
ORIGINAL ARTICLES

Communicating terminal diagnoses to Hispanic patients

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ABSTRACT

Objective: This study addressed factors physicians employ in their communication of a terminal diagnosis and a hospice referral to Hispanic patients.

Method: The research method used was an exploratory qualitative in-depth semi-structured interview with thematic analysis. The interviews were with ten physicians in Central Florida. The interviews were conducted in Spanish and/or English with physicians who serve terminally ill Hispanic patients.

Results: The findings provide vital information on factors that impact communication of diagnosis and hospice referral. Themes emerged relating to role of family members and end-of-life decision-making. Language barriers and limited knowledge of cultural factors and beliefs impacted communication related to end-of-life decisions. Gaps in training and education for physicians were also identified.

Significance of results: These results suggest that discussing end-of-life issues with the diverse category of Hispanic patients and families will be enhanced by eliminating language barriers, increased understanding of the role of family members, and knowledge of cultural factors and beliefs related to end-of-life decisions.

KEYWORDS: End of life, Hospice knowledge, Communication, Decision-making, Referrals

INTRODUCTION

Physicians have the responsibility and burden of discussing a terminal diagnosis with their patients. This task is increasingly challenging and complex despite the progress of technology and medical advances, because despite all of the efforts made to preserve and prolong life, there naturally comes a time in which death is inevitable. At this time, physicians are confronted with the responsibility of discussing these final issues with their patients. This responsibility is further complicated when communicating with Hispanic patients whose primary language is Spanish, and who display varied cultural beliefs pertaining to end-of-life issues.

Palliative care is an important health care concern, particularly among the Hispanic population, where there are language and cultural barriers to accessing palliative care (Talamantes et al., 2000). Studies suggest that patients' and families' lack of knowledge regarding palliative care options is a barrier to receiving such care. Health care needs are also prevalent among people who work but are uninsured, including those who do migrant work who are not part of the system, yet need to access palliative care. Racial and ethnic disparities in palliative care settings exist, with the disparities related to treatment patterns, pain management, and utilization of hospice care (Payne et al., 2003). In 2000, the National Hospice and Palliative Care Organization's study reported, 82% of hospice patients were non-Hispanic white, 8.2% were Black or African-American and 3.4% were Hispanic or Latino (Gelfand et al., 2001; Lackan et al., 2004).

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Communication preferences with health care providers and the manner in which cultural beliefs impact decision-making about palliative care choices at end of life with individuals who are Hispanic are critical issues to explore, which may in turn increase the utilization of palliative care within this population. Many terminally ill individuals and families learn about hospices from someone other than their physician, and most learn about valuable hospice features and services only after enrollment in hospice care (Casarett et al., 2004). Unfortunately, physicians are frequently unaware of preferences of terminally ill individuals for end-of-life care, despite evidence that communication interventions improve patient outcomes (Tulsky et al., 2005; Goldstein et al., 2008).

According to the National Health Interview Survey, 2000, people of Hispanic origin have the highest incidence of cancer of the cervix and of the liver of any group. For all cancer sites combined, residents of poorer counties (those with $\geq 20\%$ of the population below the poverty line) have 13% higher death rates from cancer in men and 3% higher death rates from cancer in women than those in more affluent counties, which are those with $< 10\%$ below the poverty line (Ward et al., 2003). Many patients and families continue to experience unmet pain and symptom management, overall dissatisfaction with care, inappropriate prolongation of the dying process, lack of control, and death in a hospital rather than at home (Carlson et al., 2008).

When examining various barriers experienced by people of Hispanic origin, it is important to consider the multiple determinants of risk and the ways in which cultural identity shapes these risk factors (Schonwetter, 2006). This is particularly true since prior studies indicate race and ethnicity were analyzed as a potential determinant of end-of-life medical care. The race and ethnicity of people with advanced cancer is related to their treatment preferences, advance care planning, and health care utilization.

Research has shown that terminally ill individuals prefer a shared approach to medical decision-making, given the pivotal role of family members in the total cancer experience (Bruera et al., 2001). Therefore, it is important to explore the preferences of people of Hispanic origin and their families, especially since care near the end of life is increasingly recognized as a family matter (Haley et al., 2002).

METHODS

The research method used was an exploratory qualitative inquiry, which consisted of in-depth semi-structured face-to-face interviews with ten

physicians by the researcher on October 1, 2006 and January 30, 2007. The qualitative data was coded using content analysis techniques (Bernard, 2002). The qualitative research design examined salient themes across the sample (Creswell, 1998) and facilitated a deeper understanding of physicians' socio-cultural contexts

Participant Selection

The ten physicians were recruited to participate in the study using convenience, purposive, and snowball sampling techniques. The first participant was the researcher's intern who then recommended associated colleagues. The researcher's network of medical social workers also assisted in recruiting physicians to participate in the study. The study was conducted in the physicians' offices and in hospital settings in the Central Florida, United States geographic area. Institutional Review Board approval was obtained. All participants were informed about the nature of the study — that their participation was voluntary and that identifying information was kept confidential.

Data Collection

Hispanic individuals seek treatment from physicians from diverse backgrounds and specialties; thus, efforts were made to reflect this diversity in the sample. Data collection included obtaining oral consent after participants read an Information Sheet for Participants, which explained the study. Demographic data were attained via a data form from physicians. This included age, gender, place of birth, length of time on the United States mainland, religion, language preference, years of practice and area of specialty. Also conducted was an extensive literature review investigating physician communication with Hispanics and end-of-life care. This process assisted the development of the semi-structured interview questions. The open-ended interviews and data collection technique allowed unanticipated issues and topics to emerge.

The interviews were conducted either in Spanish or in English depending on the physicians' language preference; the results were audiotaped and transcribed. Physicians who expressed interest in participating in the interview asked the researcher to schedule a meeting time with their office manager. Others designated a weekday during their lunch break time, while others asked to be interviewed at five in the afternoon. The medical offices in which the interviews were conducted had waiting rooms crowded with patients. The physicians were treating unexpected medical emergencies, and they were often delayed in local hospitals treating their patients who were hospitalized. Seven of the scheduled interviews

Table 1. Demographic information for physicians (n = 10)

Age	Sex	Place of birth	Language preference	Length of time in the U.S.	Religion	Years of practice	Area of specialty
52	M	Colombia	Spanish	25 years	Catholic	15	Internal Medicine
49	M	US-NY	English	49 years	Catholic	18	Internal Medicine
46	F	Cuba	Spanish	12 years	Catholic	21	Internal Medicine
38	M	Jamaica	English	20 years	Protestant	6	Internal Medicine
45	M	Cuba	Spanish	39 years	Catholic	22	Internal Medicine
48	M	Germany	English	21 years	Protestant	21	Pediatric Oncology
52	M	US-PA	English	52 years	Protestant	22	Pediatric Oncology
52	M	US-NY	English	52 years	Catholic	23	Internal Medicine
48	M	Puerto Rico	Spanish	17 years	Catholic	25	Gerontology
33	F	US-PA	English	33 years	Catholic	4	Pediatric Oncology

were cancelled and rescheduled two and/or three times. Scheduling these interviews required persistence, patience and flexibility.

The demographic data pertaining to the ten physicians interviewed include their age, gender, place of birth, length of time in the United States mainland, religion, area of specialty and years of practice (See Table 1). Data were drawn from face-to-face interviews with eight males and two female physicians. The median age of the physician was 46.3 years. The youngest physician was a female age 33 and the three oldest were males age 52. The birthplaces of the physicians varied: Four were born on the United States mainland, two in Cuba, one in Colombia, one in Germany, one in Jamaica, and one in Puerto Rico. Four out of ten physicians in the study self-identified as Hispanic. Within the Hispanic group, one was a female born in Cuba; and the three others were males born in Colombia, Cuba, and Puerto Rico. The median time as residents of the United States for the six physicians not born on the mainland was 22.3 years. The median years of practice in the United States were 17.7 years. The years of practice among the ten physicians ranged from four years to 25 years. One physician reported practicing medicine in Cuba for 11 years prior to leaving that country. Six of the physicians have a specialty in internal medicine, three in pediatric oncology, and one in gerontology. Seven physicians self-identified as Catholic and three as Protestant.

Data Analysis

The qualitative data were transcribed to create a written verbatim account. To preserve participants' confidentiality and anonymity, all identifiable information (such as names and locations of physicians) captured on the tape was removed from the transcript. Interviews conducted in Spanish were

Table 2. Study themes in the language of the participants and the researcher

Interview questions	Themes from participants responses
<ol style="list-style-type: none"> How do Hispanics respond to a hospice referral? Do their responses differ from individuals of other cultural backgrounds? If so, how? Do you have any hesitations in referring Hispanic patients to hospice? If so what are they? How is hospice discussed with the patient and family? Do terminally ill Hispanics prefer to rely on family members? Are family members likely to be the sole caregivers for Hispanics? Did referring Hispanic patients to hospice services affect your relationships with them and their families? If so how? Did you encounter any barriers to getting Hispanics connected with hospice? What advice would you give to hospice providers in order to increase the number of Spanish speaking clients in the program? 	<p>Theme One: Physicians' knowledge about cultural beliefs of Hispanic patients regarding a terminal diagnosis and a hospice referral.</p> <p>Theme Two: Managing the role of family members in end-of-life health care decisions is central.</p> <p>Theme Three: Barriers regarding hospice health care providers' limited Spanish language proficiency.</p> <p>Theme Four: Gaps in training and education for physicians.</p>

transcribed in Spanish and then translated into English. Coding and thematic categorization of the interviewees' responses were included in the qualitative content analysis utilizing the questions from the structured interview. Interviews were analyzed using content and thematic analysis (Pope et al., 2000) across the sample to identify and explore trends in medical practice related to end-of-life discourse, criteria used to initiate referrals to hospice, and overall hospice utilization perspectives.

Findings

The findings of the study were insightful and echoed that physicians reported feeling hesitant to refer Hispanic clients to hospice due to physicians' limited knowledge of Hispanic clients' cultural beliefs, and physicians' uncertainty regarding the role of family members in end-of-life health care decisions. There were also organizational barriers based on hospice health care providers' limited Spanish language proficiency. Several physicians identified the need for educational training about the Hispanic community and its diversity.

DISCUSSION

Respondent quotes illustrated significant points of consensus or disagreement areas. Four themes emerged (Table 2) related to methods physicians employ to discuss a terminal diagnosis and hospice services with a Hispanic patient and family.

Theme One

The first theme pertains to physicians' knowledge about cultural beliefs of Hispanics when addressing a terminal diagnosis and hospice referral. The physicians were all aware of the hospice criteria and the necessary process in which to refer patients to hospice. They all had referred patients seeking palliative care to hospice organizations. Additionally, they discussed some of the approaches used when discussing a hospice referral with Hispanic clients. A Jamaican 38-year-old male physician stated "I noticed with the Hispanics there is a lot of family interplay, and giving them as much information as I can and giving them my take on it helps. Let's say for example I would say, 'If they were my mom or my dad this is what I would want'. They appreciate that and they get a better sense as to where they are and where they want to be. It works well this way most of the time".

A 46-year-old female physician born in Cuba stated "The culture is different. I believe this is a cultural problem. In Cuba, the family is not only the spouse, children, mother and father. Cubans include the grandmother, the aunt, and the cousin; the con-

cept is that they will take care of the patient until he closes his eyes. Mostly the female who is still single will be in charge of the patient. The patients prefer the family to be in charge, the patient wants to know as little as possible. The family will request that you tell the patient as little as possible. In the United States, your commitment is to the patient. The family counts only if the patient agrees. That's why I try to tell them, 'You are sick. Do you want me to talk to your children?' and if he or she wants, I continue".

A 52-year-old, White male born in New York, stated "Patients respond to the referrals by listening to my insight. It is difficult when you deal with patients from Mexico; when they are in this country they believe there are indeed a lot of medical opportunities in the United States. The biggest thing is breaching the privacy of the family dynamics. They don't want to let people know anything that is going on in their family. In my experience, Hispanics want to do as much among the family as they can."

A 48 year old, male, born in Puerto Rico stated "The biggest problem that I found is that the family does not want strangers in their home. But when they realize that they need help, the situation is more understandable for them. Latin families are very close; At least the families that I deal with are extremely tight. I have found very few cases where the family is not involved. There is always a family member living in the same place."

The physicians discussed their experiences in discussing a terminal diagnosis with their patients and families. They expressed some uncertainty about how to integrate family members into the process. The Hispanic physicians identified cultural differences which include the broad definition of family among Hispanics and their expectation to be involved in health care decisions. The physicians explained the contrast between the Hispanic families' perspective regarding health care and the legal mandates of the medical system. Furthermore, issues regarding Hispanics' belief that modern Western technological advances can cure almost all medical conditions and their hesitancy to have non-family members provide in-home medical care tend to create additional challenges for physicians. This is perhaps the case for Hispanic immigrants from rural and poor communities (Randall & Csikai, 2003). These challenges also may occur with Hispanics who have not acculturated to the beliefs and traditions of the dominant society.

Theme Two

Managing the role of family members in end-of-life health care decisions is central to this theme.

The process of discussing hospice services with the Hispanic patients and their family members often reveals controversial areas among health care providers. This issue is often addressed with uncertainty and apprehension: therefore, this study aimed to gather pertinent information on this issue.

A male, age 45 and born in Cuban noted "It depends on a lot of things; once we have exhausted all possible measures to help the patient and we have no other recourse, if they have the family support for hospice services, and they are willing to go through hospice end-of-life treatment, then they are referred".

A male, age 48 born in Puerto Rico stated "I met with the patient and the family in the room to discuss hospice benefits. I like to involve the family and patient and let them know that it is important to learn about these benefits, and to give them the opportunity to evaluate if the program will benefit the patient and the family. As soon as the hospice explains the program, there is small percentage of families that refuse the program".

A male age 48 born in Germany concluded "I have surely seen how Hispanic family members rely a great deal on their families by living together, and they tend to travel together when visiting the physician".

A White male physician age 52 born in Pennsylvania described the role of family in this manner. "I think that the definition of family in the majority of Latin families is more extensive; it is not simply the mother and father but frequently the in-law, the grandmother, and aunts. There is large involvement of people who are related by marriage or bloodlines that are nearby, and they make every attempt to be very supportive. I try to identify the primary caregiver, who is usually the mom and dad, and then I ask for the people they want to be involved in the discussion. If they said, 'Yes', that's fine if they said, 'No', then that's not fine. I also measure that when we're discussing the inevitability of death. I do try to have this conversation just with the father and mother alone if the patient a child, because I want them to know that the decision is really their decision and it is not someone else's or what they are expected to do. The job of everyone is to support them in whatever decision they make. I like to have one opportunity to separate them from the big group, so they can say freely what they want without worry about what someone else is hearing or thinking".

The findings indicate that physicians attempt to consider the role of family members in discussions about hospice service with Hispanic individuals and strive to involve family members as much as possible. Physicians in the study discussed the patient's terminal diagnosis with family members

and followed the families' leads in discussing the diagnoses with the patients.

Theme Three

The third theme pertains to barriers regarding hospice health care providers' limited Spanish language proficiency. The participating physicians' responses described the manner in which they discussed a terminal diagnosis, and also how they suggested a hospice referral with their Hispanic patients and families.

A 52 year old male physician from Colombia stated succinctly, "Increase the number of Spanish-speaking team members".

Another male physician, age 48, born in Puerto Rico reiterated "I recommend having Spanish-speaking workers. I have a lot of patients that do not speak English. They are like my mother; they are never going to learn English. The only way that I could engage my mother in any part of this program is if they have people that speak her language and people whom she can identify with. This is the most important part. It is a compassionate type of care".

A female, age 43 and Cuban born, highlights obstacles that occur with language barriers, as she notes "Hospices need to have Spanish-speaking nurses and team members who visit. Because, for example, I have a Latin patient who is in hospice and the personnel that visit her are American [non-English speaking], therefore they don't understand each other and the daughter who has to act as a translator is at work. There are no nurses who speak Spanish and that affects the relationship, because she seems as someone distant, a stranger. They should increase the number of Spanish speaking personnel in hospices.

A 52-year-old White male born in New York stated "It really depends; there are many Hispanics. Some are just as comfortable in English-speaking environments as they are in their traditional environment. But others are most comfortable speaking Spanish, interacting and behaving in a more traditional Latino culture. I think it's helpful to those people, at least for the introductory phase, to meet and see another Latino person face to face. If it's going to be another Anglo person it should be someone who is extremely comfortable in that environment and can relate to them [Hispanics] in a way they are accustomed to being related to. I think that would be helpful. The other thing I think is that hospices need to say that their goal is not replace their support system but to enhance it".

They unanimously agreed and suggested that hospice organizations need to increase Spanish-

speaking workers, Spanish-speaking team members, and public education in Spanish.

Theme Four

The fourth theme is drawn from the physicians' responses, which provide significant information about gaps in training and education for physicians. The following statements illustrate physicians' feelings of uncertainties regarding Hispanics and the need for training in these areas.

A White male age 52 born in Pennsylvania, stated "I feel that perhaps that Hispanics are less willing to accept hospice services than Anglos. My perception may be wrong, but I think that denial of death and of a terminal illness lasts longer and is more pervasive in the Latino population. There is not as much acceptance of the inevitability of a death but maybe I'm wrong".

A 48-year-old male born in Germany, expressed this suggestion. "It would be helpful if hospices would give training on working with the Hispanic/Latino people; if I had a book or some information that I could look at about the different aspects of health care and experiences of what really is important to Hispanic patients and family members. If only I had facts that I do not have now. I have different experiences; I need help not to fumble in the really difficult areas".

Physicians in the study expressed not having sufficient knowledge regarding changes that occur when family members relocate from their country of origin; moreover, they were concerned with the shifts that occur as a result of family composition, especially when coping with a terminal diagnosis. They also expressed the desire to learn specific information about the various Hispanic groups and their beliefs about death, which could facilitate discussion when making a hospice referral.

CONCLUSION

Hispanics are the fastest growing segment of the population of the United States (US Census, 2000.) Therefore, accurate data and evidence-based research directed at improving care for Hispanics who are seriously ill are vital in order to address the range of their health care needs. This rapid growth among the Hispanic community highlights the urgent need to address future planning regarding palliative health care choices.

The responses from the physicians reveal that end-of-life discourses do occur between terminally ill Hispanic patients and their family members regarding hospice referrals. The results highlight that cultural factors impact the dialogue between

the physicians, patients, and their families (Berzoff et al., 2008). Organizational barriers that impede the referral process were also identified by the physicians and they made practical recommendations. The findings also address the need for education and training opportunities for physicians about health beliefs and decision-making processes among Hispanics. The findings in the study indicate that hospice referrals and health care decisions among Hispanics are intertwined within the context of the physicians, patients, and their families. Therefore, professional caregivers, family members, and people who are terminally ill must be considered integral collaborative members of the cancer care team (Juarez et al., 2001).

This study draws attention to communication within a multicultural society when addressing terminal illness. Therefore, as stated by many experts, further research regarding decision-making is critical in order to systematically study regional differences in the attitudes and beliefs regarding communication at the end of life with dignity (Chochinov et al., 2002).

These factors are essential in order to successfully deliver end-of-life care to individuals and families in our diverse societies. Identifying the obstacles in communication regarding a terminal diagnosis is central in accessing palliative care treatment. Therefore, knowing more about how families impact palliative care decision-making will contribute to our understanding of the factors related to the use of palliative care by people of Hispanic origin. The knowledge gained from this exploratory study will facilitate an increased awareness among physicians regarding communication of palliative care options to Hispanic terminally ill patients and their families.

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