

COMMUNICATION WITH HEALTHCARE PROVIDERS AT END OF LIFE: THE
PERSPECTIVE OF DECEDENTS' NEXT OF KIN

A Dissertation Presented

by

JILL M.TERRIEN

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Dedication

This work is dedicated to my family. To my parents, John and Ginny Lussier, who provided me with all the opportunities and support to advance my education.

Special thanks to my father, who gave me the ultimate experience as an end-of-life caregiver. His courage and strength in facing his own mortality was inspiring.

To my husband Stephen, and children Zachary and Hailey who have unconditionally supported my research and education with their love and understanding, you are my life and I am forever grateful.

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Abstract

Communication with healthcare providers (HCP's) at the end-of-life (EOL) is a crucial process that can make a difference in the quality of the EOL experience for patients and their families. Targeting EOL communication interventions between patients, their families, and HCP's is better informed from an understanding of what family members perceive as good and bad communication. The purpose of this study was to explore experiences related to communication with HCP's in central Massachusetts during EOL care.

Data from the parent study (n = 373) included responses from an open ended question at the end of the survey. The larger, qualitative descriptive study, from the parent study, (n = 218) that examined the open ended question revealed communication as the overarching theme. A secondary analysis of this open ended survey data using qualitative content analysis was used to describe next of kin's perspectives of communication with HCP's during the decedents' end-of-life experience (n = 171).

Family members (children = 38.4% and spouse = 22.0%) comprised the majority of the sample. Decedents were mostly 80 or older (47.6%), died in an acute care setting of mostly cancer(33.0 %) and cardiovascular disease (32.3%). .

Accessing information, emerged as the overarching theme. *Continuum of information, healthcare provider sensitivity, having the answers* and *raising awareness* were revealed as subthemes. The majority of respondents reported good aspects versus bad aspects of communication at the EOL. The framework for a good death (Emanuel & Emanuel (1998) under-girded the study but was not supported as it relates to these

findings. The framework was useful in capturing the multidimensional process that each patient and their family could experience during the EOL process.

The findings from this study provide insight for HCP's about which aspects of communication are helpful at the EOL. Continuing education of the health care team on these identified helpful communication aspects will provide better access for patients and families for a quality EOL experience.

CHAPTER I

STATE OF THE SCIENCE ON COMMUNICATION AT THE END OF LIFE

Introduction

Quality end-of-life care for many patients and their families remains an elusive outcome in the United States. Patients have reported prolonged and painful deaths, communication that is poor between nurses, physicians, patients and families, and the care received is unwanted, invasive and expensive (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments [SUPPORT], 1995; Field & Cassel, 1997). Although a decade has elapsed since these reports, research continues to reveal that many patients and their families still report poor symptom control (Morrison, 2005b), ineffective communication with physicians (Cherlin et al., 2005), and lack of respect (Teno et al., 2004) during the end-of-life care experience. This dissertation focuses on communication during the end-of-life care experience. Improving the ineffective communication amongst patients, families and healthcare providers is necessary to provide end-of-life care that is high quality (Grady, 2005; National Institutes of Health [NIH], 2004). The findings from SUPPORT, the Institute of Medicine (IOM), and most recently the NIH have made a national priority of improving end-of-life care and providing quality end-of-life care to patients and their families.

End-of-Life Care Definition

Many terms in the literature are used synonymously with end-of-life care, including supportive care (National Cancer Institute, 2006) or palliative care (National Consensus Project for Quality Palliative Care [NCP], 2005). These terms indicate that patients at end of life and their family members need care that is sensitive to their needs

during a period of indeterminate duration. This period is indefinite as each individual with a chronic, debilitating illness will experience a continuum of changes in functionality, with numerous transitions. For example, patients with pancreatic cancer could die within weeks after diagnosis, whereas patients with amyotrophic lateral sclerosis, breast cancer or HIV-AIDS could live for years. Therefore, healthcare providers cannot definitely predict or prognosticate how long an individual will live after being diagnosed with a chronic or terminal illness. This uncertainty is distressing to patients and their families. Regardless of a patient's disease, the goal of end-of-life care is to relieve symptoms, optimize function, and support the best possible quality of life (NCP, 2005). For the purposes of this research, end-of-life care will be viewed through the definition of palliative care according to the National Consensus Project (NCP, 2005, p. 3):

[End-of-life care is] a philosophy of care and an organized, highly structured system for delivering care. It expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making, and providing opportunities for personal growth.

Domains of End-of-life Care

Hundreds of studies have identified domains or key concepts relevant to care at the end of life (e.g., Emanuel & Emanuel, 1998; Steihauser et al., 2000; Yabroff, Mandelblatt, & Ingham, 2004) and many countries have developed guidelines for end-of-life care. To standardize care and research on patients at the end of life, these studies and guidelines were reviewed by a consortium of five national palliative and hospice care

organizations to determine the key concepts and domains common to all studies (for review see Ferrell, 2005). The goal of this consortium, which called itself the National Consensus Project for Quality Palliative Care or National Consensus Project (NCP), was to develop a set of clinical guidelines to promote consistently high quality end-of-life care for patients and their families (NCP, 2005). The domains of the guidelines (Table 1) can be utilized by specialists or primary care providers across settings, e.g., the home, hospital, outpatient setting, or nursing home. These domains have been useful in evaluating current end-of-life care and identifying areas that need improvement. Current work with the domains is ongoing in conjunction with the National Quality Forum (NQF). The NQF is endorsing the domains as a standard framework to evaluate the quality of palliative and hospice care across all settings (National Quality Forum, 2007). This next step defines palliative care globally and sets a standard for certification and reimbursement across settings where care is delivered (B. Ferrell, personal communication, January 25, 2006).

Table 1

Domains of End-of-Life Care

Domain number	Domain name
1	Structure and processes of care
2	Physical aspects of care
3	Psychological and psychiatric aspects of care
4	Social aspects of care
5	Spiritual., religious and existential aspects of care
6	Cultural aspects of care
7	Care of the imminently dying patient
8	Ethical and legal aspects of care

From the NCP, 2005

The eight NCP domains for end-of-life care are underpinned by fundamental clinical processes: assessment, information sharing, decision-making, care planning, and care delivery. Communication cuts across all of the domains and is an integral aspect of coordinating and delivering quality care for patients, families and healthcare providers.

Background and Significance of End-of-Life Care

End-of-life care has become an important research area in U.S. health care for two major reasons: poor patient outcomes at end of life and the increasing population of older Americans (> 65 years). The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) was a significant step in identifying the gaps in communication in end-of-life care. This study systematically examined problems with communication in end-of-life care.

Increasing End-of-Life Care Population. The population of Americans who will need end-of-life care (those over 65 years old) is growing. More than 70% of deaths in the U.S. are estimated to occur in individuals over the age of 65, and the majority of those deaths are attributed to cardiovascular diseases, cancers and chronic medical conditions such as chronic obstructive pulmonary disease (COPD) and diabetes (Hoyert, Heron, Murphy, & Kung, 2006). Overall, Americans are living longer and by the year 2030, the oldest old cohort of the U.S. population (those over 85 years of age) will increase to 9 million and comprise 20% of the population over 65 years old (Field & Cassel, 1997; Morrison, 2005a; Sengupta, Velkoff, & DeBarros, 2005). The impact of this older cohort is an increasing prevalence of chronic and terminal disease in individuals who will need healthcare providers and systems that are prepared to deliver quality end-of-life care.

Inadequate Communication and Patient Preferences

Studies on end-of-life care for hospitalized patients have reported several poor outcomes: inadequate communication between patients, their family members and healthcare providers; poor pain control (SUPPORT, 1995, Field & Cassel, 1997); frequent aggressive treatment; final days of care in an intensive care unit (ICU); and late preparation of do-not-resuscitate (DNR) orders (SUPPORT, 1995). The 2-phase SUPPORT study investigated the end-of-life experiences of over 9,000 adults hospitalized with life-threatening illness, including cancer, respiratory disease, heart failure and multisystem organ failure. The results of Phase I, in which 4301 patients and their healthcare providers were observed for 2 years, showed that 47% of physicians were unaware of their patients' preferences for cardiopulmonary resuscitation, almost half (46%) of DNR orders were written 48 hours before patient death, and for 50% of patients

who died in the hospital, family members reported that their loved one was in moderate to severe pain at least half of the time 3 days before death.

In Phase II, a 2-year, controlled clinical trial, 4804 patients with the same characteristics as those in Phase I were randomly assigned to an intervention or control group. Patients in the intervention group were assigned a highly trained nurse to communicate with them, their family and physician about pain, resuscitation preferences and prognosis. The goal of the intervention was to improve patient outcomes by decreasing utilization of the ICU, by sharing decision-making amongst physicians, patients and families, and by improving pain control. The results of the Phase II intervention showed no significant difference between the intervention and control group and those of Phase I. This large study highlighted that overall care delivered to patients and families at the end of life, regardless of diagnosis, was inadequate and expensive. Most importantly, even with intervention (Phase II) patients' preferences for care at the end of life were not communicated to their healthcare providers (Covinsky et al., 2000). Reflection and further investigation on the poor outcomes of the SUPPORT study indicate that innovative changes are needed at the system level as well as reform in the way healthcare providers communicate with seriously ill patients to improve care and facilitate patient preferences (Lynn et al., 2000a, 2000b).

Building upon the SUPPORT study, government reports by the Institute of Medicine (IOM) found that a significant number of patients suffer from poor symptom management such as the underutilization of pain control and that patients' end-of-life experiences have not been well documented (Field & Cassel, 1997). Gathering information systematically on the end-of-life experience is necessary to benchmark

standards of care and best practices to improve the quality of the end-of-life experience (Lunney, Foley, Smith, & Gelband, 2003).

End-of-Life Care and Communication

The importance of communication among health care providers, patients and their families has been demonstrated in several studies to be essential for providing quality end-of-life care (Anselm et al., 2005; Cherlin et al., 2005; Field & Cassel, 1997; Teno et al., 2004). Since communication is such a complex process, involving not only the exchange of information, but also thoughts and feelings that individuals share about an experience (American Hospital Association, 2006), it is not surprising that communication becomes an issue at times of heightened emotion. In the U.S., death is viewed as a medical failure rather than an outcome everyone will come to experience. This death-denying culture impedes communication amongst patients, families and health care providers and can make care at the end of life more stressful than is necessary (Boyle, Miller, & Forbes-Thompson, 2005).

Another factor that may contribute to ineffective communication is the lack of formal education to prepare healthcare providers to work with patients and families at the end of life (Paice et al., 2006; Sheehan & Schirm, 2003). End-of-life care challenges providers to work with an interdisciplinary team of health care providers and with patients who may be experiencing changes in their disease leading to death as an outcome. When death is imminent, families may be emotionally overloaded and unable to process the information being communicated by healthcare providers. Thus communication becomes an issue between patients and healthcare providers, families and healthcare

providers, and among family members due to conflicts that may arise at times of heightened emotion and crisis.

Healthcare providers and patients. Healthcare providers have an obligation to communicate with patients in an honest and open manner. However, for many providers talking about the end of life with a patient is very uncomfortable (Boyle et al., 2005), arouses feelings of guilt and sadness (Ruopp et al., 2005), and may come at a time that is unexpected and sudden (Von Gunten, Ferris, & Emanuel, 2000). In addition, providers caring for patients with a terminal or life-altering illness often have to make difficult decisions about numerous tests and hospitalizations. In such stressful situations, it is not surprising that communication with patients would be compromised. In fact, communication between physicians and patients with chronic and terminal illness has been shown to be most effective when physicians practiced in a setting where they were not rushed, had time to answer patient questions, and were accessible to patients to clarify information (Carline et al., 2002).

Physicians are not the only ones reluctant to talk about end-of-life issues; patients also resist such discussions. Less than 60% of patients with advanced chronic obstructive pulmonary disease (COPD) were found to have discussed end-of-life care with their physicians (Knauff et al., 2005). Most of these patients (75%) reported that they would rather discuss staying alive than talking about death, consistent with the death-denying culture of Americans. Many physicians (64%) in the same study reported lacking the time to discuss end-of-life care. Physicians also reported feeling that they were taking away patients' hope, that patients' were not ready to discuss end-of-life care, or that talking about end-of-life care would be too stressful for patients (Knauff et al., 2005).

However, terminally ill patients in another study (Emanuel, Fairclough, Wolfe, & Emanuel, 2004) reported that discussing death and dying was helpful and evoked little stress. Similarly, terminally ill patients were found to prefer open and honest communication with their healthcare providers (Heyland et al., 2006).

Healthcare providers, patients and families. Patients often designate family members to communicate with healthcare providers on their behalf. This proxy or surrogate representation can result in ineffective communication as family members may have difficulty telling the patient bad news (Cherlin et al., 2005), feel that not enough explanation is given for life-prolonging treatments (Clayton, Butow, Arnold & Tattersall, 2005), and that the stress of a dying or seriously ill loved one creates tension and impedes communication (Ogle & Hopper, 2005).

Problems in communication at end of life may come from both healthcare providers and family members. A mixed-methods study of communication between physicians and primary family caregivers of patients with incurable cancer (Cherlin et al., 2005) found that physicians never told caregivers of the patient's incurable illness, that hospice discussions occurred too late in the patient's illness to be effective, and that life expectancy of the patient was not discussed. The study also found that caregivers were ambivalent about the details they wanted to know and had difficulty understanding and accepting bad news. In other studies, family members have identified poor or ineffective communication by healthcare providers at the end of life about medical decision-making (Teno et al., 2004), conflict with the goals of care (Tulsky, 2005a), and lack of time for discussing death and dying (McGraw, Dobihal, Baggish, & Bradley, 2002). Good or effective communication has been identified as healthcare providers being good listeners

(McGraw et al., 2002), being honest and straightforward with information, and being emotionally supportive (Tulsky, 2005b). These findings highlight the highly emotional state of patients with incurable illness and their families, the challenges of communicating at a time of crisis, and the need to tailor communications to each situation. To enable family caregivers to hear and process key information such as changes in the patient's condition and prognosis, healthcare providers may need to repeat the same information several times.

On the other hand, family members of cancer patients who had died the previous year identified communication with health care providers as crucial in helping their loved ones make decisions about end-of-life care (Royak-Schaler et al., 2006). These first-degree relatives reported in focus groups that communication with healthcare providers was positive when they were open to questions and informed family members before decision-making. Communication was facilitated by healthcare providers who showed compassion and used terminology that was easy to understand. Family members were frustrated with communication when their healthcare provider inappropriately timed discussions about end-of-life care and were unavailable to answer questions (Royak-Schaler et al., 2006).

Healthcare providers recognize that communication with patients at end of life is suboptimal (Anselm et al., 2005). Attending physicians, residents and nurses at a 600-bed tertiary care facility participated in interdisciplinary focus groups to share their perspectives on barriers to communication at the end of life. Data analysis of focus group transcripts identified four themes that impede communication in end-of-life care: the recipients of care, the healthcare system, healthcare providers, and the nature of

discussing care at the end of life. Recipients of care included patients and their families. Within this theme, the barriers to communication were conflicts between care giving and patient cultural values about discussing care. For example, patients from Anglo-Saxon cultures are more open to patient-provider dialogue about treatment decisions. In other cultures, doctors are viewed as the decision makers, limiting the involvement of patient and family and compromising communication. When patients are unable to communicate, family members have a difficult time accepting bad news and making decisions, further limiting communication.

Examples of healthcare system barriers are the impersonality of large teaching hospitals where more than 50% of deaths occur in the ICU setting, staff shortages, and lack of institutional resources such as consult services for palliative care and ethics. Healthcare providers in this study reported that the impersonality of the ICU interfered with private communication among providers, patients, and family members. Healthcare providers' role in impeding communication stems in part from their lack of training in end-of-life care, specifically in leading end-of-life discussions with patients and their families. The providers recognized that end-of-life issues are difficult, emotional and uncomfortable topics and that their professional education and training did not prepare them for this role. All these barriers were aggravated by the nature of the discussion topic: end of life. Even those from relatively open Anglo-Saxon cultures find that open discussion of end-of-life care is unacceptable. Therefore when a patient's course of illness changes, and treatment or life support has to be withdrawn, family members and healthcare providers alike may tend to accept death as a failure rather than an integral part of the life cycle.

Communication and Setting of End-of-Life Care

Hospitals. Communication between healthcare providers, patients and family caregivers is likely to be influenced by the setting in which end-of-life care is provided, most often a hospital since the majority of all deaths (75%) occur in an institutionalized setting. Hospitals account for 50% of decedents' last place of care, followed by nursing homes (25%), and private homes (25%) (Morrison, 2005b; Sheehan & Schirm, 2003; Teno et al., 2004; Teno, 2005). One in 5 Americans is estimated to die in the ICU or shortly after discharge from that setting. The ICU is a place where patients and their families have numerous encounters with healthcare providers for decision-making, advance care planning, and withholding or withdrawing of life support. Communication among healthcare providers, patients and their families has been identified as the most important factor in end-of-life care in the ICU (Boyle, Miller, & Forbes-Thompson, 2005). However, communication in this setting has been shown to have several problems: conflict with the goals of care has been reported amongst clinicians and family members (Clarke et al., 2003), clinicians may be unavailable for discussion (Norton, Tilden, Tolle, Nelson, & Eggman, 2003), and the unnatural setting and technological advances discourage a compassionate and caring environment (Beckstrand, Callister & Kirchhoff, 2006). Communication in the ICU is complicated by patients being unable to speak due to illness or treatment, resulting in family members or other patient surrogates being called upon for decision-making.

In a recent study, physicians and nurses collaborating on improving the communication process in the ICU setting utilized family conferences to discuss delivering bad news or the withdrawal of life-sustaining treatments (Stapleton, Engelberg,

Wenrich, Goss, & Curtis, 2004). The study found that families were most satisfied with the communication process when healthcare providers spent time discussing withdrawal of treatment, supported the families' decisions and gave special effort to comforting the families' loved one.

Nursing homes. Nursing homes are another setting for ineffective communication between providers and patients/their families about end-of life care (Shield, Wetle, Teno, Miller & Welch, 2005; Teno et al., 2004; White, 2005). Families report that communication is poor because physicians are not available, they visit with patients when family members are not present, and they are difficult to contact for discussing decisions or changes in goals of care. Although advance directives (ADs) are required in both hospital and nursing home settings, ADs have not been as effective in communicating patient wishes as anticipated (see below).

The home. Dying at home or in a home-like setting is the preference of most Americans, yet fewer than 25% reach this goal (National Institutes of Health, 2004; Ratner, Norlander, & McSteen, 2001). A few of the many factors that influence whether a patient dies at home include the functional status of the patient, their demographics (age, socioeconomic status), the input from the healthcare system (such as the intensity of home care offered and available) and social support (available, willing and able caregivers) (for review, see Gomes & Higginson, 2006). Patient preferences were identified as the most powerful influence in achieving death in the home setting; however healthcare providers and caregivers were the key variables in actualizing the patient's wishes. Pertinent to communication with healthcare providers is the lack of advance care planning by patients and their families. Furthermore, the resources for patients that wish

to die at home are variable and may not be available to provide sufficient support for the patient and family (Gomes & Higginson, 2006).

Advance directives. The Patient Self-Determination Act (1990) refers to the right of competent adults to make their own medical treatment decisions, and includes the right to complete advance directives (AD's), saying how and/or by whom decisions should be made in the future in the event a person becomes incapacitated and unable to make his or her own decisions. AD's are a written state of instruction in a form recognized by each individual state law that addresses the provision of health care in the event of a person's incapacity or inability to communicate. Forms vary state to state but may include a living will, durable power of attorney or a health care proxy (McDonald et al., 2003). In Massachusetts, the health care proxy form is the legally recognized advance directive. It designates a patient's health care agent and an alternate (Central Massachusetts Partnership to Improve Care at the End of Life, 2006; Hospice & Palliative Care Federation of Massachusetts, 2007).

Although AD's were developed to improve communication amongst patients, families and healthcare providers, this outcome has not been supported by evidence (Tulsky, 2005b). AD's generally lack clarity (Nolan, 2003) and cause family members or surrogate decision-makers to guess about their loved ones' decisions regarding treatment or withholding of treatment (Inman, 2002). Patients at the end of life may be hospitalized several times, exposing them and their family caregivers to healthcare providers that are unaware of their individual situation. Each encounter with a new healthcare provider at this vulnerable time may create uncertainty, mistrust and a change in the way the patient and his/her family make decisions about their wishes. Even if an AD is available, it may

not be followed and may be disregarded by healthcare providers and families due to the lack of clarity of the AD (Nolan, 2003) or the decisional conflict that can occur amongst families when their loved one is unable to participate in the process (Heyland, Rocker, O'Callaghan, Dodek & Cook, 2003).

Communicating about Hospice

Hospice is an underutilized resource that provides support and care for patients and their families at the end of life (National Hospice and Palliative Care Organization [NHPCO], 2006) so that they may live as fully and comfortably as possible. Hospice care may be provided in the home, nursing home, hospice facility, or in a specialized unit in a hospital that focuses on quality of life in the dying process. Unfortunately the possibility of hospice care is usually not communicated to patients and families in a timely manner to be fully effective. Hospice care as a Medicare benefit is traditionally available to all patients with a prognosis of dying within 6 months or less, but the average length of hospice care in the US is 22 days, with the more common length of care less than 7 days (NHPCO, 2006). Indeed, spouses and first-degree relatives of deceased cancer patients reported in one retrospective study that healthcare providers offered hospice too late and the information they communicated about hospice was fragmented and incomplete (Royak-Schaler et al., 2006; Wotton, Borbasi & Redden, 2005). Although most respondents in that study (66%) reported that hospice was a positive experience, they felt it was offered as a last resort. They also indicated that both nurses and physicians assumed that patients and families knew much more about hospice than they actually did. This assumption added stress and frustration to the overall end-of-life experience.

Cost of Poor Healthcare Provider Communication at End of Life

The costs of poor communication at the end of life affect finances, emotions, and limits health-care resources. The financial cost of most deaths arises from their occurrence in the hospital setting where care is advanced, highly technological, and expensive. The emotional cost to society is that the American public expects advances in science and medicine to overcome extreme odds in terminal and chronic illnesses and to avoid death (Angus et al., 2004). Sustaining life beyond the point of meaningful quality drains limited resources, not the least of which is provider time, and is distressing to both families and the healthcare team (Ferrell, 2006). Research has demonstrated that patients want to die at home, surrounded by family in a peaceful atmosphere (NIH, 2004; Ratner, Norlander & McSteen, 2001). To help patients and families achieve this goal and to strike a balance between preserving life and providing a peaceful death, healthcare providers need to develop better communication skills, not only with patients at end of life and their families, but also with the other providers caring for each patient.

Given all that is known about the insufficiencies of communication during the end-of-life care experience, what is missing in this body of knowledge? What more is there to learn?

Improving Communication at End of Life

The next logical step to improving the problem of poor communication is translating the research knowledge to the communities where healthcare providers practice. Specifically, healthcare providers need to tailor their communications with patients to their specific cultural attitudes about death and dying, to demographic characteristics such as age and education, to their family members' involvement with the

patient, and to the other provider's caring for the patient. The healthcare providers are in a position to take the lead and improve communication. Families have provided information about the care of their loved ones which needs to be taken seriously. Numerous studies have concluded that communication between healthcare providers, their patients, and those that care for them is a driving force in determining the quality of care at the end of life. How is it that we know this key information and do not have it enacted in the community where each patient receives their care? It is possible that each community has its own set of unique communication issues that need to be identified so healthcare providers are better informed and prepared to take the lead. Healthcare providers not only are leaders but are viewed by patients, families and society as the accountable and responsible parties in driving quality healthcare. The process of improving end of life care begins with improving communication.

Summary

Quality end of life care is the goal. All the parties involved in this process: healthcare providers, patients and their families agree that this goal is not being met and it is directly related to communication (NIH, 2004; SUPPORT, 1995; Teno et.al, 2004). How do we translate what is known to the community level? Healthcare providers need to be the leaders and be accountable to those patients and families they care for at end of life. In order to help them take the lead, they need the information from their community that will help them to communicate better, thus leading to an improved end of life experience.

CHAPTER 2

INTRODUCTION TO THE STUDY

Introduction

Communication at the end of life between healthcare providers, patients and their families is an essential component of providing quality end-of-life care, but despite the best intentions of all parties involved (healthcare providers, patients, and their family members), this goal remains unmet (Field & Cassel, 1997; National Institutes of Health [NIH], 2004; SUPPORT, 1995). For healthcare providers to take the initiative in improving communication at end of life, they need to be aware of the needs and concerns of their patients and families. Although much is known at the national level about communication at the end of life (e.g., see NIH, 2004), little is known about this topic at the local level. The findings from this study will contribute data that is local, useful and gives access to the healthcare providers and their community an awareness of the quality of the dying experience. This chapter will address a survey study about end-of-life care in central Massachusetts, specifically on communication issues that were revealed in responses to an open-ended question. These responses will provide the data for this research. The chapter will conclude with the study purpose, specific aims, and the framework that under-girds the study.

Background

End-of-life Care Survey in Massachusetts

The impetus for the proposed study stems from a national and state initiative to improve the quality of end-of-life care. To identify ways to achieve this goal in Massachusetts, the Massachusetts Commission on End of Life Care surveyed residents

throughout the commonwealth on their attitudes and concerns about care at the end of life (Asp, Spring, & Sokolowski, 2005). To determine their attitudes, expectations, and experiences with the dying process, a 73-item survey was mailed to 3,000 residents chosen at random from those ≥ 35 years old. The survey, which had a 25% response rate, gathered basic demographic information as well as data related to advance care planning, knowledge of hospice services, spiritual beliefs and customs related to death and dying, preferred medical practices, financial concerns, pain management and social support systems. In response to items addressing communication, respondents indicated their willingness to talk about death, but less than 20% had actually done so. The respondents also indicated a preference for their primary care physician to initiate the discussion about death, for honest answers about their treatment options, and for understanding these options. Another item related to communication, having a good relationship with their health care providers, was also rated as “very important.”

End-of-life Care in Worcester

Building on this statewide survey, the Central Massachusetts Partnership to Improve Care at the End of Life (CMP, 2006; Kaufman & McCluskey, 2006) surveyed next of kin listed on death certificates in 2004 about end-of-life care received by the deceased person. Of the 3045 death certificates recorded in Worcester, the largest city in central Massachusetts, 900 were selected at random. The retrospective survey (Appendix A) was mailed to the next of kin and asked for the decedent’s demographic data, the respondent’s relationship to the decedent, and 27 questions based on the framework of 8 domains for quality palliative care (NCP, 2005; see Table 1).

Respondents were asked to answer each question by rating its importance to the decedent on a 4-point Likert-type scale, from 1 to 4 where “very important,” “fairly important,” “not important,” and “don’t know,” were rated respectively. They were also asked to rate how often (always, usually, sometimes, or never) each criterion was met in the decedent’s care. The survey concluded with an open-ended question: “Are there any other things you wish to share about what was good or bad about your experience?”

Of the 373 completed surveys, 218 had written responses. These responses were reviewed in a qualitative descriptive study that used content analysis to assess the number of positive, negative, mixed and not applicable responses. The specific aims of this study were to describe the positive and negative experiences of decedents end-of-life care in central Massachusetts as described by next of kin, to explore the end-of-life experiences in relation to the eight NCP domains, and to identify new themes or experiences that emerged from the qualitative data. An expert panel of nurse researchers (hence called the research team) identified two themes (communication, and values and preferences) and four categories (the desire to be present at the time of death, securing a peaceful death with dignity and respect, attending to the needs and wishes of the dying individual and family, and supportive environment) (Boucher, Bova, Klar, Sullivan-Bolyai, & Theroux, 2007). Among these themes, communication was overarching. Families reported the lack of clear, consistent, concrete understandable information from healthcare providers. Thus, this study addresses communication with healthcare providers from the perspective of the 218 next of kin who chose to write their views on this issue.

Purpose and Specific Aims

The purpose of this study was to explore experiences related to communication with healthcare providers in central Massachusetts during end-of-life care. Data derived from the targeted community, which is also the community from where healthcare providers work, is valuable. This analysis, driven from community data, can improve the quality of care and ultimately shape the care to be delivered in a more culturally relevant context. Specifically, this study explored the communication experiences of decedents' next of kin who responded in writing to an open-ended question at the end of a mortality follow-up survey (Kaufman & McCluskey, 2006). Healthcare providers include physicians, nurses and any personnel identified by next of kin as care providers to the decedent.

The specific aims of this study were to:

- 1) Explore communication issues identified by next of kin during decedents' end-of-life care.
- 2) Identify the positive and negative aspects of communicating with healthcare providers during the end-of-life care experience as perceived by next of kin.
- 3) Describe next of kin's perceptions of the healthcare providers' role in communicating with patients and next of kin during the end-of-life care experience.
- 4) Identify barriers and facilitators perceived by decedents' next of kin in the communication process with healthcare providers during the end-of-life care experience.

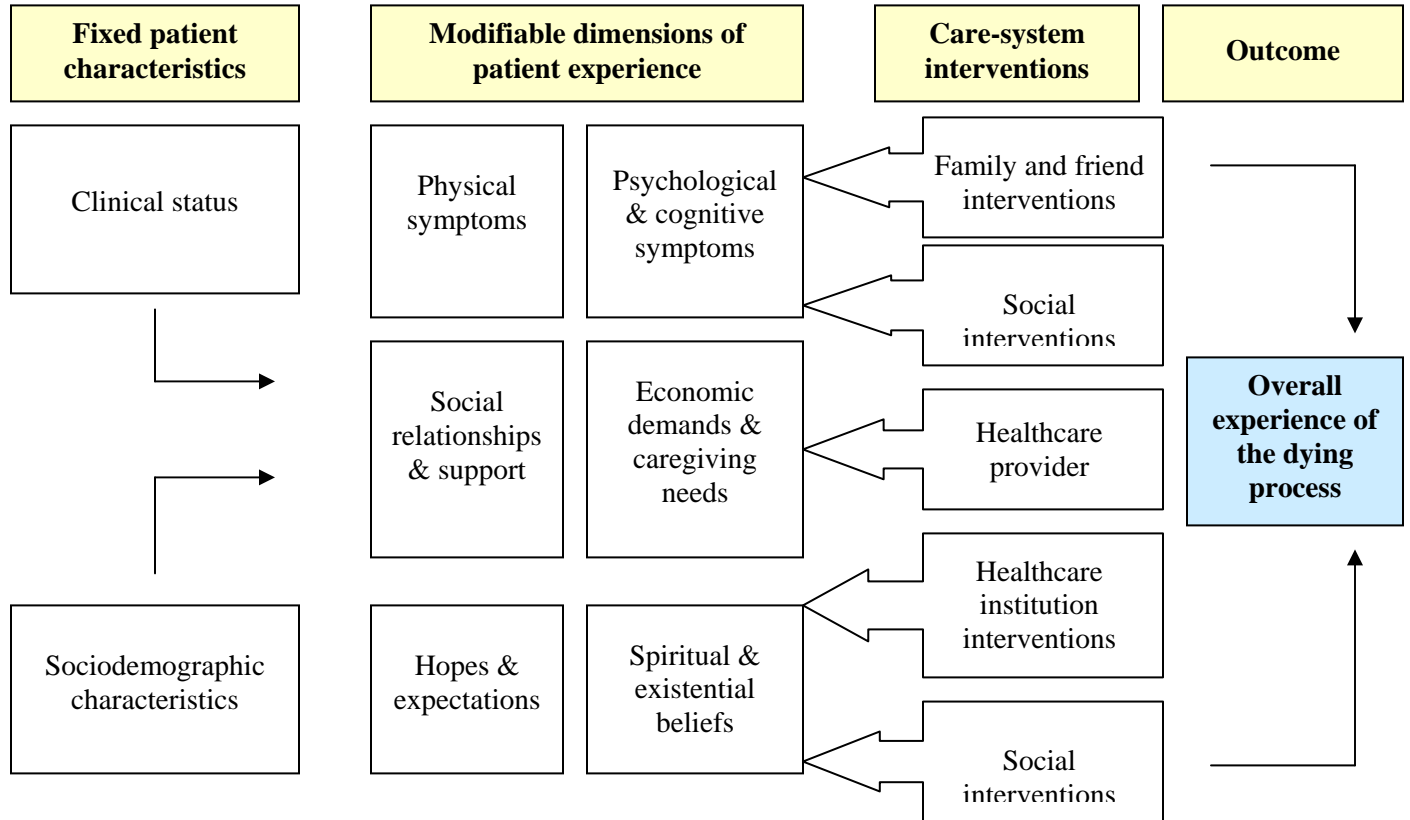
Framework

This qualitative descriptive study of communication with healthcare providers at the end of life, from the perspective of decedents' next of kin, was under-girded by the framework for a good death (Emanuel & Emanuel, 1998). This framework was chosen because it is multidimensional and considers the viewpoints of all individuals in the end-of-life experience: the patient, his/her family, and healthcare providers.

This four-component framework (see Figure 1) analyzes three dimensions of the patient experience (fixed patient characteristics, modifiable dimensions of the patient experience, care-system interventions) that lead to the outcome (overall experience of the dying process). Examples of the patient's fixed characteristics are disease status, prognosis, age and race. Examples of modifiable dimensions are the patient's pain, available support such as family and friends, and the patient's spiritual beliefs. Care system interventions include the care setting (hospital, home) and interventions used by healthcare providers (advance care planning, palliative care consulting). The fourth component (outcome) culminates in the patient's overall experience of the end-of-life care process.

This framework captures the multidimensional experience of dying and the numerous processes and interactions between the patient, healthcare providers, and the healthcare system. It includes specific variables relevant to the patient, his/her family, healthcare providers, and the healthcare system, thus making it applicable to any care setting. The arrows in Figure 1 denote the relationship amongst all the dimensions and the iterative process of give and take as patients traverse the end-of-life process.

Figure 1. Framework for a Good Death



This research focused on communication between the healthcare providers, patients and their family. For the purposes of this study, the framework has been modified to include the patient, family and friend interventions, and healthcare provider interventions with communication as a give and take process throughout the end of life care experience. It was hypothesized that with optimal communication amongst family (next of kin), the patient and the healthcare provider, that a good end of life care experience will be the outcome.

Significance

Next of kin in Worcester, Massachusetts have identified communication with healthcare providers as a significant issue impacting the quality of care at end of life. Listening to next of kin is essential groundwork to improving communication, thus improving care for those patients and families at end of life. The findings from this study provide healthcare provider insights into communicating with this population. These insights provide an in-depth view of the range of next of kin communication experiences, thus increasing the healthcare providers' awareness of the need to tailor their communication patterns. Since healthcare providers are directly responsible for this patient population and their families, they are also responsible for taking the first step in opening the channels of communication at end of life.

Implications

The findings from this study provide several benefits. First, they offer information that is important and relevant for healthcare providers to improve the communication process during end of life care. Listening to what next of kin have to say about communication during their loved ones' end of life experience illuminates for

healthcare providers where the disconnect may be between a good end of life care experience or not. This knowledge is essential for improving the quality of care to those dying in Worcester. Second, the study findings allow the Worcester experience to be compared to national data on end-of-life care and to serve as a benchmark for healthcare systems and providers in central Massachusetts. This outcome is important in translating knowledge from the national level to the local community. Finally, this information may allow healthcare providers to develop strategies to improve communication with patients at the end of life and their next of kin.

CHAPTER 3

METHODOLOGY

Introduction

The study is a secondary analysis of open ended survey data using qualitative content analysis to describe next of kin's perspectives of communication with healthcare providers during the decedents' end-of-life care experience. The qualitative data for this study came from 218 written responses to a survey that concluded with an open-ended question: "Are there any other things you wish to share about what was good or bad about your experience?" A preliminary analysis of these responses by a nursing research team identified two themes (communication, and values and preferences) and four categories (the desire to be present at the time of death, securing a peaceful death with dignity and respect, attending to the needs and wishes of the dying individual and family, and supportive environment) (Boucher et al., 2007). Communication was the overarching theme. Families reported the lack of clear, consistent, concrete understandable information from healthcare providers. To examine these responses in more detail, this study utilized secondary analysis, specifically supplementary analysis (Heaton, 2004), of these written responses to describe communication with healthcare providers from the perspective of the next of kin who chose to write their views on this issue. Secondary analysis is a valid research technique to generate new knowledge from an existing data set, or as in this research, to analyze a data set in more detail than in the primary study (Hinds, Vogel, & Clarke-Steffen, 1997).

Design Rationale

A qualitative descriptive approach is desirable for this research as the experience of receiving end-of-life care from the next of kin's perspective has not been explored in central Massachusetts. Communication between individuals at the end of life and their healthcare providers is a concern at the national level, but the impact of this issue at the local level is unknown. Qualitative description is a distinct method of naturalistic inquiry which presents the facts of a phenomenon in everyday language (Sandelowski, 2000; Sullivan-Bolyai, Bova & Harper, 2005). The goal of qualitative description is to understand the human experience embedded within a specific text. In terms of this study, this goal was realized by analyzing the written responses of next of kin about their experiences of end-of-life care.

The goal of this study was not to develop a theory or to interpret the data in any way, but to obtain a rich description of the communication experiences of next of kin as they traversed end-of-life care with the decedent and interacted with healthcare providers. This description will help providers in central Massachusetts to better understand this experience.

Setting

The setting for the original survey was Worcester, Massachusetts, the third largest city in New England and the second largest city in Massachusetts, with a population of approximately 176,000 (City of Worcester, 2006). Worcester has 2 large tertiary care hospitals, UMass Memorial Health Care and Saint Vincent Hospital, which serve Worcester and the surrounding communities. UMass Memorial Health Care is the clinical partner of the University of Massachusetts Medical School and the largest health care

system in central and western Massachusetts with 830 beds. It is a not-for-profit, integrated health care system designed to provide all levels of health care, from primary to quaternary (UMass Memorial Health Care, 2006). Saint Vincent Hospital is a 348-bed for-profit acute care hospital located in the Worcester Medical Center. The medical center provides an integrated continuum of care—from diagnosis to treatment and from emergency and preventive medicine and routine check-ups to highly specialized surgeries and innovative treatments (Saint Vincent Hospital, 2006).

Sample

The original sample consisted of respondents to a survey (Appendix A) about care at the end of life in Worcester (Kaufman & McCluskey, 2006). These respondents were listed as next of kin on death certificates of individuals who had died in 2004 in Worcester. Of the 3045 death certificates on file in 2004, 900 were randomly chosen to identify next of kin to whom surveys were mailed. Of the 900 surveys mailed, 373 responses were received (41.4%). These 373 responses contained 218 written responses (58.4%) to the open-ended question: “Are there any other things you wish to share about what was good or bad about your experience?” The open ended written responses from the 218 next of kin were reviewed according to the inclusion and exclusion criteria.

Inclusion Criteria

Decedents included in the parent study were adults greater than age 18 or older, who died in Worcester, Massachusetts in the year 2004. The death was not related to trauma or emergent nature and could not have occurred within 24 hours of admission where death was pronounced. Participants in this study were next of kin listed on the death certificate who responded to the parent study and then to the open-ended survey

question: “Are there any other things you wish to share about what was good or bad about your experience?” The content of these responses were included in this study with content specific to communication.

Exclusion Criteria

Responses were excluded from this study if they were written in a language other than English, the handwriting was illegible, or the content did not address communication.

Procedures

Data Collection

The data were obtained from the research team who performed the preliminary analysis. The data was kept in a locked file cabinet in the researcher’s office. Each subject’s number remained consistent with the parent study number and the preliminary analysis by the research team. No subject names were on the transcribed data. The same numbers were utilized to identify subjects throughout the secondary analysis.

Data Management

The data were kept confidential with subject identifiers only accessible by a locked file cabinet. The quantitative demographic data were accessible to describe the sample. Demographics were run through the SPSS version 14.0 to describe the decedents and the participants in the study.

Data Analysis

Data consisted of written responses that were transcribed verbatim for the preliminary analysis. The researcher initially read the transcribed data to gain a general sense of the information and reflect on its meaning (Creswell, 2003) before beginning the process of qualitative content analysis. Content analysis is a systematic process for

developing codes or labels that describe data gleaned from careful reading of the transcribed responses. Content analysis uses 6 analytic strategies common to many qualitative traditions, including qualitative description. These strategies are coding data from written responses; recording insights and reflecting on data; sorting through the data to identify patterns, phrases, sequences, and important features; looking for commonalities and differences among the data and extracting them for further consideration and analysis; working to decide on a small group of generalizations that hold true for the data; and examining these generalizations in light of what is known about the area of research (Miles & Huberman, 1994).

The purpose of qualitative analysis is to extract themes and salient ideas from the data to gain a new perspective on the phenomenon of interest. Content analysis goes beyond counting words to examine language (written text) intensely to classify the large amount of text into efficient categories that represent similar meanings. A codebook was created to list, organize and arrange codes and data. Codes were consolidated where possible, and ongoing attempts were made to compare and contrast patterns within and across data (Creswell, 2003). The purpose of coding is to cluster large pieces of data into a smaller number of focused, descriptive themes (Miles & Huberman, 1994). Some of the codes refer back to the organizing framework; others emerged during analysis (Sandelowski, 2000). Finally, these themes were reconstructed into a meaningful description of the phenomenon of interest, in the words of the respondents. A summary of the data includes specific quotations or narratives that substantiate the themes. This analysis provides knowledge and understanding of communication with healthcare providers at end of life (Hsieh & Shannon, 2005).

Process

The results emerged from the researcher's immersion in the data. This process began with extensive review of the written transcribed responses and journaling to gain a general sense of meaning from the information. The researcher attended meetings with the research team to discuss and validate findings and then to further reflect on depicting the findings in the participants own words. The process was further explicated by constructing a data analysis table (Appendix B) to code, sort and cluster the data into descriptive themes and subthemes. The data analysis table categories included the participants own language, good(+), bad(-), neutral or neither, comments and notes from the researcher and implicit versus explicit response to communication with healthcare providers. The use of good and bad as analysis categories evolved from framing the responses within the context of the open-ended question, "Are there any other things you wish to share about what was good or bad about your experience?"

Trustworthiness

Establishing rigor or trustworthiness in qualitative inquiry includes four components: credibility, transferability, dependability, and neutrality (Lincoln & Guba, 1985). Initially the researcher randomly read through the transcribed data and compared it with the original data set to ensure accuracy and quality. There were no errors or omissions found in 63 comparisons of transcribed data with the originals. The researcher ensured credibility through prolonged engagement with the data: reading, re-reading, taking notes and reviewing the data. Transferability was addressed by constructing rich descriptions of the phenomenon. Dependability and confirmability involved auditing the research process. The researcher consulted regularly with her dissertation committee to

provide oversight of the process. The committee consists of methodological experts in qualitative methods and content experts in end-of-life care. The researcher also met with the research team to validate the analysis process and confirm findings. Neutrality was achieved through the use of “bracketing” which is the researcher blocking prior assumptions about the data that could impose personal feelings or preconceptions on the data or their interpretation (Ahern, 1999). This was important as the researcher has several years of experience as a healthcare provider in the oncology and end-of-life population and has had a recent personal experience with the death of a family member. It was necessary to reflect on these personal and professional experiences to avoid any effect on the findings. A journal was initiated at the start of analysis to record reflections, questions and decisions that emerged during the analysis.

Limitations

The major limitation to this study was the secondary data analysis. The data set contains a finite amount of information. However, preliminary analysis revealed that the data have rich descriptive content related to communication with healthcare providers at end of life.

Another limitation is that the respondents for this analysis self-selected twice from the original random sample of all decedents’ next of kin in Worcester in 2004. They were among the 373 who chose to respond to the 900 surveys originally mailed. They self-selected a second time by choosing to answer the open-ended question at the end of the survey. Another limitation is the researcher was not involved in the development of the parent study and could not be part of the design process or questions that were developed. However, the researcher had access to the principal investigator

(P.I.) as he is part of the researcher's dissertation committee. This could be viewed as a strength as the P.I. was accessible for validating any questions that arose.

Protection of Human Subjects

The original survey study was approved by the Institutional Review Board (IRB) at Saint Vincent's Hospital, Worcester, MA. This approval was reviewed by the University of Massachusetts Medical School IRB, which did an expedited review exempting this proposed secondary analysis from further review.

Summary

The purpose of this study was to explore experiences related to communication with healthcare providers in central Massachusetts during end-of-life care. Specifically, the study explores the communication experiences of decedents' next of kin who responded in writing to an open-ended question at the end of a mortality follow-up survey (Kaufman & McCluskey, 2006). These responses have been described through qualitative content analysis to obtain a rich description of next of kin's perspective of communication with healthcare providers at end of life. This study was a secondary analysis of data preliminarily reviewed by a research team who identified communication as an overarching theme throughout the data. The information from this analysis is anticipated to benchmark communication at end of life with healthcare providers in central Massachusetts, an experience that has not been documented. Furthermore, the findings will inform healthcare providers throughout central Massachusetts of perceptions needed to tailor their communication with patients and families at end of life, thus improving the quality of end-of-life care.

CHAPTER 4

RESULTS

Introduction

Qualitative content analysis was used to describe communication with healthcare providers at the end of life from the perspectives of next of kin. The parent study utilized the eight NCP domains to develop their survey (Kaufman & McCluskey, 2006) and in this study the framework for a good death (Emanuel & Emanuel, 1998) under-girded this research. The results revealed rich, descriptive representations of the participant's thoughts, feelings and experiences with their next of kin's communication during the end-of-life care experience with healthcare providers. The overarching theme of *accessing information* emerged with four related subthemes which were *continuum of information* (not having enough information, miscommunication of information, availability of healthcare providers to share information and well informed), *healthcare provider sensitivity* (time, number of providers and approach), *having the answers* (knowing what to expect, desire to be present and prognostication), and *raising awareness* (language, education and culture). Participant demographics are summarized as follows according to the sample criteria, relationship with decedent, demographic and clinical characteristics of the decedent, along with the decedent's activities of daily living (ADL) performance. A detailed description of the overarching theme and subthemes are summarized according to the specific aims of the study and include illustrative quotes.

Participants

The study participants meeting inclusion criteria included 170 (78 %) next of kin of the 218 surveys with written responses to the open-ended survey question "Are there

any other things you wish to share about what was good or bad about your (end of life) experience?” The next of kin were mostly women (67.7%) and were daughters (38.4%) of the decedents (see Table 2). The decedents were mostly Caucasian (95.9%), the majority were female (54.1 %) and ranged in age at the time of death from 42 to 99 years (M = 77, Median = 79, SD = 12.1), with most being age 80 or older (47.6%). Decedents were mostly married (41.2%), spoke English as a primary language (92.9%) and were Catholic (57.1%). The respondents reported that their next of kin died of cancer (33.0%) or cardiovascular disease (32.3%) in an acute care setting (60.6%) and had no utilization of hospice services (77.1%). The majority of decedents had an identified health care proxy (78.8%) and a Do Not Resuscitate (DNR) or comfort care order in place (64.7%) (see Table 3). Respondents were asked about the decedents activities of daily living (ADL's) one month prior to death and the majority were able to walk, toilet, feed, dress, bath and remember important people and events (see Table 4).

It should also be noted that the decedents in this study and the participants who chose to respond to the open ended survey question (n = 170), were not statistically different from those that did not respond (n = 155) in regards to age, race, gender, cause of death, place of death, or utilization of Hospice.

Table 2

Relationship of the Respondents to the Decedent

Relationship	N	%
Daughter/Son	63/21	38.4/12.8
Wife/Husband	36/10	22.0/6.1
Sibling/Kin/Other	15/10/10	8.5/6.1/6.1
Missing	6	3.5

Table 3

Demographic and Clinical Characteristics of the Decedents

Variable	N	%
Gender		
Female	92	54.1
Male	78	45.9
Age Group		
Under Age 60	24	14.1
60 to 79	65	38.2
80 and Older	81	47.6
Race/Ethnicity		
Caucasian	163	95.9
Hispanic	1	0.6
African American	1	0.6
Missing or Unknown	5	2.9
Primary Language		
English	158	92.9
Spanish	1	0.6
European	1	0.6
Missing or Unknown	10	5.9
Marital Status		
Married	70	41.2
Widowed	50	29.4
Divorced	18	10.6
Single	18	10.6
Missing or Unknown	14	8.2
Religion		
Catholic	97	57.1
Protestant	48	28.2
Jewish	4	2.4
Other	5	2.9
Missing or Unknown	16	9.4
Cause of Death		
Cancer	56	33.0
Cardiovascular Disease	55	32.3
Pulmonary Disease or Infection	37	21.8
Alzheimer's Disease	12	7.1
Other	10	5.8
Health care Proxy in Place		
Yes	134	78.8
No	25	14.7
Missing or Unknown	11	6.5
Do Not Resuscitate or Comfort Care in Place		
Yes	110	64.7

HCP Communication at EOL

No	39	22.9
Missing or Unknown	21	12.4
Place of Death		
ICU	55	32.4
Hospital (Not in ICU)	48	28.2
Nursing Home	36	21.2
Home	21	12.4
Hospice Residence	9	5.3
Missing or Unknown	1	0.6
Length of time in the place where death occurred		
Hours	22	12.9
Few Days	41	24.1
1 to 3 weeks	40	23.6
4 to 24 weeks	25	14.7
25 to 52 weeks	4	2.4
Greater than year	21	12.4
Missing or Unknown	17	10.0
Use of Hospice		
Yes	38	22.4
No	131	77.1
Missing or Unknown	1	0.6

Table 4

ADL Performance Level of Decedents 1 month before death

Activity	Yes (%)	No (%)	Missing (%)
Walk	101 (59.4)	69 (40.6)	0
Bathe self	89 (52.4)	81 (47.6)	0
Dress self	98 (57.6)	72 (42.4)	0
Use toilet	109 (64.1)	61 (35.9)	0
Feed self	131 (77.1)	39 (22.9)	0
Ability to remember important people or events	135 (79.4)	33 (19.4)	2 (1.2)

Overarching Theme and Subthemes

The overarching theme and four subthemes reflect communication issues next of kin wrote about when describing their loved ones experience with healthcare providers at end of life. They also include the positive and negative aspects, the healthcare provider role and the barriers and facilitators perceived by next of kin when communicating with

healthcare providers during the end of life experience. The overarching theme, *accessing information*, was threaded throughout participant responses and was the main finding in this study. *Information* was important to decedents and their families in discussing their wishes, treatment options, changes in care and the many transitions involved in the end of life experience. *Accessing information* was viewed by next of kin as a significant function of healthcare providers and their role in the end of life experience. Being available and the having access to discuss information with healthcare providers was a key element in the end of life experience.

Four related subthemes were linked to the overarching theme (see Figure 2). The first was *continuum of information* where participants described levels of information pertaining to communication during the end of life experience. Continuum seemed appropriate as there was a range of information discussed by participants from *not enough* through *well informed*.

The next three subthemes emerged as *healthcare provider sensitivity*, *having the answers* and *raising awareness*, which were also related to the overarching theme. *Healthcare provider sensitivity* involved participants discussing references to the amount of *time* and that there were *too many providers* involved in the care of their loved one. Participants also wrote about the *approach* that the providers used such as impersonal, blunt or “spent a lot of time with us,” or that it was compassionate, professional and helpful at a difficult time. These aspects emerged to form the second subtheme *healthcare provider sensitivity*.

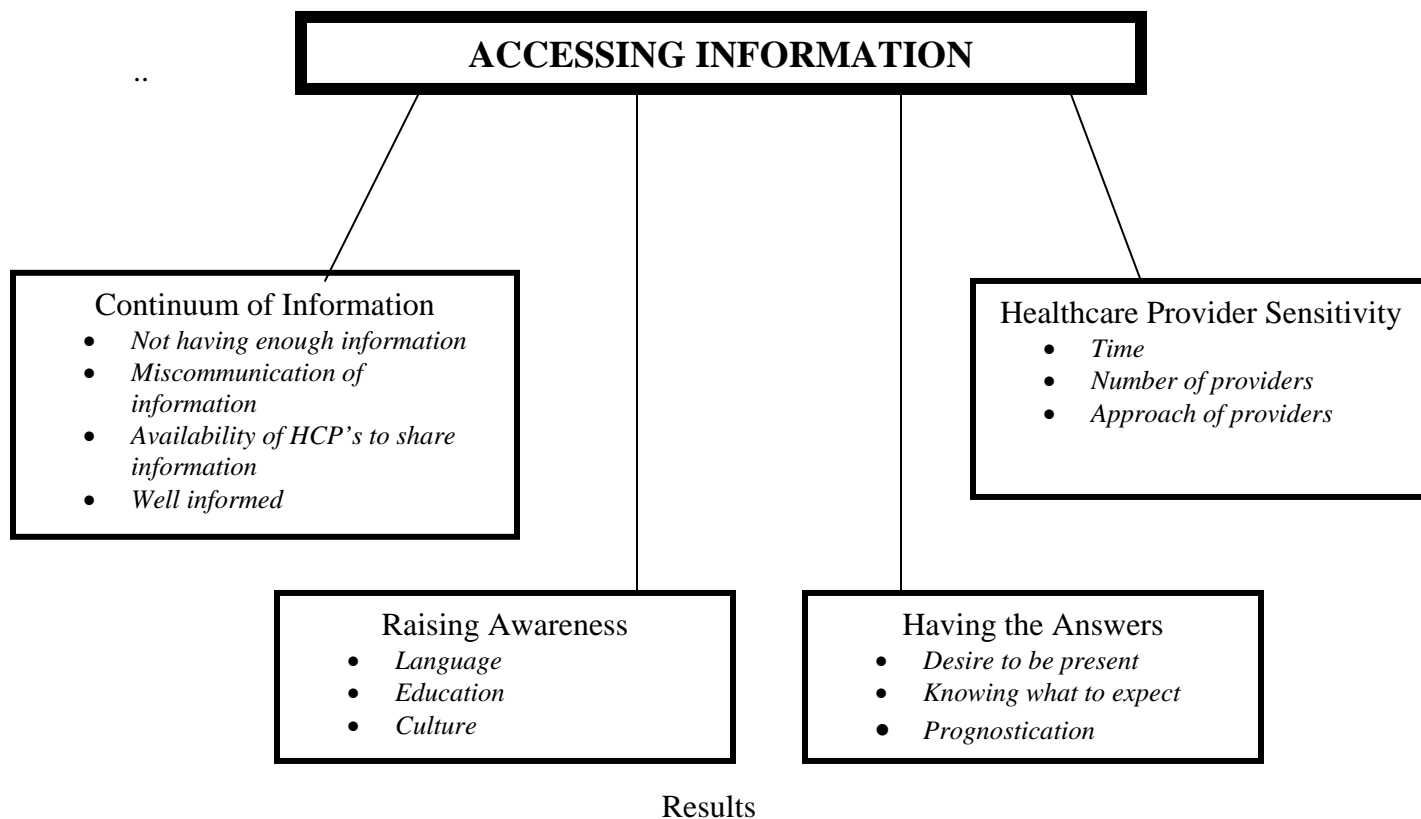
The third subtheme, *having the answers*, was described by participants as *knowing what to expect* such as when there was a change in condition or treatment; *desire*

to be present which was directly related to when the decedent was dying and the family wished to be there; and *prognostication* in which participants have an expectation that healthcare providers know and are supposed to communicate exactly when their loved one will die.

And lastly, the fourth subtheme emerged as *raising awareness*. This was described by participants as *language* when healthcare providers spoke with an accent or “poor English” or did not use language understood by the decedent and next of kin; *education* such as a lack of training of healthcare providers, not being adequately trained and wondering if they needed a “refresher class” on dealing with patients; and *culture* which was referenced as the “death denying culture” of our society and the “lack of discussion” amongst families regarding wishes and end of life preferences. This lack of discussion was referenced by the participant as almost a self-analysis and speaks of our American culture in general. Additionally many participants described having good care, outstanding care and excellent end-of-life care provided to their loved one’s which made the end of life experience bearable, helpful and was appreciated.

These subthemes will be presented framed by the specific aims of the study.

Figure 2. Overarching theme and subthemes



Aim 1

Explore communication issues identified by next of kin during decedents' end-of-life care.

Continuum of Information

Many participants (n = 57) wrote about communication issues and these fell out as the subtheme *continuum of information*. Participants described *not having enough information* such as when the decedents were transferred between facilities or in the hospital setting where they would go from a regular room to an intensive care unit (ICU). *Miscommunication of information* occurred when decisions about care or treatment were not enacted, specifically related to resuscitation. The *availability of healthcare providers*

to share information was related to decedents wanting to see or talk to their primary care doctor. Many felt they lost this connection when they went to a hospital setting or were managed by specialists. Many participants (n = 13) also described that they were *well-informed* and wrote that they were “satisfied with the sharing of information” and the “detailed information received” in the care of their family member. Being well informed was associated with good care and satisfaction. The communication issues identified as the *continuum of information* will be described and framed by illustrative quotes.

Not having enough information

Not having enough information was described in relation to making decisions about treatment (n = 5) or changes that occur during patient transitions in the place where they received care (n = 7) or in the process of dying (n = 4). Participants noted that they were not given enough information as a “poor exchange” with healthcare providers; “Very poor exchange of [*sic*] information between doctor and myself. Sometimes nursing home nurses seem to withhold some information or weren’t allowed to (give information).” Others referenced wanting to be informed as they did not live in the area where their loved one was receiving end of life care; “We wish we were contacted on a regular basis since we were out of town. If my son hadn’t visited weekly we would not have known of her decline.” This participant illustrates that even though information may be given, it can take time to absorb that dying is a possibility:

...My Dad was having trouble breathing, the Dr. went in and told him you’ll have a respirator and you’ll be moved to a nursing home for the rest of your days....My father was petrified, he did not know he was **dying!**

For some participants (n = 4) their loved one was transferred between facilities and they expressed “anxiety” and not being notified of the plan of care such as in this quote, “...there wasn’t much communication available. She was moved out of the hospital too quickly. In the two & a half months of being ill, my mother was transferred 11 times.” Many participants referenced the transfers as disturbing or unnecessary as with this quote:

...ALL treatment failed and she was given last rites. The hospital discharged her back to (nursing home) –the nursing home where she passed a few hours later.

This was horrible and unnecessary and caused great distress to her family.

Healthcare providers need to take into account how families receive and understand information and if they have no questions, it could be assumed that they are all set. Exploring with patients and families the plan of care or transitions in care is essential to be certain that enough information has been given for decisions to be made and communication to be open. Also, words used by healthcare providers may not be at the “level” of the patient and the family. These participants describe these points with the following quotes:

I think doctors and nurses should give more information instead of waiting for the family to ask questions that they don’t have. Had the family known more about her situation we would have been able to think of decisions before they were an emergency. People tend to not think clearly in emergencies.

And with this participant, “...I seriously doubt my parents heard anything...THIS is what happens when unfamiliar terminology and less than adequate details are given to families on the assumption that the professional jargon is understood by all...It’s NOT.”

Miscommunication of information

Participants referenced *miscommunication of information* when decisions were made and then appeared not to be enacted such as comfort measures only (n = 3), patient and family wishes not followed (n = 4) and conflicting information about comfort measures (n = 2). Miscommunication was an issue that seemed to be related to decision-making and the communication was not carried out the way the decedent and their next of kin had agreed to. Participants wrote about decisions to forego any further medical interventions and provide comfort measures only as with this participant:

Communications among staff was sometimes ignored—i.e. my mother and I (health care proxy) had decided no more medical intervention, comfort measures only, a transporter came to room to take her to CT. If I had not been there, it probably would have been—that is not a comfort care measure.

In one instance, a participant wrote about the “frustration” of communication and wishes not being followed regarding after death care. In this response, the next of kin also references five places their next of kin received care, however the time frame of these transfers is not known, but illustrative of the process that patients and their families may experience during end of life transitions:

...After death his body was left untouched for 1 ½ hours until the undertaker arrived...3 different people had come to ask us which funeral home would be used...On admission that information was put in writing in his record (before his death)...Why didn't they read the record?...Why didn't they make the call? Because they didn't know the number?! This anecdotal detail is illustrative of the

general level of frustration that my father, my sister and I experienced throughout his stays in 3 different nursing homes and 2 hospitals.

Conflicting information was referenced in regards to healthcare provider communication with treatments for symptom control (n = 4) and references to hospice (n = 4). In this case pain control, “Conflicting advice concerning the use of morphine. Doctor advised its use to the maximum allowed, but the nurses advised cutting back so that she (decedent) would be more able to understand and follow their instructions and questions.” One participant wrote about their loved one awaking from a coma in a lot of pain which was distressing to the family and something they did not think could happen.

In reference to hospice, a few participants wrote of requesting hospice and receiving conflicting information from the healthcare provider. Some participants (n = 3) surmised that denial or refusal of hospice had to do with their occupation in the medical field, in particular being nurses themselves:

I wanted my husband to have hospice, but the doctor did not want hospice. I expressed & my husband at the end of his life wanted hospice, too. He and I discussed this with his (healthcare provider), refused my request. I did get nurses at home, but it was not enough in such a trying time...I am also a registered nurse, so maybe that had something to do with his decision. I don't know. I think people in the medical community have a long way to go in end of life care...

Respondents wrote of the miscommunication of information and wishes that were not followed such as, “DNR indicated yet resuscitation started against our orders.” In the case of this next respondent, medical intervention was being continued against their wishes which were confusing:

...He was given a bag of chemotherapy, then asked if he wanted DNI/DNR...I received a call from the oncologist...your husband has 2 days to live...he (decedent) thought the doctor was talking about the IV (instead of the DNI/DNR). I had code reinstated.

With this last quote, it illustrates how decisions are overturned by families which can often occur with patients during the course of the end of life experience. This does not help with communication and can cause further conflict and miscommunication amongst everyone involved in the care of the patient during the end of life process.

Availability of healthcare providers to share information

Participants wrote that their loved ones wanted to be able to access their information with a healthcare provider, above all their primary care doctor, but felt this type of access was not available, “Her own doctor was not allowed to participate in her care...patients must be allowed to see their own doctors.” A few respondents (n = 2) used the term abandonment, “I felt abandoned by the physician once my husband went home.” But most participants (n = 5) described wanting “contact” with their loved one’s primary care provider. One participant felt that insurance companies may be the cause of their loved one’s primary care provider not being involved in their end-of-life care:

Numerous trips to the hospital in the month following surgery (3 or 4) resulted in her own doctor not allowed to participate in her care (new rules, I presumed done by insurance companies)...Patients should (must) be allowed to see their own doctors. Her doctor was not informed regularly of her status—except by me...When a patient young or old is sick or injured; their own doctor is the most important person in their lives. Please review this new policy and insist that PC

doctors can and should be actively involved in patient's care (that is visible to patient).

Participants wrote that their loved one's desired a continued relationship with their primary care providers and that this "close" relationship was desirable as the patient's setting changed or as other healthcare providers became involved in their care. This participant gives insight into how important the access is to healthcare providers with whom they have an established relationship. Continuity of care is challenging with referrals to specialists, however involvement in the patient's care by the primary care provider is important, as illustrated in the following quote:

One thing that I know bothered her was that once she was given her diagnosis—acute leukemia with no treatment options—it was as if her doctors turned her over to hospice and forgot about her. She had been a patient of one doctor for a number of years—she never heard another word from him. I believe her primary doctor contacted her shortly after her diagnosis, but not after that. That saddened her very much—she felt she had close relationships with both MDs. A phone call or a card would have meant the world to her.

Participants wanted access to healthcare providers to receive an "update", news of progress or decline and to know that their loved one was being "cared for." They wanted them available by phone or in person, but desired to be able to reach them. Other phrases written were, "nurses and doctors hard to reach", "contacting them was difficult", "they (healthcare providers) were hard to reach", along with the following statement:

During my mother's stay at (location), not once did I see or talk to a doctor about her condition. No doctor or nurse came to me to tell me the status of her health (such as progress, decline, therapy, status, etc.)...

One participant wrote about her loved one's primary care physician as a "wonderful doctor" and illustrates the bond, the caring and the communication that seems palpable in this quote:

Dr...is a wonderful doctor, many times when Dad came home from the hospital he would call at nite to talk with him & see how he was. He even called on Christmas day. Maybe the staff should learn from him. He is a wonderful, kind, caring and compassionate man. There should be more people like him in the medical field...

Well informed

Although much of the earlier results were more on the negative, clearly patients and their loved ones were able to access information that "guided their care", was "compassionate" and "very professional." Participants described that they were *well informed* (n = 13) in regards to treatment, the plan of care, the sharing of medical information, and "detailed information" that assisted with decision-making. Information was desired in the form of face to face communication, the telephone or with educative materials. Some respondents wrote that "...all medical information shared with family...this was appreciated." Decision-making was referenced by many participants in relation to information. A few participants (n = 3) wrote that they were informed by friends that had gone through similar experiences and took their cues from them to aid in the end of life experience. This participant discusses such details as follows:

When a decision had to be made...the resident offered the patient and family detailed information as to the risks involved and possible results. This made her (patient) decision and the families much easier to make. We always had access to information regarding her condition both by phone and in person...handled with great dignity and respect.

One participant wrote of the information being conveyed visually and then being able to feel confident that they had made the right decision to withdraw treatment, “The ER doctor said there is nothing we can do for your wife...Dr...showed my son and I the MRI of her brain. All doctors and nurses were very caring during this most difficult time.”

One respondent wrote of the accessibility of their nurses and home health aides being “available whenever I needed them.” They also continued their response citing a company attached to their health insurance, “They (insurance) also had a company...made themselves known to me to let me know they were available 24-7 for any questions or just to have someone to talk to.”

There were numerous experiences with accessing information that were helpful and comforting to families. These included the sharing of information, ease of contacting the doctor, and expressing that they were well informed. “My fiancé was well informed before his surgery,” and “ Doctors...awesome...nurses...fabulous.”

A couple of shared experiences illustrated the helpful ways physicians and nurses guided families in this process:

...doctors and nurses were very caring...the doctor who spoke with us was very patient and explained what would be the quality of life in the near future for our

Dad. With his guidance and information, we're confident that we made the right decision...

And with this quote, "...(patient) was given the finest and most professional medical care...doctors, nurses and other medical staff were always available, helpful and sensitive to his many needs..."

One participant described "informing" the medical team of their loved one's wishes and the team carried out those wishes. This quote references a team approach with the family and healthcare providers as follows:

While my mother did not have a Health Care Proxy or a Do Not Resuscitate Order, she had made her wishes well known to me and to her other children (brother and two sisters) and to her sole surviving sister (aunt). We informed the medical staff at the time of her illness of these wishes/desires...Her doctor and the staff...treated her well and treated her appropriately...

To summarize the communication issues identified in this study, next of kin provided details about accessing information that aided and hindered the communication process with healthcare providers. Having information and the ability to access healthcare providers to receive that information was a significant finding. Participants described a continuum of information that explained the communication issues in this study from not enough to well informed. The next three subthemes are related to accessing information and will be described within the context of the following aims.

Aim 2

Identify the positive and negative aspects of communicating with healthcare providers during the end-of-life care experience as perceived by next of kin.

Overall responses were mostly positive (n = 79) (46.5 %) compared with negative responses (n = 57) (33.5%) and mixed responses (n = 34) (20%) that contained both positive and negative aspects of communication with healthcare providers at the end of life. The subtheme of *healthcare provider sensitivity* emerged through examining the positive (+) and negative (-) aspects of communicating with healthcare providers. These were referenced as compassion, understanding, warmth and kindness. The aspects of *healthcare provider sensitivity* fell out as *time(+/-)*, *the number of providers (-)* and the *approach of providers* to patients and families (+/-). Certain aspects were more negative, such as *the number of providers*, but there were many positive findings in the subtheme of *healthcare provider sensitivity*.

Time (+/-)

Time was referenced both positively and negatively in communicating with healthcare providers and included many descriptions such as caring and compassionate (n = 10), being available (n = 7), and having a rapport with patients (n = 2).

The positive aspect of healthcare providers taking time to communicate with patients and their families included references to sensitivity, “.given the finest and most professional medical care...doctors, nurses and other medical staff were always available, helpful and sensitive to his many needs...” , “The staff was very available and sensitive to our feelings/emotions,” and “...staff showed immense compassion to myself and my family...enormous amount of time and caring with us...made it bearable.”

Participants were satisfied and felt cared for when they were not rushed through difficult decisions. When healthcare providers appear relaxed and ready to answer questions or are not rushed, patients and their families are appreciative.

The negative responses regarding time included the appearance of healthcare providers being too busy (n =3), only doing what was necessary and nothing more (n = 2) and feeling unappreciated (n = 3). These participants talk about the details of time being a negative aspect of communicating with healthcare providers, “I had asked him some questions regarding her condition and was not given honest answers. I do not care how busy physicians are. You are dealing with real people with real feelings...” A perception of doing the minimum of care and being unsupported by healthcare providers was shared as, “...nurses were busy and curt, doing what needed to be done and no more. There was not any level of caring, supportive environment...” An inability for taking the time to discuss the situation and listen to the patient was illustrated as:

...it would have made him happier if all of his doctors took some time and discussed his situation with him more...doctors should want to listen and appreciate the patient’s point of view...he enjoyed discussing important matters...doctors should want to have a more personal rapport with patients who can appreciate this...doctors were short and in some cases rather blunt.

Too many providers (-)

Respondents referenced the number of healthcare providers as a negative aspect of communication related to continuity of care (n = 5) and interfering with transitions in care (n = 3). Examples include knowing the patient, being able to determine patient’s wishes and perceived continuity of care. Participants described being frustrated, lacking effective communication, and that too many people were involved in their care.

This participant wrote about the changes that happened as, “...we were not able to effectively communicate with all of her healthcare providers...” This participant spoke of

the home care services during end-of-life care and the lack of continuity as, "...the only complaint my mother had was too many different people came in and they came too often..." And this participant acknowledged the need for interns to learn by the following observation:

She saw many different doctors and interns during her illness. Although we can appreciate that these interns need to learn, it can be frustrating to the patient that so many doctors have to see them. It would be easier if one or two could attend.

Respondents wrote of the difficulty in communication when the transfers were numerous and when they were not aware of the changes. This participant actually counted the number of healthcare providers involved in her loved one's end of life care to cite the following:

Bad---wasn't much communication available...transferred 11 times...51 doctors involved in her care between the 2 places (referenced 2 hospitals)...doctors and nurses have many patients to care for and don't always see the same patients every day, so they don't see what is happening...

Approach (+/-)

The way in which patients and families were approached to discuss end of life decision-making or care preferences was referenced both positively and negatively. Positive approaches included phrases such as affection and concern (n = 8), compassion (n = 5) and professionalism (n = 6). The way in which patients and families are spoken to and the demeanor of the healthcare providers as they bring up sensitive issues is clearly important as written about in this study. Life ending decisions are difficult to make for patients and their families.

Healthcare providers' approach to patients and loved ones when communicating during end of life care was also referenced as being "respected" and that healthcare providers "went the extra mile" to make sure they were understood. This was appreciated and an important finding to reinforce the appropriate balance healthcare providers need to find when communicating with patients and their families during end of life care as the following noted: "The nurse and attending were very caring and compassionate. Their expressions of grief, towards someone they hardly knew, will never be forgotten." and "...his physician was forthright and compassionate."

Other references to the approach included recognition of signs of individual attention with utmost professionalism by healthcare providers as noted in the following statements. These include several references to honesty, affection, concern and compassion. "Staff treated patients as if they were family members...displaying signs of affection and concern for the comfort of the patients.", "...Dr.s and nurses were exceptional during the entire process...Dr.s and staff very professional, realistic and honest throughout.", and "...nurses and nursing assistants who watched over her and gave her compassion, patience and gentle care."

Participants expressed that healthcare providers were proficient and skilled in their approach. There were respondents that linked the approach of healthcare providers with "being professional" or displaying "professionalism" as with this quote: "...I was exceptionally pleased with the info and concern provided me which indicated to me that hospital personnel were very concerned about her health and care. Very professional."

The negative aspects were few in relation to the approach but are important to discuss. Participants referenced that the healthcare provider approach was impersonal (n

= 2) or that the healthcare provider made decedents feel unimportant (n = 2) during the end of life care experience. Healthcare providers that seemed to make light of the patients complaints or that they were “feeling not listened to” were viewed in this study as negative. One comment discussed “the lack of effort” put forth by the healthcare provider to make sure their loved one’s complaints were understood. And in this quote, the participant talks about themselves and the patient: “...his healthcare provider made me feel that his (patient) complaints and mine were unimportant...was and still am very upset about this...”

Next of kin provided detailed information about the healthcare provider’s positive and negative aspects in the process of communication. Responses were mainly positive and provide healthcare providers reinforcement and validation about the way in which they communicate with patients and families during the end of life experience.

Aim 3

Describe next of kin’s perceptions of the healthcare provider’s role in communicating with patients and next of kin during the end-of-life care experience.

Participants described needing information at specific points in their loved ones transitions during the end of life experience. They wrote about healthcare providers having that information or *having the answers* at specific intervals in the end of life transitions and wanting that information communicated to them. They wrote about the expectations they desired from the healthcare provider in that role. The subtheme of *having the answers* emerged as participants described healthcare providers as being expected to and having the ability to predict when their loved one would die. Time reference spanned from hours to days to months, but they clearly wrote that they

expected healthcare providers to tell them how long it would be and they expected it to be accurate. The aspects of *having the answers* include the *desire to be present* when their loved one was dying, *knowing what to expect* through the transitions in caring for patients and *prognostication* as in estimating when patients will die. These are the roles that respondents identified that healthcare providers were responsible for in communicating during end of life care.

Desire to be present

The *desire to be present* was referenced by participants (n = 9) as an important event with their loved one. Respondents wrote of the desire to be with their loved ones when they died and referenced healthcare providers as the communicators, “Nurse did not give us enough information and family was not present at death.” or there was a miscommunication, “...I was told I could not stay with her...It was a communication mistake...because of the nurses actions my daughters and I were able to be with her when she passed.”

Respondents did not want their loved ones to be alone at the time of death. They wanted to be with them as they “passed on” and referenced being alone in this process as regretful and something they did not want to miss out on. Participants also wrote that it was their loved one’s wishes and they wanted them honored as with this quote, “...not knowing how imminent her death was...my only regret is that she died alone.” A phrase from this participant illustrates the patient’s wishes being carried out, “...she did not want to die alone and she didn’t.”

A few participants wrote about not being able to be present at the death of their loved one, but appreciated when they were notified that their loved one was not alone in

the dying process. This respondent wrote of the withdrawal of life support and the healthcare provider notifying them of their loved one's passing:

...with his (healthcare provider) guidance and information, we're confident that we made the right decision to remove our dad from life support. I would also like to thank the nurse who called to inform me of my fathers passing. She told me she sat with him as he passed and for that I am very grateful for her kindness. No one should die alone...God bless all of you!

Participants wrote about wanting to be present to say goodbye or see their loved one for the last time before they died. One respondent wrote of her inability to have closure and tell her mother she loved her, and say goodbye with this quote:

...the doctor kept coming out asking questions. I wasn't even aware how serious she was...by the time we got back to her, she had passed away...I remember screaming because I wanted to tell her I loved her. I know she knew, but wasn't there in time...I believe they did everything they could for her.

Other respondents wrote of the experience negatively when the communication was viewed as late or non-existent by healthcare providers. Participants really wanted to say goodbye, but even when patients are expected to die, it is difficult for healthcare providers to predict and make sure the family is present as with this quote:

I was not notified until he passed away...and had I been told he was that serious I would have stayed (at the facility). He died within an hour after I left. I had no chance to say goodbye and be with him when he died. This has been a terrible burden to me...I was devastated in the end...Never said goodbye...

Knowing what to expect

Respondents wrote about healthcare providers as communicants of the process of dying (n = 6). Particularly they referenced what to expect at various stages such as the use of life support and the way their loved one appeared, that they wanted guidance and wanted more details about the process and the outcome. Participants wrote of needing to be prepared and wanting more details regarding the changes in their loved ones appearance, how various treatments or non-treatment would affect their loved one and in particular how their loved one was experiencing the dying process. Even with explanation, this can be traumatic and upsetting to families as with this participant:

...horribly shocked to see my sister, not just hooked up to every machine, but the full face mask. I should have been told what to expect as I'm sure you know what a shock it is to people to see their loved ones like that.

And with this participant quote:

...(decedent) was put on life support, not explained properly or what to expect...it was tragic...I should have stuck with my decision...I blame myself for his death and cry everyday...I chased them down every day and asked so many questions...

Respondents found healthcare providers guidance of families expectations in their loved one's end of life and wanted more detailed information, "... (the healthcare providers) helped us a lot through the 2 days...(decedents) wishes were expressed and followed," and "... (healthcare providers) absolutely wonderful with all of us...could have used more detailed information about the final death stages..." ,or in this respondents words, "We knew the outcome but not the path..."

Prognostication

Respondents made clear statements about their need for healthcare providers to estimate when their loved ones would die (n = 8). Patients and families perceive that healthcare providers have the training and expertise to know exactly when patients will die. This was revealed in the following statements, “Mother...passed away in 4 hours when we were told 3-4 days...”, and by this participant “...it was NEVER conveyed that he was even close to death or death was even a possibility at that point.”, “...we did not expect death so imminent...”, and lastly “...I knew this was a possibility at any time it was kind of shock because of the info we were given...I’m sorry about the way I feel.”

And with the urgency in this statement, “...I had to run the halls looking for a nurse to help me know if this was his time (to die)...”

In the following quote, the participant wanted more information, and specifically makes reference to the healthcare provider as if he/she knew that their loved ones death was closer:

...Although we knew she was close to death, the nurse did not give us enough information to realize that she was hours from dying (we thought days)...family was very upset that they were not with her when she died.

Respondents in this study see the healthcare provider role as being able to estimate how long someone will live with a life-limiting illness. Respondents wrote about changes in their loved one’s appearance and knowing when these were expected to be communicated regarding the end of life experience.

Aim 4

Identify barriers and facilitators perceived by decedent's next of kin in the communication process with healthcare providers during the end-of-life care experience.

Healthcare providers may be unaware of their effect when communicating with patients and their families. Communication may be enhanced or impeded based on the way they are trained in end of life care or from their cultural background or that of the patient. The barriers and facilitators in this study emerged as the subtheme *raising awareness*. Barriers in this study fell out as *language* (n = 4) and *education* (n = 6). *Language* was referred to as a difficulty in understanding information during the end of life care experience. This included the lack of lay terms to describe various medical terms, the complex medical situations or the process of dying. Participants wrote of the lack of education of healthcare providers as impeding communication. The facilitators were not clearly found in this study, however participants (n = 4) referenced America as a death denying *culture*. Although this appears as a barrier, the same respondents wrote of having prior discussions with their loved ones as facilitating decision-making during the end of life experience.

Language

Language barriers were described by participants as difficulty with English, hard to understand their accent, "...sometimes it was hard to understand her doctors (foreign language)," "trouble understanding the doctor (accent)," and "Had trouble understanding foreign accents of some doctors." There is a lot of information exchanged when caring for someone that is dying or transitioning to death. Healthcare providers and patients come from diverse backgrounds and cultures and it is not possible to have translators

available on demand, especially in smaller hospitals or nursing homes. Making sure that patients and their families understand and agree to a plan is a priority at all times in healthcare, but takes on a special meaning when discussing end of life care. Also the end of life population tends to be older and may have hearing deficits. This participant describes both of these situations:

...very little time spent directly with patients...most (healthcare providers) spoke very poor English. My father had a hearing problem and could not understand them---they made little effort to be certain he understood them...doctor came only twice in 2 weeks he was there...he spoke very poor English...doctor made no apparent effort to rectify this...several times he was very incorrect in his understanding.

Education of healthcare providers

The education and training of healthcare providers in end of life care is not required and was written about by respondents. Participants made direct statements indicating that healthcare providers may not receive enough education regarding end-of-life care and they may not realize the fear that patients and their families experience as with these quotes: "...that dr. needs classes on how to deal with scared patients...dying is scary to both the patient and the family," and with this phrase, "...there just aren't enough well-trained caring staff."

Or in this participant's words, they (the family) needed to educate the healthcare provider about the sense of hearing and the final death stages:

...nurse told me in front of her (decedent) that my aunt wouldn't make it through the day...Shameful!...I had to take this nurse to the hallway and explain to her...I

then informed this burnt out version of a nurse not to speak like that in front of my aunt again...NEVER, EVER talk to a dying patient's family member like that in front of the patient...THEY (the patient) CAN HEAR YOU!!!

Healthcare providers also experience stress, fatigue and a gamut of emotions themselves working with patients that are dying—even when death is expected. This participant linked the stress of work with the healthcare provider's inadequate training, "End of life caregivers need to be special people and most of them are. Some, however, may be not [*sic*] so adequately trained or even over-worked, so their ability to give proper attention may be strained/limited..."

Death denying culture

Although everyone will die at some point, our culture struggles with the end of life. The need to discuss the end-of-life realities, transitions in the dying process and patient preferences deserves more attention. Participants referenced needing more discussions amongst families and the need for more counseling (n = 4) to facilitate the end of life experience. Respondents communicated the positive experience of hospice and the hospice residence. This participant synthesizes what healthcare providers, patients and their families are experiencing and references hospice as a solution:

...In my opinion, ours is a culture which avoids discussion about death...This is my second experience with hospice. The hospice staff helps both the patient and family to be supportive of each other during these final days. "Hospice is about living—not dying", said our care manager. It truly was that—as we were all together in the last moments of a life well lived.

Prior discussions amongst families themselves and with healthcare providers facilitated the communication process. Participants wrote about the difficult decisions placed on them when their next of kin could not communicate their wishes. However participants described having a prior discussion with their loved ones and having counseling available to discuss end of life issues as helpful to this family in this quote:

...knowing our loved ones intentions helped us know the very difficult decisions to disconnect life support measures were what they would have wanted. It is the worst feeling we have experienced to have to make a life-ending decision for someone. We don't know how we could have made the decision had we not known what they would have wanted.

Summary

In summary, the overarching theme of *accessing information* emerged with four subthemes of *continuum of information* (not having enough information, miscommunication of information, availability of healthcare providers to share information and well informed), *healthcare provider sensitivity* (time, number of providers and approach), *having the answers* (knowing what to expect, desire to be present and prognostication), and *raising awareness* (language, education and culture) from qualitative content analysis of responses to the open-ended question, "Are there any other things you wish to share about what was good or bad about your experience?". This analysis and findings specifically looked at communication with healthcare providers at the end of life from the perspective of the next of kin. The findings revealed an insider's view of the effects, both positive and negative, that healthcare providers have

during the communication process with patients and their families during the end of life care experience.

Next of kin provided information in detail that reflects the need to access information. Patients and families need to be allowed time to question and absorb facts, and for healthcare providers to approach patients and families with sensitivity to their culture. On the positive side, healthcare providers communicated with compassion, caring and professionalism that allowed next of kin peace of mind. This study brought out both negative and positive aspects of healthcare provider communication that can be used to educate and improve the end of life care experience in Worcester, Massachusetts and beyond.

CHAPTER 5

DISCUSSION

Introduction

The purpose of this study was to explore experiences related to communication with healthcare providers in Worcester, Massachusetts during end of life care. The topic was important as it has been reported nationally that the end of life care experience for patients and their loved ones may not be optimal or even the accepted standard of care. Learning what next of kin have to say about their loved ones experience during end of life care in Worcester, Massachusetts provides a local view of this experience in a community that can utilize this information and develop strategies to improve the outcomes locally and possibly serve as a model for other communities. Additionally, the findings of what is done well needs to be communicated to healthcare providers. This may serve to validate and reinforce that their communication approach and skills with patients at the end of life makes a difference. These findings also provide insight that healthcare providers can utilize in educating the interdisciplinary teams they work within, the healthcare systems that provide access for patients and families to end of life care, and to promote care at the end of life that is consistent across settings. The findings will be discussed framed within the aims of the study.

Aim 1

Explore communication issues identified by next of kin during decedents' end-of-life care.

Communication issues identified by next of kin in this study were similar to those that have been reported in the literature. Accessing information, lacking an

understanding of information and receiving conflicting information has been reported in both qualitative and quantitative studies (Andershed, 2006; Clayton, Butow, Arnold & Tattersall, 2005; Fridh, Forsberg & Bergbom, 2007). In a recent study reflecting on the decade that has elapsed since the SUPPORT study (SUPPORT, 1995), findings continue to reveal those patients and their families or surrogate decision-makers frequently misunderstand their options. What has also been reported is that patients that are dying do not communicate their wishes to their family members or surrogates even when there is an advanced directive in place (Collins, Parks & Winter, 2006). In this study the majority (78.8%) of decedents had a healthcare proxy in place, and over half of the decedents (59.4%) were able to care for themselves up to one month before their death. Interpretation of these statistics could indicate that by having a healthcare proxy in place, decedents may have communicated their wishes and were alert enough to inform their next of kin and healthcare providers at least thirty days before they died.

Other issues were the lack of presence of doctors and/or nurses by several respondents to give information and/or clarify information. This finding is consistent with studies on communication and the sharing of information with patients and their families (Stapleton et al, 2004; Tulsky, 2005a; Tulsky, 2005b). In the acute care setting such as the hospital or ICU, there are numerous shift changes and personnel changes that occur in a 24 hour period. It is common that patients and their families see numerous providers and that answers to the questions may be delayed as end of life decision-making is difficult and sensitive. In the nursing home setting, physicians and nurse practitioners are not onsite at all times, but provide care as needed which may be

intermittent. Both of these settings could hinder the process of decision-making regarding end-of-life transitions and discussions for patients and their families.

Some participants in this study identified the lack of communication with the decedent's primary care physician. They referred to the lack of communication with the treating physician and or team and the desire to have their own physician involved in the case. Two participants referenced this as "abandonment". Although patients and their families desire their primary care or family physician to remain involved, healthcare system constraints and time constraints could limit their availability which has been reported (Carline et al., 2003; Cherlin et al., 2005). Patients do not want to be abandoned by their physicians when they are nearing the end of life. Some of this may occur due to the withdrawing of active treatment or it has been identified that physicians have difficulty with death and as it is viewed as treatment failure (Carline et al., 2003). Also, often times when patients are being treated by specialists, the primary care providers are involved in their care. However this may be through consults between healthcare providers and not directly with patients. Although the patient's primary care provider is continuing to be active in their care with their specialists, patients and families may be unaware. This can happen when patients traverse care settings which can be common in end of life care. Communicating changes with the patient and their family and being proactive in discussing these changes could alleviate the feelings of being abandoned.

Other issues that emerged were positive regarding access to information. Participants discussed the availability of healthcare providers to communicate face to face and also by phone. This is consistent within the literature as patients and family members have consistently reported positive outcomes and quality end of life care when

they have had access to healthcare providers to readdress or explain any changes (Boyle, Miller & Forbes-Thompson, 2005; Heyland et al., 2006). In addition to positive feedback about information, when decedents and their families were informed of changes, the time taken by healthcare providers to explain and offer guidance facilitated decision-making. This is consistent with the findings from Steinhauser, et al (2001), in which communicating information about the day to day changes in care was facilitated by healthcare providers. This information allowed families to understand, focus and led to overall satisfaction with care.

It has been documented that quality end-of-life care includes communication that is optimal between the healthcare providers and patient and the healthcare provider and the family (Engelberg, Downey & Curtis, 2006). Most of the studies have been done in the ICU setting. It has been shown that satisfaction with the end of life experience for patients and their families includes patient-centered goals of care, frequent communication with the family to address and clarify goals of care, and providers that are skilled and comfortable with counseling patients and families through these difficult decisions.

The findings in this secondary analysis are consistent with the parent study where questions were explored regarding communication. Communication issues in the parent study concluded that overall communication is poor regarding the sharing of information and expectations during the end of life care process (Kaufman & McCluskey, 2006).

Aim 2

Identify the positive and negative aspects of communicating with healthcare providers during the end-of-life care experience as perceived by next of kin.

Next of kin reported more positive aspects in communicating with healthcare providers in this study as opposed to negative. This is an encouraging promising finding towards progress made since the landmark SUPPORT study where death in the acute care setting was one of prolonged suffering, lack of symptom management and systematically examined problems with communication (Collins, Parks & Winter, 2006; McCahill, Ferrell & Virani, 2001; SUPPORT, 1995). Participants wrote about the numerous instances in which they were included in end of life discussions and that their loved one's wishes were followed.

The positive aspects of communicating with healthcare providers during the end-of-life care were referenced as healthcare providers that spent a lot of time caring for the decedent. Participants associated sensitivity and a caring approach while "attending" the decedent as comforting. These findings have also been demonstrated in the literature (Heyland et al., 2006) and are consistent with the participant responses in this study.

The negative aspects of communicating with healthcare providers included miscommunication, the lack of time spent in communicating, too many healthcare providers caring for the patient and an approach that was hurried. These negative issues are consistent with studies by Anselm et al.(2005); Cherlin et al., (2005); Field & Cassel, (1997); Teno et al., (2004). In large teaching hospitals, unfortunately this was not an unexpected finding. Specifically participants spoke of the numbers of residents or nurses that attended to the decedent which could have impacted the miscommunication. In one instance a patient had "11 transfers" and "51 doctors" that had participated in their care.

Aim 3

Describe next of kin's perceptions of the healthcare provider's role in communicating with patients and next of kin during the end-of-life care experience.

This study revealed that participants explicitly see part of the role of nurses and physicians in end-of-life care includes the ability to predict when a patient will die. Not only do they see healthcare providers as being able to prognosticate, but to also notify family members to be present when their loved ones are actively dying. Family members desire to be present with their loved one so they do not "die alone", to tell them they love them one more time and/or to say goodbye. This was an important theme in these findings and one that healthcare providers need to recognize in conversations with patients and families (Andershed, 2006; Royak-Schaler et al., 2006). Educating patients and their families about the difficulty in estimating survival and the variability of survival is a critical discussion for healthcare providers to lead.

Most participants view the healthcare providers as someone leading them through the stages of their loved one's dying process. Knowing what to expect and having some preparation for it was important to participants. These findings are not uncommon to other studies where family members want information communicated that allows them to know what to expect, to make decisions and plan the care of their loved one (Andershed, 2006). A poignant quote by the respondent that said, "We knew the outcome but not the path..." illustrates what other studies have documented. What this translates to for healthcare providers is that they need to listen, explain, redirect and continually assess patients and their families for information they are lacking to prepare them for and during the end of life experience.

Aim 4

Identify barriers and facilitators perceived by decedent's next of kin in the communication process with healthcare providers during the end-of-life care experience.

Barriers and facilitators were the most difficult to define in this study due to the design of the study as a secondary analysis from next of kin's perspectives. In the literature barriers and facilitators were looked at in the terminally ill COPD population specifically related to physician-patient communication. Barriers identified by more than 50% of participants were related to wanting to stay alive and not talk about death, and not knowing who their primary caregiver was to have this discussion. For facilitators, participants described trust in their doctor, having good care and that the doctor cared about them as a person (Knauff et al., 2005). In this study, it was difficult to identify these findings as respondents were next of kin and not the decedents themselves.

In this study language was a barrier that was identified. Participants explained that their next of kin could not understand the physician due to their accent. This impeded communication and made the healthcare provider appear as they were uncaring. This is consistent with the transforming ethnic demographics of the population and the need to not only be culturally competent, but to be health literate (Crawley, 2005). Communicating with patients of all cultures needs to be a priority to decrease or prevent potential health disparities. Although language was identified as a barrier with relation to "accent" it also impeded the communication for information delivery and exchange between the healthcare provider and the patient. If information is not understood,

particularly regarding end-of-life care, shared decision-making cannot occur leading to poor outcomes and frustration for both parties involved.

The culture of dying in America is one of denial. This was pointed out by one participant as, “ours is a culture that denies talking about death.” This poignant comment is consistent with findings in studies that have addressed end of life issues in older adults (Inman, 2002) and those that are actively dying (Beckstrand & Kirchoff, 2005). Our U.S. healthcare culture seems to avoid discussions surrounding planning and implementing wishes of those dying and therefore leaves decision-making up to their families and the interdisciplinary teams that care for them. The majority of patients in this study died in the acute care setting (60.6%) with cancer and cardiovascular diseases (65.3%) being the primary causes of death. These are both chronic conditions that allow time for discussion. It continues to be reported from large studies that patients predominantly wish to die at home, yet this is not being achieved (Teno et al, 2004). From these statistics, Worcester, Massachusetts is consistent with the national findings.

Participants expressed in their writing whether or not healthcare providers had the educational preparation to care for their loved ones. Good end of life care is a balance amongst many factors such as the patient’s disease state and family dynamics to name a few. Underlying a healthcare provider’s role in caring for patient’s and their families at end-of-life is an assumption that they have received that preparation. It is not clear how much training in end of life care physicians and nurses receive in their formal education, but there are programs designed specifically to integrate this content in the curriculum (AACN, 1997). After formal education there is opportunity for ongoing continuing education (CE) and programs that may be available in academic hospitals, however there

is currently not a standard or mandatory requirement (Fineberg, 2005). As the population ages it is imperative that healthcare providers seek out opportunities to work with patients and their families at end of life.

Additional Findings

Having good care, and respect and dignity were additional findings in the study. These findings are consistent with studies that have linked communication and the provision of a good death (Beckstrand, Callister & Kirchhoff, 2006). Nurses have identified that communication amongst the healthcare team; managing symptoms and following the patient's wishes facilitate a good death. Also, healthcare providers that communicate realistic expectations about the patient's recovery is helpful for families with decision-making. Other suggestions that nurses have contributed to enhancing the end-of-life experience in the ICU setting include changes to the environment. These suggestions are space for families to sleep so they can be with their loved ones, availability of a chapel, and a quiet environment that promotes dying with dignity.

It was noted that approximately 78% of the decedents in this study were reported to have no Hospice services of any kind. Hospice is a model of care that allows patients and their families' access to a unique set of benefits and services and has been shown to deliver high quality end of life care (Casarett, Van Ness, O'Leary & Fried, 2006; Miller, Weitzen & Kinzbrunner, 2003). In Worcester, Massachusetts patients have access to a minimum of 2 Hospice care organizations. It is unclear from this study why these decedents at the end of life were not enrolled because they were not interviewed. In review of the data specific to Hospice services, participants that had Hospice, those that responded to this question had more positive comments regarding communication overall

(59.5%) than the total sample of positive responses in this study (46.5%). This implies that patients that have Hospice services have a more positive experience at the end of life related to communication. This is an exciting finding and is a service available to healthcare providers in this community.

Study Limitations

The study limitations include the use of secondary analysis as a data set. The researcher has relied on the data collection method of another group and was not involved in the design of the study. However the principal investigator of the parent study was available to clarify and answer the researcher's questions. This study used an approach of reanalysis of the concept (communication with healthcare providers at the end of life) that has not been specifically addressed in the primary analysis by the research team (Hinds, Vogel & Clarke-Steffen, 1997). This form of secondary analysis known as supplementary analysis, allowed a more in-depth investigation communication that was not fully addresses in the parent study (Heaton, 2004). Also, participants were asked to provide contact information if they were willing to be contacted at another time which would have allowed member checks. Unfortunately greater than 30 months has elapsed since participants were recruited to this study which would potentially introduce recall bias and possibly bring back memories and situations to participants that could cause undue stress. The open ended survey question is an excellent method to collect data that perhaps the original survey did not explore; however participants self-select to respond to the question, which introduces selection bias. It is unknown why non-responders chose not to respond and therefore their data is not included.

The participants in this study do not reflect the overall diversity of Worcester, Massachusetts. The sample in this study was 95.9% Caucasian and 92.9% English speaking. The census in the year 2000 lists Worcester, Massachusetts as a 77.1% Caucasian population with 28.1% of households speaking languages other than English. The Hispanic population is the second largest at 15.1% in Worcester (U.S. Census, 2000). It is important to access minority populations to assess their communication with healthcare providers in the end of life care experience. It is unknown why this occurred; one could hypothesize that language was a factor or perhaps that writing in response to survey was not a common cultural practice. Of the total sample of 373 respondents to the parent survey, there were a total of 7 non-Caucasian respondents. Of these 7, only 2 (28.6%) responded to the open-ended survey question which could support the above hypothesis.

And lastly, the next of kin responded to the survey and were interpreting the “good” and “bad” experiences during end of life care on behalf of the decedent. This proxy or surrogate reporting is common when working with patients and families that are terminally ill, but is not optimal (Engelberg, Patrick & Curtis, 2005).

Implications for Nursing and Health Policy

Issues identified by next of kin in communication with healthcare providers during the end of life care experience in Worcester, Massachusetts were consistent with national findings reported in the literature over the last decade. Communication with patients and their loved ones during this period is time-consuming and essential to educate families, discuss prognosis, and the withholding or withdrawing of treatment. These are but a few of the areas that can necessitate numerous discussions. Healthcare

provider reimbursement has not supported the “time” that physicians, nurses and numerous other providers may spend with patients and their families in providing quality end of life care (Shugarman, Lorenz & Lynn, 2005). Policy changes need to be directed at improving reimbursement for continuity of care and coordination of care across disciplines and settings. As our country continues to diversify culturally, healthcare providers need to be cognizant of how they affect communication at end of life and remain prepared to deliver quality end of life care.

Research Implications

Further research based on these findings should consider a prospective study design both with patients and providers. Although surrogate reporting and retrospective survey design have been used in the end-of-life care population, it has been demonstrated that talking with patients during the dying process is delicate, but not upsetting or additionally stressful. Since most of the decedents died in the acute setting, that would be the setting to begin this future research.

Health Literacy

One of the greatest strides to be made in end of life care and communication with healthcare providers is the inclusion of culture and health literacy in their practice. Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Health Resources and Services Administration [HRSA], 2007). Limited health literacy is more prevalent amongst minorities, older adults, the medically underserved and those that are poor. A patient’s health literacy may be affected due to cultural barriers, low English proficiency or a healthcare provider’s use of words they don’t

understand. When communicating with patients and families at the end of life, the capacity to understand and process information may be impaired due to stress, fatigue and many other factors (Scudder, 2006; Timmins, 2006). It is essential that healthcare providers work together and tailor their communication to patients and their families so the quality of care can be optimal. Limited research has been done on health literacy and end of life care. Future research needs to address the aging and diverse population to be ready and available to deliver and communicate quality end of life care and work to eliminate health disparities.

Community/Global Awareness

Lastly, it should be noted that these findings and their implications have been directed at the Worcester community, but are consistent with findings nationally. Globally, end of life care cannot be compared with the U.S. based on dollars spent on end of life care, life expectancy, cause of death and many endpoints (Blank & Merrick, 2005). This impacts communities that are growing in diversity with immigrants from Kenya, Ghana, China and Japan to name a few. It is imperative that healthcare providers be aware of the patient's cultural background in assessing their end of life care needs to provide the highest quality care at such an important milestone.

Conclusion

Next of kin have provided a rich description about what was good or bad about their loved ones end of life care experience in communicating with healthcare providers. It is an intimate view of a process that everyone will go through in varying degrees, yet will not be fully aware of until they experience it. As the population expands and longevity increases, knowing patients wishes will be essential to providing optimum end

of life care. It continues to be a delicate balance of providing highly technical care and juggling the highest quality of life for each individual. Future research needs to continue to be patient-centered. Healthcare providers need to continue to educate themselves and others on how communication with patients and their families will determine the best outcomes for that individual and be sensitive to the individual end of life experience that occurs.

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End of Life Care Survey
A survey of families with recent decedents describing eight domains of the dying experience.

Today's date: _____ Name of person who died: _____ Date of Death: _____

Your name: _____ Your relationship to the person who died: _____

Location of Death (Please check):

Home	If yes, did he/she receive hospice care?	Yes	No	Don't Know
Coast Pond Hospice				
Nursing Home	If yes, did he/she receive hospice care?	Yes	No	Don't Know
Saint Vincent Hospital (Worcester Medical Center/Med City)				
UMass Memorial Health Care (University or Memorial campus)	If yes, did he/she die in the Intensive or Cardiac Care Unit (ICU/CCU)?	Yes	No	
UMass Memorial Health Care (University or Memorial campus)	If yes, did he/she die in the Intensive or Cardiac Care Unit (ICU/CCU)?	Yes	No	
Other (describe) _____				

How long was he or she in the place where death occurred? _____

Characteristics of person who died:

Age _____ Race _____ Sex _____ Religion _____ Veteran (Y/N) _____

Primary language spoken at home _____ Marital Status _____

Did your loved one have a **Health Care Proxy***? Yes _____ No _____ Not sure _____

If yes, who? _____ Relation _____

Did your loved one have a **Do Not Resuscitate (or Comfort Care) order****? Yes _____ No _____ Not sure _____

Was your loved one able to:

Walk?	6 months before death	1 month before death
Bathe self?	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Dress self?	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Use toilet?	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Feed self?	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Able to remember important people or events?	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no

*Health Care Proxy – a legal document in Massachusetts that allows you to name someone to make medical decisions for you if you cannot speak for yourself

**Do Not Resuscitate Order – a written order by a doctor that prevents emergency measures if your heartbeat or breathing stops

Questions	How important was this to your loved one?				How well was this achieved?			
	Very	Fairly important	Not important	Don't know	Always	Usually	Sometimes	Never
1. Did doctor(s) meet needs of your loved one?								
2. Did the nurses meet needs of your loved one?								
3. Did your loved one know what to expect from his/her condition?								
4. Was your loved one's pain controlled well enough?								
5. Were his/her uncomfortable symptoms controlled well?								
6. Was your loved one kept clean?								
7. Was his/her level of mental alertness acceptable?								
8. Was your loved one's anxiety well controlled?								
9. Was there someone available to listen to your loved one?								
10. Did your loved one feel like she/he was not a burden to others?								
11. Did your loved one have his/her financial affairs in order?								
12. Was your loved one able to resolve unfinished business & say good-bye to important people?								
13. Was there a financial reason why your loved one could not obtain good end of life care?								
14. Was dignity and respect maintained for your loved one?								
15. Was your loved one able to observe spiritually meaningful rituals?								
16. Did your loved one feel like life had meaning?								

Questions	How important was this to your loved one?				How well was this achieved?			
	Very	Fairly important	Not important	Don't know	Always	Usually	Sometimes	Never
17. Was the appropriate amount of information shared with your loved one?								
18. Was he/she spoken to in his/her own language?								
19. Were your loved one's dietary practices followed?								
20. Were other relevant cultural practices honored?								
21. Immediately before death, were your loved one's troublesome symptoms relieved?								
22. Immediately before death, was your loved one's environment kept clean?								
23. Were his/her significant family/friends notified and present at the time of death?								
24. Did death occur in the place where your loved one preferred?								
25. Was a legal decision-maker identified (health care proxy)?								
26. Did your loved one have the chance to express any wishes regarding end of life?								
27. Were his/her wishes regarding end of life followed?								

Are there any other things you wish to share about what was good or bad about your experience? (Please use reverse side if necessary.)

Would you be willing to be re-contacted for additional information?

If yes, phone number where you can be reached: _____

Best time to call: _____ am _____ pm

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS SURVEY.

Appendix B: Data Analysis Table

Subject ID#	Participant's Own Language	Good/+	Bad/-	Neutral or Neither	Researcher's Comments	Communication Implicit or Explicit