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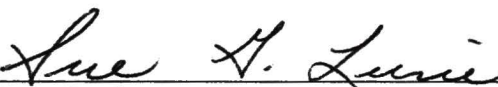
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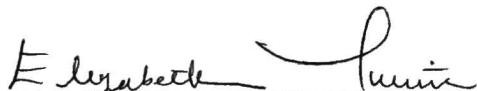
Aspects of communication between caregivers and patients/families are noted consistently in the literature as important to perceptions of quality of care at the end of life (EOL). Healthcare interpreters, along with providers, can be “deliverers of bad news.” EOL encounters create challenging and unique role and performance demands for interpreters; as active participants in these conversations, interpreters intervene in various ways that impact the communication process. While they may view providers as having the central role in an encounter, aspects of their performance suggest the pivotal nature of their own participation. This exploratory, qualitative research aimed to understand and represent interpreters’ perceptions of the EOL communication they facilitate when providers and pediatric patients and families don’t share language or culture. Their perspectives were revealed in their stories of EOL encounters, as they recounted personal reactions to specific circumstances and conversation exchanges as well as how they handled interpretation in particular situations.

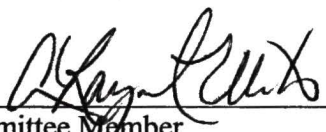
INTERPRETER NARRATIVES: END-OF LIFE CONVERSATIONS  
IN A PEDIATRIC HOSPITAL:

Corinne Neitzke Warren, BA

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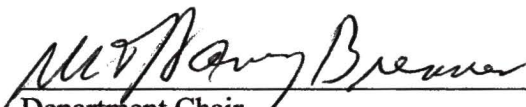
  
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INTERPRETER NARRATIVES: END-OF-LIFE CONVERSATIONS  
IN A PEDIATRIC HOSPITAL

THESIS

Presented to the School of Public Health

University of North Texas  
Health Science Center at Fort Worth

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By

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Fort Worth, Texas

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## CHAPTER 1

### INTRODUCTION

A growing body of research is addressing the quality of end-of-life care, and some of the expansion of this literature is focusing on pediatric palliative and end-of-life care. Although not exhaustively, the perspectives of patients, families, physicians, nurses and other hospital staff have been explored in order to identify characteristics of high quality end-of-life care and factors which impact it. Various aspects of communication between caregivers and the patient and/or family are noted consistently in the literature as important during this challenging period of care. Also cited as important and relevant to the communication process is the particular need for providers to take into account ethnocultural differences in situations where the patient and provider do not share language or culture. This research aimed to understand and represent health care interpreters' perspectives on the communication they facilitate between English-speaking providers and limited or non-English-speaking pediatric patients and/or their families during end-of-life conversations.

#### A "Qualitative Difference"

In its draft Report of the Children & Adolescents Task Force of the Ad Hoc Committee on End-of-Life Issues, the American Psychological Association (APA, 2005) (APA) writes that "end-of-life care and the death of a child is qualitatively different from the death of an adult—both for the families and for caregivers" (p. 7). The report notes that "the process of grieving and bereavement in cases involving children is more difficult for families, in part, because the anticipated milestones of life will now never be

achieved (e.g., graduating from high school, going off to college, marrying, etc.)” (p.37).

For parents

their traditional roles to protect their children and provide for them, are ultimately unfulfilled when a child dies. In addition to bereavement from the loss, there can be a deep sense of grief over the potential for what might have been. Parents may also experience guilt about what has or hasn't been done during life and question how they might have prevented the death, assume responsibility for the genetic transmission of certain diseases, or second guess various treatment decisions along the way. One must recognize the degree of anguish in these situations—for the patient, for family members, and for care providers. (p. 3)

The APA draft report (2005) acknowledges providers' sense of loss, writing that “the death of a child can be an especially difficult experience for pediatric caregivers because it is so rare that young patients die” (p. 3). In 2002, for example, the number of deaths for children and adolescents from birth through 19 years of age was 53,854, representing only 2.2% of the 2.4 million deaths in the United States that year (NCHS, Table 4). Buckman (1992) writes that facing terminal illness in children may be difficult for providers also because it may raise the “sense of therapeutic failure” (p. 21). In his discussion of why communicating bad news to patients (or families) is difficult, Buckman notes that “over the past few decades, the medical profession has entered into a reciprocating relationship with the general public that has fostered the illusion that all diseases are fixable” (p. 21). He notes that physicians in training “are taught (appropriately) to deal with the myriad of reversible or treatable conditions,” (p. 21) but adds that “the curriculum is so full of these conditions that there is virtually no teaching on the subject of therapeutic impotence. What do you do when you cannot reverse the disease?” (p. 21). Other researchers have identified other reasons why

physicians may find this communication difficult, which are presented in the Literature Review for this thesis.

### Language, Culture

This thesis is a study of end-of-life conversations in a pediatric hospital that take place through interpreters. The research plan, described in detail below, called for conducting focus groups or individual interviews with staff interpreters at Children's Medical Center in Dallas, TX (CMCD). While communication issues relating to language difference may appear to be the focal theme of this research, in actuality, the larger field of engagement may be cultural difference. Indeed, Kreuter and McClure (2004), citing the work of Rogler, Malgady, Constantino and Blumenthal (1987) write that "because language is fundamental to effective communication, linguistic accessibility has been termed 'the lowest common denominator of cultural sensitivity'" (p.446). Writing on cultural issues at the end of life, Kagawa-Singer and Blackhall (2001) note that "although each individual has a perspective that is influenced by many factors such as personal psychology, gender, and life experiences, culture fundamentally shapes the way people make meaning out of illness, suffering and dying, and therefore also influences how they make use of medical services at the end of life" (p. 2994).

### The Meaning of a Child's Death

If the death of a child is "qualitatively different" (APA, 2005) from the death of an adult, a question posed by Koenig and Davies (2003) in their background paper on cultural dimensions of care prepared for the Institute of Medicine's (IOM) 2003 report titled *When Children Die: Improving Palliative and End-of-Life Care for Children and*

Their Families (Field & Behrman, 2003) is relevant: “What is the meaning and significance of the loss of an infant or child?” (p. 509). They write that in the United States

a key cultural feature of our efforts to improve the care of dying children . . . is a profound yet generally unspoken background assumption: we believe that death in childhood is “unnatural” and unthinkable, that morally it should or ought to be controllable. Because death in childhood is an unspeakable tragedy, almost an obscenity, we devote nearly unlimited resources to preventing it. (p. 511)

Koenig and Davies write, however, that the death of a child may be experienced differently in other societies. This theme is presented in more detail in the literature review for this thesis (Chapter 2).

#### Issues of Care

With regard to issues of care, the APA Task Force (APA, 2005) notes that “although there are many similarities in palliative end-of-life (EOL) care for children and adults, children are not simply small adults and their care presents a number of unique issues” (p.6). Similarly, the IOM report (Field & Behrman, 2003) states that “care for children necessarily differs from care for adults, reflecting children’s developing physiological, psychological, and cognitive characteristics and their legal, ethic, and social status” (p. 21). Meyer and colleagues (2006), citing other investigators, write that “despite recognition that children have significantly different causes of death and special developmental considerations, the unique palliative care needs of dying children and their families have received less empirical inquiry” (p. 650) than adults.

## Quality End-of-Life Care

The literature review that follows includes citations for the work of numerous researchers who sought to identify characteristics of high quality end-of-life care from a variety of perspectives including (adult) patients, family members, physicians, nurses, and non-medical hospital staff. This work has consistently reported that the quality of communication is an important factor in perceptions of the quality of care. Perspectives that are underrepresented in the current end-of-life literature include health care interpreters, as well as the patients and families and the care providers who use them during this period of care. This researcher has not located any existing research on pediatric end-of-life care in the context of language and cultural differences mediated by interpreters. This research serves as one of the earliest explorations of communication issues as they relate to the roles and perceptions of health care interpreters working in pediatric end-of-life care in a hospital setting.

### Purpose of the Study

As previously mentioned, the purpose of this study was to understand and represent health care interpreters' perspectives on the communication they facilitate between English-speaking providers and limited or non-English-speaking pediatric patients and/or their families during end-of-life conversations.

Citing numerous researchers, the previously-mentioned IOM document (Field & Behrman, 2003) states that "most literature on communicating bad news takes the perspective of those who must deliver the news" (p. 115). The focus has been on

providers as deliverers of bad news. Yet health care interpreters too may be considered deliverers of bad news, and as Hwa-Froelich and Westby (2003) write, “research on interpreters and interpretation covers many topics, but few investigators have considered the interpreter’s perspective and how it may influence the interpretation process” (p. 78). They note that “the perspective of the interpreter and the varied roles he or she may play adds to the complexity of the interpreting interaction” (p. 82).

Bolden (2000) has described interpretation as

a complex activity that cannot be understood as the straight forward rendering of other people’s talk in another language. Interpreters’ actions are shaped not only by other people’s talk, but also by their own independent analysis of the ongoing activity and the specific requirements it poses for the participants.” (p.415)

The premise that interpreters are “visible,” that “the interpreter’s role goes beyond the role of language switcher,” and that the interpreter “expands beyond the ‘transparent language boom box’ to the ‘opaque co-participant’ and exercises agency within the interaction” (Angelelli, 2003b, p. 13) is the basis for valuing the interpreter’s perspective in this research.

### Research Questions

The three research questions explored in this qualitative study were: (1) For interpreters, does/how does the interpretation of end-of-life conversations (in the pediatric hospital setting) qualitatively differ from interpretation of non-end-of-life conversations? (2) How do interpreters describe their personal experiences of interpreting end-of-life conversations involving patients who are children and/or their

families? (3) Do interpreters perceive themselves to have a role that impacts on the quality of end-of-life care for terminally ill children and their families?

### Delimitations

This research was conducted at one institution, Children's Medical Center Dallas (CMCD), Dallas County, Texas, and included staff interpreters employed full or part time by the Translation Services Department at CMCD. Neither contracted interpreters working physically in the medical center, nor telephonic interpreters working for a contracting organization from a remote site were included. All staff interpreters employed by CMCD work in the English-Spanish language combination, and prospective participants were required to have experience interpreting at least one end-of-life encounter during their employment at CMCD.

### Limitations

A number of limitations apply to this study. First, this research was conducted specifically in the context of an urban pediatric medical center located in the Southwestern United States, which may limit the ability to generalize findings to other settings. In addition, because all interpreter informants were from one medical center, they may have been biased toward possible institutional guidelines or requirements in the performance of their interpretation duties (Davidson, 2000). Second, the interpreters who participated in the study were self-nominated, and their views may not be representative of the interpreters at this institution who did not participate. In addition, as reported in more detail in the Results (Chapter 4), it should be noted that participant characteristics differed in the following ways from the total interpreting staff in the medical center: the

ratio of female to male interpreters; the ratio of interpreters working scheduled work shifts versus “as needed” (“PRN”) work shifts; and the ratio of interpreters who work in assigned locations versus those who provide “at large” coverage throughout the hospital. Also of note, contracted interpreters, (working in person or telephonically) were not represented in the study. Third, while 42% of the interpreting staff at CMCD participated in the research (17 of 41 interpreters), the narratives that appear in the Results (Chapter 4) represent the perceptions of a relatively small number of subjects. Fourth, while the focus group was chosen as the primary, preferred research technique for collecting data, ultimately only 11 interpreters participated in one of two focus groups (one group with 6 participants and a second group with 5 participants), and 6 interpreters participated in the study through individual interviews. This mix of data collection techniques was required in order to maximize recruitment, which was difficult to accomplish due to interpreter work schedules. Focus group data, generated through group interaction, and interview data, generated via a one-on-one interaction between the participant and the researcher, are derived differently and therefore may represent different thought and interaction processes. Fifth, the research was limited to interpreters working with Spanish-speaking patients and/or families from multiple cultures which share this language, and English-speaking care givers (whether or not English was the native language of the care giver). Because language is only one component of culture, it cannot be assumed that all Spanish speakers have other cultural characteristics in common. Also, the results may not be applicable to interpreters who work with providers and patients and/or families in other language combinations and ethnocultural backgrounds. Finally, it should be

acknowledged that the analysis of qualitative data has the potential to be influenced by the “identity of the researcher” (Meyer, Ritholz, Burns, & Truog, 2006, p. 655).

### Assumptions

As previously noted, the theme of communication appears routinely in the growing body of literature on end-of-life care. It has often focused on patient-provider interaction in specific contexts such as the breaking of bad news, or the need for information exchange leading to decision-making of various types at various stages of illness. The present study took the broad perspective that “for many patients . . . making decisions about medical care in the context of a terminal or life-threatening illness is a prolonged process, and receiving bad news and discussing advance directives are only small parts” (Wenrich et al., 2001, p. 868). Wenrich and colleagues add that “few studies have examined the entire spectrum of communication between physicians and dying patients from diagnosis to death” (p. 868). Similarly, the previously mentioned Institute of Medicine report notes that “communicating about diagnosis and prognosis is usually not a one time event but a continuing process as care goals and plans are considered and reconsidered and new information becomes available” (Field & Behrman, 2003, p. 118).

In addition, this study recognizes that end-of-life conversations may involve other care givers in addition to physicians, such as nurses, child life specialists, pastoral care representatives, and social workers, each of whom “have distinct contributions to make in the care of pediatric patients and families” (APA, 2005, p. 7). In a similar vein, Contro’s research team (2004) wrote that

it is our belief that many different disciplines play significant roles in the care of children with incurable illnesses . . . . Many staff members in many disciplines, such as unit clerks, respiratory therapists, social workers, chaplains and others, often have frequent contact with the population, making their interactions quite important in overall care.” (p. 1251)

While the above statements describe the anticipated context going into the research, participating interpreters were asked to speak about how they define end-of-life conversations as well as with whom they interact during those encounters.

### Definition of Terms

*Cross-cultural communication; intercultural communication.* Gudykunst (2000) writes that although these two terms are frequently used interchangeably, the meanings differ. He states that

cross-cultural research involves comparing behaviour in two or more cultures (e.g. comparing self-disclosure in Japan, the USA, and Iran when individuals interact with members of their own culture). Intercultural research involves examining behaviour when members of two or more cultures interact (e.g. examining self-disclosure when Japanese and Iranians communicate with each other). (p. 314)

Not all authors make this distinction in their published research, therefore, when the thesis refers to the work of a particular author, the terminology used in the author’s original publication was used.

*Cultural competence.* This is a term widely used in the literature for which “no single definition . . . . is yet universally accepted, either in practice or in health professions education” (U.S. Department of Health and Human Services, n.d.). The Bureau of Health Professions of the Health Resources and Services Administration states that “most have a common element, which requires the adjustment or recognition of

one's own culture in order to understand the culture of a patient. Neither is there consensus about how best to provide the necessary knowledge, skills, experience, and attitudes to effectively serve diverse populations" (U.S. Department of Health and Human Services, n.d.). Other terms that appear in the literature and have their constituents include culturally sensitive, culturally appropriate, and culturally flexible. The literature review for this thesis (Chapter 2) cites the definition that appears below for the concept of culturally effective care used by the American Academy of Pediatrics (1999). The literature review also discusses alternative points of view to this terminology.

the delivery of care within the context of appropriate physician knowledge, understanding, and appreciation of cultural distinctions. Such understanding should take into account the beliefs, values, actions, customs, and unique health care needs of distinct population groups. Providers will thus enhance interpersonal and communication skills, thereby strengthening the physician-patient relationship and maximizing the health status of patients. (p. 167)

*Culture.* There are many definitions of culture in the literature. The literature review for this thesis cites the definition preferred by Koenig and Davies (2003) who quote from Barnes et al. (2000): " 'the conscious and unconscious structures of communal life that frame perceptions, guide decisions, and inform actions. It is the web of meaning in which each person lives'" (p. 523).

*End-of life care.* The Institute of Medicine's report titled When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families (Field & Behrman, 2003) states that "*end-of-life care* focuses on preparing for an anticipated death . . . . and managing the end stage of a fatal medical condition" (p. 2; italics appear in the

original). It should be noted that not all authors who use this term, including many of those cited in this thesis, provide a specific definition in the text of their published article.

*Ethnocultural.* The literature review for this thesis notes that Koenig and Davies (2003) use the term “ ‘ethnocultural’ difference to refer to patterns of values, beliefs, and attitudes found among individual who share a common language and may claim the same ancestry, religion, folk or dietary practices, or general world view” (p. 523).

*Hispanic/Latino.* The terms “Hispanic” and “Latino” appear to be used interchangeably in the literature. This thesis has used them interchangeably based on the use of both terms by the United States Census Bureau (U.S. Census Bureau, 2000), and the findings of the 2002 National Survey of Latinos (Pew Hispanic Center/Kaiser Family Foundation, 2002).

In 1997, the Census Bureau standards for federal data on race and ethnicity were revised, and by January 1, 2003, all censuses and surveys were expected to be in compliance. Six racial categories were designated, and respondents are permitted to self-identify with more than one of the following categories: American Indian or Alaska Native; Black or African American; Native Hawaiian or Other Pacific Islander; White; and Some Other Race (U.S. Census Bureau, 2000). The Census Bureau has formulated its ethnicity classifications as “Hispanic or Latino” and “Not Hispanic or Latino” and states that “Hispanics and Latinos may be of any race” (U.S. Census Bureau, 2000). The Census Bureau takes care to note that “the federal government treats Hispanic origin and race as separate and distinct concepts” (U.S. Census Bureau, 2006b) and that “Hispanics

are asked to indicate their origin in the question on Hispanic origin, not in the question on race” (U.S. Census Bureau, 2000).

The terms “Hispanic” and “Latino” are used interchangeably in the previously mentioned 2002 National Survey of Latinos (Pew Hispanic Center/Kaiser Family Foundation, 2002). When survey participants were asked whether they prefer one term over the other, 53% indicated they did not have a preference; 34% preferred the term “Hispanic;” and 13% preferred the term “Latino.” Relating to the topic of culture, the survey indicated that 85% of respondents believe that Hispanics from different countries “all have separate and distinct cultures,” while 14% believe they “share one Hispanic/Latino culture.” In addition, 49% believe that “Hispanics from different countries are not working together politically,” while 43% believe they are “working together to achieve common political goals.”

*Interpretation, consecutive.* The California Healthcare Interpreters Association (2002), citing Green (1995), define this activity as “the ***mode*** of interpreting whereby the interpreter relays a message in a sequential manner after the speaker has paused or completed a thought. In other words, the interpreter waits until the speaker has finished the ***utterance*** before rendering it in the other language” (p. 67; bold, italics appear in the original text).

*Interpretation, simultaneous.* The California Healthcare Interpreters Association (2002), citing a definition used by the National Council on Interpreting in Health Care, define this activity as “converting a speaker’s or signer’s message into another language while the speaker or signer continues to speak or sign” (p. 75).

*Interpretation; Translation.* The literature review for this thesis cites Valdés and Angelelli (2003) for their explication of these terms:

interpreting and translation are defined by members of the translation and interpreting profession as the rendering of one message produced in one language (the source language) into another (the target language). The term *interpreting*, however, is used professionally to refer only to ‘spoken’ or ‘oral’ messages communicated by speakers, while the term *translation* is used to refer exclusively to the rendering of written texts. (p. 59; italics appear in the original text)

It should be noted that while the researcher has used these terms in this context, not all authors in the literature observe this distinction. Therefore, when the thesis text is referring to the work of a particular author, the terminology used by that writer has been used. In addition, some of the interpreters who participated in this research did not always observe this distinction.

*Palliative care.* The Institute of Medicine’s report titled When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families (Field & Behrman, 2003) states that

viewed broadly, *palliative care* seeks to prevent or relieve the physical and emotional distress produced by a life-threatening medical condition or its treatment, to help patients with such conditions and their families live as normally as possible, and to provide them with timely and accurate information and support in decisionmaking. Such care and assistance is not limited to people thought to be dying and can be provided concurrently with curative or life-prolonging treatments. (p. 2; italics appear in the original)

In addition, this report notes that

traditional views of patient management have often referred to a “switch” from curative (or life-prolonging) care to palliative care. This phrasing suggests that the two are separate worlds—even mutually exclusive—with an abrupt transition in patient care from one to the other . . . an alternative perspective proposes that providing some elements of palliative care closer to the time of diagnosis than

happens traditionally may benefit patients and families and may coexist with and support active curative or life-prolonging treatment.” (p. 85)

It should be noted that not all authors who use this term, including many of those cited in this thesis, provide a specific definition in the text of their published article.

### Importance of the Study

This research stands to make a contribution to the current knowledge base in several ways: the investigation is relevant and timely given the current demographics in the state of Texas and the changing demographics in the United States population; the roles and performance of interpreters merit increased attention as their potential impact on communication is increasingly understood; awareness of the concepts of communicative competence may result in practical application in health care settings, particularly those involving intercultural communication; a broader and deeper understanding of how culture influences both illness and health care is necessary in an increasingly multi-cultural society; the focus on pediatric end-of-life communication will extend the work of previous research on interpreters and end-of-life care.

### *Growing Population Diversity*

#### *United States*

The United States Census Bureau released the following population estimates for 2005: about one third of the nation’s population belongs to a minority group, and Hispanics continue to be the largest of those groups; of the total estimated population of 296.4 million in 2005, Hispanics, at 42.7 million, represented 14.4% of the total; the Hispanic population grew by 3.3% from July 1, 2004 to July 1, 2005, making it the

fastest growing minority group; in the one-year period July 1, 2004 to July 1, 2005, 49% of the nation's population growth was attributed to Hispanics; compared to the national population overall, the 2005 Hispanic population was younger, with a median age of 27.2 years, versus a national median of 36.2 years; the proportion of the Hispanic population that was under age 18 was approximately one-third (at nearly 14.5 million), while the proportion of those under age 18 nationally was about one-fourth (at nearly 73.5 million); of the 73.5 million children under age 18 nationally, 19.7% were Hispanic (U.S. Census Bureau, 2006b). Based on the U.S. Census Bureau's 2005 American Community Survey (U.S. Census Bureau, 2006c), persons of Mexican origin comprised 64% of the Hispanic population in the United States.

According to the report *America's Children: Key Indicators of Well-Being 2006* (Federal Interagency Forum on Child and Family Statistics, a), 21% of children under age 18 in the United States in 2005 had at least one foreign-born parent; in 2004, 19% of children ages 5-17 spoke a language other than English at home; in 2004, 5% of children ages 5-17 spoke a language other than English at home and had difficulty speaking English. As reported in the document *Health, United States, 2005* (NCHSb, p.133) the fertility rate in 2003 for Hispanic women ages 15-44 years was 96.9 per 1,000, 66% higher than the fertility rate for non-Hispanic white women, for whom the rate was 58.5 per 1,000.

#### *State of Texas*

Based on the U.S. Census Bureau's 2005 American Community Survey (U.S. Census Bureau, 2006d), the state of Texas population estimates include the following: a

total population of nearly 22.3 million; 28.3% of state residents were under the age of 18; persons of Hispanic or Latino origin represented 35.5% of the state's population; 15.9% of residents were foreign-born; 33.6% of residents age five and over spoke a language other than English at home. Based on 2004 population data, the U.S. Census Bureau (U.S. Census Bureau, April 5, 2006) estimated that the number of people of Mexican origin residing in the state of Texas was 6.5 million, representing approximately one-third of the total state population for that year.

#### *Dallas County, Texas*

For Dallas County, Texas, population estimates, based on the U.S. Census Bureau's 2005 American Community Survey (U.S. Census Bureau, 2006a), include the following: an estimated total population of 2.3 million; 28.9% of the county's population was under 18 years of age; residents of Hispanic or Latino origin comprised 36.8% of the population; 24.6% of county residents were foreign-born; 39.4% of the population age five and above spoke a language other than English at home.

#### *A Focused Literature Review, Context for Analysis*

Preparation of the literature review for this thesis was guided by several specific objectives: (1) to provide a more detailed profile of interpreter roles and performance than normally appears in the medical literature (as compared to the communication or linguistics literature) (2) to highlight concepts of communicative competence, particularly from the perspective of selected references from the communication and linguistics literature (3) to prepare a context for the analysis of the research findings

through a less “naive” (Koenig & Davies, 2003) view of ethnocultural differences and how they may be considered in both communication and care processes at the end of life.

It is anticipated that as health care providers become aware of how interpreter roles and performance can be “consequential” (Angelelli, 2003b, p.24), they will recognize that interpreters can provide a care perspective important to hear. In addition, Hudelson (2005) writes that medical interpreters “represent an untapped source of insight into common communication problems” and that their insights “can contribute to strengthening physicians’ cross cultural communication skills” (p.311). With this recognition, it is hoped that the under-representation of interpreters’ views in the medical literature will be corrected. It is also anticipated that the literature review’s treatment of communicative competence, especially in the context of intercultural interactions, will increase provider sensitivity to the complexities of effective communication, particularly in end-of-life conversations. Finally, with the growth of the literature focusing on cultural “competence” (or sensitivity, or appropriateness, or flexibility, or effectiveness) in health care, it is important for providers to be knowledgeable about how culture (their own, their patients,’ and the culture of Western medicine) affects care, and to be aware that their uninformed or inappropriately applied efforts or gestures may not enhance their care of patients whose ethnocultural background is different from their own.

### *Adding to the Literature*

With its focus on a pediatric setting, this study will add to the very small body of literature that represents the interpreters’ perspective in end-of-life conversations. This study will extend in particular, the work with interpreters by Norris and colleagues

(2005) and Hudelson (2005) in a number of ways: by focusing on pediatric patients and their families; by making explicit interpreters' definitions of end-of-life conversations; by expanding the range of potential participants in these conversations beyond the focus on physicians; by exploring how interpreters' participation in end-of-life conversations may be a qualitatively different experience for them than when they perform interpretation of non-end-of-life conversations; and by exploring whether/how interpreters perceive themselves to have a role that impacts on the quality of end-of-life care for terminally ill children and their families.

Finally, this research is mindful of the statement in the IOM report on palliative and end-of-life care for children (Field & Behrman, 2003): "among the most common phrases in this report are 'research is limited' and 'systematic data are not available'" (p. 17). It is anticipated that this research will add to the understanding of communication issues at the end of life for pediatric patients and/or their families and health care providers who must use interpreters to bridge language and cultural differences. Subsequently, the knowledge gained can be incorporated into the existing knowledge base pertaining to communication at the end of life, with the intent that it will ultimately be applied in the service of quality care.

## CHAPTER 2

### REVIEW OF THE LITERATURE

Ellis (2004) writes that “the role of a literature review and the influence of existing knowledge more generally is a highly contested and widely debated topic within qualitative research” (p. 91). Citing Glaser and Strauss (1967), Ellis writes that “some contend that literature should not be consulted prior to data collection and analysis for fear of bias” (p. 91). However she also notes, citing Morse (1994) and Guba and Lincoln (1994) that others “present a case for getting to know everything there is about the setting, the culture and the study topic prior to entering the field in order to avoid ‘reinventing the wheel’” (p. 91). Strauss and Corbin (1990) write that investigators

will come to the research situation with some background in the technical literature and it is important to acknowledge and use that . . . . However, there is no need to review all of the literature beforehand . . . . because if we are effective in our analysis, then new categories will emerge that neither we, nor anyone else, had thought about previously. We do not want to be so steeped in the literature as to be constrained and even stifled in terms of creative efforts by our knowledge of it. (p.50)

Still, Strauss and Corbin (1990) write that technical literature “can be used to stimulate theoretical sensitivity by providing concepts and relationships that are checked out against actual data” (p. 50). They describe theoretical sensitivity as a “personal quality of the researcher” which “indicates an awareness of the subtleties of meaning of data” (p. 41). They relate this to the previous reading, personal, and professional experience the investigator brings to the research project. They note that

though you do not want to enter the field with an entire list of concepts and relationships, some may turn up over and over again in the literature and thus appear to be significant. These you may want to bring to the field where you will look for evidence of whether or not the concepts and relationships apply to the situation that you are studying, and if so what form they take here.” (p. 50-51)

Thus, it is in the spirit of Strauss and Corbin that the following literature review for this thesis was constructed.

The initial literature searches performed in preparation for this thesis did not uncover an extensive body of published research on end-of-life communication through interpreters, particularly in the context of pediatric end-of-life care. However, literature does exist in broader subject areas related to this thesis topic such as:

- 1) quality in health care
- 2) the patient-provider relationship
- 3) cultural considerations in health care communication (many subtopics exist in the literature; one example particularly relevant to this thesis topic is the delivery of “bad news”)
- 4) end-of-life/palliative care (in general)
- 5) end-of-life/palliative care for children
- 6) interpreters in health care

With these broad subject areas in mind, an overview of selected literature appears below. It should be noted that all of the cited references are from the English-language literature; most of the studies cited, unless otherwise noted, refer to research conducted in the United States; the work of many of the cited studies or authors is from the biomedical perspective and may reflect “Western bioethics” that are “based upon

monocultural Western European-American concepts, values, and beliefs” (Kagawa-Singer and Kassim-Lakha, 2003, citing Veatch, 2000, p. 580).

### Quality in Health Care

Few would argue that quality of medical care in the United States is not a major theme of interest to the public as well as health care providers, clinical practitioners, and policy makers. With total national health expenditures for 2004 increasing 7.9% over 2003, the \$1.9 trillion spent represented 16% of gross domestic product (GDP) (Smith, Cowan, Heffler, & Catlin, 2006). While the Organisation for Economic Co-operation and Development (OECD, 2006) calculated the percentage slightly lower at 15.3%, it reported that the United States had the highest percentage of GDP, surpassing the 8.9% average for all 30 OECD countries. The OECD also reported that the United States ranked considerably ahead of other member countries in per capita health care spending at \$6,100, more than twice the OECD average of \$2,550. Questions regarding the return on this investment and the evidence base of interventions performed are being asked by many people and organizations in health care.

### *Defining and Measuring Quality*

In the Institute of Medicine’s (2006) third phase of its health care quality initiative *Crossing the Quality Chasm*, quality was defined as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.” Phase one of the initiative, begun in 1996, focused on understanding the scope of the issue and establishing a framework to define the nature of quality; phase two resulted in a series of reports that “laid out a

vision for how the health care system and related policy environment must be radically transformed in order to close the chasm between what we know to be good quality care and what actually exists in practice;” phase three is concerned with “operationalizing” the vision created in phase two (Institute of Medicine, 2006).

### *Quality in Children’s Health Care*

While the first phase of the Institute of Medicine’s quality initiative established the “serious and pervasive nature of the nation’s overall quality problem” (Institute of Medicine, 2006), Dougherty and Simpson (2004) have written that “extensive quality problems have been documented across all sectors of health services for children and adolescents” (p. 185). They write that although “quality of care is on the national agenda . . . . what continues to be in short supply are individuals and organizations that can give voice to children’s issues and concerns in the midst of broader quality debates” (p. 195).

Leatherman and McCarthy (2004) note that

a relative shortage of credible quality data on children’s health may be explained by the common method of prioritizing quality issues based on cost and prevalence. Given that children suffer from many rare conditions and their expenditures per capita are less than for adults, issues related to child and adolescent health care may be undervalued. (p. 22)

Citing the work of Forrest and colleagues (1997), Leatherman and McCarthy write that “an alternative approach would be to prioritize based on ‘services that modify health states and behaviors that predispose individuals to future morbidity and mortality’” (p. 22).

In their review of three articles commissioned by Agency for Health Care Research and Quality (for an invitational meeting in 2002 that focused on measuring the quality of children's health care), Dougherty and Simpson (2004) state that "although substantial progress has been made in the development of quality measures and the implementation of quality-improvement strategies for children's health care, interest in quality of care for children lags behind that for adult conditions and disorders" (p. 185). Specific areas where measures are lacking were identified, as well as the concern that even when available, they are not being applied on a regular basis. Mindful of the Institute of Medicine's report on palliative and end-of-life care for children (Field & Behrman, 2003), Dougherty and Simpson write that "very troubling is the complete lack of available measures for children at the end of life in the face of documented quality problems for this group of children" (p. 188).

Notwithstanding the quality issues outlined above, the Institute of Medicine report (Field & Behrman, 2003) credits the substantial reduction in childhood mortality since 1900 to "a century's worth of advances in public health, living standards, medical science and technology, and clinical practice" (p. 42).

In 2002, a total of 2.4 million deaths were reported in the United States (all ages) (NCHSa, Table 4). For the population as a whole, the five leading causes of death, in descending order, were heart disease, cancer, stroke, chronic lower respiratory diseases, and unintentional injuries (NCHSb, Figure 29). As previously mentioned, the final data for children in 2002 established the total number of deaths for children and adolescents from birth through 19 years of age at 53,854, representing approximately 2.2% of total

deaths in the United States for that year (NCHSa, Table 4). The causes of death for children by age group in 2002 included: deaths of children under one year of age are considered infant mortality, and approximately 66% of these deaths occur in the first month after birth, attributable to health problems of the infant or the pregnancy (such as prematurity or birth defects); ages 1-4 years: unintentional injuries (11 per 100,000), birth defects, homicide, and cancer (each at three per 100,000); ages 5-14 years: unintentional injuries (seven per 100,000), cancer (three per 100,000), birth defects, and homicide (each at one per 100,000); adolescents ages 15-19 years: injury (including homicide, suicide and unintentional injuries) accounted for over 75% of adolescent deaths), followed by cancer, heart disease and birth defects (Federal Interagency Forum on Child and Family Statistics, b).

Based on 2003 data: the United States infant mortality rate was 6.8 per 1,000; the mortality rate for children ages 1-4 years of age was 32 per 100,000; the mortality rate for children ages 5-14 years of age was 17 per 100,000; the mortality rate for adolescents ages 15-19 years of age was 66 per 100,000 (Federal Interagency Forum on Child and Family Statistics, a).

Meyer and colleagues (2006), referencing the work of other investigators, write that “most pediatric end-of-life care occurs in acute care hospitals, typically in critical care settings. Two thirds of deaths in the pediatric intensive care unit (PICU) follow withdrawal of life-sustaining treatment, and withdrawal of mechanical ventilation is the most proximate cause of death” (p. 650).

In a study to elicit parents' perspectives on the quality of inpatient pediatric care, Homer and colleagues (1999) administered a telephone survey, in either English or Spanish as appropriate, to 3,622 parents whose child had been discharged from a children's hospital. While not focused on end-of-life care, the purpose of the survey was to identify the most frequent problems with care, and those that had the strongest impact on parents' overall perceptions of quality of care. Citing numerous investigators, Homer and colleagues noted that "parental satisfaction with outpatient care is strongly influenced by the clinician providing clear information to the parent that addresses parental concerns and by demonstrating sensitivity to the parent's emotional needs" (p.1124). Results from that study indicated that "problems with information to parents correlate most strongly with parents' overall ratings of quality . . . followed by issues related to the partnership between the family and care providers" (p. 1125). In addition, "patients with chronic conditions, in poorer health status, of low income, minority, non-English speaking, and those not undergoing a surgical experience all rated the care lower and indicated more problems across most dimensions of care" (p. 1127). Homer and colleagues concluded that "parents seem to be reporting that their needs would be best met in programs that are family centered and that emphasize communication with and support for parents as well as for children" (p. 1128). They add that their data

reinforce the need for clinicians and institutions servicing children to recognize that there are dual patients in pediatric care—both the actual patient and the parent(s). Families play an essential role in the health of children, and excellent pediatric care must be family as well as child centered. (p. 1128)

Citing Shelton and Stepanek (1994), Homer and colleagues write that “from the perspective of the parent, in complex inpatient settings as well as in ambulatory care, clear communication addressing the parents’ concerns remains the cornerstone of good quality of care” (p. 1128).

### *Quality Care in Intercultural Medical Encounters*

In order to explore the cultural factors that influence perceptions of the quality of their medical care, Nápoles-Springer and colleagues (2005) conducted 19 focus groups with Latinos, non-Latino Whites and African-Americans, all in community settings. The authors write that data pertaining to elements of culturally competent care are lacking at the level of the medical encounter from the point of view of “ethnically and linguistically diverse consumers” (p. 5). Based on participants’ comments, the investigators concluded that “specific recommendations for physicians to enhance the quality of medical encounters can be grouped into two general areas: interpersonal style and communication” (p. 13). Citing some of the investigators who have previously addressed the issue of quality care among culturally-diverse population groups, the authors note that

much attention has been devoted to the development of cultural competence indicators as measures of quality of care due to the growing diversity of the US population and the need to eliminate health disparities. Cultural competence measures have been developed at the health plan or system level, but less work has been done to develop valid consumer-reported measures that reflect cultural competence based on the perspectives of ethnically diverse groups. Quality-of-care indicators developed by the National Committee on Quality Assurance (NCQA), the Agency for Healthcare Quality and Research (AHQR), and the Foundation for Accountability (FACCT), generally do not address cultural factors. (p. 14)

### *Quality Care at the End-of-Life*

In order to determine the factors considered important at the end of life, Steinhäuser and colleagues (2000) conducted a national survey with 1,462 seriously ill adult patients, recently-bereaved families, and physicians and other care providers involved in end-of-life care. The authors concluded that “patients, families, and care providers each play a critical role in shaping the experience at the end of life” (p. 2482). They call for additional research “to define both the common ground and areas for negotiation as participants gather to construct quality at the end of life” (p. 2482). They advise that “physicians also should recognize that there is no one definition of a good death. Quality care at the end of life is highly individual and should be achieved through a process of shared decision making and clear communication that acknowledges the values and preferences of patients and their families” (p. 2482). Thus, “efforts to evaluate and improve patients’ and families’ experiences at the end of life must account for diverse perceptions of quality” (p. 2476).

### **Patient-Provider Relationship**

As noted above, much research is currently being focused on identifying and measuring dimensions and components of quality medical care. As one line of inquiry, many investigators have explored patient satisfaction with various aspects of their care experiences. Researchers have measured, in various settings, elements of satisfaction ranging from the structural characteristics of the health system to specific aspects of the patient-provider relationship, such as interpersonal aspects of care, informational aspects

of care, the technical or medical skills and professional competence of providers, and communication skills of providers. Particularly relevant to this thesis are the aspects of communication in the patient-provider relationship.

In their review of the literature on doctor-patient communication, Ong and colleagues (1995), citing other researchers, characterize the relationship between doctor and patient as one of the most complex types of interpersonal relationships, writing that “it involves interaction between individuals in non-equal positions, is often non-voluntary, concerns issues of vital importance, is therefore emotionally laden, and requires close cooperation” (p. 903). Acknowledging the work of numerous other investigators, Woloshin and colleagues (1995) write that

the physician-patient relationship is built through communication and the effective use of language. Along with clinical reasoning, observations, and nonverbal cues, skillful use of language endows the history with its clinical power and establishes the medical interview as the clinician’s most powerful tool. Language is the means by which a physician accesses a patient’s beliefs about health and illness, creating an opportunity to address and reconcile different belief systems. Furthermore, it is through language that physicians and patients achieve an empathic connection that may be therapeutic in itself. (p. 724)

Flores (2002) notes that

the physician-patient interaction has been the cornerstone of excellence in health care and, when poor communication occurs, there is an increased risk for poor outcome. Success in communication with the physician provides the patient with a sense of having his or her health care needs understood and creates the first bridge to the healing process. When the patient speaks the same language and has the same sociocultural experiences as the physician, communication is maximized. When the physician neither speaks the same language nor has the same sociocultural experiences as the patient or his or her family, then the cornerstone of our health care system is fractured. (p. 638)

In a literature review focused on language, culture and the physician-patient relationship, Ferguson and Candib (2002) found that

race, ethnicity, and language have substantial influence on the quality of the doctor-patient relationship. Minority patients, especially those not proficient in English, are less likely to engender empathic response from physicians, establish rapport with physicians, receive sufficient information, and be encouraged to participate in medical decision making. (p. 353)

They add that “these characteristics have all been linked to patient satisfaction, patient compliance, and care outcomes in the general literature on the doctor-patient relationship” (p. 359).

### Culture in Health Care

Focusing on cultural patterning of sickness and care, Kleinman and colleagues (1978), citing the previous work of numerous investigators, write that

illness is culturally shaped in the sense that how we perceive, experience, and cope with disease is based on our explanations of sickness, explanations specific to the social positions we occupy and systems of meaning we employ. These have been shown to influence our expectations and perceptions of symptoms, the way we attach particular sickness labels to them, and the valuations and responses that flow from those labels. How we communicate about health problems, the manner in which we present our symptoms, when and where and to whom we go for care, how long we remain in care, and how we evaluate that care are all affected by cultural beliefs. Illness behavior is a normative experience governed by cultural rules: we learn “approved” ways of being ill. It is not surprising then, that there can be marked cross-cultural and historical variation in how disorders are defined and coped with. The variation may be equally great across ethnic, class, and family boundaries in our own society. And doctors’ explanations and activities, as those of their patients, are culture-specific. (p. 252)

Kagawa-Singer and Kassim-Lakha (2003) write that “most clinicians lack the information to understand how culture influences the clinical encounter and the skills to effectively bridge potential differences” (p. 577). They call for new strategies in medical

training that will help “reduce cross-cultural miscommunication and increase the likelihood of improving health outcomes” (p. 577). Writing from an anthropological perspective, these authors discuss “the fundamental relationship between culture and health” (p. 577) and present a strategy, a “culturally-based systems approach” (p. 578) they believe will help clinicians “attend to cultural differences and build the skills necessary for cross-cultural expertise” (p. 585-586). They write that

effective cross-cultural interactions require that the clinician integrate multiple cultures in the clinical encounter: his or her own culture, that of the patient/family, and the health care institution’s culture. Successful integration of these arenas constitutes cultural competency, or ethnorelative practice: that is, the ability to evaluate behavior relative to its cultural context so that the physician and patient/family are able to reach mutually desired goals of medical care. (p. 578)

### *Cultural Values and Cultural Scripts*

Spencer-Oatey (2000) writes that “different cultures may have different conventions as to what is appropriate behaviour in what contexts” (p. 1). Many authors and investigators have employed various terms to convey this concept, including “cultural values,” “cultural norms” and “cultural scripts.” Yet often, there is no clear definition provided for the terminology, and it is not clear that these terms are used in a consistent manner among writers.

In their examination of “culture as an explanatory variable,” Bond, Zegarac and Spencer-Oatey (2000) caution that

use of . . . culture-level values or dimensions is ‘appropriate when one seeks to understand how differences between *cultures* in their symbolic systems, institutions, rates and styles of behaviour and so on are related to cultural value emphases’ (Schwartz 1994: 117, emphasis added). They are not appropriate,

however, 'when one seeks to understand how differences between individual persons in beliefs, attitudes, or behaviour are related to individual differences in value priorities' (Schwartz 1994: 117). (p.54)

The authors note that "'culture' values . . . do not apply to individuals . . . We must instead use values measured at the individual level . . . This strategy avoids the 'ecological fallacy' (Hofstede 1980: 29) of shifting from one level (culture) to another level (the individual)" (p. 54).

A cultural script, according to Bond, Zegarac and Spencer-Oatey (2000), is "a set of assumptions which we draw upon in making decisions relating to a particular type of situation" (p. 62). They write that "the notion of script provides an intuitive and simple explanation of the observation that people from different cultures behave in different ways in similar situations" (p. 65). Long (2004) has investigated "cultural scripts for a good death" in the post-industrial societies of the United States and Japan. Based on her ethnographic research focusing on end-of-life decisions, Long writes that "scripts of good death are . . . parts of the larger cultures in which they exist, stories and concepts from which people choose in order to select, interpret, and justify behaviour surrounding the process of dying" (p. 914). She maintains that it is through "advocates" and "experts" such as "medical professionals, media, educators, government officials, and religious leaders" that scripts become known, but notes that they "are not the only versions of cultural scripts of dying" (p. 917). She writes of the "important gap . . . between cultural scripts and the ways that ordinary people talk about dying" (p. 926). She continues that "while experts explain and advocate particular roads to death, many of the common metaphors used by patients and caregivers express common sense

understandings of dying that remain outside of articulated scripts, and in a sense transcend them” (p. 926). She notes that

ordinary people rarely perceive that there is a single correct script to be followed. Rather, they recognise multiple answers to the existential and ethical issues at the end of life, and using cultural metaphors, draw from a number of scripts simultaneously or consecutively. (p. 914)

Based on her research, Long would “caution those who would use the explicit scripts articulated by experts as indicators of culturally specific ideas of a good death” (p. 926). She states that “in a post-industrial society, people interpret and utilise their ideas in light of their own experience and creatively recombine elements from them, contributing to the maintenance, creation, and reinterpretation of notions of the good death” (p. 926).

### *Culture and Terminology*

In a policy statement issued by the American Academy of Pediatrics (1999), culturally effective pediatric health care has been defined as

the delivery of care within the context of appropriate physician knowledge, understanding, and appreciation of cultural distinctions. Such understanding should take into account the beliefs, values, actions, customs, and unique health care needs of distinct population groups. Providers will thus enhance interpersonal and communication skills, thereby strengthening the physician-patient relationship and maximizing the health status of patients. (p. 167)

In their background paper prepared for the Institute of Medicine’s 2003 report on palliative and end-of-life care for children, Koenig and Davies (2003) join others who acknowledge that “there are no widely accepted definitions of terms such as cultural competence, cultural sensitivity, or culturally appropriate care” (p. 522). However, Koenig and Davies argue against the term “competence,” writing that

no one physician can ever be fully “competent” because it is impossible to learn by memory a full compendium of the world’s cultural practices and beliefs. The language of “competence” also suggests that all dimensions of cultural difference are encapsulated within the bounds of the patient-family-care provider relationship, ignoring social forces that inevitably impinge on the most virtuous clinician. (p. 522-23)

Citing Crawley and colleagues (2001), Koenig and Davies note their preference for “the notion of culturally ‘sensitive’ or ‘appropriate’ care, which focuses on specific skills, such as communication, rather than on mastery of cultural traits” and because it “also fosters the notion of respect for diverse beliefs, and self-reflection of one’s own cultural background (p. 523).

In addition, Koenig and Davies (2003) are precise about other use of terminology in their discussion of health care issues relating to culture. Quoting from Barnes et al. (2000), Koenig and Davies consider culture to be ““the conscious and unconscious structures of communal life that frame perceptions, guide decisions, and inform actions. It is the web of meaning in which each person lives”” (p. 523). Koenig and Davies use the term “‘ethnocultural’ difference to refer to patterns of values, beliefs, and attitudes found among individuals who share a common language and may claim the same ancestry, religion, folk or dietary practices, or general world view” (p. 523). They write that when properly used, the term “ethnicity” has a similar definition, however they maintain that “within biomedicine the term ethnicity has unfortunately been appropriated as a ‘politically correct’ replacement for race” (p. 523). Their preference for the term ethnocultural is based on their intent to focus their analysis

on the cultural domain, while at the same time avoiding an ‘essentialist’ view of cultural difference. Suggesting that ethnic culture is an essential feature of

individuals or families—rather than a complex, dynamic resource, embraced or abandoned and constantly changing—is dangerous and inaccurate. Much naïve work in cultural competence education seems to suggest that culture predicts behavior in a straightforward way. This approach is inherently reductionistic and risks stereotyping individuals and families. (p. 523)

Similarly, Kreuter and McClure (2004) state that the types of population characteristics collected during public health surveillance and epidemiological tracking such as “age, race, sex, geographic boundaries” are able to “provide at best only a crude proxy for culture and other shared values, beliefs, experiences, and living conditions of a group,” and that “population groups defined only by broad racial/ethnic categories have been shown to include many distinct subgroups” (p. 441). They note that in public health practice and research “culture is commonly conflated with race and ethnicity, especially for nonmajority populations” (p. 440). Kreuter and McClure cite the recommendations of health communication and health promotion planners who advocate an approach which calls for identifying subgroups and then understanding “that which is shared by members of the group and may influence health” (p. 441). Kreuter and McClure note that the “conceiving of culture as a categorization variable that is relatively simple and fixed, rather than a complex, dynamic, and adaptive system of meaning” (p. 440) is limiting. Indeed, as Orr (1996) writes, “many components are included in an individual’s cultural makeup: race, language, dialect, geographic origin, migratory pattern, religion, employment pattern, history, art, literature, folklore, proverbs, music, food, customs, symbols, family structure, relationships, sexual dominance and others” (p. 2004).

### *Culture and End-of-Life*

Crawley and colleagues (2002), writing on “strategies for culturally effective end-of-life care” (p. 673) note that “community and cultural ties provide a source of great comfort as patients and families prepare for death” (p. 673). They advise that “physicians should assess the cultural background of each patient and inquire about values that may affect care at the end of life” (p. 673).

Kagawa-Singer and Blackhall (2001), in a case study presentation and discussion of cultural issues relevant to health care at the end of life, write that “encounters between patients and physicians of dissimilar ethnicities are becoming more common, yet the literature in end-of-life care has only recently begun to investigate the influence of cultural differences on the clinical encounter” (p. 2994). They note that “studies have shown cultural differences in attitudes toward truth telling, life-prolonging technology, and decision-making styles at the end of life” (p. 2993). In their discussion of truth-telling, citing some of their own previously published work, they state that “although informed consent is a major tenet of US health care, truth telling about diagnosis, and especially about the prognosis of potentially fatal illnesses like cancer, is not the norm in much of the world” (p. 2997). They note that this issue

is more complex than simply whether or not to tell the truth. It also includes the problem of how to tell and to whom. Even a patient who does not want direct disclosure may wish to know the truth through other means: indirectly, euphemistically, ‘delicately’ . . . or nonverbally. (p. 2997)

Kagawa-Singer and Blackhall (2001) identified “communication/language barriers” (p. 2995) as an important issue that is influenced by culture in end-of-life care. They note that ignoring this issue may result in “bidirectional misunderstanding” and “unnecessary physical, emotional, and spiritual suffering” (p. 2995). Citing other researchers, they caution that “misperceptions caused by lack of cultural sensitivity and skills can lead to unwanted or inappropriate clinical outcomes and poor interaction with patients and their families at critical junctures as life comes to a close” (p. 2994).

Krakauer and colleagues (2002) have written on the institutional, cultural, and individual barriers to quality end-of-life care for minority patients. They contend that “although major efforts have been undertaken in the past decade to improve end-of-life care, there is growing evidence that improvements are not reaching those at especially high risk for inadequate end-of-life care: minority patients” (p. 182). Citing the work of numerous other investigators, Krakauer and colleagues note that

physicians’ attitudes toward end-of-life care vary significantly along religious and cultural lines. In addition, modern medicine itself is a culture, and medical education an acculturation process that helps determine physicians’ attitudes. Thus, the process of dying, perhaps more than any other moment in the course of medical care, can accentuate cultural differences between patients, families, and providers. (p. 184)

As previously mentioned, Koenig and Davies (2003) note that death in childhood, in the United States, is perceived as “an unspeakable tragedy” (p. 511). However, citing the work of Scheper-Hughes (1992) in Brazil and Barnes et al. (2000), Koenig and Davies write that

the question of whether the loss of a child is experienced in a fundamentally different way in societies with different values or significantly higher childhood

death rates is of more than academic interest. Clearly if a family bears eight children and only expects two to survive to adulthood, the experience of death will not mirror that of a United States middle class family whose only child dies, although feelings of grief and loss will be as deeply felt, albeit differently expressed. In resource-poor environments it may not be possible to devote significant means—emotional or financial—to stave off a child's death, even one that is theoretically preventable. One might argue that the U.S. focus on child death as a tragedy is in some ways a feature of affluence. Unlike many countries today and unlike most periods of human history, we have the privilege to focus on extending the lives of children with chronic, life-threatening conditions. Significantly, immigrants to the United States may have markedly different expectations about child death shaped by the experience of severe poverty, health care systems marked by inequality, and war or other catastrophes. (p. 510-511)

In addition Koenig and Davies write that

when cultural gaps between families and health care providers are profound—accentuated by language barriers and varied experience shaped by social class—negotiating the difficult transitions on the path to a child's death, always a daunting challenge, becomes even more difficult. All domains of end-of-life care are shaped by culture, including the meaning ascribed to illness, the actual language used to discuss sickness and death (including whether death may be openly acknowledged), the symbolic value placed on a child's life (and death), the lived experience of pain and suffering, the appropriate expression of pain, the styles and background assumptions about family decision making, the correct role for a healer to assume, the care of the body after death, and appropriate expressions of grief. (p. 510)

## Communication in Health Care

### *Communicative Competence*

#### *In Intercultural Communication*

In *The Ethnography of Communication*, Saville-Troike (2003), writes that communicative competence

involves knowing not only the language code but also what to say to whom, and how to say it appropriately in any given situation . . . communicative competence extends to both knowledge and expectation of who may or may not

speaking in certain settings, when to speak and when to remain silent, to whom one may speak, how one may talk to person of different statuses and roles, what nonverbal behaviors are appropriate in various contexts, what the routines for turn-taking are in conversation, how to ask for and give information, how to request, how to offer or decline assistance or cooperation, how to give commands, how to enforce discipline, and the like—in short, everything involving the use of language and other communicative modalities in particular social settings. (p. 18)

Saville-Troike states that “cross-cultural communication is defined by interaction . . .

between participants who have significantly different linguistic and cultural

backgrounds” (p. 168), and that “clear cross-cultural differences can and do produce

conflicts or inhibit communication” (p.18). She maintains that “the concept of

communicative competence must be embedded in the notion of cultural competence, or

the total set of knowledge and skills which speakers bring into a situation” (p.18).

### *In Medicine*

Skelton, Kai and Loudon (2001), citing the work of numerous investigators as

they write on cultural issues in medical communication, observe that

our understanding of medical communication across cultures, or beyond the culture of the western, industrialized world, remains slight . . . of the huge amount of work that has been undertaken in the last 25 years on medical communication almost nothing has been concerned with cross-cultural issues. Perhaps the only thing we do know is that patients across cultures believe that ‘good communication’ (however defined) is an important feature of successful doctor-patient encounters. (p. 257)

In their discussion of interpersonal relationships between patients and providers, Skelton

and colleagues believe that

there is a western presumption that patient-centered medicine—essentially a construct of western research—is ‘good.’ And moreover, that it is realized through the kind of surface behaviour which forms the stock-in-trade of the communication skills teacher (ask open questions, negotiate management, and so on). Perhaps the primacy of both the patient-centered paradigm and the interest in

surface behaviour need to be challenged if we are to promote more effective communication for other cross-cultural contexts. (p. 258)

Skelton and colleagues note that

different cultures conduct professional relationships differently. The concept of power, for example, is one area of difference; and the concept of politeness is another. As far as the former is concerned, the distribution of power and the extent to which consultations in different cultures are both patient-centered and successful, may vary widely. (p. 258)

### *In the Delivery of Bad News*

In the Institute of Medicine's report on improving palliative and end-of-life care for children (Field & Behrman, 2003) the authors describe the difficult circumstances physicians may face when they inform families of bad news. They write that

physicians usually will have the difficult task of telling parents what they cannot bear to hear—that their child's life is in jeopardy or that their child has died. Sometimes, as in the emergency department, physicians will be informing people they have never met before. Likewise, with a dying newborn, the neonatologist and the family may be strangers. At other times . . . when tests show that a child's cancer has returned, physicians will be informing families they have known for the months or years of the child's illness. In some instance, the news of a child's death may come from an inexperienced resident who happens to be on duty in the intensive care unit but who has had no relationship with the family. (p. 113)

As noted previously, numerous reasons why physicians may find the delivery of bad news to be difficult have been identified. Wenrich and colleagues (2001), citing other researchers, note "issues around fear of dying" (themselves) and "psychological traits in some physicians that may lead to a need to overcome death" (p. 873). Based on their own work on communication at the end of life, Wenrich's research team proposes two other reasons: "physicians must strive to achieve a delicate balance between providing honest information and doing so in a sensitive way that does not discourage

hope” (p. 973), and physicians “may be trained or used to thinking of giving bad news as a 1-time event” (p. 873), despite the fact that they “often must give their patients a spectrum of bad news that begins with the initial terminal diagnosis and continues through the eventuality of failed treatments, physical decline, and ultimately, death” (p. 873). Gillotti and colleagues (2002), also citing the work of other researchers, note possible difficulties in delivering bad news relating to “medical disclosure,” such as “patient autonomy and patient rights;” “uncertainty of prognosis;” the potential for “expressions of emotion;” and “socialization to a detached style of interaction” (p. 1013).

In the context of the previously-mentioned concept of communicative competence, Gillotti, Thompson and McNeilis (2002) note that this concept has served as a framework in which to study provider-patient interaction. They write that “research on communicative competence argues that some communicative behaviors are more effective in terms of meeting goals than are other behaviors, and that context determines the behaviors that are most appropriate and effective” (p. 1012). Citing previously reported research, Gillotti and colleagues indicate that situations requiring the delivery of bad news are “particularly troubling for both patients and health care providers” (p. 1012). Referring to Buckman in his oft-cited 1992 book titled *How to Break Bad News*, they write that

bad news is typically defined as information that ‘negatively alters’ the patient’s perspective of his or her future. The interaction still involves information giving and seeking, as do most medical consultations, but the emotional component and subsequent patient retention are different than other medical interactions.  
(p. 1013)

In their own research, Gillotti and colleagues (2002) applied a “communicative competence framework to the bad news delivery context in an attempt to ascertain those communicative behaviors that are associated with more vs. less competent bad news delivery” (p. 1012). The authors drew some “tentative conclusions” about the “relations between specific communicative behaviors and perceptions of competence during the process of delivering of bad news” (p. 1020). They note that it is important for providers “to know that the requirements of delivering bad news differ from those of other medical interactions” (p. 1020). They indicate that “it may be less important to communicate large amounts of information or attempt to verify information than would normally be the case in health care interaction” (p. 1020) and that “health care providers may be well advised to focus little of their communication on information seeking, giving or verifying during the initial bad news delivery consultation, but rather to save most communication of information for a follow-up scheduled shortly afterwards” (p. 1011).

#### *In Pediatric End-of-Life Care*

In an essay titled “To Show our Humanness—Relational and Communicative Competence in Pediatric Palliative Care,” Browning (2002) critiques many of the current approaches to communication training on end-of-life care for health care professionals.

He notes that

the language of communication skills training in palliative care reveals a unidirectional view of difficult conversations with families. The idea of “breaking bad news” emphasizes the importance of having the right “strategy” when approaching families, and tends to emphasize a single, rehearsed communication event. These approaches often give too little attention to the relational foundation of mutuality and reciprocity that is integral to holding difficult conversations. (p. 25-26)

He writes that

making time available, finding a quiet place to talk, maintaining eye contact, sitting instead of standing, learning to be empathic. All of these are important in the complicated and challenging endeavor of communicating well with children and families at the end of a child's life. But our tools will only do their job well if we understand and embrace the relational context in which we use them. (p. 27-28)

In addition to inadequacy of physician training in end-of-life communication skills, it is worth noting that low levels of funding for research relating to end-of-life issues for children mean that the evidence-base upon which care givers can rely for guidance is limited. The Institute of Medicine's report (Field & Behrman, 2003) states that "research to support improvements in palliative, end-of-life, and bereavement care for children and their families, constitutes only a tiny fraction of research involving children," and that "research involving children and their families occupies a small niche in the world of research on palliative and end-of-life care, which itself is small in comparison to other areas of clinical and health services research" (p. 353).

#### *Patients and Families Value Communication*

Using focus group methodology to elicit the views of patients, family members, and physicians and other health care providers, Curtis and colleagues (2001) identified "12 domains of physicians' skills at providing end-of-life care" (p. 41). Their results indicated that the two domains relating to high quality end-of-life care identified most often by the patients and families were "emotional support and communication with patients" (p. 41). In another paper published on the same study, Wenrich and her co-authors (2001) focused on "which aspects of communication between patients and

physicians are important in end-of-life care” (p. 868). Six primary components of communication emerged in the data as important to patients, families and care givers, and the authors grouped them into two categories: “basic communication skills (listening and encouraging questions), and areas specific to end-of-life care (giving bad news sensitively, talking about dying, and knowing when patients are ready to talk about dying)” (p. 873). The authors comment that “the component raised most often, talking with patients in an honest and straightforward way, spans basic communication skills and end-of-life care, with its dual emphasis on truthfulness and presenting information in an understandable manner” (p. 873).

Wenrich and her colleagues note that

although giving bad news came out in our analyses as a separate component of communication with dying patients, all 6 of the communication components dealt with communicating about bad news in one form or another. The comments of focus group participants suggest that once a terminal diagnosis is made, communication with physicians consists of a wide spectrum of ongoing communication about bad news. What patients and family members ask of physicians in this ongoing communication are honesty, sensitivity, and a willingness to talk about dying and listen to the patient. (p. 873)

A study by Mack and colleagues (2005) on the care of children terminally ill with cancer explored, from the perspectives of parents and physicians, “the determinants of high-quality care at the end of life” (p. 9156). Based on survey data obtained by asking parents and physicians to rate various aspects of care, they found differences in the two perspectives, concluding that “for parents of children who die of cancer, doctor-patient communication is the principal determinant of high-quality physician care. In contrast,

physicians' care ratings depend on biomedical rather than relational aspects of care"

(p. 9155). Specifically, the research indicated that

parents rated the quality of care provided by oncologists more highly when they felt they had received clear information about what to expect during the end-of-life period, when news was delivered with sensitivity and caring, and when doctors communicated directly with the child when appropriate. In contrast, medical outcomes, including time spent in the hospital and pain control in the last month of the child's life were not important determinants of parental ratings of the quality of physician care. These findings contrast with the correlates of physician-rated care, with high-quality care characterized by little pain and minimal time in the hospital at the end of life and not associated with communication factors . . . . we found no association between parent ratings of physician care quality and physician ratings of care quality. (p. 9159)

These investigators note that "the differences in ratings raise the concern that physicians and parents may not be working toward shared goals" (p. 9159) and that "the factors associated with parents' quality ratings suggest additional areas of communication-related competence needed in physicians who provide end-of-life care" (p. 9160). They reported that parents who rated the quality of care given their child as high "were those who felt most prepared for the end-of-life care period," which the investigators believe suggests that "beyond the need for sensitive communication, parents need to understand how the end of the child's life may unfold" (p. 9160).

Meyer and colleagues (2006) published qualitative findings relating to parents' recommendations for improving the quality of end-of-life care and communication in the pediatric intensive care unit. Two of the six priorities identified by parents for improving care were "honest and complete information" and "communication and care

coordination” (p. 649). Citing numerous investigators, Meyer and her research team write that

family needs and preferences for information and communication style may be influenced by the nature of the child’s illness and death trajectory, previous illness and loss experiences, personality styles and family dynamic, and cultural and religious backgrounds. Unfortunately, the prevailing mode of end-of life discussions focusing on laboratory values, organ systems and individual treatments may be too specific and disjointed to facilitate understanding and decision-making or to meet the family’s psychosocial needs. End-of-life discussions that focus on organ systems or offer information only on a need-to-know basis may not hit the mark and can leave some families feeling overwhelmed, underinformed, or wondering what the information means relative to their child’s quality of life and survival. (p. 653)

The authors note that “many parents emphasized that information needs to be forthcoming and communicated by clinicians in a manner that ‘connects the dots’” (p. 653). The authors cite the work of other investigators in their recommendations “that clinicians ask parents directly about their communication preferences and to remain attuned to parental cues and to periodically check the ‘goodness of fit’ between their communication style and parent preferences” (p. 653). Similarly, the American Psychological Association’s draft report (2005) on end-of-life issues with children and adolescents states that

quite commonly, communication problems between families and the team may be attributed to mismatches in expectations, styles, cultural misunderstandings, and needs relative to how much, how soon, and by whom information should be exchanged . . . . Families may feel underinformed, underinvolved, or even left out of the process, and subsequently experience a host of emotional responses to the situation. (p. 11-12)

As part of the process of creating a pediatric palliative care program at a children’s hospital in California, Contro and colleagues (2002, 2004) conducted a needs

assessment with hospital staff and patients' families to understand their experiences with end-of-life care and seek their recommendations for quality improvement. Based on their interviews with families, Contro and colleagues (2002) report that

one of the most striking findings was how a single event could cause parents profound and lasting emotional distress. Parents recounted incidents that included insensitive delivery of bad news, feeling dismissed or patronized, perceived disregard for parents' judgment regarding the care of their child, and poor communication of important information. Such an event haunted them and complicated their grief even years later. (p. 15)

Specifically relating to the delivery of bad news, Contro and her research team (2002) report that

families stressed their need for a familiar person to deliver difficult news about diagnosis, treatment, and prognosis. This was especially critical with the news that their child was going to die. Participants also emphasized that difficult news should be conveyed with compassion and care, using straightforward non-technical language. Above all, family members recommended giving difficult news directly and honestly while still allowing for hope. Parents also mentioned they would have appreciated better preparation that bad news was coming. (p. 16)

For the small number of Spanish-speaking families participating in the study "several distinct issues emerged consistently" (p.17) according to Contro and colleagues (2002).

They write that

the language barrier between these families and hospital staff permeated every aspect of the families' experiences. The lack of a common language compromised parents' ability to acquire complete information and to fully understand their child's medical condition, treatment, and prognosis. In addition, cultural differences could be detrimental to care. For example, if the Spanish-speaking parents' expectation were not met, this became a barrier to trust and confidence in the medical team. These families reported feeling isolated, confused, and distrustful of the hospital system. (p. 17)

Citing the work of other investigators, Contro and colleagues (2002) write that "researchers in the field of thanatology have long recognized the role of language and

culture as it relates to a person's response to the death of a loved one. The Spanish-speaking families in our assessment described a heightened sense of despair resulting from their inability to communicate with staff" (p. 17). These researchers call for further study of how language and culture affect care.

In another published paper based on the same needs assessment, Contro and colleagues (2004) report the results of a survey exploring the degree of comfort and expertise that physicians and staff felt in delivering end-of-life care. The investigators included hospital staff in the assessment, based on the belief that "many different disciplines play significant roles in the care of children with incurable illnesses" (p. 1251). They indicate that

the responses from staff members other than nurses and physicians accentuated the need for a broad approach, in terms of staff training and support. Many staff members in many disciplines, such as unit clerks, respiratory therapists, social workers, chaplains and others, often have frequent contact with the population, making their interactions quite important in overall care. (p. 1251)

Their findings indicated that

staff members reported feeling inexperienced . . . in 4 aspects of interacting with pediatric patients and families, ie, communicating with patients about end of life issues, communicating with patients' families about end of life issues, discussing the transition to palliative care, and discussing do not resuscitate status . . . those who felt inexperienced reported feeling distressed and inadequate in their communications with patients and families. (p. 1249)

The authors note that "caring for dying children is a stressful job," and that stress may increase when staff members have not been adequately trained or are not skilled in managing symptoms, or do not have appropriate communication skills (p. 1248). In turn, this may "affect the quality of care" (p. 1248).

## Interpreters in Health Care

Valdés and Angelelli (2003) write that

interpreting and translation are defined by members of the translation and interpreting profession as the rendering of one message produced in one language (the source language) into another (the target language). The term *interpreting*, however, is used professionally to refer only to 'spoken' or 'oral' messages communicated by speakers, while the term *translation* is used to refer exclusively to the rendering of written texts. (p. 59; italics appear in the original text)

### *Standards of Practice, Codes of Ethics, and Training*

In a project commissioned by the National Council on Interpreting in Health Care, Bancroft (2005) reviewed interpreting standards and codes of ethics worldwide, and described the California Standards for Healthcare Interpreters as one of several "highly influential documents that have garnered a great deal of attention within the U.S. and abroad" (p.25).

These standards (California Healthcare Interpreters Association, 2002) characterize four common roles enacted by interpreters, stating that "the most important consideration when choosing a role is that the interpreter's actions continue to support the primary relationship between the patient and the provider, in the context of the health and well being of the patient " (p.41). These four roles, "in order of increasing complexity and controversy" (p. 41) include that of "message converter" in which the interpreter will "convert the meaning of all messages in from one language to another, without unnecessary additions, deletions, or changes in meaning" (p.42); "message clarifier" in which interpreters "are alert for possible words or concepts that might lead to a misunderstanding" (p.42) and may need to take action for clarification; "cultural

clarifier” in which interpreters go “beyond word clarification” to maintaining an alertness for “cultural words or concepts” (p. 43) that could lead to miscommunication or misunderstanding; “patient advocate” (p. 44) in which interpreters recognize a problem and intervene to “actively support change in the interest of patient health and well-being” (p. 45).

Dysart-Gale (2005) looks to the body of communication studies in her discussion of interpreter practice. Calling for research that combines “the contributions of interpreters, clinicians, patients, communication scholars and others to improve medical interpreter codes of ethics and the theoretical models on which they are built” (p. 101), Dysart-Gale maintains that

examination of a number of communicative models, both those focusing on information transmission and those emphasizing the creation of shared meaning represents a promising avenue for such research and may help to articulate standards of medical interpreter practice that will offer interpreters a solid ethical footing from which to better serve their clients and collaborate more productively with other health care workers. (p.101)

Kaufert and Putsch (1997) write that

there are currently major gaps between ethical codes of conduct for interpreters in healthcare and the realities of medical interpretation. Issues such as poverty and class distinctions, the use of language, beliefs about health, and family process influence the positions and assumptions that patients and healthcare provider carry into, and through, the process of delivering healthcare. Interpreters are both witnesses and participants in this process. They often recognize the nature and consequence of medical discourse, and the risks when it breaks down. (p. 84)

In their presentation of case studies involving a Vietnamese patient and a patient from Nigeria, Kaufert and Putsch (1997) write that the

vital role played by the interpreters . . . illustrates how power is asserted and how role conflict is inherent in cross-cultural communication that involves conflicting

ethical value systems. In models of interpretation that acknowledge and legitimate the interpreter's role as mediator, a culture broker, an advocate, or a professional team member, there has been a move toward the formal specification of the obligations and rights of intermediaries. (p. 84)

They caution, however, that such specifications should only be developed after "detailed study of the broad issues involved" (p. 84).

Given the complexities of interpreter roles and performance described above, consideration of interpreter training and credentialing becomes relevant. Bancroft's (2005) worldwide review of interpreter standards of practice and codes of ethics concludes that

trained interpreters are sorely needed, but in medical and community interpreting there is no consensus on the standards of practice that would promote skilled interpreting and also protect the safety and well-being of clients. As a result, there is an urgent need for a cohesive set of national standards to guide medical interpreter training. (p.4)

Hwa-Froelich and Westby (2003), writing on the current state of training and certification for the interpreting profession, cite the absence of "consistent national or state certification guidelines for interpreters" as well as a lack in existing programs of "instruction in cultural awareness of multiple cultures and training on how to translate and interact in culturally appropriate ways during interpreting interactions" (p.79). They indicate that "training varies widely across (medical and educational settings) because there is no universal agreement on definitions of roles, practices or competency" (p. 83).

#### *Views of Interpreting from the Linguistics Literature*

In her book titled *Interpreting as Interaction*, Wadensjo (1998) contrasts two views of language and mind. She writes that

a *monological* model of language and mind treats interpreting as a transfer of messages from one linguistic system to another, and interpreters as ‘channels,’ which are temporarily hosting primary speakers’ messages in their brains. This can be contrasted with a *dialogical* model of language and mind, which treats interpreting as interaction between participants in a social event. A dialogic—or interactionistic—conceptualization of interpreting allows the exploration of various communicative activities, their nature and their mutual interdependence in social interaction. (p. 275, italics appear in the original text)

Angelelli (2004) has described a shift away from the view that interpreting is solely a “cognitive act,” or a “highly sophisticated case of information processing” that focuses on “decoding and encoding processes,” which has “isolated the act of interpreting from the interaction in which it is embedded” (p. 133). She notes that studies in the last decade have alternatively explored the performance of the interpreter as a “co-participant” in the interaction (p. 133). She writes that

interpreters who are capable of highly complex information-processing tasks are also social human beings who facilitate cross-linguistic and cross-cultural communication. As such, they are engaged in the co-construction of meaning with other interlocutors within an institution, which is permeable to cultural norms and societal blueprints. (p. 132)

This, Angelelli (2004) writes, represents a “paradigm shift in the conceptualization of the role of the interpreter (from an invisible mechanical language expert to a visible co-participant with agency in the interaction)” (p. 132).

Citing previous work by linguistics researchers, Angelelli has devised a model of the “visible interpreter” (2003a, 2004) which incorporates the social and cultural factors interpreters themselves bring to the medical encounter, proposing that

the interpreter is visible with all the social and cultural factors that allow her/him to co-construct a definition of reality with the other co-participants to the interaction. The interpreter is present with all her/his deeply held views on power, status, solidarity, gender, age, race, ethnicity, nationality, socio-economic

status, plus the cultural norms and blueprints of those social factors that are used by her/him to construct and interpret reality. As the interpreted communicative event (ICE) unfolds, the interpreter brings not just the knowledge of languages and the ability to language-switch or assign turns. The interpreter brings the self. The self cannot be artificially blocked as the ICE unfolds to create the illusion of an “invisible” interpreter. (2003a, p. 16)

Angelelli (2004) notes that the visible model is “highly complex,” as “the interpreter’s views of all of these social factors interact with the parties’ views of those same social factors” (p. 9). Also contributing to the complexity are the “various layers of institutional and societal influences” (p. 9) surrounding the encounter, and the nature of interpretation as “a highly sophisticated process that involves the juggling of these social factors plus the information processing between languages and cultures, performed under pressure” (p. 9-10).

Angelelli (2004) states that interpreter visibility and participation are not only “present in the linguistic co-construction of the conversation” (p. 11), but are

essential in: communicating cultural gaps as well as linguistic barriers; communicating affect nuances as well as the content of the message; establishing trust between all parties to the conversation; facilitating mutual respect; putting the parties at ease during the conversation; creating more balance (or imbalance) during the conversation (by aligning with one of the parties); advocating for or establishing alliances with either party; managing the requested and given information. (p.11)

Angelelli (2003b) maintains that “as visibility increases, the interpreter’s role is more consequential” (p. 24).

### *Interpreters Are “Uniquely” Positioned*

Writing about her experiences as an English-Spanish language medical interpreter working at a university medical center in California, Haffner (1992) advises that “health

care professionals must recognize that the situation always is bicultural and not merely bilingual" (p. 259). Citing Whorf (1956), Putsch (1985) writes that "language is the framework in which the world view of a culture is molded, and it describes the boundaries and perspectives of a cultural system" (p. 3344). Putsch characterizes communication through an interpreter, writing that

a language barrier disarms a communicant's ability to assess meanings, intent, emotions, and reactions and creates a state of dependency on the individual who holds the keys to the entire process—the interpreter. Interpretation requires a great deal of skill. Interpreters find it necessary to describe and explain terms, ideas, and processes that lie outside of the linguistic systems of clients. The interpretation process must account for divergent world views. (p. 3344)

He adds that "special procedures, issues such as death and dying, and patients in the intensive care unit, recovery room, or social work department all add stress and complexity to the interpreter's role" (p. 3345).

Kaufert and Putsch (1997) further describe the circumstances in which interpreters perform their jobs, writing that

patients and healthcare providers . . . often come from different educational, cultural, or class backgrounds. They may hold disparate views of illness and treatment, and may not agree on a common set of cultural values regarding decision making. This is the interface at which interpreters in healthcare do their work, and disparate views as well as disparate expectations are the basis for the dilemmas that they often face. (p.72)

In key informant interviews conducted with hospital interpreters in Geneva, Switzerland, Hudelson (2005) sought to "gain insight into common sources of patient-provider communication difficulties observed by interpreters in their work" (p. 311). She notes that "interpreters' bilingual and bicultural position allows for the identification of communication barriers that may be difficult for physicians to recognize" (p. 311).

Based on the interpreters' descriptions of the occasions where they witnessed communication difficulties, Hudelson identified several areas "where physicians and patients were likely to differ, and where mutual lack of awareness of those differences could lead to misunderstandings" (p. 313). These included "(1) ideas about the patient's health problem; (2) expectations of the clinical encounter; and (3) verbal and non-verbal communication styles" (p. 313).

Also based on the interpreters' descriptions, Hudelson (2005) describes four areas of emphasis in physician training that could improve communication with patients who speak languages different from their own. The following comments are presented in their entirety, as originally written by Hudelson in the published article.

*Awareness of potential sources of misunderstanding*

Interpreters' descriptions generally indicated a lack of awareness of differences in patient/provider perspectives. It is both unfeasible and unnecessary for physicians to be familiar with the specific cultural beliefs and communication styles of their patients, but a heightened awareness of potential communication pitfalls would help physicians to identify or avoid them.

*Basic knowledge about patients' countries of origin (geography, politics, religion)*

Interpreters said that some patients were reluctant to communicate openly with physicians who appeared to know little or nothing about their country, and felt that it was important to show interest and ask questions about a patient's country in order to establish rapport.

*Recognition of the difficulties of translation*

Interpreters felt that physicians needed to be more aware of how difficult it can be to meaningfully translate medical concepts and terms. Some physicians demanded word-by-word translation, which was often impossible and itself a potential source of miscommunication. Other used medical concepts that were

unknown to patients. Interpreters said that communication would be facilitated by the use of simpler, less technical language.

#### *Adaptation to patients' communication styles*

Interpreters were most vocal about the need to use more conversational styles with patients. They felt that the direct, closed questioning style used by many physicians was difficult for patients. They suggested that a more narrative approach to information gathering would not only contribute to the therapeutic alliance, but also improve the quality of information provided by patients. (p. 315, italics appear in the original text)

Hudelson (2005) concludes that “although patient/provider differences in terms of social and cultural background, education and experience create the potential for misunderstanding, it is the *lack of awareness* of these differences and their potential effect on clinical communication that is at the root of the problems described” (p. 315, italics appear in the original text). She adds that “interpreters are uniquely placed to facilitate increased awareness of such differences and their importance for clinical communication” (p.315) yet, citing the work of other researchers, notes that “despite their potentially important contribution . . . . the voice of medical interpreters is surprisingly absent from the literature” (p. 311).

#### *Interpreters and End-of-Life Care*

A qualitative study (Norris et al., 2005) using focus group methodology and grounded theory for data analysis was conducted with medical interpreters in the Seattle area in order to “develop insights into how physicians could improve communication about terminal or life threatening illness with patients from different cultures and speaking a different language” (p. 1017), and to help physicians “understand the

challenges faced by medical interpreters in these situations” (p. 1021). Norris and colleagues report that their study data supported the development of three frameworks. The first identified “basic professional skills and qualities interpreters considered important for both physicians and interpreters in language-discordant settings” (p. 1021). The second “identified skills specific to physicians that focused around communication, nonabandonment, educating patients and families about the dying process, and coordinating care with other providers” (p. 1021). The third “identified challenges and struggles experienced by interpreters during communication about end-of-life care” (p. 1022). In their discussion of the interpreter-centered framework (the third framework), Norris and colleagues write that challenges faced by interpreters

included the tension between providing strict interpretation and being an advocate or cultural broker; personal difficulty interpreting bad or difficult news; the interpreter feeling abandoned or abused by clinicians; and striking a balance between a focus on the patient and a focus on the family. (p. 1019)

These authors also provide a list of the recommendations offered by interpreters “to physicians, healthcare institutions, and interpreters about ways to improve communication about end-of-life care in language-discordant encounters” (p. 1022). Norris and colleagues maintain that the findings of their study “highlight the fact that not understanding the challenges facing interpreters during the communication about end-of-life care may lead to frustration for all participants and to poor communication” (p. 1022).

## CHAPTER 3

### METHODS

#### Approach to Study Design

Creswell (2003) suggests that as investigators develop a research proposal, their first decision will be the selection of an appropriate design framework for the research question. The three research questions identified for this study were: (1) For interpreters, how does the interpretation of end-of-life conversations (in the pediatric hospital setting) qualitatively differ from interpretation of non-end-of-life conversations? (2) How do interpreters describe their personal experiences of interpreting end-of-life conversations involving patients who are children and/or their families? (3) Do interpreters perceive themselves to have a role that impacts on the quality of end-of-life care for terminally ill children and their families?

The qualitative research framework was selected for this study, and the research questions were explored by drawing from the phenomenology strategy of inquiry, which, as described by Bassett (2004), “uses the lived experiences of the participants . . . . As such, it explores the feelings and beliefs of individuals involved” (p. 155).

#### Data Collection

The focus group was chosen as the primary, preferred research technique for collecting data for specific reasons. Stringer (2004) writes that focus groups are “a potent means for collecting qualitative data on health-related subjects, which are concerned with perceptions, values and beliefs” (p. 6). Similarly, Greenbaum (2000) writes that the goal of a focus group is “to delve into attitudes and feelings on a particular topic, to

understand the ‘why’ behind the . . . . behavior” (p. 3). He continues that “one of the most important reasons to use focus group research is to benefit from the interactions of the participants in the room” (p. 10), and “with this type of interaction among the participants, issues will often emerge from the discussion that would normally not evolve if the moderator was asking opinions of each of the participants in a one-on-one format without encouraging the group interaction” (p. 11).

Despite the researcher’s preference for collecting data through focus groups, it was necessary to offer interpreters an alternative way to participate in order to maximize enrollment in the project. Interpreters whose schedules could not accommodate focus group dates and times were offered individual interviews with the researcher. A total of 17 staff interpreters at Children’s Medical Center Dallas were recruited: 11 interpreters participated via two focus groups (one group with 6 participants and a second group with 5 participants) and 6 interpreters shared their experiences through individual interviews. All group and individual discussions were conducted using the same questions. The researcher’s previous experience in qualitative interviewing and data analysis in the health care field, along with her experience as a health care interpreter, qualified her to serve in the moderator role for this study. Each focus group was scheduled as a two-hour session, and each interview was scheduled as an hour and a half session. All focus groups and interviews were audiotaped; audio recordings were subsequently transcribed by the researcher. An assistant was present during each focus group to take notes. Institutional Review Board approvals (described below) were obtained prior to the initiation of the research.

## Sampling Procedures

In order to maximize the potential for interpreter participation and to minimize interference with the operations of the Translation Services Department (TSD) at Children's Medical Center Dallas (CMCD), the Director of the TSD assisted the researcher in identifying potential dates and times for the focus groups.

Recruiting this purposive sample was accomplished with a flyer (Appendix A) briefly describing the study purpose and procedures, the inclusion/exclusion criteria for participants (i.e. staff employment by CMCD; English-Spanish language combination; experience interpreting at least one end-of-life conversation while employed at CMCD), proposed dates for the focus groups, and instructions for contacting the researcher to register for the study. The TSD Director disseminated the recruiting flyer via 3 successive email distributions to all staff interpreters, and posted the flyer in the interpreters' break room, the interpreters' dispatch office, and the interpreters' cubicle/work area. While a number of interpreters responded to the recruiting flyer and initiated contact to convey interest, it was necessary for the researcher to personally visit the TSD on three occasions to negotiate more convenient dates and times for the focus groups, and to recruit interpreters who preferred to participate via an individual interview. All focus groups and interviews were carried out in March, 2007. With the exception of one interview, which was conducted in the interpreter's home, all discussions were conducted on the premises of CMCD.

## Research Instruments

Five documents were prepared for the research: a recruiting flyer; a participant consent form; a participant demographic questionnaire; a focus group moderator's guide; and an individual interview moderator's guide (both guides used the same discussion questions). The research recruiting flyer (Appendix A) has been described above in the section outlining sampling procedures.

As interpreters arrived for the focus groups or interviews, they were invited to partake in the light meal or refreshments that were offered in the conference or interview room, and received a written consent form (Appendix E) to read and sign prior to the discussion. A copy was provided to all participants to keep for their records.

Also prior to the start of each discussion, interpreters were asked to fill out a demographic questionnaire (Appendix B), which did not ask for their name or any identifying information that could specifically link their participation to the data.

The researcher developed a focus group and an interview moderator's guide (Appendices C and D; both guides used the same questions) which related to the previously identified research questions and consisted of a series of open-ended questions to be discussed by the interpreters during each session. At the beginning of each interview and focus group discussion, the researcher introduced herself, reviewed the purpose of the study (as outlined on the recruiting flyer), described how the interview or group discussion would proceed, notified participants that the discussion would be audiotaped to facilitate analysis, and reiterated key consent form provisions: that all data collected would remain confidential and be reported without identifiers, and that

participation on the part of the interpreters would be voluntary and that they could withdraw from the group at any time without penalty of any kind. At the conclusion of each focus group or interview, the researcher thanked participants for attending and answered any remaining questions they had about the study.

### Data Analysis

Strauss and Corbin (1990) maintain that their views on grounded theory procedures and techniques for analyzing qualitative data have relevance for researchers who, alternatively, wish to focus on “theme analysis” or simply explore “new ways of thinking about phenomena” (p.12). Their discussion of researchers who decide to provide “**accurate description** when doing their analysis and presenting their findings” (p. 21; bold face is in the original text) provides an overview of the approach to analysis that was undertaken in this study. They note that “researchers who advocate or primarily produce accurate description also typically intersperse their own interpretive comments,” and that “illustrative materials are meant to give a sense of what the observed world is really like” (p. 22).

During the transcribing of the audio recordings the researcher was struck by how vividly interpreters recalled their stories of end-of-life encounters. Because of their vitality, it was determined that the most faithful way to represent these experiences would be through short narratives. The selection process began with an initial, global coding of all transcripts, which was entered into an electronic file using Microsoft Excel software. Although Excel is a spreadsheet application and not a relational database management system, it is possible to perform basic data management functions such as running queries

to sort and filter data in a variety of ways. Following the initial coding, the researcher performed an iterative series of analytical exercises intended to identify resonant or unique themes discussed by each interpreter and ultimately, common themes that emerged among participants. Once common themes were identified, further categorization and reduction of the data resulted in the four primary themes presented in the narratives which appear in Chapter 4: the nature of end of life, perceptions of role, complexities of performance, and perceptions of quality. Individual quotations were then selected to illustrate these themes. It should be noted that this particular reporting of narratives represents but one writing framework. A large amount of rich data was collected during this study and there is much potential to revisit it to look for other ways to represent interpreter perspectives.

### Institutional Review Board Approvals

In order to comply with ethical research procedures, appropriate documentation for the research plan was submitted for review to the University of North Texas Health Science Center Institutional Review Board and the University of Texas Southwestern Institutional Review Board (which approves research protocols for Children's Medical Center Dallas). Research was initiated following approval from both institutions.

### The Setting

The following institutional profile is presented in order to provide additional context for the research, and was compiled based on information obtained from multiple sources within Children's Medical Center Dallas (CMCD): the CMCD website (Children's Medical Center Dallas, b); the CMCD 2005 annual report (Children's

Medical Center Dallas, a); conversations and email correspondence with the Director of the Translation Services Department, and various staff members from the Finance Department, the Marketing Department, and the Pastoral Care Department.

CMCD, located in the city of Dallas, in Dallas County, Texas, is a tertiary and quaternary hospital providing medical services for children only, from birth to 18 years of age. CMCD serves patients by referral to its inpatient units and outpatient clinics and services. Through numerous pediatric subspecialties, CMCD provides care for a wide variety of disorders and diseases and also performs kidney, liver, heart and bone marrow transplants. A palliative care service was recently established. Among the 14 Level I pediatric trauma centers in the country recognized by the American College of Surgeons, CMCD is the only such facility in the state of Texas and in the Southwest United States. It is also among the 14 national pediatric research centers designated by The National Institutes of Health. Members of the medical staff include faculty members of the University of Texas Southwestern Medical Center at Dallas, for which CMCD is the primary pediatric teaching facility.

Licensed for 406 beds at the time of the research, CMCD is among the top 10 pediatric hospitals in size in the United States, and its pediatric intensive care capacity is also one of the nation's largest. CMCD defines its four primary service regions to be Dallas, Legacy (an internally used geographic designation), Fort Worth, and East Texas. In 2005, CMCD cared for 126,425 children which included children from 60% of the state's 254 counties, and 49 of 50 states, plus Washington, D.C., Guam, Puerto Rico and the U.S. Virgin Islands. CMCD estimates that by 2010, the population of children it

serves will increase by 30% which it expects to accommodate by expansion plans currently underway.

In 2005, CMCD inpatient admissions totaled 20,682; outpatient visits totaled 216,067; surgical cases totaled 19,697; and emergency visits totaled 90,639 (2005 Annual Report, p. 58). In 2005 there were 165 inpatient deaths; inpatient deaths for January through June 2006 totaled 65. In 2005, 41% of the children served were of Latino/Hispanic origin.

As a private, not-for-profit medical center, CMCD receives no county or state or hospital district funding. In addition to patient care revenue, it relies heavily on endowment and fundraising for program and facility maintenance and expansion. In 2005, CMCD provided \$34.4 in charity and uncompensated care.

#### *The Translation Services Department*

The Translation Services Department (TSD) at Children's Medical Center Dallas (CMCD) originated in 1994 and is currently a stand-alone department reporting to the Vice President for Ancillary Services. TSD employs a director, an administrative assistant and 21 full time interpreters. An additional 19 interpreters are CMCD employees but do not have either full time or part time status. They are considered "PRN" interpreters, whose services are used "as needed" (i.e. to cover staff interpreter vacation times, specific patient appointments, and other shifts as required). On occasion, as needed, the director is also available to interpret. All staff (employee) interpreters work in the English-Spanish language combination. In order to cover gaps in staff availability or the need for other language combinations, CMCD uses contract

interpreters who are not CMCD employees, or telephonic interpretation services provided by an outside company. Of the 40 staff interpreters, 27 are female and 13 are male; the Director is a male; length of employment as interpreters at CMCD ranges from less than 1 year to 12 years; all but a few of the staff interpreters are native speakers of Spanish.

A minimum of two years of interpreting experience is a prerequisite to be considered for employment as an interpreter at CMCD, and although not required, experience with medical terminology is an advantage for hiring. Interpreter candidates undergo a pre-screening process which includes evaluation of their performance in simulated interpreting encounters, their knowledge of anatomical and medical terminology, and the quality of their written translations of sample patient consent forms. If their performance on the pre-screening evaluation is acceptable, they will then undergo an evaluation by an outside company, and must surpass a pre-determined minimum score on that assessment to be eligible for hire.

Interpretations at CMCD include not only interactions between patients and families and assorted care providers and hospital staff, but also patient and family education classes on topics such as asthma or diabetes care. In addition to providing interpretation services, the TSD also performs translations of assorted documents including consent forms for treatment, consent forms for participation in studies, patient care instructions, discharge instructions, and patients' prior medical records that are written in Spanish.

Although interpreters are available at CMCD 24 hours per day, 7 days per week, staffing levels are the heaviest 8 a.m. to 6 p.m. Monday through Friday, when interpreters

are covering both the inpatient and outpatient services at CMCD. Weekend staffing is more frequently provided by the PRN staff interpreters than by full time staff interpreters. Shift scheduling and staffing needs are determined by analysis of both the timing and the volume of interpretation requests received by the TSD.

Although five staff interpreters are assigned to specific units or services (surgical, imaging, emergency, cancer), the majority receive their assignments throughout the hospital from a dispatcher. The TSD is located in a separate building from the hospital, where the Director, the administrative assistant, and the dispatcher have their offices. For the most part, in order to minimize response times, interpreters are expected to remain in the hospital while receiving their assignments via dispatch, rather than return to the building that houses the TSD. However, several cubicles are set up in the TSD to which interpreters may return at various times to complete their administrative tasks or work on translation assignments. In 2005, TSD received a total of 107,602 requests for interpretation, and carried out 91%, or 97,928 requests. The 9% that were not handled were due to a variety of reasons that did not necessarily relate to the TSD.

## CHAPTER 4

### RESULTS

#### Context

Interpreter narratives are presented below, and represent four primary themes that emerged from the data: the nature of end of life; perceptions of role; complexities of performance; perceptions of quality. In order to promote a fuller appreciation for the narratives, some contextual information is warranted. The focus groups and interviews with interpreters were conducted in English, which is not the native language for the large majority of participants. While every effort was made to represent the narratives intact as spoken by interpreters, minor editing (such as punctuation and omission of extraneous language) was performed on passages where the meaning or speaker's intent otherwise might have been obscured. Pseudonyms were used to assure the anonymity of participants. This research focused on conversations between patients and families who spoke Spanish, and providers who were speaking in English (regardless of whether English was the provider's native language). Most of the time, interpreters at Children's Medical Center Dallas (CMCD) facilitate conversations that involve adult family members of child patients. Although interpreters do have encounters that involve conversations with patients, the narratives presented in this report deal with adult speakers.

Interpreters themselves noted that their perspectives may be influenced by the areas of the hospital in which they work (i.e. day surgery, emergency room, intensive or critical care, oncology, etc.) as well as their shift (i.e. day, evening, overnight, weekend).

None of the participants reported having received any type of training or guidance relating specifically to end-of-life conversations. Asked to identify the approximate number of end-of-life encounters in which they have participated, interpreters reported a range of 2 to 100, which may relate to the length of time each has been employed at CMCD, as well the departments or locations to which they are dispatched or assigned.

### Participant Characteristics

Seventeen interpreters participated in the research, which represented nearly 42% of the full time and “PRN” interpreting staff at CMCD. As previously mentioned, the researcher made three personal visits to the Translation Services Department (TSD) to stimulate enrollment following the email distributions of the recruiting flyer. The primary reasons for non-participation (among the staff interpreters who spoke with the researcher) were incompatible work schedules with focus group dates and times, and busy personal lives that did not allow them time for individual interviews during their off-work hours. Ultimately, two focus groups (with a total of 11 interpreters) and six individual interviews were completed. Table 1 illustrates the fairly even ratio of males to females among participants (47% to 53%, respectively); the ratio of participants assigned to specific units or services in the medical center to those working “at large” throughout the hospital; the ratio of participants working scheduled shifts to those working “PRN” assignments. Proportionally, participants differed in each of those characteristics from the total interpreting staff at the hospital at the time of the research.

Table 1

*Interpreter Gender and Work Characteristics*

Interpreter characteristic	Study participants <sup>a</sup>		Children's Medical Center Dallas staff <sup>b</sup>	
	No.	%	No.	%
Male	8	.47	14	.34
Female	9	.53	27	.66
Assigned	5	.29	5	.12
At-Large	12	.71	36	.88
Scheduled	14	.82	21	.51
PRN	3	.18	20	.49

<sup>a</sup>*n*=17. Study participants represented 42% of Children's Medical Center

Dallas interpreting staff. <sup>b</sup>*n*=41.

Table 2 reports participants' native language, country of birth, number of years living in the United States, age, and education status. According to the Director of the TSD, all but one of the staff interpreters at CMCD are of Latino/Hispanic origin. All 17 interpreters participating in this study identified themselves as Latino/Hispanic.

Table 2

*Participant Demographic Characteristics*

Characteristic	Interpreter Response	No.
Native language	Spanish	13
	Spanish and English	2
	English	1
	Not designated	1
Country of birth <sup>a</sup>	Mexico	8
	Colombia	3
	United States	2
	Panama	2
	Panama Canal Zone	1
	Chile	1
Years living in	Average: 22 years	
United States <sup>b</sup>	Range: 5 – 41 years	15
Age	Median: 46 years	
	Range: 30 – 72 years	17
Education	16 of 17 participants reported at least some college education.	

<sup>a</sup>All study participants self-identified as Latinos/Hispanics. <sup>b</sup>Participants who were born outside the United States.

Table 3 reports the length of time interpreters have worked in a variety of settings. This table also reports the number of hours they work per week; the number of encounters they perform in a day; and the number of end-of-life encounters in which they have participated.

Table 3

<i>Interpreting Characteristics</i>		
Characteristic	Average	Range
No. years interpreting <sup>a</sup>	8	1.5 - 15
No. years health care interpreting <sup>b</sup>	5	0.6 - 11
No. years interpreting-CMCD <sup>b,c</sup>	5	0.6 - 11
No. hours per week <sup>b,c,d,e</sup>		Variable - 40
No. encounters per day <sup>b,c,e</sup>		10 - 50
No. EOL encounters <sup>b,c,e</sup>		2-100

<sup>a</sup>Any setting. n=16. <sup>b</sup>n=17. <sup>c</sup>Children's Medical Center Dallas. <sup>d</sup>14

participants work 40 hours; one works 30; one works four; one works variable hours. <sup>e</sup>Range renders average meaningless.

### The Nature of End of Life

End-of-life conversations are complicated encounters. Families, providers and interpreters are challenged by the complex interplay among situational, emotional,

interpersonal, and cultural milieus within which they operate as a child reaches the end of life. (In addition to the narratives that appear below, other supporting narratives for this theme appear in Appendix F.)

### *Situational Milieu*

Interpreter stories of end-of-life encounters reflect their experiences with a wide variety of topics, circumstances, and approaches. These conversations may take place in the context of sudden, unexpected events or may involve serial conversations that evolve over a long illness. Some interpreters described scenarios that did not entail a physical death, yet represented an end to the way of life that a child and family had known.

Elena:           End-of-life conversation for me would be anything that revolves around either telling the parents . . . . that you know that their child is going to die, there's nothing else we can do for them, or after the fact when they're already dead or going through disconnecting the ventilators or machines, or after the fact sometimes the patient dies and family, if it's an accident . . . comes afterwards . . . . and they're just coming, like going through what happened, what we did.

Sergio:           . . . . one of my first experience was a girl that choked with a grape—was 14 or 17 years old—an adolescent, and she choked when she was right here—she was already purple when, I would say, in convulsions of because of lack of oxygen . . . . The other thing is, for example, cases like when severely injured people come to the ER . . . . that were normally healthy half an hour before, and that face death.

María:           . . . . basically once you find out they're terminal, that starts the end of life. And that might be a long, long time before they actually die. And they may not even die. And so you have these conversations that uh, have to do with maybe preparing the parents or trying to get them to, uh, understand what the doctors are trying to do, um, like maybe the doctors want to, think that a DNR, a 'do not resuscitate' order is um, appropriate, and getting that, in terms of . . . . different cultural perspectives is, sometimes it takes a long time for people to come to an understanding of where you're at and what people's intentions are.

Cristina: . . . . one particular case here . . . . it was a transfer patient, and he'd been here, what, over three years? . . . . he rejected, and then . . . . physical changes started to happen in him, and of course, you know, I think if any parent, when you've been, when your child is sick and you see them, and you go through them with this it's very hard to be objective and understand what's happening. So . . . . one of the doctors on the team . . . . I can think of about at least three or four times where I would go in there with him towards the end of the day . . . . and he would be there with her and talk to her for about 15, 20 minutes, and just kind of go over everything again, and everything they'd done, and this is where he was, and this is, this is where he's at now, and you know 'There's nothing else we can do' and 'You have to be ready.' In this particular case it was the mother, the specialist and myself, and of course the little boy was there, but he was so young. . . . so that when I left, he passed on a weekend, like on a late Friday night or on a Saturday. When I left, I made sure that I had a way of knowing if he would pass on the weekend so I could come by. I mean we're not supposed to do that but you get attached . . . . So for me that was an end of life because—because progressive—he'd broken it down in steps.

Víctor: . . . . one of my hardest experiences was with a child that was probably autistic . . . . he was basically unable to recognize anyone and he was here illegally, he was five years old, basically brought to this hospital as a measure of last resort by a grandmother because the parents had abandoned this child. And the mother, the grandmother is, um, basically was turning the child over to the hospital. So there was an end of life there for that parent and for that grandparent—a conscious decision to surrender this child. And it was very, very, very difficult to go through that whole process. But it's a death of sorts—not physical but it was that kind of an encounter . . . .

### *Emotional Milieu*

Encounters that involve the possible death, impending death, or actual death of a child have an emotional impact on all participants. One interpreter described the effect on her, noting that “even if we are not supposed to, we get very emotional, and we get tired. We get so stressed.” Families are in pain and caregivers are affected.

Elena: It's horrible. You never get used to it, and I always say I hope I never get used to it. Because if I get used to it, that's even worse than having to give it. But it's the most awful feeling in the world to give bad news—tell parents something they never want to hear, they should never have to hear.

Roselia: The doctors that I have interpreted for in those situations they are, they are touched, and you can feel it in the tone of their voices and their attitudes. . . . they are more, their voice is softer. Their words are not as matter of fact delivery facts, but you can feel that there's caring there.

Raúl: . . . many people take things very different . . . Some parents . . . they have a hard time, you know, saying 'Yeah—well I have to, to let go, but it's ok' . . . and some other ones it's just . . . a big drama, a big terrible situation where families, relatives start yelling and some of them pass out in place because of all the sadness . . . end-of-life conversations are much more emotionally draining . . . for the interpreter, from my point of view. Obviously for families and for the doctors they are also very emotionally draining, because I've gotten to see nurses, you know, crying in the hallways or in the parking lot because it's such a sad night or something, and so mostly, that's the reason, that's different—the emotional load.

Gloria: . . . you are talking about a human being . . . parents are going to go through news that is very painful, very emotional. And we Hispanics have the tendency to be very dramatic . . . we cry, we do gestures—'Oh my God, I'm gonna die'—all of these things in Spanish. 'Oh my little one—why me?' I mean we are very verbal, emotional. And that sometimes shocks the doctors . . .

### *Interpersonal Milieu*

Interpreters described how the number, identities, and responsibilities of participants who are present during an end-of-life conversation depend on the circumstances of the encounter. Encounters may take place with a parent alone with the child and a provider; with many members of the child's extended family or faith community who have come to the hospital to offer support to the parents; or with a variety of staff members who have cared for the child.

Raúl: The emergency room . . . many times when you go to the critical care area it could be just one parent, just one because of the situation that happened so fast. Those are also really bad . . . it's very difficult in the whole sense because . . . half an hour ago, the child was healthy, playing . . . and then all of a sudden the child is about to die. And there is only one parent that doesn't have anybody else. And, if they have the kids around, Mom, just have the kids all over the place and Mom's crying and the kids are looking at Mom crying . . .

Roselia: . . . . the parents and the family are very, very deeply involved—there's a lot of other members from the family that are present—the parents want them to be present. . . . uncles, cousins, of course grandparents, even friends and they want them there—they definitely want them there.

Inés: . . . . we go in the room with the family—parents decide which member of the family are going . . . . parents will . . . . lean on the family for their . . . . decisions to, when it's a DNR or something like that, and they want the family to get involved in the decision. If they belong to a special community, religious community, they want them able to come, stay with them and help them.

Emilio: . . . . all the family that comes in—the staff gets nervous, upset, having all, all that people there sometimes. And sometimes they tell you 'But why, what's the reason why they have to come—everybody in their family—their friends and neighbors and everything. Why does everybody have to be here?' . . . . because that's cultural. We bring, whenever somebody's going to die, it's a show of respect and a show of support to come to hospitals and uh stay with them, whatever—offer support . . . . and I also understand at the same time—I'm acculturated enough that I understand the point of views of the physicians and the nurses that, I mean, it's hard to work in here as it is.

Roselia: . . . . we call it a care conference. And it's a care conference because all the doctors that have been involved with the care of that child, their nurses of the different shifts, the chaplains, the Child Life, the social workers—everybody from the . . . . staff that has been involved in the care of that child is present in that room.

In the exchange below, two interpreters described how complications during elective dental surgery resulted in the need for a broad range of providers to meet with the family following a child's unexpected death.

Inés: Everybody was in shock of course because it was something that nobody expected that going to happen . . . . very, very unexpected.

Cristina: And talk about—you asked how many people?—I think the whole anesthesia department was there from the head guy . . . .

Inés: Everybody—chaplain . . . .

Cristina: Uh huh, from administration upstairs, uh, all sorts of nurses, case managers . . . .

### *Cultural Milieu*

Interpreters talked about cultural differences they perceive in the context of death and dying and their stories highlight contrasts in attitudes, communication styles, customs, and spiritual support.

#### *"Attitudes are different"*

Drama, hope, miracles—interpreters used these terms to describe the ways in which they believe Latino/Hispanic family attitudes toward death differ from attitudes in the United States.

Gloria: . . . . this is a topic that is very delicate, it's a topic that, Hispanics don't talk too much about death. It's a topic that is dramatic. It's very, very stressful, sad and it is a topic that is delicate . . . . It causes pain.

Sergio: I would say Hispanics, when they bring a child here, they come with two great expectations—'The doctors are going to cure my child'—not to treat—to cure. And 'If the doctors can't, I'm going to wait for a miracle.' So there is hope—huge, huge hope all the time. There's no place to think of death in many parents . . . . for me the big, big difference is Americans are prepared to talk about death—very open, very free, very naturally, I would say. The Hispanics don't talk about death. They accept it, as something inevitable . . . . I find for example that for Americans, you can talk about death as you can talk about anything else and generally you're much more receptive to the subject. And it's just that you accept much more easily to discuss the situation. For the Hispanic, it's always traumatic . . . . Because if I'm waiting for the doctor to cure my child, or a miracle, there's no place for death. Attitudes are different.

Gloria: I have had one case that the doctor said that the baby has to be disconnected—that was one of the choices. This doctor was pushing to do that. And the parents decided to take the baby away from (this hospital) and move to another hospital—because they didn't want to hear that there wasn't any hope, or that medically you cannot do anything else. And the parents got very upset

because they told the doctor 'What kind of religion do you have where you don't have any hope?' That was a tough encounter.

Emilio: . . . . Americans, generally understand everything as a process. They follow the process, they know 'My child's in the hospital, my child's sick, my child's very sick, my child's about to die,' and, and it's very logical, the process. Because they know, ok, the child is most likely dying, and 'I'm accepting this.' So whenever the child dies, it's very logical for the Americans to understand, 'Ok now, we do this, we're sad and everything, and what's next?' They follow the process. For the Hispanic families it's not like that. We're completely different in that sense. We are opposing the thought of death, and uh the thought of losing, I mean the losing . . . .

Inés: Even the word cancer—you're saying to an Anglo family—cancer—they take it like it is. For a Hispanic family it is like death, you're telling death. Instead of cancer, just say death. Death is you know different—it's very cultural I think that it's very important to address that for providers.

### *"A style to talk about death"*

In addition to differences in attitudes toward death, a number of interpreters commented on differences in communication approaches to conversations that deal with end of life.

Heriberto: I think that culture plays a very, very important role on the way the family would like to be told or informed about end-of-life situations. Uh, it is my perception that the Latino families need to be given this information in a more subtle, not so direct way, a more caring way, pampering the parents with words—in such a way that the information is sinking in little by little, like, like give it in drops, and drops and drops of information so the information can be swallowed. I think that's, that's, that will be the uh, the, the method of communication that the Latino families will prefer. On the other hand, I've seen, of course less numbers, those parents that prefer a very direct way to receiving information.

Sergio: Americans have a style to talk about death. When I say, you are very straightforward, I mean, we beat around the bush. We don't go directly into the things. For example if, typically, in, I would say Colombia . . . . I would say my country . . . . the doctor starts preparing the patient and family, ok, way ahead of time so that's, to avoid a shock . . . . Now, that has to be planned and I think that you have to do the mental exercise before you do it in reality. And then, for

example with the, discussing the things with the interpreter, 'Ok, we have to deal with this—what would be the best way?'

Gloria: I had this bad experience with a doctor . . . . She came from a place that, a country that emotions are not—she was kind of—what her attitude was like 'What kind of—it's too much!'—like she's putting on this show, you know? . . . . the parents reacted to her coldness . . . . They reacted as saying 'What kind of a doctor are *you*? Why, you are saying that you don't have any—there is always hope!' . . . . and the doctor says 'No—this kid is here . . . . '—just like wasting time . . . . It was difficult for me . . . . that was my first experience and I delivered what I needed to deliver, it was just that I . . . . could see that the doctor didn't understand the Hispanic culture. And I had a conversation, after everything finished with that doctor . . . . and I told her that I observed that she was a little bit overwhelmed with the reaction—the overreaction of the Hispanic but 'I want you to know that our culture is like that—that we, we dramatize—we put this big . . . . you know, that's the way we act.' And she thanked me for that, actually. She said that she had never seen, you know, that she thought that this was too much. And I said 'No—there are people and civilizations that react . . . . different to pain, and we Hispanics have the tendency to dramatize . . . . And that's the way we handle the pain.' And she said that she would be more, she would consider what I said. She thanked me for that. She was too direct or too rude . . . . for the Hispanic.

Sergio: Now normally in a completely Hispanic setting . . . . I don't know how much have we changed lately, but if a patient is dying, normally the doctors and the caregivers call the family aside, you see, first talk with them. Here, they don't mind coming in to the patient's room and discussing the thing. Just a few days ago there was a doctor and a chaplain that went into the room and told them 'Ok, the . . . . do not resuscitate papers that you had signed—I don't know how much time ago—they expired yesterday. Are you ready to sign it again?' She had never thought about it again. Maybe she had signed it long time ago—this is the mother. The child is 17 and he's in the room. She was awfully uncomfortable talking or discussing the thing in front of her child. And here the doctor is pushing 'Ok, are you going to sign? Are you going to do it again? Ok, but you can have some time. You don't have to sign it today, but we want to know that, if you are going to do it.' And there was the child staring. . . . I think it was the most rude encounter that the doctor or the chaplain can do.

The notion that cultural differences in communication styles may be related to providers' perceptions of their vulnerability under the laws of the country where they practice was expressed by one interpreter.

Sergio: My impression is that they (providers) would say good communication is saying what we have to say, not keeping anything, not hiding anything, not delaying it . . . . They want to put it in black and white and then go and write it down in the chart—‘I said it, I wrote it, I documented it—ok, it’s there’ . . . . I would say it’s more protective—that the caregiver is protecting himself or herself from any discussions or any issues, or especially legal issues. And that is very complicated here. Many things are done because of the fear of a legal issue. And if the caregiver is motivated by fear, I don’t think he or she is giving the best care . . . . most of the families don’t understand, because the legal issues that you have here, we don’t have them in our countries. So there’s no place in their minds for legal action. They only receive the, I would say, the rude, the harsh discourse of the caregiver. But they don’t understand what’s going behind. That’s a cultural difference to the legal issues here that we completely ignore, and that motivates a lot of attitudes and communication styles.

*“Certain things are done differently”*

If death is, in the words of one interpreter, “very cultural,” differences in rituals, customs and mementos would be expected. At CMCD, it is customary for a provider close to the family to offer a “memory box,” either in the last moments of the child’s life (if s/he is unconscious) or shortly after the child has died—a practice that resonates deeply with many of the interpreters. The small box includes an assortment of cards which can be used for various purposes (i.e. to take an ink print of the child’s hand or foot, or for staff to write messages of condolence); a place to insert a picture of the child; and space to store mementos, such as a small plastic bag containing a lock of the child’s hair (which may be clipped at the bedside.) Usually at the same time, a disposable camera is offered to the family to take a photograph of the child before the body is removed for funeral preparations. Many interpreters were not previously familiar with this practice, and have seen families react in a variety of ways. They also observe that

families may not be ready at that moment to accept the box, and should be given some time to absorb the child's death.

Heriberto: . . . . I believe that there are some . . . . culturally-related situations where it, really the culture that gets in the way of communication, and not the communication by itself . . . . there are times when . . . . a patient died, the parents are offered the option of getting a picture with the patient . . . . that's a piece of communication that the providers do feel that it is important, but that's something that I have never seen before happening until I started working here. And it seems like that's culturally-speaking, expected on the American culture. But in the Latino culture I don't ever remember seeing something like that taking place—taking your picture with your son or daughter being dead already, as a memento for you to share . . . . I've seen all sorts of reactions . . . . accepting the picture and accepting the locket, accepting the box . . . . things that will physically help them, help them remember . . . . their child. I personally don't think that anyone will need anything like that to remember his son or daughter . . . . and I've seen reactions of 'No, no, thank you—I don't want to do that.'

Julia: . . . . certain things are done differently than we would do in the Hispanic culture, and which were quite shocking to me . . . . one of them would be like taking a picture right at that moment . . . . and that they even suggested it was to me . . . . just blew my mind . . . . apart from taking a picture there's this little memory box that the chaplain brings and they take the footprint of the baby and a lock of his hair . . . . And now that is nice—that's not what I'm talking about—I'm just talking about the picture.

Lurdes: . . . . when she asked me to tell that to Mom, the baby had already passed away, and I asked her first because I want to be sensitive also to the medical staff . . . . you go 'This might be offensive to the parents.' We're trying to tell them in a very sensitive way . . . . 'I want to warn you what the response could be.' And then when I saw the dad . . . . he was the strong guy in the family. Mom was . . . . 'Don't talk to me anymore.' So I talked to Dad . . . . I initially started 'This is something cultural from this country. This might affect Mom. Please, if you don't like this, it's fine, just tell me no' . . . . When I told Dad, he said . . . . 'You know what?—Don't even dare to ask my wife.' I mean he was upset . . . . And I told them (providers) that—not in a sarcastic way . . . . there's some parents, especially they been living here for more time probably they are already aware or familiar with this, with this custom, but they weren't, you know. . . . they had been here only for a short period of time. And it's cultural . . . . so it is awareness—it's just cultural awareness . . . . I wouldn't like to have a picture of my family member you know, already dead. I want to remember that person

alive and happy . . . because I identify because I am a Latino and I mean if I feel bad, I wouldn't like to be asked that question.

Inés: . . . some say 'I don't want pictures' and other ones say 'I do,' but the chaplain comes and says or somebody from Child Life says 'We take a picture and we keep it for six months and if you wanted to come and pick them out later we'll keep it for you.' Or, 'If you decide later that you want the picture . . .'  
. . . I've seen like a family originally say 'No,' then say 'Yes' . . . I think it's a little overwhelming for families to go to that thing right away 'cause they try to rush things—don't give the family time to . . . settle and understand what is going on . . . what is happening at that moment . . . they are not ready . . . I think it should be timed to let them go to step by step through the things before they rush things sometimes.

*"Prayer is good and all of that, but . . ."*

Another topic that resonated strongly with interpreters related to the ways they believe families react to chaplains at the hospital. Pastoral Care at CMCD offers spiritual and emotional support to families in times of death, however, some interpreters do not feel those needs are met for Latino/Hispanic families, for cultural reasons.

Cristina: . . . culturally, um, I think um, Hispanics create a very strong bond—and almost like another member of their family relationship with either their priest or their pastor. So to bring, to bring someone here from the hospital that's a chaplain that's a total stranger for them—I don't really think, um, I know, does not meet the need, their spiritual aspect of that, of that particular experience they're going through . . . the chaplains here are . . . caring and everything, but it's just, it's just awkward for me. Um, when I'm trying to, especially if they're praying, um, because I think, I don't know—it's just awkward.

Emilio: . . . prayer is good and all of that but . . . to bring the person who's here, who's a paid person at the hospital to do the role of the spiritual or comforting person is really, is really awkward for some . . . some families ask 'Who is this? Is this a priest? Is this a Catholic priest?' or 'What kind of religious person is this?' In some cases they are . . . they're just the person appointed to do the emotional support. . . that doesn't fit very, very well with the Hispanics.

Julia: Every time that I ask 'Would you like for the chaplain, for us to call the chaplain?' I have to explain it's the hospital's priest, the hospital's pastor—I always have to explain.

Paloma: Sometimes you even have to go deeper than that because . . . if the person is Catholic, and you say 'I can bring the hospital's pastor,' they'll go like 'No, I don't need a pastor.' And if they're a Christian, and I said I'm gonna bring a priest, they say 'No, I don't believe in priests.' So you have to go more deeply and say that it's somebody that can give you emotional support.

### Perceptions of Role

As interpreters recounted their personal experiences with end-of-life conversations, concepts of role emerged. Several interpreters talked about the obligation to convey meaning, which may involve interpretation of cultural nuances and expectations. How interpreters are perceived may vary according to whose perspective is considered. While some of the narratives illustrate interpreters' self perceptions, others illustrate family perceptions, and others illustrate providers' perceptions. (In addition to the narratives that appear below, other supporting narratives for this theme appear in Appendix G.)

Raúl: The main thing about the difference between interpreters in the legal ground and the interpreters in the medical field is that we . . . communicate the meaning of the conversations . . . in the legal field, you interpret things perfectly . . . you have to interpret everything that is said exactly. But in our field, you have to interpret things as said also, but make sure that the goal, the goal is that the message is getting, is the main thing that goes to the family or the patient . . .

Emilio: I think there's uh, there's a difference, cultural difference between, uh, what is said in a conversation for uh, for an English-speaking family versus a Spanish-speaking family . . . I guess what I'm trying to say is the, the approach is different. So if we are interpreting, we're not only interpreting the conversation, but also the, the feeling towards the, towards that kind of, ah, situation. We're trying to convey a message between two cultures, so it's not the same as just interpreting the conversation, or what is said in the conversation . . .

it's not only the communication, the language—we know both cultures. So we understand all the little things that come with culture.

Ernesto: . . . . I suppose the expectations from Hispanic parents, uh, what is it that they're going to hear from the doctors might differ because they are Hispanic. They come from a different culture, as to what the doctor expects the parents want to hear . . . . it makes a difference, the background of the person to the things that you should say to them so that they understand the situation.

*"A key role"*

Interpreters recognize that communication flows through them. They believe that participants in the conversation depend on them to function effectively in a role that requires them to observe interaction closely and act in ways that accomplish the goals of the communication for all parties.

Lurdes: . . . . when you are interpreting in an end-of-life situation, somehow interpreters become like the focus because every single part, Child Life, Pastoral Care, doctors, nurses . . . . use you to talk to the parent.

María: . . . . I think like, the interpreter has a big part in the quality of the communication—I mean literally, right? But, but the way that you set up the conversation at the beginning has a lot to do with how it goes during the rest of the session . . . . from my perspective, if you have a relationship with the family then that is already sort of part of the setup, you know. But if it's the first time that you are coming to talk with them, then, then I think that by letting the um family know ahead of time, even before you start interpreting, that this is a place where um their participation is going to be significant and that they have every right and confidence to ask questions and make comments and let their wishes be known . . . . sometimes . . . . they're on this emotional charge that you know, is very difficult—you're in a different environment from your normal, everyday life if you're in this situation and you have this sort of fog—so it's good to help people remember that 'Yes, you can ask questions,' that this is a safe place, or 'People are going to listen to you . . . . according to what you have to say' . . . . I tell them 'Make sure that you say everything that you want to say, and if there's a comment that you want to make in the middle of the talk, then go ahead and make it,' and then ask the question, 'Did you get all your questions asked?' . . . . I think regardless of whether the doctor says 'Did you get all your questions answered?' I'm gonna say that as an interpreter because they, this is the opportunity they have to talk with the doctor . . . . And I consider that part of closing the session. If, if

as the interpreter . . . . I'm managing the communication and I know that there might be something left unsaid . . . . I feel the obligation to give the opportunity to have that interaction. I'm not telling them what to say, but I, I think that they need to have that . . . .

Víctor: I think you have a key role as an interpreter because everybody's hinging on you . . . . I walk into a room and I listen to see what's going on. And I'm looking at the mother, I'm looking at the doctor—I'm doing whatever the doctor's asking me to do. I'm looking at the mother and I see that this woman is about to fall apart. And that's when you alert the provider that there's a problem here—'Your parent is nowhere near capable of understanding a thing you said'—nothing to do with the words. She hasn't eaten in 48 hours, she was beaten at home, she doesn't have a penny to her name, and her husband has eloped with some, somebody else. How can she even possibly hear this discussion when all this other stuff is sitting in there? You gotta clear that. And if the doctor isn't seeing that, you are, for whatever reason he isn't, because you are the trafficker, you can understand both languages, or because my focus is on the entire room, whereas the provider's is on the patient. So I have a different perspective, that's all—not better, it's just different.

Emilio: . . . . the main person who makes a good clear conversation is the provider—himself or herself. But then, there is the role of the interpreter there—we're in a way, in a way we're moderators of the flow of the communication. To give you an example, if the doctor's talking, giving the message, and Mom's crying, I just stop interpreting. I just stop because the doctor wants to keep going, finish, and leave. But communication is not happening in that case because Mom is not listening to the information. So then if I just keep on interpreting, my words will be lost—lost, and nobody would acknowledge a good communication or interpretation. So in that sense . . . . if you notice that the parents are not understanding the information, then we can, we can clarify or we can stop. If everybody, if the doctor and the parents are talking at the same time, I just stop. Stop. In that way I'm the moderator of the flow of information in the room.

*"You're their connection"*

Interpreters are fully aware that families may feel a bond with them stemming from a shared language and perhaps culture, and some described experiences that illustrate how families reach out to them during moments of intense emotion.

Cristina: . . . . sometimes I have encounters in my day where I'm, you know, standing there and the person that I'm interpreting for takes a break to go get something or answer the phone or something, and the mom starts talking to me, you know, sharing about, you know, uh, 'They haven't told me this' or 'Do you

know where I can go do this?' I mean because you're, you have to understand—this person that you're helping doesn't speak any English, so you're their connection to you know, this environment that they brought their child, and you know it's an instant connect, whether you want it or not, so it's very difficult.

Emilio: . . . . I remember a case . . . . I was in the room and um, other people were trying to help Mom, but Dad was crying a lot so he came to me—he made a connection to somebody who understands me culturally. And he came to me and he started crying on my shoulder. It was, it was very hard. But we have to do it.

Inés: I am in the, now working in ambulatory surgery now. A baby passed away suddenly so then here I come, with both providers, there is the anesthesiologist that saw him, and I was behind them because I was going to interpret for them. As soon as we opened the door, and the mother and the grandmother saw us, they just grabbed me . . . . they just hold on to me, start crying, then they know that it's you, the person that is going to be with them. Everybody was in shock of course because it was something that nobody expected that going to happen.

Interpreters believe providers recognize that families seek emotional support from interpreters, but they also feel there are times when providers take advantage of that connection and use them as buffers for their own emotional distress.

Roselia: . . . . once when I was in a care conference . . . . I was sitting between the mother and the father and I gave them the information the doctors wanted them to have, that there was nothing else more to do about the child . . . . he was ready to be disconnected and the mother just finally just started crying and turned to me and grabbed me and wouldn't let go. And just crying and crying. And what I did is just embrace her with all the love that I was feeling at that time for her, not even saying a word, and the doctor allowed the mother to cry for a pretty good four or five minutes without letting me go. And I was just tapping her shoulder and embracing her and the doctors just waited there and then after the mother had finished, one of the doctors said, 'Thank you Roselia for responding the way you did.' But for me there was no other way to respond.

Inés: . . . . so many times the providers want that we stay there just for the emotional support for them knowing that somebody that speaks the language, that understands the culture, will stay with them to give them support. Even sometimes we're going to leave if the provider finishes . . . . they say 'Stay here

because they need you at this mo, in this moment they need you, and we need you here . . . .’

Emilio: Yeah, and sometimes they push you, like the social worker and the chaplain use you as a shield and, and they push you back in the room and they stay out because they, they want a little relief or something.

Cristina: Yeah, because they can’t handle it, ‘cause they don’t know how to speak the language and here is this person going all emotional on them we we’re uh, like he said, like a barrier.

*“I feel related to the parents”*

Families identify with interpreters, but interpreters also identify with families—both culturally and as parents. This emotional engagement can be challenging, but it also allows interpreters to provide insight to providers as families react to difficult news and make decisions.

Inés: . . . . it always have an emotional impact on me . . . . I only think in the mother . . . . ‘cause I am a mother. Then I think ‘Oh my God, I just can’t imagine what the mother is feeling,’ you know . . . . then becomes my personal feelings in that situation. When I am there I am . . . . doing my job as a professional and everything, but you always pray and think in that mother, in that family that are going to have that loss no matter what . . . . I’ve had the experience before being a mother and after I’ve been a mother . . . . it is a big difference . . . . Even, before I felt . . . . you know crying and stuff. Now, my feelings are different because I, nothing is compared with the feeling of being a parent. Their love for their children is not compared with anything.

Emilio: It’s different when you’re a parent. For example what one of my coworkers, he, he’s not married, he doesn’t have any children, and he can handle some of these things easier then, because I feel related to the parents because I have a daughter. So I can, I put myself in that situation.

Raúl: Well, I think my, my culture, my education, I feel that it just, it plays a really, really important role that I identify a lot more with the families, about what’s going on in their minds and when, when they’re going through one situation. Some families they do have, you know outrages—they might seem outrageous reactions to some things or that they’re needing to start onto one thing or another. But because I belong to the same culture, I have the opportunity to

understand that, and to communicate to the providers a little more insight about why they're, whether they're taking one or the other decision.

*"It requires a lot more stuff—not just the words"*

Some interpreters question whether providers appreciate their emotional stamina, understand how they function in an encounter, or recognize the diversity of their skills.

Without that awareness, they feel that providers don't value the ways in which interpreters can contribute to the quality of an encounter in general and the quality of the communication in particular.

Raúl: . . . the end-of-life communications . . . are certainly, and really a real heavy load for interpreters to cope and . . . it does take somebody with, like I don't know if you have that . . . expression in English—stomach—with a lot of stomach, and to handle it, because it's not for everybody—not everybody can see . . . the things that you see, and say things that you say, and be in situations that you are. It's difficult and really it's, we are privileged here to have, you know, people who are special that does this, and, in their own way, definitely in their own way, but is able to handle it . . . not everybody can do it.

Víctor: I think that the role of the interpreter is widely misunderstood, and that I'm sitting here with some wonderful colleagues whose talents are not being used right, appropriately . . . a lot of people don't have a clue what we do or what we can do. I think they need to expand their awareness of what's available with good translators, you know, interpreters, because this hospital has some excellent ones.

Sergio: . . . I think that some caregivers are too rude, too disrespectful—of attitudes—of culture. They, they never ask me 'What do you think? What's, can we explore a little bit thing about what Mom is thinking, what Dad is thinking, what the family is expecting.' No—they have something in mind and they go straight . . . I would try to understand it as a cultural difference . . . the thing is that the attitudes are different, in Hispanics and Caucasians . . . if attitudes are different, communication is not the same—should be different. Because you have certain specific considerations . . . maybe when you're going to deal this, the subject of end of life, just the caregivers who are going to come in to sit down with the interpreter and say 'Ok, this is the situation we want to discuss' and together plan a strategy—'How could we put this subject on top of the table with

the family?' . . . I think that if interpreters were taken into account I think things could be much, much nicer. But we're never asked . . .

Victor: . . . you know most of the time we're seeing pretty mundane things—it's a cold, and diarrhea, and snot, that sort of thing—you get 90 per cent of that . . . but then you get slammed with something that, that is truly, that you will never forget in your life—in a moment. And so I mean for instance, one of my fellow translators, Paloma, she had just started here and she's in the uh, emergency dock over there just as an ambulance is coming with a family DOA child (dead on arrival), and the mother basically falls in her lap right there on the dock while they're trying to take care of this kid. She just starts here, and she has to console this mom who's hysterical, and she's never been through this before. I thought what a way to get started. And I don't think we've done that kind of, the necessary preparation for us because again I think it is perceived as something almost trivial, you know, the interpretation. That—oh yeah—anybody that speaks Spanish—can just throw, 'Throw 'em in there.' You know, 'That's fine—you speak Spanish, you come over here'—throw 'em in there. And it requires a lot more stuff, not just the words . . .

Cristina: There's times that I've been called and I get there and they say 'Oh, we don't need you. He used so and so'—housekeeper, secretary, you know. Didn't even bother to call, doesn't even bother to turn and say thank you for coming.

María: . . . I got very angry with the chaplain in a withdrawal of life support situation because it was clear to me at that point that people really don't have a clue as to what interpreters and translators do . . . before the baby was taken off of the life support, the, the, a lot of family had gathered um in the room and so they wanted to have some prayers. And so the chaplain says 'Ok, I'm going to open the Bible and read the Twenty- Third Psalm and then I want you to interpret.' And I just turned around and looked at her and I said 'Excuse me?' I said 'Just one moment please'—fortunately, not 10 seconds earlier, I had seen that there was a copy of the Spanish Bible in the foyer, the anteroom to the ICU room. And I said 'Let me go get the Spanish Bible that's sitting over there'—'cause that work was done 500 years ago or more. You know, I wasn't about to like interpret the Twenty-Third Psalm off the top of my head, just out of you know, memory or whatever . . . And it really, I was in shock that, that she just had no clue what she was asking me to do. I mean people know the Twenty-Third Psalm by heart, and like I don't happen to know it to recite it with her. You know, there's already certain words that are set up for that. And um, she really didn't understand because then after that, um, she proceeded to um, pull out a rosary book . . . and I said 'You know, I really shouldn't be interpreting this. This is, it's a rosary, I, I think it's a rosary, I'm not actually Catholic,' um and so I don't know what, what

book I needed to look at . . . and I was already so mad that I didn't think on my feet to ask if someone might have had a rosary book in the room . . . fortunately I have a good command of religious language because I used to work in a church in Spanish, and so I think I did ok but, and I kept looking around to see if I'm like 'Oh my God. How is anybody going to react if I'm just interpreting off the top of my head this prayer, this written, established prayer?' . . . And I have heard some interpreters say that they really ask the dispatchers 'Do not send me to an interpreting assign, encounter with the chaplain—if it's chaplain, don't send me.' Because, religious language is very specific, and you don't, if you're not comfortable with it . . .

### Complexities of Performance

Perhaps the concept that most consistently permeated the focus group and interview discussions was the emotional impact that end-of-life conversations have on participants. Many of the narratives focused on how interpreters attempt to manage their own feelings as well as the delivery of the message during these encounters. (In addition to the narratives that appear below, other supporting narratives for this theme appear in Appendix H.)

### *Managing Emotions*

As they recalled specific encounters, some interpreters described their earliest experiences with end-of-life conversations; some described especially difficult encounters; some described conversations that evoked conflicts of emotions; and others described attempts to balance their attachments to families with a need to create emotional distance in order to perform effectively as interpreters.

*"You're the one that has to tell them"*

Elena: When you walk into a hospital room and they're already doing CPR, it's bad. And it's most likely going to end badly. And so, the staff is in there and the parents are standing there . . . was like 12 people in his room, and I walk in and I'm just standing there with them and I know it's bad because I'm

part of the medical staff . . . . The parents don't know that and I can't tell them anything . . . . you hear the staff like saying 'Give me this, give me this, give me this, give me this.' And I'm not going to interpret that because it, I mean they're not speaking to the parents and so, I'll be like 'They're just giving him medicine, they're doing CPR'—you know, the basics . . . . 'This is what you're seeing them do right now.' But I'm not interpreting everything they're saying. And the moment they said 'time of death' and my head just dropped. Because I knew, I mean—that means something to me—that doesn't mean anything to them. And the doctor still hasn't told them anything but they've just 'called' him . . . . as soon as they stopped doing compressions, I mean I was already crying . . . . the doctor was coming over . . . . to tell them there was, it was too late, he was dead . . . . But still, in that situation . . . . I know the parents are standing there not having a clue what's going on. I mean they see they're doing CPR but they don't know that that's really bad. And too, when they call time of death . . . . they've done everything they can do . . . . And I know that before the parents do and that's hard . . . . The worst part out of all of that, because usually the parents don't understand enough English to understand that—is that they listen to the doctor, they're looking at the doctor, while the doctor is telling them, they look at you—'What did he say?' You know, even though they're supposed to be looking at the doctor but they're like 'Ma'am?' you know, and you're the one that has to tell them in the words that they're going to understand the worst things they're ever going to hear in their life.

### *Early Experiences*

Cristina: When I started working at (this hospital) that was one of my earlier experiences—the end of life—interpreting, and uh, I felt so inadequate about it . . . . I think that in pediatrics, it's, it's very unique. I mean, it's a difficult situation . . . . whether it's an adult or children, but I think with children it's, it's so much more difficult . . . . the first one I did—I was totally unprepared for it . . . . I remember (the dispatcher) told me . . . . this is what this is, and so I thought I could handle it. But once I got there, I mean, I broke down—broke down in the middle of the interpretation like a baby . . . . I've noticed that as time I've gotten where uh, I can handle it better. At least I can stay, you know, more professional about it and um, I can do what I need to do . . . . it's not that you don't get attached, but you, I think your professional mode kicks in, you know?

Inés: . . . . when I came here, the first time that I went to an interpretation with that, I went and did, because you have to have your strength and everything, but as soon as I get out of that room, I start crying—the doctor grabbed me and said 'Is that a member of your family?'

Paloma: The first six months that I started working at this hospital, which was five years ago . . . . I cried for a broken nail . . . . I will wake up my grandmother in California—‘Please Grandma, you have to pray for this—I know you’re closer to God than I am. Please pray, pray, pray.’ And she’ll like ‘Yes, Sweetie, I will.’ And then my aunt called me once, ‘Paloma, you better stop doing this because you’re having your grandmother waking up every day. She’s praying for this kid that she doesn’t even know. You cannot take this job. You’re not going to be able to do it.’ And I kept doing that, kept doing it, and to my mom as well . . . . and she was so worried that ‘How can you do this? . . . . I know you—you’re not capable of doing this job, Paloma.’ I was ‘No, no, no, I will—I’m sorry, I won’t call you again . . . .’

### *Conflicts of Emotion*

Some circumstances evoke conflicts of emotions within interpreters when they participate in encounters which involve parental responsibility for the death of a child.

Cristina: . . . . another type of situation that um, I’ve experienced a couple times, which is um, when a patient, when a child dies due to abuse. And uh, that’s very difficult. Because at the same time you’re informing that parent, you know if he’s suspect of the injuries, and uh, it’s, it’s difficult, very awkward.

Elena: Every time it’s something involving something careless, like not buckling them in, or kids playing outside in street, you know, or playing out in the yard alone—Mom in the house . . . . and living close to the street and not being attentive . . . . I mean it’s hard too when you see a parent that comes in has run over their own child because the child walked behind the truck, or whatever reason. And it’s like ‘You can’t leave them alone!’ . . . . I mean that’s more of an accident . . . . not buckling them up is something totally different. Or if you say ‘Did put them in the car seat?’ and then they tell you they did but then later they say ‘No, he was in a different part of the car.’ So that—usually that’s the part where we have more, or at least for me, where I have more conflicting, because I’m like, if it’s the law, and it’s only the law because it’s going to save your kid. It’s not there to, you know, make your life harder—to take a couple minutes and do it—that’s the most precious thing you have. Take the time—I mean it’s not that long—30 seconds to buckle them in. And those are the things, because you feel so bad for them, that they shouldn’t have to be going through that, so you’re like ‘I feel horrible for you but, wake up!’ You know? . . . . so that’s hard when you are there . . . . I mean you have to, instead of fighting, though you’re thinking that and that’s running through your head—you have to put it aside and just, I mean, help the family with the situation they’re going through. Because in the end you can’t change anything—at that point it’s done.

## *Attachments, Distance*

A number of interpreters described their attempts to be “objective,” become “detached,” or to create “distance” during intensely emotional encounters. While some view these attempts as necessary tactics to allow them to perform their interpretation effectively, others acknowledge that distance is difficult to achieve, and under certain circumstance, may not be desirable.

Gloria: We have to deliver our interpretation very objectively—and without emotions. And for me, when I see a parent crying because the child just died, or is disconnected, and in a few hours, or in one hour, is going to die—what is hard for me is to see the mother crying and saying what she has to say and I have to interpret. And I do it—that does not interfere with the interpretation. It’s just that some tears roll onto my cheeks, and I have the tendency because I’m Hispanic to hold and touch, while, like consoling, because I cannot verbally do it because I need to be the voice of the chaplain . . . .

Víctor: . . . . my worst situations were completely unexpected. . . . the way I defend myself, and after two years doing this, I used, I’m very visual, and auditory—forgive me for borrowing this from Star Wars or Star Trek—but it works. Whenever I see a call that says for example, ICU, or um, trauma, one of those, I say to myself ‘The shield’s up.’ I need it to create this wall just to, to know that I’m gonna walk in here and have no clue what I’m gonna be hit with, but I better be ready. That’s me . . . . when I put shields up, that means to me I back out. I sort of take a more logical—‘cause I can get sucked into this thing so fast as it happened. I think probably my worst, my two worst situations I didn’t have my shields up and I took a blow. I mean, one of them I had to stop, just walk out because I was just shattered, and so I had to really put myself together again before I could continue. And I can’t do that when it’s something that critical. I have to hold it together. I, there’s a lot of other people falling apart around me. I can’t—they cannot afford me to also lose it. And so I take that stand, more of a detached, logical, cold, try not to feel a thing, you know just keep it very objective. It’s not easy to do. But anyway, that’s what I do.

Raúl: . . . . we all have different theories right now . . . . what do you do when you are interpreting. To me personally, for example, when you are interpreting, you have to, no matter what’s going on, you cannot break, you cannot break like crying or anything like that when you’re there because you have to be the strong

voice in there. You have the responsibility to be the voice and you have to be the strong one here. And, if you break to one side or the other you cannot be an, effective as a communicator. It might be cold sometimes, it might be thought, I mean, some of my colleagues told me that, that I'm a little too cold sometimes, but I'm really trying to detach myself a lot, I mean, as much as possible from my emotions, and just go towards the communication and obviously make the communication the best possible that it can go. . . . I don't think it's the place of an interpreter to go there and hug the family and comfort them or anything like that, because that's not the place of the interpreter. I mean, I may be wrong. . . . You know, there's things that you do, there are some times that you do things that you feel like, proud, because you did a pretty good consent form, that you explain it to the family, you say—'Ahhh, I feel good because they understood, they got the message' . . . but you don't feel right about that, you don't feel good about . . . communication—no matter how good, how well you do it, you don't feel satisfied with that . . . end-of-life encounter. It's hard to feel like 'I did good.'

Ernesto: . . . in these encounters of end-of-life is when I put more distance because I have to concentrate so much more on every single word. I cannot filter anything at all, you know. Usually as an interpreter we interpret concepts. When a doctor is speaking, uh, you may try to go word for word, but it doesn't correspond in Spanish most of the times, because there are different structures, they are different languages. So you interpret the concept as closely as using the words the doctor uses. But uh when you are doing an end of life, you really want to get a lot closer to the words he's actually saying—every single one of them. He's saying an article here, then you have to find a way to put it in there. And it's a very intellectual exercise to actually do that. So that's the time I think when I try to step back even further . . . when I go to these places I have my shields up and you know, full speed ahead and damn the torpedoes and all that stuff. But really, the moment I step out of my house when I know I'm coming to work here, that's the moment when I start preparing, 'cause who knows? I mean, I have a dispatcher working with me and she might find out some of this information for me, but I may not. So I'm gonna have to find out on my own. And even if I find out two minutes before and I'm prepared for those two minutes, it might not be enough, you know. For example these DNR requests, or um, funeral arrangements, or um, I don't know, Child Life speaking to the siblings—those are hard . . . But you know, no matter how long you prepare, if you allow yourself to be involved emotionally, some of the intellectual part is going to go out of the window, and you're not going to do your job as an interpreter.

María: . . . I think it's really um, it's difficult to put that distance when, like, for example in oncology there, you, I've seen the patient um so often in all the different stages of treatment, like maybe there's the initial diagnosis, and then there's some of the treatment and then there's difficult talks about how, you

know, whatever the tests come back as . . . so there's all these stages . . . then there's this time in between when their patient's not getting better. So you go through this whole thing, and, and, I've been consistently with these families and maybe sometimes it's you know a month, two months, three months, four months, a year um, you get to know them and then there's not any idea, there's no way that I can pretend to put a distance. I mean to me it sounds like a nice idea but . . . because of in my situation, I already, I know those people. I know how the mom is, I know how the dad is, I know what the dynamics of the grandmother are, the siblings . . . it becomes really hard . . . And if I were to try to do that sometimes it comes across as rude . . . it doesn't work the same way . . . I do make an effort to not get so involved . . . sometimes I think that . . . I don't want to say it's beneficial, but I don't want to say that it's detrimental that I have emotions about what the situation is. I don't think it's bad if I've been the interpreter throughout the entire three-month hospital stay and the day that you know we're withdrawing life support that I cry. That's just human, and it's gonna be that way . . .

Emilio: . . . after 10, or almost 11 years here I've noticed that in some cases I'm able not to get attached to the situation . . . I can compare it, this to those situations when I just started, or my first three or four years. After one of those conversations I would be depressed for several days, for a week, two weeks, just remembering the whole thing. And um, and thinking, well, how is that the doctors don't show any emotions? And some, some do and some don't . . . and for the . . . for the first like eight, nine years, oh, probably seven, eight years, I had, it was very hard for me every time I went to one of these conversations. Nowadays, when I have some of these conversations . . . I don't feel it as much or as bad as I used to. And I feel guilty sometimes—I feel guilty after I get out of the room—when I'm driving home I feel guilty—I said—'I'm getting so hard.'

### *Managing Interaction*

Many factors can influence both the interpreters' ability to facilitate a conversation effectively and the way they choose to manage the interaction. Interpreters believe they perform under demanding circumstances that require them to be adaptable and perceptive, to take initiative, and to balance the sensitivities of all participants in the encounter.

*"Sometimes you don't know what to expect"*

It is not uncommon for interpreters to be dispatched to a call and not know the nature of the encounter they face. Even when they are aware, they often do not have much advance notice, and they may know little or nothing about the history of the case or about the patient and members of the family.

Luis: Sometimes I wish they (providers) were more sensitive to us, you know, to prepare us . . . . to let us know what to expect. I mean because . . . . you go from something very simple to something that it causes you a big impact, because you are, it's kind of unexpected . . . . you come in and say good morning, afternoon, whatever pertains, and uh, all of a sudden you find out . . . .the patient has been deceased for the last two hours. You know, it's difficult to absorb.

Lurdes: What I try to do . . . . is this—if I see that the opportunity, I ask the nurse or the physician 'Can you tell me a little bit of the background? What am I going to deal with now?' If there's time . . . . sometimes we get there, we don't know what are we expecting . . . . so I try, as much as I can you know, to maximize the time, use it, but sometimes you don't know what to expect.

María: . . . . if the interpreter can get as much information on the situation as possible, so you know what you're walking into . . . . I think that sometimes these conversations happen several times over because you can't get everything in the first time you talk about it, or the second time you talk about it. Maybe the third time you talk about it with um, they finally start to dawn 'Oh, my child is so sick that they're terminal,' you know, that this is going to cause them to die, or they're going to die from complications or whatever the thing is. They might not get that until the third or fourth time that you talk about it. And so you might be the interpreter that comes in on the fourth time that you talk about it, but somebody else was there the first and the second and the third, but it's the same, hopefully, and not necessarily always the same provider, or different providers. But whatever information they can offer it's good to be able to know where they understand . . . . the situation is. And what I think is more difficult is to really get a sense of—you know, we can get the side of the provider more easily because we're hospital staff. But also getting a sense of where the family is is sometimes difficult, but that clearly would um, impact the, the quality of the communication.

## *More Than Language*

Interpreters understand their requirements for language proficiency, but they also described a need to be attuned to what may be taking place beyond the words—an ability to recognize non verbal behaviors, assess their meaning and respond with actions that further the communication process

Víctor: There's two things that I've learned, sometimes the hard way. Two key ingredients to any kind of an encounter—one is to first—I have my ears really tuned—I call them my sensors, you know—walk into a room and I get a sense of what's going on. Sometimes nothing is said and you know that there's a big problem. There's tension—you feel it—you know something's wrong here. So then the doctor starts . . . you gotta see, ok, where is the problem? And then direct the conversation a little bit . . . to tell the doctor 'Hey doctor'—that's the second element—one is to listen, and the second element is to make sure that everybody in that room that has a role . . . understands what's going on . . . You smooth things so that, so the communication can happen.

Sergio: Very often we perceive . . . the Hispanic families have some very different attitude towards death but you, there's not a chance to explore—what are they thinking? What did they mean? Did they have a religion? Do they believe in God? Are they waiting for a miracle still? . . . But caregivers never ask 'Are you ready to let this happen? Should we stop here?' . . . exploring the attitudes, where is each one in the family. 'What do you think? What does your husband think? What do your children expect of this child?' . . . Now the thing is I have . . . a little bit of further experience in non verbal communication, because I have a background in languages . . . we deal with the verbal and non verbal aspects of communication, and I've particularly done a little bit of, I would say research study, the meaning of silence . . . Sometimes when a person doesn't speak he or she is saying much more, and much more profound, and much more intelligently . . . Sometimes I feel this mother is uncomfortable . . . she has something that she couldn't say. So very often I say 'Give me a minute. I think Mama has something else.' So I talk with the mother in Spanish . . . 'Just give me because I want to explore—there's something there that's not coming out and maybe it's important' . . . I think that in one way or another you can say 'Ok doctor, I got some answers but I don't have the complete picture that I want' . . . very often they agree, 'Ok, good that you explore a little bit more.'

### *Participants and proficiencies*

End-of-life conversations may be lengthy and involve many participants who arrive and depart at various times or bring varying levels of language proficiencies into the encounter. In this context, managing encounters can become even more complex when side conversations take place within the room, when family members disagree, or when parents speak intimately between themselves as they make decisions about care for their child.

Raúl: They can be very lengthy because there are like developments all the time. There could be 'Well, this thing is happening.' 'Well, this doctor's coming.' 'Oh I want this person to come,' and then this other person has to ask, you have explain the same thing to the same, to the brother and then the brother doesn't agree with this, and then, then, I mean there's all sorts of variances . . . .

Elena: . . . . if you see that family's interfering, I mean the family has a conflicting view of what the parents want to do, we have the option of pulling the parents out or asking the other family members to step out a moment . . . . sometimes the families, there's too much family and too much people I mean screaming and crying and, you know, that maybe you're not going to be able to talk to the parents or people, too many coming in . . . .

Elena: . . . . sometimes I'm interpreting for the parents and a family member then starts to speak to the doctor . . . . if it's end of life, you always tread a little more lightly . . . . So whatever questions they have, I just kind of adapt to the situation. If it's the physician or a nurse that's trying to speak in broken Spanish, I'm always listening. And if it doesn't sound clear to me, I will add . . . . I might change the word to the correct word, and just kind of interject here and there as needed. But as long as I see like the parents are understanding . . . . I just kind of let them be. If there is a family member, especially in an end-of-life conversation, that speaks English and is speaking directly to the provider, I immediately switch to interpret from the family member for the parents. So I interpret between their own family . . . . sometimes we come to a situation where we ask the parents 'What do you want to do?' . . . . And if they're discussing among themselves I will tell the doctor they're talking about what we just told them. They're trying to come to a decision between themselves. . . . I'm always listening in case something sticks out, like . . . . 'They're having questions about

this,' or 'They're not sure what you said about this,' or 'They're talking, saying this, but you said something else,' you know—in case there's something that could be clarified . . . for the most part, if it's the two parents discussing between themselves what they want for treatment for their child, I don't interrupt. We just let them talk. And I'm not interpreting.

Varying levels of language proficiency can also increase the potential for misunderstanding on either the family or the provider side of the conversation. Families may question the interpreter's rendition, or providers may question the interpreter's choice of language. In these situations, participants' confidence and trust in that interpreter may be threatened.

Raúl: . . . it's difficult when you are in an encounter . . . when you have the family . . . the mom and the relative that speaks English—speaks half English and half Spanish. That is difficult sometimes, many times, because they can even, they can get the interpreter off balance a lot. I mean, they can interpret in terms of understanding one thing themselves and they think that you are not interpreting the right way. They can blame you inside of the room . . . the family, I mean . . . The same thing with a relative that either, it's a relative, or a friend from church or whatever and we're talking end-of- life conversation, and many times the end-of-life conversation crashes a lot with the friends from church, because that's the church friend that says 'Oh, no, no, no—they're killing your child—they are letting your child die' . . . and then if they speak English or something, they start saying something different 'Oh no, no, no, I hear that the doctor is saying that he might be living, he might survive' or something you're saying, and it becomes like a really big mess . . . and they take it against the interpreter. The interpreter just ends up, you know, being the bad guy there.

Raúl: . . . one of the providers speaks a little bit of Spanish and then you're saying something, a word that they're not used to hearing from, because their limited language, and they start questioning you in that 'No, no, no—I said *that*,' and then that just kind of like gets you, throws you off the track because you have to be like, to earn the trust of the family when you're there. They have to, to have it as a given that you are trustworthy interpreting in that room. You know because if not, they're just not going to feel well at all. They, this thing can bring so many other problems, so you have to say, you have to tell the doctor 'No, I used this word because it's equivalent to this and this and this and this . . . you're understanding something else.' But, it could be very, like it starts getting a little

tense inside of the room—it can involve an interpreter in that situation because it gets the interpreter in a tense situation.

*“In the line of fire”*

In addition to the vulnerabilities they may feel with a variety of language proficiencies in the room, interpreters also talked about how as “the messenger,” they are vulnerable to the perceptions of others in the encounter.

Paloma: And keep in mind that sometimes, usually, parents don’t know anything. And even though you’re next to them . . . and the doctor says ‘Well, your baby, I’m sorry, but has passed away’ and you don’t see the reactions on them. They’re waiting for you to say it . . . and it was like, ‘Oh my God! So it took me like a little brief moment to, and just say in Spanish, ‘I’m sorry but your baby just passed away.’ And they look at you—they don’t look at the doctor.

Inés: And they just grab you—they just fall into you ‘cause you are . . . support at the moment, that the pillar that (they) have there at that moment to lean on.

Paloma: I had one that almost tried to hit me—that ‘Why am I saying that?’

Julia: . . . they get angry, and you know, they don’t get angry at the doctor. Well, I’m sure it’s at the doctor, but still you are the one giving the news . . . so they want to hold you accountable for that.

Cristina: Yeah . . . you’re the messenger.

Emilio: Yeah, they tell you ‘But you told me that everything was going to be ok’ and then you have to say ‘No, I’m sorry, I didn’t tell you—the doctor did. I interpreted that for you.’

Cristina: Yeah, and you have to understand, it’s, it’s horrible so they lose all perspectives, so, you know, they’re gonna forget really, what your role is. They’re gonna put you, you know, in the line of fire, so to speak.

## Perceptions of Quality

### *"The way we are supposed to work"*

As interpreters talked about their participation in end-of-life encounters they often referred to what they understand to be the expectations for interpreting performance. They describe the need to be "accurate," "very objective," or to interpret "exactly the way the doctor is saying it." Some described themselves as "just a voice," or believe that they "should cause as (little) attention as possible." While some interpreters explicitly place responsibility for the quality of communication on providers, many described encounters where they acted as "clarifiers" and "advocates," which they believe improved the communication. (In addition to the narratives that appear below, other supporting narratives for this theme appear in Appendix I.)

Enrique: . . . . from English to Spanish I like to go, like very slow, you know, try to, you know, grab all the words and make you know, the most perfect interpretation. It's the way I do.

Roselia: . . . . the way we are supposed to work, and it's, those are the rules of interpretation, is that we are supposed to interpret a hundred percent accurate what the doctor is saying. Whether it's a good communication or is not a (good) communication, that really depends on the doctor.

Inés: . . . . the provider is the one that has to have . . . . a good communication in order to provide whatever the parents need to hear or to understand. As we see the parents, the expressions, and the answers back to the provider, we can tell if they are having good communication or not. Then we act as clarifiers, advocacy . . . . if the parents, we do that and we gave the parents information they need, or they are pleased with, we are good communicators.

Cristina: . . . . you have to understand that because the way we're trained . . . . we're not supposed to be in the room. You know, we're supposed to be transparent . . . . because as far as we're concerned, we're not there, in a way . . . . when they communicate . . . . I think that it's (the communication) only as good as the provider, but at the same time, because we have the roles of advocate and

clarification . . . . sometimes we make a difference—even if the provider isn't very good or isn't very clear.

### *Interpreter's Prerogative?*

Even as interpreters ascribe the primary responsibility for the quality of communication to providers, their active participation in encounters suggests ways in which they believe that they can also impact quality. In addition to actively managing interaction (i.e. as “moderators” or “traffickers”), there are times when interpreters intentionally intervene with language or gesture in attempts to make the message easier for families to receive. At times, interpreters feel they have some prerogative to choose what and how they interpret. In instances where they perceive a lack of warmth, empathy, or cultural understanding on the part of the provider, they may purposely change the tone in their interpretation, rephrase passages of the speech, or omit hurtful or offensive comments.

Sergio: I think the interpreter has to do many things to try to soften things when they are not nice, as much as we can . . . . for example using very direct language. You have to try and soften things . . . . Sometimes it's impossible . . . . sometimes . . . . I would say the care givers are so harsh, so rude, so disrespectful that the parents, the mother especially . . . . 'I don't want that doctor to come back into this room. I refuse to talk to him, and let him know that I don't want him in this room' . . . . the process is being done very poorly. Now if you see . . . . the parent is, you find that he ends up really hurt and uncomfortable, you know something is really bad. And sometimes it's impossible for us just to turn around things to make it a little bit nicer.

Heriberto: . . . . due to the nature of the uh, of the uh encounter, I'll be very careful to interpret with words that mean the same, but that are caring to an extent. For example, I can tell you when the . . . . physician says 'Your child is about to die' . . . . and I would say 'su niño/niña esta a punto de . . . . ' (your son/daughter is about to) and I have the choice to use the word 'morir' (die) or 'fallecer' (pass away), and I go for the softer one, which would be to me 'fallecer' . . . . they mean the same but to me 'fallecer' is more caring. 'Morir' is

too abrupt, too, too direct. And even though the outcome is the same, you are just being caring towards the parents, acknowledging that they are going through a difficult situation, nonetheless, the interpretation does not suffer in any way and it doesn't deviate the main idea. And it does not take away from the meaning that the . . . source of the information intended right from the beginning, which is to make the parents perfectly clear what is about to happen. And there may be, there are reasons for them (providers) to do it in x, y or z way. In many instances it might be because they want to make aware the parents that perhaps doing some extra support, it is no longer, medically-speaking, indicated. So, at times, that's why they may sound like too direct, and that's the way the interpretation has got to be done. Yet caring, using words that they understand . . . . that's really up to . . . . the style I guess, of the interpretation . . . or the vocabulary richness that a given interpreter has . . . . So sometimes it is a call that interpreters make at that very moment . . . .

Roselia: . . . . if you don't have a love for a job that you are doing you better change jobs. So in my interpretation that I do is no matter how hard the doctor is, in his words or how matter of fact he is, thank God, my tone of voice is of somebody that cares . . . . and just the tone of my voice makes a difference . . . . I see it every day. And that's where I'm grateful that I'm there—without having to change one word.

Paloma: . . . . my first week working here and that was the first thing I was told—you do word by word, word by word—doesn't matter what he said—if he said 'Doctor, you're stupid' you're going to have 'Doctor you're stupid'—I mean doesn't matter, ok? And I've had the doctor say 'Well Mom, uh, yeah, your baby's not going to make it—there's nothing else we can do—not even a miracle will save him.' And I will say, 'Well Mom, there's nothing we can do—he's really sick,' and 'I refuse to say the rest of what you said.' And he goes like 'What?' '(I said) 'Who are you to say not even a miracle's going to save him?' And he goes like—'You just say . . . . ' . . . . No, I'm not! And Mom will say 'What happened? What did you say?' and (I said) 'Mom, that he lost his hope . . . . but you keep praying.'

Elena: . . . . maybe it's not part of interpretation but we're human, and then these parents are going through the worst things of their life. If you put your hand on their back when they need it, it's not going to change anything for the worse, in my opinion . . . . and you might make it a little easier for them.

### *The Value of Continuity*

Interpreters noted that both families and providers value the continuity of an interpreter who has already established a relationship with them during previous encounters. They believe that continuity positively affects “the rapport between the parents, interpreter and the doctor,” but acknowledge that maintaining this continuity can be difficult, especially if staffing pressures require them to move on to their next call. Interpreters want to support the families they come to know, and gain some sense that their skills are appreciated when families want to specifically request them by name for future encounters.

Emilio: . . . . you the interpreter basically determines when the call ends. Because you're there, and they are not going to tell you, like, 'another case is in the ER' . . . . nobody tells you that. Everybody's busy, so the interpreter makes the decision, 'Ok, uh, I guess I've been here for 45 minutes, nobody's talking to the parents, nobody's saying anything, I'm feeling uncomfortable because I'm the only one staying here in the room, the social worker and everybody left' . . . . but then, you face that decision—'Should I wait a little longer to see if they need my support, or should I just get rid of this call?' . . . . You have to wait until somebody else has another update . . . . or the chaplain wants to offer some prayer, or the social worker wants to offer the little memory box or the nurse wants to tell the parents if they want to help uh, with the cleaning of the patient or funeral arrangements, whatever comes up. But they don't really tell you 'Ok, thank you, you can go.' And on the other hand we have as a pressure that if there's two or three interpreters in the hospital for the whole hospital at that time, you cannot stay there for five hours because that means that somebody else has to take care of the other calls. But at the same time you don't feel like leaving the family because you know that they need you there.

Paloma: . . . . do not pressure with time . . . . I mean from the interpreter's point of view. 'Cause you know we have just uh, uh a limited time of interpreters, and we or someone keep an interpreter for three, four hours because the patient has died. I think, it's a, you know it's a human being who is passing away and we should be allow to stay as much . . . .

Julia: . . . they've told us 'No interpretation is happening so you do not need to be there.' So you call, and say 'Ok, I've finished this call.' But I believe that it would be so much easier for the family, for the doctors—you're involved, you're on top of the case, you know what's going on—for you to be the same person going there time after time after time and that doesn't happen all the time.

Raúl: . . . obviously they (providers) like when the families feel comfortable with an interpreter and everything . . . they ask for this interpreter, for this other interpreter because he knows the family and he knows the case . . . the providers were asking for us, because . . . some cases . . . were like very difficult because of all the history of the patient—like bringing the family from Mexico or something . . . or if it was a cancer patient or something, I mean, you get a chance to get really involved with the family . . . The interpreters and the hospital personnel, you know, they work really close . . . the oncology cases for example . . . when the child has had a tumor . . . and then the tumor is being taken out, but then the tumor comes back and it gets worse and you know this is not going to have a good outcome, it's just going to end up being, you know, something really sad. . . . but we try to be discouraged because all interpreters have the same capacity to do the same thing—it's like nurses going to be just assigned to one patient specifically whenever they come, you know—they have to see other patients—they have to see a variety . . . we try not to establish one interpreter just for this because this is, it could be sometimes difficult to get this interpreter. We're supposed not to be part of the, in that sense of the encounter

Inés: And the parents really . . . thank us when we interpret for them and they understand everything . . . 'It's good that you were here,' or 'I would like—do you think that you could come back every time . . . ' 'Can I call you?' 'What is your name?'

### *Compassion and Commitment*

Although interpreters clearly remember difficult encounters where they felt providers did not serve well the needs of patients and families, they generally admire and respect the providers in their institution, feel they are compassionate and good at respecting cultural beliefs and practices, and are professionals from whom they can learn. Interpreters care deeply about their own work, and the gratitude expressed by families for their assistance is meaningful.

Victor: I hold the providers in the highest esteem and it is my sincere desire and hope to do whatever thing possible, whatever is in my power, to make them the best they can be in that situation.

Lurdes: You know there's a saying that . . . this might be very simple but, it's even a scripture in the Bible that I based on. It says 'Treat others as you would like to be treated.' You know, if I would be in the hospital, or my family would be in the hospital, I would like all the, you know, all the questions, I would like all the attention, I mean the necessary attention . . . working at a hospital I know that this is a busy place and sometimes it's hard to be sensitive and at the same time be alert, but I mean it's a, I think it's a gift—it's a gift we have to try to have it. You know so it's, that's what I try to do . . . if I treat this lady as if (this) would be my, my family, and then my job is done.

Roselia: I personally believe that even if it's just telling them about an update from a surgery or getting a consent for a surgery—in any moment we need to have compassion as an interpreter—compassion and care for what we are doing . . . you end up crying with the parents . . . at least the times that I have had that situation I end up crying with the parents . . . It can be the worst news you can have for anybody, but if there's no love in you, it's just going to be a matter of fact communication . . . That's the only thing that is within your control—the way you care. Because you are, the only thing that you are doing as an interpreter is you're interpreting what they say. But the way you say it, and the way you really care, what's in your heart, that's what makes the whole difference.

Cristina: Sometimes family members in end of life have told me 'Thank you,' at the end . . . that means that it had value to them . . . And it's, you know, a 'Thank you' that says it's more than a 'Thank you' . . . 'You were here, you helped us understand . . . we really appreciate it—we really appreciate you.'

## CHAPTER 5

### CONCLUSIONS AND RECOMMENDATIONS

#### Quality of Communication, Quality of Care

The objective of this research was to produce an exploratory and descriptive account of the perceptions of health care interpreters about the end-of-life communications they facilitate in a pediatric hospital setting. Three research questions were identified when the study was conceived: (1) How does interpretation of end-of-life conversations qualitatively differ from interpretation of non-end-of-life conversations? (2) How do interpreters describe their personal experiences of interpreting end-of-life conversations involving patients who are children and/or their families? (3) Do interpreters perceive themselves to have a role that impacts the quality of end-of-life care for terminally ill children and their families?

The premise upon which the value of this study lies is that the quality of the communication between caregivers and the patient and/or family is important because it is intimately linked to perceptions of the quality of care. In research on the quality of care for children terminally ill with cancer, Mack and colleagues (2005) concluded that “for parents of children who die of cancer, doctor-patient communication is the principal determinant of high-quality physician care” (p. 9155) and that parents valued communication “that was delivered with sensitivity and caring”(p.9159). In another examination of quality of care from the parents’ perspective, Homer and colleagues (1999) found a strong relationship between “problems with information to parents” and “parents’ overall ratings of quality” (p. 1125). In addition, that study reported that

aspects of “the partnership between the family and care providers” were also important to parents’ perceptions of quality of care (p. 1125).

For the small number of Spanish-speaking families who participated in a needs assessment conducted as part of the development of a palliative care program in a children’s hospital in California (Contro, Larson, Scofield, Sourkes & Cohen, 2002) “the lack of a common language compromised parents’ ability to acquire complete information and to fully understand their child’s medical condition, treatment, and prognosis” (p. 17). The researchers also reported that “a barrier to trust and confidence in the medical team” may be created if cultural expectations are not met (p. 17). Spanish-speaking families in that study “reported feeling isolated, confused and distrustful of the hospital system” (p. 17).

In the case of the present study at Children’s Medical Center Dallas (CMCD), the interpreter’s participatory role in end-of-life communications becomes relevant when issues of quality are explored for patients and families who do not share culture or language with their providers.

### Narrative Themes

The narratives that appear in this thesis were selectively chosen to speak directly to the three research questions that framed the inquiry. Some of the narratives were representative of participants’ views on particular subjects; some were selected to illustrate a range of interpreter responses to a particular topic; and some were intended to represent observations or experiences that resonated deeply with individual interpreters. While the narratives presented do not necessarily imply consensus on individual topics,

the overall weight of the data collected supports the finding that the unique characteristics and nature of end-of-life conversations create challenging and unique role and performance demands for interpreters. As active participants in these conversations, interpreters frequently and often autonomously intervene in a variety of ways to affect the communication process between care providers and families. Interpreters, along with providers, can be “deliverers of bad news.” While they may view the provider as having the central role in such conversations, interpreters’ descriptions of various aspects of their own performance during end-of-life conversations illustrate the pivotal nature of their own participation in many of these encounters.

The present research findings were reported under four primary themes that emerged from the data. The first focuses on the nature of end of life in the context of the interplay of situational, emotional, interpersonal, and cultural milieus. The narratives presented here illustrate that interpreters at CMCD recognize the varied circumstances under which end-of-life conversations take place as well as the variety of providers and patient/family members who may participate. In an environment of heightened emotions and cultural differences, interpreters may be required to deliver news of a child’s sudden or unexpected death from illness, trauma, or a surgical procedure, or may be required to facilitate a series of conversations which take place over time with a family whose child is diagnosed with a life-threatening condition. They are asked to interpret encounters that may deal with decisions pertaining to “do not resuscitate” orders, the withdrawal of life support, or a transition to hospice care. Interpreters also consider a variety of post-death conversations to be end-of-life encounters, such as the presentation of a “memory box,”

pastoral care visits for prayers or assistance with funeral arrangements, informing siblings of a death, and discussion of autopsy results. They may interpret conversations that involve as few as one parent and one provider, or be called to encounters where multiple providers speak with a large group of family members whose close friends or valued members of their faith community are also present. Physicians, medical students, nurses, chaplains, social workers, and child life specialists are among the providers for whom they interpret.

The second theme, perceptions of role, highlights the different ways in which concepts of the interpreter's role emerged, depending on whose perspective is being considered. The narratives reveal that interpreters perceive themselves to have an important role in the encounter because, as one interpreter noted, "everybody's hinging on you." They believe that families feel an "instant connect" to interpreters through language and culture and may view them as someone—both figuratively and literally—to "hold on to." In addition, interpreters themselves often identify with families through culture or as parents. Regarding providers, some interpreters openly expressed doubts about whether they understand the emotional demands placed upon interpreters, appreciate the ways in which they function during an encounter, or recognize the diversity of skills they employ during end-of-life conversations.

The third theme, complexities of performance, deals with the ways interpreters manage their personal feelings as well as the interaction among participants during end-of-life encounters. Some of the narratives reveal how interpreters responded to their very first end-of-life encounters at the hospital; others highlight the dilemmas of emotional

conflicts of interest; others illustrate how interpreters balance attachments to families with the need to create a distance that they feel is necessary to allow them to perform interpretation effectively. End-of-life conversations may be complex interactions—they can be long and may involve many participants who bring varying levels of language proficiencies into the encounter. At times, interpreters feel their performance is vulnerable to misperceptions by other speakers in the room.

Several of the narratives that appear under the fourth theme, perceptions of quality, express interpreter opinions that are consistent with what Norris and colleagues (2005) described as a “tension between providing strict interpretation and being an advocate or cultural broker” (p. 1019). Still, there are times when CMCD interpreters feel they have some prerogative to choose what and how they interpret. Interpreters also described how families and providers value the rapport that is created when an interpreter who has already established a relationship with them returns for subsequent encounters. This perception is similar to the findings of Contro and colleagues (2002) who reported that families “stressed their need for a familiar person to deliver difficult news about diagnosis, treatment, and prognosis,” which “was especially critical with the news that their child was going to die” (p.16). Pressures of time and staffing have resulted in Translation Services Department policies at CMCD that are intended to make efficient use of interpreters’ time. Although family or provider requests for specific interpreters might be viewed as indicators of confidence and quality, the interpreter’s need to move on to the next call sometimes impedes continuity. Finally, under this theme, interpreters

describe how deeply they care about their work; how they want to represent providers in a positive light; and how much a “thank you” from the family means to them personally.

### Valuing the Interpreter’s Perspective

CMCD interpreters recognize that they are active participants who perform a variety of functions during end-of-life encounters; they believe they possess a repertoire of skills that enables them to be adaptable and perceptive, to take initiative, and to balance the sensitivities of all participants in the encounter; and they feel they perform under demanding circumstances that require them to manage their emotions as well as the interaction in the moment. The individual perspectives of CMCD interpreters were revealed in their stories of end-of-life encounters as they described personal reactions to circumstances and conversation exchanges as well as how they proceeded to handle the interpretation in particular situations. Interpreters’ descriptions of how they work call to mind Hudelson’s (2005) observation that “interpreters’ bilingual and bicultural position allows for the identification of communication barriers that may be difficult for physicians to recognize” (p. 311). Hwa-Froelich and Westby (2003) noted that interpreters’ perspectives and the different roles they may choose to enact “adds to the complexity of the interpreting interaction” (p. 82).

Thus, the basis for valuing the interpreter’s perspective on communication at end of life lies in recognizing what Bolden (2000) has concluded—that interpreting is not simply converting the language of the speaker into the language of the listener. She observes that the actions of interpreters are influenced by the situation, their own perceptions, and the talk of others in the interaction (p.415).

## Future Research

The data collected during this study suggest opportunities for future research that may more fully plumb interpreters' experiences with end-of-life encounters.

While interpreters' stories revealed their own perspectives on their relationships with families during end-of-life communications, they also provided a window into the ways in which patients and families relate to the interpreters who work with them. Explorations of reciprocal cultural identification between interpreters and families might yield interesting insights, and explorations focusing on factors that influence families' trust and confidence in interpreter performance may also be fruitful.

While it was not a topic presented in this current reporting of findings, most of the interpreters in the study expressed an overall preference for the simultaneous mode of interpreting (performed while a speaker continues to speak) as opposed to the consecutive mode (the interpreter waits for the speaker to finish before performing the interpretation). They described a variety of reasons for this preference, commenting "I don't have to remember too much information," "out of necessity to try to keep up with physicians," "it's easier to do simultaneous because I don't have to think too much about it." However the five members of one focus group unanimously felt that simultaneous interpreting was not appropriate in end-of-life conversations. As one interpreter put it,

I definitely am of the opinion that simultaneous interpretation is not appropriate to use in end of life. Wouldn't you all agree--not in end of life? . . . . It's too impersonal. It's more sensitive to do the consecutive. Besides, the type of information you're having to relay in an end of life requires sensitivity, time, you know, give time to the person, especially the parent who's receiving that message to, you know, process some off that.

Interpreter comments on the two modes of interpreting suggest opportunities to explore how each might affect the communication process, and how patients and families in particular, experience the encounter depending on the mode.

Although the interpreter narratives were not specifically analyzed for gender differences in response, one striking contrast appeared, relating to interpreter displays of emotion during end-of-life encounters. The majority of female interpreters described experiences where they have cried during these encounters. In contrast, the majority of male interpreters expressed concerns about being able to remain “strong,” needing to create emotional distance, being perceived as “cold” or becoming inured to the emotional circumstances of the encounter. Exploration of the ways in which gender differences may affect the interpreting process and thus the interaction during difficult conversations might produce illuminating findings.

An additional focus for future research might be to understand the various ways in which a perception of “rushing” enters the care experience and what effects it might have on communication and family perceptions of quality of care. Interpreters raised this notion in many contexts: providers use of ad hoc interpreters (relatives, housekeeper, secretary) instead of waiting for an interpreter to arrive; providers not taking time to brief interpreters before they enter the encounter; interpreters having to move on to the next call; immediate presentation of the memory box without allowing a family to have some moments alone with their child after death. One interpreter described her experiences with parental consents for children having procedures in day surgery.

... the nurse asks them why are there for, what is the reason they came to the hospital, what type of surgery they're going to have. And much of the time they say 'I don't know.' What do you mean you don't know? Did not the nurse ask to check that they don't really even have a consent that has been signed? So the nurse asks 'Did you sign this consent?' and tries to explain about the content. 'Well yes, but I really don't know exactly.' I think they don't know it because they were so pressed with time that at the end they didn't have time to put every answer they had in its place. ... And you already have the barrier of the language ... Because the doctors really hate to have to have an interpreter there. ... Because it ... takes twice their time for a consultation that if it was not an interpreted meeting. They're really pressed with time—I mean it's just unbelievable. I just cannot understand ... how many surgeries we have everyday.

Another thread running through many of the stories recounted by interpreters during the research related to their perceptions of providers' "cultural sensitivity" or "cultural awareness." While interpreters named a variety of cultural traits or characteristics which they themselves attribute to Latinos or Hispanics in general, most did not qualify their comments in terms of their own heritage or subgroup (i.e. Mexico, Colombia, Chile, Panama, Puerto Rico). Whether this type of attribution reflects a "naive" (Koenig & Davies, 2003) view of ethnocultural differences could be investigated. In addition, some narratives hinted at perhaps an ethnocentric sensibility of cultural differences. Future research might explore this, focusing not only on how interpreters view cultural sensitivity or cultural awareness relative to the providers they work with, but also in the context of their personal heritage or country of origin if they are different from the patient or family for whom they are interpreting. Subsequently, what might interpreters' views mean for families and providers in such scenarios?

As previously mentioned, the focus group was the primary, preferred method of data collection for this study, with the individual interview as a second-choice alternative for interpreters who were not available to meet in a group. Focus groups are characterized by group interaction, while individual interviews consist of one on one interaction between the participant and the researcher. While similar topics may be raised by participants in both types of discussion, focus groups provide participants with opportunities to promote (or inhibit) sharing and learning, to challenge or confirm their own or others' opinions, and to arrive at group consensus or agree to disagree. Particular topics in a focus group discussion may become amplified by virtue of the number of people offering opinions, the length of time a group spends on the topic, and at times, the emotions expressed on the subject. During this research, interpreter discussions of family responses to the memory box and chaplains at the hospital were two topics that became amplified during focus group discussions. While both of these topics were also raised by a number of interpreters who participated in individual interviews, additional depth and complexity on these subjects emerged in the focus groups. Because such amplification occurred in the context of this research, perhaps these topics merit additional exploration to establish whether they resonate more widely among staff interpreters and CMCD families.

To the researcher's knowledge, this study is unique in its qualitative focus on interpreters' perspectives of end-of-life communication in a pediatric hospital setting. The decision to use narratives to report findings was made when attempts to employ other writing formats failed to adequately represent the wide-ranging experiences and

emotional intensity of the stories shared by interpreters during this research. Because the data collected during this study were extensive and rich, there remain ample opportunities for additional analyses that focus on other aspects of interpreters' experiences with end-of-life communication.

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**APPENDIX A**  
**RECRUITING MATERIALS**

APPENDIX A  
RECRUITING MATERIALS

*E:MAIL Message (Three Distributions)*

To: (Distribution List of Staff Interpreters at Children's Medical Center Dallas)  
Subject Line: Opportunity to Participate in a Research Study

(Text for Body of Message)

*TO: All Staff Interpreters at Children's Medical Center Dallas*

*SUBJECT: Opportunity to Participate in a Research Study*

*Please see the announcement below for a research study that will be conducted at Children's Medical Center Dallas. Please note that your participation would be completely voluntary, and is NOT a requirement of Children's Medical Center or of the Translation Services Department. This email message has been distributed only to assist the researcher in announcing the study.*

## **ATTENTION STAFF INTERPRETERS AT CHILDREN'S MEDICAL CENTER DALLAS**

You are invited to participate in an upcoming focus group research study that will take place at Children's Medical Center Dallas. The purpose of the research is to listen to the health care interpreter's perspective on the communication they facilitate in the hospital between English-speaking care givers and limited or non-English speaking pediatric patients and/or their families. The research will focus specifically on end-of-life conversations.

A light meal or refreshment will be available to interpreters before the discussions begin. Focus Groups will take place in a conference room on the premises of Children's Medical Center (specific location to be announced) on the dates and times listed below. Please let us know which of the following dates work best for your schedule by contacting the Study Coordinator below.

OPTION A: Month xx, 2006	5 p.m. to 7 p.m.
OPTION B: Month xx, 200x	6 p.m. to 8 p.m.
OPTION C: Month xx, 200x	5 p.m. to 7 p.m.

If you would like to participate in the study but cannot attend on any of the above dates, please contact the Study Coordinator to discuss other options.

Please note that your participation would be completely voluntary. It is NOT a requirement of Children's Medical Center Dallas or the Translation Services Department. The information collected during the focus groups will not identify individual interpreters at any point, including in the subsequent report summarizing the study results.

The only requirements for participation in this study are:

- To be employed as a staff interpreter by Children's Medical Center Dallas (full time, part time, or PRN)
- To interpret in the English-Spanish language combination
- To have experience in interpreting at least one end-of-life conversation during your employment at Children's Medical Center Dallas

If you have any questions about the study please contact the Study Coordinator for more information.

**STUDY COORDINATOR:** Corinne Warren  
University of North Texas Health Science Center  
Fort Worth, TX  
Cell Phone: 305-502-9444  
Email: cwarren@hsc.unt.edu

**APPENDIX B**  
**DEMOGRAPHIC QUESTIONNAIRE**

## APPENDIX B

### DEMOGRAPHIC QUESTIONNAIRE

Participant #: \_\_\_\_\_  
(Office Use Only)

Thank you for completing this questionnaire. The information you provide will be very useful for this research study on medical interpreters and end-of-life conversations. To maintain anonymity, we are not asking for any identifying information on this form. Please circle or fill in the appropriate information below.

**Gender:**  
(Circle one)

Male  
Female

**Age:** \_\_\_\_\_

**Household  
Income Level:**  
(Circle one)

Working class  
Middle class  
Upper class

**Highest Level of  
Education Completed:**  
(Circle one, and then note  
any additional type of  
specialized training you  
have received)

Primary school (K-8<sup>th</sup>)  
High school  
Some college  
College degree  
Post-graduate degree

Specialized training  
(of any kind;  
please indicate type)

---

**Country of Birth:**

\_\_\_\_\_

**Native  
Language(s):**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Race/Ethnicity:**  
(Circle one)

Asian  
Pacific Islander  
African/Black  
American Indian or  
Alaska Native  
White/Caucasian  
Latino/Hispanic  
Other: \_\_\_\_\_

**TOTAL Number of  
Years Living in U.S.  
(if born outside U.S.)**

\_\_\_\_\_

**Other  
Languages  
Spoken:**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**TOTAL number of  
Yrs. Interpreting  
Experience (in any  
setting):**

\_\_\_\_\_

**Languages for  
Which You  
Interpret at  
this Hospital:**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Assigned to a specific  
unit/service/location?:**  
(Circle one)

No  
Yes (please specify)  
\_\_\_\_\_

**TOTAL number of  
Yrs. Interpreting in  
any type of Health  
Care Setting:**

\_\_\_\_\_

**Average  
Number of  
Hrs. You  
Interpret at  
this Hospital  
per week:**

\_\_\_\_\_

**Average Number of  
Interpreting Encounters  
Per Day:**

\_\_\_\_\_

**Length of Time  
Interpreting  
at this Hospital:**

\_\_\_\_\_

**Approximate Number of  
End-of Life Encounters You  
Have Interpreted During  
employment at Children's  
Medical Center:**

\_\_\_\_\_

**Prior to your employment at this hospital, have you participated in any type of  
training that was specifically intended to prepare you to work as an interpreter?**

No \_\_\_\_ Yes \_\_\_\_ (If yes, please describe)

**Did this hospital require any specific previous work experience, qualifications, education, or training in order for you to be considered for employment as an interpreter at this hospital?** No \_\_\_\_\_ Yes \_\_\_\_\_ (If yes, please describe)

**Were you required to pass any type of language proficiency assessment before being hired as an interpreter at this hospital?** No \_\_\_\_\_ Yes \_\_\_\_\_ (If yes, please describe)

**Were you required to pass any type of assessment of your interpreting ability before being hired as an interpreter at this hospital?** No \_\_\_\_\_ Yes \_\_\_\_\_ (If yes, please describe)

**Was there any type of specialized training related to interpreting provided to you by the hospital after you were hired?** No \_\_\_\_ Yes \_\_\_\_ (If yes, please describe)

**Have you received any type of specialized education, training, or guidance relating to end-of-life conversations (from either the hospital or some other source)?**  
No \_\_\_\_\_ Yes \_\_\_\_\_ (If yes, please describe)

**Since you were hired, have you had, or do you have opportunities for continuing education or further training relating to interpreting (either sponsored by the hospital, or on your own)?**

No \_\_\_\_\_ Yes \_\_\_\_\_ (If yes, please describe, and indicate whether you have, or are intending to participate )

**In the space below, please share any other comments you have on continuing education or training for interpreters.**

**APPENDIX C**  
**FOCUS GROUP MODERATOR'S GUIDE**

## APPENDIX C

### FOCUS GROUP MODERATOR'S GUIDE

#### End-of-Life Conversations in a Pediatric Hospital: Communication Through Interpreters

#### INTRODUCTION, EXPLANATION, GROUP PROCESS

(5 minutes)

##### **A. Moderator introduces herself and explains the project's purpose.**

Hello everyone. My name is \_\_\_\_\_ and I am a Master's Level Student in the School of Public Health at the University of North Texas Health Science Center in Fort Worth. I'd like to introduce my assistant \_\_\_\_\_ who will be observing our discussion this afternoon. As you know, we are going to be talking about the end-of-life conversations you interpret here at the hospital. You are here because of your interest in this topic and the valuable perspectives you can share as interpreters. Some of the published medical literature has already explored the perspectives of adult patients, families, and care providers on end-of-life communication, and we plan to use *your* insights, as interpreters, to add to this field of study. Before we begin, let me tell you about how this focus group will proceed, and answer any initial questions you may have.

##### **B. Explain focus group process.**

A focus group is a research technique for collecting information, similar to survey questionnaires, except that rather than asking questions on a one-to-one basis, the questions are presented to the entire group and everyone is invited to respond and talk to each other. We are interested in your own opinions, in other words, what you think and feel about each topic. After we take care of some preliminary paperwork, our discussion will last about an hour and a half, and we will take a five minute break about halfway through. To cover everything and end on time, I will move the discussion along, but everyone will have an opportunity to speak. You do not need to answer any questions or make any comments on discussion topics that you are uncomfortable with. I'd like to ask you to speak clearly, one at a time, when you share your opinions. There are no right or wrong answers. We are interested in your opinions and you do not have to agree with each other—we are interested in hearing different opinions. It is important to us that you give us your honest opinions.

**C. Have participants read and sign consent forms.**

**(10 minutes)**

Before we begin our discussion, I'm going to pass out the informed consent document that we've prepared for this study. We're going to take about 10 minutes for all of you to read the form completely, and then initial and date all four pages at the bottom. The last page, Page 4, will also require your signature. If you have any questions as you read through the consent form, please raise your hand and I'll walk over and address your question individually. At the end of 10 minutes, I'll be collecting your signed consent forms, but in return, I will give each of you a copy of the form with my signature to take home and keep for your own records.

**D. Orally reiterate key confidentiality provisions in consent form.**

**( 5 minutes)**

*(After consent forms have been collected):* Just to reiterate the confidentiality information explained in the consent form, I'd like to remind everyone that we will be tape-recording your comments this afternoon for me to review and summarize your thoughts in a report. The audiotape will be kept confidential, and it will be destroyed after the report is completed. My assistant will also be taking notes this afternoon so that I can focus on guiding the discussion. Even though the discussion will be recorded, everything that is said during the group discussion is confidential. Everything you say in this discussion will be kept private and no names will be used in my report. Are there any questions you'd like to ask at this point?

**E. Have participants complete demographic information form.**

**(10 minutes)**

We have one other form that I'd like everyone to fill out this afternoon before we begin our discussion. It is a participant information form that asks you for some demographic information. You will see that we are not asking for your name or any other identifying information on the form. We'll take about 10 minutes for all of you to complete it, and again, if you have any questions as you fill out the form, please raise your hand and I'll walk over and address your question individually.

**F. Respondent introductions:**

**( 5 minutes)**

*(After participant information forms have been collected):* Now that our paperwork is finished, let's start our discussion by having everyone introduce him/herself. Please tell us your first name only, how long you've worked at the hospital, and whether you work in a specific unit, or cover all units and services throughout the hospital.

**G. Begin discussion:**

**(90 minutes)**

Before we start with our first topic, I'd like to remind you that we are interested in everyone's perspective on the discussion questions. You may not agree with all the comments that are offered, and you may not reach a consensus on each issue, but everyone's ideas are valuable.

**GROUP DISCUSSION QUESTIONS:**

1. What do you consider an "end-of-life" conversation? (How would you define it?)
2. Is interpreting end-of-life conversations *different* from interpreting other kinds of medical conversations (not related to the end of life)? How/What makes them different?
3. a. How would *you* describe "good" communication in the context of the end-of-life conversations you interpret? Who plays a role in the *quality* of the communication? In what ways?  
  
b. How do you think *patients and families* would describe "good" communication in end-of-life conversations? Why do you say that?  
  
c. How do you think *care providers* would describe "good" communication in end-of-life conversations? Why do you say that?
4. As the only speaker of both languages in these conversations, are there things that you are able to observe about the communication process that the other parties might not see or understand? Examples?
5. What ideas do you have that might improve the possibilities for "good" communication during end-of-life conversations?

**APPENDIX D**

**INDIVIDUAL INTERVIEW MODERATOR'S GUIDE**

## APPENDIX D

### INDIVIDUAL INTERVIEW MODERATOR'S GUIDE

#### End-of-Life Conversations in a Pediatric Hospital: Communication Through Interpreters

#### INTRODUCTION, EXPLANATION, INTERVIEW PROCESS (5 minutes)

##### A. Interviewer introduces herself and explains the project's purpose.

Hello, I'm \_\_\_\_\_ and I am a Master's Level Student in the School of Public Health at the University of North Texas Health Science Center in Fort Worth. As you know, we are going to be talking about the end-of-life conversations you interpret here at the hospital. You are here because of your interest in this topic and the valuable perspectives you can share as an interpreter. Some of the published medical literature has already explored the perspectives of adult patients, families, and care providers on end-of-life communication, and we plan to use *your* insights, as an interpreter, to add to this field of study. Before we begin, let me tell you about how our interview will proceed, and answer any initial questions you may have.

##### B. Explain interview process.

During this interview we are interested in your own opinions, in other words, what you think and feel about each topic. After we take care of some preliminary paperwork, our conversation will last about an hour and a half, and we will take a five minute break about halfway through. To cover everything and end on time, there may be times when I will move the interview along. You do not need to answer any questions or make any comments on topics that you are uncomfortable with. I'd like to ask you to speak clearly when you share your opinions. There are no right or wrong answers. We are interested in your opinions, and it is important to us that you give us your honest opinions.

**C. Have participant read and sign consent forms.**

**(10 minutes)**

Before we begin our interview, I'm going to give you the informed consent document that we've prepared for this study. We're going to take about 10 minutes so that you can read the form completely, and then initial and date all four pages at the bottom. The last page, Page 4, will also require your signature. If you have any questions as you read through the consent form, please let me know. When you're finished, I'll collect your signed consent form, but in return, I will give you a copy of the form with my signature to take home and keep for your own records.

**D. Orally reiterate key confidentiality provisions in consent form.**

**( 5 minutes)**

*(After consent form has been collected):* Just to reiterate the confidentiality information explained in the consent form, I'd like to remind you that we will be tape-recording your comments this afternoon for me to review and summarize your thoughts, along with all of the other participants in the study, in a report. The audiotape will be kept confidential, and it will be destroyed after the report is completed. Even though our conversation will be recorded, everything that is said during the interview is confidential. Everything you say in this interview will be kept private and no names will be used in my report. Are there any questions you'd like to ask at this point?

**E. Have participant complete demographic information form.**

**(10 minutes)**

We have one other form that I'd like you to fill out this afternoon before we begin our interview. It is a participant information form that asks you for some demographic information. You will see that we are not asking for your name or any other identifying information on the form. We'll take about 10 minutes for you to complete it, and again, if you have any questions please let me know.

**F. Begin interview:**

**( 90 minutes)**

*(After participant information form has been collected):* Now that our paperwork is finished, I'd like to start our interview by asking you to state your first name only, tell me how long you've worked at the hospital, and whether you work in a specific unit, or cover all units and services throughout the hospital.

## INTERVIEW QUESTIONS:

1. What do you consider an “end-of-life” conversation? (How would you define it?)
2. Is interpreting end-of-life conversations *different* from interpreting other kinds of medical conversations (not related to the end of life)? How/What makes them different?
3. a. How would *you* describe “good” communication in the context of the end-of-life conversations you interpret? Who plays a role in the *quality* of the communication? In what ways?  
  
d. How do you think *patients and families* would describe “good” communication in end-of-life conversations? Why do you say that?  
  
e. How do you think *care providers* would describe “good” communication in end-of-life conversations? Why do you say that?
4. As the only speaker of both languages in these conversations, are there things that you are able to observe about the communication process that the other parties might not see or understand? Examples?
5. What ideas do you have that might improve the possibilities for “good” communication during end-of-life conversations?

**APPENDIX E**  
**PARTICIPANT CONSENT FORM**

## APPENDIX E

### PARTICIPANT CONSENT FORM

#### DESCRIPTION OF STUDY

Although there are millions of people in the United States whose sole language is Spanish, there are not very many health care professionals who can communicate with them in their native language. Many of the people seeking health services at facilities and clinics in the Dallas-Fort Worth Metroplex are in need of doctors, nurses, and other health professionals who can communicate with them in Spanish. When the health professional does not speak Spanish, an interpreter or translator is often needed.

The interpreter not only performs the important function of facilitating the information exchanged between the patient and the provider, but he or she also becomes a *participant* in the encounter.

We are conducting a research study to specifically explore, from the point of view of interpreters, the challenges of communication through interpreters during end-of-life conversations in a pediatric hospital. The objectives of the study are to understand in what ways these conversations may be different from non-end-of-life conversations; to understand interpreters' experiences with this type of conversation; and to understand how the role of communication plays a part in the quality of end-of-life care.

Information on end-of-life conversations during this study will be gathered using two research methods: focus groups moderated by one of the study investigators, and one-on-one interviews conducted with individual interpreters by one of the study investigators.

#### **TO FOCUS GROUP PARTICIPANTS:**

You are being asked to participate in a focus group discussion with your interpreter colleagues, guided by a group moderator, who is one of the study investigators. The group discussion should take 90-120 minutes. The group discussion questions we will talk about will deal with communication that takes place through interpreters between English-speaking health professionals and Spanish-speaking patients and/or their families. They are the same questions that participants in the individual interviews will be asked.

#### **TO INDIVIDUAL INTERVIEW PARTICIPANTS:**

You are being asked to participate in a one-on-one interview with one of the study investigators. The interview should take 90-120 minutes. The questions you will be asked will deal with communication that takes place through interpreters between English-speaking health professionals and Spanish-speaking patients and/or their families. They are the same questions that participants in the focus group will discuss.

#### **TO ALL PARTICIPANTS:**

You will be asked to read and sign the attached Informed Consent document, which provides additional details about the study. The Study Coordinator will also sign the document, and you will receive a copy to keep for your own records. **Thank you very much for your participation and contribution to this study.**

Page 1 of 6

Participant Initials \_\_\_\_\_

Date \_\_\_\_\_

The University of Texas Southwestern Medical Center at Dallas  
Children's Medical Center Dallas  
University of North Texas Health Science Center at Fort Worth

### CONSENT TO PARTICIPATE IN RESEARCH

Title of Research: **End-of-Life Conversations in a Pediatric Hospital: Communication Through Interpreters**

Sponsor: **Not Applicable**

Investigators:

Telephone No.  
(regular office hours)

Telephone No.  
(other times)

Principal Investigator: <b>Sue Lurie, PhD</b>	817-735-2541	817-625-8163
Co-Investigator: <b>Corinne Warren</b>	305-502-9444	305-502-9444
Co-Investigator: <b>Robert Bash, MD</b> (UTSW Faculty Sponsor)	214-648-3896	214-456-7000

**PURPOSE:** The purpose of this research study is to explore interpreters' perspectives on the communication they facilitate between English-speaking health care providers and limited or non-English-speaking pediatric patients and/or their families during end-of-life conversations that take place in a pediatric hospital.

This research is being done because a growing number of studies is addressing the quality of end-of-life care. Various aspects of communication between caregivers and the patient and/or family are noted consistently as important during this time of care. Also noted as important and relevant to the communication process is the particular need for providers to take into account cultural differences in situations where the patient and provider do not share language or culture. Health care interpreters can provide a valuable perspective on communication during end-of-life care.

**PROCEDURES:** Information on end-of-life conversations will be gathered for this study using two research methods: focus groups moderated by one of the study investigators, and one-on-one interviews conducted with individual interpreters by one of the study investigators. Please mark below which research method you are participating in:

\_\_\_\_\_ Focus Group

\_\_\_\_\_ Individual Interview

Page 2 of 6  
Participant Initials \_\_\_\_\_  
Date \_\_\_\_\_

#### **TO FOCUS GROUP PARTICIPANTS:**

You are being asked to participate in a focus group discussion with your interpreter colleagues, guided by a focus group moderator, who is one of the study investigators. The discussion should take approximately 90-120 minutes. The group discussion questions we will talk about will deal with communication that takes place through interpreters between English-speaking health professionals and Spanish-speaking patients. They are the same questions that participants in the individual interviews will be asked. You do not need to answer any questions or make any comments on discussion topics that you are uncomfortable with. The group discussion will be audiotaped and later transcribed in order to help with the collection of information and the analysis of the information by the study investigators. The audiotape will be destroyed after the analysis is completed. There will also be a notetaker present to assist in the collection of information during the group discussion.

In addition, before the group discussion begins, you will be asked to fill out a participant information questionnaire that asks for some demographic information. The questionnaire will not ask for your name or any identifying information that could specifically link your participation in the focus group to the information collected on the questionnaire. You do not need to answer any questions that you are uncomfortable with.

#### **TO INDIVIDUAL INTERVIEW PARTICIPANTS:**

You are being asked to participate in a one-on-one interview with one of the study investigators. The interview should take approximately 90-120 minutes. The questions you will be asked will deal with communication that takes place through interpreters between English-speaking health professionals and Spanish-speaking patients and/or their families. They are the same questions that participants in the focus group will discuss. You do not need to answer any questions or make any comments on interview topics that you are uncomfortable with. The interview will be audiotaped and later transcribed in order to help with the collection of information and the analysis of the information by the study investigators. The audiotape will be destroyed after the analysis is completed.

In addition, before the interview begins, you will be asked to fill out a participant information questionnaire that asks for some demographic information. The questionnaire will not ask for your name or any identifying information that could specifically link your participation in the interview to the information collected on the questionnaire. You do not need to answer any questions that you are uncomfortable with.

Page 3 of 6

Participant Initials \_\_\_\_\_

Date \_\_\_\_\_

**POSSIBLE RISK(S):** The only potential risk to you in participating in this study would be a breach of confidentiality in which your comments during the focus group discussion or the individual interview would accidentally be revealed to someone other than the study investigators. Focus group participants are asked to keep all comments made during the focus group discussion confidential, and the study investigators will take all precautions necessary to protect your confidentiality as a research study participant. You do not need to answer any questions or make any comments on focus group or interview topics that you are uncomfortable with. The only personal identifying information that will be collected during the focus group or individual interview, such as your name, will be on this consent document. During focus group discussions and interviews, only first names will be used to protect the identity of participants.

**POSSIBLE BENEFITS:** You may receive no direct benefit from participating in this study.

**Benefit to others:** The information gained from this research study may lead to ideas for improving communication between patients and/or families and care providers who do not share the same language or culture.

**ALTERNATIVES TO PARTICIPATION IN THIS RESEARCH:** There are two options for participation in the study: as a member of a focus group, or through an individual interview. An additional alternative is not to participate in this study.

**PAYMENT TO TAKE PART IN THIS RESEARCH:** No payments will be made for participation in this study.

**COSTS TO YOU:** It is important that you report any illness or injury to the research team listed at the top of this form immediately. Compensation for an injury resulting from your participation in this research is not available from the University of Texas Southwestern Medical Center at Dallas or Children's Medical Center Dallas, or the University of North Texas Health Science Center at Fort Worth. You should know that by signing this form you are neither waiving any of your legal rights against nor releasing the principal investigator, the University of North Texas Health Science Center at Fort Worth, the University of Texas Southwestern, Dallas, Children's Medical Center, Dallas or any of their respective agents from liability for negligence with respect to the conduct of this study. If you are harmed and you feel that this harm justifies pursuing a legal remedy, you have the right to do so.

Page 4 of 6

Participant Initials \_\_\_\_\_

Date

**VOLUNTARY PARTICIPATION IN RESEARCH:** You have the right to agree or refuse to participate in this research. If you decide to participate and later change your mind, you are free to discontinue participation in the research at any time. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. Your participation or refusal to participate, or any comments or answers you give during the research study, will have no negative consequences, will not affect your legal rights, and will in no way affect the quality of care you may receive at any of the University of Texas Southwestern Medical Center Dallas facilities, Children's Medical Center, Dallas facilities, or the University of North Texas Health Science Center at Fort Worth facilities. If you are a student or employee of the University of Texas Southwestern, Dallas, Children's Medical Center, Dallas, or the University of North Texas Health Science Center at Fort Worth, your participation, or nonparticipation will in no way affect your academic standing or employment status.

**RECORDS OF YOUR PARTICIPATION IN THIS RESEARCH:** You have the right to privacy. Your demographic information and discussion group or interview comments will be kept as confidential as possible under current local, state and federal laws. However, the Office for Human Research Protections, possibly other federal regulatory agencies, and the Institutional Review Boards of the University of North Texas Health Science Center at Fort Worth and the University of Texas Southwestern, Dallas may examine the written transcripts resulting from the audiotaping of the focus group discussion or interview and the resulting analysis of the study data. In case the final results of this study should be published, your name will not appear in any published material.

**YOUR QUESTIONS:** If you have any questions at any time about the study, you may contact the Principal Investigator, Dr. Sue Lurie, at (817) 735-2451. If you have any questions about your rights as a participant in this study, you may contact the Chairman of the Institutional Review Board, University of Texas Southwestern, Dallas at (214) 648-3060 or Dr. Jerry McGill, Chairman of the Institutional Review Board, University of North Texas Health Science Center at Fort Worth at (817) 735-5457, during regular office hours.

**OTHER CONSIDERATIONS:** None

Page 5 of 6

Participant Initials \_\_\_\_\_

Date

**YOU WILL HAVE A COPY OF THIS CONSENT FORM TO KEEP.**

Your signature below certifies the following:

- You have read (or been read) the information provided above.
- You have received answers to all of your questions.
- You have freely decided to participate in this research.
- You understand that you are not giving up any of your legal rights.

\_\_\_\_\_  
Participant's Name (printed)

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Legally authorized representative's name (printed)  
(if applicable)

\_\_\_\_\_  
Legally authorized representative's signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name (printed) of person obtaining consent

\_\_\_\_\_  
Signature of person obtaining consent

\_\_\_\_\_  
Date

**ASSENT OF A MINOR: (if applicable)**

I have discussed my participation in this research with my mother or father or legal guardian and my study doctor, and I agree to participate in this research.

\_\_\_\_\_  
Signature (participants from 10 to 18 years old)

\_\_\_\_\_  
Date

Page 6 of 6

Participant Initials \_\_\_\_\_

Date

## **APPENDIX F**

### **THEME 1—NATURE OF END OF LIFE: SUPPORTING NARRATIVES**

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#### Sub-themes:

##### *Situational Milieu*

Luis: . . . . you're talking about before, during the death process, after—it is a very broad subject.

Raúl: . . . . it's everything that has to do with communicating and also facilitating the ending of the life of somebody, of the patient, in this case a child. . . . it can be the hospice care . . . . when you told the family that the diagnosis is, it's just something that's not going to have any positive outcome . . . .

Elena: . . . . another one . . . . was actually a sexual abuse case for us, our part of it, and the abuser, which would have been the stepdad I guess you could say, committed this thing and we have to discuss that with Social Work, Child Life, Mom, and bring that up with the kids and talk to them about Dad not being home any more, which for them he was dead—so that would be another type of end-of-life conversation which . . . . still affects the pediatric patient . . . .

##### *Emotional Milieu* (no additional supporting narratives)

##### *Interpersonal Milieu*

Elena: . . . . if there's a family that's here and they have a lot of extra family members that are here for support—they don't really require as much of us as maybe a mom that's here, that the baby, the newborn baby that's here from El Paso with a heart problem, and Dad is not able to come. Then that mom, of course, we're not going to leave her by herself.

Heriberto: . . . . some families . . . . much rather keep it very personal and very much within their family nucleus. So it would be like parents—mother, father—perhaps some siblings, and if that is the case then Child Life also participates. And there are some other instances when this set of parents . . . . decide to go ahead and open this information to more family members and extended family. And extended family might be . . . . the grandmother . . . . or grandfather, or both, aunts, uncles, cousins—sometimes a lot of people. It could possibly be a very large group of people.

## *Cultural Milieu*

### *- "Attitudes are different"*

Julia: I had a case where there, the mom was Anglo and the dad was Hispanic. And they had just told them they were going to disconnect their child. And the mother said 'Ok, oh well, uh, we still have two hours until that happens, let's go eat something.' And the dad was sitting there with his hands, with his face in his hands and tears streaming down, you know. And I, I just, I could—stark contrast uh, of how these two families were handling, how these two people were handling the situation. And she tried to coax him, yeah, she tried to coax him—say 'Come on, come on.' The dad did not speak English and mom was Anglo, so uh, the mom says 'We still have two hours 'til this happens, let's go and have supper. We haven't had anything to eat all day long,' or something like that. And Dad was just there, he was just, you know his face in his hands, tears streaming down his cheeks and she'll say 'Come on. After you eat you'll feel better' or something like that. And I'm going 'Oh my God!' I could not believe it. It's, I was just—it was very hard to see that.

### *- "A style to talk about death" (no additional supporting narratives)*

### *- "Certain things are done differently"*

Roselia: There's also another thing that is very important is that they really want to have a period of mourning. I would say, there's, for them it's very important, it's sometimes, I mean I know that being in a hospital and having that situation, it's, life still goes on and the social workers and the child life staff and chaplains—they have other things to do. And sometimes I think that for Hispanics . . . they are not given enough time to be left alone with the child. Because there are things that the hospital has prepared, like, what is called something like a memory box, and the staff that is responsible for that usually wants to go ahead and go ahead with the program. Culturally speaking when a father and a mother . . . have lost a child—they shouldn't be a problem. And sometimes, they don't like the program. . . . each parent is different and we, we sometimes mention before we do any interpretation to the social worker or the child life or something, they want to do something that is not something that is done in our culture—like for that memory box. Just take it easy—let the parents have some time on their own before they can, you know, come in and ask for certain things.

Cristina: Well the memory box shocked me too. Because I just, culturally I don't think Hispanics are in that, I don't know, they don't think that way . . .

-*"Prayer is good and all, but . . ."*

Julia: But I think that uh, it just depends. I believe, um—some families are, like I've been working in day surgery these past three weeks, and some families are in, in such an anxious state that when a chaplain, even . . . one that does not speak their language, uh comes on in and, and we pray, because, you know, I'm part of the group there and that's why I'm saying *we* pray, I believe that that really helps them even if they haven't brought someone with them, or just simply because of the way the chaplain presents himself and speaks . . . .

## **APPENDIX G**

### **THEME 2—PERCEPTIONS OF ROLE: SUPPORTING NARRATIVES**

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#### Sub-themes:

*"A key role"* (no additional supporting narratives)

*"You're their connection"*

Paloma: I was working once at night and at night we don't have the privilege to have a dispatcher. So I remember having a case on CC3 where the baby passed away, or the young kid . . . and Mom just fell on top of me, so I had to fall with her, and both were like down on the ground and I couldn't move because she was just like kind of holding me, or like passing out, and we were just like 'Ok Mom, ok Mom, ok Mom.' And there was a time that my legs were numb, completely numb, and I was like 'Can you please call another interpreter and tell them to come over?' And you know, I had to call them and this person couldn't help Mom 'cause she didn't want to stand up. So he had to just lay down, and just have to move a little, and Rogelio, another interpreter, he just has to lay down right next to him, you know, keep comforting Mom.

*"I feel related to the parents"*

Julia: You put yourself in that situation . . . then you begin to question yourself—'Hey—wait a minute—this is a parent, this is a child—this parent just lost his child' and imagine, and not that you want to get yourself in this emotional state, but uh, just to feel, be sensitive to the situation.

*"It requires a lot more stuff—not just the words"*

Roselia: . . . many times I get in there and they already did the interpretation. The doctor, the anesthesiologist is coming out and saying 'Oh, don't worry, I already did it with a cousin,' or 'The patient is 16 years old—he speaks English and he translated for the parents.' I mean it's his call—I'm not there to tell him what to do. So it's his problem. But there are many doctors that wouldn't do that, because they are not, there, it could be a problem.

## **APPENDIX H**

### **THEME 3—COMPLEXITIES OF PERFORMANCE: SUPPORTING NARRATIVES**

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#### Sub-themes:

##### *Managing emotions*

-“*You’re the one that has to tell them*” (no additional supporting narratives)

-*Early experiences*

María: . . . . my first day in oncology, you know, the doctor says ‘Ok, are you ready? I need an interpreter’ and we go right into the room. And he’s telling the mother that they, you know that, that they needed a ‘do not resuscitate’ order—it was my first day on oncology and he, the doctor didn’t say a word. ‘Ok are you ready?’ . . . . and I’d already been interpreting for four hours straight. I don’t think I had lunch that day until 3 o’clock in the afternoon. My first day—it was crazy! And I was just, my jaw must have dropped to the floor because I had no idea what he was gonna come and talk to her about, and all of a sudden he turns around and, and, actually, well, I’ll just say he turns around to me and he says ‘You’ve never done this before have you?’ I’m like, ‘Whatever gave you that idea?’

-*Conflicts of emotion* (no additional supporting narratives)

-*Attachments, distance* (no additional supporting narratives)

##### *Managing interaction*

-“*Sometimes you don’t know what to expect*”

Inés: A lot of times the provider thinks because the patient has been for several days, we, the interpreters know, even if we never have been there . . . . that we are talking about patients. And we do go there and they probably sometimes think ‘Oh, we thought that you knew this.’ Sometimes they assume that we are, we already know what’s going on.

-*More than language* (no additional supporting narratives)

-*Participants and proficiencies* (no additional supporting narratives)

-“*In the line of fire*” (no additional supporting narratives)

## **APPENDIX I**

### **THEME 4—PERCEPTIONS OF QUALITY: SUPPORTING NARRATIVES**

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#### Sub-themes:

*“The way we are supposed to work”* (no additional supporting narratives)

*Interpreters’ Prerogative?* (no additional supporting narratives)

*The Value of Continuity*

Paloma: . . . . do not pressure with time . . . . I mean from the interpreter’s point of view. ‘Cause you know we have just uh, uh a limited time of interpreters, and we or someone keep an interpreter for three, four hours because the patient has died. I think, it’s a, you know it’s a human being who is passing away and we should be allow to stay as much . . . .

Roselia: Most of the time what happens is once you start having a care conference with a parent, usually what the doctors prefer is that person that did the interpretation keeps coming and uh following interviews that they have with the parent—following times that they have to talk to the parents so there will be some kind of rapport between the parents, interpreter and the doctor—not having to change . . . . sometimes we even have to leave after we’ve interpreted for the doctor . . . . if the child life person is not there, we don’t wait for them, we have to report back to the department . . . also with the social worker, sometimes she’s not there . . . . they call back for an interpreter but it doesn’t necessarily have to be you—it could be somebody else. When possible they like to have the same person, yes, yes, yes because they want to have at least a continuity of the same person.

*Compassion and Commitment* (no additional supporting narratives)







