

A Case Study of Hispanics and Hospice Care

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Abstract

The issues of death and dying that have given impetus to the hospice movement include the effect on people with terminal illnesses and their families, impending death, renewed attention to long-term care centers and other alternatives to hospitalization, the scarcity of resources, the emphasis on holistic health, and recognition of the rights of people who are dying to die with dignity. Hospice offers patients compassionate care that is focused the pain relief and symptom management so that they can die a good death. In the US, hospice is considered the gold standard of care for terminally ill patients. Yet, racial and ethnic minorities are under-represented among those who receive this type of care. The present research takes a qualitative approach to exploring factors that influence hospice care among Hispanics in a hospice care setting. It discusses structural and cultural factors that influence the care among older adults. The research reveals organizational and professional that exist.

Key words: Hispanics, end of life, hospice

1. Introduction

For more than three decades, the dramatic attention accorded to hospice care in the United States divulges the intersection of a variety of interests and needs (U.S. General Accounting Office, 1979), as well as shift in trends toward care (Centers for Medicare and Medicaid, 2009) and practice approaches (Bern-Klug, 2010; Csikai & Chaitin, 2006; Reith & Payne, 2009). The issues of death and dying that have given impetus to the hospice movement include the effect on people with terminal illnesses and their families, medical advances that enable life to be prolonged in the face of degenerative diseases and impending death, renewed attention to long-term care centers and other alternatives to hospitalization, the scarcity of resources, the emphasis on holistic health, and recognition of the rights of people who are dying (Tannock & Boyer, 1990).

The 20th century was witness to changing attitudes toward people who are dying and to a self-determination focus for their care and treatment. In the early part of the 20th century, the family and physician provided care in the home as a matter of course. However, care gradually shifted to hospitals, where diagnosis, treatment, and cure were emphasized and the focus was on the physical condition of the dying person. Social and emotional needs were largely ignored (Steinhauser, et al., 2000). Fortunately, since the late 20th century, the US has witness a steady increase in the number of people who are electing to forgo aggressive, invasive interventions at end of life and instead are choosing hospice care when faced with terminal illnesses (National Hospice and Palliative Care Organization, 2010). Moreover, hospice is considered the “gold standard” of care for individuals with life-threatening illness and diseases.

Hospice was created to provide compassionate and cost-effective care for all patients and families facing a terminal illness. It was the first statutorily created, home-based, per diem-reimbursed approach to end-of-life care (Feeg & Elebiary, 2005).

This model of care offers the dying person the right to make decisions about his or her care, the right to a pain-free death, choose palliative care versus curative treatment, and die with dignity. Researchers and practitioners have argued that these are the domains of a good death (Hill, 1992; SUPPORT, 1995; Emanuel & Emanuel, 1998; Steinhauser, et al., 2000) and should be components of optimal care for those who are dying. Yet, racial and ethnic minorities underutilize hospice care (Givens, Tjia, & Zhou, 2010; Han, Remsburg, & Iwashyna, 2006; Kagawa-Singer & Blachal, 2001).

Less than 8 percent of African Americans and 6 percent of Hispanic Americans used hospice care in 2010. Studies have identified several issues related to hospice access and use by these two groups, with lack of diverse staff and cultural barriers as being two important factors (Bullock, 2010; Carrion, 2010). Furthermore, Smith and colleagues (Smith, Sudore, & Perez-Stable, 2009) argued that Hispanics may experience barriers due to language and literacy as well as concerns about discrimination, but did not conduct this research with patient currently in hospice care settings. They did, however, present a case study to document these issues for Hispanic patients and their families.

To further understand this phenomenon, the present research uses a case study approach to exploring factors that influence hospice use among Hispanics currently receiving care. It discusses the structural and cultural factors that influence the care among older adults. The research reveals that organizational and professional barriers exist.

2. Background

According to the U.S. Census (2011), some 50 million Hispanics live in this country, and the number is projected to increase by 15% by the year 2050. The Hispanic population aged 65 years and older will increase 224 percent by 2030 (U.S. Administration on Aging). Furthermore, Hispanics tend to have high morbidity and mortality rates (Healthy People 2012) than some other groups. As this population continues to grow in number and ethnic diversity, so does the concern about the disparities in how care is provided. Moreover, as Hispanics continue to be the fastest-growing ethnic group in the U.S. population, with a 43% increase between 2000 and 2010, it behooves social scientists to continue our exploration for answers to questions that help to explain health and health care disparities.

In many U.S. regions, Hispanics represent a diverse population. In central Florida, Hispanics include individuals with Cuban, Mexican, Puerto Rican, and Central and South American backgrounds, as well as other pan-Hispanic origins. Because culture is a complex and multifaceted construct, shaped by the interaction between numerous sociodemographic factors and continuously redefined by historical experiences and social realities, research that focuses on a single race/ethnic minority group is justified when exploring social phenomenon, such as hospice care. A better understanding of factors that influence behaviors toward end-of-life care among Hispanics can assist practitioners in developing optimal care plans.

Racial and ethnic minority groups are considered a hard-to-reach population to engage in health care research (Benoit, Jansson, & Phillips, 2005). Choosing the appropriate methodology that is culturally sensitive to Hispanics was important in the present research. The topic of terminal illness can be a sensitive issue for researcher participants, as well as for the researcher. Issues around end-of-life care often create emotional upheaval for the terminally ill patient and the family. Therefore, case study research is a qualitative approach that is well suited for exploring sensitive issues in their natural settings (Yin, 2009; Csiernik, Birnbaum, & Pierce, 2010). Data collection that is based on random sampling or specific attribute representativeness will seldom be able to produce the kind of insight that a sample of convenience in its natural social context will produce (Gerring, 2005). More specifically, case studies have been documented as an illustrative method for assisting practitioners to identify strategies for improving care for terminally ill Hispanic patients and their families (Smith, Sudore, & Perez-Stable, 2009).

3. A Case Study in Hospice

3.1 Setting and Sample

In existing research regarding Hispanics and hospice, a case study approach has not been used. It was important for the research to take place in its natural setting and include direct observation, interviews, field notes, and artifacts beyond what the conventional qualitative interview may consider as research data (Yin, 2009). Furthermore, the case itself exemplifies “a phenomenon of some sort occurring in a bounded context (Miles & Huberman, 1994, p. 25).

The case of one hospice care setting provides insight and better understanding of the issue at hand because it is a setting in which the participants were actually receiving care at the time of the observations. A social phenomenon in a single continuum of care, observed occurring in the natural setting, does represent the experiences of others in like settings, with like features (Thomas, 2011). Participant observations included shadowing clinical field staff, namely primary nurses, patient family counselors, chaplains, certified nurses' assistants, and a hospice physician. Visits were made to patients in their homes, in a hospice house, in the hospital, and in nursing homes. Visits with hospice hospital nurses, a hospice hospital social worker, admission nurses, and a non-caregiving hospice representative greatly enhanced knowledge and understanding of the broad range of services offered.

Observing the hospice team members' day-to-day interactions with the patients, caregivers, and family members, along with interdisciplinary team meetings, provided an understanding of the provision of care to Hispanics (Reese & Sontag, 2001). Interacting with office clinical staff, clinical team supervisors, clerical staff, and other personnel yielded explanations of their responsibilities and duties. Reviewing hospice newsletters, brochures, announcements, and websites provided additional and meaningful information. In essence, hospice care was observed on a daily basis, with a focus on the meanings of the behavior, language, and interactions of the culture-sharing group (Creswell, 1998).

3.2 Study Design

The single case of one hospice care facility discussed in the present research was chosen with a view to illuminating the dynamics between the patient, family, staff members and, in particular, the social worker. In keeping with the recommendations for best practice in case study research, this study took place in its natural setting (Gerring, 2005), and included direct observation, interviews, field notes, and artifacts beyond what might be considered research data in the framework of the conventional qualitative interview (Yin, 2009). The participant observations were made while shadowing clinical staff and visiting patients and families in their homes, at doctors' offices, and in hospital settings. The staff, patients, and family members were informed about the research study and volunteered to participate. Approval for the study was received from the University's Internal Review Board (IRB) and the hospice organization's IRB.

To help maintain the focus of the research while conducting observations in the natural setting, with natural daily occurrences taking place, a short list of bullet points was used as a reference (Thomas, 2011). Furthermore, it would be impossible to obtain a true picture of the experience without the social context in which the care was provided. The present research extends the previous work (Carrion, 2010) to illustrate issues of within-group and cross-cultural challenges for Hispanic patients, family members, and researchers.

3.3 Observations of the Phenomenon

In case study research, unlike in quantitative reports, the most important aspect of the research design and analysis is to make sure that the study is focused and concise so as to avoid producing vast amounts of irrelevant information. To this end, observations were documented and interviews with family members were conducted by the native Spanish speaking researcher, and were then audio-taped, transcribed, and translated from Spanish into English. Using the constant comparative method, preliminary analysis took place simultaneously with data collection so that the discussion questions could be modified to elicit more complete information from participants and to explore in greater depth the concepts arising in earlier groups (Miles & Huberman, 1994).

Understanding the Phenomenon

The observation documents and transcripts were analyzed according to the methods of multiple close readings by the researcher and research assistants. Small segments of the transcripts were coded into discrete concepts by the researcher team, independently. Codes were developed and revised until the researchers reached an agreement on their application. Initial codes emerged directly from the data. The researchers then compared these codes in order to elucidate the larger themes that emerged.

4. Findings

4.1 Language barriers during the hospice referral

During one visit to a medical office, a Cuban-born office manager posed the following question to the hospice social worker who was responsible for facilitating hospice referrals:

Can you assure me that this 82-year-old Cuban [born] man, whom the physician wants to refer to hospice, gets a Spanish-speaking nurse if we refer him to you? I'm trying to convince his 80-year-old Cuban [born] wife to agree to hospice for her husband, but she does not want anyone she does not understand in her home.

The hospice provider nodded her head, and it was apparent that she had heard similar requests in the past. She gently stated, "We will do our best to meet the patient's and family's needs." The office manager was insistent and repeated:

In this case, a Spanish-speaking nurse is what they really need; the wife brings the patient to this office every week. She drags him here and they sit here for hours and wait to be seen; neither of them can walk, instead they shuffle. The doctor can't see him weekly; sometimes the nurse talks to both of them, does the best she can, and sends them home. But next week they're here again. You know the doctors are very busy. He tells me to handle them. I was waiting for you to come by to see if you can help.

These types of requests are difficult to fulfill due to the limited number of Spanish-speaking nurses in the hospice organization. However, when the patient or family makes a request based on language preferences, social workers have the responsibility to address the request in keeping with the practice standards that prioritize the patient's interests and make them a primary. It is also important to respect and promote the right of the individual to self-determine his/her care.

In this case, the hospice worker explained the dilemma that the hospice staff experiences when the preference for a Spanish-speaking nurse is expressed. She explained that the hospice organization may not always have a bilingual nurse in place at every shift to honor the request for a Spanish-speaking nurse. While the office manager's question was not answered directly, assurances were given that the patient's needs would be met. Subsequently, the hospice social worker followed through with the office manager's request for a Spanish-speaking nurse and assured her that provisions would be made for translation services. Language barriers during the hospice referral was a reoccurring theme in the data and one that helped frame an issue to be addressed in meeting the needs of Hispanic patients. It was difficult to provide optimal care when language was a barrier.

4.2 Organizational factors impacting language barriers

During participant observation by the researcher of staff interaction in an administrative office, one of the two Spanish-speaking nurses within the hospice organization inquired about the details of the research. After a brief sketch of the project, the nurse responded, "Your research is what caused me to stop visiting my patients today. I schedule my patients' visits a week in advance, but today I had to stop and go do an admission for a Spanish-speaking patient." It was apparent that the nurse did not understand the depth of the research being conducted. The nurse further stated that it was unfair to cancel visits with existing patients, and detailed the urgent need for more Spanish-speaking nurses, social workers, and other staff. She also added "I only get one thousand dollars a year extra for being bilingual; I'm going to go to human resources and ask them to take their money." Her assumptions illustrate that since she is a Spanish-speaking nurse, she is asked to work longer hours and perform duties that she perceives to be outside of her job description and to do so without adequate pay.

While the researcher was conducting one-hour participant observations, constant requests were heard over the paging system, "Spanish caller on the line. Can a Spanish speaker please pick up?" The need for Spanish-speaking staff and assistance was evident. Although Spanish-speaking hospice staff members were in great demand, they received the same amount of pay for answering calls in both English and Spanish, translating for staff on the phone, and for communicating with "walk-ins" as their English-speaking counterparts did. The Spanish-speaking office workers in the hospice houses would also leave their workstations to translate as needed. Several of the bilingual Hispanic hospice workers expressed frustration about constant interruptions throughout the day and hours of lengthy translations related to patient and family issues, yet the expectation to fulfill their assign job duties remained. Questions arose about whether the hospice team members and the organization were adequately prepared to meet the patients' medical, psychosocial, and spiritual needs, considering the lack of Spanish-speaking hospice staff.

4.3 Language barriers experienced by hospice family members

Language barriers were prevalent among hospice care providers, patients, and families in this case study; these emerged during home visits and continued to be seen in hospital visits. During one observation, the researcher was asked by the hospice hospital social worker to translate for a Puerto Rican patient who had recently been admitted into the hospital's hospice program. She was told that neither the patient nor the family spoke English. The 56-year-old patient was in the hospital owing to severe abdominal pain, and after a week of extensive medical examinations, the family was informed that she had stage-four stomach cancer. The patient's nuclear and extended family crowded the hospital hallway—only two visitors at a time were allowed at the patient's bedside. Infection control procedures required everyone who visited the patient—staff and visitors alike—to wear gloves, a gown, a head cap, shoe coverings, and protective eyewear to shield both the patient and the visitors from infectious disease. The patient was moaning and groaning in pain. She placed her hands on her abdomen and said “dolor” (Spanish for “pain”) repeatedly. The hospice hospital social worker requested that the patient be asked in Spanish about her pain level on a scale of one through ten. The patient stated that her pain level was at ten—the highest—and the hospice social worker immediately contacted the nurse, who administered pain medication.

After the pain was controlled, the social worker and the researcher functioning as a translator again went through the infection control procedure and put on the required attire to enable her to determine whether the patient would agree to be discharged to the hospice house. This would allow hospice nurses to manage her pain so that she could return home. The hospice house affiliated with the hospice functioned as a place of transition from the hospital to allow individuals and family members to plan caregiving issues accordingly. When the patient was asked in Spanish about her willingness to go to a nearby hospice house upon discharge, she responded by asking if she could wait for her daughter to arrive, adding, “Whatever my family decides will be fine with me.” Later that morning, during a meeting with the patient's sister and daughter, it was discovered that, by family request, the patient was not fully aware of her diagnosis. Her daughter asked the hospice hospital social worker to arrange a meeting with the physician to explore discharge plans. It was obvious that the daughter did not want to rely solely on the advice of the hospice hospital social worker.

During the translation, the patient's daughter was reminded hospice social worker that the patient had been admitted into the hospice program with her consent, and that it was her role to facilitate the discharge plan. The daughter was not satisfied with this response and stated, “I want to know what else the doctor can do for my mother before she leaves the hospital.” The hospice hospital social worker solicited help from the hospice hospital admissions nurse to reiterate the role of hospice and to explain to the daughter why the physician had initially referred her mother to the hospice. Given the lack of translators available, the researcher continued translating for both the nurse and the social worker. At the insistence of the patient's daughter, a discharge-planning meeting was arranged with the physician, and the services and function of hospice were further explained to the patient's family.

On another occasion, a home team hospice social worker requested that the researcher provide translation services to a hospice caregiver and a continuous care nurse. Such barriers are reflected in the story told by Dominga, who was born in Puerto Rico. She is 80 years old and has a fifth-grade education:

Yes, last night at 12 o'clock [midnight] a white man knocked on my door and said he was a nurse that was here to help me; I was scared. I told him to go away, but he did not. I waited a little bit, looked through the peephole and there he was. I said, “Go away, go away.” I did not want to talk too loud. The next thing I knew, the phone rings and they were saying something, a lot of things I did not understand. Then I heard the word “hospice.” I did not know what they were saying so I hung up. I called my daughter quietly and told her about the white man at my front door passing for a nurse and the telephone call with somebody saying the word “hospice.” She said, “Mom, don't worry. I'll find out what this is about.” When I called her back, she [my daughter] said, “Let the man in because the hospice nurse ordered a night nurse.” I was so nervous; a man I don't know in my house with my husband being sick. My daughter remained on the phone with me and she said, “Mom, let him in. The hospice sent him.” He wanted to go into my bedroom and watch my husband sleep. I can't sleep with a stranger watching me. My daughter spoke to him and told him to sit in the living room. He sat down. I went to the room but I could not sleep knowing there was a stranger in the house. When it got light outside I sent him home. I felt bad. I don't want to take food out of his mouth but I was so tired I could not sleep with him sitting in the living room.

Dominga's experience demonstrates the confusion and conflicts that arose from her inability to comprehend English fully and to become familiar with the range of hospice services. It also highlights her reliance on her daughter as a translator, along with her discomfort with a male stranger in her home, especially in her bedroom. Concerns were raised regarding her own health and peace of mind while she was striving to care for her terminally ill husband.

Functioning as a translator while conducting participant observations enriched the data collection process and provided the researcher insights to the research topic. Although the researcher's initial purpose was to accompany the hospice team members. However, due to the hospice staff's urgent need to communicate with Spanish-speaking patients and families the bilingual researcher assisted by translating as needed. Nevertheless, it could have potentially impeded the study should the researcher have gone beyond solely translating. The fact that the researcher was also a social work practitioner created the potential for crossing professional boundaries (NASW Code of Ethics, 1996, p. 9). Despite perceived or real commonalities between the social worker and the patient, social workers are responsible for upholding social work ethics and avoiding blurring their roles as researchers. Fortunately, this was achieved in the study.

This case study illustrates multiple factors regarding older Hispanics, hospice, end-of-life considerations, and terminal diagnoses. Older Hispanic individuals repeatedly referred to the difficulties they experienced as a result of language barriers, gender differences, lack of general knowledge of hospice services, and distressing, yet avoidable, events. Providers of hospice care need to be knowledgeable of the racial and ethnic background, culture and beliefs of the patients and families whom they serve. By doing so, practitioners are positioned to facilitate patient and family members' hospice care in an equitable and competent manner.

5. Discussion

The research findings of this case study, based on observations and interactions, highlight a particular cultural aspect of our work with Hispanics in hospice and the ways in which they are negotiated within the care setting. Language is a cultural component of practice behaviors barriers and the barriers identified in this study warrant greater attention. Although there are structures in place to ameliorate language barriers, there is still an urgent need for bilingual clinical team members and translation services in hospice settings. The lack of these services hinders the quality of care received by Hispanics. The inability to navigate the medical systems (Ward et al., 2004), the lack of culturally competent providers, and hospice organizations' failure to address language barriers create additional health disparities. The findings also demonstrate a distinct need for culturally competent and culturally responsive practice (Bender, Negi, & Fowler, 2010) that is ethical and inclusive. While this study is limited due to its six months of participant observation and its geographic specificity, it provides a preliminary discourse pertaining to a significant issue regarding ethnic and cultural diversity in social work practice in hospice settings. The themes that emerge in this research can be used to construct a larger-scale examination using a deductive approach to hypothesis testing and more confirmatory analysis.

The findings are likely to occur in other practice settings and research that extends this exploration in various health settings is recommended. The literature review suggests that to identify areas of need for under-represented populations, especially mentally ill frail older adults (Cummings & Kropf, 2011) could greatly increase access for these persons. In regions of the US where Hispanics are entering nontraditional resettlement communities (Archuleta, 2011) and maintaining life-long residency, innovation programs may be a method for addressing the lack of utilization. Edwards-Joseph (2012) described an innovation approach to recruiting and training paraprofessionals in developing countries that may prove to be beneficial to meeting the needs of Hispanics in hospice care in the US. It is important for practitioners to be knowledgeable and conscientious of the impact of language barriers experienced by terminally ill Hispanics and to intervene with culturally appropriate practice approaches.

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