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CHOICES RELATED TO MAXIMIZING QUALITY OF LIFE
AT END OF LIFE

by

Theresa Lynn

A dissertation submitted to the Graduate College
in partial fulfillment of the requirements
for the degree of Doctor of Philosophy
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CHOICES RELATED TO MAXIMIZING QUALITY OF LIFE AT END OF LIFE

Theresa Lynn, Ph.D.

Western Michigan University, 2015

Humans, including those residing in the United States, can live in denial of their own mortality. Because of this, futile care is sometimes provided, often at great monetary expense and for little or no return in terms of quality or length of life. At least two opportunities exist for making choices regarding care at the end of life in the U.S.: completing advance directives and choosing hospice care. This dissertation consists of three studies related to this topic. The first is a quantitative study about advance directives and attitude toward death. The advance directive completion rate among adults in the United States is 18-36%. Much research has been conducted in an attempt to understand why the completion rate is not higher, but what has not been studied is the potential influence of one's attitude toward death. Results from a survey in southwest Michigan indicated there was no association between attitude toward death and the completion of advance directives; however, mean death attitude scores differed by religiousness. The second and third studies in this dissertation are qualitative research studies related to hospice care. In the first of these, the experience of the hospice referral from the perspectives of the patient, the caregiver, and the provider showed that several issues exist. Providers reported discussing hospice earlier and more often than was noted for the patient or caregivers. Also, the needs of caregivers influence patients' decisions

about whether and when to sign on to hospice care. Caregivers may be ready for hospice care to be provided before the patient is ready. Non-hospice palliative care may be an effective means of providing both patients and caregivers the support they need prior to the last 6 months of a patient's life. The results of the second qualitative research study showed how end of life care might be informed by the fears, sources of strength, and hopes of the hospice patient, the caregiver, and the provider. A provider who understands a patient's and caregiver's fears about suffering may be able to alleviate those fears in advance.

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CHAPTER I

INTRODUCTION

The most common attitude toward death in the United States is denial (Lehto & Stein, 2009). Although the human brain is hardwired to survive (Davis & Panksepp, 2011) human mortality cannot be escaped. Death anxiety, the disquiet one may feel related to death, may result in millions of dollars spent in futile care or care that does not prove to be beneficial in extending life or giving quality of life (Huynh et al., 2013).

Chastek et al. (2012), in a quantitative study of 28,530 patients with cancer, found that the cost of care in the last month of life was \$25,260 compared to the cost of care in the sixth month prior to death, which was \$7,835. Ciric (2013) states that care at the end of life is one of several reasons that health care in the U.S. is cost-prohibitive and estimates that if health care spending continues to increase at its current rate it will outpace the national gross domestic product in the year 2070.

Expensive health care is not consistently extending life as noted by Barthold, Nandi, Rodriguez, and Heymann (2013). These researchers found that, among industrialized countries, the U.S. ranks 22nd in efficiency of health care dollars spent, i.e., a comparison of the increase in life expectancy with the financial cost of achieving that increase. Additionally, expensive health care may not be meeting the wishes of those who receive it. Parr et al. (2010), in a quantitative study of 396 patients at the end of life, found that up to 22.1% of patients did not receive the care they desired or received care they did not desire. It appears that despite large spending in the U.S., opportunities exist

for improvement related to care at the end of life. The need for this improvement has reached an urgent stage as the largest segment of the U.S. population advances into old age. By the year 2030, 61 million people will be between the ages of 66 and 84 (Knickman & Snell, 2002).

Planning and communication may influence purposeful health care choices that provide desired care in one's physical, emotional, social, and spiritual aspects of life (Managed Care Weekly Digest [MCWD], 2013; National Hospice and Palliative Care Organization [NHPCO], n.d.). Participating in advance health care planning by completing advance directives is one way to direct one's care at the end of life if one becomes, because of the progression of one's terminal illness, unable to make one's own health care decisions (Pollack, Morhaim, & Williams, 2010; U.S. Department of Health and Human Services [HHS], 2008).

The current advance directive completion rate among adults in the U.S. is 18 to 36% (Pollack et al., 2010; U.S. Department of HHS, 2008). The absence of advance directives can contribute to an atmosphere of conflict among family members and health care professionals and may result in people receiving treatments they would have otherwise declined (Centers for Disease Control and Prevention [CDC], 2012; Keenan, Varon, Walsh, Kish, & Fromm, 1996). Other research has shown that individuals who are more likely to have advance directives tend to possess particular demographic characteristics (Alano et al., 2010; Dobbins, 2007; Golden, Corvea, Dang, Llorente, & Silverman, 2009; Sam & Singer, 1993; Su, 2008; Wu, Lorenz, & Chodosh, 2008).

Although much research has been done to explore reasons that the advance directive completion rate is not higher in the U.S., what has not been explored is the

potential influence of one's attitude toward death. Death attitudes, as measured by the Death Attitude Profile–Revised (Wong, Reker, & Gesser, 1994) include fear of death, death anxiety, approach acceptance, and escape acceptance. The research question in Chapter II of this paper examines whether there is an association between one's attitude toward death and whether one has completed an advance directive.

Another option afforded individuals in the U.S. in the last 6 months of life that may influence care at the end of life is the selection of hospice care. Hospice care, palliative in nature, focuses on comfort and quality of life. The national median length of stay in hospice programs, despite the fact that it is a 6-month benefit, was 18.5 days in 2013 (NHPCO, 2014).

Many quantitative and qualitative research studies have been conducted in an attempt to understand why the median length of stay is not longer, including research on referrals to hospice care. Although the perspectives of different individuals involved in the process of the hospice referral experience have been studied, the median length of stay in hospice care continues to decline¹ (NHPCO, 2014). Many providers believe that it is patients and caregivers who delay the process of admission to hospice (Hyman & Bulkin, 1990; Ogle, 2003), and many patients and caregivers desire providers to be the one to initiate a discussion about admission to hospice care (Schrader, Nelson, & Eidsness, 2009).

No research has been published that analyzes the patient's, the primary caregiver's and the provider's experiences of the same hospice referral process—i.e., the process by which an individual becomes a hospice patient. Examining these three

¹ The national median length of stay in hospice care in 2000 was 27 days (MedPAC, n.d.).

perspectives of the same experience may illuminate reasons why the national median length of stay is short compared to the length of time that is available to individuals to benefit from hospice care. The qualitative research question for Chapter III is, what is the experience of hospice referral among the patient, the family member, and the provider most involved in the decision to become a hospice patient?

Barriers to patients receiving hospice care sooner rather than later include patients' and family members' fears of death and a common misperception that if hospice has been suggested, the patient must be imminently dying (Hyman & Bulkin, 1990; Klinger, Howell, Zakus, & Deber, 2014). Another barrier is the provider's perception that introducing the subject of hospice may destroy a patient's hope (Baile, Lenzi, Parker, Buckman, & Cohen, 2002). The strength to have a difficult conversation about topics such as admission to hospice care may come from one's inner resources (Anandarajah & Hight, 2001).

Fear, strength, and hope may not be overtly discussed in a conversation about care at the end of life, but all are very likely present and influential. What happens to fear, strength, and hope for the patient, the family and the provider after the barriers have been overcome and an individual has entered hospice care? How might exploring this be helpful in a quest to maintain and even improve quality of life at the end of life? Chapter IV of this paper delves into the concepts uncovered in Chapter III and explores the narratives of the hospice patient, family member, and provider more deeply. The first qualitative research question in Chapter IV is what are the fears, hopes, and sources of strength expressed by hospice patients, their caregivers, and their referring health care providers? The second research question is, what can these responses inform our

understanding of and the care provided to patients and their caregivers? Answers to these questions are viewed through the lens of narratology.

Increased understanding of a possible association between attitude toward death and advance directive completion may assist in providing personalized care that the individual desires at the end of life while simultaneously curbing futile health care spending. Increased knowledge about hospice referral experiences from the perspectives of all involved in the process may help improve quality of life by reducing or eliminating barriers to the use of the hospice benefit. Increased information about how fear, hope, and strength manifest in some hospice patients, their family members, and their providers may help create a framework that offers a way of identifying and assessing end of life needs before they become critical. Tools may be developed that assist in an individual having critical conversations aimed toward increased quality of life at the end of life before his or her unique opportunity passes.

Having choices about end of life care may be considered both a privilege and a burden. Although human beings may struggle with the concept of their own mortality, it may be considered a privilege to be able to select and individualize the care received during the months, weeks, and days of the final journey (NHPCO, 2010). Care that is tailored to one's values supports the humanity of the dying individual and offers personal and professional caregivers the opportunity to participate in a passage that all will eventually experience for themselves (Exley & Allen, 2007). The burden is, perhaps, that the choices will be exercised only once during one's lifetime, and this may create a sense of pressure to choose well and wisely (Exley & Allen, 2007). Exploring human fears and

understanding sources of strength to make choices related to the end of one's life support the hope that this leg of life's journey will be lived in the best way possible.

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CHAPTER II

ASSOCIATION BETWEEN ATTITUDE TOWARD DEATH AND COMPLETION OF ADVANCE DIRECTIVES

Introduction/Background

The purpose of this study was to determine whether there is an association between attitude toward death and whether one has executed an advance directive. An advance directive provides instruction regarding preferred health care treatment when one cannot make decisions for oneself. The living will portion of the advance directive specifies the desired treatment, and the durable power of attorney for health care portion gives permission to a specific individual to make health care decisions on behalf of another individual (National Hospice and Palliative Care Organization [NHPCO], 2005). Laws about whether these documents are legally binding vary from state to state in the U.S. (NHPCO, 2005).

An advance directive guides care and aids in medical decision-making that supports the individual's wishes when the individual becomes unable to express those wishes (NHPCO, 2005). An advance directive may also reduce stress and conflict among family members and between family members and health care providers (Centers for Disease Control and Prevention [CDC], 2012). Not having advance directives can result in expensive treatments and procedures being performed at the end of life that an individual may not have desired (CDC, 2012; Keenan, Varon, Walsh, Kish, & Fromm, 1996). Despite the benefits of advance directives and despite the Patient Self Determination Act of 1990, which mandated that health care facilities inquire about a

completed advance directive and inform individuals of their right to complete an advance directive (Patient Self Determination Act, 1990), estimates of the prevalence of advance directive completion in the United States range from 18% to 36% of the adult population (Pollack, Morhaim, & Williams, 2010; U.S. Department of Health and Human Services [HHS], 2008).

Some individuals do not know what advance directives are or why it may be important to have advance directives (Alano et al., 2010; Douglas & Brown, 2002; Golden, Corvea, Dang, Llorente, & Silverman, 2009; Salmond & David, 2005). Some fear that having an advance directive will result in a reduced level of care overall, highlighting a lack of trust in the health care system (Bullock, 2006; Johnson, Kuchibhatla, & Tulsky, 2008). A belief that the physician and/or family will see that the patient receives the desired care may be present (Cohen, McCannon, Edgman-Levitan, & Kormos, 2010; Dupree 2000; Kierner, Hladschik-Kermer, Gartner, & Watzke, 2010; Sahm, Will, & Hommel, 2005) or that God controls when death occurs, making advance directives irrelevant (Bullock, 2006; Cohen et al., 2010; Dupree, 2000). Some simply procrastinate, believing an advance directive may be necessary later, but not now (Douglas & Brown, 2002). Those who do have advance directives tend to have the following characteristics: older age, being female, being Caucasian, having a higher education, being religious, and being of higher socioeconomic status (Alano et al., 2010; Dobbins, 2007; Golden et al., 2009; Sam & Singer, 1993; Su, 2008; Wu, Lorenz, & Chodosh, 2008). Although in one study it was found that adults possessing higher health literacy were less likely to have executed advance directives (Campbell, Edwards, Ward,

& Weatherby, 2007), other studies indicate an association between higher health literacy and completion of advance directives (Vollandes et al., 2008; Waite et al., 2013).

Attitudes and their association with death-related variables have been measured in several studies. Education on end of life has been shown to positively influence health care professionals' and students' attitudes toward death and older people as well as toward care of patients who were dying (Barrere, Durkin, & LaCoursiere, 2008; Eskildsen & Flacker, 2009; Frommelt, 2003; Smith-Cumberland & Feldman, 2006). In a 2006 study on the effect of end of life education, study participants who dropped out of the study were less likely than those who completed the study to state that talking about and planning for death was important (Braun, Karen, & Zir, 2006).

Families with an ill loved one who may be at the end of life often want their physicians to be more straightforward about their loved one's illness, prognosis, and planning for end of life (Braun, Beyth, Ford, & McCullough, 2007). Among health care professionals, a positive attitude toward death and advance directives makes them more likely to not only have their own advance directives but also to discuss advance directive completion with their patients (Black, 2007; Campbell et al., 2007; Douglas & Brown, 2002). Patients who are asked by a health care professional to complete an advance directive are more likely to do so (Alano et al., 2010).

Individuals who have devoted thought to making decisions about advance directives may desire to control their own health care or avoid aggressive care at the end of life (Eisemann & Richter, 1999). Attitudes toward advance directive completion may also be influenced by race and ethnicity (Bullock, 2006; Dupree, 2000; Eleazer et al., 1996; Johnson, Elbert-Avila, & Tulsky, 2005). For example, African-Americans may not

trust the health care system or providers to provide adequate care if advance directives are in place or to follow completed advance directives (Bullock, 2006; Dupree, 2000). African-Americans may also be more likely to rely on family members to make end of life decisions for them, or on God to control one's time of death (Dupree, 2000; Johnson, Elbert-Avila, & Tulsky, 2005). Steenpass and Smith (2008) found that Hispanics and African-Americans were less likely to have advance directives than Caucasians. Eleazer et al. (1996) found that Asians are not likely to put end of life wishes in writing.

Individuals with anxiety about death or their own mortality may be more likely to not complete advance directives and to prefer life-prolonging treatment at the end of life (Ejaz, 2000; Golden et al., 2009). Those with less fear of death have been shown to be more likely to have completed advance directives (Dobbs, Emmett, Hammarth, & Daaleman, 2012).

Although multiple studies have shown that death-related thoughts and feelings may be associated with advance directive completion, none have examined the potential relationship between four death attitudes and the completion of advance directives. The current study analyzes fear of death, death avoidance, approach acceptance of death, and escape acceptance of death attitudes to explore the possibility of a relationship between these attitudes and the completion of advance directives.

Methods

Subject Recruitment

Study participants waiting for an appointment in the offices of a primary care physician, chiropractor, or ophthalmologist were asked by the staff at the appointment registration desk if they would like to participate in the study. Participants gathered for an

activity at a senior living or activity center were approached for study participation by either the program activity director or the researcher.

A cross-sectional survey research design was used in this study conducted with individuals in waiting areas of physician offices in the southwest Michigan area as well as with individuals involved with activities at two senior centers in southwest Michigan. The population was adults 18 years of age or older gathered in the offices of a primary care physician, chiropractor, ophthalmologist, or clinic or at a senior living center in southwest Michigan.

Measures

A survey tool collected information about seven factors previously identified as being associated with advance directives in the literature: age, sex, race, education, religiosity, income, and health literacy. Due to the small sample size, information about age was initially collected categorically and was later dichotomized into groups of individuals 18-59 years of age and 60+ years of age. Race was dichotomized into Caucasian and non-Caucasian. Education was categorized into two groups: high school degree or less and bachelor's degree or higher. Religiosity was defined as whether the individual taking the survey considered himself or herself religious (Alano et al., 2010). Income was divided into two groups: at or below \$76,385 (the estimated household median income in Michigan for a family of 4 in 2010/2011 [U.S. Department of HHS, 2010-2011]) or above \$76,385. Health literacy, measured with the Newest Vital Sign (Weiss et al., 2005), was categorized as adequate or less than adequate.

Yes/no questions were asked about the presence of a living will and a durable power of attorney for health care, and definitions were provided for each. A living will

was defined as “a written document that specifies the health care treatment you want if you become unable to make health care decisions for yourself.” A durable power of attorney for health care was defined as “a written document that identifies who you want to make health care decisions for you if you become unable to make health care decisions for yourself.” A yes answer to the presence of either a living will or a durable power of attorney for health care or both was counted as yes to having advance directives.

The survey tool also included the Death Attitude Profile–Revised which collected data about death attitudes. The reliability of the Death Attitude Profile–Revised, measured by internal consistency, had alpha coefficients of 0.84 to 0.97. Regarding validity, all items in the Death Attitude Profile–Revised achieved 70% to 90% agreement with other validated scales (Wong, Reker, & Gesser, 1994). The Death Attitude Profile–Revised measures level of agreement with five different death attitudes. Fear of death/dying (shortened to fear of death by Wong et al., 1994) and death avoidance are both negative attitudes toward death. The approach acceptance subscale measures one’s agreement with the idea that what happens after death is positive, serene and beautiful. The escape acceptance subscale measures one’s agreement with the notion that death is a welcome alternative to the difficulties of this life. The neutral acceptance subscale was found by two studies to be measuring two constructs—natural acceptance of death and neutral acceptance of death—rather than one construct (Clements & Rooda, 1999-2000; Ho, Chan, Chow, Pon, & Ng, 2010). Since the other death attitude subscales could be used individually (Clements & Rooda, 1999-2000), the neutral acceptance subscale was not used in the current study.

Two medical doctors, one an expert on care at the end of life and former chair of a university institutional review board and the other a hospice medical director, hospital chief of staff and an internist with his own practice, reviewed the survey instrument tool and the methodology. As health care professionals adept at discussing death and dying with their patients, their review was helpful in determining the order of the questions on the survey as well as streamlining the data collection process. The researcher then conducted a pilot study in the office of a primary care physician in southwest Michigan to test the proposed data collection process. No revisions were required in the tool or the methodology. The final tool was comprised of 46 items with an overall fifth-grade reading level (Online-utility.org, n.d.) and could be completed in approximately 10 minutes. Approval was obtained from Western Michigan University's Human Subjects Institutional Review Board (HSIRB) to conduct this research.

Research Procedure

Each participant received an informed consent letter and a survey to be completed anonymously. Consent to participate was demonstrated by returning completed surveys to a box in a central location at each site.

The estimated size of the target population was 2,000 adults, i.e., the total number of adults in the physicians' offices and senior centers. For a confidence level of 0.05, an effect size of 0.5 and statistical power of 0.8, the minimum sample size required for the study was 64 individuals (DanielSoper.com, n.d.). Participation rate was estimated at 33% of individuals approached about participation. Seventy-one surveys were collected for the sample, but due to missing data on advance directives, only 67 surveys or 94% of the total collected surveys were used.

Data were entered into an SPSS database. Frequencies and mean death attitude scores were obtained, and chi-square and multivariable binary logistic regression tests were conducted to determine whether there was an association between attitude toward death and the presence of an advance directive after controlling for potential confounders.

Results

Data for the seven variables studied have found to be associated with the presence of advance directives and the sites where surveys were conducted are displayed in Table 2.1. Most participants 60 years of age and older had advance directives (73%) compared to 18-59 year olds whose advance directive completion rate was 13%. Other demographic variables include sex, race, education, religiosity, income, and health literacy. At the different sites, the percentage of advance directive completion ranged from a low of 20% of the sample among those who participated at the clinic and a high of 65% of the sample among those who participated at the senior centers. Chi-square analysis showed age and sex to be significant predictors of advance directive completion.

The results of an analysis of the association between the demographics, sites and the presence of advance directives in this study are shown in Table 2.2. Crude analysis shows that both age and sex are significantly associated with advance directive completion. However, adjusting for these variables in a multivariable model found age to be a confounder. There was a significant association only between older age and advance directive completion.

Table 2.1

Selected Characteristics of Participants Completing Advance Directives

Variable	N	Have Advance Directive		Sig.
		Yes n (%)	No n (%)	
Total Participants	67	26 (39)	41 (61)	
Age (N = 67)				.000***
18-59 years	38	5 (13)	33 (87)	
60+ years	29	21 (73)	8 (27)	
Sex (N = 67)				.008**
Male	17	2 (12)	15 (88)	
Female	50	24 (48)	26 (52)	
Race/ethnicity (N = 67)				1.000
Caucasian	64	25 (39)	39 (61)	
Non-Caucasian	3	1 (33)	2 (67)	
Education (N = 66)				.578
High school diploma or less	50	18 (36)	32 (64)	
Bachelor's degree or higher	16	7 (44)	9 (56)	
Consider Yourself Religious (N = 67)				.134
No	14	3 (21)	11 (79)	
Yes	53	23 (43)	30 (57)	
Household Income (N = 65)				.515
\$76,385 or less/year	49	17 (35)	32 (65)	
More than \$76,385/year	16	7 (44)	9 (56)	
Health Literacy (N = 50)				.285
Marginal or possibly limited	10	5 (50)	5 (50)	
Adequate	40	9 (23)	31 (77)	
Sites				.055
General practitioners' offices	13	5 (39)	8 (61)	
Specialty physicians' offices	24	6 (25)	18 (75)	
Clinic	10	2 (20%)	8 (80)	
Senior centers	20	13 (65%)	7 (35)	

Significant at $p < .01$. *Significant at $p < .001$.

Table 2.2

Association Between Demographics and Advance Directive

Variable	Crude			Adjusted ^a		
	OR ^b	(95% CI)		OR	(95% CI)	
		Lower	Upper		Lower	Upper
Age 60+	17.33***	4.99	60.12	14.36***	4.03	51.17
Female	6.92*	1.43	33.49	4.12	.69	24.64
Caucasian	1.28	.11	14.89	-	-	-
High school education	1.38	.44	4.34	-	-	-
Consider self religious	2.81	.70	11.26	-	-	-
Above median household income	1.46	.46	4.62	-	-	-
Health literacy adequate	.29	.07	1.23	-	-	-
Site	1.57	.99	2.50			

^aAdjusted for age. ^bOdds ratio.*Significant at $p < .05$. ***Significant at $p < .001$.

Scores on the DAP-R range from 1 to 7 and correspond with the following levels of agreement: strongly disagree (1), disagree (2), moderately disagree (3), undecided (4), moderately agree (5), agree (6) and strongly agree (7). Table 2.3 displays death attitudes and the meaning of high and low scores.

Table 2.3

Death Attitudes and Meaning of High/Low Scores

Death Attitude	Low Number – Disagree	High Number – Agree
Fear of death	Not afraid of death	Afraid of death
Death avoidance	Does not avoid something because it is death-related	Avoids anything that is death-related
Approach acceptance	Does not believe there is an afterlife or that it will be serene and beautiful	Believes there is an afterlife and that it will be serene & beautiful
Escape acceptance	Does not welcome death as an escape from this life	Welcomes death as an escape from this life

The mean score for the attitude fear of death was 2.96; 79% of study participants had some level of disagreement with this attitude. The attitude death avoidance had a mean score of 3.07; 73% of participants disagreed with this attitude. The approach acceptance attitude had a mean score of 5.51 and agreement by 76% of participants. The attitude escape acceptance had a mean score of 4.54. Eighteen percent of participants were undecided regarding this attitude, and 51% agreed with it. Frequencies of agreement and disagreement with each of the death attitudes as well as the mean score of each attitude are listed in Figure 2.1.

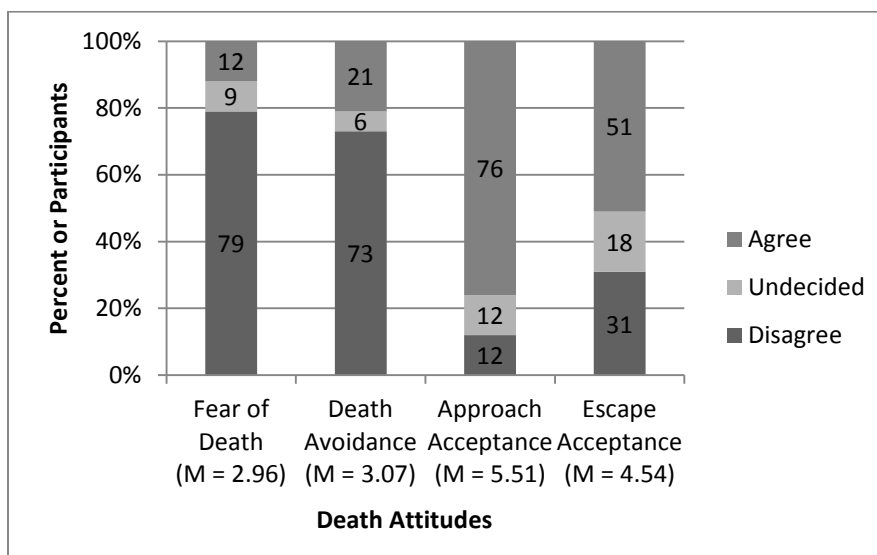


Figure 2.1. Types, frequencies, and mean scores of death attitudes.
 Levels of agreement/disagreement: strongly disagree (1), disagree (2), moderately disagree (3), undecided (4), moderately agree (5), agree (6), and strongly agree (7).

The association between level of agreement with each death attitude and the likelihood of having advance directives was analyzed using chi-square analysis. Odds ratios for both crude and adjusted analyses are listed in Table 2.4. The crude odds ratio shows that all the death attitudes except fear of death were associated with advance directive completion. The adjusted odds ratio represents the model when controlling for age. When age was controlled in binary logistic regression, none of the death attitudes were significantly related to the presence of an advance directive.

Table 2.4

Association Between Death Attitude and Advance Directive: Crude and Adjusted Analyses

Death Attitude Subscale	Crude			Adjusted ^a		
	OR ^b	(95% CI)		OR	(95%) CI	
		Lower	Upper		Lower	Upper
Fear of death	.87	.59	1.28	1.04	.64	1.70
Death avoidance	.67*	.47	.96	.70	.46	1.08
Approach acceptance	1.88*	1.10	3.22	1.64	.82	3.28
Escape acceptance	1.60*	1.07	2.38	1.44	.90	2.30

^aAdjusted for age. ^bOdds ratio.

*Significant at $p < .05$.

A comparison of means shows that for all death attitudes except fear of death, there is a significant difference in the death attitude score for participants with advance directives compared to those without advance directives. When religiosity is added as a variable, the results are different. Among those who consider themselves religious, the only significant difference between mean death attitude scores of those with and without advance directives is with the escape acceptance attitude toward death. Among participants who do not consider themselves religious, there is a significant difference between the means of those with and without advance directives for the death avoidance and the approach acceptance death attitudes. Table 2.5 lists mean death attitude scores by presence/absence of advance directives and religiosity. Figure 2.2 depicts mean death attitudes scores by advance directives and religiosity.

Table 2.5

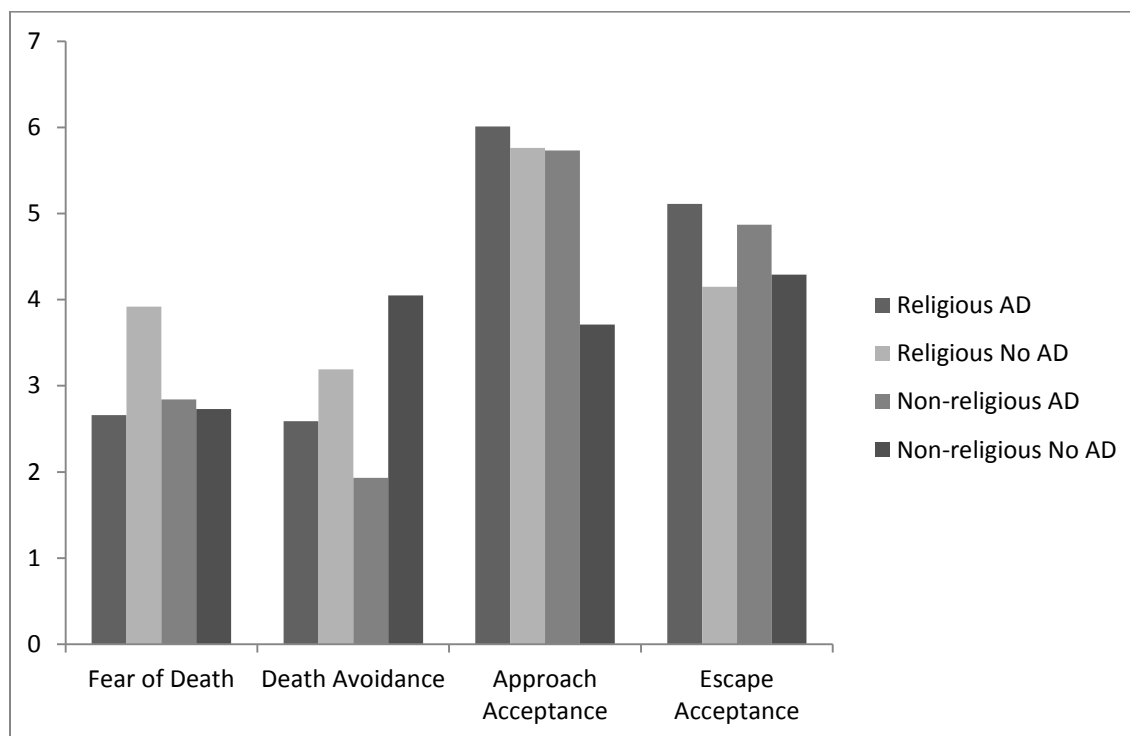
Comparison of Death Attitude Mean Scores by Presence/Absence of Advance Directives and Religiosity

Death Attitude	<i>M (SD)</i>	Sig.	Religious – yes ^a		Religious – no ^b	
			<i>M (SD)</i>	Sig.	<i>M (SD)</i>	Sig.
Fear of death		.488		.751		.193
AD yes	2.82 (1.13)		2.84 (1.08)		2.66 (1.77)	
no	3.05 (1.43)		2.73 (1.35)		3.92 (1.32)	
Death avoidance		.023*		.171		.044*
AD yes	2.52 (1.35)		2.59 (1.35)		1.93 (1.45)	
no	3.42 (1.67)		3.19 (1.71)		4.05 (1.45)	
Approach acceptance		.008**		.324		.037*
AD yes	5.98 (.95)		6.01 (.94)		5.73 (1.17)	
no	5.21 (1.35)		5.76 (.85)		3.71 (1.36)	
Escape acceptance		.016*		.017*		.605
AD yes	5.08 (1.32)		5.11 (1.39)		4.87 (.83)	
no	4.19 (1.51)		4.15 (1.43)		4.29 (1.79)	

^aWith advance directives, $n = 23$; without advance directives, $n = 30$.

^bWith advance directives, $n = 3$; without advance directives, $n = 11$.

*Significant at $p < .05$. **Significant at $p < .01$.



For each death attitude, mean scores are displayed for those with and without advance directives and for those who did and did not consider themselves religious.

Figure 2.2. Mean death attitudes scores by advance directives and religiosity.

Discussion

Regarding the research question, for all death attitudes except fear of death, there was a significant difference in mean death attitude scores among those with advance directives compared to those without advance directives. However, when the variable of religiosity was added, the results were only significant in the same three death attitudes according to whether one did or did not consider oneself to be religious. Among study participants who considered themselves to be religious, those with advance directives agreed more strongly with the death attitude escape acceptance than those who did not have advance directives. Among study participants who did not consider themselves religious, those with advance directives disagreed more strongly with the death attitude

death avoidance than those who did not have advance directives. Lastly, among study participants who did not consider themselves religious, those with advance directives agreed more strongly with the death attitude approach acceptance than those who did not have advance directives.

No significant differences between mean death attitude scores for fear of death and the presence/absence of advance directives were found regardless of whether one considered oneself religious. This does not support Dobbs et al.'s (2012) finding that there is an inverse relationship between fear of death and the presence of advance directives.

Religious individuals with advance directives agreed more with the escape acceptance attitude toward death than religious individuals without advance directives. Having this type of acceptance of death represents a desire to leave the difficulties of this world (Wong et al., 1994). It is logical that individuals with this death attitude would be more likely to have advance directives as advance directives could be considered a tool to avoid having futile health care treatment at the end of life that may create a barrier to escaping this world. An advance directive may also be perceived as preventing a delay in entering a positive afterlife. In this study it was non-religious individuals with advance directives who agreed more strongly with the approach acceptance attitude than non-religious individuals without advance directives. Wong et al. (1994) define death acceptance as the "cognitive awareness of one's own finitude and a positive (or at least neutral) emotional reaction to this cognizance."

There were only three non-religious study participants who had advance directives. Two of these individuals had the same death avoidance score (1—strongly

disagree) and similar approach acceptance scores (6–agree and 7–strongly agree). The third individual, however, was undecided about the death avoidance attitude and only moderately agreed with the approach acceptance attitude. Were this study to be repeated, it would be desirable to have a larger sample overall, but it would be particularly important to have a larger subset of non-religious individuals with advance directives.

Among non-religious individuals, those without advance directives were more undecided about the death attitude death avoidance than were those participants with advance directives. The latter group disagreed strongly with this death attitude. It is again important to note that the latter group was composed of just three individuals with relatively widely varying scores.

The role of religion in this study is not immediately obvious. The difference between religion and spirituality may be a noteworthy distinction. Some individuals may consider themselves religious or spiritual (Cicirelli, 2011), and this may have affected the outcome of this study. *Religious* may be defined as relating to shared ritual and unique traditions of a faith community, and *spiritual* may be defined as relating to meaning and purpose of life and connectedness with a power greater than oneself (Gilbert, 2007; Neal, 2007).

Black (2007) found that health care professionals, including physicians, with an approach acceptance attitude toward death were more likely to initiate a conversation about advance directives with their patients than health care professionals who did not possess this attitude toward death. Gordon (1999) found that patients who were asked by a physician or nurse about their preferences for care at the end of life were three times as likely to complete advance directives. Health care professionals may also want to

consider exploring an individual's religious or spiritual beliefs in a conversation about advance directives.

In the study, a higher percentage of participants who considered themselves religious had advance directives compared to those who did not consider themselves religious. This is consistent with the literature which states that being religious is associated with having advance directives (Alano et al., 2010). Most of the surveys were collected in rural communities, and this may have influenced the results. In a qualitative study of family members of nursing home residents with dementia, Gessert, Elliot, and Peden-McAlpine (2006) found individuals from rural communities to be more accepting of the possibility of death for their loved ones than those family members who lived in urban areas. Future research could employ data collection methods that permit a comparison of rural and urban death attitudes and advance directive completion.

The results of the study also showed that there was a positive association between age and the presence of an advance directive. Among the participants in the study sample, the older one was, the greater the odds were that one had an advance directive. There may be multiple explanations for this result. Compared to younger adults, older adults may be significantly less afraid to discuss death (Sessanna, 2008). Some studies have shown that anxiety about death is lower among older adults than it is among younger adults (Fortner & Neimeyer, 1999; Hallberg, 2004; Schrader, Nelson, & Eidsness, 2009-2010), and some have shown no difference between the two age groups (Conte, Weiner, & Plutchik, 1982; De Raedt, Koster, & Ryckewaert, 2013; Moody, Beckie, Long, Edmonds, & Andrews, 2000). Future research could include a longitudinal study to discover whether attitudes toward death change over time.

Another finding was that more than half of study participants who lived at senior living centers had advance directives which may make advance directive completion in these settings more of a social norm. People may prefer to discuss their own advance care planning with someone who has been specifically trained to discuss it (Michael et al., 2013). Perhaps individuals moved into assisted living when their spouse died and as a result they felt their own mortality more acutely, and perhaps facility admission staff are specially trained in the methods of having discussions about advance directives. Widowed individuals are more likely than married individuals to choose to spend their end of life in a facility other than their home (Wilson, Cohen, Deliens, Hewitt, & Houttekier, 2013); and individuals without partners are more likely to have advance directives (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013). Perhaps widowed study participants had been exposed to hospice care with their dying spouse and wanted to ensure that comfort care for themselves (Bischoff et al., 2013). Individuals whose spouses died after having completed advance directives are more likely to do their own advance care planning (Carr, 2012).

Perhaps the very act of moving into a senior living center was part of a larger advance care plan for these study participants. Finding themselves alone after the death of a spouse, an individual's adult children may have encouraged them to enter assisted living as a way of initiating some form of advance care planning. The more encouraging an adult child is for his or her elderly parent to do advance care planning, the more likely that child is to be selected by the parent to be the durable power of attorney when the parent does execute advance directives (Boerner, Carr, & Moorman, 2013).

The advance directive completion rate among 60+ year olds living in the community was similar to the advance directive completion rate of the same age group living in senior centers. Among all study participants who had executed advance directives, half lived in the community and half lived in senior centers. These do not support Hopp's (2000) finding that most adults who live in the community (as opposed to living in a facility) do not have advance directives. However, Black and Reynolds' (2008) finding that older adults living alone are less likely to have advance directives may have contributed to this if the households of older study participants in the community included other people. The advance directive completion rate of this study is also not consistent with results found by Hirschman, Abbott, Hanlon, Bettger, and Naylor (2012), that residents of assisted living facilities had higher advance directive completion rates than residents who lived in the community or at home.

Demographically, some of the results of the study are consistent with the literature on advance directives. A higher percentage of advance directives were found with older people and women. The outcome on race/ethnicity could not be determined because too few individuals who identified as non-Caucasian participated in the study.

The sample was representative of the two-county population in race and education only. A larger sample from each county may have been more demographically representative of each county overall. More important would be the collection of a sample that is representative of attitudes toward death in the two counties. Most of the surveys were collected at the sites of health care practitioners. This excludes those who may not see a health care practitioner, and who may, subconsciously or otherwise, fear

death. Or some individuals may have a death avoidance attitude that is manifested by avoiding visits to health care practitioners.

One of the major strengths of this study is that, to the researcher's knowledge, it is the first to analyze the association between four attitudes toward death and the presence of advance directives. The other major strengths are the strong reliability and validity of the Death Attitude Profile–Revised.

Limitations include measuring religiosity with one question with dichotomous answers. A more sophisticated tool showing degree of religiosity and distinguishing religiosity and spirituality may show more nuanced results. The NIA/Fetzer Short Form for the Measurement of Religiousness and Spirituality (Idler et al., 2003) contains measures of religiosity and spirituality that may pertain to health and would likely provide a more thorough analysis of religiosity/spirituality.

Another limitation is the use of a small convenience sample in two southwest Michigan counties; therefore, the results are not generalizable. Additionally, it might have improved the study to use a different household income figure than the figure for a family of four because that family size may not represent the family size of many older adults. More pertinent information might have been collected if a household income for a family of one or two had been used.

Conclusion

In this study, death attitudes, religiosity, and the presence/absence of advance directives combine in varying ways that make rendering any definitive conclusions difficult. More research is needed to fully analyze the relationships among the three variables and particularly to understand the nuanced influence of religion and spirituality.

Age was found to be significantly associated with having advance directives, supporting previous research. Learning whether attitudes toward death change as one ages, particularly as attitudes relate to changing religious or spiritual beliefs could also be a focus of future research.

Most study participants who lived at senior living centers had advance directives. The possible influence on advance directive completion of residing in assisted living may be a topic for future research. A potentially confounding variable in the current study is the rural vs. urban demographic, and it may be important to include this variable in any future studies.

Future research on death attitudes, advance directive completion and the role of religiosity should be done with larger groups of individuals representing the population demographically. A wide range of death attitudes and relatively equal numbers of those with and without advance directives should be represented. Lastly, the influence of diagnosis and quality of life and their relationship to attitude toward death and advance directive completion would add valuable information to the field of advance care planning.

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CHAPTER III

PATIENTS', FAMILY MEMBERS' AND PROVIDERS' PERSPECTIVES OF THE EXPERIENCE OF HOSPICE REFERRAL

Introduction/Background

In the United States, hospice care is a 6-month palliative² care benefit covered by Medicare (Title XVIII, Health Insurance for the Aged and Disabled, Sec. 1812), Medicaid, and private insurance. It is designed to increase quality of life by providing holistic comfort care as well as pain and end of life symptom management to individuals with a prognosis of 6 months or less (National Hospice and Palliative Care Organization [NHPCO], 2014a), and some evidence suggests that, in addition to increased quality of life, hospice care might also add days to a patient's life (Connor, Pyenson, Fitch, Spence, & Iwasaki, 2007).

Because hospices are required to pay for the costs associated with a patient's terminal diagnosis (medication, oxygen, medical supplies and equipment, professional hospice staff), there is little or no out of pocket cost to the patient or family for hospice care (NHPCO, 2014a). However, despite (a) the opportunity to benefit from increased quality of life for up to 6 months, (b) the potential to extend length of life, and (c) the affordability of hospice care, the national median length of service for a patient in hospice care was 19.1 days in 2011, 18.7 days in 2012, and 18.5 days in 2013 (NHPCO,

² Hospice care is palliative (comfort) care at the end of life (Center to Advance Palliative Care [CAPC], 2014). In this article, we use the terms *hospice* and *palliative* interchangeably. Palliative care that is not hospice care we refer to as non-hospice palliative care.

2014b). In this study the multiple perspectives of those involved in the decision-making processes that result in a hospice admission were examined. Information from an analysis of these perspectives and the ways in which they are different and similar might increase understanding about hospice length of service and might ultimately lead to increased use of more of the potential full 6-month hospice period.

Regulations for admission to a hospice program require a provider to refer the patient to hospice care and the patient, or the patient's legal representative if the patient is unable to make his or her own decisions, to elect the hospice benefit (NHPCO, 2014a). Both actions must formally occur before an admission can take place. Researchers have found many reasons for delay by providers: inaccurate prognostication (Brandt, 2006; Brickner, Scannell, Marquet, & Ackerson, 2004; Christakis & Lamont, 2000); discomfort with discussing death/hospice (Wyatt, Ogle, & Given, 2000); a belief that the patient and/or family are unwilling to acknowledge the likelihood of death within 6 months (Hyman & Bulkin, 1990; Ogle, 2003); a desire to continue to fight the disease (Sanders, 2004); a lack of knowledge—or enough knowledge—about hospice (Weggel, 1999); a desire to avoid the patient and/or family thinking the provider was giving up hope (Kelly, 2006); a fear that hospice referral meant losing control of the management of the patient's illness (Richards & Takeuchi, 2006; Weggel, 1999); ignorance of the patient's culture related to the perception of hospice care (Carrion, 2010); and a perception of a negative financial impact of referring a patient to hospice (Richards & Takeuchi, 2006).

Providers who delay a hospice referral, intentionally or unintentionally, are, however, only part of the story of the short length of stay in hospice care. Studies show that even though a patient might be referred to hospice care by a provider, a delay in

being admitted to hospice care might result because of the patient's or family member's perspective related to the following reasons: a lack of willingness to acknowledge the probability of death within 6 months (Casarett, Crowley, & Hirschman, 2004); a desire to continue to fight the disease; a belief that the hospice referral was too soon (Kapo, Harrold, Carroll, Rickerson, & Casarett, 2005); a lack of knowledge about hospice care (Chung, Essex, & Samson, 2009; Melvin, 2010; Schockett, 2005); a desire not to have strangers in the home (Ogle, 2003); a feeling of being threatened with the idea of hospice coming into the home (Vig, 2010); and a desire to care for the patient without outside help (Sanders, 2004; Waldrop, 2009).

Nationwide, hospice patients are not experiencing a longer length of service despite the knowledge about reasons for delay that health care professionals have access to as a result of research to date (NHPCO, 2014b). A dynamic might be occurring that is not yet fully understood. An analysis of the same referral process from the perspective of those involved in the decision-making might uncover new knowledge. Providers might utilize this knowledge to assist patients and their family members to benefit from hospice services for a longer time period.

Abstracts in four databases were searched in September of 2012 and again in August of 2014 using four different combinations of search terms related to communication around end of life. Table 3.1 displays a dearth of studies related to patient-family-physician (provider) end of life communication.

Table 3.1

Number of Research Studies on End of Life Communication Among Patients, Families, and Providers

Search Terms	Number of Results ^a by Database			
	CINAHL	Medline(Firstsearch)	PubMed	Scopus
	2012/2014	2012/2014	2012/2014	2012/2014
Patient-physician communication end of life	11/13	34/43	506/619	79/98
Patient-family communication end of life	43/57	41/55	32/39	160/216
Physician-family communication end of life	6/8	9/11	9/10	34/41
Patient-family-physician communication end of life	0/0	1/1	0/0	4/4

^aSome results are duplicated.

After duplicate articles were eliminated, 38 articles remained in the category of physician-family communication at end of life. Of these, authors described the needs of the family and end of life care for their loved one in only 8 articles. Other researchers describing provider-family communication discussed family members only as surrogate decision makers for the patient, i.e., not as having needs of their own but only in relation to how they could serve the needs of the patient.

To date, researchers might have overlooked the importance of the web of relationships in which a patient exists in addition to being an individual. They might have underestimated its importance and its effect on patients' decision-making as the dearth of research focusing on family needs related to their loved one's care at the end of life suggests. In the current study, because the family is the third entity in the triad of those

involved in end of life decision-making, we also examined the perspective of the primary caregiver.

Family members might influence decision-making about hospice directly or indirectly, and as a result, patients might not make end of life decisions based solely on what they as individuals need to receive or experience (Hauser et al., 2006). The patient's perception of what his or her family needs during his or her final months of life might also influence decision-making (Singer, Martin, & Kelner, 1999). In a cross-sectional, stratified, random national survey in which 1,462 patients, family members, and providers participated, more than 70% of patients rated the following as very important at the end of life while providers did not rate them as important: not being a burden to family, friends, or society and being able to help others (Steinhauser et al., 2000). In a qualitative study involving 126 participants, patients identified relieving the burden of their illness on and strengthening relationships with those they love as being two of the top five categories of good care at the end of life (Singer et al., 1999).

The author sought to identify dynamic(s) not yet understood about the hospice referral process by utilizing a research design developed for this study. In a search of the four databases listed above, no examination of the same referral process from the perspective of the patient, the patient's caregiver family member and the provider was found. The unique approach utilized for this study might uncover information that could direct future research and lead to the development of tools that support patients and their families experiencing longer hospice service and, presumably, increased quality of life. The research question for this study is, what is the experience of the hospice referral from the perspectives of the patient, the caregiver family member and the provider? Western

Michigan University's Human Subjects Institutional Review Board approved this research project.

Methods

Subject Recruitment

In December of 2012 the author mailed a packet of information to each of five hospices in the western Lower Peninsula of Michigan. Each packet contained a personalized letter of invitation to join the research study, the research study's abstract and several handouts that would be used in meeting with clinical staff to explain the research. Two hospices consented to participate in the research, and two hospices declined to participate. The administrator of the fifth hospice was interested in participating but was unable to obtain permission to do so. In the spring of 2013, the author met with registered nurses (RNs) at each of the participating hospices. Each RN received a packet containing information to assist him or her to identify potentially eligible study participants and to invite these individuals to have a discussion with the author about participating in the study.

The following patient inclusionary criteria were developed for being invited to participate in the study: the patient can speak English; according to the hospice RN's best estimate, the patient has a prognosis of at least 2 months; the patient's hospice admission is his or her first hospice admission; the patient is alert and oriented; the patient is able to physically tolerate being interviewed for the study as evidenced by the ability to stay awake and talk for at least one hour; and the patient's physical symptoms are stable. The following criteria were developed for family members to be invited to participate in the study: the family member can understand and speak English, and the family member was

a person closely involved in the patient's decision to elect hospice care. Provider inclusionary criteria included the following: the individual must be the provider most closely involved in the patient's decision to become a hospice patient and may not already be involved in this study for another patient.

Within a week of the training meetings with the two hospices' RNs, a patient and her caregiver husband agreed to participate in the study. However, when the author contacted the husband the following day, the patient was too ill to be interviewed and the husband asked for a delay until his wife felt better. The patient died a few days later. During the summer of 2013, four more patients and their caregivers consented to participate in this study. The first of these changed her mind about participating; the provider of the second patient declined to participate; the third patient was discharged from hospice care before an interview could take place; and the fourth became unable to participate when her caregiver husband was hospitalized.

The first of the five sets of interviews of patients, their caregivers and their providers occurred in September of 2013. Between October 2013 and January 2014, another patient agreed to participate but when we contacted her she changed her mind stating she believed she was recovering from her brain cancer. Multiple reminder phone calls were made during this time period to encourage the participating hospices to refer patients. HSIRB approval was granted to include in the study the hospice at which the author is employed. In February of 2014 a breakfast was held at each participating hospice and the study protocol with the RNs and their supervisors was reviewed. Table 3.2 lists all the referrals received for this study and the outcomes of these referrals.

Table 3.2

Study Referrals and Outcomes of Referrals

Referral Number	Time of Referral	Outcome of Referral
1	May 2013	Patient died before she could be interviewed.
2	June through September 2013	Patient decided she did not want to participate.
3		Patient's provider declined to participate.
4		Patient was discharged from hospice care.
5		Patient's caregiver husband was admitted to hospital.
6	September 2013	Author interviewed triad.
7	February 2014	
8	March 2014	
9		
10	June 2014	

Measures

The author utilized a narratological approach (Hays & Singh, 2012) within a modification of the explanatory model of illness (Kleinman, Eisenberg, & Good, 1978; “Techniques for Taking a History,” 2005) to analyze the data collected. In narratology, individuals tell their experiences in stories that hold personal and cultural relevance for them. Researchers analyze the story’s plot structure, content and purpose to understand larger frameworks (Hays & Singh, 2012). Narratology supports narrative health care which allows providers to understand deeply the patient’s experience of illness, to forge a trusting alliance with the patient in which information is mutually shared, and to support the patient in accessing care (Charon, 2001). Charon (2001) described narrative

competence as “the ability to listen to the narratives of the patient, grasp and honor their meanings, and be moved to act on the patient’s behalf” (p. 1897). A narratological approach to analyzing the data might also afford a look at multiple perceptions of the same event and to compare participants’ individual interpretations of turning points in the collective storyline (Clandinin & Connelly, 2000).

The explanatory model of illness, designed by Kleinman (“Techniques,” 2005), seeks the patient’s perspective of his or her illness. Whereas the provider might be more likely to focus on aspects of the disease and its physiological effects on the patient’s body, the patient might be more likely to describe his or her experience of being ill. This experience might include emotional and social dimensions as well as physical dimensions of how his or her life is affected, all of which might combine to create deep meaning for the patient (Kleinman et al., 1978). The author also utilized Rosenstock’s (2005) discussion of decision-making related to health. Individuals move through stages before making a decision resulting in a behavior. A cue to action is the event that triggers the actual behavior and typically occurs when an individual has moved through stages to the extent that a certain level of readiness for change exists.

In the interviews with patients, their family members and their providers the author explored perceptions of critical conversations and reflections on the journey to hospice care. These included time of diagnosis, discussions about prognosis, introduction of the idea of hospice care, referral to hospice care and election of the hospice benefit. The author began with predetermined open-ended questions to elicit the interviewee’s story and utilized follow-up probing questions to procure additional perspectives not discussed in the initial responses.

The interviews were transcribed and coded for events, internal experiences and meanings (Hays & Singh, 2012) and field notes were utilized to track decisions made during the analysis (Clandinin & Connelly, 2000). This was accomplished utilizing a three-dimensional inquiry space (Clandinin & Connelly, 2000) in which stories were analyzed for personal and social voices, for temporal facets (past, present and future) and for place. Tensions and interruptions in the stories were also noted (Clandinin & Connelly, 2000).

Data Collection

Between September 2013 and July 2014, the author conducted 16³ semi-structured interviews lasting from 15 to 50 minutes. All interviews were digitally recorded and transcribed verbatim. The author is a doctoral student with 16 years of hospice experience as an RN, a bereavement coordinator, and an executive director.

Data Analysis Methods

Utilizing QSR NVivo 10 for Windows, the data were coded two separate times for common themes and turning points in the story. During the second round of coding, all themes added during the first round analysis were examined. A total of 21 themes were identified and a timeline was constructed for each patient using the turning points in the patient's, the caregiver's and the provider's stories.

³ The author interviewed two physicians for one of the patients—the patient's primary care physician and the hospital physician who referred the patient to hospice care. The latter physician was Dr. C. She did not specifically recall the referral and was unable to access her visit notes. Her comments are more general and are included where pertinent.

Findings

Context

All interviews with patients and caregivers occurred at the patients' and/or caregivers' homes. All interviews with providers took place in the providers' offices or on the telephone. Members of the first triad were Rachel⁴ (patient), Liza (caregiver family member), and Dr. N (provider). Rachel was 96 years old and lived with her small dog in a middle class neighborhood in a city in the western Lower Peninsula of Michigan in the United States. At the time of the interview, Rachel's daughter Liza lived with her husband at their rural summer home located 30 minutes south of Rachel's home. Both Rachel and Liza discussed their experience of hospice care in glowing terms. Dr. N was a young physician whose practice was in the city where Rachel also lived. She was familiar with and had recommended many patients to hospice care.

Members of the second triad were Paul (patient), Lindy (Paul's girlfriend and caregiver), and Nurse Practitioner (NP) E. Paul and Lindy lived in her home in a small west Michigan town. Paul was in his early 40s, had had several strokes and was unable to walk or talk. He communicated by typing messages on a laptop computer. Paul also had a co-morbidity of acquired immune deficiency syndrome (AIDS). On hearing of his AIDS diagnosis 13 years ago, Paul's parents and siblings rejected him and have not communicated with him since then. On the subject of Paul's AIDS diagnosis, both Paul and Lindy were guarded in their responses. Paul's demeanor was an unusual combination of reticence and an urgency to tell his story. Lindy and Paul met one year ago, and despite gentle probing, neither shared how they met each other. Lindy never knew Paul as

⁴ Pseudonyms have replaced all names included in this study.

a healthy individual and answered questions about Paul's illness carefully. NP E was the provider who referred Paul to hospice care. Her office was located in a city approximately two hours south of where Paul and Lindy lived. She was the only provider in the five triads who did not follow the patient into hospice care. At the time of admission, the hospice transferred Paul's care to the hospice's medical director.

Members of the third triad were Ken (patient), Nina (Ken's wife and caregiver) and Dr. S (provider). Ken was a robust 89 years of age and looked to be in his early 70s. He and Nina lived in a mobile home in a small town in the western Lower Peninsula of Michigan. Ken was congenial and a colorful story teller. Nina had a gentle demeanor. She wept occasionally when she shared sad memories during the interview then she repeatedly laughed and apologized for crying. Ken and Nina's children lived in New York, Florida, California, and Michigan in the United States. Dr. S was a pulmonologist and had been in practice for approximately 25 years. His office was located in a small city approximately 45 minutes north and west of Ken's home. He expressed familiarity with and appreciation for hospice care.

Members of the fourth triad were Victor (patient), Anya (Victor's wife and caregiver), and Dr. G (provider). Victor and Anya lived in a small west Michigan town. Victor was a calm man in his 70s with an enviable amount of stamina and a peace that seemed to emanate from him when he spoke. He was a retired pastor and an appreciative and loving husband, father, and grandfather. Anya was patient and fiercely protective of Victor. She was, at times, impatient with him when he would try to do more than his body would physically allow. They had hung photographs of their children and grandchildren on a beam in the ceiling. The photographs were strategically placed so

Victor and Anya could see them from their favorite seats in their living room. Dr. G had been an oncologist for more than 30 years and stated he was familiar with and comfortable with hospice. His office was in a city 20 minutes west of Victor's and Anya's home.

Members of the fifth triad were Mark (patient), Jenny (Mark's sister and caregiver), and Dr. T (provider). Mark was in his 70s. He was friendly and called hospice "hopskice." Jenny was Mark's younger sister. She lived with and cared for both Mark and Mark's son who had Down Syndrome. She had, until 7 months prior to the interview, also been the caregiver for her husband who died under hospice care. Dr. T had been Mark's family physician for years. His practice was located in a rural town approximately 30 minutes east of where Mark and Jenny lived. He stated he was familiar with the local hospice and that he appreciated the support both he and his patients received from hospice.

Hospice Diagnosis and Path to Hospice Care

Rachel and her daughter stated that Rachel's hospice diagnosis was chronic immune demyelinating polyneuropathy (CIDP) although both were aware that CIDP was a chronic and not fatal illness. Dr. N made the hospice referral because of Rachel's age and her chronic debilitating conditions: CIDP, chronic hemolytic anemia and heart disease. Rachel had been hospitalized and was rehabilitating in a nursing home when a rehabilitation nurse suggested she return home with hospice care. Hospice would provide her with services she needed and would allow her to stay in her own home. Rachel concurred, and the nurse called Dr. N who agreed to refer Rachel to hospice care. They informed Liza of the referral to hospice after it occurred.

Rachel and Liza welcomed hospice care, Rachel for support and services and Liza for her peace of mind because someone would be checking on her mother regularly. This was a “soft” entry into hospice care because hospice was welcomed by the patient and family. It was a non-traditional entry because someone other than the patient’s provider initiated a conversation about hospice care which led to the referral. Rachel was appreciative of the care she received from hospice. “Well, I’ve had nurses and doctors, aides . . . I mean . . . you just notify them and you get help right away.” Liza was relieved by the support hospice provided. “I think it’s great. I like that fact that. . . . You know . . . I wouldn’t even come down here [to summer home] if she didn’t have something like that up there watching her.”

After Paul’s hospitalization and return home, a home health care nurse visited him. Medicaid regulations prohibited her from conducting more than a limited number of visits (U.S. Department of Health and Human Services, 2010). She suggested to Paul and Lindy that they pursue hospice care for Paul because of the services it would provide him. Paul agreed because he knew Lindy needed more help caring for him. Lindy contacted Paul’s Nurse Practitioner E for a hospice referral but was jolted by the realization that qualifying for hospice care meant that Paul was in his last 6 months of life. Although NP E was surprised Paul met the criteria to become a hospice patient, she made the referral to hospice care at Lindy’s request and based on the recommendation of his home health nurse, stating stroke as Paul’s hospice diagnosis. This was a “hard” entry into hospice care because the reality that hospice care is for end of life jarred the caregiver. This was also a non-traditional path to hospice because someone other than the patient’s provider initiated a discussion about hospice which led to the referral to hospice.

Dr. S suggested hospice care to Ken and Nina when Ken decided to discontinue chemotherapy for his lung cancer after taking the medication for 10 days. The timing of the referral was such that both the patient and his wife knew this was their last and only choice in treatment options. Ken remembered only that Dr. S said, “If I were you, I’d go home and get hospice care.” Nina also remembered Dr. S mentioning hospice only once. Dr. S stated that he made hospice care part of the discussion from the beginning with the patients he sees. He recalled at least one conversation about hospice with Ken and Nina before recommending it, but neither Ken nor Nina remembered that conversation. According to Nina, Ken was quiet for several days after Dr. S recommended hospice to him. This was a “hard” (because the recommendation was somewhat upsetting to Ken and Nina) and traditional (because it was Ken’s provider who recommended) entry into hospice care.

Victor, Anya, and oncologist Dr. G all stated that Victor’s hospice diagnosis was metastatic renal cell carcinoma. He had survived prostate cancer years before his current cancer was diagnosed in a hospital emergency department. He then had surgery and enjoyed three years with his family and his congregation before a CT scan revealed the cancer had metastasized. Multiple rounds of chemotherapeutic drugs were tried but did not produce the desired results. Weakened by radiation, Victor broke his leg and received a hip replacement. A friend of Anya’s then recommended they consider getting hospice care. The friend had experienced hospice services for her husband and described them to Anya as being helpful. Anya asked Dr. G about a referral, and Dr. G postponed referring until Victor tried one more medication. When that did not produce the desired result, Dr. G referred Victor to hospice. Rather than feeling upset by the referral, Anya perceived

hospice only as help. This was a “soft” (because hospice was welcomed by Victor and Anya), non-traditional (because someone other than the provider recommended) entry into hospice care.

Mark did not know the name of his hospice illness, but his sister reported it as congestive heart failure (CHF). Dr. T acknowledged the patient did have CHF although he stated he believed the hospice diagnosis was chronic obstructive pulmonary disease (COPD).⁵ Before his illness became so severe that it prevented him from driving, Mark used to visit his physician alone. Dr. T stated that on one of these visits he introduced the subject of hospice care because Mark was starting to require frequent hospitalizations for exacerbation of symptoms manifested by difficulty breathing. He did not, at that time, recommend or refer Mark to hospice care. He also noted that it was difficult to discern how much Mark understood. Mark did not share this conversation with Jenny, and Jenny did not realize the terminal nature of his disease. The last time Jenny drove Mark to a hospital for relief of his shortness of breath, a palliative⁶ care physician was called in to consult. According to Mark and Jenny, this physician told them that the only way he could return home was with hospice care.⁷ Mark was shocked to learn of his limited prognosis, and Jenny was angry no one had discussed it with them until this point. She recalled her reaction,

⁵ The hospice listed Mark’s primary hospice diagnosis as CHF. COPD was listed as a comorbidity.

⁶ A palliative care physician is board certified in Hospice and Palliative Medicine (American Board of Internal Medicine [ABIM], 2014).

⁷ Dr. C explained that she talks first with patients and caregivers about their goals, and that if Mark’s goal had been to return home, she likely said that if that is what he desired, his best option was to go home with hospice.

What?? You know, . . . we didn't know this. . . . What's going on? . . . It was a real slap. . . . I hadn't heard anything. I knew about congestive heart failure but that if you took care of it, that you can live with congestive heart failure.

This was a “hard” (because the hospice recommendation was distressing to Mark and Jenny), non-traditional (because someone other than Mark's provider recommended) entry into hospice care which led to the hospice referral.

Four of the five patients had a non-traditional entry into hospice care. In this study, 80% of the journeys to hospice care were initiated by someone other than the patients' providers. None of the patients had a soft (i.e., welcomed), traditional (hospice recommended by the primary provider) entry into hospice care.

Effect of Illness and Life Expectancy

For some time, all the patients except Rachel had been living with an illness that would eventually become terminal before their providers recommended hospice. Rachel's illnesses were chronic but not necessarily fatal conditions.

Rachel volunteered that the most significant impact her illness had on her life was that it forced her to stop participating in her favorite hobby.

Well, I belong to a group. . . . We went out to the Veterans' facility, and we sewed one day a week for 'em, mending their clothes. And it was hard for me to do that anymore and that was bad. I just love to sew and, we had such a good time helping those veterans.

Her strength to endure came from her faith. “I believe in the Lord, and it's His time to tell me something so that's all I know. I just sit. I don't know. But the Lord did and that was my deal.” Dr. N stated she did not have a conversation about life expectancy with Rachel, her patient, or Liza, Rachel's daughter.

Paul shared that he contracted the AIDS virus from his former wife. “My wife is why I'm like this now.” On hearing of his AIDS diagnosis, Paul reported becoming

suicidal. “That was in July of ’01. Went home looking for a knife to die.” His first realization that he was ill was when he “went to the ER three times before going out of town, to the ER two times and then spent two weeks in the hospital. Was on the scared side.” Disowned by his family, he eventually went to live in a nursing home. After much consideration Lindy permitted him to move into her home.

Honestly, at first, I didn’t know if I wanted to have anything to do with him because I just lost my dad to an illness already. And I didn’t know if I could handle losing another person. You know? So, but it was kinda scary.

Paul has outlived his original 5-year prognosis.

Ken remembered when he first became ill. “Well, I had pneumonia and I’d just get over it and get it right back.” After a visit to his primary care physician, Ken then saw a specialist. “He told me that I had cancer in one . . . in my lungs. Went to Florida last winter and spent the winter down there. I had a hard time. I was bleeding in my lungs.”

He returned to Michigan and saw the specialist again. He had another x-ray, and

the next thing I knew he ordered some pills for me of \$6,000 a month. I took them for 10 days. The skin was coming off my hand. It was coming off my head. My hair was standing right straight on end. And I said “this stuff is gonna kill me. I might just as well die.” So I quit. I only took ‘em 10 days. The rest of ‘em I threw away.

Ken had two concerns. One was for his wife.

[I’m] just hoping that she’s going to be able to resist . . . exist after I’m gone, but she has got her own problems. She can’t remember. A lot worse than I am. I can’t remember a lot but it’s her short memory. She can’t remember. . . . It’s going to be tight for her when I go, but we’ve got kids that will take care of things, I think.

Ken’s second concern was about his own death. He first discussed the deaths of his parents.

My dad died right in my arms. I had just put him to bed. Just laying in bed and he died right in my arms. Had a heart attack. Mother suffered, suffered, suffered. She suffered bad. I’d say the last three days of her life she spent screaming. I just hope

I ain't in a lot of pain and so on and so forth but whatever comes, comes. And I hope I'm man enough to take it.

Nina remembered what she felt when the physician confirmed the presence of Ken's cancer.

I didn't want to believe it. . . . Wake me up from this horrible nightmare I'm having. It was, you know. And I tried to put it off and I thought you know we can't do that because you gotta accept it and go on and make the best of it.

Much of Nina's story centers on their child who died at an early age.

Maybe some of my experiences stem from our youngest child. Um, she was born with all sorts of medical problems. And, um, she lived to be 14 and then she passed and went to heaven. I guess I figured if I can get through that . . . that's how I've survived all these years.

According to Nina, Dr. S said Ken could live another 3 to 12 months. Ken did not recall Dr. S giving him a prognosis.

Anya remembered details of Victor's illness.

Well, I think that from the moment they told us that it had grown into his heart there was that sense that when they made the decision to go to [health center] and we made the decision to have the big surgery, there was a real strong possibility that he would not live through that surgery. And then when we beat that one, we had our three years, and we went back and found it was metastasized, it was a huge disappointment. 'Cause we thought maybe we had it licked.

Victor's attitude toward his illness was unrelenting. "You know I may have the attitude of darn it all but let's do what needs to be done," yet, he stated he is a realist. "I'm fully aware that maybe nothing can be done." Dr. G sometimes questioned how realistic Victor was about his illness.

Victor has been unwilling to step back from any of the many things he does. I had a disagreement with him that his wife brought up. In the middle of really being quite sick, he wanted to go lead a mission trip to . . . the high plains of Arizona. 10,000 ft., 100 degrees. Entirely, you know, entirely inappropriate. And his wife thought so too, and she called me to help. But Victor has always . . . been seeking to remain . . . 100% active at his previous rate or as best as he could do. Now people who strive for that do better than people who don't strive for that, but . . .

I've always felt that his expectations were unrealistic with regard to this. He'd like to be perfectly well until the day he goes and then he goes and that day should be a long time from now. It's a very human and expected response, but he really lives it that way.

Victor's prognosis was 6-8 months, and at the time of the interview he had already lived longer than that time frame.

Mark's will to live had been fueled by all the house projects that required his attention, but it took him longer to complete them because he stopped frequently to rest. "Whatever you want done I can do. I still can, but it takes me like about a month or two to get it done now." He did not want to leave Jenny with projects to complete after his death. "[I will] get things done I want to get done . . . so she don't have to worry about anything." Jenny discussed how she depends on Mark. "He's been there for me . . . since I was a babe. Anything I needed or needed help with. 'Brother!' After he's put in 16 hours, he comes over, helps me fix stuff."

If Mark forgot to take his medication, the consequences were serious. "Well, usually, I would say that I'll get tired, my chest starts hurting, my legs start hurting. . . . I'll look like a zombie." Mark's prognosis was 6 months if his disease followed a relatively normal course. He had already outlived the physician's original 6-month estimate.

Dosing Hospice

Described in the dictionary as a pharmacologic term, the word *dose*, used as a verb, means "to give a dose to, especially to give medicine to" (Merriam-Webster, 2014). Used in this context, it refers to giving small amounts of information about hospice over time as opposed to giving the information all at once. Most of the providers stated it is important to talk about hospice early and often, before it was needed and before the

symptoms of a patient's illness reached crisis proportions. It was a common perception among the providers in this study that patients and their family members were more receptive to hearing about hospice when the prospect of becoming a hospice patient was still some distance into the future. None of the patients or caregivers, however, remembered hearing about hospice from their provider more than once, and when they did hear it, it was being recommended for immediate use.

Rachel's physician, Dr. N, stated,

Getting to know these patients and their family and trying to make the decision on when to refer I think comes with time and really is an art. It's an art of medicine that's not taught in our training and I think learning when that time comes for each of your patients is, again, a work in progress and something that we all need to think about. . . . A lot of times we get caught up in treatment of the illness and symptom management and all of those very important things but keeping in mind that there is a time when we're not going to do them any favors or any good by continuing treatment. . . . Making that referral to hospice is an important thing to start . . . before you think even that time comes.

Paul's provider, NP E, said,

I think we need to pretty much normalize hospice care. I think it should be part of the conversation . . . the same way we changed DNR [federal Do Not Resuscitate law] and now you go to [the] emergency room for a crushed finger and they ask you, "If something happens to you, what do you want us to do? We're not planning that anything is going to happen but if something happens." I think we need to bring hospice in at that level, that early, so people start considering the benefits instead of waiting all the way to the end.

Ken's physician, Dr. S, stated,

My usual approach is if I think somebody's going to be ready for hospice 6 months from now, I begin to have those discussions with them now. . . . Sometimes I'll ask them a hypothetical question. "If somebody said to you 'you can choose right now. You can live 6 months really comfortably, or you can live 12 months but you'll be quite miserable for much of it,' what would you choose?" Well, they always choose the "give me 6 months comfortable." It looks like the first time I mentioned [hospice] to him was on [date], once we had a definitive diagnosis. I told him that the decision that he needed to focus on next was whether he was going to pursue chemotherapy or go directly into a [non-hospice] palliative care or hospice approach.

At that point, Ken chose to pursue chemotherapy.

Victor's oncologist, Dr. G, described dosing difficult news this way.

The goal of that discussion is to first of all establish that this is where we are—that this will be a fatal illness. Second, to look at ways that we may change the trajectory of [the] course [of the illness], either for him to feel better or to live longer. And then, third, to move him and his family into a realistic mode as is reasonable with regard to those issues.

Dr. T, Mark's general practitioner, stated that he dosed hospice, giving small amounts of information over time, but typically waited until other options had been tried.

When I'm seeing we've kind of exhausted our resources and things [are] just getting no better, they continue to have whatever their issue is – exacerbation or decline. Then I . . . need to talk about that and say “hey, have you considered this [hospice]?” And talk about . . . “I don't see things improving. I'm not sure there are other treatment options that are going to alter the picture.” Sometimes I'll plant the seed and let them think about it and have a little exacerbation or two and then I may say, “you know . . .,” so they come back and totally change their point of view. 'Cause they do get tired of fighting.

Advice for Others Who Are Ill, Their Families, and Their Providers

For those who are ill, Victor stated it is important “to be able to speak up for yourself, to have an advocate.” Other patients and caregivers recommended possessing a strong faith. Rachel said, “I pray that they all accept what comes to them and be graceful with it.” Ken encouraged those who are ill to “make their peace upstairs.” Nina said,

Put your trust in the Lord and just have faith in Him. If the Lord don't want 'em to die, they're not gonna die. But if he's ready to take them home, make certain that they've accepted him as their Savior so that they will go home. They will meet again in heaven. And just get your ducks all in a row.

Mark believes “you gotta trust. He's the one takes care of you, actually.”

The advice to caregivers was more practical in nature. Liza's message to families was

if they can get on hospice or something like it, do it. It's . . . just a marvelous thing. Go ahead, do it, take what you can get. Get the help you need. It . . . doesn't

run the caregiver down to the ground you know. Going at both ends, it's better for the person too because they're better taken care of. I'd say go for it.

Lindy echoed, "hospice is wonderful, and use the services that are there." Anya

encouraged family members "you just really need to advocate for your loved one."

For providers, Dr. T stated it might be helpful

to reduce the reluctance to bringing [hospice] up. I mean, it's always kind of a tough zone to get into to know is it the right time for [the patient]. You know, medically you may feel it is. Emotionally, are they in a spot where they can understand and say "yeah, that's a good idea?"

NP E suggested it could be helpful to have education on hospice be "part of CMEs

[continuing medical education] for nurses or for doctors that once a year they need to

have something in hospice, something that is mandatory if you want to renew your

license."

Dr. G stressed for providers that the hospice "philosophy and team needs to be part of [the care of] everyone who has a fatal illness." He told a story.

I had a terribly ill acute leukemic patient who failed his treatment, and I got him a stem cell transplant which cured him, and he went to his doctor for his five year check-up. Last visit he got a clean bill of health, walked out, got run over by a truck. When I tell that story it's almost like it's ironic or you know it's the twist at the end that seems odd but, you know, we're all going to die, and we can be prepared or not prepared. So thinking about being prepared is probably more important than we give it credit for at the moment.

Jenny was emphatic,

Doctors can be more up front. I mean, we knew he was having problems and next thing we know this lady's coming in telling us he's gotta go on hospice if he wants to go home. I'm sitting here going "why hasn't this been discussed?" And then the doctors too, they use . . . big words that you don't understand.

Mark agreed, "Yeah. They could tell me that a long time ago. 'You got a terminal illness.

We can put you to this. You might live longer, you might not.' That's the gamble of life."

Discussion

For three of the male patients, the family member most involved in the decision to become a hospice patient was the spouse or significant other. The fourth male patient's caregiver was his sister. For the widowed female patient, the daughter was the most involved family member. In all cases the caregiver/family member was female. All patients and caregivers had some knowledge of hospice prior to being referred. Usually another family member or friend had had hospice care.

Rosenstock (2005) proposed the Health Belief Model that describes how an individual is moved to action to consent to a medical test, either to prevent or to detect an illness. The decision to consent to such a test is the result of an individual's readiness which is defined as how susceptible the individual perceives himself or herself to be to having the illness for which the test is required and how serious the individual perceives the consequences to be if the illness is contracted or found to be present. Achieving the necessary level of readiness is the result of a process of multiple events occurring and heightening an individual's awareness. The individual moves through stages of change that lead to a state of readiness. Once this readiness is achieved, a cue to action occurs which is an event that triggers the action required to move forward and consent to having the test performed (Rosenstock, 2005).

Rosenstock's model can be used to examine the process involved in becoming a hospice patient. Table 3.3 lists the stages of change leading to readiness and the cues to action (to consent to or recommend/refer to hospice care) for the study participants. Achieving the goal of support for the caregiver is the result of the cue to action in four triads. Patient goals are the result of the cue to action in two triads.

Table 3.3

Patient Readiness and Cue to Action

Patient	Stages of Change Leading to Readiness	Cue to Action	Result
Rachel	Husband died 23 years ago. Patient was 96 years old. History of multiple chronic illnesses. Hospitalization and rehabilitation in a nursing home. Increasing dependence on daughter at a time when daughter desired to spend time at her summer home some distance away from patient.	As recommended by rehab nurse, hospice would provide services and let patient stay at home. Requested to be referred to hospice.	Achieved patient and caregiver goal of staying at home. Achieved caregiver goal of additional support.
Paul	Multiple trips to hospital emergency department. Received AIDS diagnosis and family disowned him. Lived in nursing home before moving to current home with girlfriend. Multiple strokes led to increased debility and patient could not care for himself. If girlfriend did not take care of him he would need to return to a nursing home. Home health nurse unable to continue to provide services patient needed.	Agreed to hospice as suggested by home care nurse because he saw that caregiver girlfriend needed extra support and assistance caring for him. Requested to be referred to hospice.	Achieved caregiver goal of additional support.
Ken	Death of 14 year old daughter in distant past. Deaths of patient's parents. Spot on lungs discovered and monitored. Cancer suspected by general practitioner. Referred to specialist. Biopsy confirmed cancer diagnosis. Chemotherapy started but patient did not tolerate. Specialist stopped chemotherapy administration. Caregiver and other family members needed increasing support.	Specialist physician suggested he go home and get hospice.	Moved to next step on continuum of care. Achieved caregiver goal of additional support.
Victor	Fatigue and initial cancer diagnosis. Surgery. Metastasis of cancer. Several types of chemotherapy tried that did not work. Family friend suggested hospice. Caregiver knew she and their children needed help.	Last chemotherapeutic agent did not produce desired results.	Moved to next step on continuum of care. Achieved caregiver goal of additional support.
Mark	Diagnosis and multiple hospitalizations for exacerbation of symptoms. Physician had initial informational conversation with patient about hospice that patient did not recall and caregiver did not know took place.	Caregiver told him he should get hospice because she perceived the hospital physician said it was the only way he [Mark] could return home from the hospital.	Achieved patient and caregiver goal of going home.

In the five triads, only two (Ken's and Mark's) physicians initiated the discussion about hospice care. In one of these cases (Ken), neither the patient nor the caregiver recalled talking about hospice care before it was needed. In the other case (Mark), either the patient did not understand, did not recall or chose not to tell his caregiver about that initial conversation with his physician. As a result, the caregiver was angry that the first time she heard about hospice was when she felt it was presented as the only way the patient could return home.

In Ken's triad, the physician sent the patient and caregiver home with a recommendation to pursue hospice. They waited a few weeks and contacted a local hospice on their own. There was a several week delay between the referral and the admission to hospice care. In Mark's triad, the hospital physician referred the patient and family to a specific hospice and made the initial call to the hospice on their behalf, arranging for a hospice nurse to conduct an admission visit at the patient's home. In Mark's case there was no delay between the referral and the admission to hospice care.

In two of the remaining three triads (Rachel and Paul), health care professionals other than the referring provider initiated a discussion about hospice care. These were Rachel's rehab nurse and Paul's home care nurse. For both these patients, hospice represented a way for the patients to continue to live at home by providing support for caregivers Liza and Lindy. In Victor's triad, a family friend who had experienced hospice initiated the hospice care discussion. When Anya was asked about her opinion of hospice care before receiving it, Anya stated that hospice represented help and support for her and Victor. In Paul's and Victor's triads, the caregiver was moved to contact the provider and request a hospice referral.

In Ken's and Victor's triads, the entry point into hospice care was clear. Being admitted to hospice was the next step in the continuum of care when the last treatments for their cancers did not produce the desired results. In Rachel's, Paul's, and Mark's triads, hospice as the next step in the continuum of care is not as obvious. All three patients had non-cancer diagnoses. There is no clear entry point into hospice for these diseases.

Patients' and caregivers' discussions about the effects of the patients' illnesses demonstrate components of the explanatory model of illness which seeks to understand the individual's experience or perspective of the illness ("Techniques," 2005). An analysis of the tensions (Clandinin & Connelly, 2000) in the patients' and caregivers' stories displays additional examples of the explanatory model of illness. These are listed in Table 3.4.

Table 3.4

Tensions Among Members of Each Triad

Triad	Patient	Caregiver	Provider	Other
Rachel, Liza, Dr. N	Increasingly dependent on caregiver	As only child was responsible for patient but was torn between her duty to her mother and her desire to enjoy her summer home some distance away from the patient	Not applicable (NA)	NA
Paul, Lindy, NP E	Guarded in all discussions about patient's AIDS diagnosis		NA	Tension with author who was a stranger to patient and caregiver

Table 3.4—Continued

Triad	Patient	Caregiver	Provider	Other
Ken, Nina, Dr. S	Buried/compartimentalized feelings about daughter who died at age 14	Every conversation about dying patient was connected with the death of their 14 year old daughter	NA	NA
	Concerned that caregiver's short term memory was becoming impaired	Might or might not be aware of problems with short term memory	NA	NA
	Concerned for caregiver's financial wellbeing after his death	Did not discuss or might not be aware of potential financial hardship after patient's death	NA	NA
	Concerned that he will be 'man enough to take' any suffering that might be connected to his death	NA	NA	Disease that might produce suffering
Victor, Any, Dr. G	Determined to live as fully as possible in time remaining to him	Frustrated with patient when he is unrealistic about abilities	Sometimes called on by caregiver to convince patient to be realistic about abilities	NA
Mark, Jenny, Dr. T	Initially unaware of terminal nature of patient's illness		Provider unknown to patient and caregiver initiated first discussion about hospice care that both patient and caregiver heard	NA
	Did not always understand what provider was attempting to communicate. Blamed provider for not being more clear, especially about patient's prognosis		Communicated prognosis to patient and was unsure how or if patient understood. Caregiver not present for this discussion.	NA

The results of an analysis of the interruptions (Clandinin & Connelly, 2000) in each of the patients' and caregivers' stories afford yet another glimpse at the personal experience these individuals had. Table 3.5 lists these interruptions. Two patients and caregivers (Rachel & Liza and Paul & Lindy) experienced interruptions in their stories some time before hospice care ever became an option for them. For the remaining patients and caregivers, the eventual admission into hospice care was itself the interruption in their stories.

Table 3.5

Interruptions in Patients' and Caregivers' Stories

Triad	Interruption
Rachel & Liza	Patient unable to continue to enjoy activity of participating in sewing group for veterans.
Paul & Lindy	Patient diagnosed with AIDS (patient interruption). Taking very ill patient into home (caregiver's interruption).
Ken & Nina	Chemotherapy did not produce desired results. Realization that treatment aimed at cure was now to be replaced with treatment aimed at comfort.
Victor & Anya	Enjoyed 3 years without symptoms, then learned the cancer had metastasized. Led to admission to hospice care.
Mark & Jenny	Physician unknown to patient and caregiver discussed hospice care, and this was how patient and caregiver learned of terminal nature of patient's illness. Led to admission to hospice care.

Place, personal voices, and social voices were analyzed together (Clandinin & Connelly, 2000). All patient and caregiver interviews occurred at or inside their homes. The voices in their stories are personal. The stories they told and the feelings they felt were real and poignant as evidenced by the discussions about the effect of the illness and their advice to others who are ill, their caregivers and their providers. Their stories were

about life, love, fear, and trust. Their lives will be personally affected by the eventual death of the patient.

The author interviewed four providers in their offices and one on the telephone who called from his office. The providers' voices are social. Their relationships with their patients and the caregivers as well as their concerns were professional. This is also evidenced in the findings about dosing hospice, i.e., giving small amounts of information about hospice at a time. All providers discussed the importance of talking about hospice with their patients early and often, but in all five triads, neither the patients nor the providers recall this occurring. Also noteworthy is the fact that there is more advice for providers than there is advice to others who are ill and their caregivers. Last, the nurse practitioner's comments were more general in nature and less about her perspective of the experience of the patient and the caregiver. She was the only provider who did not follow the patient into hospice care because the hospice's medical director assumed responsibility for managing the patient's care on his admission.

The temporal nature (Clandinin & Connelly, 2000) of the patients' and caregivers' stories was similar in many respects. With regard to the past, most of the interviews focused on the experience of the illness. Some participants also discussed deaths of other loved ones. Discussions about the present fell into three major categories: controlling symptoms of the illness, accomplishing tasks while that was still possible and concurrent struggles. Talk about the future for patients was about going to heaven and hoping for a good life for their loved ones without them. Future talk for the caregivers centered on missing their loved one after his or her death.

The stories of the five triads were also analyzed regarding plot structure, content, and purpose (Hays & Singh, 2012) to view each story in a larger framework. These results are displayed in Table 3.6.

Table 3.6

Stories of Five Triads Analyzed According to Plot Structure, Content, and Purpose

Triad	Plot Structure	Content	Purpose	Larger Framework
Rachel, Liza, Dr. N	Revolved around tension of Rachel's increasing dependence and Liza trying to meet her own needs	Emphasized the positive experience of hospice care. It helped solve the major tension they experienced.	Showed faith as the lens through which the patient lived and told her story	Hospice was not simply about death and dying but was, rather, about quality of life.
Paul, Lindy, NP E	Revolved around the patient's illness, particularly his AIDS diagnosis	Expressed carefully in a guarded fashion.	Protected the patient.	Dark, heavy and oppressive. Patient might not ever recover from family's estrangement.
Ken, Nina, Dr. S	Revolved around stories of the past.	Connected past to present and future in concerns about caregiver after patient's death and patient's ability to handle potential suffering.	Reassurance that caregiver will thrive and that patient had resources to help cope with suffering.	The holistic nature of hospice care might help address concerns and bolster feelings of reassurance.
Victor, Anya, Dr. G	Revolved around patient's illness and all the stages he has experienced.	Focused on relationship between patient and caregiver—that they valued each other and have created a loving family.	Emphasized patient's attempt to live life as fully as possible and support caregiver provides to accomplish this.	Love provides the strength to carry on.
Mark, Jenny, Dr. T	Learning that patient's illness will reach and had reached the terminal stage	Emphasized interdependence of patient's and caregiver's relationship.	Importance of hospice to help patient achieve the goal of living comfortably at home.	Important that physician speak early on about prognosis in a simple and candid fashion so patient and caregiver can make plans.

Recommendations for Future Research

The experiences of these five triads offer many considerations for future research on how best to link a patient and his or her caregiver with the resources and support they both need in the patient's last months of life. The first category of research considered is about communication, either the way something is communicated or to whom it is communicated. Despite a provider initiating a conversation about hospice, the patient and caregiver do not benefit from the conversation if they do not recall or understand it. It is not uncommon for patients to not remember the details of difficult news they receive from their provider (Gabrijel et al., 2008). One topic of future research might be to study the effect of a provider presenting a brochure or other written information tailored to a patient's illness. Giving the patient and caregiver something to take home and read once they were in the proper frame of mind to absorb the information might be of great benefit. Ken's and Nina's transition to hospice care might have felt more comfortable to them if they had read about it prior to Ken's needing it.

Research on checking the recall and understanding of the patient and caregiver might benefit as well. In addition to communicating verbally, human beings also communicate non-verbally with, for example, eye contact, body posture and silence, all of this occurring within the context of culture and all of which influence meaning of the message as it is received (Finset & Piccolo, 2011). After providing information about hospice, a provider could simply ask a patient or caregiver to tell him/her what they understand about the hospice information the provider gave them. Jenny knew her brother had CHF but she did not know what the eventual outcome would be for him. A

provider checking her understanding could have helped to avoid her later confusion and anger.

Another topic for future research is the effect of the provider mentioning hospice care at every visit as an option for the patient and caregiver to consider. Discussing hospice might be less stressful each time the provider initiates the conversation, and it might serve to help the provider, patient and caregiver make a joint decision about when the time is right to bring in hospice care.

Saying or implying there is nothing more that can be done for a patient when curative care does not produce the desired result ignores the field of palliative medicine⁸, certified by the American Board of Medical Specialties in 2006 (ABMS, 2006). Hospice care, or palliative care at the end of life, treats a patient until he or she draws the last breath and then provides grief support for the family after the patient's death (NHPCO, 2014b). Although none of the providers literally said "nothing more could be done," one patient (Ken) remembers only that the physician said "if I were you, I'd go home and get hospice." It was a marked and somewhat rocky transition for Ken and Nina that might have been more seamless had they perceived hospice being presented with more of a sense of hope for ongoing quality of life. Future research could analyze the potential impact of specialized training on having the conversation about the transition from non-hospice palliative care to hospice care. Training could include preparing the patient with a "warning" sentence (Lee, Back, Block, & Stewart, 2002), asking open-ended questions, using non-verbal communication and being comfortable with silence (Levetown, Meyer, & Gray, 2011). A provider might want to discuss his or her willingness to continue to

⁸ Palliative medicine includes hospice medicine and hospice care (CAPC, 2014).

follow the patient on the palliative care journey (Sweeny, 2009). Learning how to end a conversation with good news such as “hospice will help you live comfortably” might also be helpful (Leydon, 2008).

Most patients who will eventually qualify for hospice care will become unable, at some point, to make their own decisions (Silveira, Kim, & Langa, 2010; Wendler & Rid, 2011). Future research could include the study of presenting information simultaneously to that individual’s durable power of attorney for health care and/or his or her caregiver. All caregivers included in the current study were also the Durable Power of Attorney for Health Care for the patients.

The second category of research opportunities relates to the role or influence of the caregiver. In the triads where the caregiver initiated the hospice referral, the provider might have underestimated the burdens shouldered by the caregiver that hospice care could help alleviate. A provider’s emphasis on the patient and his or her disease process might eclipse the needs of the caregiver. Future research could analyze the effect of attention a provider gives to the caregiver’s journey of providing increasing care just as he or she monitors the progression of the patient’s journey toward end of life.

Although none of the provider study participants mentioned not being sure of when to initiate a discussion about hospice or when to refer to hospice care, three of the five caregivers were ready for hospice support before the provider discussed it. If the provider presents information about hospice care long before the patient qualifies for it, he or she could reduce the chance of missing opportunities for support to both the patient and caregiver. Future researchers could analyze the effectiveness and impact of a uniform point at which hospice is introduced: perhaps at the point of diagnosis, or the first or

second visit after the diagnosis. A uniform initiation point might be especially helpful in cases involving non-cancer diagnoses. It might also eliminate or least reduce pressure on the provider to determine the appropriate time to initiate the conversation.

This is similar to the U.S. Patient Self Determination Act of 1990 (PSDA) in which federal law requires that providers such as hospitals, skilled nursing facilities, home health agencies and hospices provide information about advance directives to their clients (PSDA, 1990). A requirement to mention hospice at a certain point could help keep it top of mind and might be less jarring to the patient and caregiver when it is eventually discussed for immediate use. Training providers to learn how to have this conversation could include continuing education units. Perhaps the training could be required continuing education for providers similar to pain and symptom management training being required for Michigan nurses (Continuing Education Requirements for Michigan Nurses, 1978) and ethics training being required for Michigan social workers (Continuing Education Requirements for Michigan Social Workers, 1978).

A patient and his or her caregiver have goals (Whellan et al., 2014). Initially, the goals might involve attempts at curing the disease; later in the disease process, the goals might include managing the symptoms and sustaining comfort to the patient's and/or the caregiver's satisfaction (Dev et al., 2013; Holland, Keene, Kirkendall, & Luna, 2014). Future researchers could analyze the difference it might make if a provider helps a patient and caregiver verbalize their goals and create a plan of care to which all agree. This might help avoid jarring surprises later in the patient's care.

Another potential avenue for future research is to create opportunities for a provider to see or experience more of the personal story of his or her patient and that

individual's caregiver. When a patient and caregiver visit a provider in the latter's office or examination room, they are experiencing the provider's arena. If the provider (or other health care professionals who give information to the provider) visited patients and caregivers in their homes, perhaps the information they would glean could help a provider to tailor his or her message to meet the patient's and caregiver's needs for simplicity and candor.

Many of the preceding recommendations for future research presume an ongoing relationship between provider and patient/caregiver. Trust that is built in a relationship over time lubricates difficult discussions (Lykke, Christensen, & Reventlow, 2011). Mark's experience of being referred to hospice involved a provider he had never met before. Medical care is frequently provided to an individual in crisis by someone working a shift at a hospital, an emergency department or an urgent care center (Meth, Bass, & Hoke, 2013; Pollock, 2002; Smith-Coggins, Broderick, & Marco, 2014). The patient might be seeking medical help because he or she is in crisis. This is a challenging scenario for a first conversation about hospice care (Lamba, Bonanni, Courage, Nagurka, & Zalenski, 2013). A discussion about hospice at the time of diagnosis might help a patient and caregiver avoid learning about hospice during a period of crisis when anxiety might be peaking.

In this study, four of the patients and caregivers were approached about hospice care by someone who was not the primary care provider. Future research might include a look at the role of non-provider health care professionals in initiating a discussion about hospice care.

The foregoing recommendations for future research assume no change in the current parameters of the health care system in the United States regarding hospice care. Hospice is a 6-month benefit; the physician or NP might refer an individual to hospice care only when the physician or NP believes the patient has a prognosis of 6 months or less (Title XVIII, Health Insurance for the Aged and Disabled, Sec. 1812). It is likely, however, that patients and their families will continue to struggle with the probability that the patient will die within 6 months, particularly as new drugs and experimental trials create hope for extending life beyond what a physician might prognosticate (Waldrop, 2006).

A solution to this problem might be to offer non-hospice palliative care to a patient before she or he becomes eligible for or instead of hospice care. Non-hospice palliative care, also comfort-oriented in nature but not relegated only to patients in their last 6 months of life, would help a patient achieve the best possible quality of life and would provide support for the family without the 6-month timeline attached to the patient's life expectancy (National Cancer Institute, 2010). Compared to acute or curative care, patients in palliative care programs tend to enjoy a higher quality and longer length of life, less depression, a lower intensity of symptoms of their illnesses (Bakitas et al. 2009; Temel et al., 2010). The Institute of Medicine (2014) also recommends palliative (hospice and non-hospice) care as presenting the best opportunity for both patients and their families to experience "the highest possible quality of life for the longest possible time" (p. 5).

When a non-hospice palliative care patient becomes appropriate physiologically and emotionally for hospice care, the transition to hospice care would likely occur earlier

and in a “softer” manner, particularly if the same team providing non-hospice palliative care continues to serve the patient and family for the remainder of the patient’s life (Hill & Hacker, 2010). The care would not change. The only difference would be that the Medicare, Medicaid, or insurance benefit would pay for all costs associated with a hospice patient’s diagnosis, relieving the patient and family of the burden of these expenses (NHPCO, 2014a). The holistic nature of palliative and non-hospice palliative care also lends itself well to research on the role of health care professionals who are not providers.

In the U.S. health care system, as it is currently structured, the reimbursement for non-hospice palliative care services is minimal, limiting the motivation of providers to offer non-hospice palliative care to individuals with advanced cancer and other chronic conditions (Smits, Furletti, & Vladeck, n.d.). As a result, most patients and their families do not receive the physical, emotional and spiritual comfort from suffering that the palliative care and non-hospice palliative care teams (physician, nurse, social worker and chaplain) provide (National Institute of Nursing Research, 2009). The earlier use of non-hospice palliative care services is an important avenue for future researchers to explore.

Limitations of the Study

Most of the study participants lived or worked in small towns in Michigan’s western Lower Peninsula. To protect their identities, we omitted or generalized some descriptive details and changed names.

Conclusion

Through an examination of the experience of five hospice referrals from the patients’, the family member caregivers’, and the providers’ perspectives, the author

illuminated some of the issues of communication among the three roles as well as the often underestimated influence and needs of the caregiver that might help explain the relatively short national median length of stay in hospice care compared to the length of the available benefit. Treating a life-limiting illness whether through a curative or a palliative approach, and living as a patient or a caregiver with a life-limiting illness both have unique challenges and complications. Several recommendations for future research are presented, particularly the development of reimbursed non-hospice palliative care programs, with the hope that ultimately patients and families will benefit from increased support in the last months of life.

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CHAPTER IV

**FEARS, HOPES, AND SOURCES OF STRENGTH EXPRESSED BY HOSPICE
PATIENTS, CAREGIVERS, AND PROVIDERS AND
HOW THEY INFORM CARE**

Introduction/Background

In health care, patients may be labeled with terms such as non-compliant, uncooperative, or manipulative (Hills, 2012) or be referred to by their diagnosis or surgical procedure (Cohen, 2012; Groopman, 2005). Family members accompanying a patient may be considered only in relation to the person receiving care or what is required to manage members of the family (Clissett, Porock, Harwood, & Gladman, 2013). The clinician following the patient may be expected to be an instrument of administrative efficiency at the expense of providing care that is relational or patient-centered (McCrae, 2013). These reductionist perspectives often ignore the humanity of the patient, the family, and the health care provider (Tian et al., 2014).

An individual who is also a hospice patient is foremost an individual. He or she has a terminal illness with a 6-month prognosis (National Hospice and Palliative Care Organization [NHPCO], 2014), but until death, the individual is alive, living with hope and fear, and finding strength to persevere despite having a life-limiting illness (Gessert, Baines, Kuross, Clark, & Haller, 2004). Family caregivers are also individuals with hopes and fears who find strength to live in relationship with a very ill loved one (Angelo & Egan, 2014). Physicians and other providers are human beings with their own hopes and fears who may require strength to have difficult conversations with others (Bernard, de Roten, Despland, & Stiefel, 2012; Pergert & Lutzen, 2012).

In a separate qualitative research study about the experience of a hospice referral, five hospice patients, their family member caregivers, and their referring providers were interviewed. Questions were asked to explore whether, after accepting hospice care, hope was maintained, whether fear existed, and what were the unique strengths that may have affected hope and fear. Contextual data were collected from participants about what they feared or were concerned about, where their strength or courage came from, and what they hoped for. Data gathered about fear, strength or courage, and hope in the five patient-caregiver-physician triads were rich and called for a separate in-depth examination, which is the focus of this paper.

The definition of *fear* is “to be afraid of” or “to worry about” (Merriam-Webster, 2014a). Among terminally ill individuals and their family member caregivers, prior research has found that fear can involve the manner and location of death (Broom & Cavanagh, 2010, 2011; Clarke, Korotchenko, & Bundon, 2011; Khalili, 2007; McSherry, 2011; Proot et al., 2003), the effect of the trajectory of the illness (Lowey, Norton, Quinn, & Quill, 2013; McSherry, 2011), the experience of end of life symptoms, side effects of medications, living with a terminal illness (Berry & Ward, 1995; Casida, 2005; Hauser et al., 2006; Kerr et al., 2014; Kwon et al., 2012; Lowey et al., 2013; McTiernan & O’Connell, 2014; Mok, Chan, Chan, & Yeung, 2003; Selman et al., 2007; Sethi & Williams, 2003; Vellone, Sansoni, & Cohen, 2002; Wess, 2007) and dwindling financial family resources (Hauser et al., 2006).

Among health care providers who work with terminally ill individuals, according to prior research, there may be a fear of death, of failing or of using narcotics to treat symptoms prior to death (Laroche, Rodriguez, Arnold, & Barnato, 2009; Merrill, Dale,

& Thornby, 2000; Spitz et al., 2011). For providers with hospice patients, alleviating fear and suffering may include the use of humor or terminal sedation (Anquinet et al., 2014; Ridley, Dance, & Pare, 2014).

Strength means “the ability to resist being moved or broken by a force” (Merriam-Webster, 2014c). End of life brings disease progression, loss of control and growing dependence on others (Kasl-Godley, King, & Quill, 2014). Suffering of terminally ill loved ones may cause distress in family member caregivers (Schaller, Liedberg, & Larsson, 2014). For some patients and caregivers, faith and prayer may provide strength and direction (Schneider & Kastenbaum, 2001). Among palliative care professionals, caring for one’s own spirituality is considered a component of good care (Vermandere, et al., 2013). Strength may also come from knowledge that others have experienced a similar difficult path of illness (Koopmeiners, 1997).

To *hope* is “to want something to happen or be true and think that it could happen or be true” (Merriam-Webster, 2014b). In the society of the U.S., the existence of hope is sometimes presented as the source of miracles that cure terminal illness (Tulsky, 2002). Some individuals may believe that choosing hospice care is a sign of giving up hope (Ford, Neitert, Zapka, Zoller, & Silvestri, 2008). Hope is more than thinking one might survive an illness. Themes of hope among ALS patients include hope for social support, for more information; hope for being as little of a burden on others as possible and to be able to adapt as abilities change with disease progression; spiritual hope, and the abilities to live in the moment as well as to transcend the self (Fanos, Gelinas, Foster, Postone, & Miller, 2008). One may also hope for a life without pain (Li, 2000) or for support in caregiving (Locock & Brown, 2010). Hope for the future can be directed toward the lives

of those one loves (Buckley & Herth, 2004) or may be present in a vision at the end of life such as seeing deceased family members (Fenwick, Lovelace, & Brayne, 2009). The generation of hope may come from spiritual care (Edwards, Pang, Shiu, & Chan, 2010), from the steady presence of a physician (Li, 2000), from feeling worthy in a relationship (Buckley & Herth, 2004), or from the receipt of information that a health care provider delivers candidly yet respectfully (Koopmeiners, 1997). Hope may help preserve quality of life (Mitsumoto & Del Bene, 2000).

Although experiences of terminally ill individuals and their personal and professional caregivers have been analyzed, no study was found that explores fear, strength, and hope from the perspectives of the hospice patient, his/her caregiver and his/her provider. Five triads were analyzed in this study. The first research question is, what are the fears, hopes, and sources of strength expressed by hospice patients, their caregivers and their referring health care providers? The second research question is, what can these responses inform our understanding of and the care provided to patients and their caregivers?

Methods

Data from a previous qualitative research study were analyzed. HSIRB approval for the triad study was obtained from Western Michigan University. Participants were asked “What do you fear?”⁹ “Where does your strength or courage come from?” and “What do you hope for?” The data were analyzed using a narratological approach. The stories’ threads, layers, and directions were viewed through the lens of movement or

⁹ Patients and caregivers were asked what they fear. Providers were asked what they were concerned about.

travel (Clandinin & Connelly, 2000). These personal stories revealed information about the end of life experience that may positively influence end of life care (Hayes & Singh, 2012).

Study rigor was supported by double coding the data to ensure consistency of category definition (Krefting, 1991). Researcher reflection on the experience, the use of field notes, and peer analysis also increased the trustworthiness of the research (Baxter & Jack, 2008).

Findings

Interviews were conducted for another research project by the researcher between September 2013 and July 2014. All research participants lived or worked in Michigan's western Lower Peninsula. A brief contextual description of each patient-caregiver-provider triad follows.

Rachel, Liza, and Dr. N

Rachel was a 96-year-old widow with a hospice diagnosis of debility. She lived alone with her beloved small dog in a mid-sized city. Throughout the interview, Rachel stated repeatedly that she was happy, noting that she had always been a loner. She commented on having lived a long life, much of it in her current home and, prior to that, in the house next door. Friends and hospice volunteers visited her regularly. Liza, Rachel's only child, and her husband lived during the summer months on a lake south of Rachel's home. Before Rachel's health prevented her from leaving the house, Liza and Rachel used to go to a sewing circle and work with others on projects for veterans. Liza laughed frequently throughout the interview. She was appreciative of hospice because it allowed her and her husband to live some distance away without worrying about Rachel.

Oncologist Dr. N's brief but comprehensive interview took place in a conference room in her office suite in the same city in which Rachel lives. Dr. N was warm and shared readily but never seemed to completely relax during the conversation. She was a young physician who had already acquired the ability to speak with her patients about the life-limiting nature of their illnesses.

Paul, Lindy, and Nurse Practitioner E

Paul was in his 40s and lived with his girlfriend Lindy and her family in her home. His hospice diagnosis was stroke. Unable to speak, he communicated by typing his responses to interview questions into a laptop computer. Paul was diagnosed with acquired immune deficiency syndrome (AIDS) 13 years ago. He stated he had contracted this disease from his former wife. Until 5 months prior to the interview, Paul lived in another state in a nursing home where he had been placed by his father and his stepmother. His entire family was estranged from him and, according to Paul, "wanted [him] dead" because of his AIDS diagnosis. After moving into Lindy's home, he and she kept from her family the fact that Paul had AIDS, referring to it only as his illness. Paul neither joked nor smiled during the interview. He stated his pain was relieved by medication but added that nothing brought him emotional or spiritual relief. At the conclusion of the interview, when asked if he had any other comments, Paul responded with, "Think before doing" and added that he had much regret. Paul and Lindy had been together for 5 months. After getting to know Paul through telephone conversations, Lindy agreed to care for him in her home. Paul referred to her as his girlfriend. Lindy also did not smile or laugh during the interview. She described being a caregiver as scary and frustrating and that she experienced feelings of helplessness. She stated that Paul's illness

was “not his fault.” Nurse practitioner (NP) E was interviewed in her office which was part of a hospital system in a mid-size city. Her responses to the interview questions were thoughtful and lengthy. She laughed easily and frequently throughout the interview, told stories to illustrate her points and seemed to enjoy the discussion.

Ken, Nina, and Dr. S

Eighty-nine-year-old Ken was a congenial story-teller. He laughed and made jokes frequently throughout the interview and appeared to enjoy having an audience. His lung cancer seemed to be an inconvenience to him. Ken was hard of hearing and interview questions had to be repeated frequently. Ken and Nina were married for decades. Nina was a quiet woman who became emotional when she talked about her husband and a child who died at the age of 14. With self-deprecating humor regarding her tears, Nina laughed when she said she was stronger than Ken and all her friends. She was grateful for the care she and Ken received from hospice. Stories about family members dominated both of their interviews. Pulmonologist Dr. S practiced medicine for approximately 25 years and was interviewed in his office in a town approximately 45 minutes away from where Ken and Nina lived. He was thoughtful and unhurried and appeared genuine in his expression. His answers to the interview questions were lengthy. He stated he was very familiar with and appreciative of hospice care.

Victor, Anya, and Dr. G – Context

Victor was in his 70s. He was a calm man, a retired pastor who seemed to radiate peace. He referred to the symptoms he experienced from his illness as inconveniences. Victor stated he was optimistic that his physician would find a way to “beat” his cancer. He joked easily during the interview and described his 50-year marriage to Anya as

“great.” Victor’s wife Anya had been his champion throughout his experience with renal cancer. She too laughed easily and described herself as “the mother and grandmother of all times.” She called Victor “incredible” and stated she is grateful for the decades they have shared together. Oncologist Dr. G was interviewed over the phone. He was thoughtful, articulate, and sober in his responses to the interview questions. With more than 30 years of experience in his field, he had cared for Victor for several years and seemed to know both Victor and Anya well.

Mark, Jenny, and Dr. T – Context

Mark was in his 70s and had both chronic obstructive pulmonary disease (COPD) and congestive heart failure (CHF). He did not know the names of either of his diagnoses but was able to describe his uncomfortable symptoms in great detail. When he was not resting or taking a breathing treatment, Mark worked on projects around their home. He laughed easily at himself and enjoyed teasing his sister and caregiver, Jenny. Jenny was the younger of the two and called Mark “Brother.” In addition to caring for Mark, Jenny also cared for Mark’s son who had Down Syndrome. She was articulate and enjoyed joking with the interviewer. Mark and Jenny appeared to live frugally. Dr. T had been Mark’s physician for years and appreciated what hospice provided for his patients. He stated he was very familiar with the local hospice. He was interviewed in his office which was located approximately 30 minutes from where Mark and Jenny live.

Fear/Concern

“What are you afraid of?”¹⁰ elicited answers related to the patient’s mortality and the caregiver’s coping. In direct response to the question, some study participants denied being afraid; however, some fears were described in answers to other questions.

Among the patients, Rachel discussed having a pain in her side and being concerned it was a heart attack. She did not report it to her hospice RN but rather waited until the next day when Liza came to see her. Liza called the hospice RN who instructed Rachel to take acetaminophen which alleviated the pain. Liza then stayed with Rachel most of the day. Paul’s fears were also connected to his physical health, “Just times when not knowing if I’ll get up the next day plus [being] wheelchair-bound the rest of my life.” Ken first stated, “I don’t know as I’m afraid of anything,” and later talked about hoping his death would not cause him to suffer. “I just hope that when it’s time to go that I don’t suffer too bad.” Victor’s fears were primarily related to his family, “I’m afraid of . . . you know, just . . . her [his wife] being without me.” He also described a fear that was more existential,

I keep pushing off doing some of the things I need to do in terms of going through all my books and papers I’ve written. I’ve got a ton of papers that related to my ministry that I’m never gonna use anymore. Nobody else is gonna use anymore but it’s stuff that’s been important and uh . . . I keep thinking well, maybe someone . . .

Mark discussed not wanting to burden his sister by not completing household projects before he died. In direct response to the question about what he feared, Mark replied,

¹⁰ Patients and caregivers were asked this question. Providers were asked “What, if anything, are you concerned about?”

I ain't afraid of anything anymore. I was [afraid of] dying like everybody else. [The hospice] minister come over and talk to me . . . just talking and explaining what's what . . . the way I could understand it. . . . These words in the Bible.

Some caregivers' responses were disease-related and others were connected to the relationship with the person who was dying. When directly asked about fear, Liza (Rachel's daughter) stated she was not afraid. "We go to the Salvation Army. When somebody dies we call it 'promoted to glory,' and to us it's a good thing." Liza did, however, fear her mother's fragility would one day cause her to fall and break a hip. She appreciated hospice now because it permitted her mother to stay home. Lindy's concerns related to Paul's eventual death. "I don't want him to suffer when it's his time . . . and that's the thing I fear the most . . . is that he's gonna suffer . . . and I don't want to see that." Nina stated that she thought "it was a very scary point" for Ken when his physician mentioned hospice. For herself, Nina feared "how lonely I'm gonna be." Anya's fear was very similar, "Oh, I'm so afraid of him [Victor] not being here." Jenny did not want Mark to die "too soon." She stated that "being without Brother would be very hard . . . he helps me fix stuff."

NP E's concerns were more global and related to the "lack of education about hospice." The other providers' concerns were about their patients. Dr. S wanted

him [Ken] to be able to live at home with his family and his loved ones around him and maintain as good a quality [of life] as long as he can. And when his time comes, I want that to be peaceful and dignified and simple and quick.

Dr. G commented on Victor's struggle with being realistic about his abilities. Dr. T stated minimal concern because hospice was present for Mark.

Strength or Courage

“Where does your strength or courage come from?” elicited answers from patients and caregivers about faith and family. Rachel said, “I believe that the Lord’s watching over me.” Her daughter Liza’s response was simply, “God.” Paul’s strength came “from Lindy and her family”; Lindy also replied, “My family.” Ken’s answer was “the Almighty.” His wife Nina replied, “My faith in God.” She quoted the Bible, “‘I will not leave thee nor forsake thee,’ and He hasn’t. I’m almost 77 years old, and I don’t think he’ll give up on me now.” Victor’s answer was, “From our faith [and] a great marriage.” Anya said, “Oh, definitely from God Almighty . . . and from Victor.” Mark’s strength came from his projects. “If I wasn’t doing nothing, I don’t think I’d be around.” His sister Jenny’s response was brief and certain, “God.”

Most of the providers’ answers were similar. Dr. N, Rachel’s physician, replied, “My family.” NP E, Paul’s provider, explained, “From God. . . . When I’m going to see a patient, usually I pray ‘Lord, help me be a healing influence for this person.’” Ken’s pulmonologist Dr. S replied, “My Christian faith.” Mark’s physician Dr. T’s response was, “My faith in people. . . . My Christian faith to some extent . . . and [being] convinced I can make a difference.” Victor’s physician Dr. G stated, “My strength comes from I know how to do this [work].”

Hope

“What do you hope for?” was the third question. Rachel wanted “to go to heaven. I want to go home.” Paul hoped that for the time he has left he is able to “do what I can from the wheelchair.” Ken’s first response was out of concern for Nina . . . “that she’s going to be able to . . . exist after I’m gone. . . . She has got her own problems.” For

himself, Ken stated, “I just hope I ain’t in a lot of pain . . . hope I’m man enough to take it.” Victor was “still hoping for a magic bullet” as well as a “peaceful transition and strength for my wife . . . and the kids.” Mark hoped for “a longer life” and to “get things done . . . so she (Jenny) don’t have to worry about anything.”

Without hesitation, all caregivers responded that they hoped for the best for their loved ones who are dying. Liza (Rachel’s daughter) wanted “her to be happy and comfortable.” She also stated, “I want “her passing [to be] peaceful.” Lindy, Paul’s girlfriend, hoped “he doesn’t suffer.” For Ken, Nina hoped “that he don’t suffer.” She also stated, “I’d like to say [that] I go before him but I know that’s not fair because I’m the stronger one of the two.” Anya’s hope was simply “for the magic bullet, just like [her husband] Victor.” Jenny’s hope for her brother Mark was to “keep him comfortable. Keep him as active as he wants to be.” Jenny’s hope was consistent with Mark’s desire to “get things done.”

For Rachel, Dr. N hoped “that her wishes are respected, her symptoms are well-managed and her family receives support.” NP E hoped “that we [providers] can get more education about hospice.” Dr. S stated, “I try not to project my values too much onto them . . . I just want for my patients what I would want for myself and that’s family, loved ones, and [being at] home.” Dr. G hoped for Victor “that his pain will remain well controlled ’til the end.” He also voiced some concern about Victor’s wife Anya. “I’m not convinced that his wife is going to do very well afterwards . . . [despite her faith, she may] very well start to feel like there wasn’t comfort there that [she was] counting on.” Dr. T was succinct in his hopes for his patient Mark, “that he has a sense of peace . . . with the remainder of his life.”

Discussion

Fear, strength, and hope were manifested among all the study participants in some form. Answers to the first research question, what are the fears, hopes, and sources of strength expressed by hospice patients, their caregivers, and their referring health care providers, are discussed first. Following this is an exploration of the second research question: how this information might inform our understanding of and the care provided to patients and their caregivers.

Fears, Strength, and Hopes

The fears and concerns expressed by patients, caregivers, and providers are listed in Table 4.1 according to whether they relate to physical, emotional, social, or spiritual dimensions of life. The fears and concerns are further categorized as relating to the period before or after the death of the patient.

Most (9) of the fears/concerns listed relate to the physical dimension of the patient; all fears in this category are pre-death concerns. Two fears are emotional, and both are classified as pre-death. Of the six social fears/concerns listed, five are post-death and one is pre-death. Two of the three spiritual concerns are post-death, and one is pre-death. Patients and caregivers expressed fears in all four categories; however, no providers expressed emotional or spiritual concerns. Additionally, no providers expressed post-death concerns.

Table 4.1

Fears/Concerns of Hospice Patients, Their Caregivers, and Their Providers

Physical	Emotional	Social	Spiritual
Rachel – heart attack (B)	Paul – not knowing if he'll get up the next day (B)	Mark – not completing projects and burdening Jenny with them (A)	Victor – no one will see or use papers he wrote (A)
Paul – being wheelchair bound rest of life (B)	Nina – that she will see Ken suffering (B)	Nina – that she will be lonely after Ken's death (A)	Mark – dying (until minister interpreted Bible in a way that comforted him) (B)
Ken – suffering (B)		Jenny – hard to be without Mark because he helps her by fixing things around the house (A)	Liza – not afraid because Rachel will be 'promoted to glory' after death (A)
Liza – Rachel might fall and break a hip (B)		NP E – lack of education about hospice ^a	
Nina – Ken will suffer (B)		Victor – Anya being without him (A)	
Dr. S – for Ken's death to be peaceful, dignified, simple, quick (B)		Anya – of Victor not being here (A)	
Dr. T – minimal concern for Mark because hospice present (B)		Dr. S – Ken to live surrounded by loved ones (B)	
Dr. G – Victor not realistic about his abilities (B)			
Dr. S – Ken to have good quality of life for as long as possible (B)			

Note. □ Patient; □ Caregiver; ■ Provider. (B) – before death; (A) – after death.

^a NP E's concern about the lack of education about hospice is macro-oriented and not specifically related to the patient or caregiver. She is the only provider who did not follow the patient into hospice care.

Sources of strength are listed in Table 4.2 and are categorized according to physical, intellectual, social, and spiritual dimensions. All but two entries are categorized as either social (6) or spiritual (10). Mark's response is listed in the physical category. It

is likely, however, that his accomplishing household projects fill him with a sense of purpose (making the activity spiritually driven) as well the knowledge that he is helping his sister (making the activity socially driven as well). Dr. G's response is listed in the intellectual category. His knowing how to do the work he does may also be considered as faith in his abilities. This response may have been a more professional (as opposed to personal) answer. Patients, caregivers, and other providers all had responses listed in the social and spiritual categories.

Table 4.2

Sources of Strength for Hospice Patients, Their Caregivers, and Their Providers

Physical	Intellectual	Social	Spiritual
Mark (P) – doing something [household projects]	Dr. G (Pr) – I know how to do this [work]	Paul (P) – Lindy's family	Rachel (P) – the Lord
		Lindy (C) – family	Liza (C) – God
		Victor (P) – great marriage	Ken (P) – the Almighty
		Anya (C) – Victor	Nina (C) – faith in God
		Dr. N (Pr) – family	Victor (P) – our faith.
		Dr. T (Pr) – faith in people	Anya (C) – God Almighty
			Jenny (C) – God
			NP E (Pr) – God
			Dr. S (Pr) – Christian faith
			Dr. T (Pr) – Christian faith

Note. □ Patient; □ Caregiver; ■ Provider.

Tulsky (2002) discusses two kinds of hope. The first is based on trust (for example, in God) or reliance (for example, on family or friends) that the best possible outcome will happen. The other kind of hope is based on the expectation that the hope will be fulfilled. There are two kinds of “expectation fulfillment” hopes: rational and irrational. The hope is rational if the outcome is very likely to occur. The hope is irrational if it is not likely to occur but is hoped for despite poor odds. An irrational hope is typically connected with faith. Miracles may be believed to be created from the presence of this kind of hope (Tulsky, 2002).

Table 4.3 lists the hopes expressed by the patients, caregivers, and providers. The hopes are categorized as being connected with trust/reliance or as an expectation that the hope will be fulfilled. The latter category is further broken down according to whether a hope is rational or irrational. Each entry is coded as being related to the death or to the time period before the death or after the death.

Most (8) of the hopes are based on trust (religious or spiritual faith) or reliance on others. Hope as an expectation of fulfillment contains six rational and four irrational hopes. Dr. G’s comment that Anya may not do well after the death speaks to Tulsky’s (2002) statement that those who hope for specific outcomes are more likely to have their hopes dashed than those whose hope is based on trust or reliance. Patients and caregivers had hopes in all categories. Providers had hopes in all categories except irrational hope.

Table 4.3

Hopes of Hospice Patients, Their Caregivers, and Their Providers

Hope as trust or reliance	Hope as expectation that it will happen	
	Rational	Irrational
Rachel – to go to heaven, to go home (A)	Paul – to do what I can from the wheelchair (B)	Victor – ‘magic bullet’ [cure for his cancer] (B)
Ken – that Nina can exist after I’m gone (A)	Ken – that I’m not in a lot of pain, man enough to take it (B)	Anya – ‘magic bullet’ (B)
Victor – peaceful transition, strength for wife and kids (D)	Jenny – keep Mark comfortable (B)	Mark – longer life to get things done so Jenny doesn’t have to worry about anything (B)
Liza – Rachel’s passing to be peaceful (D), for Rachel to be happy (B)	Dr. N – Rachel’s symptoms are well-managed (B)	Jenny – keep Mark as active as he wants to be (B)
Nina – that Ken doesn’t suffer, to die before Ken although not a fair hope because she’s stronger than him (i.e. will do better without him than he would do without her) (B)	Dr. G – Victor’s pain will remain well-controlled until the end (B)	Dr. G regarding caregiver – Anya may not do well after Victor’s death – faith may not provide comfort she is counting on (A)
Dr. N – Rachel’s wishes are respected, family receives support (B)	Liza – for Rachel to be comfortable (B)	
Dr. S – that Ken will be at home with family & loved ones (B)		
Dr. T – the Mark has a sense of peace with the remainder of his life (B)		

Note. □ Patient; □ Caregiver; ■ Provider. (B) – before death; (D) – death; (A) – after death .

How These Data Inform Our Understanding and Care

Most of the fears expressed by patients and caregivers related to the patient’s physical comfort. Knowing this about his or her patient and caregiver, a provider may alleviate these fears by understanding them more specifically (e.g., pain or difficulty breathing) and explaining what can be done to prevent these conditions from happening or to treat them if they do occur.

Most social and spiritual fears expressed by patients and caregivers were related to the time after the patient's death. Because only one of the providers expressed a post-death fear or concern, providers in general may have difficulty identifying with or anticipating these fears in others. In one instance, a patient had been afraid of dying until the actions of a hospice chaplain ameliorated this fear. A provider may directly employ or recommend using the services of professionals in other disciplines to help lessen the post-death fears faced by patients and caregivers.

Most of the sources of strength identified by patients and caregivers were social or spiritual. These might be thought of as one category—relationships. In this study, social strength came from relationships with others and spiritual strength came from a relationship with God, however a patient or caregiver thought of God (Young, Nabarajah, Skeath, & Berger, 2014). Providers also identified sources of strength in these relationship categories and may, consequently, more quickly identify problems that could arise when a source of strength no longer exists. For example, a caregiver whose strength comes from his or her significant other who is the patient may struggle as that individual physically declines and after the patient's death when that person is no longer available to the caregiver as he or she once was. A provider might use this knowledge to help connect a caregiver with resources that can be utilized after the patient's death to support the caregiver during his or her time of grief. A provider who knows that a caregiver is the source of a patient's strength may take care to involve the caregiver in discussions or decisions about the patient's care and treatment or to recommend rest for a caregiver to help maintain the strength he or she gives to the patient.

Most patients' and caregivers' hopes and all of the providers' hopes relate to the period before the patient's death and are connected with the patient's experience prior to death. All hopes with the expectation of fulfillment are pre-death hopes and are listed in either the rational or irrational categories. All rational hopes are related to the patients' physical selves, primarily their physical comfort. The irrational hopes are all related to the patient living longer than is likely. Only the hope as trust or reliance category lists hopes in all three time dimensions: pre-death, connected to the death event itself, or post-death. Providers had hopes in all categories except irrational hope.

The hopes of five patients and caregivers are listed in the category of hope as trust and reliance. These individuals are less likely to be disappointed because their hopes are not tied to a particular, specific outcome (Tulsky, 2002). The hopes of seven patients and caregivers are listed in the category of hope as expectation of fulfillment. These individuals are more likely to be disappointed because their hopes are about very specific outcomes (Tulsky, 2002). The content of the providers' hopes—both in the trust and reliance as well as the expectation of fulfillment categories—are very similar to those of patients in caregivers in the same categories.

None of the providers had irrational hopes; however, four individuals (two patients and their caregivers) are listed as having irrational hopes. In these two cases, the caregiver's hopes are the same as or similar to the hopes the patients have for themselves.

Because all the providers' hopes were pre-death and none of their hopes were irrational, it may be more of a challenge for a provider to identify with or anticipate patients' and caregivers' hopes that are about the death event or after the death or about hopes that are irrational. Providers are unlikely to affect a patient's or caregiver's

irrational hope because it is likely based on a strong faith long-held by the patient or caregiver (Tulsky, 2002). However, a provider may support hopes for the peaceful death of a patient by discussing with a patient and caregiver what they can be provided with—from hospice care, for example—to help assure a peaceful transition. If this conversation is unfamiliar or uncomfortable for a provider, she or he may arrange for the discussion to take place with someone who is more knowledgeable and comfortable with it. Regarding the hopes a caregiver has for the post-death experience, a provider may link the caregiver with resources that can assist with planning and support for the post-death period.

Much information can be gained in a candid, respectful, and gentle conversation between a provider, a patient and a caregiver by asking three questions: what are your fears, where does your strength come from, and what are your hopes? The answers to these questions can guide treatment decisions, alleviate concerns, and create links with resources that will be helpful to a patient and a caregiver who are already in hospice care.

The importance of relationships to nearly all study participants suggests an opportunity for providers to intentionally foster trusting relationships with hospice patients and their family members. Trust generated in the relationship a patient and caregiver have with their provider can establish a foundation a provider may use to have conversations about end of life.

A provider who elicits a patient's and caregiver's fears and attempts to understand what they mean to each individual might be able to allay the fears with more information about the care that can be provided at end of life. A provider who understands what a patient and a caregiver identify as sources of strength can connect the patient and caregiver with resources that will build on their strengths. A provider who knows the

hopes of his or her patients and caregivers can better tailor end of life care to meet the needs of the patient and caregiver.

Relationships a provider has with his or her own family and/or with God may support him or her in finding the strength needed to have end of life conversations with the patient and caregiver. A provider who finds strength in his or her competence may have that competence enhanced by allowing the patient and caregiver to teach him or her. A provider who is respectfully curious about what the patient and caregiver are experiencing may strengthen the relationship and contribute to hope.

Acknowledging the relationship between patient and caregiver is also crucial. Patients and caregivers find strength in their connection to each other and likely take into consideration each other's perspective when facing something difficult such as fears associated with end of life. As demonstrated by this study's participants, caregivers are affected by thoughts, actions, discussions, and decisions made for or by their loved one who is a hospice patient. The role of the caregiver in a discussion and decision about hospice care should not be underestimated.

Patients, caregivers, and providers are all human beings cast into roles that give them unique perspectives and experiences. The nature of being human is, however, what connects them to each other, despite the individual roles to which they find themselves assigned. Recognizing one's humanity and the humanity of others may be what permits conversations about end of life fear, strength, and hope to take place.

Acknowledging our humanity while working in a health care system designed to maximize efficiency may be challenging. Building relationships and trust takes time, a commodity most providers likely have in limited quantities. Future research might focus

on the use of professionals such as nurses, social workers, and chaplains to devote more visit time to the patient and caregiver to function as a bridge between them and the provider/health care system. This team approach model works well in hospice care and could likely be successful throughout the health care system (Rosenfeld & Rasmussen, 2003). A nurse or social worker might take on a case manager role, serving to connect fragments of care and be the constant that patients and caregivers need as they travel through the health care system. The relationship formed over time and the trust that could potentially be generated among the patient, caregiver, and case manager may help increase the understanding of the patient's and caregiver's fears, strengths, and hopes. This understanding may help retain and protect our humanity, the recognition of which is needed to have conversations about care at the end of life.

Limitation

A limitation of this research is that the questions asked of participants were part of a larger study. The answers to these questions might have been explored more in depth had it been known in advance that these three questions would comprise a separate study.

Conclusion

Five hospice patients, their primary caregivers, and their providers were interviewed and asked what they feared or were concerned about, where their strength or courage came from, and what they hoped for. A narratological framework was utilized to examine individual and aggregate responses to these questions. Suggestions are made for providers on ways their care for individuals and caregivers at or near the end of life may be improved related to understanding the fears, strengths, and hope of hospice patients and caregivers. Opportunities for future research are also offered.

The current environment of the U.S. health care system is not designed to promote relationships, except, perhaps, in hospice and palliative care. Yet it is relationships that have been identified in this study as being integral to initiating and maximizing quality end of life care. Ironically, the efficiency of the delivery of health care in the U.S. will likely be enhanced if provisions are made for nurturing relationships between providers and patients/caregivers. This is, perhaps, most important in care at the end of life.

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CHAPTER V

CONCLUSION: CHOICES RELATED TO MAXIMIZING QUALITY OF LIFE AT END OF LIFE

Discussions about choices to maximize quality of life at the end of life may be difficult in a society that largely denies death (Lehto & Stein, 2009). Advance directives are the plans one puts in place to provide guidance for health care in the event that one becomes unable to make his or her own decisions. The advance directive completion rate among adults in the U.S. is 18% to 36% (Pollack, Morhaim, & Williams, 2010; U.S. Department of Health and Human Services, 2008). Much research has been conducted in an attempt to understand why the completion rate is not higher, but what has not been examined is whether there is an association between advance directive completion and one's attitude toward death. Chapter II of this dissertation is an analysis of the potential association between attitude toward death and whether one has completed an advance directive. Hospice care is another choice one may make for care at the end of life. Hospice care is a 6-month benefit (National Hospice and Palliative Care Organization [NHPKO], 2014); however, the median length of stay in hospice in the U.S. has been declining and in 2013 was 18.5 days (NHPKO, 2014). Researchers have studied hospice patients, patient caregivers and providers to understand why the median length of stay in hospice care is not longer, but what has not been studied together are the perspectives of the hospice patient, his or her caregiver and his or her provider. Chapter III is an examination of the perspectives of the hospice patient, caregiver, and provider related to the experience of admission to hospice care. Chapter IV is an exploration of the fears,

strengths, and hopes of the hospice patient, caregiver, and provider after the admission to hospice care and how knowing these may inform our understanding and care of individuals and their loved ones at the end of life.

Chapter II, a quantitative analysis of a possible association between one's attitude toward death and the presence of completed advance directives, presented no association between death attitudes and whether one had completed advance directives. Religion as a variable, however, may have some association with advance directive completion. The mean death attitude score of study participants with advance directives compared to those without advance directives was significantly different for the death attitudes of death avoidance and approach acceptance among individuals who did not consider themselves religious. The mean death attitude score of study participants with advance directives compared to those without advance directives was significantly different for the death attitude of escape acceptance among individuals who considered themselves religious. The exact nature of any possible influence of religiousness as it relates to attitudes about death and advance directives should be a topic for future research. It is suggested that the definition of the variable of religion be broadened to include spirituality.

The mean scores for the death attitudes fear of death and death avoidance were low, representing some degree of disagreement with these death attitudes among participants in the study sample. It is also suggested that future research with death attitudes and advance directives include a sample in which both agreement and disagreement with all the death attitudes are present.

Chapter III, the qualitative examination of experiences of hospice referral from the perspective of the hospice patient, his or her caregiver, and the provider most closely

involved in the decision to become a hospice patient, revealed several noteworthy considerations that may help explain the relatively short median length of stay in hospice care. Comprehensive communication between the patient/caregiver and the provider was impeded when either the patient/caregiver did not understand what the provider was saying or did not recall the provider discussing hospice care. In addition, caregiver needs for additional support and the influence of the caregiver on decision-making related to hospice care may be underestimated by the provider. Recommendations for future research include analyzing a variety of methods of communication between the provider and the patient/caregiver; exploring the influence and needs of the caregiver; examining the effect of shifting the location of conversations about hospice care to the patient and caregiver's environment; and exploring opportunities for introducing non-hospice palliative care.

Chapter IV, the qualitative analysis of the fears, strengths, and hopes of the hospice patient, caregiver, and provider, yielded rich information that may help inform care at the end of life. Most of the fears expressed related to physical, pre-death experiences of the patient. Emotional, social and spiritual fears about pre- and post-death experiences of both the patient and caregiver were also expressed. Strengths described largely included those in the social and spiritual realms, indicating that relationships with others and with God, however God is perceived, were important to study participants. Physical and intellectual strengths were also described. Most hopes expressed fell in the category of trust (in faith) or reliance (on others) and related to all time periods (pre-death, the death itself, and post-death). All hopes listed in the category of hope as expectation of fulfillment were pre-death hopes, both rational (e.g., the patient's

symptoms are well-managed) and irrational (e.g., a cure will be found for the patient's illness). Understanding patients' and caregivers' fears, strengths, and hopes can guide treatment decisions, alleviate concerns, and create links with resources for hospice patients and their caregivers.

Integrating the results of these three studies provides information that may be helpful related to choices that maximize quality of life at the end of life. This information may be considered in three categories: relationships, spirituality, and communication.

Connected with the death of an individual are the deaths of relationships with loved ones. Education about advance directives that includes a discussion of the benefits to loved ones of advance directive completion may help increase the advance directive completion rate. Fears related to pre-death and post-death experiences as well as to death experiences should be explored with an individual as well as those with whom the individual has relationships. The needs of loved ones should be considered alongside the needs of the individual nearing end of life.

Spirituality is a source of strength for many individuals, health care providers included. An exploration of one's spirituality in a discussion about advance directives may help with planning. The services of a spiritual care professional may be useful in a discussion about end of life care and treatment. Providers who struggle with having end of life discussions with patients may be assisted by the knowledge that hope comes in many forms for both patients and caregivers.

Good communication regarding care at the end of life is vital for discussions between providers and patients/caregivers. Gaining information about fears, strengths, and hopes can serve to guide a conversation about advance directives when death is

expected to be some distance into the future as well as about end of life care when death may be more imminent. Recognizing that patients and caregivers need to both hear and understand what is being communicated to them may assist a provider in having a discussion about care and support related to a terminal illness diagnosis.

The consideration of one's mortality is a complex undertaking that may be made more difficult by the influence of a society that largely denies death. Tools such as advance directives and supports such as hospice care can serve to attenuate discomfort related to planning for and experiencing end of life, but only if they are used. Research in this dissertation has identified some of the barriers and the benefits associated with utilizing advance directives and hospice care. Future research that builds on the results of the studies included in this dissertation may enhance the use of advance directives and hospice care and support choices that maximize quality of life at the end of life.

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Appendix

Human Subjects Institutional Review Board Letter of Approval

WESTERN MICHIGAN UNIVERSITY



Human Subjects Institutional Review Board

Date: September 2, 2011

To: Amy Curtis, Principal Investigator
Theresa Lynn, Student Investigator

From: Christopher Cheatham, Ph.D., Vice Chair

A handwritten signature in cursive script that reads "Christopher C. Cheatham".

Re: HSIRB Project Number 11-08-11

This letter will serve as confirmation that your research project titled "Attitude toward Death & Execution of Advance Directives" has been **approved** under the **exempt** category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you may **only** conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: September 2, 2012

WESTERN MICHIGAN UNIVERSITY



Human Subjects Institutional Review Board

Date: October 25, 2012

To: Amy Curtis, Principal Investigator
Mary Lagerwey, Co-Principal Investigator
Theresa Lynn, Student Investigator for dissertation

From: Amy Naugle, Ph.D., Chair

Re: HSIRB Project Number 12-07-01

This letter will serve as confirmation that your research project titled "Experience of Hospice Referral: Patients' Family Members' and Physicians' Perspectives" has been **approved** under the **full** category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note: This research may **only** be conducted exactly in the form it was approved. You must seek specific board approval for any changes in this project (e.g., ***you must request a post approval change to enroll subjects beyond the number stated in your application under "Number of subjects you want to complete the study."*** Failure to obtain approval for changes will result in a protocol deviation. In addition, if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

Reapproval of the project is required if it extends beyond the termination date stated below.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: August 15, 2013

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