AT THE GRAVE WE MAKE OUR SONG*: A PALLIATIVE CARE STUDY IN RURAL GUATEMALA

by

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* The Book of Common Prayer (1979)

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Guatemalan palliative care beliefs and practices have received limited attention and research, resulting in a lack of preparation and services for this population in the United States. Guatemala ranks at the bottom of the Latin American Association for Palliative Care Index (Pastrana, Torres-Vigil, & DeLima, 2014), which includes training of medical students and physicians in end-of-life (EOL) care practices. In addition, a study commissioned by the Worldwide Palliative Care Alliance placed Guatemala in the category of isolated palliative care provision, indicating limited availability of morphine and few palliative care services in relation to population size (Lynch, Connor, & Clark, 2013). Finally, the United Nations Refugee Agency reported that the provision of palliative care in Guatemala is both restricted and inadequate, specifically with regard to the availability of and access to pain control (Smyth, 2014).

Guatemalans are the sixth largest Hispanic/Latino immigrant group in the United States, and this population is expected to increase (Pew Hispanic Trends Project, 2010). Most of the health-related literature on older Latinos focuses on established populations in California, Texas, and Florida. In addition, the research on Hispanics/Latinos in the US is often aggregated into a single population demographic when in reality the population is widely diverse (Dominguez et al., 2015). In a recent study on religious change in Latin America, investigators found that the majority of Guatemalans embraced the centrality of religion through a strong belief in Catholic traditions (Pew Research Center [PRC], 2014). The study also reported that Guatemalans are less likely to have completed secondary education and are more likely to avoid political engagement as compared to other Latino sub-groups.

Although palliative and EOL care are considered different services, these terms are often used interchangeably with palliative care being the broader term. Using the palliative care guidelines from the Institute for Clinical Systems Improvement, hospice or EOL care is indicated specifically when life expectancy is estimated to be six months or less (McCusker et al., 2013). Palliative care can be initiated without this time limitation. Beginning palliative care closer to the start of a terminal diagnosis or illness can be beneficial (McCusker et al., 2013).

For the past two decades, the Hispanic/Latino population in North Carolina has increased as a result of employment opportunities and family reunification (Larson & McQuiston, 2012). Immigrant Guatemalan communities have been identified specifically in rural eastern North Carolina. In the summer of 2015, a college of nursing research team from a university in North Carolina set out to understand decision making, family involvement, and cultural practices that influence palliative care from the perspectives of rural Guatemalans living in their country of origin with the intention of improving palliative care for this population in the US.

Review of the Literature

A review of the literature included databases from CINAHL, PubMed, OVID, and ProQuest using the terms: end of life care, palliative care, complementary and alternative therapy, Guatemalan, Latino, and older adult. This literature review focused on understanding the cultural beliefs and practices of Guatemalans when possible, specifically during suffering or illness. For this study, the literature review was organized into three categories: decision making, spirituality, and cultural competence related to Latinos and palliative care.

Decision Making

Numerous studies indicate that older Latinos prefer a family-centered decision making model for palliative care during the EOL (Cruz-Oliver, Talamantes, & Sanchez-Reilly, 2014; Kelley, 2010; Kreling et al., 2010; Kwak & Haley, 2005; Miller & Pinzón-Pérez, 2011; Yennurjalingam et al., 2013). Other studies suggest that Latinos prefer that their dying family member have limited autonomy (Austerlic, 2012; Kreling et al., 2010; Kwak & Haley, 2005).

Kreling et al. (2010) compared Latinos from Central and South America and White non-Latino family caregivers and discussed the rationale for this belief. The Latino family serves in a protective role by receiving health information on behalf of the patient, thereby minimizing the decision-making responsibility by the dying family member. By limiting patient autonomy in a cultural context, the family members are protecting the individual from harm and from information that would limit hope for the future (Kreling et al., 2010). The Latino family further views this as a way to remove the burden of treatment decisions from the patient (Kwak & Haley, 2005). In a multicenter study with 387 Hispanic caregivers in the US and Latin America, Guatemalan caregivers indicated a significantly higher percent of passive decision-making preference among patients when compared to Chilean and Argentinian caregivers (Yennurjalingam et al., 2013).

In a comprehensive review of the literature on EOL care and Latinos, Cruz-Oliver et al. (2014) found Latinos are less likely to have advance directives and have mixed views on the use of aggressive EOL therapies. However, Kelley (2010) reported that Mexican elders preferred less aggressive, comfort-focused EOL care, yet had not communicated their preferences to a family member or physician. Hospice was also found to be used less by older Latinos, but when hospice was used, caregiver burden was reduced (Cruz-Oliver et al., 2014). These investigators found that *hospicio*, the Spanish word for hospice, was translated as “orphanage or place for poor or homeless people” (p. 93), giving this service a negative connotation. Kreling et al. (2010) discovered Latino caregivers had more misconceptions about hospice and were referred less often by health care professionals to hospice services when compared to White non-Latino caregivers. Open communication with hospice staff about the patient’s dying process was reported as disturbing to Latino caregivers as well. Only one article was found in the literature review which reported the use of complementary and alternative medicine with terminally ill children (Ladas et al., 2014).

Cultural beliefs and values impact decision making and how the patient communicates with the health care provider. Investigators reviewed Latino values and palliative care, and found that the five most prominent values were *familismo, personalismo, respeto, confianza,* and *dignidad* (Adames, Chavez-Dueñas, Fuentes, Salas, & Perez-Chavez, 2014). To exemplify, *familismo* refers to the importance of family consensus, while *personalismo* refers to harmonious relations among family members. With regard to *respeto*, this value entails a hierarchical relationship between family members and authority figures. *Confianza* signifies mutual trust and sharing deeper feelings within a relationship, while *dignidad* is associated with feeling valued and experiencing self-worth. *Confianza,* for some Latinos, may result in less medical disclosure from the patient until trust is established with the provider. Based on these values, Adames et al. (2014) make recommendations for palliative care to include actively engaging family members, identifying the spokesperson for the family, providing patients and families with all viable treatment options, respecting cultural ceremonies or rituals, spending additional time with the family if needed, and assessing what culturally humane care means to the family.

Spirituality

Spirituality is integral to many cultures in the provision of EOL care (Puchalski et al., 2009). Krikorian et al. (2012) defined spirituality as “humanity’s means of seeking and expressing meaning and purpose” (p. 802). These investigators also found that being at peace is associated with spiritual well-being, which allows the dying person to say goodbye, share thoughts and feelings, and find meaning in life (i.e., hope). Finally, spirituality seems to mediate adaptation and well-being during EOL (Krikorian et al., 2012). Putman, Lea, and Eriksson

(2011) conducted a focus group with primarily Guatemalan participants to explore how religion facilitated coping with traumatic post-civil war events. Many fatalities during this time period suggest that a spiritual history may provide a framework to implement culturally relevant interventions during palliative care (Puchalski et al., 2009).

Older Latino women have been considered lay ministers or spiritual leaders of the Catholic faith more often than men as a result of their spiritual depth and wisdom (Espin, 1997; Menjívar, 2002; Padilla, 2003). Malcolm (2003) and Miranda (2007) are the only authors who have identified the unique role of female spiritual leaders in the Latino community who are called *rezadoras*. Their role is to comfort the family and the dying through prayer and preparation of home altars. In contrast, Esteinou (2015) reported that in Mexico, the *rezador* (pray-er) was a man who prays with the community after a death. Priests are considered an important resource for Latino families during EOL care (Miller & Pinzón-Pérez, 2011; Menjívar, 2002).

Designated Latino women are more likely than men to pray daily (PRC, 2014). Prayer is specifically viewed as a comfort practice for individuals at the EOL (Gaudio et al., 2013). According to the National Consensus Project (NCP) for Quality Palliative Care, prayer is the second most common pain control method for hospitalized patients (Puchalski et al., 2009). Prayer is used during the *novenio*, or the nine days and nights of prayer after a death for the Latino family and the deceased. During the *novenio* procession, bells are rung, songs are sung, and prayers are recited throughout the community (Esteinou, 2015).

Another cultural value, *fatalismo,* is considered the practice of suffering with dignity and accepting “hardships as the will of God” (Austerlic, 2012, p. 5). Investigators (Espinosa de los Monteros & Gallo, 2011), concluded that *fatalismo* may act as a barrier to cancer screening opportunities for Latinas after accounting for structural barriers (i.e. health insurance). Gaudio et al. (2012) also found that pain and suffering can be a test of faith—a belief that God will make things better, or as illness progresses, a loss of faith (Gaudio et al., 2012). Spirituality has the potential to influence health care practices and behaviors which may limit the access and treatment opportunities of the patient.

Cultural Competence

Austerlic (2012) defines culturally competent care as being both the sensitive approaches to access health services and the ability to provide quality care to diverse populations. This is most notably achieved through respecting cultural values, beliefs, and behaviors. Castañares (2008) recommends that health care providers should first examine their own cultural views for EOL care before attending to the Latino population. Lobar, Youngblut, and Brooten, (2006) also support the practice that health professionals should become more aware of their own religious beliefs and recognize the individual cultural needs of the patient and family at the EOL. Lobar et al. (2006) suggests that nurses should discuss patient and family desires, recognizing that ceremonies and rituals are often performed at this time and appropriate accommodations should be made. Cultural competency involves seeking more knowledge of heterogeneous cultural groups when assessing needs and barriers to health services at the EOL (Castañares, 2008). In an extensive literature review on suffering and distress of patients at EOL, researchers recommended that care providers focus on symptom control, a comforting environment, and performing social, psychological, cultural, and spiritual needs assessments for all patients nearing the EOL (Krikorian et al., 2012). Miller and Pinzón-Pérez (2011) recommend that nurses working with Latino families at EOL recognize the importance of the extended family.

Heyman and Gutheil (2010) interviewed 84 Latino elders served by home health agencies and found that the intervention groups, who received Spanish-language material from an informational session on EOL care with a bilingual social worker, showed more positive attitudes and increased comfort scores with EOL care compared to the control group (standard information with no verbal component). Studying similar effects of educational interventions, Fischer, Cervantes, Fink, and Kutner (2015) conducted a randomized controlled trial with 64 Latino adults and concluded that a bilingual patient navigator helped Latinos organize advance care planning and discuss pain management. The findings from these studies support the recommendations for one-on-one interventions from bilingual health professionals to discuss EOL care with Latino families. Similarly, lay religious and community members are valuable resources for Latinos seeking palliative care. Castañares (2008) presented three case studies with Latino immigrants that emphasized the importance of utilizing community health services partnered with lay health promoters, or *promotores de salud*, to increase the use of hospice and palliative care.

One of the most influential leaders in palliative care, Dr. Betty Ferrell, was the lead investigator of the End-of-Life Nursing Education Consortium (ELNEC) project, an international initiative to provide resources and training to nurse educators on palliative care (American Association of Colleges of Nursing, 2015). A program evaluation of the ELNEC-International curriculum conducted with 38 nursing participants from 14 countries concluded that developing countries, such as Guatemala, could benefit from EOL resources made available to more health professionals (Paice, Ferrell, Coyle, Coyne, & Callaway, 2008). Furthermore, Ferrell, Otis-Green, Baird, and Garcia (2014) found that patients with advanced illnesses often struggle with forgiveness and that nurses find these discussions challenging. In this study, Ferrell et al. cited

Byock's (2004) four themes of apologies, seeking forgiveness, and expressions of love and gratitude, and concluded that seeking forgiveness improved emotional status and peace.

This literature review reveals the high prevalence of family-centered decision making at the EOL for Latinos. Spirituality plays a significant role in palliative care through prayer, rituals, and lay spiritual leaders. Self-reflection from health care providers and increased understanding of cultural beliefs is essential to provide culturally sensitive care to Latino populations in the US.

Study Context

A description of the study location provides the context in which this study took place. Guatemala neighbors Mexico, Belize, Honduras, and El Salvador. The lowlands of Guatemala are located on the southern Pacific coastline and the highlands, or the mountains and jungle regions, cover the remaining land. The highlands are home to the indigenous Maya people, in part because they were able to seek greater shelter against the Spaniards (Anderson, Griffith, Horst, & Stansifer, 2015). Today, the mountains isolate these poorer communities from education and access to health care. According to the United States Agency for International Development (2010), the western highlands contain the lowest percentage of access to food and health services and the highest percentage of malnutrition.

At the peak of their empire, the Maya were extremely advanced and were known for their calendar, numerical system, architecture, and religious beliefs. The 16th and 17th century invasion by Spain deeply impacted the Maya culture, ultimately placing this indigenous Guatemalan population into a lower class status. The Spaniards introduced Catholicism which became the dominant religion across Latin America (PRC, 2014). Like many Latin American countries, the blending of traditional, indigenous beliefs and practices with Catholicism produced religious practices that are still evident today (PRC, 2014).

Almost 150 years after the Spanish conquest, Guatemala experienced a 30-year civil war. From 1960–1996 the Maya fought for agrarian reform against the Guatemalan military and wealthy multinational corporations. The Maya were often conflicted with sides and some joined guerilla groups while others were coerced by food and other resources to work with the Guatemalan military (Miller, 2011). This war was noted for extreme human rights violations and in 1981, the Inter-American Commission on Human Rights recognized that the government was responsible for thousands of missing persons and executions, estimated to include 200,000 Maya (Miller, 2011). Political unrest continues in Guatemala. In 2015, both the Vice-President and the President were forced to resign their positions due to political corruption (Beaudoin, 2015).

Today, many Guatemalans live together with extended family in simple dwellings and eat a basic diet of tortillas, beans, and coffee. The women's role is maintaining the household and child care, while men in rural areas are mostly farmers. Stray dogs, crowing roosters, and fireworks are common sights and sounds. For example, fireworks are set-off for birthdays, anniversaries and funerals. Maya women and girls wear traditional clothing called *huipiles*, while men and boys are more likely to wear Western or modern clothing to fit into mainstream society.

Methods

Design

This qualitative descriptive study reports on seven interviews with Guatemalans conducted in the summer of 2015, as part of a long-standing university college of nursing study abroad program (Larson, Ott, & Miles, 2010). In 2008, this college of nursing established a partnership with a Guatemalan community-based organization that provides language classes and coordinates community service projects. Students enrolled in the course live with a Guatemalan host family, eat meals together, interact with family members in the home and community, and help with household chores. The research team for this study was comprised of two nursing faculty (one bilingual) and a senior nursing honors student. The two nursing faculty have expertise in qualitative research with Latino populations, public health and palliative care. The university institutional review board gave full approval for this international study.

Sample

The study included six host families and one community leader. The majority of host families had been known to the nursing faculty since inception of the program, which facilitated open communication of this subject. The six host families included: two couples (husband and wife), and four married women (husbands not present). All were middle-aged adults. The community leader was a young adult, single male. All participants received 100 quetzales (US $13) for their time through a grant from a local chapter of Sigma Theta Tau International.

Data Collection

Prior to the interview, the female head of household was contacted for a preferred date and time within a given two-week period. The interviews were conducted by the bilingual nursing faculty and the nursing student. Interviews occurred in the participants’ homes or worksite. The duration of the interviews were 40-50 minutes and all interviews were completed within a 10-day time period. A structured interview guide was developed jointly by the nursing student and the palliative care nursing faculty. The interview guide was translated into Spanish and approved by two native speakers. The five questions were:

- When a loved one is in their final stages of living, what is the most important thing to do?
- In the final stage of living, what is the role of family members, relatives and friends?
- Who makes the decisions about the care for a family member at this stage of life?
- Are there certain things that you feel need to be done for a person in this stage of life?

- What things would be used to help pain or other symptoms?

Data Management and Analysis

Interview responses were handwritten by the bilingual nursing faculty and clarified during the interview process. The handwritten responses were transcribed by a member of the research team. The research team read each transcript separately. A matrix was developed to compare the seven transcripts with each interview question. Content analysis was used for coding and analyzing data (Bernard & Ryan, 2010). The team created a set of code words based on the literature. Ferrell et al. (2014) and Byock's (2004) concepts of forgiveness informed this process. Finally, the research team applied the code words separately to the transcripts until consensus was achieved.

Findings

The over-arching theme was *Relief of Suffering* that shaped the beliefs and actions concerning EOL care by these Guatemalan families. According to the family members in this study, both the dying and the caregivers sought relief of suffering through three support systems. The support systems were the family, the community *rezadora*, and the priest.

The Family

Decision making within the family was pervasive among all participants. The responsibility of adult children in decision-making for elderly parents was mentioned in six interviews. Only one example was given where the adult children and the physician made the decision for an elderly father to receive "hospital care and treatment." Some further elaborated that if spouses were present, the main decision-making role rested with the wife or husband or, in the case of a dying child, decision-making rested with the parents or oldest brother. All family members talked about the EOL care occurring in the home.

Additionally, the family had a paramount role in care-giving. This role included listening to the dying, and providing love through affection and care for the person. One wife said, “In the ears you need to say ‘I love you, you are not alone.’” Sharing messages such as this with the dying person brings about peace and relief. The physical and socioemotional needs were also addressed by one woman in this way, “Attend to necessities, giving them food, talk, help them move; show that they are still living, listen to them.” Physical care that the family provided included bathing, moistening lips, feeding, skin care, and changing linens.

When asked what the most important thing to do at the EOL, one participant stated, “To ask the dying person what he would like to eat, drink or even smoke. Several families remarked that the “desires of the dying person should be given the greatest [attention].” Another example of including the desires of the dying person to make decisions about providing care is, “The person might want music, their alternative food, give them what they want. Let them talk about the past.” Further, one woman described the need to “take care of the dying person with much love.” No family members specified the decision making involvement by the dying family member. However, many statements indicate the dying member’s needs were understood. All families mentioned the use of medications such as Tylenol, antibiotics, and analgesics for pain or other symptom relief. One specified the use of morphine while another mentioned plants and teas. One family member made the connection between spirituality and medication in this way: “First you must ask God’s forgiveness. If you don’t ask God for forgiveness, the medicine does not work.”

One family member related unique cultural beliefs:

> So no one can sit on the end of the bed because death begins at the feet and someone sitting there would not permit death to enter… If there is a half of a candle, it needs to be

> changed or other family will die…Lemon to help the person die. Lemon is poison for the body in the final stages of dying.

The Community *Rezadora*

A majority of the families revealed the importance of the *rezadora,* a community lay spiritual leader that was called upon to sing prayers. One woman said she has “a skill to talk to God, as important as the priest.” The work of the community *rezadora* was summarized by one man in this way, “everyone knows her and she recites prayers loudly and this helps the dying leave this earth.” The *rezadora* is seen at the house during the final days or hours before death and sings daily during the *novenio* (nine days of mourning).

The Priest

The priest’s role included the traditional sacraments such as prayer, blessings, baptism, communion, and the anointment with oil. An example of this was expressed by a female participant in this way, “The priest came to the house. He stayed alone two hours with him. He came out and said ‘He will now die in peace because he talked and expressed his concern.’” This relates the priest’s role to provide peace between man and God and its significance at the EOL to guide the individual and family during this process. A majority of the participants relayed the involvement of the priest to fulfill spiritual needs during the final hours of life.

Discussion

These findings contribute to the current knowledge available on palliative care with rural Guatemalans. The over-arching theme, *Relief of Suffering*, is consistent with the World Health Organization’s (2015) definition of palliative care as improving quality of life for families and patients by preventing and/or relieving suffering. The important role of the family in caregiving and decision making to reduce pain and suffering at the EOL was supported by the literature

(Adames et al., 2014; Cruz-Oliver et al., 2014; Yennurajaliingam et al., 2013), as was the role of the priest (Miller & Pinzón-Pérez, 2011; Menjívar, 2002).

This study extends the limited information about the role of the community *rezadora* in rural Guatemala (Esteinou, 2015; Lobar et al., 2006; Miranda, 2007). The community *rezadora* was found to support the family and the dying person through prayerful singing during the *novenio*. This ministry may be more common in rural areas where priests are fewer in number. Lay community members could take on this role with Latino populations in the US (Castañares, 2008; Puchalski et al., 2009). Our research expands Menjívar's (2002) work about the important role of female leaders in the church to provide spiritual support and relief from suffering. Palliative care nurses may benefit from recognizing this strong draw on the community from Guatemalans during EOL care. Developing community partnerships between Latino lay ministers and professional palliative caregivers to increase the utilization of palliative care services for US Guatemalans.

According to the participants, physicians had a presence in EOL care only in reference to medication and nursing care had no presence in EOL care for these families. This apparent lack of support by health care professionals during this critical life transition reflects the low ranking of Guatemala by the Latin American Palliative Care Index (Pastrana, Torres-Vigil, & DeLima, 2014). Guatemalan families provide the caregiving and support that is traditionally supported by the nursing role in the US at the EOL. Therefore, Guatemalans in the US may be unfamiliar with or have difficulty understanding palliative nursing care. The International ELNEC would be a useful training tool for Guatemalan nurses.

For nurses that are involved in caring for Latino patients in the US at the EOL, greater preparation should be in place to facilitate communication and relationship resolution during

EOL care. The responses from families support Ferrell's et al. (2014) trends that individuals at this stage of transition need forgiveness, love and thankfulness. All of these themes were noted by Guatemalan caregivers in this study as significant final acts practiced with the family member and needed for a peaceful death. This research draws similar recommendations to the study from Ferrell et al. (2014) to promote training for nurses to facilitate communication and resolution during EOL.

Conclusions

This study provides health care professionals with further understanding of the perspectives of rural Guatemalan palliative care practices. International ELNEC training programs to improve quality EOL care between Guatemalan nurses and families may be a valuable next step. Palliative nursing care in the US might consider incorporating these unique cultural practices and rituals, such as the role of the community *rezadora*. More research on the potential role of *rezadoras* in the US would be beneficial to increase understanding of Guatemalan palliative care beliefs and practices.

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