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# Considerations for Working With Hispanic/Latino Patients Receiving Hospice: Social Workers' Perspectives

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**Considerations for Working With Hispanic/Latino Patients Receiving  
Hospice: Social Workers' Perspectives**

by

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MSW Clinical Research Paper

Presented to the Faculty of the  
School of Social Work  
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St. Paul, Minnesota  
in Partial fulfillment of the Requirements for the Degree of  
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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. The project is neither a Master's thesis nor a dissertation.

## Abstract

Hospice care provides physical, emotional, and spiritual support to patients with a terminal illness and their families through the end of one's life. Social workers are a part of the multidisciplinary team that support patients and families along with nurses, chaplains, and other disciplines. While this service at the end of life is meant for anyone in need, of the patients receiving hospice annually, only 6% are Hispanic/Latino. Previous research identifies that there are several barriers to the Hispanic/Latino population accessing hospice care. With both the aging and Hispanic/Latino populations dramatically on the rise in the U.S., this research set out to explore social workers' considerations in serving the Hispanic/Latino population receiving hospice services with cultural sensitivity and how to increase hospice outreach and education to this population. Research was conducted through four ( $n = 4$ ) semi-structured interviews. The findings were developed through an open-coding process and the following themes were identified: *family involvement; communication; and, self-awareness and cultural competence*. These themes were compatible with previous research, but offered additional depth and specificity as to how hospice social workers can support and serve Hispanic/Latino patients receiving hospice services. Future research calls for additional study as how to continue reaching out to this population and providing hospice education and services.

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**Considerations for Working With Hispanic/Latino Patients Receiving Hospice:  
Social Workers' Perspectives**

**Introduction**

In the United States, the older adult population—aged 65 and older—is anticipated to nearly double between 2012 and 2050, from 43.1 million to 83.7 million (Ortman, Velkoff, & Hogan, 2014). This dramatic increase will affect both older adults and the people and organizations that work with them, including businesses, family systems, media, urban planning, and industries. Additionally, society will see an increase in older adults *across* race and ethnicity, as the minority population is expected to become the majority by 2043 (Ortman et al., 2014).

In light of this, the number of minority older adult populations is projected to increase by 217% compared to the already staggering 81% increase for older white adults (Administration on Aging [AA], 2015). The Hispanic/Latino population, according to the Pew Research Center, is projected to reach 106 million here in the United States by year 2050 (Pew Research Center, 2014). This rise in the Hispanic/Latino population is attributed to an increase in the population's U.S. births (Pew Research Center, 2014). A 2010 Stanford study of the health and health care of Hispanic/Latino older adults explored in detail the makeup of this specific group of older adults. The study found that the majority of older Hispanic/Latino adults are women. While over half of the older

adult Hispanic/Latino men are married, only 37% of older adult Hispanic/Latino women are married. Additionally, the study asked where these older adults were living and recognized a disagreement in the existing literature about whether or not Hispanic/Latino older adults live with family because of cultural tradition or because of financial need. While the majority of the study's foreign-born participants identified that they live with their children for reasons of cultural tradition, these same study participants, per recorded demographics, less personal income, more mobility issues, and more difficulties with activities of daily living (Talamantes & Sanchez-Reilly, 2010). Due to the growing number of older Hispanic/Latino adults in the United States, it is important to understand the unique health care needs within this culture. This will enable health care workers and others to reach the needs of the millions of Hispanics/Latinos with cultural sensitivity and understanding, and most specifically for purposes of this study, enable health care workers to meet the end-of-life needs of this population.

There is currently a shortage of board-certified geriatricians in the United States, particularly geriatricians who speak Spanish and/or are fully understanding of the Hispanic/Latino culture as it relates to health care (Brittain, 2013). According to Bruce Brittain (Changing Aging), there should be 300 older adult patients to every one geriatrician; however, in 2013, this ratio was 870 older adult patients to one geriatrician, and the number of providers is not increasing with the increase of older adults (2013). This geriatrician shortage is due to a few factors: few departments nationally specialize in geriatrics, partly because of few resources available; medical school costs are high in relation to the relatively low pay of working in geriatrics; and there is lack of expert geriatric training during medical school (Association of American Medical Colleges

[AMA], 2012). Furthermore, Latino physicians are largely underrepresented in the field (AMA, 2012). For example, in the state of California, which is home to the largest number of Hispanic/Latinos in the United States, 40% of the population is black or Latino, yet less than 10% of physicians in the state are of the same background (AMA, 2012).

The increase in health care needs of older adults across demographics means an increase in health care costs. Out-of-pocket health care costs have increased by 49% for older adults between years 2000 and 2010, with an annual cost of \$4, 843. This is considerably more than the total population averaging an annual cost of \$3,157 (AA, 2011, p. 13). In 2010, older adults accrued over twice as much in total expenditures on their health than did the total population. Older Americans spent 65% on insurance, 18% on medical services, 17% on drugs, and 3% on medical supplies (AA, 2011, p. 13). As has been illustrated, health care for older adults can be very costly. Hospice care is a service that seeks to increase quality of life for patients while being covered by Medicare, Medical Assistance, and most private insurance programs.

Nationally in 2011, 1.65 million individuals received hospice services (National Hospice and Palliative Care Organization [NHPCO], 2011). Among those in hospice, 1,059,000 of these patients died while on hospice; 313,000 patients remained on hospice into 2012 as “carryovers”; and 278,000 patients were discharged still alive for reasons such their health and thus their prognosis actually improving or a newly expressed desire for curative treatments (NHPCO, 2011). The majority of hospice patients remained on hospice for only seven days (35.8%); the next largest proportion was on hospice for eight to 29 days (27.0%). Only 8.7% of patients remained on hospice for three to six months.

In terms of gender, 56.4% of hospice patients were identified as female and 43.6% as male. More than one-third of all hospice patients were 85 years of age or older and 83.3% of hospice patients were 65 years of age or older. Sixteen percent of the hospice population accounted for ages 35-64. Cancer diagnoses accounted for 37.7% of hospice admission diagnoses, followed by dementia, heart disease, and lung disease as the next leading hospice admission diagnoses. In terms of ethnicity, only 6% of patients who received hospice care were Hispanic/Latino, 8.5% were Black/African American, 2.4 % Asian, Hawaiian, or other Pacific Islander, and 0.2% American Indian or Alaskan Native, (NHPCO, 2012).

According to the 2010 Stanford study on Hispanic/Latino older adults, more Hispanic/Latinos die at home compared to other ethnic groups, but not necessarily while on hospice (Talamantes & Sanchez-Reilly, 2010). Overall, the Hispanic/Latino population uses hospice significantly less than non-Hispanic groups. The study reported that while the causes of this remain unclear, one cause could be a lack of information and lack of Spanish-speaking hospice workers. Per previously conducted research, Spanish-speaking hospice patients do prefer Spanish-speaking hospice workers. (Talamantes & Sanchez-Reilly, 2010),

Social workers, particularly those who focus on aging populations, can help bridge the gap between the hospice care that Hispanic/Latino patients want and the services they receive. Social workers are bound by their code of ethics to provide culturally competent services to clients, including hospice patients and families. The Administration on Aging speaks to the importance of this code in saying:

Cultural competence is critical to reducing health disparities and improving access to health care that is respectful of, and responsive to, people's diverse needs.

Culture involves a number of things, including personal identification, language, thoughts, *communications*, actions, customs, beliefs, values, and institutions that are often specific to ethnic, racial, religious, geographic, or social groups. For the provider of health information or health care, these elements influence beliefs and belief systems surrounding health, healing, wellness, illness, disease, and delivery of health services. (Administration on Aging, 2015)

The following research focuses on the experiences of Hispanic/Latino patients on hospice care services, identifies barriers to Hispanic/Latino access of hospice, and describes interventions to overcome these barriers. The research statement for this study is: "Considerations for Hispanic/Latino Patients Receiving Hospice: Social Workers' Perspectives."

## Literature Review

This literature review examines several considerations of hospice services as experienced by the Hispanic/Latino community, including beliefs about the health care system, beliefs about death and end of life care, acculturation, caregiver availability, and satisfaction with hospice services. The literature review then moves to the limited research that exists on overcoming these barriers, including research on rituals, communication, and education. The research then moves on to the study itself, exploring experiences of Hispanic/Latino patients on hospice via qualitative interviews with hospice social workers and their considerations in working with Hispanic/Latino patients and their families. In order to best understand the following studies, it is first important to identify several terms.

### Definitions

**Hispanic.** The term *Hispanic* historically refers to areas of North and South America that were conquered by Spaniards and to the modern countries that can trace their history to Spain. This includes Mexico, Central America, and portions of South America. Latina/o is a more general term than Hispanic and is used to describe the rest of Latin America without these Spanish traces. Brazil, for example, was settled by Portugal rather than Spain, so Brazil is an example of a Latino, but not a Hispanic country (Chicano & Latino Studies, 2000). In terms of serving hospice patients and families, it is most important for a person to self-identify their ethnicity as this is telling of a person's history and cultural roots. This study will use the term Hispanic/Latino in order to be most inclusive. To support the study of the Hispanic/Latino population in general, despite the fact that it includes a variety of different countries, Merydawilda Colon found

in her 2012 study of acculturation and Latino use of hospice services that all Latino groups in her study (Puerto Ricans, Dominicans, Central Americans, and South Americans), had similar attitudes toward hospice regardless of country of origin (Colon, 2012a).

**Acculturation.** Across the literature, the term *acculturation* is often used to mean, “the process of change that takes place as a result of continuous contact between cultural groups” (Colon, 2005). For example, the literature may speak of the acculturation of the Hispanic/Latino population in terms of proficiency of English as an indicator of U.S. orientation and identification. The consideration of acculturation is important as it informs a person’s relationship between past cultural traditions and the customs of their new community. As it relates to hospice, acculturation may influence a person’s understanding of this philosophy of care.

**Hospice care.** *Hospice care* falls under the wider palliative care umbrella and designates a holistic model of care that serves individuals at the end of life (NHPCO). Palliative care, which is defined as patient and family-centered care that enhances quality of life throughout the “anticipating, preventing, and treating” of suffering (NHPCO), can be utilized alongside curative and aggressive treatments to address comfort. Throughout the course of disease progression, a patient will discuss with their palliative care team the point at which the comfort measures take precedence over the curative treatments. It is at this time that a person may be referred from palliative care to hospice care services. Typically, a person becomes eligible for the hospice care benefit when a physician has given a prognosis of six months or less. Hospice care provides the services of a physician, nurse, social worker, chaplain, aid, and oftentimes a volunteer to a sick person

with the goal of keeping that individual comfortable in the final months, weeks, and days of their life. Hospice services can be provided in a person's place of residence, in a specific hospice house, or in a facility. Bereavement services are offered to the patient leading up to their death, and then are most often utilized by the surviving family members.

Bereavement refers to the feelings of grief and loss experienced by a person when a loved one has died. Hospice care is required to provide bereavement services to family members free of charge for one year following a person's death (National Palliative Care & Hospice Organization, 2015). Bereavement services play a vital role in the holistic model of hospice care in that the service not only serves the patient, but also the patient's social system, most often their immediately family members.

### **Review of Grey Literature and Empirical Studies**

The following section reviews 10 studies in five different sections: barriers to care; acculturation; caregiver availability; satisfaction with hospice services; and overcoming barriers. This is an overview of both grey literature and empirical studies.

**Barriers to care.** There are several studied topics as to why the Hispanic/Latino population experiences barriers to accessing hospice care services, including beliefs about health care, beliefs about death, and beliefs about end-of-life care.

***Beliefs about health care.*** Research indicates that beliefs about health care contribute to the Hispanic/Latino population's use, and subsequent experience of, hospice services. In 2004, researchers Born, Greiner, Sylvia, Butler, and Ahluwalia conducted a series of four focus groups of inner city African Americans and Latinos ( $n = 27$ ) to explore knowledge, attitudes, and beliefs about end-of-life care among inner city African

Americans and Latinos. Results from this study indicated mistrust of the health care system as a theme and a barrier to accessing hospice care services. Born et al. (2004) identified the institutional mistrust produced by historic injustices of these minority populations and connected this to current disparities in the health care of whites and nonwhites. One research participant described how the feeling of mistrust was experienced by both the majority and minority cultures: a patient mistrusting a doctor of color and also a white doctor mistrusting a patient of color. Results of this study are relevant to the current study in that Born et al. describes minorities' perceptions of health care services, which then influence their perceptions and use of hospice services.

In conducting a study utilizing a cross-sectional phone-based survey of adults living in the United States on beliefs of pain management between Hispanic and non-Hispanic groups ( $n = 123$ ), Carrion, Cagle, Van Dussen, Culler, and Hong (2015) stated that, "Hispanics are more likely to experience severe levels of pain prior to death and less likely to visit health care practitioners for their pain," and additionally, "a complex interplay of cultural norms, provider mistrust, and poor knowledge may serve to explain these differences" (Carrion et al., 2015). The researchers surveyed patients over the course of six weeks who were selected by random sampling techniques, oversampling for Hispanic and African American groups to ensure representation. Seventy-five percent of Hispanic respondents reported that pain medicine could not control pain compared to 67% of non-Hispanic respondents who believed that pain medicine could indeed control pain. Forty-three percent of Hispanics compared to 9.5% of non-Hispanics reported that admitting to pain was a sign of weakness. As pain and symptom management is a primary tenet to the philosophy of hospice care, this study is important to consider when

examining the use and understanding of hospice care services by the Hispanic/Latino population.

In another study, Kirkendall, Holland, Keene, and Luna (2015) analyzed the data produced by hospice care surveys provided by 2980 caregivers in which 152 cared for a Hispanic patient and 2828 cared for a non-Hispanic patient. Kirkendall and colleagues (2015) described the way in which Hispanic/Latino families viewed their physician as an authority with control over treatment decisions and that there is a great deal of trust in the physician's referrals. Kirkendall et al. (2015) reviewed the common referral process from the emergency department to hospice services to be as such: Hispanic families are referred to hospice by an emergency department physician following an emergency. Thus the patient and family do not receive hospice information from their trusted provider, but rather from a provider who does not know the patient's medical history. In addition to not adequately educating on hospice services in a culturally sensitive manner, the emergency department provider could unintentionally be insensitive during the visit, leaving the patient and family feeling distrustful of both the medical system and hospice specifically (Kirkendall et al., 2015). Additionally, Kirkendall et al. (2015) suggested that there is immediate distrust between Spanish-speaking Hispanic/Latino patients and non-Spanish speaking providers. To establish this important trust and constancy, Kirkendall et al. (2015) recommended Hispanic/Latino patients have access to providers who they are able to see consistently, build a relationship with, and who are culturally sensitive to the patient's needs and beliefs about the health care system and death and dying. This study informs the researcher on the importance of relationship between a

provider and the Hispanic/Latino community, thus informing best situations for a hospice referral to be made.

***Beliefs about death.*** Research on patients, caregivers, and families of hospice give insight into the Hispanic/Latino beliefs about death and end-of-life care. Deborah Carr (2011) asked, “Why don’t Blacks and Latinos prepare for the inevitable?” in her study of racial differences in end-of-life planning and use of advanced care directives. Carr analyzed data from the New Jersey End of Life study ( $n = 305$ ), which included noninstitutionalized adults aged 55 and older. One group was categorized as a “healthy” control group while the other included patients diagnosed with a major chronic illness. Data was collected from 2006–2008 through face-to-face interviews. Carr concluded that Western society’s older adults wanted to protect their family from the burden of caretaking, and thus an increase in advanced care planning, whereas within the Latino community this tendency is reversed. Older adults are to be protected from the burden of having to plan for end-of-life, and family often take care of it at the time of decline and death (Carr, 2011). Carr’s research showed that while Hispanics completed fewer advance care directives than whites, the rate of end-of-life *discussions* were the same compared to non-Hispanic whites, counter to the assumption of Carrion and Nedjat-Haiem (2013) that Latinos do not discuss death and dying because it is taboo. Carr (2011) suggested that Hispanics prefer discussing end-of-life concerns with the *entire* family, versus electing a single person to make their health care decisions on their behalf. Specifically, one-third of Hispanics in Carr’s study had held informal end-of-life discussions compared to 85% of whites. One in 10 Hispanics had completed an advance care directive compared to two-thirds of whites (Carr, 2011). This study on the use of

health care directives of the Hispanic/Latino informs the researcher on the perception of advanced care planning and thus end-of-life by this cultural group of interest within this study.

***Beliefs about end-of-life care.*** Hospice knowledge and intentions of use among Latinos has been researched by Selsky, Kreling, Luta, Solomon, Makgoeng, Gomez-Duarte, Barbo, and Mandelblatt (2012). Their 2012 study sought to identify why hospice use is low among Latinos. A cross-sectional survey of 331 Latino immigrants from Central and South America was conducted. Logistic regression and multiple imputations were used to test associations between cultural values, acculturation, and hospice knowledge and intentions. A challenge faced by hospice workers was that, “Many Latinos believe that families should keep the patient’s prognosis a secret from the patient. We found that endorsement of the idea that one should maintain secrecy about prognosis at the end of life decreased intentions to use hospice” (Selsky et al., 2012). Selsky and colleagues (2012) recognized that these views were in conflict with the values of hospice care, including patient autonomy. A qualitative example of this concern was expressed by interviews held by Carrion and colleagues (2013). One participant shared that the health care worker “started off talking about death and Mom’s expectations...I told her, ‘Listen, I didn’t let her know the extent of what is happening...I didn’t want her to start freaking out.’ She said, ‘Don’t you think she needs to know...so that she could get ready? At what point will you tell her?’ (Carrion et al., 2013). This poses a challenge for hospice workers as how to address patient-informed consent and patient autonomy. In consideration of prognosis, in order to qualify for hospice care services, one must elect to forego curative treatments. Hospice referrals for the Hispanic/Latino population can be

late into an individual's illness progression, if ever at all. Hispanic/Latino patients have been reported to display a tendency to desire exhausting all curative treatment options before choosing hospice because admission to hospice can mean "losing hope and accepting death" (Kirkendall et al., 2015).

While the research of Carr (2011) and Selsky et al. (2012) suggests that older Hispanic/Latinos do not want to talk about death, author Nydia Garcia Preto, stated in her study of healing and growth after the death of a loved one, *Living Beyond Loss*, that Latinos view death as a part of life and an event that is unavoidable. According to this ideology, death is embodied rather than unacknowledged, which is counter to other studies' perceptions of the Hispanic/Latino populations attitudes toward death as it relates to accessing hospice care, (as cited in Walsh & McGoldrick, 2004, p. 149]. Preto argues that Latinos prefer to die at home and go to the hospital only when it is the only option as there is a perception that among the Hispanic/Latino population that if you go to the hospital you will die (p. 150). This reflects the Hispanic/Latino mistrust of the health care system as studied above.

**Acculturation.** There is an assumption made across the literature (Colon, 2012a; Gelfand et al., 2001) that acculturation plays a role in one's understanding of and thus access to hospice care services; however research measuring a direct correlation between acculturation and attitudes of Hispanic/Latinos toward hospice is limited. Researcher Merydawilda Colon, a leader amongst the literature in her study of Hispanic/Latino use of hospice services, studied the role of acculturation and accounted for the variable of socioeconomic status. In her questionnaires, including a bi-dimensional acculturation scale, submitted by 380 Latinos of various nationalities from southern New Jersey, Colon

found that acculturation did not play as significant a role in attitudes toward hospice services as did the role of socioeconomic factors, contradictory to the findings of Gelfand and colleagues (2001). A positive relationship to attitudes toward hospice included factors such as income, education, and familiarity with the word “hospice.” Even if respondents were not familiar with the word hospice, the majority of respondents, upon learning more about the service, indicated that if they had an incurable illness with a life expectancy of six months or less they would choose hospice (Colon, 2012a). This finding calls attention to the need for further hospice care education among the Hispanic/Latino community. Colon (2012a) found that a majority of respondents indicated that if they had an incurable illness they would both want everything possible done to keep them alive and that they would also use hospice (Colon, 2012a). Colon (2012a) saw this contradiction as a challenge that could be overcome with education about the realities and implications of aggressive treatments when death is inevitable.

**Caregiver availability.** Across the literature, researchers refer to a tendency among Hispanic/Latino families to want to care for their own sick family members, and thus not need or want outside help. While traditionally this is true, research suggests that factors such as acculturation are changing this tendency (Carrion et al., 2013). For example, Carrion and Nedjat-Haiem conducted a study of older Latinos at the end of life and the perspectives of both family caregivers and professional, paid caregivers, (2013). Qualitative data was collected in Central Florida through in-depth, open-ended, semi-structured interviews where n=13 of family (unpaid) caregivers and n=7 of paid caregivers. In observing the realities of family members able to provide caregiving, the researchers stated that, “despite these cultural and social pressures to provide familial-

based in-home care, hospice-type support and paid caregivers are still needed by many.” The researchers went on to refer to a study that indicated that 30% of Mexican Americans reported that they would not have an available caregiver if they became ill and needed help (Carrion et al., 2013). Acculturation also plays a role in the belief of availability of a caregiver. According to Adams et al. (2006), fifty-two percent of first generation Hispanics believed that elderly parents should live with their adult children, whereas 33% of second generation and 32% of third generation Hispanics believed the same, (Adams et al., 2006). This is all to say that providers cannot assume that a Hispanic/Latino patient has the caregiving help of family and that hired help may be necessary. Additionally, Medicare’s Hospice Benefit requires for a person to be eligible for hospice services as a Medicare-covered benefit, there must be an available caregiver. Carrion and colleagues (2013), as reviewed above, call this assumption erroneous as it could disproportionately keep Hispanic/Latino individuals from qualifying for the beneficial hospice services. Carrion et al. (2013) also addressed today’s reality of immigration patterns, which can make for a situation where family members are not able to join one another to provide caregiving (2013).

### **Satisfaction with Hospice Services**

Kirkendall et al. (2015) offered insight into how the social worker could best support a Hispanic/Latino patient and family receiving hospice services through the study of 2980 caregivers via their responses to the Family Evaluation of Hospice Care (FEHC). Kirkendall (2015) reported that of the 152 Hispanic/Latino caregiver respondents, 71% were more likely than non-Hispanic caregivers to feel that the hospice team did something inconsistent with the patient’s wishes. Additionally, Hispanic/Latino

caregivers reported that they would have liked more religious/spiritual contact than was offered (47% less likely than non-Hispanic caregivers to report having as much religious and spiritual care offered as they would have liked.) In contrast to not enough spiritual care being offered in the opinions of Hispanic caregivers, these same Hispanic caregivers were 3 times more likely to report that the patient received more help with feelings than he or she wanted (Kirkendall et al., 2015). As it is much of the hospice social worker's role to process death and dying/grief and loss with a patient, this is an important finding to consider in how a social worker is to approach a patient clinically.

For purposes of this study, it is important to consider the research of populations in which the Hispanic/Latino population is the minority and in which they are in the majority, as this may influence implications for practice by hospice workers. One study that did just this is Adams, Horn, and Bader (2006) who examined Hispanic access to hospice services in a largely Hispanic community and found different results than that of previous studies. Utilizing retrospective chart reviews of 500 Medicare beneficiaries, the researchers studied Hispanics' access to hospice services utilizing the framework of Aday and Anderson's model for access to medical care. The researchers hypothesized that more Hispanics were dying in the community than were dying on hospice and that the number of Hispanics accessing hospice was less than the number of whites accessing hospice. Through their study, the researchers concluded that there were the same number of Hispanics dying in the community as were dying on hospice and that actually the only service whites had greater access to was that of volunteer services provided by hospice (Adams et al., 2006).

## **Overcoming Barriers**

In their research, Kirkendall et al. (2015) recommended that hospice programs modify the way in which emotional support is provided by offering more untraditional forms, such as facilitating religious rituals and addressing religious/spiritual concerns as part of psychosocial support for the patient rather than just for a chaplain. Carrion et al. (2013) agreed that there is a need for culturally and linguistically appropriate education, specifically in regards to pain medications and pain management. Carrion et al. (2013) offered the realistic and concrete suggestion that hospice organizations conduct outreach to recruit more Spanish-speaking hospice volunteers who are able to connect with patients culturally.

**Rituals.** Offering rituals has been suggested by the literature as a way to increase support to Hispanic/Latino patients on hospice. Author Nydia Garcia Preto recommended that Hispanic/Latino family members who are not able to be present for the death of a loved one due to issues of immigration perform cultural rituals with friends and/or relatives that do live nearby as a way of healing (as cited in Walsh & McGoldrick, 2004). Merydawilda Colon's study of Latinos' attitudes toward hospice care, though, found more than one-half of respondents would not want the services of a folk healer rather than hospice (Colon, 2012a). This could imply that the use of rituals would not replace that of hospice care, but rather would be appreciated as an additional component to existing hospice services.

**Communication.** Language is, of course, a contributing factor to the access of hospice care by the Hispanic/Latino population. Qualitative examples of this were included in Carrion et al. (2013): "We need more information in Spanish. You see, my

husband does not know all the information I know about his condition because he does not speak English. The doctors speak to me in English, the materials are in English. I'm sure it is the same for other people who do not speak English" and "A non-Spanish speaking counselor came here for the first time when this all happened and she sort of started off talking about death, what were Mom's expectations, and asking what if she would die...It made me feel a little uncomfortable. You know, but I handled it well. Mom did not understand what she was saying" (Carrion et al., 2013). These examples call for a need to increase culturally sensitive materials and education among hospice, or else hospice is not living up to its mission.

**Education.** Further education was recommended by the literature as a way to increase the use of hospice by the Hispanic/Latino population. Researcher Merydawilda Colon offers specific and concrete examples of how to further educate the Hispanic/Latino community on hospice care services. She stated, "one has to be where the Latinos are and be willing to genuinely interact with them" (Colon, 2012a). Colon made unique suggestions, such as offering hospice care education materials in both English and Spanish not only in health care settings, but also in schools, Latino-owned beauty salons, and Latino-owned auto shops. Colon also suggested the use of a video produced in Spanish of a Hispanic/Latino family utilizing hospice services that includes subtitles in English that could be shown at a church service. Colon recommended that education materials be at an eighth-grade reading level to ensure accessibility by a majority of people. Colon made the point that social workers are most fit for this role of education because social workers have skills in communication, navigating systems, resources, and coping skills (Colon, 2012a). It is especially important to note that

literally translating hospice education materials into Spanish is not enough as *hospicio* (*hospice* in Spanish) commonly means “orphanage” or “place for poor people,” (Selsky et al., 2012). Thus, hospice services must be translated in a culturally sensitive manner, and it might be best to communicate the education through existing Latino social networks and organizations (Selsky et al., 2012).

## **Conceptual Framework**

As hospice care is a holistic philosophy that serves the patient not only physically, but also emotionally and spiritually, it is only fitting to consider a well-rounded conceptual framework. Ecological systems theory is one that considers whole systems in relation to the individual person and offers social workers a “bigger picture” lens. Other health care disciplines turn to social workers to gain a wider understanding of the patient. This lens has been widely used by social work researchers when considering culturally sensitive work with the Hispanic/Latino population. The ecological perspective considers four categories, or levels, as identified by Urie Bronfenbrenner, including microsystems, mezzosystems, exosystems, and macrosystems (Forte, 2007). Social workers interested in the duality of the person and situation and the system and its environment can use these categories to classify behavior that takes place in these systems (Ashford & LeCroy, 2013). In the case of considering Hispanic/Latino’s use of hospice services, there are a variety of influential factors, including personal beliefs and direct practice with the patient (micro), relationships with providers and health care systems (mezzo), the systems that do not directly involve the patient, but nonetheless effect the patient (exosystem), and contributions of policy such as the Medicare Hospice Benefit (macro). The following describes each category more specifically as it relates to hospice and the Hispanic/Latino culture.

### **Micro**

Micro practice or direct client contact is an important lens through which to orient oneself as a clinician, as a key role of the hospice social worker is to provide individual

therapeutic support to patients (NHPCO). Microsystems involve direct in-person contact among system participants (Ashford & LeCroy, 2013). In a “typical” hospice scenario, the patient’s primary caregiver, immediate family members and closest friends, hospice nurse, social worker, chaplain, and attending physician serve as the patient’s microsystem. Within the microsystem, the patient’s physical, emotional, and spiritual needs are directly met through each discipline’s clinical interventions such as pain/symptom management, psychosocial assessment and counseling, and spiritual support. It is at the micro level that the unique needs of the Hispanic/Latino patients already on hospice are met.

### **Mezzo**

An individual patient is often involved in or supported by wider systems that are important for the social worker to consider as they best assess and provide direct support to their patient. Mezzosystems are sets of microsystems, such as a community or neighborhood (Ashford & LeCroy, 2013). In the case of hospice, this includes the community in which a patient lives and their access to health care education and outreach. Additionally, the mezzosystem includes the network of care facilities available to a patient (if hospice is provided outside of the home). In the case of the Hispanic/Latino population, mezzosystems refer to cultural communities that inform a person’s traditions and rituals.

### **Exosystem**

A hospice social worker is only able to provide resources to a patient to the extent that the widest system allows, thus it is of the utmost importance for a hospice social worker to also be involved at a policy level. The exosystem is defined by larger institutions with which a person does not have direct contact but that greatly affect a

person's life (Ashford & LeCroy, 2013). As it relates to hospice, the exosystem includes a person's access to additional care beyond that of in-home hospice services. This might include a need for additional hired help or privately paid room and board at a skilled nursing facility or assisted living. The guidelines as to who qualifies for state assistance and who does not is also a part of the exosystem. As has been reviewed in the literature, the Hispanic/Latino population less often accesses hospice care at the level of the exosystem than whites.

### **Macro**

Microsystems, mezzosystems, and exosystems are all located within the macrosystem, which is the system that has the greatest influence on social activities (Ashford & LeCroy, 2013). Culture, defined as a system of shared meanings and values (Ashford & LeCroy, 2013), is the most dominant macrosystem and applies directly to the purposes of this research. Much of this research identifies the role of culture as it pertains to the experience of Hispanic/Latino patients on hospice as crucial and as impacting the ways that hospice social workers can best support a patient, including a patient's culture, traditions, and rituals at the end of life.

### **Professional Lens**

Upon graduating with my undergraduate degree from Marquette University, I spent a year serving as a full-time volunteer with the Jesuit Volunteer Corps Northwest and AmeriCorps programs. My placement was with a home-based palliative care program in central Washington. This region has a large Hispanic/Latino community, yet I found that this was greatly underrepresented in the patient census of our palliative and hospice care programs. I began with a goal to recruit Spanish-speaking volunteers to

serve our patients, yet quickly learned that this could not be the first step as a culturally sensitive education needed to come first. It was in the process of formulating a hospice cultural outreach committee where I learned that there are big questions to be answered before addressing the underrepresentation of the Hispanic/Latino community on hospice. Three years later I designed this study to begin addressing these questions.

### **Personal Lens**

I have long been drawn to Latino cultures since first traveling to El Salvador as a high school student and then later traveling throughout various parts of Central America with a medical/public health organization as an undergraduate student. During my undergraduate career, I lived in Santiago, Chile for six months and studied Spanish. Time and time again, my greatest takeaway from these experiences was that as humans we are far more alike than we are different, despite differences in culture and geography. It is with this lens, one that views society as one human family, that I am motivated to work across cultures and communities. As the Hispanic/Latino community is one that particularly values family and quality time, the hospice philosophy of care could be very fitting if a few cultural barriers were first addressed, as this study seeks to do.

As was mentioned in the introduction, we as social workers are called by our code of ethics to provide culturally competent services. It is our responsibility as hospice workers to address the vast underrepresentation of Hispanic/Latino patients receiving hospice services and to ask what is our role in providing services across cultures.

## **Methodology**

### **Study Design and Rationale**

The purpose of this study was to learn how to work with cultural sensitivity as social workers with Hispanic/Latino patients and families receiving hospice care. The study additionally sought to learn what barriers keep Hispanic/Latinos from utilizing hospice and how to overcome these barriers and better serve this population.

Furthermore the study explored how hospice can reach out to more Hispanic/Latino patients and their families. The researcher used qualitative phone interviews with semi-structured questions as the study design. The statement of the study was, "Considerations for Working With Hispanic/Latino Hospice Patients: Social Workers' Perspectives." This design was appropriate, as it allowed the researcher to be more exploratory in studying hospice professionals' experiences with the Hispanic/Latino population.

### **Sample**

The aim of this study was originally to recruit eight to 10 hospice social workers to interview by phone using a semi-structured interview design. In the end four participants participated in qualitative interviews. Recruitment criteria for this study included: (a) currently serving as hospice social worker and (b) at least one year of hospice work experience. The research sample consisted of health care professionals who serve as hospice social workers and were contacted via a letter of permission obtained from the agency. The sample method used for this study was just that: obtaining a letter of permission from a specific agency. The researcher also asked research participants at the end of each interview to ask if participants would be able or willing to

identify further social workers in their region who may be interested in participating in the study. Upon receiving the initial letter of consent from the social work supervisor, a nurse manager in this case, the initial letter of recruitment was forwarded to the hospice social worker staff by the nurse manager. Those initial participants interested in participating in the study were able to contact the researcher by phone or e-mail, as indicated on the letter of recruitment. From there, the researcher sent the initial participants the information regarding the interview along with the letter of informed consent (Appendix A). The letter of informed consent was signed, scanned, and e-mailed back to the researcher.

### **Recruitment**

Throughout the research process, there were several plans of recruitment. This researcher experienced several barriers to accessing potential participants who met recruitment criteria, as will be further explained in the Limitations section. Plan A included initial recruitment that began through convenience sampling (availability in the local Minnesota metro area). Information about the interview and a request for information was sent to the potential participants prior to working with the researcher. Plan B was to widen the scope of recruitment and reach out to social workers outside of the Minnesota metro area. Per the recommendation of a committee member, the researcher reached out to a contact of hers located in Washington state. It was from there that the researcher was able to connect with the interested nurse manager and pursue a Letter of Permission and the process unfolded as described above.

As this study aimed to recruit hospice workers versus patients, there was no need to obtain additional review outside of the University of St. Thomas Institutional Review Board.

### **Data Collection**

This study used a semi-structured interview design for this study including about 10 research questions and several follow-up questions. This design method allowed the researcher to explore the meaning of concepts and experiences. Demographic information was obtained, such as location of hospice agency, role of clinical social worker with hospice, outreach conducted to Hispanic/Latino population (if any), and years of experience. Qualitative questions sought to ask participants their views on barriers to accessing hospice care, overcoming barriers, experiences with Hispanic/Latino patients once being admitted to hospice, and increasing outreach efforts. The researcher took field notes throughout the phone interview process. Interviews ranged in time from 35 minutes to 55 minutes. Participants were asked to choose a private location to speak with the researcher on the phone so as to increase comfort for the participant and ensure confidentiality. The researcher utilized a private, password protected recording device that recorded each qualitative phone interview. The researcher took specific measures to ensure the confidentiality and privacy of the participants, such as keeping recorded interviews in a safe and secure location, removing identifying information from transcribed interviews, and then discarding recorded interviews upon analysis of the data. The researcher independently transcribed all interviews to also increase confidentiality. Measures were taken to ensure the validity of the research questions, such as reviewing

the related literature, review from the research committee, and review of the Institutional Review Board.

The interview questions were designed to reflect the relevant literature reviewed above, including acculturation, beliefs about death & dying and end-of-life care, education, and rituals. The questions focused on considerations of hospice social workers specifically in their work with Hispanic/Latino patients and families. Interview questions can be viewed in Appendix C.

### **Data Analysis**

The purpose of the study was to explore hospice workers' experiences working with Hispanic/Latino patients and families receiving hospice services, while also asking hospice workers to identify barriers and how to overcome them. Qualitative data, which can be described as theory generating versus theory testing (quantitative), was obtained through the use of open-ended questions and was then analyzed using open coding.

R. Moone (personal communication, October 25, 2014)

The researcher then identified themes derived from the open codes, such as commonly referred words or phrases, and then created categories in order to interpret meaning. Data was revisited once more after initial coding to find any potentially missed concepts or categories.

The researcher protected qualitative data gathered using a private, password protected recording device in which recordings were securely and properly destroyed upon completion of the findings and clinical research paper.

## Findings

The following illustrates the findings from the qualitative phone interviews conducted by the researcher with hospice social workers ( $N = 4$ ), which resulted in the construction of three distinct themes: (a) family involvement; (b) communication; and (c) self-awareness and cultural competence. Under each theme were several subthemes. The subthemes included under family involvement were patient representative, children as a bridge, and high number of family members present throughout process. The second theme of communication included subthemes of use of interpreter, focus on symptoms, and bilingual materials. The third and final theme of self-awareness & cultural competence included subthemes of self-study, study of other cultures, and nonassuming and nonjudgmental stance. All four participants ( $n = 4$ ) reflected on their approaches in working with Hispanic/Latino patients and families to be unique compared to their work with other cultural groups in a number of ways. The following table illustrates the themes and subthemes that arose in the data:

Table 1

*Themes/Subthemes and Sample Responses*

Category	Thematic Category	Sample Response
<i>Theme 1: Family involvement throughout hospice experience</i>		
F1	Patient Representative	Next, I always ask if the patient has a representative, a point person, and who that might be.
F2	Children as a bridge	So they often are the bridge to their parents or grandparents receiving these services.
F3	High number of family	One day I was at the inpatient facility and a Hispanic patient passed away. And he probably had between 60-80 family members there.
<i>Theme 2: Communication</i>		
C1	Conversation of symptoms	You need to communicate that you just take one day at a time. vs. conversation of death
C2	Use of an interpreter	She [interpreter] was bilingual and bicultural. So I think she really understood where he was coming from and why he was asking that.
C3	Bilingual Materials	It is so important to make sure that as an agency you have all of your required documents to also be available in Spanish.
<i>Theme 3: Self-Awareness &amp; Cultural Competence</i>		
S1	Self-study	Being able to just acknowledge with yourself, it's not even something you have to acknowledge outwardly with them, but I know I am this young white woman.
S2	Study of other cultures	The clinician has to first educate themselves on the patient and the family prior to their first meeting.
S3	Nonassuming/nonjudgmental	The biggest mistake you can make right away is to assume what patient prefers before asking what they are most comfortable

*Note.* F= family involvement, three subthemes, C=communication, three subthemes. S=Self-awareness & cultural competence, three subthemes

## **Family Involvement**

Participants shared their considerations throughout interviews in working with Hispanic/Latino patients receiving hospice services. Family involvement was the most prominent theme in participants' considerations throughout the four qualitative interviews ( $n = 4$ ). This theme included the role of a patient representative, patient's children serving as a bridge between the patient and the hospice team, and also the high number of family members involved in the hospice process. The role of social workers in family involvement was to be aware of this importance and to encourage and facilitate this involvement. Several subthemes arose that provide examples of participants' experience of family involvement, including patient representatives; children as a bridge; and high number of family members involved.

**Patient representative.** Across interview questions and interview topics, the role of the patient representative came up among all four participants ( $n = 4$ ). When participants were asked how they approached death and dying, how they built therapeutic rapport, and how they conducted education with patients, patient representatives all came into play. The role of patient representative was to serve as a filter between patient and hospice team. It was up to the patient representative to decide to what extent the patient should be involved in discussions of death and dying and, also, to what extent they should know of their prognosis. Each social worker recommended that upon first meeting with a Hispanic/Latino patient and family to ask if there was an identified patient representative, a person with whom the social worker should do the communicating. One participant stated, *"I always ask if the patient has a representative, a point person, and who that might be."*

Two participants ( $n = 2$ ) specifically added that they ask whether or not the patient would like to be present for conversations with the patient representative. Participants ( $n = 4$ ) explained that the patient representative was most often an eldest son or another adult child. One respondent further described the patient representative as, *“the person that we kind of need to talk to...it seems that information from the family will go through that person and information from us will go through that person.”*

Identifying this patient representative was also described as a way to build therapeutic rapport with patients. Demonstrating one’s understanding and knowledge of the value of a patient representative was a way for social workers to express cultural sensitivity and understanding. As it relates to death and dying, the use of a patient representative allowed for social workers to have end-of-life conversations in a way that was culturally respectful and understanding. If the patient preferred not to talk about death and/or dying, the social worker was often allowed to speak of this with the patient representative. One social worker described identifying these preferences as “checking in” and would begin each patient visit this way, as described above, as a way to build rapport and trust, asking, *“Is it okay that we talk about this? Who would you like me to address the questions to? Because you know culturally it might be the husband or the oldest son.”* These clarifications communicated to a family that the social worker was privileging their traditions and considerations.

**Children as a bridge.** In discussions of patient representatives, children of the patient who served as a “bridge” or middle person between the patient and hospice team often came up. The patient representative who also served as a bridge was most often described as the oldest son or another adult child. In terms of acculturation, social

workers indicated that in their experience the children of patients were often more acculturated. One social worker described children as the people who often suggested hospice to their parents, perhaps because the children had more “exposure” and “experience” of the available resources in health care due to their experience with US medicine. Social workers ( $n = 2$ ) also spoke of caution in regards to the boundaries with this child, whether the child was young or an adult. Children serving as a bridge between the patient and hospice team came up most often in the conversation of acculturation, where social workers perceived children of the patient to have grown up within U.S. culture when the patient was a first-generation immigrant. This means that the children of the patient were the ones with an understanding of U.S. health care and western practices. The first participant described these children as a “bridge,” and also described this as a “difficult position” when social workers expect the child to be the one relaying end-of-life conversations to the patient. One respondent further described this difficult position:

*So they often are the bridge to their parents or grandparents receiving these services...that puts them in a difficult position having to talk about difficult issues. So we really try to minimize that role and maximize our Spanish-speaking staff's involvement.*

The above situation speaks to adult children of patients. One social worker ( $n = 1$ ) shared that the situation of younger patients, which often means younger children acting as a bridge, is occurring more often in her experience. She brought up the issue of young children expected to do the translating for their parents as a common practice within the Hispanic/Latino community. Due to the difficulty of conversations around end-of-life decision-making and death and dying, the social worker saw a potentially negative

psychological impact among young children who had to act as a translator between a social worker and a parent-patient. Thus, the social worker's agency decided to not allow any child under the age of 18 to be the translator for a hospice visit. If the child is over the age of 18, the agency's social workers must be sure to clarify with the child the level of difficulty in holding end-of-life conversations and ask whether the child is comfortable in this role. This social worker felt it was her responsibility to advocate not only for her patient, but also the children of her patient by protecting the extent of their involvement.

*They go to the grocery store, the child translates for the parent...But we have decided now that nobody under the age of 18 is allowed to translate for a patient...we can cause a psychological problem and emotional distress for these kids.*

**High number of family involvement throughout process.** The third and final subtheme included under family involvement was participants' experiences of the number of family members involved in a patient's hospice experience as compared to other cultural groups. The presence of multiple family members is described at a patient's start of care. The clinical social worker encourages the patient to have as many family members present as possible. This presence of multiple family members is also seen at the time of a patient's death. Social workers considered home hospice and also the inpatient hospice house as conducive to the large number of family members involved in a patient's experience as compared to the hospital setting, which has space restrictions. Three of the four research participants ( $n = 3$ ) made this comparison. When describing family involvement, words that often came up were "many," "everybody," and "a lot." Family involvement was reflected upon in both a social worker's education with families and also rituals at end-of-life.

Family involvement is experienced and valued by hospice social workers from the beginning of a patient's admission to hospice. One participant described her technique to gather as many family members as possible to have initial conversations around hospice philosophy of care and goals of care. This participant described this start of care as:

*asking what everybody understands about it [hospice] and having a conversation while everybody is in the same room, and helping to facilitate that conversation, and reassuring people that we are not there to take over their lives.*

Furthermore, in emphasizing family involvement, all four research participants ( $n = 4$ ), discussed hospice care being driven by the patient and family. This is to say that the patient and family were the ones deciding the goals of care and to what extent hospice was involved. Allowing the patient and family to decide what is best in terms of patient care was consistently described by participants as they shared experiences of working with families. Words used to describe these experiences were “flexibility” and “tailored.” A participant described this rapport building with families as:

*We are not there to tell them [families] what they have to do. We are not there to say it is our way or no way. We are there to say this is what we've seen helpful. How can we support you?*

High numbers of family members were also described at the time of death of a patient. One participant offered a case example of ritual and family members' presence at the time of death:

*One day I was at the inpatient facility and a Hispanic patient passed away. And he probably had between 60 and 80 family members there, and they lined the hall from his room, they lined the hall all the way out the door, so when the funeral home came, he passed down the hall on the gurney with all of his family members singing to him.*

**Family involvement conclusion.** The initial theme that arose from qualitative interviews was participants' greatest consideration in their work with Hispanic/Latino patients receiving hospice services. Family involvement was the most common way participants provided education on hospice services, were able to build therapeutic rapport with patients, and were able to discuss death and dying. This was the greatest consideration by social workers in their work with Hispanic/Latino patients receiving hospice services.

### **Communication**

Participants continued to reflect on their considerations in working with Hispanic/Latino patients receiving hospice services. The next most dominant theme was communication. Throughout interviews, participants ( $n = 4$ ) spoke of communication as a consideration in working with Hispanic/Latino patients and families. The theme of communication included the conversation of symptoms versus the conversation of death, the use of an interpreter both to interpret between social worker and patient and also to offer a bicultural perspective to the social worker, and lastly, the importance of providing written materials in both English and Spanish.

**Conversation of symptoms versus conversation of death.** Communication looked different between specific cultural groups receiving hospice services, even in regards to word choice. It was understood that speaking directly to a Hispanic/Latino patient about death would typically be culturally insensitive. All four participants were asked how they approach the topic of death and dying with their Hispanic/Latino patients as compared to other cultural groups and how this may look similar or different. One research participant gave several examples of language he used when discussing death

and dying with a patient. He used language such as, “planning for the future,” “if things were to change,” “symptoms got worse,” or “what happens next?” Another research participant offered the following example:

*So I talk about the symptoms...keep them as comfortable as possible. So I talk to them about how you have the ability to access all these supports, you have your nurse, you have your social worker, you have your spiritual care, which is very important.*

Another research participant described being careful not to use the word “terminal,” but rather to speak with her patients in terms of comfort and pain management. The participant framed this conversation by asking a patient how the aggressive treatment made the patient feel, and she said that a typical answer in response is “miserable.” From there, the participant is able to frame hospice’s approach as comfort. The participant suggested focusing on symptoms:

*You need to communicate that you just take one day at a time, that if your symptoms are managed and you are more comfortable you will be better able to enjoy your time with your family, that there can be quality in your days. That is what is important to communicate to the Hispanic/Latino population.*

A case example given by one participant included a conversation with a patient in which the family was trying to decide to what extent to let the man know his condition was terminal and he was dying. The social worker was asked by the patient representative for her input on what to tell the man. Having worked with Hispanic/Latino patients and families before, the social worker felt that it would be culturally disrespectful to directly tell the patient that he was dying. So instead the social worker told the patient representative, “it’s up to you to decide what’s right in your heart and what feels best.” The social worker further described this case being in tension with American health care values in that typically the patient would have needed to know the extent of his prognosis

as it relates to a patient's informed consent that hospice care serves patients with a life expectancy of 6 months or less. The social worker and the interpreter in this situation decided it was most appropriate for the patient representative, who knew the patient best, to decide how best to share information.

**Use of an interpreter.** The third and final subtheme under communication was participants' use of an interpreter. Half of the research participants ( $n = 2$ ) reflected on their use of interpreters as resources in working with Hispanic/Latino patients and families, both as resources for themselves as clinicians and as resources to family members to interpret conversations and interpret across cultures. Codes that arose within this subtheme were "use of an interpreter," "asking bicultural colleague," and "bicultural interpreter as a resource." These same participants, who self-identified as non-Hispanic/Latino themselves, shared that they tended to lean on their interpreters if there were questions related specifically to cultural considerations. In an example provided by a participant in her own professional experience in which she was unsure of how to proceed with a Hispanic/Latino family, she described the benefit her interpreter offered both in respect to language and cultural barriers:

*But I think the interpreter and I were on the same wave length. So she was bilingual and bicultural. So I think she really understood where he was coming from and why he was asking that.*

One research participant shared a case example of a time when interpreters were not as easily made available by the hospital system. In this case, the nurse and the social worker were both English speakers, and the social worker did not feel that they were able to connect with the Spanish-speaking patient and family in a helpful way, especially

during a time as sensitive as end-of-life decision making. The participant described this challenge:

*And I mean we got through it, but who knows what exactly was communicated to that family. And it was so difficult for us to understand what they were trying to tell us. So it was awful.*

**Bilingual materials.** Two of the participants ( $n = 2$ ) also shared the importance of having written materials provided in both English and Spanish. One participant attributed low rates of Hispanic/Latino patients receiving hospice to a lack of education materials in Spanish. The participant said “*And another thing is not all of our written materials, so materials that talk about our programs, often are just in English.*”

Another participant, in an opportunity to express last thoughts in the interview, shared that it is important that all paperwork and consent forms be offered in both English and Spanish per a patient’s preference: “*but really anything that the patient is going to be signing needs to be in Spanish, not only interpreted.*”

Additional mediums of education materials to be provided in Spanish were recommended by two participants ( $n = 2$ ). This included the recommendation that hospice education be conducted by Spanish-speaking radio, as is utilized by the hospice agency for whom the research participants work. One participant ( $n = 1$ ) shared that her specific agency hired a full-time worker specifically assigned to conduct hospice education and outreach within the Hispanic/Latino community. The participant described the outreach worker’s role to include, “*hospice education to the Hispanic/Latino community. She goes to local clinics, speaks in churches, attends community events.*”

**Communication summary.** Communication, as the second most dominant theme, was cited as key by participants to their work. Culturally appropriate

communication, direct work with patients and families, and indirect work such as community-level education and outreach, was considered by participants to be very important in working with Hispanic/Latino patients. An increase in interpreter availability and written materials in Spanish were suggested, as was additional outreach, such as use of radio and use of a dedicated outreach worker.

### **Self-Awareness & Cultural Competence**

The third, and final, theme to emerge from the qualitative interviews was social workers' self-awareness and cultural competence. The subthemes included self-study, study of other cultures, and assuming an open and nonjudgmental stance.

**Self-study.** All four research participants ( $n = 4$ ) made reference to their own cultural identity, either specifically identifying or acknowledging that it is different from the Hispanic/Latino population. Two participants ( $n = 2$ ) self-identified as “white,” one participant ( $n = 1$ ) self-identified as “Hispanic,” and one participant ( $n = 1$ ) said that she was “not a part of the Hispanic/Latino community” herself. One respondent described self-study as, *“being able to just acknowledge with yourself, it’s not even something you have to acknowledge outwardly with them, but I know I am this young white woman.”*

**Study of other cultures.** In addition to the study of participants' own cultural background, participants also reflected on the importance of studying traditions and tendencies of other cultural groups. Three of the four participants ( $n = 3$ ) mentioned studying the Hispanic/Latino culture and cultural tendencies as a part of their work with Hispanic/Latino patients. These findings included words such as “training” provided by the hospital, “handouts” and “cheat sheets,” and also “educate themselves on the patient.” Caution was also mentioned as important by two of the participants ( $n = 2$ )—that there is

no “one size fits all” tendencies when it comes to the study of specific cultural groups.

The participant describes being cautious in the following way:

*The hospital sometimes gives a one-size-fits-all training, like, here’s a checklist. This is what Native American patients believe and feel. This is what Latino patients believe and feel. I think that’s a little bit dangerous sometimes.*

All three participants agreed, however, that having some education and information on a specific culture was more helpful than having no information.

**Assuming an open and nonjudgmental stance.** Related to the above subtheme, which recommended education of other cultures, two participants also suggested that social workers must be cautious regarding a too-simple education. Two research participants ( $n = 2$ ) spoke to the danger of making assumptions about a Hispanic/Latino patient prior to meeting a patient and learning of their goals and preferences. The first participant cautioned social workers by saying:

*The biggest mistake you can make right away is to assume what a patient prefers before asking what they are most comfortable with.*

The next participant recommended being aware of assumptions that could inhibit the building of a therapeutic alliance:

*And I think that that’s a huge way to build a relationship and build rapport and show them that we are not coming in and assuming, because we know what it’s like when somebody assumes they know all about us, and that doesn’t feel good.*

**Self-awareness and cultural competence conclusion.** Participants indicated that self-awareness, education of other cultures, and intentionality in assuming an open and nonjudgmental stance were considerations in working with Hispanic/Latino patients receiving hospice. Per participants, self-awareness and cultural competence was a way to build therapeutic rapport and alliance with patients.

## **Summary**

Participants in the study shared many considerations in their work with Hispanic/Latino patients receiving hospice services. The majority of participants expressed these themes, although there were several outlier responses that were also shared. The themes and subthemes are explored and analyzed in the following discussion.

## Discussion

The literature review and qualitative interviews used the ecological perspective to focus on hospice social workers' considerations in working with Hispanic/Latino patients receiving hospice services. Much of the research aligns, but there were also times when the new data differentiated from existing research. Themes of family involvement and communication were as important to participants as indicated by the existing literature. The subtheme of acculturation was observed differently by participants compared to existing research, and the subthemes of self-study and study of other cultures were emerging ideas as it relates to this research topic. Below, the themes and subthemes described in the findings are compared to the literature review.

As much of this research revolves around cultural considerations, the lens chosen to view this work was ecological systems theory, using Bronfenbrenner's ecological perspective model of four categories: microsystems, mesosystems, exosystems, and macrosystems (Forte, 2007). Participants reflected on these lenses in their work by sharing their experiences in direct practice, describing their education at a community level, and describing how they feel policy affects their patients and access to hospice care.

It is important to understand participants' own backgrounds and experiences as it relates to their relationship with the Hispanic/Latino community. All four research participants (currently practicing hospice social workers) self-identified their ethnicity. Only one of the four research participants ( $n = 1$ ) self-identified as Hispanic. Two of the research participants ( $n = 2$ ) self-identified as white, and one participant ( $n = 1$ ) self-identified as "not a part of the Hispanic/Latino community." Three of the four participants ( $n = 3$ ) were women, and one participant ( $n = 1$ ) was a man. The research

participants, no matter what their ethnicity, gender, or amount of social work experience, were in agreement that their considerations in their work with Hispanic/Latino patients receiving hospice services was unique compared to other populations.

### **Family Involvement**

As was described in the literature, family involvement was an important consideration as reported by research participants. The extent of family involvement covered all three subsequent subthemes. Most of the literature was in agreement as it relates to the subthemes of the necessity of a patient representative, the likelihood of children serving as a bridge between patient and hospice team, and the high number of family members present throughout a hospice experience (Carr, 2011; Carrion, 2013; Kirkendall et al., 2015; Selsky et al., 2012). Differences emerged within the specifics of acculturation and caregiver availability (Carrion & Nedjat-Haeim, 2013; Colon, 2012a).

**Patient representative.** Both the reviewed literature and research findings addressed the need and role of a patient representative. The literature review highlighted a number of tensions between Hispanic/Latino cultural tendencies and the work of a hospice team. In past research, Kirkendall and colleagues (2015) explored Hispanic/Latino patients' beliefs about health care. For example, Kirkendall and colleagues (2015) described the mistrust between Hispanic/Latino patients and emergency room physicians with whom the patient did not have a relationship. The researchers concluded that low use of hospice care by the Hispanic/Latino population could be contributed to referrals that were made by physicians with whom the patient did not have a relationship. Research participants managed patients' mistrust through the use of communication via a patient representative, a selected family member or contact

person of the patient with whom the health care worker should communicate. This same patient representative was not a health care agent or formal power of attorney, but rather informal spokesperson. Throughout the interviews, the use of a patient representative was highlighted and recommended as a response to this historic mistrust. This allowed hospice social workers to build trust and rapport with both patients and their families.

The consideration of utilizing a patient representative was further described by participants in facilitating end-of-life decision making. Researchers Selsky and colleagues (2012) and Carrion and colleagues (2013) studied the conflict between social workers' responsibilities and the tendency by Hispanic/Latino patients to keep prognosis a secret and/or to keep from talking about death. Carrion and colleagues (2013) offered the case example of a patient who was approached by a non-Spanish speaking counselor what talked about death and dying. The patient was upset by this, and the daughter stepped in to communicate to the counselor. Participants recognized that this tension between informing a patient of their prognosis and also respecting culture tendencies existed, but the participants approached the issue by again indicating that they sought to ease the tension through the elected patient representative. Participants described first asking a patient whether or not they would like to be present for end-of-life oriented conversations. If the patient chose not to be present, the social worker would hold these conversations with the patient representative and allow the representative to relay as much as they felt appropriate to the patient. Most of the participants reflected on the challenge that is presented by this tension in cultures, between that of the Hispanic/Latino community and the health care community, but also decided that it was most important to prioritize cultural sensitivity.

**Children as a bridge.** The research reflects on the role of acculturation as it relates to Hispanic/Latino patients' experiences of hospice. Findings in current research also produced data on the role of acculturation, specifically on the use of children as a bridge between the patient and hospice team. Overall, research participants found that acculturation did play a role in patients' understanding of hospice. This is to say that the amount of time a patient had spent in the United States and taking in US culture influenced their experience of hospice. This finding is different than the findings of Colon (2012a) in which socioeconomic status rather than acculturation was a significant influence in whether or not a Hispanic/Latino individual would pursue hospice services. Findings of the qualitative interviews agreed with the findings of Gelfand and colleagues (2001) who did find acculturation to play a significant role in a Hispanic/Latino individual's hospice experience. Research participants were even more specific than acculturation in general and specified that the key factor is not necessarily the patient's acculturation, but their child's. A patient's understanding of and experience of hospice was influenced more by their child's acculturation than their own. Participants reflected on this being likely due to the fact that oftentimes it was the child serving as the patient representative. Furthermore, the interview findings found that a patient's child was likely to be more familiar with hospice services and would often offer education to the patient throughout the patient's time on the program. This offers hospice educators and outreach workers a recommendation to not only reach out to those nearing end-of-life, but also adult children of patients.

**High number of family involvement.** The high number of family members present throughout a Hispanic/Latino patients' hospice experience is cited in both the

previous literature and the present data. All four ( $n = 4$ ) research participants reflected on the presence of many family members when a patient began hospice and when a patient died. The encouragement to involve many family members was cited by participants as a way to build rapport with patients. Carr (2011), as did research participants, found that Hispanic/Latino patients were likely to make health care decisions as a gathered family, rather than individually. This speaks to the importance of the research participants to gather as many family members as possible at the start of a patient's hospice care so that multiple people are able to hear the education and be a part of the process.

The existing literature did differ from participant findings in regards to caregiver availability. None of the interview participants spoke to a lack of family presence or caregiver availability, as did Carrion and Nedjat-Haeim (2013). Rather, each interview participant spoke to high numbers of family members who were present and available throughout a patient's hospice experience. As to Carrion and Nedjat-Haeim's finding that a lack of available caregivers kept Hispanic/Latino patients from qualifying for Medicare's hospice benefit, this was not reflected in the participant interviews. Because research participants were hospice social workers, they would not meet patients who were not eligible for the program. Thus, this could be an area that calls for further research.

### **Communication**

Communication is a broad topic addressed by both the existing literature and the current research. In both cases, this was most often broken down into culturally sensitive communication around death and dying, the use of interpreters, and also included wider

education initiatives. Communication is of course a primary factor when working across languages, but it is also a primary factor when working across cultures.

**Conversation of symptoms versus conversation of death.** Research participants overwhelmingly agreed on the necessity of maintaining a focus on symptoms in their work with Hispanic/Latino patients as opposed to a focus on death. The former focus entails discussing a patient's symptoms and providing hospice education around a person's symptoms versus holding conversation around death and a patient's anticipation of their own death. This focus on symptoms allowed participants to build rapport with patients and families. The existing research seems to lack a specific discussion around the focus of symptoms, but it does speak to the challenge that is navigating end-of-life conversations with Hispanic/Latino patients when "death" often cannot be outwardly discussed.

Researchers (Kirkendall et al., 2015; Colon, 2012a) addressed the extensive aggressive and curative measures a Hispanic/Latino patient often wanted to pursue either before or during hospice services. Two current research participants ( $n = 2$ ) addressed this issue of a desire to pursue further treatment in a way that maintained rapport with a patient and family. In one case, a research participant framed her hospice education all around a patient's previous experience with aggressive treatment, comparing the two experiences. The first experience often made the patient feel "miserable," and the other provided comfort measures. A second research participant suggested at the end of an interview that "code status" (a patient's wish to receive life-sustaining measures or to receive comfort measures only) was often unique in the case of Hispanic/Latino patients. This participant said that her Hispanic/Latino patients often wanted to remain a full code

through the end of life, but she has never experienced a patient calling 9-1-1. Rather, maintaining full code status allowed the patient to hold on to hope, which is what they wanted during that time.

Choice of language around death and dying and also how to remain compliant with a patient choosing to forego curative, aggressive treatment in order to qualify for hospice services calls for further study.

**Use of an interpreter.** Each research participant ( $n = 4$ ) spoke of the importance of using an interpreter and/or, if they were bilingual themselves, clarifying which language the patient was most comfortable speaking in. Additionally, the majority of the research participants spoke to leaning on their interpreter not only as a language interpreter, but also as a bicultural interpreter. The existing literature also spoke to the importance of interpreters in working with Hispanic/Latino patients receiving hospice services. Carrion et al. (2013) offered two qualitative examples of instances in which an interpreter was not present and family members were left to interpret. According to Carrion et al. (2013), in these cases where there was no interpreter present, there was also no person to offer bicultural insights. In these two qualitative examples, a patient was left with a misunderstanding of the situation and was also offended. Three of the four research participants ( $n = 3$ ) spoke to utilizing their interpreter as an additional resource to further understand the tendencies and traditions of the Hispanic/Latino population, as was also suggested by Carrion et al. (2013). The fourth research participant, who identified as bilingual and bicultural herself, explained that she always asks a bilingual patient which language they are most comfortable speaking in rather than assuming one

way or the other. This, too, speaks to the importance of meeting interpretation needs in working with Hispanic/Latino patients receiving hospice.

None of the existing research treated the concern for children serving as interpreters, as did two of the research participants ( $n = 2$ ). These two participants described using children this way as “dangerous” and also “psychologically damaging” if children (either adult or youth) were expected to be interpreting conversations of death and dying between their parent and hospice team. This issue calls for further attention in the literature.

**Bilingual Materials.** Much of the existing literature spoke to the need for an increase in bilingual materials and further education, as did the interviews. First, a need for increased materials was addressed by participants. A majority of the research participants felt that there were not enough bilingual materials made available to the wider community to provide education on hospice services. One research participant also specifically mentioned that the paperwork to sign onto the program needs to be provided in both English and Spanish, not only interpreted by an interpreter. Colon (2012a) and Selsky et al. (2012) shared similar concerns, stating that bilingual materials and also wider community education needs to be bilingual and culturally appropriate. Providing education on a micro level, but also a mezzo and community level, was recommended by both the existing literature and current research. One research participant ( $n = 1$ ) said that her agency hired a specific bilingual/bicultural worker to conduct hospice education and outreach to the Hispanic/Latino community. Carrion et al. (2013) also recommended that a worker who is able to connect culturally with community members conduct outreach.

A second, and very important, issue to be addressed by only one researcher and by one interview participant was the issue of the mistranslation of the word “hospice” into Spanish. Selsky and colleagues (2012) along with one research participant ( $n = 1$ ) described the Spanish translation of “hospice” into “hospicio” (as it is translated across the United States) to be an inappropriate translation and a deterrence to community members pursuing hospice care. This translation into the word “hospicio” is more commonly understood as “orphanage” or “place for poor people” across Hispanic/Latino cultural groups. This is a language issue that urgently needs to be addressed. The research participant offered that she most often refers to “hospice” as “end-of-life care” when she translated to Hispanic/Latino patients so as not to create misunderstanding.

### **Self-Awareness and Cultural Competence**

Self-awareness & cultural competence was the third, and final, theme to arise from the current research. This theme was also addressed by the existing literature, although not to the same extent as the interviews. Several subthemes were addressed by the existing literature, while others call for further study.

**Self-Study.** Each research participant ( $n = 4$ ) discussed the importance of their own self-study and self-awareness, whether this outwardly expressed or only within themselves. Research by Kirkendall and colleagues (2015) of Hispanic/Latino caregivers who felt as a majority that the hospice team did something inconsistent with the patient’s wishes speaks to the importance of self-study by hospice social workers. In order to meet patients’ wishes, all four research participants ( $n = 4$ ) found it vital to be familiar with their own cultural backgrounds and how that might play out in the therapeutic alliance.

Research participants found their first step in working with Hispanic/Latino patients to be learning more about themselves.

**Studying of other cultures and assuming an open and nonjudgmental stance.**

A majority of research participants spoke to the importance of becoming familiar with other cultures, while never making assumptions about or judging another culture prior to getting to know a patient and family. Colon (2012a) agreed: “One has to be where the Latinos are and be willing to genuinely interact with them.” This is a concise way of summing up interview participants’ careful consideration to engage in self-awareness, practice cultural competence, and assume a nonjudgmental stance.

**Implications for Social Work Practice**

Research informs implications for social work practice. As is illustrated by the existing literature and current interviews, there are important considerations for hospice social workers in their support of Hispanic/Latino patients receiving hospice services. It is also important to note that clinical social workers as a whole are called by their code of ethics to, “understand culture and its function in human behavior and society, recognizing the strengths that exist in all cultures” (National Association of Social Workers). Thus, implications for social work practice, as it relates to this research topic, include the hospice social worker’s micro considerations in their work with Hispanic/Latino patients and their families, mezzo considerations of facilitating community-wide hospice education and outreach, and macro-level considerations of advocating for access to hospice care should a person lack access to insurance due to documentation status.

**Micro-level implications.** Much of the motivation to conduct this specific research study was to gain tangible skills and considerations as a clinical social worker

working with Hispanic/Latino patients receiving hospice services. These skills and considerations have been highlighted throughout the interviews, including the themes of utilizing and understanding family involvement, communication, and self-awareness and cultural competence. An emerging idea from the interviews was the identification of the social worker as the professional among the multidisciplinary hospice team with the education and training for having difficult and sensitive conversations, like that of death and dying, with patients and families. In addition, the hospice social worker must use their training and skills to hold the difficult conversations that come with end-of-life rather than a young or adult child taking on this role as the interpreter. The interviews also imply that the clinical social worker must take specific steps in building an alliance with a Hispanic/Latino patient receiving hospice, including using a patient representative, involving extended family in care, and understanding the role of culture and ritual in the patient's end-of-life experience. These are all micro-level implications for clinical social workers in their work with Hispanic/Latino patients receiving hospice services.

**Mezzo-level implications.** Just as hospice social workers spend time individually with patients and families, they also take part in community-wide education and work. It has been identified that productive hospice outreach depends on education at a community level in addition to an individual level. This should be performed by an assigned outreach worker and be held in churches, community fairs, clinics, and other larger gatherings. Hospice social workers can serve as advocates and coordinators of this education and outreach within their agency settings.

**Macro-level implications.** Lastly, it has been found through the qualitative interviews that the Hispanic/Latino patient population is impacted by a lack of insurance,

oftentimes due to documentation status. Some hospice agencies have foundation funding enabling them to meet this need, but this funding is not unlimited. Social workers, in support of their patients at a micro-level, need to advocate at a policy or macro-level to ensure access to quality care and hospice services for all.

### **Implications for Policy**

One research participant described social workers' role very well when he said:

*Social workers are often at the front line of pushing for those kind of [support] services, and I think we have been here, too.*

Participants were specifically asked how they see policy effecting Hispanic/Latino patients' access to and experience of hospice services. Unanimously, participants responded that insurance is the greatest barrier to accessing care. As hospice care is an elected Medicare benefit, if a person is undocumented and ineligible for Medicare, Medicaid, or private insurance, they do not have access to the hospice care benefit. Each participant spoke to the funding raised each year by their agency foundation to support patients without insurance. As a consequence of these efforts, this agency has never had to deny anyone hospice services. While this has been a good resource, it is an unsustainable funding mechanism, as there is not an unlimited amount of charitable funding. To ensure that hospice care is accessible to all patients across socio, economic, and cultural groups, social workers must advocate at a macro level.

### **Implications for Future Research**

While the interview data adds to the existing literature, there is still a need for further research. Some questions were answered by the qualitative interviews, but others emerged about how to best serve Hispanic/Latino patients receiving hospice services. The topics that call for further research include: end-of-life discussion, the experience of

children serving as health care translators for their parents, and the mistranslation of the word “hospicio” across translated education materials.

**End-of-life discussion.** Interview participants expressed a desire to know more about how best to discuss issues of death and dying with Hispanic/Latino patients in a way that is culturally sensitive but ensures that a patient understands their limited prognosis. A primary tenant of hospice social work is to provide psychosocial support as it relates to end-of-life. If a social worker is unable to discuss death or dying with a patient due to the patient’s cultural preferences, this can be challenging, thus this scenario calls for more attention.

**Children as translators.** There is very little existing literature on the topic of children (either adult or young) who are put in the difficult position of translating for a hospice patient and who may therefore experience secondary negative effects due to the sensitivity of such conversations. While family members are required to sign a waiver should they choose to forego a professional translator, family members are still choosing this option and experiencing the negative effects, per research participants. So as to best support family members in addition to the hospice patient, this would be beneficial research.

**Translation of hospice.** The mistranslation of the word hospice into “hospicio” urgently needs to be addressed, as this is a national issue. Different focus groups and outreach efforts would be helpful in finding a better term or phrase to more accurately interpret hospice services.

## **Strengths and Limitations**

This qualitative study explored the considerations of hospice social workers in their approach to working with Hispanic/Latino patients receiving hospice services. The insights, experiences, and suggestions shared by the participants in how they considered their work with Hispanic/Latino patients were rich and powerful. There is a lack of information on how to best approach this topic, and these participants' responses help to educate other social workers. There were, however, both strengths and limitations to the study.

**Strengths.** The strength of the study was in its qualitative design. This design allowed participants to share in-depth experiences and share across parameters versus being confined to a survey or that of quantitative research, and allowed each unique social worker to emphasize what they felt to be the most important considerations in caring for Hispanic/Latino populations. Each research participant had unique experiences to share, thus offering diversity of experience within the sample. This is a very specific topic within hospice care services, so for each participant to share their commitment to best serving their Hispanic/Latino patients was a true strength.

**Limitations.** There were multiple limitations to the study that offer guidance in future research, this includes the small sample size, recruitment from a single agency, and the breadth of the Hispanic/Latino population.

First, the sample size of four participants was small. The researcher made several attempts in recruitment and utilized different recruitment strategies. This could speak to

the level of specificity of the topic, which may have made it difficult to recruit social workers who felt they had enough experience to share.

Second, by nature of pursuing a letter of recruitment and recruiting from a specific agency, results of the study stem from one agency rather than several agencies. This limitation kept the researcher from being able to generalize the results, and thus calls for further research among more hospice social workers and from varying locations.

Finally, the researcher chose to utilize the category of Hispanic/Latino so as to gather as much existing research as possible on the topic. As this is already an understudied population, the researcher wanted to remain as broad a focus as possible, although this does limit the research in that what could be true for a Hispanic individual could be different for that of a Latino individual. This is to say that the patient population being studied in this research is very diverse in and of itself, and the researcher continually acknowledged this throughout the qualitative interviews. This data adds to existing research, but it calls for further attention to specific cultural groups within the wider Hispanic/Latino definition.

### **Conclusion**

The findings of the current study adds new information to the existing literature on considerations of working with Hispanic/Latino individuals and families utilizing hospice services. The current research found information that was compatible with the existing literature including the importance of family involvement, culturally appropriate education and outreach materials, and the importance of a social worker's self-awareness. The topic of acculturation varied as did caregiver availability between existing literature and current research. The subtheme of identifying a patient representative and also the

issue of children serving as interpreters were emerging topics of this research and call for further study.

The topic of end-of-life care is a difficult and sensitive topic across cultural groups and across the United States. A person's specific culture plays a significant role in their access to, understanding of, and experience of hospice care services. Even within the Hispanic/Latino community there is great diversity. Participants of this study, through their professional experiences and education, utilize culturally sensitive skills and considerations to best support their Hispanic/Latino patients through end-of-life issues, and these participants also continue to ask questions and seek to improve their work.

Hospice care services strive to offer holistic and dignified care during a patient's final chapter of life, thus the care is patient-centered and acknowledges that a person's end-of-life is as unique as the life they have lived. Clinical social workers have the education and skills necessary to be at the forefront of advocating for and providing culturally sensitive and appropriate hospice care services.

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## **Appendices**

### **Appendix A**

#### **Letter of Informed Consent**

Dear hospice social worker,

My name is Elizabeth Turbak, and I am a graduate student of social work at the University of St. Thomas/St. Catherine University in St. Paul, MN conducting clinical research. The purpose of my study is to learn more about the experiences of Hispanic/Latino patients and families receiving hospice care services. Information gathered through this study will help to identify how to best serve Hispanic/Latino patients on hospice with cultural understanding, identify barriers to accessing hospice care services to begin, and how to overcome these barriers. Ultimately, my research will be completed as a clinical research paper and presentation. The statement of my study is: Considerations for Working with Hispanic/Latino Patients on Hospice: Social Workers' Perspectives.

I hope that you will consider participating in a phone interview that explores hospice social workers experience work with Hispanic/Latino patients on hospice and identify and overcome barriers to care. The phone interview may take place in a private location of your choosing. I have selected you as a possible participant because you are a hospice social worker, have at least one year of hospice social work experience, and work with a diverse patient population. If you agree to participate, the interview with the researcher will take approximately 60 minutes to complete. The qualitative data gathered from your interview will be compiled and analyzed by myself as the researcher. I will code the data for themes and subthemes to produce final results.

Your participation in this study will be anonymous and poses minimal risk to you as a participant. Minimal risk includes your name and contact information being collected by me, but I will take the necessary steps to assure the confidentiality of your contact information. There are no benefits for participation. I appreciate the time commitment you are willing to make as a busy professional. I hope that you feel the time you spend is worth it, and that participating in my study will be a contribution to support Hispanic/Latino patients and families and further cultivate culturally sensitive hospice care services. I will provide you with an opportunity to have me send you a summary of my study once all the findings have been gathered.

To protect your anonymity, I will record interviews on a private and password protected device and transcribe the interviews myself. In the transcriptions, all identifying information will be removed. The digital files of interviews will then be destroyed. I will share written and recorded information only with my research chair. I shall keep all data and consent forms in a secure location for a period of three years as required by federal guidelines and all data stored electronically will be protected. The data will then be destroyed. Your participation in this study is entirely voluntary. You

may “pass” on a question or end your participation in the interview at any time. Should you decide to discontinue participation, you can let me know at any time by phone or e-mail. I will immediately end the interview, and if any information was already collected, it will be destroyed immediately. If you have questions, please feel free to contact me. If you have any concerns about your rights or any aspect of the study, you may also contact the Institutional Review Board at the University of St. Thomas in St. Paul, MN at 651-962-6035.

**Statement of Consent**

I have had a conversation with the researcher about this study and have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I am at least 18 years of age. I give permission to be audio recorded for this study.

**You will be given a copy of this form to keep for your records.**

\_\_\_\_\_  
**Signature of Participant**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Print Name of Study Participant**

\_\_\_\_\_  
**Signature of Researcher**

## Appendix B

### Letter of Permission

#### AGENCY LETTER HEAD

January 25, 2016

Dear Elizabeth Turbak:

I have reviewed your research proposal, entitled “Considerations for Working with Hispanic/Latino Patient on Hospice: Social Workers’ Perspectives, and grant permission for you to recruit social workers for your study. It is understood that your study aims at furthering knowledge of how clinical social workers can best support Hispanic/Latino patients receiving hospice services. It is further understood that:

- Participation is completely voluntary and the participants may withdraw from the study at any time throughout the research process without consequence.
- There are minimal risks for participants of the study, including names and e-mail addresses being obtained by the researcher.
- The researcher, though, will maintain confidentiality through storing identifying information on a private and password-secured laptop. Identifying information will later be removed from interview transcriptions and destroyed.
- The study will begin once the researcher has obtained Institutional Review Board approval and will end on May 16, 2016.

Sincerely,

*Official Signature*

*Name of Signer*

*Title of Signer*

## **Appendix C**

### **Interview Questions**

1. Tell me more about your role as a clinical social worker with hospice.
2. How do you see Hispanic/Latino patients represented on hospice and why?
3. What role have you seen acculturation, the process of taking on a new culture, play in Hispanic/Latino use of hospice and experience while receiving hospice services?
4. How do you approach death and dying with Hispanic/Latino patients/families with cultural sensitivity? How does that look similar or different to other cultural groups with whom you work?
5. What does your hospice education look like when working with Hispanic/Latino families compared to other cultural groups?
6. How do you build therapeutic rapport with Hispanic/Latino patients on hospice?
7. What rituals have you seen practiced by Hispanic/Latino patients around end of life?
8. How would you describe the experience, in terms of positive or negative, of hospice services for your Hispanic/Latino patients/families?
9. How does policy/legislation influence hospice use and experience of Hispanic/Latino patients? Can you give any examples?
10. Are there questions I did not ask that you would like to speak to? Can you recommend any other hospice social workers to participate in this study?