated the need to initiate hospice discussions after the patient and family have accepted the dying process. She lamented that the sequence of events is not initial enrollment in community palliative care, followed by hospice enrollment when the patient and family can see for themselves the cancer patient is dying. Such a sequence would more accurately accommodate the context of pervasive discrimination and mistrust in the healthcare system. Once patients and families could see for themselves that a patient was dying, then mistrust in the healthcare provider and lack of a therapeutic relationship mattered less. In contrast, the current dominant EOL healthcare culture is eager to promote hospice enrollment as early as possible in the terminal illness trajectory, reflecting the Eurocentric roots of hospice.

Lack of choice given to EMTALA-admitted hospital patients. A hospice-accepting factor that borders on coercion into hospice turns on hospital admission under the Emergency Medical Treatment and Labor Act (EMTALA; U.S. Centers for Medicare and Medicaid Services, 2012). Prohibiting hospitals from denying admission based on ability to pay or citizenship, EMTALA does not offer an exit plan from the same hospital admission. That is, healthcare coverage is provided as long as patients are in the hospital but ceases when patients are discharged, creating pressure to find creative solutions to ensure continuity of care. At the same time, hospitals experience financial pressure to ensure patient throughput and hospital bed availability for others. To limit hospital costs, some discharge planners may opt for repatriation to Mexico, which has been ethically questioned (Young & Lehmann, 2014). To accomplish discharge, some may seek local community healthcare resources such as hospice (Jaramillo & Hui, 2016). In this manner, structural violence (Farmer et al., 2006) is inflicted on marginalized U.S. Mexicans with terminal cancer and their families. Illustrating the power imbalances and oppression inherent in the medical system as it currently exists, from the Eurocentric healthcare perspective, obtaining charity hospice for such persons is a gift. However, marginalized and mistrustful U.S. Mexicans in this study did not enthusiastically embrace the requirement to give up curative therapy for hospice enrollment, nor did they welcome into their homes healthcare providers who may have triggered the first steps toward deportation for themselves or other family members. Nonetheless, when options were presented in such a way that patients and families believed they have no choice, then they reluctantly accepted hospice care. All interviewed healthcare providers familiar with the hospital setting and EMTALA-admitted patients acknowledged there iwa pressure to enroll such persons in hospice because it was the only way to successfully discharge them from the hospital. In this manner, a lack of choice in the eyes of EMTALA-admitted patients becomes a hospice-accepting factor in marginalized U.S. Mexicans who previously resisted hospice. There are ethical implications to this practice, particularly if it was as prevalent as described by study participants. It begs for institutional and national oversight to ensure that vulnerable and terminally ill patients are not receiving hospice care when they would rather, simply, go home with no healthcare support at all. The critical grounded theory methodology employed in this dissertation study permitted this uncomfortable topic to manifest. The observations and complaints from a particular community health worker deeply embedded in this population and in the provision of ethnically concordant palliative care were incorporated into the interview guide and interviews with healthcare providers, who confirmed its practice.

Rebuilding trust. A final hospice-accepting factor involves rebuilding trust in an effort to mitigate mistrust. Several healthcare providers, who are distinguishable from marginalized U.S. Mexicans by virtue of ethnicity, education, income, or citizenship spoke about the importance of gaining trust. Some did so by demonstrating respect and reliability, which is similar to establishing rapport and being respectful, described in the research literature (Carteret, 2011; Del Río, 2010; Juckett, 2013; Talamantes, 2000; Tellez-Giron, 2007). Others directly acknowledged the existence of mistreatment and discrimination giving rise to mistrust and then used highly skilled conversational strategies to distinguish the current situation. The difference between these two approaches is yet another reflection of the difference between an “othering” approach derived from Eurocentric research and a “situated” approach derived from an effort to fully understand the perspective, or standpoint, of the U.S. Mexican.

Summary of Clinical and Policy Implications

The results of this study have several policy and clinical implications that will be summarized here.

The need to focus on mistrust rather than cultural differences. First, study findings strongly suggest that limiting the focus of improving EOL and hospice care for U.S. Mexicans to cultural accommodation ignores the more relevant issue of mistrust in the U.S. Mexican population. There is no need for cultural accommodation among Americanized U.S. Mexicans—called Mexican Americans by many in this study—who are eager to enroll in hospice despite their rich cultural history. It is the marginalized U.S. Mexicans who do not want to enroll in hospice, and they reject hospice because they mistrust the healthcare system. Consequently, comparative cultural studies and related institutional modules on culturally competent care may simply be furthering stereotypes and failing to paint a comprehensive picture of how to provide supportive EOL and hospice care to U.S. Mexicans. The findings from this study strongly suggest a need to incorporate training around trust-building and communications skills, including acknowledging and validating societal mistreatment of this group and their right to feel mistrust. As well, training should include awareness of the impact of presenting suspicious Medicare paperwork to U.S. Mexicans who cannot read and write in either English or Spanish. Such training should be provided to all members of the healthcare team with the understanding that these skills are transferrable to other populations with high levels of institutional mistrust, such as African Americans. It is imperative that this training is characterized as mitigating harm imposed on these populations by dominant, Eurocentric powers. This added contextual feature will begin the long process of compensating U.S. Mexicans for prior wrongs, consistent with social justice. It will reframe the problem as societal and not the fault of U.S. Mexicans. It will begin to level the power differential for affected U.S. Mexicans in the healthcare setting.

The need to develop the role of interpreter-as-advocate. The second implication of this study is that there is a need to develop the role of interpreter-as-advocate. Verbatim translations between English and Spanish are not levelling the power dynamic between marginalized U.S. Mexicans and healthcare providers or earning trust. The idea of interpreter-as-advocate is not new (Butow et al., 2011; Hsieh et al., 2013). From the perspectives of Hispanic patients, families, interpreters, and community health workers, the results of this study strongly suggest that a “good” interpreter is one who advocates for ethnically concordant patients and families to ensure accurate and culturally appropriate communication. A “good” interpreter ensures that not just words, but concepts, are being communicated and that patients and families understand the consequences of those concepts. A “good” interpreter also anticipates conversational missteps on the part of healthcare professionals and is quick to mitigate any harm brought to the patient and family as a consequence of those missteps. Metamorphosing the role of interpreter to include professional advocacy duties needs to occur at multiple levels, including within professional interpreter organizations as well as healthcare institutions. Because it directly impacts the power dynamic between patient and healthcare provider, some healthcare providers are liable to resist relinquishing full transparency and to feel uncomfortable with losing control of the conversation. However, empowering marginalized U.S. Mexicans in the healthcare encounter is critical to providing patient- and family-centered EOL and hospice care.

The need to reach a consensus on translation of hospice into Spanish. A third important practical implication of this study—and related to interpreter-as-advocate—is that there is a need to come to a consensus on the best way to handle the impossibility of translating the American hospice concept directly into Spanish. If they have heard of it before, the Spanish word *hospicio* has tremendous negative connotations for some U.S. Mexicans. In Mexico, a *hospicio* is a place people are sent who are indigent or have disabilities and no family to assume their care. In effect, going to a *hospicio* amounts to abandonment by family, which, by and large, is anathema in collectivist cultures. These *hospicios* were created by the Catholic church (United Nations Educational, 2018) and can be equated with institutionalization. In Mexico, although rare, there are American-style hospices, and even they avoid the Spanish word *hospicio*. Mexican hospices simply use the English word *hospice* in their business names or use the direct translation of “palliative care” ("Hospice Cristina," 2018; "Hospice Vida Plena," 2018; "Mitigare—San Miguel Hospice," 2018). In this study, the spectrum of strategies to translate hospice ranged from simple direct translation into *hospicio* to using only the English word *hospice* with an explanation that described American hospice. Those familiar with scenarios using the word *hospicio* described considerable backlash in some instances. One sensitive interpreter described initiating pre-planning with healthcare providers to allow a sidebar discussion to define *hospicio* and possibly mitigate the shock by distinguishing it from the American concept. Even without consensus on how to translate the word *hospice*, healthcare providers can begin assessing patients’ and families’ knowledge and interpretation of the word *hospicio* and build the conversation from that point.

The need to grow community palliative care in marginalized communities. A fourth and important policy implication from this study is the importance of growing community palliative care in the marginalized U.S. Mexican population. There is a misconception among Whites that there is a potentially perfect match between hospice, in which family provides EOL care, and the Mexican tradition of “we take care of our own.” However, the imposition of White healthcare staff inside the home and the need to relinquish curative therapy to enroll in hospice derail any potential parallels. Community palliative care is enthusiastically recommended by multiple participants as an intermediate step between a terminal diagnosis/prognosis and possible hospice enrollment. Enrolling in community palliative care avoids the mistrust around cessation of curative therapy and allows more flexibility in whether healthcare visits occur in the clinic or the home. Enrolling in community palliative care also avoids the awkward translation of the word *hospice* and provides considerable time for trust-building in the event it becomes necessary to broach the subject of hospice. The role of community health workers in this setting cannot be overemphasized. As advocates, they have the knowledge to help patients and families navigate the healthcare system as well as nursing and medical crises.

The need to protect EMTALA-admitted terminally ill patients from coercion to discharge from hospital into hospice. Finally, this study begins to expose the institutionalized practice of steering terminally ill U.S. Mexicans who have been admitted to the hospital under EMTALA toward hospice to accomplish hospital discharge. If this is a pervasive practice, then it should be further investigated, documented, and ethically monitored. Other studies have discussed the practice of repatriation (Young & Lehmann, 2014), but none have detailed the plight of EMTALA-admitted terminally ill U.S. Mexicans. It is imperative that policy-makers at the national level develop an ethical *exit* from the hospital. Two solutions may be found in supporting community palliative care and funding insurance to pay for that service. In addition, ethics consultations should be triggered in a protocol designed to protect terminally ill persons admitted under EMTALA. Such oversight should be monitored by governing bodies such as the Centers for Medicare and Medicaid Services or The Joint Commission to counter the capitalistic pressure to achieve hospital throughput and available hospital beds.

Strengths and Limitations

A strength of this dissertation study as a whole is that it pairs research on the healthcare behaviors of vulnerable persons with a research methodology that mitigates the pitfalls encountered by previous Eurocentric research efforts. This study privileges the voices of vulnerable persons and allows for flexibility in data acquisition as the study evolves. Another strength is that my committee offers a strong background in critical methodology research. In an interesting example of the importance of epistemology, the progression of the dissertation manuscripts themselves mirror my personal process of conscientization, illustrating another overall strength of the dissertation. Unfortunately, a strong weakness of this study is that access to terminally ill marginalized U.S. Mexicans in the original study design did not coalesce. In addition, although I benefitted from a community advisory board, I did not have a person who identified as U.S. Mexican on my dissertation committee.

Future Research

Future research should grow from the primary findings and policy implications of this study. The need to justify national spending on community palliative care can be demonstrated through community based participatory research illustrating its value in this population. Investigating the plight of EMTALA-admitted terminally ill patients should be a priority; however, it can only be accomplished with cooperation from hospitals and their palliative care services.

References

See Cumulative References.

Cumulative References

"Fields of Tears." (2010). Migrant Farm Workers: Fields of Tears. Retrieved from http://www.economist.com/node/17722932.

Acuna, R. (2015). *Occupied America: A History of Chicanos* (8th ed.). New Jersey: Pearson.

Adams, C., Bader, J., Horn, K., & Hernandez, I. (2008). The association among primary caregiver and hospice services for Mexican Americans and Anglos. *Journal of Hospice & Palliative Nursing, 10*(1), 17–25.

Adams, C., Horn, & Bader, J. (2005). A comparison of utilization of hospice services between Hispanics and Whites. *Journal of Hospice & Palliative Nursing, 7*(6), 328–336.

Adams, C., Horn, K., & Bader, J. (2006). Hispanic access to hospice services in a predominantly Hispanic community. *American Journal of Hospice & Palliative Medicine, 23*(1), 9–16.

Adams, C., Horn, K., & Bader, J. (2007). Hispanics' experiences in the health system prior to hospice admission. *Journal of Cultural Diversity, 14*(4), 155–163.

Aday, L., & Andersen, R. (1974). A framework for the study of access to medical care. *Health Services Research, 9*(3), 208–220.

Agency for Healthcare Research and Quality. (2004). *2004 National Healthcare Disparities Report*. (publication No. 05-0014). Rockville, MD: United States Department of Health and Human Services.

Ahalt, C., Walter, L., Yourman, L., Eng, C., Pérez-Stable, E., & Smith, A. (2012). "Knowing is better": Preferences of diverse older adults for discussing prognosis. *Journal of General Internal Medicine, 27*(5), 568-575. doi:10.1007/s11606-011-1933-0

Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes, 50*(2), 179–211. doi:10.1016/0749-5978(91)90020-T

Ajzen, I. (2011). The theory of planned behaviour: Reactions and reflections. *Psychology and Health, 26*(9), 1113–1127. doi:10.1080/08870446.2011.613995

Albritton, T., & Wagner, P. (2002). Linking cultural competency and community service: a partnership between students, faculty, and the community. *Academic medicine : journal of the Association of American Medical Colleges, 77*(7), 738–739.

Alsina, A., Torres, E., Antunea, I., Gonzalez, H., Bowers, V., Huang, J., . . . Potter, T. (2009). Outcome of liver transplantation in a Hispanic population: 100 liver transplants in Puerto Ricans. *Puerto Rico Health Sciences Journal, 28*(4), 301–306.

American Cancer Society. (2015). Cancer Facts and Figures for Hispanics/Latinos 2015–2017. Retrieved from Atlanta, GA: http://www.cancer.org/acs/groups/content/@research/documents/document/acspc-046405.pdf.

American Cancer Society. (2018). Cancer Facts and Figures for Hispanics and Latinos. Retrieved from https://www.cancer.org/research/cancer-facts-statistics/hispanics-latinos-facts-figures.html.

American Heart Association. (2016). Get With the Guidelines Stroke Overview. Retrieved from http://www.heart.org/HEARTORG/Professional/GetWithTheGuidelines/GetWithTheGuidelines-Stroke/Get-With-The-Guidelines-Stroke-Overview_UCM_308021_Article.jsp#.WDPOcvkrLIU.

Andersen, R., & Newman, J. (2005). Societal and individual determinants of medical care utilization in the United States. *Milbank Quarterly, 83*(4).

Andersen, R. (1995). Revisiting the behavioral model and access to medical care: does it matter? *Journal of Health and Social Behavior, 36*(1), 1–10.

Anderson, J. (2004). Lessons from a postcolonial-feminist perspective: Suffering and a path to healing. *Nursing Inquiry, 11*(4), 238–246. doi:10.1111/j.1440-1800.2004.00231.x

Anderson, J. (2000). Gender, ‘race’, poverty, health and discourses of health reform in the context of globalization: A postcolonial feminist perspective in policy research. *Nursing Inquiry, 7*(4), 220–229.

Anderson, J., Rodney, P., Reimer-Kirkham, S., Browne, A., Khan, K., & Lynam, M. (2009). Inequities in health and healthcare viewed through the ethical lens of critical social justice: Contextual knowledge for the global priorities ahead. *Advances in Nursing Science, 32*(4), 282–294. doi:10.1097/ANS.0b013e3181bd6955

Andrews, T., Ybarra, V., & Matthews, L. (2013). For the Sake of our Children: Hispanic Immigrant and Migrant Families’ Use of Folk Healing and Biomedicine. *Medical Anthropology Quarterly, 27*(3), 385–413. doi:10.1111/maq.12048

Armstrong, K., Ravenell, K., McMurphy, S., & Putt, M. (2007). Racial/ethnic differences in physician distrust in the United States. *American Journal of Public Health, 97*(7), 1283–1289. doi:10.2105/AJPH.2005.080762

Ashcroft, B., Griffiths, G., & Tiffin, H. (2013). *Postcolonial Studies: The Key Concepts* (3rd ed.). New York: Routledge.

Ayón, C., Wagaman, M., & Philbin, S. (2018). No te dejes pisotear por nadien: Examining Latino Immigrants’ Efforts to Resist Discrimination. *Journal of Social Service Research, 44*(1), 78–95. doi:10.1080/01488376.2017.1395381

Bach, P., Guadagnoli, E., Schrag, D., Schussler, N., & Warren, J. (2002). Patient demographic and socioeconomic characteristics in the SEER–Medicare database applications and limitations. *Medical Care, 40*(8 Suppl), IV-19–25.

Bade, K., Murphy, J., & Sullivan, M. (1999). Lessons from the field—health care experiences and preferences in a Latino community. *Bioethics Forum, 15*(4), 33–42.

Bakitas, M., Lyons, K., Hegel, M., Balan, S., Brokaw, F., Seville, J., . . . Ahles, T. (2009). Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The project ENABLE II randomized controlled trial. *JAMA—Journal of the American Medical Association, 302*(7), 741–749. doi:10.1001/jama.2009.1198

Balboni, T., Vanderwerker, L., Block, S., Paulk, M., Lathan, C., Peteet, J., & Prigerson, H. (2007). Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *Journal of Clinical Oncology, 25*(5), 555–560. doi:10.1200/JCO.2006.07.9046

Barnato, A., Anthony, D., Skinner, J., Gallagher, P., & Fisher, E. (2009). Racial and Ethnic Differences in Preferences for End-of-Life Treatment. *Journal of General Internal Medicine, 24*(6), 695–701. doi:10.1007/s11606-009-0952-6

Barnato, A., Berhane, Z., Weissfeld, L., Chang, C., Linde-Zwirble, W., & Angus, D. (2006). Racial variation in end-of-life intensive care use: A race or hospital effect? *Health Services Research, 41*(6), 2219–2237. doi:10.1111/j.1475-6773.2006.00598.x

Beauchamp, T., & Childress, J. (2013). *Principles of Biomedical Ethics* (7th ed.). New York: Oxford University Press.

Beecher, H. (1966). Ethics and clinical research. *New England Journal of Medicine, 274*(24), 1354–1360.

Begley, A., & Blackwood, B. (2000). Truth-telling versus hope: A dilemma in practice. *International Journal of Nursing Practice, 6*(1), 26–31. doi:10.1046/j.1440-172x.2000.00178.x

Ben, J., Cormack, D., Harris, R., & Paradies, Y. (2017). Racism and health service utilisation: A systematic review and meta-analysis. *PLoS ONE, 12*(12). doi:10.1371/journal.pone.0189900

Benzein, E., Norberg, A., & Saveman, B. (2001). The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliative Medicine, 15*(2), 117–126. doi:10.1191/026921601675617254

Bhabha, H. (1994). *The Location of Culture*. London: Routledge.

Björk, E., & Dahlberg, K. (2013). Interpreters in cross-cultural interviews: a three-way coconstruction of data. *Qualitative Health Research, 23*(2), 241–247.

Blackhall, L., Frank, G., Murphy, S., & Michel, V. (2001). Bioethics in a different tongue: The case of truth-telling. *Journal of Urban Health, 78*(1), 59–71. doi:10.1093/jurban/78.1.59

Blackhall, L., Frank, G., Murphy, S., Michel, V., Palmer, J., & Azen, S. (1999). Ethnicity and attitudes towards life sustaining technology. *Social Science and Medicine, 48*(12), 1779–1789. doi:10.1016/S0277-9536(99)00077-5

Blackhall, L., Murphy, S., Frank, G., Michel, V., & Azen, S. (1995). Ethnicity and attitudes toward patient autonomy. *Journal of the American Medical Association, 274*(10), 820–825.

Blumer, H. (1969). *Symbolic Interactionism*. Berkeley and Los Angeles CA: University of California Press.

Born, W., Greiner, K., Sylvia, E., Butler, J., & Ahluwalia, J. (2004). Knowledge, Attitudes, and Beliefs about End-of-life Care among Inner-City African Americans and Latinos. *Journal of Palliative Medicine, 7*(2), 247–256. doi:10.1089/109662104773709369

Bostean, G. (2013). Does selective migration explain the Hispanic Paradox? A comparative analysis of Mexicans in the U.S. and Mexico. *Journal of Immigrant and Minority Health, 15*(3), 624–635. doi:10.1007/s10903-012-9646-y

Boucher, N., Guadalupe, E., Lara, L., & Alejandro, M. (2014). Health Care and End-of-Life Decisions: Community Engagement with Adults in East Harlem. *Journal of Community Health*. doi:10.1007/s10900-014-9929-4

Bowers, B. (1988). Grounded theory. *NLN publications*(15–2233), 33–59.

Bowers, B., & Schatzman, L. (2009). *Dimensional Analysis* (Morse Ed.). Walnut Creek, CA: Left Coast Press, Inc.

Braun, U., Beyth, R., Ford, M., Espadas, D., & McCullough, L. (2014). Decision-making styles of seriously ill male Veterans for end-of-life care: Autonomists, Altruists, Authorizers, Absolute Trusters, and Avoiders. *Patient Education and Counseling, 94*(3), 334–341. doi:10.1016/j.pec.2013.10.013

Braun, U., McCullough, L., Beyth, R., Wray, N., Kunik, M., & Morgan, R. (2008). Racial and ethnic differences in the treatment of seriously ill patients: a comparison of African-American, Caucasian and Hispanic veterans. *Journal of the National Medical Association, 100*(9), 1041–1051.

Braveman, P. (2006) Health disparities and health equity: Concepts and measurement. *Vol. 27. Annual Review of Public Health* (pp. 167-194).

Braveman, P., & Gruskin, S. (2003). Defining equity in health. *Journal of Epidemiology and Community Health, 57*(4), 254–258. doi:10.1136/jech.57.4.254

Brown, A., & Patten, E. (2013). *Hispanics of Mexican Origin in the United States, 2011*. Retrieved from Washington, DC: http://www.pewhispanic.org/2013/06/19/hispanics-of-mexican-origin-in-the-united-states-2011/.

Brown, B. (2003). The history of advance directives. A literature review. *Journal of gerontological nursing, 29*(9), 4–14.

Bustillo, N., McGinty, H., Dahn, J., Yanez, B., Antoni, M., Kava, B., & Penedo, F. (2017). Fatalism, medical mistrust, and pretreatment health-related quality of life in ethnically diverse prostate cancer patients. *Psycho-Oncology, 26*(3), 323–329. doi:10.1002/pon.4030

Butow, P., Goldstein, D., Bell, M., Sze, M., Aldridge, L., Abdo, S., . . . Eisenbruch, M. (2011). Interpretation in consultations with immigrant patients with cancer: How accurate is it? *Journal of Clinical Oncology, 29*(20), 2801–2807. doi:10.1200/JCO.2010.34.3335

Campinha-Bacote, J. (2002). The process of cultural competence in the delivery of healthcare services: A model of care. *Journal of Transcultural Nursing, 13*(3), 181–184. doi:10.1177/10459602013003003

Caralis, P., Davis, B., Wright, K., & Marcial, E. (1993). The influence of ethnicity and race on attitudes toward advance directives, life-prolonging treatments, and euthanasia. *The Journal of clinical ethics, 4*(2), 155–165.

Carrion, I. (2010). When do Latinos use hospice services? Studying the utilization of hospice services by Hispanics/Latinos. *Social Work in Health Care, 49*(3), 197–210. doi:http://dx.doi.org/10.1080/00981380903493038

Carrion, I., Cagle, J., Van Dussen, D., Culler, K., & Hong, S. (2015). Knowledge About Hospice Care and Beliefs About Pain Management: Exploring Differences Between Hispanics and Non-Hispanics. *American Journal of Hospice and Palliative Medicine, 32*(6), 647–653. doi:10.1177/1049909114536023

Carrion, I., Park, N., & Lee, B. (2012). Hospice use among African Americans, Asians, Hispanics, and Whites: implications for practice. *American Journal of Hospice & Palliative Medicine*, *29*(2), 116–121. doi:http://dx.doi.org/10.1177/1049909111410559

Carteret, M. (2011). Cultural Values of Latino Patients and Families. *Dimensions of culture: Cross-cultural communications for healthcare professionals.* Retrieved from http://www.dimensionsofculture.com/2011/03/cultural-values-of-latino-patients-and-families/.

Casarett, D., Fishman, J., Lu, H., O'Dwyer, P., Barg, F., Naylor, M., & Asch, D. (2009). The terrible choice: Re-evaluating hospice eligibility criteria for cancer. *Journal of Clinical Oncology, 27*(6), 953–959. doi:10.1200/JCO.2008.17.8079

Centers for Disease Control and Prevention. (2015). Healthy People 2010. Retrieved from https://www.cdc.gov/nchs/healthy_people/hp2010.htm.

Centers for Disease Control and Prevention. (2017). Health of Hispanic or Latino Population, Table P-11a. Age-adjusted percent distributions (with standard errors) of type of health insurance coverage for persons under age 65 and for persons aged 65 and over, by selected characteristics: United States, 2015. Retrieved from https://www.cdc.gov/nchs/fastats/hispanic-health.htm.

Cervantes, R., Padilla, A., & Salgado de Snyder, N. (1991). The Hispanic Stress Inventory: A culturally relevant approach to psychosocial assessment. *Psychological assessment: a journal of consulting and clinical psychology, 3*(3), 438.

Charmaz, K. (2014). *Constructing Grounded Theory* (2nd ed.). Thousand Oaka, CA: Sage Publications, Inc.

Chen, X., & Fan, R. (2010). The family and harmonious medical decision making: Cherishing an appropriate confucian moral balance. *Journal of Medicine and Philosophy, 35*(5), 573–586. doi:10.1093/jmp/jhq046

Choi, H., Fernandez, A., Jeon, S., Schmidt, J., Connolly, E., Mayer, S., . . . Lee, K. (2015). Ethnic Disparities in End-of-Life Care After Subarachnoid Hemorrhage. *Neurocritical Care, 22*(3), 423–428. doi:10.1007/s12028-014-0073-x

Christakis, N., & Iwashyna, T. (2003). The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. *Social Science & Medicine, 57*(3), 465–475.

Clark, D. (2007). From margins to centre: a review of the history of palliative care in cancer. *Lancet Oncology, 8*(5), 430–438.

Colón, M. (2012). Acculturation and Attitudes of Latinos Toward Hospice. *Journal Of Social Work In End-Of-Life & Palliative Care, 8*(3), 229–248. doi:10.1080/15524256.2012.708110

Colón, M., & Lyke, J. (2003). Comparison of hospice use and demographics among European Americans, African Americans, and Latinos. *American Journal of Hospice & Palliative Medicine, 20*(3), 182–190.

Colón, M., & Lyke, J. (2015). Comparison of Hospice Use by European Americans, African Americans, and Latinos: A Follow-Up Study. *American Journal of Hospice and Palliative Medicine*, *32*(2), 205–209. doi:10.1177/1049909113511143

Connor, S., Pyenson, B., Fitch, K., Spence, C., & Iwasaki, K. (2007). Comparing hospice and nonhospice patient survival among patients who die within a three-year window. *Journal of Pain & Symptom Management, 33*(3), 238–246.

Contro, N., Davies, B., Larson, J., & Sourkes, B. (2010). Away from home: experiences of Mexican American families in pediatric palliative care. *Journal Of Social Work In End-Of-Life & Palliative Care, 6*(3–4), 185–204. doi:http://dx.doi.org/10.1080/15524256.2010.529020

Cooper, Z., Rivara, F., Wang, J., MacKenzie, E., & Jurkovich, G. (2012). Racial disparities in intensity of care at the end-of-life: are trauma patients the same as the rest? *Journal of Health Care for the Poor & Underserved, 23*(2), 857–874. doi:http://dx.doi.org/10.1353/hpu.2012.0064

Corbin, J., & Strauss, A. (2015). *Basics of Qualitative Research*. Los Angeles CA: Sage Publications, Inc.

Cordova, T. (1994). Roots and Resistance: The Emergent Writings of Twenty Years of Chicana Feminist Struggle. In F. Padilla (Ed.), *Handbook of Hispanic Cultures in the United States: Sociology* (pp. 175–202). Houston TX: Arte Publico Press, University of Houston.

Cort, M. (2004). Cultural Mistrust and Use of Hospice Care: Challenges and Remedies. *Journal of Palliative Medicine, 7*(1), 63–71. doi:10.1089/109662104322737269

Costas-Muniz, R., Sen, R., Leng, J., Aragones, A., Ramirez, J., & Gany, F. (2013). Cancer stage knowledge and desire for information: mismatch in Latino cancer patients? *Journal of Cancer Education, 28*(3), 458–465. doi:http://dx.doi.org/10.1007/s13187-013-0487-8

Creswell, J. (2013). *Qualitative Inquiry and Reseach Design: Choosing Among Five Approaches* (Third ed.). Los Angeles, CA: Sage Publications, Inc.

Crist, J., Garcia-Smith, D., & Phillips, L. (2006). Accommodating the stranger en casa: how Mexican American elders and caregivers decide to use formal care. *Research & Theory for Nursing Practice, 20*(2), 109–126.

Cruz, R. (2011). *Oregon Migrant and Seasonal Farmworker Health Status* Retrieved from State of Oregon: http://www.oregon.gov/Hispanic/pdfs/cruz_litreview_msfw_updated.pdf.

Del Gaudio, F., Hichenberg, S., Eisenberg, M., Kerr, E., Zaider, T., & Kissane, D. (2013). Latino values in the context of palliative care: illustrative cases from the Family Focused Grief Therapy trial. *American Journal of Hospice & Palliative Medicine, 30*(3), 271–278. doi:http://dx.doi.org/10.1177/1049909112448926

Del Río, N. (2010). The influence of latino ethnocultural factors on decision making at the end of life: Withholding and withdrawing artificial nutrition and hydration. *Journal of Social Work in End-of-Life and Palliative Care, 6*(3), 125–149. doi:10.1080/15524256.2010.529009

Duffy, S., Jackson, F., Schim, S., Ronis, D., & Fowler, K. (2006). Racial/ethnic preferences, sex preferences, and perceived discrimination related to end-of-life care. *Journal of the American Geriatrics Society, 54*(1), 150–157. doi:10.1111/j.1532-5415.2005.00526.x

El-Jawahri, A., Greer, J., & Temel, J. (2011). Does palliative care improve outcomes for patients with incurable illness? A review of the evidence. *Journal of Supportive Oncology, 9*(3), 87–94. doi:10.1016/j.suponc.2011.03.003

Elliott, A. (2001). Health care ethics: Cultural relativity of autonomy. *Journal of Transcultural Nursing, 12*(4), 326–330.

Ely, M. (1991). *Doing qualitative research: Circles within circles* (Vol. 3): Psychology Press.

Emergency Medical Treatment and Active Labor Act, 42 U.S.C. §1395 (1986).

Enguidanos, S., Vesper, E., & Goldstein, R. (2013). Ethnic differences in hospice enrollment following inpatient palliative care consultation. *Journal of Hospital Medicine, 8*(10), 598–600. doi:10.1002/jhm.2078

Enguidanos, S., Yip, J., & Wilber, K. (2005). Ethnic variation in site of death of older adults dually eligible for Medicaid and Medicare. *Journal of the American Geriatrics Society, 53*(8), 1411–1416.

Ennis, S., Rios-Vargas, M., & Albert, N. (2011). The Hispanic Population 2010, U.S. Census Bureau. Retrieved from http://www.census.gov/prod/cen2010/briefs/c2010br-04.pdf.

Espino, D., MacIas, R., Wood, R., Becho, J., Talamantes, M., Finley, M., . . . Martinez, R. (2010). Physician-assisted suicide attitudes of older Mexican-American and non-hispanic white adults: Does ethnicity make a difference? *Journal of the American Geriatrics Society, 58*(7), 1370–1375. doi:10.1111/j.1532-5415.2010.02910.x

Fan, R. (2011). The Confucian bioethics of surrogate decision making: Its communitarian roots. *Theoretical Medicine and Bioethics, 32*(5), 301–313. doi:10.1007/s11017-011-9191-z

Fanon, F. (2008). *Black Skin, White Masks* (R. Philcox, Trans.). New York: Grove Press.

Farmer, P. (2004). *Pathologies of power: Health, human rights, and the new war on the poor* (Vol. 4): Univ of California Press.

Farmer, P., Nizeye, B., Stulac, S., & Keshavjee, S. (2006). Structural violence and clinical medicine. *PLoS Medicine, 3*(10), 1686–1691. doi:10.1371/journal.pmed.0030449

Field, M., & Cassel, C. (1997). *Approaching death: improving care at the end of life*: National Academies Press.

Finley, M., Becho, J., Macias, R., Wood, R., Hernandez, A., & Espino, D. (2012). Attitudes regarding the use of ventilator support given a supposed terminal condition among community-dwelling Mexican American and non-Hispanic white older adults: a pilot study. *Thescientificworldjournal, 2012*, 852564. doi:http://dx.doi.org/10.1100/2012/852564

Finley, M., Macias, R., Becho, J., Wood, R., Hernandez, A., & Espino, D. (2013). Correlates associated with the desire for PEG tube placement at the end of life among community-dwelling older Mexican Americans: A pilot study. *Aging Clinical and Experimental Research, 25*(1), 69–74. doi:10.1007/s40520-013-0005-1

Fischer, S., Cervantes, L., Fink, R., & Kutner, J. (2015). Apoyo con Cariño: A pilot randomized controlled trial of a patient navigator intervention to improve palliative care outcomes for latinos with serious illness. *Journal of Pain and Symptom Management, 49*(4), 657–665. doi:10.1016/j.jpainsymman.2014.08.011

Fischer, S., Kutner, J., Sauaia, A., & Kramer, A. (2007). Lack of ethnic differences in end-of-life care in the veterans health administration. *American Journal of Hospice and Palliative Medicine, 24*(4), 277–283. doi:10.1177/1049909107302295

Ford, C., & Harawa, N. (2010). A new conceptualization of ethnicity for social epidemiologic and health equity research. *Social Science & Medicine, 71*(2), 251–258.

Fosler, L., Staffileno, B., Fogg, L., & O'Mahony, S. (2015). Cultural differences in discussion of do-not-resuscitate status and hospice. *Journal of Hospice and Palliative Nursing, 17*(2), 128–132. doi:10.1097/NJH.0000000000000135

Fowler, M. (2008). *Guide to the code of ethics for nurses: Interpretation and application*. Silver Spring, MD: American Nurses Association.

Frahm, K., Brown, L., & Hyer, K. (2012). Racial Disparities in End-of-Life Planning and Services for Deceased Nursing Home Residents. *Journal of the American Medical Directors Association, 13*(9), 819.e817-819.e811. doi:10.1016/j.jamda.2012.07.021

Frank, G., Blackhall, L., Murphy, S., Michel, V., Azen, S., Preloran, H., & Browner, C. (2002). Ambiguity and hope: disclosure preferences of less acculturated elderly Mexican Americans concerning terminal cancer—a case story. *Cambridge Quarterly of Healthcare Ethics, 11*(2), 117–126.

Frankl, V. (1959/2006). *Man's Search for Meaning* (I. Lasch, H. Kushner, & W. Winslade, Trans.). Boston, MA: Beacon Press.

Franzini, L., Ribble, J., & Keddie, A. (2001). Understanding the Hispanic paradox. *Ethnicity & Disease, 11*(3), 496.

Freedman, B. (1993). Offering truth: One ethical approach to the uninformed cancer patient. *Archives of Internal Medicine, 153*(5), 572–576. doi:10.1001/archinte.153.5.572

Freeman, H. (1991). Race, poverty, and cancer. *Journal of the National Cancer Institute, 83*(8), 526–527. doi:10.1093/jnci/83.8.526

Freeman, H. (2006). Patient navigation: a community centered approach to reducing cancer mortality. *Journal of Cancer Education, 21*(1 Suppl), S11-14.

Freeman, R., Gwadz, M., Silverman, E., Kutnick, A., Leonard, N., Ritchie, A., . . . Martinez, B. (2017). Critical race theory as a tool for understanding poor engagement along the HIV care continuum among African American/Black and Hispanic persons living with HIV in the United States: a qualitative exploration. *International Journal for Equity in Health, 16*(1), 54.

Galvan, F., Bogart, L., Klein, D., Wagner, G., & Chen, Y. (2017). Medical mistrust as a key mediator in the association between perceived discrimination and adherence to antiretroviral therapy among HIV-positive Latino men. *Journal of Behavioral Medicine, 40*(5), 784–793.

Gamboa, E. (2000). *Mexican Labor & World War II: Braceros in the Pacific Northwest, 1942–1947*. United States of America: University of Washington Press.

Garcia-Reyes, W., Lara-Solares, A., Guevara-Lopez, U., Flores-Rebollar, A., & Loaeza Del Castillo, A. (2008). Como Se Dan las Malas Noticias de Enfermedad Terminal por un Grupo Medico no Especializado en Cuidados Paliativos. *Anestesiologia, 31*(1), 9–14.

Garcia, J. (2016). Latinos in Oregon. *The Oregon Encyclopedia.* Retrieved from http://oregonencyclopedia.org/articles/hispanics_in_oregon/#.VpQVh_krLIU

Garrett, T., Baillie, H., Garrett, R., & McGeehan, J. (2009). *Heatlh care ethics: Principles and problems* (Fifth ed.). Upper Saddle River, NJ: Prentice Hall.

Gelfand, D., Balcazar, H., Parzuchowski, J., & Lenox, S. (2001). Mexicans and care for the terminally ill: Family, hospice, and the church. *American Journal of Hospice and Palliative Medicine, 18*(6), 391–396. doi:10.1177/104990910101800608

Gelfand, D., Balcazar, H., Parzuchowski, J., & Lenox, S. (2004). Issues in Hospice Utilization by Mexicans. *Journal of Applied Gerontology, 23*(1), 3–19. doi:10.1177/0733464803253592

Gelfman, L., Meier, D., & Morrison, R. (2008). Does Palliative Care Improve Quality? A Survey of Bereaved Family Members. *Journal of Pain and Symptom Management, 36*(1), 22–28. doi:10.1016/j.jpainsymman.2007.09.008

Givens, J., Tjia, J., Zhou, C., Emanuel, E., & Ash, A. (2010). Racial and ethnic differences in hospice use among patients with heart failure. *Archives of Internal Medicine, 170*(5), 427–432. doi:http://dx.doi.org/10.1001/archinternmed.2009.547

Glaser, B., & Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago, IL: Aldine.

Glaser, B., & Strauss, A. (1966). *Awareness of dying*: Transaction Publishers.

Glaser, B. (1978). *Theoretical Sensitivity*. Mill Valley CA: The Sociology Press.

Gold, M. (2004). Is honesty always the best policy? Ethical aspects of truth telling. *Internal Medicine Journal, 34*(9–10), 578–580. doi:10.1111/j.1445-5994.2004.00673.x

Gonzales-Berry, E., & Mendoza, M. (2010). *Mexicanos in Oregon: their stories, their lives*. Corvallis, Oregon: Oregon State University Press.

Gonzalez-Barrera, A., & Lopez, M. (2013). *A demographic portrait of Mexican-origin Hispanics in the United States*. Retrieved from Washington, D.C.: http://www.pewhispanic.org/2013/05/01/a-demographic-portrait-of-mexican-origin-hispanics-in-the-united-states/

Goodreads. (2015). Wade Davis Quotes. Retrieved from http://www.goodreads.com/author/quotes/4652058.Wade_Davis

Gordon, A. (1996). Hospice and minorities: a national study of organizational access and practice. *Hospice Journal, 11*(1), 49–70.

Green, C. (2006). The quality of cancer pain management for racial and ethnic minority Americans: Unequal burdens and unheard voices. *Journal of Cancer Pain and Symptom Palliation, 2*(1), 19–27. doi:10.1300/J427v02n01_05

Green, D., Creswell, J., Shope, R., & Clark, V. (2007). Grounded Theory and Racial/Ethnic Diversity. In A. Bryan & K. Charmaz (Eds.), *The Sage Handbook of Grounded Theory*. Thousand Oaks CA: Sage Publications Ltd.

Gregg, J., Solotaroff, R., Amann, T., Michael, Y., & Bowen, J. (2008). Health and disease in context: A community-based social medicine curriculum. *Academic Medicine, 83*(1), 14–19. doi:10.1097/ACM.0b013e31815c67f0

Guadagnolo, A., Liao, K., Giordano, S., Elting, L., & Shih, Y. (2015). Variation in intensity and costs of care by payer and race for patients dying of cancer in texas: An analysis of registry-linked medicaid, medicare, and dually eligible claims data. *Medical Care, 53*(7), 591–598. doi:10.1097/MLR.0000000000000369

Gutheil, I., & Heyman, J. (2006). “They don’t want to hear us”: Hispanic elders and adult children speak about end-of-life planning. *Journal of Social Work in End-of-Life and Palliative Care, 2*(1), 55–70. doi:10.1300/J457v02n01_05

Haag, M. (2019). Thousands of Immigrant Children Said They Were Sexually Abused in U.S. Detention Centers, Report Says [Press release]. Retrieved from https://www.nytimes.com/2019/02/27/us/immigrant-children-sexual-abuse.html

Haas, J., Earle, C., Orav, J., Brawarsky, P., Neville, B., Acevedo-Garcia, D., & Williams, D. (2007). Lower use of hospice by cancer patients who live in minority versus white areas. *Journal of General Internal Medicine, 22*(3), 396–399. doi:10.1007/s11606-006-0034-y

Hall, J. (1999). Marginalization revisited: Critical, postmodern, and liberation perspectives. *Advances in Nursing Science, 22*(2), 88–102. doi:10.1097/00012272-199912000-00009

Hall, J., Stevens, P., & Meleis, A. (1994). Marginalization: a guiding concept for valuing diversity in nursing knowledge development. *ANS. Advances in nursing science, 16*(4), 23–41.

Hanchate, A., Kronman, A., Young-Xu, Y., Ash, A., & Emanuel, E. (2009). Racial and ethnic differences in End-of-Life costs Why do minorities cost more than whites? *Archives of Internal Medicine, 169*(5), 493–501. doi:10.1001/archinternmed.2008.616

Hardy, D., Chan, W., Liu, C., Cormier, J., Xia, R., Bruera, E., & Du, X. (2011). Racial disparities in the use of hospice services according to geographic residence and socioeconomic status in an elderly cohort with nonsmall cell lung cancer. *Cancer, 117*(7), 1506–1515. doi:10.1002/cncr.25669

Hardy, D., Chan, W., Liu, C., Cormier, J., Xia, R., Bruera, E., & Du, X. (2012). Racial disparities in length of stay in hospice care by tumor stage in a large elderly cohort with non-small cell lung cancer. *Palliative Medicine, 26*(1), 61–71. doi:http://dx.doi.org/10.1177/0269216311407693

Hassouneh, D., Akeroyd, J., Lutz, K., & Beckett, A. (2012). Exclusion and control: Patterns aimed at limiting the influence of faculty of color. *Journal of Nursing Education, 51*(6), 314–325. doi:10.3928/01484834-20120323-04

Hassouneh, D., & Lutz, K. (2013). Having influence: Faculty of color having influence in schools of nursing. *Nursing Outlook, 61*(3), 153–163. doi:10.1016/j.outlook.2012.10.002

Healthy People 2020. (2018, January 30, 2018). Retrieved from https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health

Hebert, P., Sisk, J., & Howell, E. (2008). When does a difference become a disparity? Conceptualizing racial and ethnic disparities in health. *Health Affairs, 27*(2), 374–382. doi:10.1377/hlthaff.27.2.374

Hede, M. (2013). Hispanic vs. Latino. Retrieved from http://hispanic-culture-online.com/hispanic-vs-latino.html

Hernandez, R., Hevelone, N., Lopez, L., Finlayson, S., Chittenden, E., & Cooper, Z. (2015). Racial variation in the use of life-sustaining treatments among patients who die after major elective surgery. *American Journal of Surgery, 210*(1), 52–58. doi:10.1016/j.amjsurg.2014.08.025

Higginson, I., & Evans, C. (2010). What is the evidence that palliative care teams improve outcomes for cancer patients and their families? *Cancer Journal, 16*(5), 423–435. doi:10.1097/PPO.0b013e3181f684e5

Hoeffel, E., Rastogi, S., Kim, M., & Shahid, H. (2012). The Asian Population: 2010, 2010 Census Briefs. Retrieved from http://www.census.gov/prod/cen2010/briefs/c2010br-11.pdf

Holmes, S. (2006). An ethnographic study of the social context of migrant health in the United States. *PLoS Medicine, 3*(10), 1776–1793. doi:10.1371/journal.pmed.0030448

Holstein, M., Parks, J., & Waymack, M. (2010). *Ethics, aging, and society: The critical turn*. New York, NY: Springer Publishing Co.

Hospice Care: Certification of terminal illness, 42 C.F.R. §418.22 (2017a).

Hospice Care: Condition of Participation: Organization and administration of services, 42 C.F.R. §418.100 (2017b).

Hospice Care: Election of hospice care, 42 C.F.R. §418.24 (2017b).

Hospice Care: Eligibility requirements, 42 C.F.R. §418.20 (2017c).

Hospice Cristina. (2018). Retrieved from https://www.hospicecristinaac.com.mx/

Hospice Vida Plena. (2018). Retrieved from http://ministeriomct.org/clinica-medica-y-consejeria-profesional/hospice-vida-plena/

hospicio. (2014). Wordreference.com On Line. Retrieved from http://www.wordreference.com/es/en/translation.asp?spen=hospicio

Hospicio Cabanas, Guadalajara. (2018). Retrieved from http://whc.unesco.org/en/list/815

Hsieh, E., Pitaloka, D., & Johnson, A. (2013). Bilingual Health Communication: Distinctive Needs of Providers from Five Specialties. *Health Communication, 28*(6), 557–567. doi:10.1080/10410236.2012.702644

Humes, K., Jones, N., & Ramirez, R. (2011). Overview of Race and Hispanic Origin: 2010. Retrieved from http://www.census.gov/prod/cen2010/briefs/c2010br-02.pdf

Hutchinson, S., Wilson, M., & Wilson, H. (1994). Benefits of Participating in Research Interviews. *Image: The Journal of Nursing Scholarship, 26*(2), 161–166. doi:10.1111/j.1547-5069.1994.tb00937.x

Index Mundi. (2010). Oregon Hispanic or Latino Origin Population Percentage by County. Retrieved from http://www.indexmundi.com/facts/united-states/quick-facts/oregon/hispanic-or-latino-population-percentage#map

Inouye, S., Van Dyck, C., Alessi, C., Balkin, S., Siegal, A., & Horwitz, R. (1990). Clarifying confusion: The confusion assessment method: A new method for detection of delirium. *Annals of Internal Medicine*, *113*(12), 941–948.

Institute of Medicine. (2014). *Dying in America: IOM's Committee's Proposed Core Components of Quality End-of-Life Care*. Retrieved from Washington D.C.: http://www.iom.edu/~/media/Files/Report%20Files/2014/EOL/Table%20-%20Core%20Components%20of%20Quality%20Care.pdf

Jacobs, E., Mendenhall, E., McAlearney, A., Rolle, I., Whitaker, E., Warnecke, R., & Ferrans, C. (2011). An exploratory study of how trust in health care institutions varies across African American, Hispanic and white populations. *Communication and Medicine, 8*(1), 89–98. doi:10.1558/cam.v8i1.89

Jaramillo, S., & Hui, D. (2016). End-of-Life Care for Undocumented Immigrants With Advanced Cancer: Documenting the Undocumented. *Journal of Pain and Symptom Management, 51*(4), 784–788. doi:10.1016/j.jpainsymman.2015.11.009

Jimenez, A. (1994). The Hispanic History of the United States: An Interpretive Essay. In A. Jimenez (Ed.), *Handbook of Hispanic Cultures in the United States: History* (pp. 13–20). Houston, Texas: Arte Publico Press, University of Houston.

Johnson, K. (2017). Portland Killings Dredge Up Legacy of Racist Laws in Oregon. *The New York Times*. Retrieved from https://www.nytimes.com/2017/06/04/us/portland-killings-racist-laws-oregon.html

Johnson, K., Kuchibhatala, M., Sloane, R., Tanis, D., Galanos, A., & Tulsky, J. (2005). Ethnic differences in the place of death of elderly hospice enrollees. *Journal of the American Geriatrics Society, 53*(12), 2209–2215.

Johnson, K., Kuchibhatla, M., & Tulsky, J. (2008). What explains racial differences in the use of advance directives and attitudes toward hospice care? *Journal of the American Geriatrics Society, 56*(10), 1953–1958. doi:10.1111/j.1532-5415.2008.01919.x

Johnson, R., Saha, S., Arbelaez, J., Beach, M., & Cooper, L. (2004). Racial and ethnic differences in patient perceptions of bias and cultural competence in health care. *Journal of General Internal Medicine, 19*(2), 101–110.

Joint Commission International. (2015). *Joint Commission International Accreditation Standards for Hospitals* (5th ed.). Oakbrook IL: Joint Commission International.

Jonnalagadda, S., Lin, J., Nelson, J., Powell, C., Salazar-Schicchi, J., Berman, A., . . . Wisnivesky, J. (2012). Racial and ethnic differences in beliefs about lung cancer care. *Chest, 142*(5), 1251–1258. doi:10.1378/chest.12-0330

Jordan, M. (2018). How and Why 'Zero Tolerance' Is Splitting Up Immigrant Families [Press release]. Retrieved from https://www.nytimes.com/2018/05/12/us/immigrants-family-separation.html

Jordan, M., & Perez, S. (2016). Shortage of Mexican Workers is Hurting US Businesses. Retrieved from https://www.marketwatch.com/story/shortage-of-mexican-workers-is-hurting-us-businesses-2016-11-25

Juckett, G. (2013). Caring for Latino patients. *American Family Physician, 87*(1), 48–54.

Kagawa-Singer, M. (2001). From genes to social science. *Cancer, 91*(S1), 226–232.

Kelley, A., Wenger, N., & Sarkisian, C. (2010). Opiniones: End-of-life care preferences and planning of older latinos. *Journal of the American Geriatrics Society, 58*(6), 1109–1116. doi:10.1111/j.1532-5415.2010.02853.x

Kim-Godwin, Y., Clarke, P., & Barton, L. (2001). A model for the delivery of culturally competent community care. *Journal of Advanced Nursing, 35*(6), 918–925.

Kim, S., Kim, J., Kim, S., Shin, I., Bae, K., Shim, H., . . . Yoon, J. (2013). Does awareness of terminal status influence survival and quality of life in terminally ill cancer patients? *Psycho-Oncology, 22*(10), 2206–2213. doi:10.1002/pon.3275

Kincheloe, J., & McLaren, P. (2002). Rethinking Critical Theory and Qualitative Research. In Y. Zou & E. Trueba (Eds.), *Ethnography and Schools: Qualitative Approaches to the Study of Education* (pp. 87–138). Oxford, England: Rowman & Littlefield Publishers, Inc.,.

Kirkendall, A., Holland, J., Keene, J., & Luna, N. (2015). Evaluation of Hospice Care by Family Members of Hispanic and Non-Hispanic Patients. *American Journal of Hospice and Palliative Medicine, 32*(3), 313–321. doi:10.1177/1049909114526969

Kirkendall, A., Shen, J., & Gan, Y. (2014). Associations of race and other socioeconomic factors with post-hospitalization hospice care settings. *Ethnicity and Disease*, *24*(2), 236–242.

Kirkham, S., & Anderson, J. (2002). Postcolonial Nursing Scholarship: from Epistemology to Method. *Advanced Nursing Science, 25*(1), 1–17.

Kirkham, S., & Browne, A. (2006). Toward a critical theoretical interpretation of social justice discourses in nursing. *Advances in Nursing Science, 29*(4), 324–339.

Kirklin, D. (2007). Truth telling, autonomy and the role of metaphor. *Journal of Medical Ethics, 33*(1), 11–14. doi:10.1136/jme.2005.014993

Ko, E., Cho, S., & Bonilla, M. (2012). Attitudes Toward Life-Sustaining Treatment: The Role of Race/Ethnicity. *Geriatric Nursing, 33*(5), 341–349. doi:10.1016/j.gerinurse.2012.01.009

Ko, E., Cho, S., Perez, R., Yeo, Y., & Palomino, H. (2013). Good and bad death: Exploring the perspectives of older Mexican Americans. *Journal of Gerontological Social Work, 56*(1), 6–25. doi:10.1080/01634372.2012.715619

Ko, E., & Lee, J. (2014). End- of- life treatment preference among low-income older adults: A race/ethnicity comparison study. *Journal of Health Care for the Poor and Underserved, 25*(3), 1021–1033. doi:10.1353/hpu.2014.0129

Kochhar, R., & Fry, R. (2014). Wealth inequality has widened along racial, ethnic lines since end of Great Recession. Retrieved from http://www.pewresearch.org/fact-tank/2014/12/12/racial-wealth-gaps-great-recession/

Kools, S., McCarthy, M., Durham, R., & Robrecht, L. (1996). Dimensional Analysis: Broadening the Conception of Grounded Theory. *Qualitative Health Research, 6*, 312–330.

Krakauer, E., Crenner, C., & Fox, K. (2002). Barriers to optimum end-of-life care for minority patients. *Journal of the American Geriatrics Society, 50*(1), 182–190. doi:10.1046/j.1532-5415.2002.50027.x

Kreling, B., Selsky, C., Perret-Gentil, M., Huerta, E., & Mandelblatt, J. (2010). 'The worst thing about hospice is that they talk about death': contrasting hospice decisions and experience among immigrant Central and South American Latinos with US-born White, non-Latino cancer caregivers. *Palliative Medicine, 24*(4), 427–434. doi:10.1177/0269216310366605

Kress, M., Jensen, R., Tsai, H., Lobo, T., Satinsky, A., & Potosky, A. (2015). Radiation therapy at the end of life: a population-based study examining palliative treatment intensity. *Radiation Oncology, 10*(15).

Kressin, N., Chang, B., Hendricks, A., & Kazis, L. (2003). Agreement between Administrative Data and Patients' Self-Reports of Race/Ethnicity. *American Journal of Public Health, 93*(10), 1734–1739.

Krogstad, J. (2015). Cuban Immigration to U.S. Surges as Relations Warm. Retrieved from http://www.pewresearch.org/fact-tank/2015/12/10/cuban-immigration-to-u-s-surges-as-relations-warm/

Krogstad, J., & Passel, J. (2015). 5 Facts about Illegal Immigration in the U.S. Retrieved from http://www.pewresearch.org/fact-tank/2015/11/19/5-facts-about-illegal-immigration-in-the-u-s/

Kübler-Ross, E., Wessler, S., & Avioli, L. (1972). On death and dying. *JAMA, 221*(2), 174–179.

Kurosawa, A. (Writer). (1952). Ikiru. In T. I. Co. (Producer).

Kuzel, A., & Like, R. (1991). Standards of trustworthiness for qualitative studies in primary care. *Primary care research: Traditional and innovative approaches*, 138–158.

Lackan, N., Freeman, J., & Goodwin, J. (2003). Hospice use by older women dying with breast cancer between 1991 and 1996. *Journal of Palliative Care, 19*(1), 49–53.

Lackan, N., Ostir, G., Freeman, J., Kuo, Y., Zhang, D., & Goodwin, J. (2004). Hospice use by Hispanic and non-Hispanic white cancer decedents. *Health Services Research, 39*(4 Pt 1), 969–983.

Larson, A. (2013). *Oregon Update: Migrant and Seasonal Farmworker Enumberation Profiles Study*. Retrieved from

Lee, M., Hinderer, K., & Kehl, K. (2014). A systematic review of advance directives and advance care planning in Chinese people from eastern and western cultures. *Journal of Hospice and Palliative Nursing, 16*(2), 75–85. doi:10.1097/NJH.0000000000000024

Leininger, M. (1996). Culture care theory, research, and practice. *Nursing science quarterly, 9*(2), 71–78.

Leventhal, H., Safer, M., & Panagis, D. (1983). The impact of communications on the self-regulation of health beliefs, decisions, and behavior. *Health Education & Behavior, 10*(1), 3–29.

Li, J., Yuan, X., Gao, X., Yang, X., Jing, P., & Yu, S. (2012). Whether, when, and who to disclose bad news to patients with cancer: A survey in 150 pairs of hospitalized patients with cancer and family members in China. *Psycho-Oncology, 21*(7), 778–784. doi:10.1002/pon.1979

Lichter, D. T. (2012). Immigration and the New Racial Diversity in Rural America. *Rural Sociology, 77*(1), 3–35. doi:10.1111/j.1549-0831.2012.00070.x

Loggers, E., Maciejewski, P., Jimenez, R., Nilsson, M., Paulk, E., Stieglitz, H., & Prigerson, H. (2013). Predictors of intensive end-of-life and hospice care in latino and white advanced cancer patients. *Journal of Palliative Medicine, 16*(10), 1249–1254. doi:10.1089/jpm.2013.0164

López-Cevallos, D., & Harvey, S. (2016). Foreign-Born Latinos Living in Rural Areas are more likely to Experience Health Care Discrimination: Results from Proyecto de Salud para Latinos. *Journal of Immigrant and Minority Health, 18*(4), 928–934. doi:10.1007/s10903-015-0281-2

López-Cevallos, D., Harvey, S., & Warren, J. (2014). Medical mistrust, perceived discrimination, and satisfaction with health care among young-adult rural Latinos. *Journal of Rural Health, 30*(4), 344–351. doi:10.1111/jrh.12063

Mack, J., & Smith, T. (2012). Reasons why physicians do not have discussions about poor prognosis, why it matters, and what can be improved. *Journal of Clinical Oncology, 30*(22), 2715–2717. doi:10.1200/JCO.2012.42.4564

Maradik, L., Boggiano, V., Nguyen, D., & Pham, L. (2013). Working in partnership with interpreters: Studies on individuals affected by HIV/AIDS in Vietnam. *Qualitative Health Research, 23*(10), 1408–1418.

Markides, K., & Eschbach, K. (2005). Aging, migration, and mortality: current status of research on the Hispanic paradox. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 60*(Special Issue 2), S68–S75.

Martinez-Tyson, D., Barnett, E., Soler-Vila, H., & Flores, A. (2009). Looking under the hispanic umbrella: Cancer mortality among Cubans, Mexicans, Puerto Ricans and other hispanics in Florida. *Journal of Immigrant and Minority Health, 11*(4), 249–257. doi:10.1007/s10903-008-9152-4

Martinez, M. (2018). *The Injustice Never Leaves You: Anti-Mexican Violence in Texas*. Massachusetts: Harvard University Press.

Martinez, O. (1994). A History of Chicanos/Mexicanos Along the U.S.–Mexico Border. In A. Jimenez (Ed.), *Handbook of Hispanic Cultures in the United States: History* (pp. 261–280). Houston TX: Arte Publico Press, University of Houston.

Maxwell, J. (2013). *Qualitative Research Design* (3rd ed.). Thousand Oaks CA: Sage Publications, Inc.

May, G. (2011). *Sonny Montes and Mexican American Activism in Oregon*. Corvallis, Oregon: Oregon State University Press.

McMaster University. (2013, 14 November, 2013). Inclusion Criteria. Retrieved from http://hiru.mcmaster.ca/hiru/InclusionCriteria.html

Meier, D. (2011). Increased access to palliative care and hospice services: opportunities to improve value in health care. *Milbank Quarterly, 89*(3), 343–380. doi:http://dx.doi.org/10.1111/j.1468-0009.2011.00632.x

Meleis, A. (2010). *Transitions theory: Middle range and situation specific theories in nursing research and practice*: Springer publishing company.

Meyers, F., Lin, A., Sribney, W., & Aguilar-Gaxiola, S. (2008). Diverse Populations Can Use Hospice Services Appropriately. *American Journal of Medicine, 121*(4), e1-e2. doi:10.1016/j.amjmed.2007.10.034

Millner, D. (2018). Blacks in Oregon. *The Oregon Encyclopedia*. Retrieved from https://oregonencyclopedia.org/articles/blacks_in_oregon/#.XKpg1ZhKjIU

Mishel, M. (1988). Uncertainty in illness. *Image: The Journal of Nursing Scholarship, 20*(4), 225–232.

Mitigare—San Miguel Hospice. (2018). Retrieved from https://www.mitigare.org/inicio

Mor, V., Joyce, N., Coté, D., Gidwani, R., Ersek, M., Levy, C., . . . Shreve, S. (2016). The rise of concurrent care for veterans with advanced cancer at the end of life. *Cancer, 122*(5), 782–790. doi:10.1002/cncr.29827

Morrison, R., Zayas, L., Mulvihill, M., Baskin, S., & Meier, D. (1998a). Barriers to completion of health care proxies: an examination of ethnic differences. *Archives of Internal Medicine, 158*(22), 2493–2497.

Morrison, R., Zayas, L., Mulvihill, M., Baskin, S., & Meier, D. (1998b). Barriers to completion of healthcare proxy forms: a qualitative analysis of ethnic differences. *Journal of Clinical Ethics, 9*(2), 118–126.

Morse, J. (1995). The significance of saturation: Sage Publications Sage CA: Thousand Oaks, CA.

Motel, S., & Patten, E. (2012). The 10 Largest Hispanic Origin Groups: Characteristics, Rankings, Top Counties. Retrieved from http://www.pewhispanic.org/2012/06/27/the-10-largest-hispanic-origin-groups-characteristics-rankings-top-counties/

Mouton, C., Espino, D., Esparza, Y., & Miles, T. (2001). Attitudes toward assisted suicide among community-dwelling Mexican Americans. *Clinical Gerontologist, 22*(2), 81–92.

Murphy, D., & Cluff, L. (1990a). Introduction: The support study. *Journal of Clinical Epidemiology, 43*(SUPPL.), V–VIII.

Murphy, D., & Cluff, L. (1990b). The support study. *Journal of Clinical Epidemiology, 43*(SUPPL.), V–X.

Murray, S., Kendall, M., Boyd, K., & Sheikh, A. (2005). Illness trajectories and palliative care. *British Medical Journal, 330*(7498), 1007–1011.

Narayan, U. (2000). Essence of Culture and a Sense of History: A Feminist Critique of Cultural Essentialism. In U. Narayan & S. Harding (Eds.), *Decentering the Center: Philosophy for a Multicultural, Postcolonial, and Feminist World* (pp. 80–100). Bloomington IN: Indiana University Press.

National Bioethics Advisory Commission. (1998). Research Involving Persons with Mental Disorders That May Affect Decisionmaking Capacity, Vol. 1 Report and Recommendations of the National Bioethics Advisory Commission. Retrieved from https://bioethicsarchive.georgetown.edu/nbac/capacity/Overview.htm#Values

National Cancer Institute. (2016). National Cancer Institute Surveillance, Epidemiology, and End Results Program. Retrieved from http://seer.cancer.gov/about/overview.html

National Hospice and Palliative Care Organization. (2010). Preamble and Philosophy: Hospice Philosophy Statement. Retrieved from http://www.nhpco.org/ethical-and-position-statements/preamble-and-philosophy

National Hospice and Palliative Care Organization. (2012). Pediatric Palliative Care. Retrieved from https://www.nhpco.org/sites/default/files/public/ChiPPS/Continuum_Briefing.pdf

National Hospice and Palliative Care Organization. (2013). National Hospice and Palliative Care Organization Facts and Figures. Retrieved from http://www.nhpco.org/sites/default/files/public/Statistics_Research/2013_Facts_Figures.pdf

National Hospice and Palliative Care Organization. (2015). NHPCO's Facts and Figures: Hospice Care in America. Retrieved from http://www.nhpco.org/sites/default/files/public/Statistics_Research/2015_Facts_Figures.pdf

National Hospice and Palliative Care Organization. (2017). National Hospice and Palliative Care Organization: Facts and Figures. Retrieved from https://www.nhpco.org/sites/default/files/public/Statistics_Research/2017_Facts_Figures.pdf

Nedjat-Haiem, F., Carrion, I., Lorenz, K., Ell, K., & Palinkas, L. (2013). Psychosocial concerns among Latinas with life-limiting advanced cancers. *Omega—Journal of Death & Dying, 67*(1–2), 167–174.

Nelson, A., Stith, A., & Smedley, B. (2002). *Unequal treatment: confronting racial and ethnic disparities in health care (full printed version)*: National Academies Press.

Noguera, A., Yennurajalingam, S., Torres-Vigil, I., Parsons, H., Duarte, E., Palma, A., . . . Bruera, E. (2014). Decisional control preferences, disclosure of information preferences, and satisfaction among hispanic patients with advanced cancer. *Journal of Pain and Symptom Management, 47*(5), 896–905. doi:10.1016/j.jpainsymman.2013.06.010

Novack, D., Plumer, R., Smith, R., Ochitill, H., Morrow, G., & Bennett, J. (1979). Changes in physicians' attitudes toward telling the cancer patient. *Journal of the American Medical Association, 241*(9), 897–900. doi:10.1001/jama.241.9.897

OHSU Research Integrity Office. (2014, July 2, 2014). IRB Help Sheet: Human Subjects Research with Decisionally Impaired Adults. Retrieved from http://www.ohsu.edu/xd/about/services/integrity/policies/upload/Vulnerable-Populations-Decisionally-Impaired-Adults-Help-Sheet.pdf

Orb, A., Eisenhauer, L., & Wynaden, D. (2001). Ethics in qualitative research. *Journal of Nursing Scholarship, 33*(1), 93–96.

Ortiz, V., & Telles, E. (2012). Racial Identity and Racial Treatment of Mexican Americans. *Race Soc Probl, 4*(1), 41–56.

Palloni, A., & Arias, E. (2004). Paradox lost: Explaining the Hispanic adult mortality advantage. *Demography, 41*(3), 385–415.

Pan, C., Abraham, O., Giron, F., Lemarie, P., & Pollack, S. (2015). Just Ask: Hospice familiarity in asian and hispanic adults. *Journal of Pain and Symptom Management, 49*(5), 928–933. doi:10.1016/j.jpainsymman.2014.09.016

Pan, C., Glynn, R., Mogun, H., Choodnovskiy, I., & Avorn, J. (1999). Definition of race and ethnicity in older people in Medicare and Medicaid. *Journal of the American Geriatrics Society, 47*(6), 730–733.

Park, N., Carrion, I., Lee, B., Dobbs, D., Shin, H., & Becker, M. (2012). The role of race and ethnicity in predicting length of hospice care among older adults. *Journal of Palliative Medicine, 15*(2), 149–153. doi:http://dx.doi.org/10.1089/jpm.2011.0220

Park, N., Jang, Y., Ko, J., & Chiriboga, D. (2016). Factors Affecting Willingness to Use Hospice in Racially/Ethnically Diverse Older Men and Women. *American Journal of Hospice and Palliative Medicine, 33*(8), 770–776. doi:10.1177/1049909115590976

Patton, M. (2015). *Qualitative Research and Evaluative Methods* (Fourth ed.). Los Angeles, CA: Sage Publications, Inc.

Pawling-Kaplan, M., & O'Connor, P. (1989). Hospice Care for Minorities: An analysis of a hospital-based inner city palliative care service. *The American Journal of Hospice Care, 6*(4), 13–21.

Pérez, D., Fortuna, L., & Alegría, M. (2008). Prevalence and correlates of everyday discrimination among U.S. latinos. *Journal of Community Psychology, 36*(4), 421–433. doi:10.1002/jcop.20221

Perkins, H., Cortez, J., & Hazuda, H. (2009). Cultural beliefs about a patient's right time to die: An exploratory study. *Journal of General Internal Medicine, 24*(11), 1240–1247. doi:10.1007/s11606-009-1115-5

Perry, C., Hatton, D., & Kendall, J. (2005). Latino parents' accounts of attention deficit hyperactivity disorder. *Journal of Transcultural Nursing, 16*(4), 312–321.

Persons born in Puerto Rico on or after April 11, 1899, 8 U.S. Code §1402 (1952).

Pew Research Center. (2011). Hispanic Trends: Demographic Profile of Hispanics in Oregon, 2011. Retrieved from http://www.pewhispanic.org/files/states/pdf/OR_11.pdf

Pew Research Center. (2012). Median Age for Hispanics is Lower Than Median Age for Total U.S. Population. Retrieved from http://www.pewresearch.org/daily-number/median-age-for-hispanics-is-lower-than-median-age-for-total-u-s-population/

Pew Research Center. (2014a). Demographic profile of Hispanics in Washington, 2014. Retrieved from http://www.pewhispanic.org/states/state/wa/

Pew Research Center. (2014b). Unauthorized Immigrants in the U.S.: Mexicans as Share of Unauthorized Immigrants, by State, 2012. Retrieved from http://www.pewhispanic.org/interactives/unauthorized-immigrants-2012/map/mexican-share/

Pew Research Center. (2014c). Unauthorized Immigrants in the U.S.: Mexicans as Share of Unauthorized Immigrants, by State, 2012. Retrieved from http://www.pewhispanic.org/interactives/unauthorized-immigrants-2012/map/mexican-share/

Phelps, A., Maciejewski, P., Nilsson, M., Balboni, T., Wright, A., Paulk, M., . . . Prigerson, H. (2009). Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer. *JAMA—Journal of the American Medical Association, 301*(11), 1140–1147.

Phillips, D., & Drevdahl, D. (2003). “Race” and the difficulties of language. *Advances in Nursing Science, 26*(1), 17–29.

Plato. (trans. 1991). *The Republic* (A. Bloom, Trans.). New York, NY: Basic Books.

Pottie, C., Burch, K., Montross, L., & Irwin, S. (2014). Informal caregiving of hospice patients. *Journal of Palliative Medicine, 17*(7), 845–856. doi:10.1089/jpm.2013.0196

Powers, B., & Knapp, T. (2011). *Dictionary of Nursing Theory and Research* (4th ed.). New York, NY: Springer Publishing Co.

PRISMA. (2015). Transparent Reportig of Systematic Reviews and Meta-Analysis Retrieved from http://www.prisma-statement.org/

Purnell, L. (2002). The Purnell model for cultural competence. *Journal of Transcultural Nursing, 13*(3), 193–196.

Pyenson, B., Connor, S., Fitch, K., & Kinzbrunner, B. (2004). Medicare cost in matched hospice and non-hospice cohorts. *Journal of Pain & Symptom Management, 28*(3), 200–210.

Ramirez, S. (2014). *Conspiracion del Silencio y Proceso de Duelo en Familia con Enfermo Terminal de la Unidad de Medicina Familiar Numero 64.* (La Especialidad en Medicina Familiar), Instituto Mexicano del Seguro Social, Toluca, Mexico. Retrieved from http://ri.uaemex.mx/bitstream/123456789/14500/1/411441.pdf

Randall, H., & Csikai, E. (2003). Issues Affecting Utilization of Hospice Services by Rural Hispanics. *Journal of Ethnic and Cultural Diversity in Social Work, 12*(2), 79–94. doi:10.1300/J051v12n02_05

Reinke, L., Shannon, S., Engelberg, R., Young, J., & Curtis, J. (2010). Supporting Hope and Prognostic Information: Nurses' Perspectives on Their Role When Patients Have Life-Limiting Prognoses. *Journal of Pain and Symptom Management, 39*(6), 982–992. doi:10.1016/j.jpainsymman.2009.11.315

Retta, E., & Brink, C. (2007). Latino or Hispanic Panic: Which term should we use? Retrieved from http://www.crossculturecommunications.com/latino-hispanic.pdf

Rhodes, R., Lei, X., Paulk, M., Stieglitz, H., & Halm, E. (2013). An Examination of End-of-Life Care in a Safety Net Hospital System: A Decade in Review. *Journal of Health Care for the Poor & Underserved, 24*(4), 1666–1675. doi:10.1353/hpu.2013.0179

Riggs, A., Breuer, B., Dhingra, L., Chen, J., Hiney, B., McCarthy, M., . . . Knotkova, H. (2016). Hospice Enrollment After Referral to Community-Based, Specialist-Level Palliative Care: Incidence, Timing, and Predictors. *Journal of Pain and Symptom Management, 52*(2), 170–177. doi:10.1016/j.jpainsymman.2016.02.011

Rising, M. (2017). Truth Telling as an Element of Culturally Competent Care at End of Life. *Journal of Transcultural Nursing, 28*(1), 48–55. doi:10.1177/1043659615606203

Rising, M., Hassouneh, D., Lutz, K., Berry, P., & Lee, C. (2019). Hispanic Hospice Utilization: Integrative Review and Meta-analysis. *Journal of Healthcare for Poor and Underserved, 30*(2).

Rising, M., Hassouneh, D., Lutz, K., Lee, C., & Berry, P. (2018). Integrative Review of the Literature on Hispanics and Hospice. *American Journal of Hospice and Palliative Medicine, 35*(3), 542–554. doi:10.1177/1049909117730555

Robert Wood Johnson Foundation. (2017). *Discrimination in America: Experiences and Views of Latinos*. Retrieved from New Jersey: https://www.rwjf.org/content/dam/farm/reports/surveys_and_polls/2017/rwjf441402

Robrecht, L. (1995). Grounded Theory: Evolving Methods. *Qualitative Health Research, 5*, 169–177.

Rolland, J. (1990). Anticipatory loss: A family systems developmental framework. *Family Process, 29*(3), 229–244.

Romero, L., Lindeman, R., Koehler, K., & Allen, A. (1997). Influence of ethnicity on advance directives and end-of-life decisions [5]. *Journal of the American Medical Association, 277*(4), 298–299.

Ruff, H., Jacobs, R., Fernandez, M., Bowen, G., & Gerber, H. (2011). Factors associated with favorable attitudes toward end-of-life planning. *American Journal of Hospice and Palliative Medicine, 28*(3), 176–182. doi:10.1177/1049909110382770

Said, E. (1978). *Orientalism*. New York NY: Vintage Books.

Sammon, J., McKay, R., Kim, S., Sood, A., Sukumar, S., Hayn, M., . . . Trinh, Q. (2015). Burden of hospital admissions and utilization of hospice care in metastatic prostate cancer patients. *Urology, 85*(2), 343–349. doi:10.1016/j.urology.2014.09.053

Satcher, D. (2001). The unequal burden of cancer. *Cancer, 91*(1 SUPPL.), 205–207.

Sayer, A. (1997). Essentialism, social constructionism, and beyond. *Sociological Review, 45*(3), 453–487.

Schatzman, L. (1991). *Dimensional analysis: Notes on an alternative approach to the grounding of theory in qualitative research* (D. R. Maines Ed.). New York NY: Aldine De Gruyter.

Schensul, S., Schensul, J., & LeCompte, M. (1999). *Essential ethnographic methods: Observations, interviews, and questionnaires* (Vol. 2): Rowman Altamira.

Schick, A. (2012). Child Farm Labor in Oregon and the U.S.: Big Dangers, Little Change. Retrieved from http://www.oregonlive.com/pacific-northwest-news/index.ssf/2012/09/child_farm_labor_in_oregon_and.html

Selsky, C., Kreling, B., Luta, G., Makgoeng, S., Gomez-Duarte, J., Barbo, A., & Mandelblat, J. (2012). Hospice knowledge and intentions among latinos using safety-net clinics. *Journal of Palliative Medicine, 15*(9), 984–990. doi:10.1089/jpm.2011.0517

Skidmore, T., Smith, P., & Green, J. (2013). *Modern Latin America* (8th ed.). Oxford, England: Oxford University Press.

Smart, J., & Smart, D. (1995). Acculturative Stress The Experience of the Hispanic Immigrant. *The Counseling Psychologist, 23*(1), 25–42.

Smith, A., Davis, R., & Krakauer, E. (2007). Differences in the quality of the patient-physician relationship among terminally ill African-American and white patients: Impact on advance care planning and treatment preferences. *Journal of General Internal Medicine, 22*(11), 1579–1582. doi:10.1007/s11606-007-0370-6

Smith, A., Earle, C., & McCarthy, E. (2009). Racial and ethnic differences in end-of-life care in fee-for-service medicare beneficiaries with advanced cancer. *Journal of the American Geriatrics Society, 57*(1), 153–158. doi:10.1111/j.1532-5415.2008.02081.x

Smith, A., McCarthy, E., Paulk, E., Balboni, T., Maciejewski, P., Block, S., & Prigerson, H. (2008). Racial and ethnic differences in advance care planning among patients with cancer: impact of terminal illness acknowledgment, religiousness, and treatment preferences. *Journal of Clinical Oncology, 26*(25), 4131–4137. doi:http://dx.doi.org/10.1200/JCO.2007.14.8452

Smith, A., Sudore, R., & Pérez-Stable, E. (2009). Palliative care for latino patients and their families: Whenever we prayed, she wept. *JAMA—Journal of the American Medical Association, 301*(10), 1047–1057. doi:10.1001/jama.2009.308

Smith, L. (2012). *Decolonizing Methodologies: Research and Indigenous Peoples* (2nd ed.). New Zealand: Otago University Press.

Smith, T., Dow, L., Virago, E., Khatcheressian, J., Lyckholm, L., & Matsuyama, R. (2010). Giving honest information to patients with advanced cancer maintains hope. *Oncology, 24*(6).

Spanos, A. (2007). A Dying Hegemony: Resisting Anti-Arab Racism in the U.S. *Human Architecture: Journal of the Sociology of Self-Knowledge* (Summer), 285–296.

Stephen, L. (2012). The Story of PCUN and the Oregon Farmworker Movement in Oregon. Retrieved from http://cllas.uoregon.edu/wp-content/uploads/2010/06/PCUN_story_WEB.pdf

Sullivan, M. (2001). Lost in translation: how Latinos view end-of-life care. *Plastic Surgical Nursing, 21*(2), 90–91.

Talamantes, M. (2000). Advance Directives and End-of-Life Care: The Hispanic Perspective. In K. Braun, J. Pietsch, & P. Blanchette (Eds.), *Cultural Issues in End-of-Life Decision Making* (pp. 83–100). Thousand Oaks, CA: Sage Publications, Inc.

Taxis, C., Keller, T., & Cruz, V. (2008). Mexican Americans and hospice care. Culture, control, and communication. *Journal of Hospice and Palliative Nursing, 10*(3), 133–141. doi:10.1097/01.NJH.0000306739.10636.5f

Taylor, J., Brown, A., Prescott, L., Sun, C., Ramondetta, L., & Bodurka, D. (2016). Dying well: How equal is end of life care among gynecologic oncology patients? *Gynecologic Oncology, 140*(2), 295–300. doi:10.1016/j.ygyno.2015.12.012

Taylor, J., Rajan, S., Zhang, N., Meyer, L., Ramondetta, L., Bodurka, D., . . . Giordano, S. (2017). End-of-Life Racial and Ethnic Disparities Among Patients With Ovarian Cancer. *Journal of Clinical Oncology, 35*(16), 1829–1835.

Tellez-Giron, P. (2007). Providing culturally sensitive end-of-life care for the latino/a community. *Wisconsin Medical Journal, 106*(7), 402–406.

Teno, J., Clarridge, B., Casey, V., Welch, L., Wetle, T., Shield, R., & Mor, V. (2004). Family perspectives on end-of-life care at the last place of care. *JAMA, 291*(1), 88–93.

Tervalon, M., & Murray-García, J. (1998). Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. *Journal of Health Care for the Poor and Underserved, 9*(2), 117–125.

Texas Department of State Health Services. (2016). Texas Cancer Registry. Retrieved from https://www.dshs.texas.gov/tcr/

The Joint Commission. (2015). *The Joint Commission Standards*. Retrieved from Oak Brook, IL:

Thomas, D. (2006). A general inductive approach for analyzing qualitative evaluation data. *American journal of evaluation, 27*(2), 237–246.

Thompson, B., Lawson, D., Croughan-Minihane, M., & Cooke, M. (1999). Do patients' ethnic and social factors influence the use of do-not-resuscitate orders? *Ethnicity & Disease, 9*(1), 132–139.

Thompson, H., Valdimarsdottir, H., Winkel, G., Jandorf, L., & Redd, W. (2004). The Group-Based Medical Mistrust Scale: Psychometric properties and association with breast cancer screening. *Preventive Medicine, 38*(2), 209–218. doi:10.1016/j.ypmed.2003.09.041

Turner, L. (2005). From the local to the global: Bioethics and the concept of culture. *Journal of Medicine and Philosophy, 30*(3), 305–320. doi:10.1080/03605310590960193

Univision Northwest. (2005). Portland, Oregon: Hyper-growth Hispanic Market. Retrieved from http://www.hmccoregon.com/events/downloads/pdfs/UnivisionApril212005.pdf

United Nations Educational, S. a. C. O. (2018). Hospicio Cabañas, Guadalajara. Retrieved from https://whc.unesco.org/en/list/815

U.S. Census Bureau. (2010). QT-P10 Hispanic or Latino by Type: 2010 Census Summary. Retrieved from http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=DEC_10_SF1_QTP10&prodType=table

U.S. Census Bureau. (2014). 2010–2014 American Community Survey 5-Year Estimates. Retrieved from http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_14_5YR_B03001&prodType=table

U.S. Census Bureau. (2016). Facts-for-Figures: Hispanic Heritage Month 2016. Retrieved from http://www.census.gov/newsroom/facts-for-features/2016/cb16-ff16.html

U.S. Census Bureau. (2016). American Fact Finder. Retrieved from https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=CF

U.S. Department of Health & Human Services, Centers for Medicare and Medicaid Services. (2016a). Coverage for Lawfully Present Immigrants. Retrieved from https://www.healthcare.gov/immigrants/lawfully-present-immigrants/

U.S. Department of Health & Human Services, Centers for Medicare and Medicaid Services. (2012). Emergency Medical Treatment & Labor Act (EMTALA). Retrieved from https://www.cms.gov/regulations-and-guidance/legislation/emtala/

U.S. Department of Health and Human Services. (2016). HCUP National (Nationwide) Inpatient Sample (NIS)—Restricted Access File. Retrieved from http://www.healthdata.gov/dataset/hcup-national-nationwide-inpatient-sample-nis-restricted-access-file

U.S. Department of Health & Human Services, Centers for Medicare and Medicaid Services. (2016b). Long Term Care Minimum Data Set (MDS). Retrieved from https://www.cms.gov/Research-Statistics-Data-and-Systems/Files-for-Order/IdentifiableDataFiles/LongTermCareMinimumDataSetMDS.html

U.S. Department of Health & Human Services, Centers for Medicare and Medicaid Services. (2016c). Medicaid. Retrieved from https://www.medicare.gov/your-medicare-costs/help-paying-costs/medicaid/medicaid.html

U.S. Department of Health & Human Services, Centers for Medicare and Medicaid Services. (2016d). What's Medicare? Retrieved from https://www.medicare.gov/sign-up-change-plans/decide-how-to-get-medicare/whats-medicare/what-is-medicare.html

U.S. Department of Health and Human Services. (2014). Healthy People 2020. Retrieved from https://www.healthypeople.gov/

Vasas, E. (2005). Examining the margins: A concept analysis of marginalization. *Advances in Nursing Science, 28*(3), 194–202. doi:10.1097/00012272-200507000-00002

Velazquez, I. (2013). Individual Discourse, Language Ideology and Spanish Transmission in El Paso, Texas. *Critical Discourse Studies, 10*(3), 245–262. doi:10.1080/17405904.2013.789975

Viruell-Fuentes, E. (2007). Beyond acculturation: Immigration, discrimination, and health research among Mexicans in the United States. *Social Science and Medicine, 65*(7), 1524–1535. doi:10.1016/j.socscimed.2007.05.010

Volker, D., & Wu, H. (2011). Cancer patients' preferences for control at the end of life. *Qualitative Health Research, 21*(12), 1618–1631. doi:http://dx.doi.org/10.1177/1049732311415287

von Gunten, C. (2008). Never mind. *Journal of Palliative Medicine, 11*(5), 669–670. doi:http://dx.doi.org/10.1089/jpm.2008.9912

Wagner, W., Holtz, P., & Kashima, Y. (2009). Construction and deconstruction of essence in representating social groups: Identity projects, stereotyping, and racism. *Journal for the Theory of Social Behaviour, 39*(3), 363–383. doi:10.1111/j.1468-5914.2009.00408.x

Ward, E., Jemal, A., Cokkinides, V., Singh, G., Cardinez, C., Ghafoor, A., & Thun, M. (2004). Cancer disparities by race/ethnicity and socioeconomic status. *Ca-A Cancer Journal for Clinicians, 54*(2), 78–93.

Warda, M. (2000). Mexican Americans' perceptions of culturally competent care. *Western Journal of Nursing Research, 22*(2), 203–224.

Webb, N., & Tucker, D. (2009). Young adults' opinions about hospice and home death. *Journal of Palliative Medicine, 12*(4), 337–342. doi:10.1089/jpm.2008.0265

Weinick, R., Jacobs, E., Stone, L., Ortega, A., & Burstin, H. (2004). Hispanic healthcare disparities challenging the myth of a monolithic hispanic population. *Medical Care, 42*(4), 313–320. doi:10.1097/01.mlr.0000118705.27241.7c

Widera, E., Rosenfeld, K., Fromme, E., Sulmasy, D., & Arnold, R. (2011). Approaching patients and family members who hope for a miracle. *Journal of Pain and Symptom Management, 42*(1), 119–125. doi:10.1016/j.jpainsymman.2011.03.008

Wilder, H., Oliver, D., Demiris, G., & Washington, K. (2008). Informal hospice caregiving: The toll on quality of life. *Journal of Social Work in End-of-Life and Palliative Care, 4*(4), 312–332. doi:10.1080/15524250903081566

Will, J. (2011a). A brief historical and theoretical perspective on patient autonomy and medical decision making: Part I: The beneficence model. *Chest, 139*(3), 669–673. doi:10.1378/chest.10-2532

Will, J. (2011b). A brief historical and theoretical perspective on patient autonomy and medical decision making: Part II: The autonomy model. *Chest, 139*(6), 1491–1497. doi:10.1378/chest.11-0516

Winston, C., Leshner, P., Kramer, J., & Allen, G. (2005). Overcoming barriers to access and utilization of hospice and palliative care services in African-American communities. *Omega: Journal of Death and Dying, 50*(2), 151–163. doi:10.2190/QQKG-EPFA-A2FN-GHVL

WIRB-Copernicus Group. (2014, July 16, 2014). Legally Authorized Representatives Children and Guardians, document HRP-021. Retrieved from http://www.ohsu.edu/xd/about/services/integrity/policies/upload/HRP-021-POLICY-Legally-Authorized-Representatives-Children-and-Guardians-ohsu.pdf

Wong, C., Holroyd-Leduc, J., Simel, D., & Straus, S. (2010). Does this patient have delirium?: Value of bedside instruments. *JAMA—Journal of the American Medical Association, 304*(7), 779–786. doi:10.1001/jama.2010.1182

World Health Organization. (2017). Equity. Retrieved from http://www.who.int/healthsystems/topics/equity/en/

World Health Organization. (2018). Social Determinants of Health. Retrieved from http://www.who.int/social_determinants/sdh_definition/en/

Worster, B., Bell, D., Roy, V., Cunningham, A., LaNoue, M., & Parks, S. (2018). Race as a Predictor of Palliative Care Referral Time, Hospice Utilization, and Hospital Length of Stay: A Retrospective Noncomparative Analysis. *American Journal of Hospice and Palliative Medicine, 35*(1), 110–116. doi:10.1177/1049909116686733

Wul, F., Arteaga, C., Torrisi, P., & Roffe, C. (2007). Conicimiento, Informacion y Toma de Decisiones en Pacientes con Cancer en el Gran Buenos Aires Sur. *Medica Paliativa, 14*(3), 158–162.

Wright, A., Stieglitz, H., Kupersztoch, Y., Paulk, M., Kim, Y., Katz, I., . . . Prigerson, H. (2013). United States Acculturation and Cancer Patients' End-of-Life Care. *PLoS ONE, 8*(3). doi:10.1371/journal.pone.0058663

Xian, Y., Holloway, R., Smith, E., Schwamm, L., Reeves, M., Bhatt, D., . . . Peterson, E. (2014). Racial/Ethnic Differences in Process of Care and Outcomes Among Patients Hospitalized With Intracerebral Hemorrhage. *Stroke*. doi:10.1161/STROKEAHA.114.005620

Yennurajalingam, S., Parsons, H., Duarte, E., Palma, A., Bunge, S., Lynn Palmer, J., . . . Bruera, E. (2013). Decisional control preferences of hispanic patients with advanced cancer from the United States and Latin America. *Journal of Pain and Symptom Management, 46*(3), 376–385. doi:10.1016/j.jpainsymman.2012.08.015

Yeung, B., & Rubenstein, G. (2013). Female Workers Face Rape, Harassment in U.S. Agriculture Industry. Retrieved from http://www.pbs.org/wgbh/pages/frontline/social-issues/rape-in-the-fields/female-workers-face-rape-harassment-in-u-s-agriculture-industry/

Young, M., & Lehmann, L. (2014). Undocumented injustice? Medical repatriation and the ends of health care. *New England Journal of Medicine, 370*(7), 669–673. doi:10.1056/NEJMhle1311198

Zahuranec, D., Brown, D., Lisabeth, L., Gonzales, N., Longwell, P., Smith, M., . . . Morgenstern, L. (2009). Ethnic differences in do-not-resuscitate orders after intracerebral hemorrhage. *Critical Care Medicine, 37*(10), 2807–2811. doi:http://dx.doi.org/10.1097/CCM.0b013e3181a56755

Zier, L., Sottile, P., Hong, S., Weissfield, L., & White, D. (2012). Surrogate decision makers' interpretation of prognostic information: A mixed-methods study. *Annals of Internal Medicine, 156*(5), 360–366.

Zinn, M. (1994). Mexican-Heritage Families in the United States. In F. Padilla (Ed.), *Handbook of Hispanic Cultures in the United States: Sociology* (pp. 161–172). Houston, Texas: Arte Publico Press, University of Houston.

Appendices

A	Study Brochure	227
B	Spanish-Language Advertisement Published in Oregon and Washington Spanish-Language Newspapers	228
C	National Institute of Nursing Certificate of Confidentiality	229
D	Copyright Permission from Sage Publishing for Chapters 2 and 3	232
E	Copyright Permission from the *Journal of Healthcare for the Poor and Underserved*	233
F	Study Protocol	234
G	Consent, Hospice User/Avoider	262
H	Consent, Key Informant	270
I	Interview Guide, Individual	278
J	Interview Guide, Family	282
K	Interview Guide, Key Informant	286

Appendix A

Study Brochure

IRB Approved: 9/25/2018

Healthcare Conversations with Mexicans

OHSU IRB # 00017421

- Tell the Latino story
- Raise the Latino voice
- Improve Latino healthcare

Please help us improve healthcare for Latinos with serious cancer.

Share the story of your family's recent healthcare experience around this serious illness.

We want to understand the challenges you faced – cultural, language, financial, discriminatory. Participation includes:

- one family conversation (60 minutes)
- 1 to 3 private individual conversations (30 to 60 minutes)
- your identity will remain confidential
- $100 Fred Meyer's gift card per family
- The investigator will come to your home or other location of your choice
- If needed, all conversations are with an interpreter from your country who speaks your language and understands your customs

Contact Maggie Rising, RN, the investigator:
(503) 758-3688 (cell), risingm@ohsu.edu (e-mail)

Or contact the healthcare person offering this brochure: ____________________ ____________________
Name contact information

Principle investigator: Dena Hassouneh PHD, RN, ANP, PMHNP, FAAN

Appendix B

Spanish-Language Advertisement Published in Oregon and Washington Spanish-Language Newspapers

Un estudio de decisiones de salud entre personas de ascendencia mexicana

OHSU IRB # 00017421

Si un miembro de su familia ha muerto de cáncer, usted puede calificar para este estudio

Puede calificar si:

1) Es mayor de 18 años de edad.
2) Un miembro de su familiar murió de cáncer.
3) El familiar estuvo en “*hospice*” o le *ofrecieron “hospice*”.
4) Es de ascendencia mexicana.

Los servicios de *“hospice*” son un tipo de cuidado de salud que se le da a varios pacientes al final de su vida. Con los servicios de “*hospice*,” las enfermeras, médicos, trabajadores sociales y otras personas ayudan a controlar síntomas como el dolor y la falta de aliento, pero no brindan tratamiento curativo. El paciente y la familia eligen inscribirse con servicios de “*hospice*.” Por eso, no es lo mismo que cuidado paliativo.

Meta: **mejorar la atención del cuidado del fin de vida dado a** familias mexicanas o mexicoamericanas.

¡Su experiencia es importante! ¡Su historia puede enseñar a los demás!

Cómo **agradecimiento** por participar en el estudio, las familias recibirán una **tarjeta de regalo de $100** para Fred Meyer’s. La participación en el estudio incluye una entrevista familiar y, posiblemente, una entrevista personal. Cada entrevista dura una hora y se realiza en un lugar y a una hora que usted elija, incluso fines de semana y en su casa. La persona que realiza la entrevista, Maggie Rising, es enfermera y docente originaria del sur de Texas que ha vivido y ha viajado extensamente en México y Guatemala. Como enfermera registrada, ha atendido a latinos y está realizando este estudio para escuchar su opinión sobre qué se podría hacer para mejorar la atención. Ella habla español y U.S.A.rá un intérprete de español durante las entrevistas. La duración total de las entrevistas durará entre 1 a 3 horas, más un posible seguimiento por teléfono dentro del mes después de la entrevista. Su identidad será mantenida en completo secreto, y Maggie tiene un certificado que le permite legalmente negarse a difundir su información.

Para más información, póngase en contacto con:

Maggie Rising, RN:
(503) 758-3688 (celular personal)
risingm@ohsu.edu (correo electrónico)

Supervisor del estudio: Dena Hassouneh PHD, RN, ANP, PMHNP, FAAN

Appendix C

National Institute of Nursing Certificate of Confidentiality

DEPARTMENT OF HEALTH & HUMAN SERVICES **Public Health Service**

National Institute of Nursing
Research
6701 Rockledge Drive
Room 8135
Bethesda, MD 20892

CONFIDENTIALITY CERTIFICATE

CC-NR-18-003

issued to

Oregon Health and Sciences University

conducting research known as

"Hospice Decision Making in Mexican Americans with Terminal Cancer and Their Families"

In accordance with the provisions of section 301(d) of the Public Health Service Act 42 U.S.C. 241(d), this Certificate is issued in response to the request of the Principal Investigator, Dr. Dena Hassouneh to protect the privacy of research subjects by withholding their identities from all persons not connected with this research. Dr. Dena Hassouneh is primarily responsible for the conduct of this research, which is funded by the American Cancer Society and Hartford Geriatric Foundation: Sigma Theta Tao International (pending).

Under the authority vested in the Secretary of Health and Human Services by section 301(d), all persons who:

1. are enrolled in, employed by, or associated with the Oregon Health and Sciences University and its contractors or cooperating agencies, and
2. have in the course of their employment or association access to information that would identify individuals, who are the subjects of the research, pertaining to the project known as "**Hospice Decision Making in Mexican Americans with Terminal Cancer and Their Families**."
3. are hereby authorized to protect the privacy of the individuals, who are the subjects of that research, by withholding their names and other identifying characteristics from all persons not connected with the conduct of that research.

This behavioral research study seeks to understand and describe the process of hospice decision making from the perspective of Mexican Americans with terminal cancer and their families.

CONFIDENTIALITY CERTIFICATE

CC-NR-18-003

issued to

Oregon Health Sciences University

conducting research known as

"Hospice Decision Making in Mexican Americans with Terminal Cancer and Their Families"

Approximately 15 Mexican American families with hospice experience will be interviewed, followed by one-on-one interviews. The interview guideline includes prompts about facilitating factors with respect to hospice decision making, which is expanded to include social forces including religion, discrimination, and citizenship. Data collection will cease at thematic saturation, which is expected to occur with 15 families and after 6 months.

A Certificate of Confidentiality is needed because sensitive information will be collected during the study. The certificate will help researchers avoid involuntary disclosure that could expose subjects or their families to adverse economic, legal, psychological and social consequences.

After completion of interviews, participants identities will be protected through alphanumeric coding. The key to the alphanumeric code will be kept separately in locked files in a locked office with access limited only to CoI Rising. During transcription of interviews, any identifying names of people, buildings, and businesses, as well as others, will be replaced with non-identifying words, the key to which will be locked an only available to CoI Rising. Upon completion of the study, identifiers will be destroyed.

This research begins on 10/20/2017, and is expected to end on 12/31/2018.

As provided in section 301 (d) of the Public Health Service Act 42 U.S.C. 241(d): "Persons so authorized to protect the privacy of such individuals may not be compelled in

any Federal, State, or local civil, criminal, administrative, legislative, or other proceedings to identify such individuals."

This Certificate does not protect you from being compelled to make disclosures that: (1) have been consented to in writing by the research subject or the subject's legally authorized representative; (2) are required by the Federal Food, Drug, and Cosmetic Act (21 U.S.C. 301 et seq.) or regulations issued under that Act; or (3) have been requested from a research project funded by NIH or DHHS by authorized representatives of those agencies for the purpose of audit or program review.

CONFIDENTIALITY CERTIFICATE

CC-NR-18-003

issued to

Oregon Health and Sciences University conducting research known as

"Hospice Decision Making in Mexican Americans with Terminal Cancer and Their Families"

This Certificate does not represent an endorsement of the research project by the Department of Health and Human Services. This Certificate is now in effect and will expire on 12/31/2018.

The protection afforded by this Confidentiality Certificate is permanent with respect to any individual who participates as a research subject (i.e., about whom the investigator maintains identifying information) during the time the Certificate is in effect.

Sincerely,

Marguerite Littleton Kearney

Marguerite Littleton
Kearney, Ph.D., RN,
FAAN Director,
Division of Extramural
Science National
Institute of Nursing
Research

Appendix D

Copyright Permission from Sage Publishing for Chapters 2 and 3

Craig Myles
Rights Coordinator
SAGE Publishing 2455 Teller Road
Thousand Oaks, CA
91320 U.S.A.

October 29, 2018

Dear Margaret L. Rising,

Please consider this letter as gratis permission to include the following two articles you authored in your dissertation for Oregon Health & Science University:

- "Truth Telling as an Element of Culturally Competent Care at End of Life" in '*Journal of Transcultural Nursing*'
- "Integrative Review of the Literature on Hispanics and Hospice" in *'American Journal of Hospice and Palliative Medicine*'

Please note that this permission does not cover any 3rd party material that may be found within the works, and you will need to properly credit the original sources, '*Journal of Transcultural Nursing'* and *'American Journal of Hospice and Palliative Medicine*'. Please contact us for any further U.S.A.ge of the material.

For our standard credit lines, you can use:

Rising, M.L. Truth Telling as an Element of Culturally Competent Care at End of Life. *Journal of Transcultural Nursing* 28(1), pp. 48-55. Copyright © 2017 by the Author. Reprinted by permission of SAGE Publications, Inc.

Rising, M.L., et al. Integrative Review of the Literature on Hispanics and Hospice. *American Journal of Hospice and Palliative Medicine* 35(3), pp. 542-554. Copyright © 2017 by the Authors. Reprinted by permission of SAGE Publications, Inc.

Best regards,

Craig Myles

Craig Myles

Appendix E

Copyright Permission from the *Journal of Healthcare for the Poor and Underserved*

November 21, 2018

Virginia M. Brennan
Journal of Health Care for the Poor and Underserved
Meharry Medical College
Johns Hopkins University Press

Dear Margaret L. Rising,

Please consider this letter as gratis permission to include the following article you authored in your dissertation for Oregon Health & Science University:

> "Hispanic Hospice Utilization: Integrative Review and Meta-analysis" in the *Journal of Healthcare for the Poor and Underserved*

Please note that this permission does not cover any 3rd party material that may be found within the works, and you will need to properly credit the copyright holders for the article named above— Journal of Health Care for the Poor and Underserved, Meharry Medical College; publisher: Johns Hopkins University Press. Please contact us for any further U.S.A.ge of the material.

Thank you,

e-signature
Virginia M. Brennan

Appendix F

Study Protocol

Hospice Decision Making in Mexican Americans with Terminal Cancer and Their Families

OHSU Knight Cancer Institute

Principal Investigator: Dena Hassouneh, PhD, RN, ANP, PMHNP, FAAN

Address or Institution: Oregon Health and Sciences University, School of Nursing, 3455 SW US Veterans Hospital Rd, Portland, OR 97239

Telephone: (503) 494-2714

Minimal Risk Protocol Template

Protocol Title

Hospice Decision Making in Mexican Americans with Terminal Cancer and Their Families

The protocol and all subsequent modifications must be reviewed and approved by the OHSU Knight Cancer Institute (The Knight) Clinical Research Review Committee (CRRC) and OHSU Institutional Review Board (IRB) prior to any patient data collection.

Objectives

The long-term goal of this study is to improve end-of-life (EOL) care for Hispanics. The purpose is to describe how Mexican Americans with terminal cancer and their families navigate cultural and social barriers to hospice enrollment. Using dimensional analysis within the context of postcolonial theory, this study **aims** to:

1) describe the meaning of hospice for Mexican Americans with terminal cancer and their families;
2) describe the influence of religion, socioeconomic status, discrimination, oppression, and other social forces on hospice decision making for Mexican Americans with terminal cancer and their families; and
3) construct a substantive grounded theory describing the process of hospice decision making for Mexican Americans with terminal cancer and their families.

Background

Introduction

The Institute of Medicine (Institute of Medicine, 2014; Nelson et al., 2002) and the American Cancer Society (ACS) (American Cancer Society, 2015; Green, 2006; Satcher, 2001; Ward et al., 2004) have called for improved quality of care at end of life (EOL) for Hispanics. Hospice care is a type of EOL care provided by an interdisciplinary team with a focus on comfort, quality of life, and symptom control (National Hospice and Palliative Care Organization, 2015). The Hispanic ethnic category is a sociopolitical construct created by the U.S. Census Bureau (USCB) to refer to persons of Cuban, Puerto Rican, South or Central American, or other Spanish descent, regardless of race (Ennis et al., 2011). An estimated 17% of the U.S. population is comprised of Hispanics, which is considered the largest minority group in the U.S. (United States Census Bureau, 2016). According to the ACS, cancer is the leading cause of death for Hispanics (American Cancer Society, 2015), and it is the second leading cause of death for Hispanics behind heart disease when heart disease includes stroke (Heron, 2015). Cancer is the leading hospice admission diagnosis (National Hospice and Palliative Care Organization, 2015).

This study focuses on Mexican Americans, who comprise 60% of the U.S. Hispanic population (Ennis et al., 2011; Gonzalez-Barrera & Lopez, 2013). Although Mexican Americans are a heterogeneous group, focusing on Mexican Americans in lieu of Hispanics acknowledges the cultural and sociopolitical heterogeneity among Hispanic subgroups. For purposes of this study, Mexican Americans are persons in the U.S. who trace their ancestry to Mexico, regardless of citizenship. Throughout this proposal, use of the word “Hispanic” is necessary where research results or data are only available for Hispanics. Significantly, the unit of study in this research is the **family** which, in this study, is not limited to relation by blood or marriage and is defined by participants. There are two primary reasons for focusing families rather than individuals. Research results support the inference that Hispanics are more likely to engage in shared, or family, decision making at EOL (Bade et al., 1999; Blackhall et al., 1995; Caralis et al., 1993; Gutheil & Heyman, 2006; Jonnalagadda et al., 2012; Kreling, et al., 2010; Nedjat-Haiem et al., 2013; Noguera et al., 2014; Yennurajalingam et al., 2013). In addition, initiating research with the whole family is intended as a form of culturally competent research, consistent with *familismo*. With *familismo*, Mexican Americans, consistent with their collectivist culture, tend demonstrate value for family over individual family members, and they maintain strong family cohesion (Carteret, 2011; Del Río, 2010; Juckett, 2013; Talamantes, 2000; Tellez-Giron, 2007; Warda, 2000). Allowing family members to designate who constitutes family for purposes of this research acknowledges the expansive definition of family sometimes found within the Mexican American culture.

The demographic portrait for many Mexican Americans in Oregon is one of poverty, hard labor, lack of citizenship, and Spanish-speaking in the home. The estimated 404,999 Mexican Americans (United States Census Bureau, 2014) make up 85% of the Hispanic population there (Ennis et al., 2011; Garcia, 2016; Pew Research Center, 2011). Of the estimated 120,000-130,000 undocumented Hispanic immigrants, 75% are of Mexican American (Pew Research Center, 2014a, 2014b). The average Oregon Hispanic income is $18,000 a year (data available on Hispanics) (Pew Research Center, 2011). Estimated numbers vary, but almost one-fourth of the Mexican Americans in Oregon are migrant farm workers (Stephen, 2012). Many migrant farm workers speak indigenous languages (Larson, 2013). Undocumented and indigenous Mexican Americans are particularly marginalized owing to legal and language barriers. Although a larger number of Hispanics reside in or around urban areas, Hispanics comprise a larger percentage of the population in many rural areas. Reflecting the new racial diversity in the rural U.S. (Lichter, 2012), Oregon Hispanics in 2010 comprised large percentages of rural counties such as Malheur (31.5%), Morrow (31.3%), Hood River (29.5%), and Marion (24.5%) compared to their overall state percentage (11.7%) (Index Mundi, 2010). Of Hispanics residing in the urban Portland metro area, reportedly 74% speak Spanish at home and 79% are Mexican (Univision Northwest, 2005).

Conceptual Basis

Although demographic characteristics of Oregon Mexican Americans vary, many who face healthcare choices at EOL must do so with limited education, English skills, finances, and medical insurance. This power differential between many Oregon Mexican Americans and the healthcare system is accounted for in this study through a postcolonial theory (PCT) conceptual framework (Anderson, 2004; Kincheloe & McLaren, 2002; Said, 1978). Postcolonial theory holds that descendants of colonized populations continue to endure discriminatory, oppressive, stigmatizing, marginalizing forces, even if they are invisible and the perpetrators remain unaware.

There are many examples of such forces for Hispanics in the healthcare system. First, the ACS and others have observed that Hispanics bear a socially unjust cancer burden in light of their exposure to carcinogenic pesticides, lack of early detection and screening, late-stage diagnoses, poor pain control, and lack of culturally competent care at EOL (American Cancer Society, 2015; Green, 2006; Satcher, 2001; Ward et al., 2004). Second, institutional biases prevent some Hispanics – particularly Mexican Americans – from accessing Medicare and Medicaid (Alsina et al., 2009; U.S. Centers for Medicare and Medicaid Services, 2016a, 2016b). Together, Medicare and Medicaid pay for 90.5% of hospice care in the U.S. in 2014 (National Hospice and Palliative Care Organization, 2015). Third, some Hispanics must navigate a significant cultural barrier created by the culturally incompatible Medicare hospice benefit enrollment process. On the one hand, many Hispanics prefer prognostic secrecy (Blackhall, et al., 2001; Frank et al., 2002; Gelfand, et al., 2001; Gutheil & Heyman, 2006; Kreling, et al., 2010). In contrast, there is a tendency toward open discussions of prognosis in the hospice decision-making and enrollment process owing to Medicare hospice benefit requirements (Code of Federal Regulations, 2017a, 2017b, 2017c; Meier, 2011). A preference for prognostic secrecy in a healthcare system that emphasizes open prognostic discussions may reduce the likelihood of receiving optimal EOL care consistent with the IOM and ACS recommendations. Four, in *Unequal Treatment*, the IOM documented the continued existence of bias against minorities in the healthcare system (Nelson et al., 2002) and minorities continue to report that they experience bias (Johnson, Saha, Arbelaez, Beach, & Cooper, 2004). These four examples support the assumption that the decision to enroll in hospice occurs within a context of a continuing invisible colonial legacy of oppression, stigmatization, bias, discrimination, and marginalization consistent with PCT. Viewing this study through a PCT framework accomplishes two important tasks: 1) it sensitizes the research team to these social forces and to pursue their impact on hospice decision-making through follow up questions, and 2) it expands the focus of the study from exclusively “culturally competent care,” which is racializing in its tendency to facilitate stereotypes, to considerations of healthcare provider bias and institutionalized discrimination.

Cultural clash

The cultural clash between hospice and Hispanic EOL preferences is a significant challenge at EOL and creates unique challenges in this study. There are two main sources of this clash. First, there is discordance between the collectivistic Hispanic preference for prognostic secrecy (Blackhall et al., 2001; Frank et al., 2002; Gelfand et al., 2001; Gutheil & Heyman, 2006; Kreling et al., 2010) and the hospice philosophy, which embraces Western / Eurocentric cultural values in its emphasis on open prognostic discussions to allow preparation for death (National Hospice and Palliative Care Organization, 2010). These Eurocentric cultural values are reflected in Medicare hospice federal regulations, which require waiver of curative therapy for the terminal condition and acknowledging a plan based on palliative or comfort care (Code of Federal Regulations, 2017a, 2017b, 2017c; Meier, 2011). Although individual hospices vary in their approach to enrollment and the extent to which they emphasize a terminal prognosis, there remains the potential for a cultural clash. The second issue is language-based. When translated into Spanish, the word hospice is *hospicio*, (*hospicio*, 2014) which has a distinctly negative meaning for Mexicans. In Mexico, *hospicios* are perceived as institutions for the unwanted and so connote abandonment. Verbatim translation of the word hospice can create confusion, as a result. As a result of these potential cultural clashes, the IOM and ACS recommendations to improve quality of care at EOL invite research to facilitate understanding how hospice enrollment is navigated by Hispanics.

Literature Review – Hispanics and Hospice

There is strong evidence in the quantitative research literature that Hispanics are mostly unaware of hospice (Colon, 2012; Pan et al., 2015; Randall & Csikai, 2003; Selsky et al., 2012). However, the research literature on Hispanics and hospice is mostly inconclusive with respect to whether Hispanics are receptive to hospice or are receiving quality hospice care. Studies relying on cancer databases to compare Hispanic hospice utilization rates to non-Hispanic White (NHW) rates suggest that Hispanics with cancer are using hospice at rates on par with NHWs (Lackan et al., 2003; Lackan et al., 2004; Smith et al., 2009) (though not with other illnesses (e.g., Givens et al., 2010, heart failure; Xian et al., 2014, intracerebral hemorrhage)). However, equal rates do not amount to equity in that those studies offer no insight into whether Hispanics with cancer are receiving quality EOL hospice care consistent with the IOM and ACS recommendations.

Unfortunately, most survey studies measuring Hispanic receptiveness to hospice rely on surveys created for NHWs and are not validated for Hispanics or the Spanish language. Nonetheless, such quantitative ethnic comparison studies provide mixed results on hospice receptiveness and satisfaction. One study with surviving caregivers of hospice patients reports that Hispanics were significantly more likely than NHWs to report receiving care against their wishes at EOL; however, they also reported overall satisfaction with hospice (Kirkendall et al. 2015). Another study with terminally ill lung cancer patients reports that Hispanics were more likely than NHWs to report that hospice is not necessary as long as family is available to provide care (Jonnalagadda et al., 2012). In a study with Central Americans, results suggest that participants who preferred maintaining secrecy about prognosis were less likely to recommend hospice care in adjusted analysis (OR 0.81, .67-.99) (Selsky et al., 2012).

The research literature also includes several definition-based studies in which researchers provide hospice definitions to healthy study participants and inquire whether they would choose hospice or recommend it in the context of terminal illness. Many of these studies do not provide the definition of hospice given to participants (Colon, 2012; Selsky et al., 2012) and, those that do, use different definitions, precluding comparisons (Pan et al., 2015, p. 929; Park, et al., 2016, p. 3; Ruff et al., 2011, p. 178). Results from these definition-based studies range from 35% (Selsky et al., 2012) to 65% (Colon, 2012) preferring hospice.

Finally, several qualitative studies with Hispanics and hospice provide exemplars supporting the inference that Hispanics want healthcare workers to respect their culture and want to maintain control of providing care to their family (Born et al., 2004; Taxis et al., 2008). With respect to prognostic disclosure preferences, however, results from two qualitative studies are in sharp contrast to one another. One reports that the open discussion of a terminal prognosis was offensive and rude (Kreling et al., 2010). In contrast, another study reports that educational materials explaining the dying process were welcomed (Taxis et al., 2008).

In conclusion, little is known about Hispanics and hospice, and much of what is known is contradictory. Specifically, it remains unclear how Mexican Americans decide whether to enroll in hospice, which occurs within the context of a confluence of cultural and potentially discriminatory forces. The proposed study design will answer these questions by allowing Mexican Americans, in their own words, to describe what hospice means to them, how discrimination and lack of insurance, for example, influenced them, and, ultimately how they decided to use hospice.

Study Design

Overview

The proposed study will occur with the input from **a community advisory board** comprised of members of the Portland, Oregon, Mexican American Community. As a dissertation, it will be supervised by a dissertation committee that includes a committee chair who is an R01 research scientist and conducts research with marginalized populations. The methodology used will be an alternative form of grounded theory called dimensional analysis (Bowers, 1988; Bowers & Schatzman, 2009; Kools et al., 1996; Robrecht, 1995; Schatzman, 1991). The intent is to retrospectively describe the process of hospice decision making from 3 perspectives: 1) the family members (sample group #1), 2) qualified agency personnel as key informants (sample group #2), and 3) qualified community health workers as key informants (sample group #3). All data collection is via interview, either in person or on the telephone. Quality of data is not compromised by telephone interviewing, and telephone interviewing even offers increased response rate, increased access to hard-to-reach participants, increased number of interviews per day, and moderate costs. However, for cultural reasons, all family interviews will only occur face-to face. Family members' perspectives will be recorded in an initial family interview followed by one-on-one interviews with interested family members. ' To facilitate adequate recruitment in a limited period of time, **the terminal cancer patient from enrolled families may be living or deceased**. .

Methodology: Dimensional Analysis (DA)

Dimensional analysis (DA) is similar to traditional grounded theory (Glaser & Strauss, 1967) in two ways. First, the philosophical roots of DA are in symbolic interactionism and American pragmatism (Blumer, 1969; Bowers, 1988; Bowers & Schatzman, 2009; Kools et al., 1996; Robrecht, 1995). Symbolic interactionism emphasizes derived, personal meanings as the impetus to social action; specifically, that people act in ways that reflect meanings derived through social interaction and personal reflection. American pragmatism adds fluidity and flexibility to grounded theory, both in its capacity to evolve as a method and to derived meanings which are continuously reassessed and changing. The second way in which DA is like traditional grounded theory is that they use the same analytical processes described in the grounded theory literature. For example, both DA and grounded theory use theoretical sampling, thematic saturation, constant comparative analysis, coding, memo writing, concept and theory formation, and ultimate development of a substantive grounded theory (Bowers, 1988; Bowers & Schatzman, 2009; Kools et al., 1996; Robrecht, 1995; Schatzman, 1991).

On the other hand, DA is distinct from grounded theory in two ways. The first is particularly helpful in cross-cultural research. In DA, the investigator delays conceptual closure, keeping the substantive grounded theory open to concepts beyond the investigator's intuitive knowledge or bias (Bowers & Schatzman, 2009; Schatzman, 1991). The rationale for delaying conceptual closure is explained by the developer of DA, Lenny Schatzman (Schatzman, 1991). Schatzman recognized an inherent tendency in the investigator to prematurely seek conceptual and theoretical development in conjunction with presumptive comprehensive knowledge (Bowers & Schatzman, 2009; Schatzman, 1991). Before developing grounded theories, Schatzman thought it important to answer the question, "What *all* is going on here?" (Bowers & Schatzman, 2009; Schatzman, 1991). In cross-cultural research, the investigator's lack of inductive knowledge could lead to false conceptual trails or, alternatively, eclipse development of important concepts not immediately apparent to an investigator from another culture. The second way in which DA is distinguishable from GT is epistemological, or how the investigator develops knowledge. Traditional GT methodological techniques include conditional matrices (Corbin & Strauss, 2015) or preconceived coding families (Glaser, 1978). In contrast, DA follows a simple but systematic form of natural analysis. Schatzman rejected the need for specialized analytical tools, believing humans since childhood have conducted a type of natural analysis that can be scientifically applied to explore dimensions and properties of ideas (Bowers, 1988; Bowers & Schatzman, 2009; Schatzman, 1991). He advocated that this natural analysis precludes the need for specialized analytical tools, with the exception of the explanatory matrix during construction of the final substantive grounded theory.

The PCT conceptual framework modifies the implementation of DA by taking into consideration the power differential between study participants and the healthcare system as well as society at large. Consideration of this power differential is not included in symbolic interactionism or American pragmatism. PCT identifies the continued, invisible colonization of previously colonized "others," evidenced by their continued exploitation, stigmatizing, oppression, and marginalization (Anderson, 2004; Kincheloe & McLaren, 2002; Said, 1978). In PCT, the dominant culture creates biased and exclusionary institutions, including healthcare, that propagate continued exploitation, stereotyping, marginalization, and oppression. Members of the dominant culture remain indifferent to the suffering of the "others" (Anderson, 2004; Said, 1978). Oblivious to their Eurocentrism, members of the dominant culture may remain unaware of the connection between institutionalized discrimination and that suffering (Anderson, 2004; Said, 1978). In the context of Mexican Americans and hospice decision-making, the unavailability of Medicare and Medicaid for hospice offers an example of such suffering. And so do the intentional and unintentional acts of bias and racism by healthcare personnel that reflect the stigmatized and marginalized status of Mexican Americans. Dimensional analysis (DA) within a PT framework is sensitized to prompt participants to speak to these otherwise invisible social forces during their interviews.

Study Population

a) Number of Subjects

It is expected that N = 15 families and N=20-30 key informants with perspectives on Mexican family hospice decision making will produce the desired data. Sample size in grounded theory is not mathematically fixed. Instead, it is directly related to theoretical saturation. Theoretical saturation in this study will occur when there is consensus among the dissertation committee and the community advisory board members that the dimensions and properties of all developing themes and theories have been fully described (Creswell, 2013). Such saturation is predicted to occur with 30-50 interviews (Morse, 1995). Each family is expected to generate 2-5 interviews (1:2-5 ratio, i.e., it is estimated that engagement with one family will result in one family interview, 1-2 individual interviews, and the possibility of 1-2 additional follow up individual interviews).Other grounded theory studies with families have sampled as many as 24 families (Perry, Hatton, & Kendall, 2005); however, the ratio of interviews to families was much closer to 1:1 in that study. A goal of 15 families as well as 30 key informants is consistent with the limited resources and time available in this dissertation research.

It is not known how many of these research participants will originate from the multiple healthcare centers in this study. Qualitative research sampling strategies strive for variation in perspectives rather than a set number of participants from particular recruitment sites.

b) Inclusion and Exclusion Criteria

1. Sampling group #1: Inclusion criteria for Mexican families are as follows:

1) Terminal cancer patient is/was 18 years of age at time of cancer diagnosis, and
2) Hospice services for terminal cancer patient
    a. offered (patient living or deceased, any length of time since death),
    b. received (patient deceased, any length of time since death),
    c. received (now off of hospice), or
    d. ongoing (patient living)
3) From 1 to 6 family members available for an interview (explaining that "family" is not limited to blood or marriage and that there may only be a single surviving family member).

And, for individual interviews, the following **additional inclusion criterion applies**:

1) Familiar with the healthcare received by the terminal cancer patient.

Exclusion criteria for terminal cancer patient are as follows:

1) Unable to provide informed consent, a representative unable to provide consent, or disagreement among the family (please see section c) vulnerable populations)

2) Patient states inability to participate due to pain, fatigue, or other symptoms.

Any data received on individuals who fail the initial screening process will be destroyed.

2. Sampling group #2: Inclusion criteria for key informants (agency personnel) are as follows:

1) Has contact with persons of Mexican descent as part of their professional or volunteer roles in hospices, hospitals, non-profits, or community groups (e.g., nurse, doctor, social worker, chaplain, priest, interpreter, massage therapist)
2) In that capacity, is exposed to hospice decision making in families that identify as Mexican,
3) Is Hispanic or Latino OR is bilingual in English and Spanish OR regularly works through a Spanish-language interpreter with persons of Mexican descent when choosing hospice or receiving hospice care.

3. Sampling group #3: Inclusion criteria for key informants (community health workers) are as follows:

1) Has contact with persons of Mexican descent as part of their role as community health worker
2) In that capacity, is exposed to hospice decision making in families that identify as Mexican,
3) Is Hispanic or Latino OR is bilingual in English and Spanish OR regularly works through a Spanish-language interpreter with persons of Mexican descent when choosing hospice or receiving hospice care.

c) Vulnerable Populations

Vulnerable populations require special consideration when conducting research. This study is guided by respect for persons, beneficence, and justice enumerated by the National Bioethics Advisory Commission (NBAC) (National Bioethics Advisory Commission, 1998). Vulnerability manifests in many ways, and the marginalized individuals included in this study are potentially vulnerable and require special consideration. However, <u>none of the following populations</u> will be included be included in the study, and so no data will be collected from them:

- Children
- Pregnant women
- Neonates
- Prisoners

The <u>potentially vulnerable marginalized individuals included in this study</u> are adult individuals with the following:

i. Decisional impairment
ii. Limited or no English-language proficiency
iii. Low healthcare literacy
iv. Undocumented immigration status
v. EOL physical, emotional, and spiritual distress

The following is a discussion justifying inclusion of these populations and describing additional safeguards to protect the rights and welfare of these populations.

i) ***<u>Decisional impairment</u>*** ***(See also Adults Unable to Consent/Decisionally Impaired)***

Due to EOL disease-processes and central-nervous-system-acting medications for symptom control (e.g., opiates, benzodiazepines), it is foreseeable that terminally ill cancer patients will exhibit <u>decisional impairment</u> (complete, progressive, fluctuating, or temporary, depending on the cause). The target population is the family unit, which may or may not include a DI adult. As the study involves family decision making, the DI is not the only individual with information about the decision making process, which can be reflected by the family, instead. Participation by the DI is not a prerequisite to family enrollment in the study. However, participation by the DI will offer an important perspective on decision making, if the family agrees to include the DI.

Only a DI with the least level of impairment compatible with the aims of the study will be included. That is, if the DI impairment is complete (unconscious/delirious), the DI will not be consented. Instead, the LAR will be consented and interviewed. If the impairment is progressive, then a consented DI may lose capacity to conduct interviews, and so no subsequent interviews with the DI will occur. In such a case of progressive impairment, the LAR will be consented (if not already) and interviewed. If impairment is fluctuating or temporary, then the DI may be able to offer interviews while lucid. If the DI is not lucid, then the LAR will be consented (if not already) and interviewed.

When possible, it is important to include the perspectives of some terminal cancer patients in this study to appreciate their role in hospice decision making. A case study describing a Mexican American terminal cancer patient has shown an ambiguous perspective that allowed simultaneously maintaining hope for recovery and preparing for a future death (Frank et al., 2002). This type of subtle ambiguity may be at the heart of understanding the navigation of the clash between the Hispanic and hospice cultures.

(1) Risks

This study does not pose additional physical or emotional risks for adults lacking capacity than for the general population. However, with decisionally impaired individuals, there is a risk that study enrollment or continued enrollment will occur without informed consent and ongoing informed consent, respectively.

(2) Four Steps taken in this study to protect decisionally impaired adults

1) A Decisionally-Impaired (DI) Adults Supplement form has been uploaded.
2) To remove coercive pressure on the terminally ill cancer patient, inclusion of the terminally ill cancer patient is not required for family enrollment or the family interview.

Consent.

Modifications to the Consent Process

We are requesting a waiver of documentation of consent for sampling groups #2 (agency personnel) and #3 (community health workers) when conducting interviews by telephone. The slight risk of breach of confidentiality is minimized by appropriate privacy protections specified in the protocol. A consent script which follows the information sheet and required elements of consent (except for signature line) will be used. Therefore, waiving written consent will not adversely affect the rights and welfare of subjects. Requiring all individuals to meet in person so they can sign a consent form would put an undue burden on potential participants who are very busy and often have difficult schedules.

Terminally ill cancer patients. To protect their interests, such terminally ill cancer patients will not be considered eligible to participate in the study or to provide informed consent if they are unconscious or delirious. Whether a DI is delirious and therefore disqualified from participation in the study will be determined by administration of the Confusion Assessment Method (CAM) (Inouye et al., 1990), which has been suggested as the superior instrument for quickly ascertaining the occurrence of delirium (Wong, Holroyd-Leduc, Simel & Straus (2010). The CAM includes an instrument and diagnostic algorithm for diagnosing delirium and requires 5 minutes to administer. The CAM assesses 4 features: 1) acute onset or fluctuating course (from baseline), 2) inattention (easily distractible or keeping track of what is said), 3) disorganized thinking (incoherent, rambling, illogical flow of ideas), and 4) altered level of consciousness (alert, hypervigilant, lethargic, stupor, coma). A patient must be positive for 1 and 2 and either 3 or 4 to be considered delirious (Wong et al., 2010). The investigator conducting the interviews has over ten years of experience administering the CAM in the hospital setting as well as inpatient hospice setting. In addition to administration of the CAM, the DI will be asked to articulate:

- That the study involves interviews about healthcare decision making relating to his/her health;
- That participation should have no effect on his/her health, but sometimes interviews can be emotionally distressing;
- That this is a study intended to improve healthcare for others in the future and will not immediately impact his/her current healthcare;
- That he/she is free to decline to participate with no consequences to the family's ability to participate in the study;
- That there are no health risks from participating in the study but there is always the possibility of breach of confidentiality, although every effort will be made to ensure deidentification of data and data security;
- That if he/she experiences discomfort or wishes to withdraw, he/she need only state this to the investigator or a family member who can convey it to the investigator; and
- That participation in the study is entirely voluntary, meaning in no way is he/she required to participate. However, consistent with OHSU policy, acceptable representatives may restore eligibility for the study and also provide informed consent if the previous standards for decisional capacity are not met (WIRB-Copernicus Group, 2014). In such circumstances, study enrollment will include informed consent from an acceptable representative or the individual's Legally Authorized Representative (LAR) in accordance with HRP-021 POLICY: Legally Authorized Representatives, Children, and Guardian. In addition, the investigator will obtain audio-recorded statements of support for including the terminal cancer patient from acceptable representatives or LAR or members present for the family meeting "who are well acquainted with the subject and likely to be familiar with his/her values" (OHSU Research Integrity Office, 2014). If there is disagreement among acceptable representatives or the LAR, the terminally ill cancer patient will not be enrolled or interviewed. If the terminally ill cancer patient regains capacity during the course of the study, he or she will be asked to consent to further participation.

3) Assent

The fourth step taken to protect decisionally impaired cancer patients from study participation against their wishes is to obtain assent when acceptable representatives or LAR have given informed consent. A terminally ill cancer patient who expresses resistance or dissent to participation or to the use of proxy consent by a LAR or acceptable representative will not be enrolled in the study. For Dis who are not unconscious or delirious, an investigator shall obtain the terminally ill cancer patient's assent after informing the subject of the following, in a manner appropriate to the subject's capacity for understanding:

- The fact that he/she is being asked to participate in research;
- That he/she has been determined to lack capacity to self-consent to research participation;
- The name of the LAR or acceptable representative who has been identified, that he or she has granted permission for the subject's participation in the research, and the extent to which the LAR will be involved in the subject's research participation;
- Information about the purpose, design, procedures, risks and benefits, and potential personal impacts of the research study; and
- That the subject may choose freely to undergo these procedures or may withdraw from participation at any time without penalty.

ii) Limited or no English-language proficiency

Accomplishing the aims of this study is dependent upon inclusion of individuals with limited or no English-language proficiency. Marginalized Mexican Americans include many who have limited English-language proficiency. Limited language skills may play a significant role in the hospice decision making process by affording barriers to understanding and navigating cultural and economic barriers.

(1) Risks

There is a risk that individuals with limited or no English-language proficiency will enroll in the study without informed consent or without understanding that they can withdraw from the study at any time without negative consequence. There is also a risk that individuals with limited or no English-language proficiency will suffer emotional harm if they or the terminally ill cancer patient are exposed to the word "hospice" or made aware of a previously unknown terminally ill cancer prognosis.

(2) Five steps will be taken in this study to protect individuals with limited or no English-language proficiency:

1) Informed consent during study enrollment and ongoing consent prior to subsequent interviews will always be obtained in the presence of a professional Spanish-language interpreter from the same region and familiar with the local dialect.
Spanish-language short-form. Oral presentation of the informed consent information will occur in conjunction with an abbreviated written consent document and a written summary of what is presented orally. The interpreter will verbally translate the full English consent form to the participant and facilitate discussion and answer the subject's questions. The participant will be allowed to read the short form. The investigator, through the interpreter, will answer any other questions the participant asks. Signatures will be obtained on the short form from the participant and an impartial witness, such as a family member or the interpreter, who will not be affiliated with the study. Signature will be obtained on the full English consent form from the co-investigator, Margaret Rising, and the impartial witness. A copy of both the English consent form and the short

consent form will be provided to the participants. Documentation will be retained in the study file.

2) Use of the terms "hospice" and "terminal" will be avoided in study brochure and recruitment conversations. Instead, the study brochure and recruitment conversations will use the terms "healthcare" and "serious". The investigator has experience as a hospice RN probing receptiveness to such frank discussions and then following the lead of others. Frank discussions and mentioning of "hospice" and "terminal" will only occur when participants signal it is appropriate. It is possible that only the individual interviews will allow such discussions.
3) All interviews will be conducted in the presence of an interpreter from the same country who speaks the same dialect and is familiar with local customs around death and dying.

iii) Low Healthcare Literacy

Accomplishing the aims of this study is dependent upon inclusion of individuals with low healthcare literacy. It is predicted that many marginalized Mexican Americans will have low healthcare literacy.

(1) Risks

There is a risk that individuals with low healthcare literacy will enroll in the study without informed consent or understanding that they can withdraw from the study at any time without negative consequence.

(2)Four steps taken in this study to protect individuals with low healthcare literacy

1) Every effort will be made to ensure that documents (study brochure and consent form) are at a third-grade reading level.

All documents will be explained by a professional Spanish-language interpreter from the same region and familiar with the local dialect.

2) Participants will be asked to repeat back to the investigator their understanding of the healthcare topics in question.

iv) Undocumented immigration status

It is foreseeable that some participants will have undocumented immigration status, and including such individuals in the study is important to providing a rich description of the hospice experience for Mexican Americans with terminal cancer and their families. Although it is possible that none of the undocumented participants will be willing to reveal their immigration status, it is important to at least attempt to capture this perspective, as it is predicted to have significant repercussions with respect to insurance as well as a perception of discrimination.

(1) Risks

There is a risk that undocumented individuals will feel coerced to participate. There is also a risk of arrest, detention, and deportation for individuals who admit to their undocumented status.

(2) Two steps taken in this study to protect individuals with undocumented immigration status

1) A National Institutes of Health certificate of confidentiality will be obtained to allow investigators to refuse to disclose names or

other identifying characteristics of research participants in response to legal demands.

2) In addition, participants will be reminded prior to interviews that they are in no way obliged to reveal their immigration status, and that if they do reveal their immigration status, the NIH CoC will permit the investigator to refuse to disclose identifying characteristics.

v) EOL physical, emotional, and spiritual distress

Because this study includes interactions with individuals at EOL and their families, it is foreseeable that some participants and/or family members will experience physical, emotional, and spiritual distress. Such distress may be inherent to the EOL process, or it may be triggered by the research process. Distressed individuals need not participate in the study; however, it is inherent that such distress may arise with any of the participants.

(1) Risks

There is a risk for incidental findings of physical, emotional, and spiritual distress, including but not limited to pain, anxiety, fatigue, and crying.

(2) Two steps will be taken in this study to protect individuals with physical, emotional, and spiritual distress

1) During the informed consent process, participants will be told that such scenarios may develop and that they will be offered at that time an opportunity to stop the interview process and will be offered an opportunity to continue as long as it is clear that they understand continuation is entirely voluntary.
2) If participants show incidental findings of physical, emotional, or spiritual distress such as pain, anxiety, fatigue, or crying, an immediate offer to stop the interview process will be made. If they indicate they wish to continue, then the voluntary nature of that continuation will be reflected on audio-tape.

d. Setting

Recruited families will receive pertinent healthcare services from any one of multiple healthcare centers. Possible healthcare systems include but are not limited to:

- Oregon Health and Sciences University (Portland) (OHSU)
- Legacy Health Systems (Portland, McMinnville, and Vancouver)
- Kaiser Permanente (Portland),
- Providence Health & Services (Portland and Hood River),
- Willamette Valley Hospice (Salem),
- Virginia Garcia Memorial Health Center, and
- Grande Ronde Hospital (La Grande)
- Healthcare systems in the Yakima, WA, área
- Healthcare systems in the Pasco, WA, area..

It is expected that most participants will be recruited by Olga Gerberg, Program Director at the non-profit *Familias en Acción,* which provides patient navigation services throughout the Portland metro area. However, it is possible that employees (e.g., case managers, registered nurses, social workers, patient navigators, chaplains) from any of the above-referenced sites will offer a research brochure and introductory letter to participants. In addition, after obtaining approval from site managers, the above-referenced sites may serve as a location to post the study brochure in a public place. No research activity will begin at these sites without IRB approval from these sites.

Community-based recruiting will also occur. For example, Spanish-language-based churches and grocery stores that primarily serve Spanish-speaking populations. In addition, Spanish-language advertisements will be posted in Spanish-language newspapers, announcements or interviews will occur on Spanish-language radio and television, and publication through the community health worker list serve (advertisement uploaded).

Agency personnel key informants are recruited through professional contacts held by the study team as well as through public postings of the Agency personnel brochure (uploaded). They will be approached directly by the investigation or they will call in response to a brochure posting. Community health worker key informants will be recruited through postings on community health worker list serves in Oregon and Washington as well as through professional contacts. They will contact the investigator using the information on the Spanish language Community Health Worker brochure (uploaded).

The only study staff are those listed on the eIRB and are faculty / students at OHSU. No study procedures such as consenting, recruitment, conducting interviews, or collecting data will be performed by any other individuals. There will be no OHSU or other employees involved in recruitment except for providing a study brochure and introductory letter. Nor will OHSU employees be involved in any other part of the study. OHSU will not be the coordinating center for any activities. Family and individual interviews will occur at the time and location selected by participants, including but not limited to their own home or the hospital room of the terminal cancer patient. Only if the investigator is invited to the hospital room of the terminal cancer patient will an interview occur on hospital premises. Otherwise, there are no plans to conduct interviews on OHSU premises.

IRB approval will only be requested from OHSU IRB.

e. Recruitment Methods

Potential family members will receive information about the study through either a culturally appropriate 1) research brochure OR a 2) study advertisement. The research brochure has been designed to avoid potentially offensive use of the terms “hospice” and “terminal cancer” in the event there is still a living patient with terminal cancer. To be culturally appropriate, avoid emotional harm, and prevent sampling bias, the research brochure deliberately replaces the word “hospice” with “healthcare,” and the word “terminal” with “serious.” In contrast, the study advertisement openly recruits families who have lost a family member to cancer while on hospice, or if they were offered hospice. This advertisement will be posted in Spanish-language newspapers and possibly used on Spanish-language radio and television shows. If a member of the team is invited for an interview on a Spanish-language radio or television show, then the questions will be arranged such that the answers to the questions reiterate the advertisement approved by the IRB (please see radio and television script). The advertisement will also be posted at clinics and other community gathering places frequented by Spanish-speaking individuals. Both the research brochure and study advertisement are designed with input from the community advisory board (CAB). The CAB consists of members of the Mexican American community willing to provide guidance and feedback to the investigator to maintain cultural competence and protect participants from unintended emotional harm. The brochure briefly describes the study at a 3rd grade reading level in Spanish and English. The brochure will be translated into indigenous languages as needed. The research brochure will include the investigator's telephone number and e-mail address. Any translated documents will be submitted along with a translation certificate for IRB review and approval prior to use.

The research brochure or the study advertisement, along with an introductory letter, will be distributed to prospective participants through community healthcare contacts, public postings at healthcare centers, and word of mouth from participants. Distribution will include mailings from hospice bereavement services. Community healthcare contacts include social workers, patient navigators, registered nurses, physicians, and chaplains employed by the healthcare organizations listed above who have contact with Mexican Americans with terminal cancer and their families. Community healthcare contacts will be given the summary sheet of inclusion criteria and the study for their personal references.. The primary community healthcare contact will be Olga Gerberg, Program Director at the non-profit *Familias en Acción*, which enrolls from 1 to 4 Hispanic cancer patients per month for patient navigation services in the Portland metro area.

After receiving the research brochure, an interested family member will contact the investigator. Contact with the investigator will occur via telephone (text or voice) or e-mail. An ensuing screening phone call will occur in which the investigator screens the potential participant and confirms inclusion criteria utilizing a telephone script. Although not a native speaker, the investigator has sufficient Spanish fluency to negotiate the initial contact with interested family members. As indicated in the Telephone Screening memo, callers will be asked whether they prefer English, Spanish, or an indigenous Mexican language. If a language other than English is preferred, while the investigator is on the phone with the interested family member, a telephone interpreter will be arranged via CTS Language Link, a business in the Portland area that specializes in on-demand professional translation services by certified interpreters and allows specification of Mexican ancestry interpreters. For telephone screening, a telephone interpreter – rather than in-person – is used to expedite communications. The concern is that the timeconsuming process of arranging an in-person interpreter before having an opportunity to meet and discuss the study will create frustration and discourage participation.

If the interested family member who calls the investigator answers “yes” to all questions, then he or she will be invited to participate in the study consistent with the telephone script, He or she will be instructed to invite 0-5family members to participate at the next meeting, and that the investigator will make a final determination at that time of who can enroll in the study. .

If the prospective participant answers “no” to any eligibility screening questions and was referred by a healthcare contact, then the investigator will follow up with the healthcare contact. It is possible that the prospective participant erroneously answered “no” to some questions, given the low healthcare literacy and preference for prognostic secrecy in this population. If it is ascertained that the prospective participant erroneously answered “no” to screening questions, then the investigator will call the prospective participant without revealing the error. The rationale behind not revealing the potential participant’s error is that erroneously answering “no” to a screening questions, particularly to whether the patient has received or been offered hospice or has terminal cancer, may be a symptom of poor health literacy or prognostic secrecy. Such a family would still be ideal for the study, provided that the information offered by the healthcare contact is accurate. In such a situation, the investigator would continue with the screening transcript, substituting the words “hospice” with “healthcare” and “terminal” with “serious.”

All payments to participants enrolled in the study will occur in the form of a $100 gift card to Fred Meyer’s grocery store. The person initiating contact with the interviewer will be given the single card per family upon completion of enrollment and the family interview. There are no circumstances under which the value of said card would be reclaimed by the investigator.

Agency key informants will be recruited through professional contacts held by study team members. They will be approached directly via telephone call or e-mail and asked if they are interested in providing a one-hour interview. Community health worker key informants will be recruited through dedicated list serves for community health workers. If they are interested, then they will contact the investigator. As a thank you for their participation, they will be given $50.00 after the interview.

f) Consent Process

For telephone interviews, which is an option limited to key informants, a participant will consent to the interview after reviewing the information sheet and then stating their consent to the interview at the beginning of the recorded interview. The information sheet will be e-mailed to the participant in advance of the interview for their review. Any Spanish speakers wishing to have a telephone interview in Spanish will have the information sheet read to them by the telephone interpreter. The information sheet will be sent to the telephone interpreter in advance of the interview.

For in person interviews, which may include either key informants or Mexican families,, informed consent will occur at a time and location of their choice. . For families, all subjects participating or present for the interview, including the terminally ill cancer patient and family members, will each sign consent or assent documents. It is anticipated that consent will occur at the family domicile. A preference for time and place will have been obtained in the initial screening phone call, at which point an appointment will have been made. All members of the family that will participate in the family interview will be present and consented at the same time. All face-to-face encounters with participants and potential participants from this point and through completion of the study will occur in the presence of a Spanish- or indigenous- language interpreter from Mexico and familiar with the local dialect and customs, if needed.

For in person interviews of key informants, consent will occur at the time and location of the participant's choice. Consent will be signed after going over the information sheet and contract. If a Spanish speaker wishes to have their in-person interview in Spanish, then arrangement will be made for an on-site interpreter.

During the family enrollment meeting, the investigator will explain the study to the potential participant family, following the same dialogue from the telephone screening script. The investigator will use either "hospice" or "healthcare" and either "serious" cancer or "terminal" cancer, depending on what is known about prognostic and hospice awareness. Next, the investigator will obtain written consent with an IRB-approved consent.

Once recording begins, the investigator will obtain brief oral consent to do study, consent to record. To ensure ongoing consent, after every 30 minutes of audio-recorded interview, the investigator will offer to take a break, specifically ensuring the cancer patient, if present, is okay with continuing. Also to ensure ongoing consent, the investigator will obtain brief oral consent to continue the study prior to each individual interview.

To minimize coercion or undue influence, the investigator will repeatedly mention during screening, enrollment, consent, and during any moments of pain, anxiety, or fatigue, that the interview process can be stopped and that participants can withdraw from the study at any time without fear of negative consequences. In addition, to minimize coercion or undue influence, the cancer patient (if living) need not participate in the study.

To ensure the participant's understanding, the study will be explained and an opportunity for questions will be given at two points in time – the initial telephone screening with an interested family member and prior to the family interview during the enrollment process. In addition, the consent process includes another explanation of the study and an opportunity to ask questions. Also to ensure participant's understanding, interpreters will be present for all interviews, when appropriate (*please see the next section*, Non-English Speaking Subjects).

Non-English Speaking Participants

To ensure comprehension by non-English speaking subjects, this study involves professional interpreters. Family members will not serve as interpreters. Telephone interpreting will be provided by CTS Language Link, a business in the Portland area that specializes in on-demand professional translation services by certified interpreters and allows specification of Mexican ancestry interpreters. A telephone interpreter will be used with non-English speaking potential participants during initial screening and recruitment as well as with some key informant telephone interviews. With the exception of some clarifying follow-up interviews, every encounter after initial family screening and recruitment will occur in the presence of an interpreter of Mexican ancestry familiar with the local dialect and customs. Because of the critical importance of understanding language nuances in qualitative research as well as the potential misunderstand or miss entirely important concepts in the interpretive process, the interpreters will receive special research-related instruction. Instead of requesting verbatim translation, which is consistent with expectations in the clinical setting, the interpreter will be invited to offer his or her explanations and interpretations of cultural and language nuances during the interview process as well as after the interview is completed (Björk & Dahlberg, 2013; Maradik et al., 2013). Inviting the interpreter into the communication process will facilitate participant comprehension during the consent and enrollment process, which will involve verbatim translation of the consent form and the Spanish short form. In addition, to ensure the investigator is communicating effectively during the interview process, the interpreter will be encouraged to engage in continuous evaluation of whether concepts are being effectively communicated. Finally, after the interview, the investigator will debrief with the interpreter. .

Adults Unable to Consent/Decisionally Impaired

Due to EOL disease-processes and central-nervous-system-acting medications for symptom control (e.g., opiates, benzodiazepines), it is foreseeable that terminally ill cancer patients will exhibit decisional impairment. Depending on the cause of the impairment (disease or medication), impairment may be complete, progressive, fluctuating, or temporary.

The following steps will be taken in this study to protect decisionally impaired adults:

- A Decisionally-Impaired (DI) Adults Supplement form has been uploaded.
- An Assent form has been uploaded.
- To remove coercive pressure on the terminally ill cancer patient, inclusion of the terminally ill cancer patient is not required for family enrollment or the family interview.

Consent. To protect their interests, unconscious or delirious terminally ill cancer patients will not be considered eligible to participate in the study or to provide informed consent. Whether a DI is delirious and therefore disqualified from participation in the study will be determined by administration of the Confusion Assessment Method (CAM) (Inouye et al., 1990), which has been suggested as the superior instrument for quickly ascertaining the occurrence of delirium (Wong et al., 2010). The CAM includes an instrument and diagnostic algorithm for diagnosing delirium and requires 5 minutes to administer. The CAM assesses 4 features: 1) acute onset or fluctuating course (from baseline), 2) inattention (easily distractible or keeping track of what is said), 3) disorganized thinking (incoherent, rambling, illogical flow of ideas), and 4) altered level of consciousness (alert, hypervigilant, lethargic, stupor, coma). A patient must be positive for 1 and 2 and either 3 or 4 to be considered delirious (Wong et al., 2010). The investigator conducting the interviews has over ten years of experience administering the CAM in the hospital setting as well as inpatient hospice setting. In addition to administration of the CAM, the DI will be asked to articulate:

- That the study involves interviews about healthcare decision making relating to his/her health;
- That participation should have no effect on his/her health, but sometimes interviews can be emotionally distressing;
- That this is a study intended to improve healthcare for others in the future and will not immediately impact his/her current healthcare;
- That he/she is free to decline to participate with no consequences to the family's ability to participate in the study;
- That there are no health risks from participating in the study but there is always the possibility of breach of confidentiality, although every effort will be made to ensure deidentification of data and data security;
- That if he/she experiences discomfort or wishes to withdraw, he/she need only state this to the investigator or a family member who can convey it to the investigator; and

That participation in the study is entirely voluntary, meaning in no way is he/she required to participate. Consistent with OHSU policy, acceptable representatives may restore eligibility for the study and also provide informed consent if the previous standards for decisional capacity are not met (WIRB-Copernicus Group, 2014). The order of priority for authorized representatives is spouse, adult child, and sibling. If there is disagreement among family members, the terminally ill cancer patient will not be enrolled or interviewed. If the terminally ill cancer patient regains capacity during the course of the study, he or she will be asked to consent to further participation.

- Assent

Assent will only be obtained from decisonally impaired adults for whom acceptable representatives have provided consent. A terminally ill cancer patient who expresses resistance or dissent to participation or to the use of proxy consent by an acceptable representative will not be enrolled in the study. Unless the terminally ill cancer patient is severely decisionally impaired (unconscious, delirious) prior to participation in research, an investigator shall obtain the terminally ill cancer patient's assent after informing the subject of the following, in a manner appropriate to the subject's capacity for understanding:

- The fact that he/she is being asked to participate in research;
- That he/she has been determined to lack capacity to self-consent to research participation;
- The name of the representative who has been identified, that he or she has granted permission for the subject's participation in the research, and the extent to which the representative will be involved in the subject's research participation;

- Information about the purpose, design, procedures, risks and benefits, and potential personal impacts of the research study; and
- That the subject may choose freely to undergo these procedures or may withdraw from participation at any time without penalty or loss of benefits to which the subject is otherwise entitled (OHSU Research Integrity Office, 2014).

Documentation of assent will be obtained through the standard OHSU IRB assent form. If the terminally ill cancer patient regains capacity during the course of the study, he or she will be asked to consent to further participation.

- **Procedures**

This study will collect data through the open interview process. Interviews will occur either with Mexican families or with key informants (agency or community health worker). Two types of interviews will occur with Mexican families: the family and individual. All family interviews will be in person. Key informant interviews, on the other hand, may be by telephone or in person and will consist of individual interviews. Two types of individual interviews will occur: one-on-one and follow-up. Key informant interviews conducted in Spanish will use a telephone interpreter or on-site interpreter, if in person. In contrast, all family-related interviews will occur in the presence of an interpreter from Mexico who speaks the local dialect and is familiar with the local customs, if needed. The investigator will have briefed the interpreter on the subject of the research, her desire that the interpreter refrain from verbatim translation (with the significant exception of the consent documents, which will be translated verbatim) and ensure full conceptual communication, and her intention to debrief after the interview to gain her insights into the interview. Verbatim recordings of interviews will be made with the Echo Smartpen by Livescribe, which will minimize any power differential due to its diminutive presence. A second simultaneous recording will be made on SONY ICD PX333 Digital Voice Recorder, also a small and unassuming device to provide a back-up in case of recording failure.

Key informant interview. The key informant interview will occur with one person at a time at a time, place, and method (phone or in person) of their choice. After obtaining informed consent during the beginning of the recorded interview, the one-on-one interview is expected to last one hour, with a possible 15 minute follow up interview either in person or by telephone to clarify concepts.

Family interview. The first interview is the family interview with 1-6 individuals chosen by the family. Permission to begin audio recording will be requested and consent to record will be stated aloud. The interview is expected to last one hour, bringing the total expected meeting time to 2 hours, taking into consideration enrollment and consent.

One of the purposes of the family interview is to engage in culturally appropriate research by acknowledging the importance of family with the family interview. Therefore, rapport will first be developed through “small talk” and introductions, including participants’ names and relation to the patient. After introductions, the family interview will begin with general opening questions such as, “Tell me the story of [the patient’s] recent healthcare experiences and decisions per the Interview Guide. The Interview Guide has been reviewed by the community advisory board. Consistent with dimensional analysis and grounded theory methodology, the exact questions used during interviews will vary, dictated by developing concepts introduced by the participants themselves. Topics are expected to encounter include diagnosis, prognosis, reacting to news of the severity of the illness, finances, navigating the medical system. Specific questions about hospice and terminal prognosis will be determined by any information provided by the interested family member, the community healthcare contact, and the investigator’s experience as a hospice nurse assessing prognostic and hospice awareness. A break will be offered after 30 minutes of interview time.

At the end of the family interview, after cessation of audio recording, subsequent interviews with individual family members will be negotiated based upon their interest and their knowledge of the healthcare decision-making process.

Individual interviews. It is expected that individual interviews will occur with one to three individuals. The purpose of the separate individual interviews is to provide an opportunity to hear different perspectives on the healthcare decision-making process. In addition, they will be conducted in private from the rest of the family, which may facilitate a more open discussion regarding hospice or prognosis. Each individual interview is expected to last one hour. These individual interviews will occur at a time and place of the individual’s choice.

Follow-up interviews. Follow-up interviews are a critical feature of high-quality dimensional analysis and grounded theory research. Follow-up interviews clarify participants’ intended meaning and also allow the investigator to pursue emerging concepts and themes. A range of zero to two follow up interviews per family is expected. A range of the number of expected follow up interviews is provided because, consistent with grounded theory analysis, the need for follow-up interviews will manifest as interview transcripts are coded and analyzed for developing themes. Follow up interviews should not last more than 20 minutes. Potential interviewees will be contacted directly by the investigator and invited to select a time and place for an interview. If the participant agrees or prefers, and if the investigator does not anticipated a highly nuanced interview, follow up interviews may occur by telephone with a telephone interpreter through CTS language link.

Total interview time. Any single participant in the study is expected to participate in the interview process from 1 to 3 hours.

Steps to prevent investigator influence. To prevent the investigator from influencing participant responses, leading questions will be avoided (Maxwell, 2013). An effort by the investigator will be made to understand and minimize the investigator's influence on the participant(s), and the investigator will refrain from questions that might cause participant(s) to feel uncomfortable or disrespected (Green, Creswell, Shope, & Clark, 2007).

Post-interview procedure. After each interview, in private location, the investigator will immediately debrief with the interpreters about their insights into the interview, inviting their explanations and interpretations of cultural and language nuances during the interview process (Björk & Dahlberg, 2013; Maradik et al., 2013). The investigator will memo regarding significant events from the interviews, record impressions of the family, the setting, topics/questions to follow up on. The investigator will also immediately listen to the digital recordings and send the digital recording to the transcription service.

- **Data**

Security. To protect anonymity of participants, transcripts will be de-identified by removing any identifying names of participants or locations. Participant identity will be coded immediately after the first interview occurs (Patton, 2015). A numeric code will be created for each family and then individual codes for each family member completing an individual interview. Pseudonyms will be created for each participant. A written key defining the relationship between codes and participants will be kept in a locked box in the investigator's office in a location separate and apart from the laptop and recording devices. The code will be sequential and segmented to allow addition of future participants as well as identification of general categorical information such as the initial interested family member or the terminal cancer patient.

Immediately following interviews, the digital recordings will be uploaded to a passcode-protected computer file in the investigator's password-protected laptop computer. A backup file will be made and stored in the OHSU encrypted cloud storage (The Box). Once these 2 files are created, the interview will be erased from the Smart Pen and the Digital Voice Recorder. English-language portions of interviews will be transcribed by the investigator. Specific sections of non-English-speaking portion of interviews will be transcribed by bilingual transcriptionists. Interview files will be electronically uploaded via the internet to a secure transcriptionist service. Completed transcripts will be sent to the investigator's OHSU e-mail account. Upon receipt from the transcription service, completed transcript data will be uploaded to The Box for back up.

Transcription. The recording file will be transcribed verbatim English-to-English. Unfortunately, the astronomical cost of paying a bilingual transcriptionist prevents professional transcription of the entire non-English portion of the interview. Instead, sensitive and nuanced sections will be identified and "spot-checked" by bilingual transcriptionists. Those sections will be portions of the interview in which participants provided substantial sensitive and nuanced information, as identified through the on-site interpreter's translations as well as the investigator's audio-review. These "spot-checks" are intended to mitigate any errors in translation by the on-site interpreter. Other checks against interpreter error include the presence of Olga Gerberg (Program Director, Familias en Accion, and community advisory board member) at some interviews. In addition, the investigator and members of the CAB will engage in random "spot-checks" of the audio-tape to ensure accurate translation. Discrepancies in translation will be resolved in consultation with an interpreter and a community advisory board member, if needed, and will automatically merit a follow-up interview if the subject matter is critical. Spanish language transcripts will be kept for subsequent reviewing of codes by participants (member checking) and, with IRB approval, by community advisory board members (outside experts), and also for more detailed analysis of metaphor and discourse by the investigator (Velazquez, 2013).

Once transcriptions are completed and returned, the investigator will review transcripts while listening to the audio files of interviews to check for accuracy and to add additional information such as non-verbal interactions and crying.

Upon completion of the study, all study materials will be destroyed with the exception of de-identified interview transcripts. De-identified interview transcripts will be stored on the OHSU password protected drive (The Box) for up to 10 years.

- **Data Analysis**

The Aims of the study will be simultaneously addressed during development of the substantive grounded theory. That is, ascertaining and describing the meaning of hospice and the influence of culture, socioeconomic status, discrimination, religion and other relevant forces on hospice decision making will ultimately give rise to the substantive grounded theory that describes hospice decision making for participants.

Construction of substantive grounded theory. Constructing substantive grounded theory is an iterative process with ongoing, multiple layers of analysis. Although the description of data analysis is linear, initial coding and theoretical development will overlap in practice. The study will increase in abstraction as the study progresses, with data collection becoming more focused with theory development. Each interview will first be analyzed close to the data, delaying conceptual closure within the four-corners of the transcript, followed by increased abstraction and theory testing and development. As the overall study increases in abstraction, interviews from newly enrolled participants will first be analyzed close to the data, delaying conceptual closure within the four-corners of the new transcript as much as possible.

The logical decisions made during data analysis will be recorded in memos made by the investigator. As the coding of participant data evolves into theoretical and conceptual ideas, the logic behind such decisions will be recorded in memos. In addition, such decisions will be made in consultation with the research team and, where appropriate, community advisory board members.

Data management software. Transcript data will be managed with Atlas.ti 8 software (http://atlasti.com/product/v8-windows/). Software will be used to manage developing coding strategies and concept development, supporting the investigator's data analysis.

- **Privacy, Confidentiality and Data Security**

Participant's privacy and confidentiality during recruitment and consent will be maintained by keeping documentation of phone calls and meetings in a locked file on the investigator's locked laptop. Any paperwork will be destroyed once it has been loaded onto the computer and backed up on the OHSU encrypted cloud storage (The Box). To protect anonymity of participants, participant identity will be coded immediately after the first interview occurs (Patton, 2015). A numeric code will be created for each family and then individual codes for each family member completing an individual interview. Pseudonyms will be created for each participant. A written key defining the relationship between codes and participants will be kept in a locked box in the investigator's office in a location separate and apart from the laptop and recording devices. The code will be sequential and segmented to allow addition of future participants as well as identification of general categorical information such as the initial interested family member or the terminal cancer patient.

Immediately following interviews, the digital recordings will be uploaded to a passcode-protected computer file in the investigator's password-protected laptop computer. A backup file will be made and stored in the OHSU encrypted cloud storage (The Box). Once these 2 files are created, the interview will be erased from the Smart Pen and the Digital Voice Recorder. Interview files will be electronically uploaded via the internet to a secure transcriptionist service. Completed transcripts will be sent to the investigator's OHSU e-mail account. Upon receipt from the transcription service, completed transcript data will be uploaded to The Box for back up.

Any individuals involved with data collection and analysis, including the research team (the investigator and her PhD committee), the community advisory board, and language interpreters, will be reminded of the duty of confidentiality to participants verbally and in writing on the top of transcripted pages. Only professional transcription companies with employees who have signed confidentiality agreements will be used. A National Institutes of Health Certificate of Confidentiality will be obtained to protect undocumented participants in the event a legal demand is placed on the investigator to reveal their identities.

- **Risks and Benefits**

a. Risks to Subjects

Breach of confidentiality – low probability, high magnitude, long duration, not reversible.

Legal exposure of undocumented immigration status – low probability (with NIH CoC), high magnitude, long duration, not reversible

Emotional upheaval due to participation in interview – high probability, moderate magnitude, brief duration, reversible

Loss of time – one to three hours – high probability, low magnitude, brief duration, not reversible

b. Potential Benefits to Subjects

There is no medical benefit to participating in the study. However, there is support in the research literature for the therapeutic benefit of research interviews (Orb et al., 2001; B. A. Smith, 1999), for example, through catharsis, self-acknowledgment, sense of purpose, self-awareness, empowerment, healing, and providing a voice for the disenfranchised (Hutchinson et al., 1994; B. A. Smith, 1999).

References

See Cumulative References.

Appendix G

Consent, Hospice User/Avoider

OREGON HEALTH & SCIENCE UNIVERSITY

IRB#: __**17421**__

Research Consent Summary

You are being asked to join a research study. You do not have to join the study. Even if you decide to join now, you can change your mind later.

1. The purpose of this study is to learn more about how to improve healthcare for Latinos, specifically, Mexican Americans. The study will also create a data repository for future analysis.
2. We want to learn
    a. What your experiences have been around healthcare received by the seriously ill member of your family
    b. If people are satisfied with their current health care and
    c. What people do not like about their current health care.
3. The Hartford Foundation for Geriatric Excellence, the Hearst Foundation, the OHSU School of Nursing, and the American Cancer Society are contributing funds for the research study.
4. Everyone who joins the study will be interviewed, sometimes more than once.
5. If you join the study, you will be asked to complete a family interview with members of your family. You might be asked to complete an individual interview, as well. Both the family and individual interviews should require 1 hour to complete.
   In addition, you may be asked to conduct one or two follow up interviews to clarify earlier statements, and those follow up interviews should take no more than 15 minutes.
   The investigator will conduct the interviews at a location and time of your choice. Your participation in this study should last approximately one month.
6. There is a small risk of breach of confidentiality.

OREGON HEALTH & SCIENCE UNIVERSITY

IRB#: 17421

Research Consent and Authorization Form

TITLE: Hospice Decision Making in Mexican Americans with Terminal Cancer and their Families

PRINCIPAL INVESTIGATOR: Dena Hassouneh, RN PhD (503) 494-2714

CO-INVESTIGATORS: Margaret Rising, RN JD PhD Candidate
(503) 758-3688

FUNDED BY: The Hartford Foundation for Geriatric Excellence, the Hearst Foundation, the OHSU School of Nursing, and the American Cancer Society are contributing funds for the research study.

PURPOSE:

You have been invited to be in this research study because you have recently had healthcare experiences involving a family member's serious illness, and you are Mexican American. Your participation in this study should last approximately one month.

The purpose of this study is to understand the healthcare experiences of Mexican Americans with serious illnesses and their families to improve healthcare for Mexican Americans and Latinos.

Participation will involve one family interview and may involve an additional one-on-one interview. All interview sessions will be audio-recorded.

The study will also store the data collected in interviews for 10 years to create a data repository for future analysis. Generally, a research repository collects, stores and distributes data for use in future research projects. Storing and gathering lots of data together can help to conduct future research and avoid re-collecting data over and over again. When researchers collect and store data together and use them for different kinds of research in the future, or share them with other scientists, this is called a research repository.

We plan to enroll approximately 15 families as participants in the study.

PROCEDURES:

If you agree to participate, all interviews will occur at a location and time of your choice and be audio-recorded. If necessary, the investigator will be accompanied by a language interpreter. Family members cannot serve as interpreters.

Family interview: A family interview will be conducted with 2 to 6 members of your family If the seriously ill family member is present, the investigator will decide whether a legally authorized representative must provide informed consent. . Your seriously ill family member need not be present.

The interview will ask questions about your healthcare experience and should last one hour. You will be asked about your satisfaction with the healthcare experience, how you made important decisions, and what factors affected those decisions, including subjects such as religion, insurance, and discrimination.

Individual interview: If you participate in the family interview, you may be asked, or you may volunteer, to participate in an individual interview. Only you, the investigator, and the interpreter (if needed) will be present. You are not required to participate in an individual interview.

Individual interviews will occur after the family interview. You will be asked questions about your healthcare experience, allowing you to expand on your responses in the family interview or provide different perspectives. This interview should last one hour.

Follow-up interview: After the family and individual interviews, the investigator may need to clarify comments made during the interview to ensure accurate reporting of information. If follow-up interviews are needed, a maximum of two will occur and will only involve you, the investigator, and the interpreter (if needed). The follow-up interview should last 15 minutes.

The maximum amount of time you should expect to commit would be 2-½ hours.

Audio-recordings: The audio-tapes from your interviews will be transcribed onto paper. All personal information in transcripts that could be used to identify you such as names, places, and specifics healthcare details, will be removed.

Results reporting: Results from this study will be published in a healthcare journal, and a copy of the article can be forwarded to you at your request. Your audio-tapes will not be reproduced in public. Quotations from your interviews may be included, but any facts that can be used to identify you such as names and places will be removed.

Repository: In the future, data collected in interviews may be used for further research to improve healthcare for Mexican Americans. Such data will be maintained in a secure and encrypted computer server. All consent forms connected the data to you personally will be destroyed. However, some identifying information from audio-tapes will remain. The same confidentiality protections applied in this study will be applied to any future studies with this same interview data.

Incidental findings: Sometimes distressing symptoms arise during the interview of seriously ill patients. For example, patients may become emotionally distressed or anxious, or they may have other medical issues such as pain or shortness of breath. If such a situation arises, the investigator will provide the opportunity to stop the interview. The interview will only continue with the expressed voluntary wishes and consent of the participant.

RISKS AND DISCOMFORTS:

There are risks to participating in the study. For example, some of the questions asked during the interview may seem very personal or embarrassing. They may upset you. You may refuse to answer any of the questions that you do not wish to answer. If the questions make you very upset, we will help you to find a counselor. Another risk is that, in spite of our efforts, confidentiality is breached.

Because this study creates a data repository, there is a risk of breach of confidentiality associated with storing data electronically. Such a breach of confidentiality could cause psychological distress or harm family relationships.

BENEFITS:

You will not benefit from being in this study. However, by serving as a subject, you may help us learn how to benefit patients in the future.

ALTERNATIVES:

You may choose not to be in this study.

CONFIDENTIALITY:

We will take steps to keep your personal information confidential, but we cannot guarantee total privacy. Your name will be replaced with numbered codes. The key to those codes will be known only to the investigator and kept in a locked location. In addition, when the audio- tapes are transcribed, names, places, and healthcare data in the transcripts that could be used to identify participants will be replaced with pseudonyms. The key will be destroyed after the study. The investigator has also obtained an NIH Certificate of Confidentiality so that no legal authority can compel her to reveal your identity except in the event of abuse, intent to harm, or certain communicable diseases (see below).

The investigators, study staff, and others at OHSU may use the information we collect and create about you in order to conduct and oversee this research study.

We may release this information to others outside of OHSU who are involved in conducting or overseeing research, including:

- The funders of this study, the Hartford Foundation for Geriatric Excellence, the Hearst Foundation and the American Cancer Society, and the funder’s representatives
- The Office for Human Research Protections, a federal agency that oversees research involving humans

Those listed above may also be permitted to review and copy your records.

Your identifiable information may be used by the investigator for future research, but it will not be shared with other investigators

We will not release information about you to others not listed above, unless required or permitted by law. We will not use your name or your identity for publication or publicity purposes, unless we have your special permission.

To help us protect your privacy, we have obtained a Certificate of Confidentiality from the National Institutes of Health. With this Certificate, the researchers can refuse to disclose information that may identify you, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings. The researchers will use the Certificate to resist any demands for information that would identify you, except as explained below.

The Certificate cannot be used to resist a demand for information from personnel of the United States Government that is used for auditing or evaluation of federally funded projects or for information that must be disclosed in order to meet the requirements of the FDA.

A Certificate of Confidentiality does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. If an insurer, employer, or other person obtains your written consent to receive research information, then the researchers may not use the Certificate to withhold that information.

However, if we learn about abuse of a child or elderly person or that you intend to harm yourself or someone else, or about certain communicable diseases, we will report that to the proper authorities.

Under Oregon law, suspected child or elder abuse must be reported to appropriate authorities.

OHSU complies with Oregon state requirements for reporting certain diseases and conditions to local health departments.

When we send information outside of OHSU, they may no longer be protected under federal or Oregon law. In this case, your information could be used and re-released without your permission.

The results of this study will be published, but all information identifying you will be removed. Only the investigator will have the key to the codes to identify you, and those codes will be destroyed upon completion of the study.

We may continue to use and disclose your information as described above indefinitely.

COMMERCIAL DEVELOPMENT:

Information about you or obtained from you in this research may be used for commercial purposes, such as making a discovery that could, in the future, be patented or licensed to a company, which could result in a possible financial benefit to that company, OHSU, and its researchers. There are no plans to pay you if this happens. You will not have any property rights or ownership or financial interest in or arising from products or data that may result from your participation in this study. Further, you will have no responsibility or liability for any use that may be made of your information.

COSTS:

There will be no cost to you or your insurance company to participate in this study.

For participating in this study, you will be given a $100 gift card to Fred Meyer's grocery store at completion of the family interview.

We may request your social security number in order to process any payments for participation.

LIABILITY:

If you believe you have been injured or harmed as a result of participating in this data collection, contact Dena Hassouneh (503) 494-2714 or Margaret Rising (503) 758-3688.

OHSU and the funder do not offer any financial compensation or payment for the cost of any injury or harm. However, you are not prevented from seeking to collect compensation for injury related to negligence on the part of those involved in the research. Oregon law (Oregon Tort Claims Act (ORS 30.260 through 30.300)) may limit the dollar amount that you may recover from OHSU or its caregivers and researchers for a claim relating to care or research at OHSU, and the time you have to bring a claim.

If you have questions on this subject, please call the OHSU Research Integrity Office at (503) 494-7887.

PARTICIPATION:

If you have any questions, concerns, or complaints regarding this study now or in the future, contact Dena Hassouneh (503) 494-2714 or Maggie Rising (503) 758-3688

This research is being overseen by an Institutional Review Board ("IRB"). You may talk to the IRB at (503) 494-7887 or irb@ohsu.edu if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research subject.
- You want to get more information or provide input about this research.

You may also submit a report to the OHSU Integrity Hotline online at https://secure.ethicspoint.com/domain/media/en/gui/18915/index.html or by calling toll-free (877) 733-8313 (anonymous and available 24 hours a day, 7 days a week).

Your participation in this study is voluntary. You do not have to join this or any research study.

If you do join the study and later change your mind, you have the right to quit at any time. If you choose not to join any or all parts of this study, or if you withdraw early from any or all parts of the study, there will be no penalty or loss of benefits to which you are otherwise entitled, including being able to receive health care services or insurance coverage for services. Talk to the investigator if you want to withdraw from the study.

If in the future you decide you no longer want to participate in this research, we will remove your name and any other identifiers from your transcripts, but the material will not be destroyed and we will continue to use it for research.

We will give you any new information during the course of this research study that might change the way you feel about being in the study.

SIGNATURES:

Your signature below indicates that you have read this entire form and that you agree to be in this study.

We will give you a copy of this signed form.

Subject Printed Name	Subject Signature	Date
Person Obtaining Consent Printed Name	Person Obtaining Consent Signature	Date
Legally Authorized Representative (print)	Legally Authorized Representative (signature)	Date

___________________________________ ___________________________________ __________

Relationship of LAR to participant

Complete if the participant is not fluent in English and an interpreter was used to obtain consent. Participants who do not read or understand English must not sign this full consent form, but instead sign the short form translated into their native language. This form should be signed by the investigator and interpreter only. If the interpreter is affiliated with the study team, the signature of an impartial witness is also required.

Print name of interpreter:

Signature of interpreter:____Date:

An oral translation of this document was administered to the subject in ______________________ (state language) by an individual proficient in English and_____________________(state language).

If applicable:

Print name of impartial witness:

*Signature of impartial witness:*____*Date:*_____________

Appendix H

Consent, Key Informant

OREGON
HEALTH & SCIENCE
UNIVERSITY

IRB#: 17421

Research Consent Summary

You are being asked to join a research study. You do not have to join the study. Even if you decide to join now, you can change your mind later.

1. The purpose of this study is to learn more about how to improve healthcare for Latinos, specifically, Mexican Americans. The study will also create a data repository for future analysis.
2. We want to learn
   a. Your observations and knowledge about healthcare received by persons of Mexican descent choosing hospice
   b. If such persons are satisfied with hospice and
   c. What such persons do not like about hospice. .
3. The Hartford Foundation for Geriatric Excellence, the Hearst Foundation, the OHSU School of Nursing, and the American Cancer Society are contributing funds for the research study.
4. Everyone who joins the study will be interviewed, sometimes more than once. If you join the study, you will be asked to complete a one-on-one interview lasting no more than one hour as well as a possible follow up 15-minute interview. The investigator will conduct the interviews at a location and time of your choice. Your participation in this study should last approximately one month.
5. There is a small risk of breach of confidentiality.

OREGON HEALTH & SCIENCE UNIVERSITY

IRB#: 17421

Research Consent and Authorization Form

TITLE: Hospice Decision Making in Mexican Americans with Terminal Cancer and their Families

PRINCIPAL INVESTIGATOR: Dena Hassouneh, RN PhD (503) 494-2714

CO-INVESTIGATORS: Margaret Rising, RN JD PhD Candidate

(503) 758-3688

FUNDED BY: The Hartford Foundation for Geriatric Excellence, the Hearst Foundation, the OHSU School of Nursing, and the American Cancer Society are contributing funds for the research study.

PURPOSE:

You have been invited to be in this research study because you have experience with persons of Mexican descent who have used hospice. Your participation in this study should last approximately one month.

The purpose of this study is to understand the healthcare experiences of Mexican Americans with serious illnesses and their families to improve healthcare for Mexican Americans and Latinos.

Participation will involve a one-on-one interview lasting one hour and possible follow up interview lasting 15 minutes. All interview sessions will be audio-recorded.

The study will also store the data collected in interviews for 10 years to create a data repository for future analysis. Generally, a research repository collects, stores and distributes data for use in future research projects. Storing and gathering lots of data together can help to conduct future research and avoid re-collecting data over and over again. When researchers collect and store data together and use them for different kinds of research in the future, or share them with other scientists, this is called a research repository.

We plan to enroll approximately 15 families as participants in the study as well as 20-30 key informants such as yourself.

PROCEDURES:

If you agree to participate, all interviews will occur at a location and time of your choice and be audio-recorded. If necessary, the investigator will be accompanied by a language interpreter. Family members cannot serve as interpreters.

Interview: The interview will ask you questions to elicit your observations and opinions about hospice decision making in Mexican families. This interview should last one hour.

Follow-up interview: After the family interview, the investigator may need to clarify comments made during the interview to ensure accurate reporting of information. If follow-up interviews are needed, a maximum of two will occur and will only involve you, the investigator, and the interpreter (if needed). The follow-up interview should last 15 minutes.

The maximum amount of time you should expect to commit would be 1-½ hours.

Audio-recordings: The audio-tapes from your interviews will be transcribed onto paper. All personal information in transcripts that could be used to identify you such as names, places, and specifics healthcare details, will be removed.

Results reporting: Results from this study will be published in a healthcare journal, and a copy of the article can be forwarded to you at your request. Your audio-tapes will not be reproduced in public. Quotations from your interviews may be included, but any facts that can be used to identify you such as names and places will be removed.

Repository: In the future, data collected in interviews may be used for further research to improve healthcare for Mexican Americans. Such data will be maintained in a secure and encrypted computer server. All consent forms connected the data to you personally will be destroyed. However, some identifying information from audio-tapes will remain. The same confidentiality protections applied in this study will be applied to any future studies with this same interview data.

Incidental findings: Sometimes distressing symptoms arise during the interview of seriously ill patients. For example, patients may become emotionally distressed or anxious, or they may have other medical issues such as pain or shortness of breath. If such a situation arises, the investigator will provide the opportunity to stop the interview. The interview will only continue with the expressed voluntary wishes and consent of the participant.

RISKS AND DISCOMFORTS:

There are risks to participating in the study. For example, some of the questions asked during the interview may seem very personal or embarrassing. They may upset you. You may refuse to answer any of the questions that you do not wish to answer. If the questions make you very upset, we will help you to find a counselor. Another risk is that, in spite of our efforts, confidentiality is breached.

Because this study creates a data repository, there is a risk of breach of confidentiality associated with storing data electronically. Such a breach of confidentiality could cause psychological distress or harm family relationships.

BENEFITS:

You will not benefit from being in this study. However, by serving as a subject, you may help us learn how to benefit patients in the future.

ALTERNATIVES:

You may choose not to be in this study.

CONFIDENTIALITY:

We will take steps to keep your personal information confidential, but we cannot guarantee total privacy. Your name will be replaced with numbered codes. The key to those codes will be known only to the investigator and kept in a locked location. In addition, when the audio- tapes are transcribed, names, places, and healthcare data in the transcripts that could be used to identify participants will be replaced with pseudonyms. The key will be destroyed after the study. The investigator has also obtained an NIH Certificate of Confidentiality so that no legal authority can compel her to reveal your identity except in the event of abuse, intent to harm, or certain communicable diseases (see below).

The investigators, study staff, and others at OHSU may use the information we collect and create about you in order to conduct and oversee this research study.

We may release this information to others outside of OHSU who are involved in conducting or overseeing research, including:

- The funders of this study, the Hartford Foundation for Geriatric Excellence, the Hearst Foundation and the American Cancer Society, and the funder’s representatives

- The Office for Human Research Protections, a federal agency that oversees research involving humans

Those listed above may also be permitted to review and copy your records.

Your identifiable information may be used by the investigator for future research, but it will not be shared with other investigators

We will not release information about you to others not listed above, unless required or permitted by law. We will not use your name or your identity for publication or publicity purposes, unless we have your special permission.

To help us protect your privacy, we have obtained a Certificate of Confidentiality from the National Institutes of Health. With this Certificate, the researchers can refuse to disclose information that may identify you, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings. The researchers will use the Certificate to resist any demands for information that would identify you, except as explained below.

The Certificate cannot be used to resist a demand for information from personnel of the United States Government that is used for auditing or evaluation of federally funded projects or for information that must be disclosed in order to meet the requirements of the FDA.

A Certificate of Confidentiality does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. If an insurer, employer, or other person obtains your written consent to receive research information, then the researchers may not use the Certificate to withhold that information.

However, if we learn about abuse of a child or elderly person or that you intend to harm yourself or someone else, or about certain communicable diseases, we will report that to the proper authorities.

Under Oregon law, suspected child or elder abuse must be reported to appropriate authorities.

OHSU complies with Oregon state requirements for reporting certain diseases and conditions to local health departments.

When we send information outside of OHSU, they may no longer be protected under federal or Oregon law. In this case, your information could be used and re-released without your permission.

The results of this study will be published, but all information identifying you will be removed. Only the investigator will have the key to the codes to identify you, and those codes will be destroyed upon completion of the study.

We may continue to use and disclose your information as described above indefinitely.

COMMERCIAL DEVELOPMENT:

Information about you or obtained from you in this research may be used for commercial purposes, such as making a discovery that could, in the future, be patented or licensed to a company, which could result in a possible financial benefit to that company, OHSU, and its researchers. There are no plans to pay you if this happens. You will not have any property rights or ownership or financial interest in or arising from products or data that may result from your participation in this study. Further, you will have no responsibility or liability for any use that may be made of your information.

COSTS:

There will be no cost to you or your insurance company to participate in this study.

For participating in this study, you will be given a $50.00 gift card to Fred Meyer's grocery store at completion of the family interview.

We may request your social security number in order to process any payments for participation.

LIABILITY:

If you believe you have been injured or harmed as a result of participating in this data collection, contact Dena Hassouneh (503) 494-2714 or Margaret Rising (503) 758-3688.

OHSU and the funder do not offer any financial compensation or payment for the cost of any injury or harm. However, you are not prevented from seeking to collect compensation for injury related to negligence on the part of those involved in the research. Oregon law (Oregon Tort Claims Act (ORS 30.260 through 30.300)) may limit the dollar amount that you

may recover from OHSU or its caregivers and researchers for a claim relating to care or research at OHSU, and the time you have to bring a claim.

If you have questions on this subject, please call the OHSU Research Integrity Office at (503) 494-7887.

PARTICIPATION:

If you have any questions, concerns, or complaints regarding this study now or in the future, contact Dena Hassouneh (503) 494-2714 or Maggie Rising (503) 758-3688

This research is being overseen by an Institutional Review Board ("IRB"). You may talk to the IRB at (503) 494-7887 or irb@ohsu.edu if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research subject.
- You want to get more information or provide input about this research.

You may also submit a report to the OHSU Integrity Hotline online at https://secure.ethicspoint.com/domain/media/en/gui/18915/index.html or by calling toll-free (877) 733-8313 (anonymous and available 24 hours a day, 7 days a week).

Your participation in this study is voluntary. You do not have to join this or any research study.

If you do join the study and later change your mind, you have the right to quit at any time. If you choose not to join any or all parts of this study, or if you withdraw early from any or all parts of the study, there will be no penalty or loss of benefits to which you are otherwise entitled, including being able to receive health care services or insurance coverage for services. Talk to the investigator if you want to withdraw from the study.

If in the future you decide you no longer want to participate in this research, we will remove your name and any other identifiers from your transcripts, but the material will not be destroyed and we will continue to use it for research.

We will give you any new information during the course of this research study that might change the way you feel about being in the study.

SIGNATURES:

Your signature below indicates that you have read this entire form and that you agree to be in this study.

We will give you a copy of this signed form.

Subject Printed Name	Subject Signature	Date
Person Obtaining Consent Printed Name	Person Obtaining Consent Signature	Date

Complete if the participant is not fluent in English and an interpreter was used to obtain consent. Participants who do not read or understand English must not sign this full consent form, but instead sign the short form translated into their native language. This form should be signed by the investigator and interpreter only. If the interpreter is affiliated with the study team, the signature of an impartial witness is also required.

Print name of interpreter: ____

Signature of interpreter:____Date: ___________

An oral translation of this document was administered to the subject in ______________________ (state language) by an individual proficient in English and_____________________(state language).

If applicable:

Print name of impartial witness: ____

*Signature of impartial witness:*____*Date:*_____________

Appendix I

Interview Guide, Individual

Interview Guide: Individual

[The individual interview guide will repeat the family interview guide to some extent. However, individuals may have different answers after having had time to think about the questions. Also, away from the family, individuals may have different answers to some of these questions. Finally, away from the family, the investigator will have the option to delve deeper into subjects that would be inappropriate in the full family setting or in the presence of the terminal cancer patient.]

Assessment of awareness of limited prognosis and hospice (to be used only in individual interviews):

Please describe for me your understanding of [patient's/your] serious illness. Does your understanding of the illness include an understanding about how this illness might affect how long [patient/you] will live? *[If "no," then proceed as "prognosis secret"; if "yes," then proceed as "prognosis open" (found below).]*

Can you describe for me some of the treatments that [patient/you] has been receiving? What do those treatments do for [patient/you]? *[Looking for answers that acknowledge hospice or comfort care.]* How do those treatments help to treat the illness/cancer (if appropriate)? *[Again, looking for answers that acknowledge hospice or comfort care. The answers to these questions will determine whether hospice is openly discussed, or vocabulary limited to "healthcare experience."]*

Hospice/Prognosis secret:

Please tell me about your recent healthcare experiences around [patient's] serious illness.

I know we discussed this before, but I wanted to ask in your opinion, Who are some of your family members who contributed most to the healthcare decisions? Who are some of the healthcare staff who helped make healthcare decisions? How did those same people help you make healthcare decisions? Are there other people in your community who helped with the decision-making?

What information about the serious illness was behind the decisions you have made lately? Who did you learn that information from?

Family dynamic questions

Again, we sort of covered this before, but I'd like to know in your opinion whether [patient] made their own healthcare decisions or whether someone else or the family made the healthcare decisions. Describe for me how your family worked together to make decisions around [patient's] serious illness. Who decided who would be the main decision-maker? How did the healthcare providers work with you on that?

Sometimes, family members play certain roles when a person is sick. For example, one might be a caregiver, while another is more the information-gatherer, and another might be the decision-maker. What have been the roles in your family?

Sometimes, other cultures are different with respect to how they prefer to manage a loved one's serious illness. How would you describe how Mexicans prefer to take care of their seriously ill loved ones?

Discriminatory / bias questions

Please think back to the doctors, nurses, CNAs, social workers, patient navigators, chaplains, and others you encountered. Who did you trust? Why did you trust them? What did that trust / distrust mean to you? How did trust / mistrust influence your decision-making?

Thinking specifically about your Mexican heritage, some patients and families experience healthcare encounters in which they feel they were respected or disrespected because of their Mexican ancestry. Can you tell me about a time when you felt that your culture was respected? Disrespected?

Thinking specifically about your Mexican heritage, some patients and families experience healthcare encounters in which they feel discrimination because of their Mexican ancestry. Can you tell me about a time when you felt that your culture was respected? Disrespected?

Socioeconomic

For a lot of people, healthcare insurance plays a big part of their healthcare experience. How has the availability of healthcare insurance affected your experience and decisions? How about the availability of other types of insurance or sick pay? A lot of people struggle to pay their medical bills. How have you handled your recent healthcare experience from a financial perspective? Finally, there are many Mexicans living here in the US who work very hard but do not have legal documentation. You by no means need to answer this question, but if you are willing, please describe any problems members of your family may have had during this healthcare experience relating to lack of legal documentation. Finally, as an immigrant to the US from Mexico, has the subject of returning home to Mexico occurred? If so, please tell me more about that.

"Healthcare" meaning

If you were to describe to a friend or family member the type of care you have received / or were offered, how would you describe it? What if you had to give it a name, like the name of a book. What title would you give it?

Closing question

Sometimes, when people are being interviewed, they think of things they would like to share but the interviewer never asks the right question. Please take this time to share with me any thoughts or questions you have had during the interview that I failed to ask about.

Hospice/Prognosis open:

Please tell me about your recent healthcare experiences around [patient's/your] terminal cancer and whether to enroll in hospice.

Can you describe for me some of the treatments that [patient/you] has been receiving?

Patients and families frequently have to make important healthcare related decisions. Who are some of your family members who contributed most to the healthcare decisions? Who are some of the healthcare staff who helped make healthcare decisions? How did those same people help you make healthcare decisions? Are there other people in your community who helped with the decision-making?

What information about the terminal illness was behind the decision whether to use hospice? Who did you learn that information from?

Family dynamic questions

Sometimes, when a family member is seriously ill, he or she makes their own healthcare decisions, while other times decisions are made as a family. Please describe for me whether [patient] made their own decision about hospice or whether someone else or the family made the decision about hospice. Describe for me how your family worked together to make decisions around [patient's] serious illness. Who decided who would be the main decision-maker? How did the healthcare providers work with you on that?

Sometimes, family members play certain roles when a person is terminally ill and dying. For example, one might be a caregiver, while another is more the information-gatherer, and another might be the decision-maker. What have been the roles in your family?

Sometimes, other cultures are different with respect to how they prefer to manage a loved one's terminal illness. How would you describe how Mexicans prefer to take care of their terminally ill loved ones?

Discriminatory / bias questions

Please think back to the doctors, nurses, CNAs, social workers, patient navigators, chaplains, and others you encountered. Who did you trust? Why did you trust them? What did that trust / distrust mean to you? How did trust / mistrust influence your decision-making?

Thinking specifically about your Mexican heritage, some patients and families experience healthcare encounters in which they feel they were respected or disrespected because of their Mexican ancestry. Can you tell me about a time when you felt that your culture was respected? Disrespected?

Thinking specifically about your Mexican heritage, some patients and families experience healthcare encounters in which they feel discrimination because of their Mexican ancestry. Can you tell me about a time when you felt that your culture was respected? Disrespected?

Socioeconomic

For a lot of people, healthcare insurance plays a big part of their healthcare experience. How has the availability of healthcare insurance affected your experience and decisions? How about the availability of other types of insurance or sick pay? A lot of people struggle to pay their medical bills. How have you handled your recent healthcare experience from a financial perspective? Finally, there are many Mexicans living here in the US who work very hard but do not have legal documentation. You by no means need to answer this question, but if you are willing, please describe any problems members of your family may have had during this healthcare experience relating to lack of legal documentation. Finally, as an immigrant to the US from Mexico, has the subject of returning home to Mexico occurred? If so, please tell me more about that.

Hospice meaning

If you were describing hospice care to a friend or family member, how would you describe it? What if you had to give it a name, like the name of a book. What title would you give it?

Closing question

Sometimes, when people are being interviewed, they think of things they would like to share but the interviewer never asks the right question. Please take this time to share with me any thoughts or questions you have had during the interview that I failed to ask about.

Appendix J

Interview Guide, Family

Question Guide: Family

(Hospice/Prognosis secret / not secret)

Okay, before we get started, I want to tell you just a little bit about myself and why I'm here. I'm studying to receive my doctorate in nursing. I will probably teach nursing in the future, but I am also interested in working with the Latino population to improve their healthcare experiences. Although I'm Anglo, I feel a strong connection with the Mexican American community, mostly because I lived the first 35 years of my life in south Texas. When I moved here to Oregon, I was surprised that there were so few Mexican Americans, and it hurt me to see that their healthcare experiences were affected by cultural, language, and power differences. I learned that the healthcare experience of Mexican Americans is different in Texas compared to Oregon. So for my research project, I'm hoping to learn from all of you what it is like to navigate the healthcare system as Mexican Americans in Oregon. In turn, I will teach others what I've learned.

There are no right or wrong answers to the questions I'm going to ask you. What [the interpreter] and I want to know is your experiences and your opinions. I want to emphasize that I am not an expert on your healthcare experience. Only you can provide that information. I will not repeat what you say to your healthcare providers, and so feel free to speak openly. Also, I've asked [the interpreter] to be sure we are accurately communicating ideas and that I'm not missing anything. So, there may be times that we consult with one another.

To start off, so that I know who each of you are and how you fit into the family picture, would you mind going around and telling me your name and how you are related to [patient]?

Hospice/Prognosis secret:

Please tell me about your recent healthcare experiences around [patient's] serious illness.

Can you describe for me some of the treatments that [patient] has been receiving?

Patients and families frequently have to make important healthcare related decisions. Who are some of your family members who contributed most to the healthcare decisions? Who are some of the healthcare staff who helped make healthcare decisions? How did those same people help you make healthcare decisions? Are there other people in your community who helped with the decision-making?

What information about the serious illness was behind the decisions you have made lately? Who did you learn that information from?

Family dynamic questions

Sometimes, when a family member is seriously ill, he or she makes their own healthcare decisions, while other times decisions are made as a family. Please describe for me whether [patient] made their own healthcare decisions or whether someone else or the family made the healthcare decisions. Describe for me how your family worked together to make decisions around [patient's] serious illness. Who decided who would be the main decision-maker? How did the healthcare providers work with you on that?

Sometimes, family members play certain roles when a person is sick. For example, one might be a caregiver, while another is more the information-gatherer, and another might be the decision-maker. What have been the roles in your family?

Sometimes, other cultures are different with respect to how they prefer to manage a loved one's serious illness. How would you describe how Mexicans prefer to take care of their seriously ill loved ones?

Discriminatory / bias questions

Please think back to the doctors, nurses, CNAs, social workers, patient navigators, chaplains, and others you encountered. Who did you trust? Why did you trust them? What did that trust / distrust mean to you? How did trust / mistrust influence your decision-making?

Thinking specifically about your Mexican heritage, some patients and families experience healthcare encounters in which they feel they were respected or disrespected because of their Mexican ancestry. Can you tell me about a time when you felt that your culture was respected? Disrespected?

Thinking specifically about your Mexican heritage, some patients and families experience healthcare encounters in which they feel discrimination because of their Mexican ancestry. Can you tell me about a time when you felt that your culture was respected? Disrespected?

Socioeconomic

For a lot of people, healthcare insurance plays a big part of their healthcare experience. How has the availability of healthcare insurance affected your experience and decisions? How about the availability of other types of insurance or sick pay? A lot of people struggle to pay their medical bills. How have you handled your recent healthcare experience from a financial perspective? Finally, there are many Mexicans living here in the US who work very hard but do not have legal documentation. You by no means need to answer this question, but if you are willing, please describe any problems members of your family may have had during this healthcare experience relating to lack of legal documentation. Finally, as an immigrant to the US from Mexico, has the subject of returning home to Mexico occurred? If so, please tell me more about that.

"Healthcare" meaning

If you were to describe to a friend or family member the type of care you have received / or were offered, how would you describe it? What if you had to give it a name, like the name of a book. What title would you give it?

Closing question

Sometimes, when people are being interviewed, they think of things they would like to share but the interviewer never asks the right question. Please take this time to share with me any thoughts or questions you have had during the interview that I failed to ask about.

Hospice/Prognosis open:

Please tell me about your recent healthcare experiences around [patient's] terminal cancer and whether to enroll in hospice.

Can you describe for me some of the treatments that [patient] has been receiving?

Patients and families frequently have to make important healthcare related decisions. Who are some of your family members who contributed most to the healthcare decisions? Who are some of the healthcare staff who helped make healthcare decisions? How did those same people help you make healthcare decisions? Are there other people in your community who helped with the decision-making?

What information about the terminal illness was behind the decision whether to use hospice? Who did you learn that information from?

Family dynamic questions

Sometimes, when a family member is seriously ill, he or she makes their own healthcare decisions, while other times decisions are made as a family. Please describe for me whether [patient] made their own decision about hospice or whether someone else or the family made the decision about hospice. Describe for me how your family worked together to make decisions around [patient's] serious illness. Who decided who would be the main decision-maker? How did the healthcare providers work with you on that?

Sometimes, family members play certain roles when a person is terminally ill and dying. For example, one might be a caregiver, while another is more the information-gatherer, and another might be the decision-maker. What have been the roles in your family?

Sometimes, other cultures are different with respect to how they prefer to manage a loved one's terminal illness. How would you describe how Mexicans prefer to take care of their terminally ill loved ones?

Discriminatory / bias questions

Please think back to the doctors, nurses, CNAs, social workers, patient navigators, chaplains, and others you encountered. Who did you trust? Why did you trust them? What did that trust / distrust mean to you? How did trust / mistrust influence your decision-making?

Thinking specifically about your Mexican heritage, some patients and families experience healthcare encounters in which they feel they were respected or disrespected because of their Mexican ancestry. Can you tell me about a time when you felt that your culture was respected? Disrespected?

Thinking specifically about your Mexican heritage, some patients and families experience healthcare encounters in which they feel discrimination because of their Mexican ancestry. Can you tell me about a time when you felt that your culture was respected? Disrespected?

Socioeconomic

For a lot of people, healthcare insurance plays a big part of their healthcare experience. How has the availability of healthcare insurance affected your experience and decisions? How about the availability of other types of insurance or sick pay? A lot of people struggle to pay their medical bills. How have you handled your recent healthcare experience from a financial perspective? Finally, there are many Mexicans living here in the US who work very hard but do not have legal documentation. You by no means need to answer this question, but if you are willing, please describe any problems members of your family may have had during this healthcare experience relating to lack of legal documentation. Finally, as an immigrant to the US from Mexico, has the subject of returning home to Mexico occurred? If so, please tell me more about that.

Hospice meaning

If you were to describe to a friend or family member the type of care you have received / or were offered, how would you describe it? What if you had to give it a name, like the name of a book. What title would you give it?

Closing question

Sometimes, when people are being interviewed, they think of things they would like to share but the interviewer never asks the right question. Please take this time to share with me any thoughts or questions you have had during the interview that I failed to ask about.

Appendix K

Interview Guide, Key Informant

Question Guide: Key Informants

How would you describe your professional role or your contact with the Latino/Mexican community?

What is your understanding of hospice? What is hospice, from your perspective?

What is your understanding of the hospice enrollment process? Another way of asking this is, How does a patient enter hospice?

How would you describe your professional or volunteer role in the family's hospice decision-making process?

Could you please describe for me the Mexican family dynamic during hospice decision making?

Can you think of particular family types that would be inclined to accept hospice compared to family types that would not be inclined to accept hospice? What are the characteristics that distinguish them?

Some cite Latino/Hispanic cultural and socioeconomic barriers to hospice. In your opinion and based on your experience, what are the greatest barriers to hospice enrollment for Mexican families? (Lots of follow up questions here) Are any of those specific to persons of Mexican descent?

Are there different barriers to hospice enrollment for Mexican families in the cancer setting versus other terminal illnesses?

Are there different barriers to hospice enrollment for Mexican families versus other Latino and Hispanic groups?

If you know, How would you describe the Oregon/Washington Mexican population compared to the Southwest (Texas, Arizona, New Mexico, and California)? Do these differences (if any) impact hospice decision making and enrollment?

(If not already discussed. .. .) In your opinion, how does religion/access to sick leave, health insurance, life insurance/documentation status/language/education/believing in the miracles of US medicine/trust in healthcare providers/poor cultural skills/prognostic secrecy/poor communication skills/the hospice regulations (i.e., consent process and giving up curative therapy) impact the process of hospice decision making for Mexican families.

What is the impact of politics around healthcare (Obama care repeal) and immigration (Wall, ICE, Census) on hospice enrollment for persons of Mexican descent?

Could you please give me some examples of hospice decision-making / enrollment with Mexican families that went poorly and that went really well. What do you think were the causes of those poor and good outcomes?

If you could change something about our healthcare teams to make it easier for Mexican families to use hospice – including Mexicans without legal residence – what would you do? Would your answer change for other Latino/Hispanic groups?

If you could change something about our medical system – policies and regulations -- to make it easier for Mexican families to use hospice – including Mexicans without legal residence – what would you do? Would your answer change for other Latino/Hispanic groups?

Is there anything you would like to tell me about the hospice experience for persons of Mexican descent that I have not asked you about?