

Running Head: PATIENT-CENTERED CARE AND MINDFULNESS IN HOSPICE

PATIENT-CENTERED CARE AND MINDFULNESS IN HOSPICE VOLUNTEER  
COMMUNICATION EXPERIENCES

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### ABSTRACT

Hospice agencies provide comforting care and improved quality of life for terminally ill patients who choose to cease curative treatments. Hospice volunteers offer social, informational, and task-oriented support to hospice patients, families, and hospice workers. Law requires that hospice organizations receiving federal reimbursements must involve volunteers in at least 5% of overall patient care (Hospice Foundation of America [HFA], 2010). This ethnographic and interview study explored the manifestations of patient-centered care (PCC), mindfulness, and communication in the hospice volunteer experience. The constant comparison methods of grounded theory (Corbin & Strauss, 2008; Glaser & Strauss, 1967) allowed for category development by comparing one incident or situation to another, and by looking for similarities and differences. A Heart Model of Hospice Volunteer Experiences is proposed based on findings from interviews with hospice volunteers and in accordance with previous literature. This model may be used to guide hospice organizations in theoretical and applied understandings of PCC, mindfulness, and communication embedded in the hospice volunteer experience. Practical implications include recommendation lists developed to assist hospice organizations in recruitment and training efforts.

*Keywords: patient-centered care, mindfulness, hospice, grounded theory*

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## CHAPTER ONE: INTRODUCTION AND RATIONALE

*“That they really care about and address the whole person is what I was really most impressed with - and not just the physical aspect of controlling pain but the entire person is important to them” (Hospice Volunteer Seven).*

Hospice professionals consider the physical, psychological, social, and spiritual needs of both the terminally ill patient and the family after the cessation of curative treatment options (The Hospice Association of America [HAA], 2010). Hospice organizations provide palliative care – a healthcare approach aimed at improving quality of life and reducing suffering for patients with terminal illness and other serious or chronic conditions (Wittenberg-Lyles, Goldsmith, Ragan, & Sanchez-Reilly, 2010). Interdisciplinary hospice teams of physicians, nurses, aides, social workers, therapists, chaplains, and volunteers collaborate and communicate together as they strive to comfort terminally ill patients and their families (Wittenberg-Lyles et al., 2010). The challenging communication interactions encountered during the final stages of life represent an important area for continued health communication research.

The number of U.S. hospice organizations exponentially increased after the first U.S. agency formed in 1974 and more growth is expected. The number of Hospice agencies participating in Medicare/Medicaid has expanded by 110 fold, from 31 organizations in 1984 to more than 3,407 organizations today (HAA, 2010). Hospice organizations anticipate continued growth as the U.S. population ages and life expectancy increases. Demographers predict that the population of persons over the age of 65 will double within the next 25 years (National Institute of Health [NIH], 2009). Patients over the age of 65 years represent 83% of all hospice patients (National Hospice and Palliative Care Organization [NHPCO], 2010). Providing further evidence of the links between the aging population and hospice service, research shows that patients 85

years and older represent over 33% of all hospice patients (NHPCO, 2010). The strong connections between age and the demand for end-of-life care reveal the practical need for improvements in hospice research and service. Individuals and families are increasingly utilizing hospice services as they experience death. In 2009, approximately 41.6% of all U.S. deaths occurred under the supervision of hospice care (NHPCO, 2010). Health communication researchers have opportunities to improve the quality of health interactions and end-of-life experiences by researching and discussing communication in the hospice context.

### **Hospice Volunteers: Statement of the Problem**

As hospice organizations expand to meet patient care demands, hospice volunteers play increasingly important roles. Hospice volunteers contribute directly to hospice services by assisting with patient care in homes and at extended care facilities. The 468,000 active hospice volunteers in the U.S. provide an estimated 22 million hours of service each year, with half of these service hours allocated to direct care in the homes of patients (NHPCO, 2010). The hospice volunteer role extends beyond the traditional function of an occasional helper as volunteer contributions have become an organizational requirement. In fact, Medicare/Medicaid rules require that hospice organizations receiving federal reimbursements must utilize volunteers for at least five percent of all patient care (HFA, 2010). Meeting this requirement, hospice volunteers provided nearly six percent of all clinical services for terminally ill patients served by U.S. hospice organizations in 2009 (NHPCO, 2010).

Hospice volunteers essentially witness the progression of death in terminally ill patients and serve as communication resources for dying patients and their families (Planalp & Trost, 2008). Volunteers contribute to hospice services in primarily three main categories. First, direct patient care involves the actual time spent with patients and families (NHPCO, 2010). A

majority (56.7%) of hospice volunteers contribute to direct care. Second, clinical support involves assistance with clerical or other forms of support for patient care and the provision of clinical service. Nearly 22% of hospice volunteers assist with clinical support. Third, almost 21% of hospice volunteer service involves general support, such as fundraising efforts and/or membership on the board (NHPCO, 2010). A recent national survey of hospice volunteer training provided a list of the top thirty volunteer activities, thereby demonstrating the wide variety of services provided by hospice volunteers. The survey identified specific tasks ranging from spending time with patients, bereavement, public relations, fundraising, vigil, courier, and companionship (Wittenberg-Lyles, Schneider, & Oliver, 2010).

Communication researchers have considered some communication experiences in hospice contexts, yet many areas of research remain unexplored. Communication scholarship has examined hospice employees and organizational operations (Considine & Miller, 2010; Planalp & Trost, 2008; Wittenberg-Lyles, 2006), the relationship between physicians and hospices (Kelly, Thompson, & Water, 2006), families and palliative care (Wittenberg-Lyles, Goldsmith, Ragan, & Sanchez-Reilly, 2010), training (Wittenberg-Lyles, Schneider, & Oliver, 2010; Worthington, 2008), and technological developments (Kuziinsky, Jahnke, & Lau, 2006). Additional research is needed to better understand communication in the hospice context as providers aim toward improving patient care experiences. Continuing debates on healthcare reform reflect the acute need for improvements across many areas of healthcare including the need to reduce the suffering of patients and families encountering negative and unsupported death experiences. Hospice communication research can contribute to healthcare reform efforts that ultimately “require a renovation in values, a fostering of communication and compassion,

and social change that recognizes the sacred time at the end-of-life as an opportunity and not failure” (Ferrell, 2010, p. xi).

### **Purpose of Study**

While designing and implementing this program of research, I primarily considered the lived experiences of hospice volunteers as they communicate with terminally ill patients, families, and other hospice team members. A research partnership with a non-profit hospice organization in a Midwestern city provided the site for this study. The participating hospice organization, referred to as Midwest Hospice for the purposes of this study, serves approximately 230 homecare patients and 110 facility inpatients each month. Midwest Hospice operates with the assistance of approximately 400 employees, with about 300 of the employee serving as nurses and hospice aides. The organization supports about 250 adult volunteers and about 75 teen volunteers. A prior phase of this hospice research involved observations of a volunteer training program at Midwest Hospice, providing a strong base of background knowledge informing the current study. An additional phase of this hospice research involved observations and transcriptions of post-training interviews between the hospice staff and the new volunteer trainees upon the conclusion of the training program. Observations of the post-training interviews further prepared for the development of the current study.

The focus of this dissertation research considers the lived experiences of hospice volunteers. I conducted a series of in-depth interviews with volunteers at the partnered hospice organization. Invited participants were encouraged to share their hospice volunteer experiences during interview conversations guided by an interview protocol.

Comparisons across groups of interview participants became possible as I grouped participants into the two categories of novice versus experienced hospice volunteers. The

participant population groups were labeled as new and experienced hospice volunteers. For the purposes of this study a new volunteer described the population of volunteers who had most recently completed new volunteer training. New volunteers included individuals serving as hospice volunteers for fewer than four months, An experienced volunteer described an individual with notable experience as a hospice volunteer. The experienced volunteers interviewed in this study included individuals serving as hospice volunteers for two or more years. While comparisons across new and experienced volunteers provided some insight, the overall purpose of this study aimed toward understanding interactions and experiences of hospice volunteers in general.

The first two overall areas explored in this research involved the following inquiries:

Inquiry One: What are the shared experiences of hospice volunteers as they reflect on their encounters with patients and families?

Inquiry Two: How do new volunteer perspectives compare with perspectives of experienced hospice volunteers?

### **Patient-Centered Care**

Shifting beyond the general areas of inquiry, I also explored potential connections and reflections relating to the concepts of patient-centered care and mindfulness in the hospice volunteer context. The third area of inquiry involved in this research explored the concept of patient-centered care (PCC). Harmonious with the hospice mission, a patient-centered care (PCC) approach considers psychological and social factors for the patient, rather than just physical needs (Sparks, Villagran, Parker-Raley, Cunningham, 2007). Care providers practicing a PCC approach encourage effective communication by exploring the perspective of the patient and by engaging the patient in consultative conversation. The use of a PCC approach necessitates

listening, assessing, and then responding to the patient's level of understanding about their own health condition (Mast, Kindlimann, & Langewitz, 2005). PCC has been associated with many positive outcomes for patients, providers, and families (Sparks et al., 2007; Wanzer, Booth-Butterfield, & Gruber, 2004). I will further discuss the outcomes linked to PCC in a review of literature provided in chapter two.

While advocates of PCC urge all healthcare providers to focus on communicating effectively with patients, the PCC approach rises as particularly salient in the hospice context. The communication challenges associated with end-of-life processes point toward a heightened need for the use of PCC practices. For example, hospice volunteers have previously identified communication challenges occurring when patients and families express negative emotions due to the struggles associating with illness (Planalp & Trost, 2008). Effective management of the negative emotions presented by patients and families requires sensitive communication and attention to the holistic needs of the patient. The use of the PCC approach in the hospice context may also prove helpful in connection to challenges associated with the denial of death. Communication may become increasingly complicated as patients and families struggle with the acceptance and/or the denial of an impending death. Hospice care-providers attempt to interact authentically with patients and families in the face of death (Planalp & Trost, 2008, Seno, 2010). Recognizing the relevance of a PCC approach in the hospice context, I explored the following third area of inquiry in this research:

Inquiry Three: To what extent, if any, do the experiences of the hospice volunteers reflect a patient-centered care approach?

**Mindfulness**

The PCC approach involves a focus on the feelings and perspectives of the patient, while the mindfulness approach to patient care incorporates a focus on the patient as well as the internal processes, thoughts, and feelings of the health provider. Researchers and clinicians have expressed a growing interest in mindfulness in the past 20 years (Brown, Ryan, & Creswell, 2007). Positive outcomes associated with mindfulness practice include enhanced mental well-being due to added clarity and vividness along with a moment-to-moment contact with life (Brown et al., 2007). Research has indicated that mindfulness practices also impact physical well-being, such as reducing pain and improving health behaviors.

Paying attention to one's present experiences represents the primary component of mindfulness (Leary & Tate, 2007). Rooted in the fundamental activities of consciousness, mindfulness involves attention and awareness (Brown et al., 2007). Behaviors demonstrative of a mindfulness approach to patient care include attentiveness, interest in the personal health concerns of patients, interest in the overall well-being of patients, clinical assessment, concern/empathy, and presence (Epstein, 2003). A mindfulness approach requires healthcare providers to introspectively examine their own perspectives while treating patients. The biomedical approach long practiced by U.S. health providers has traditionally emphasized cognitive and technical knowledge. Recent shifts toward mindfulness in medical practice emphasize the importance of caring for patients in a more holistic, reflective, and insightful manner. Studies show that patients typically value the personal or thoughtful interactions encountered during a visit with a medical provider who practices healthcare with a mindfulness approach (Epstein, 2003).

The mindfulness approach addresses the physical, mental, and social contexts of patients and their families. Similar to the role of PCC in hospice care, mindfulness represents an important connection to the hospice mission of holistic comfort care. Due to the important role of family in the context of hospice care, the mindfulness approach can help to address the patient and family as a unit of care (Wittenberg-Lyles et al., 2010). The introspective and thoughtful medical practices associated with the mindfulness approach can potentially ease the emotional burden of healthcare providers, patients, and families. Therefore, the fourth area of inquiry in this research involved the following:

Inquiry Four: To what extent, if any, do the experiences of the hospice volunteers reflect a mindfulness approach?

### **Methodological Choices**

The four areas of inquiry I developed while designing this study included a focus on the overall experience of hospice volunteers, a comparison between new and experienced volunteer experiences, the role of patient-centered care, and the role of a mindfulness approach. The questions discussed during the interview process explored relational, emotional, and spiritual aspects of the hospice volunteer experience. By sharing in conversations with volunteers actively engaged in hospice service, I utilized semi-structured interviews and a grounded theory approach to understand better the communication experiences of these essential volunteer members.

Due to the sensitive and highly-contextual nature of studying communication interactions related to end-of-life care, I utilized an ethnographic approach to investigate the primary areas of inquiry. Qualitative research methods represent a growing methodological tool being used by health communication researchers (Kreps, 2008; Lederman, LeGreco, Schuwerk, & Cripe, 2008). Ethnographic research allows for direct observations of a particular culture that may offer

insight not accessible without some form of researcher-immersion (Van Maanen, 1988).

Ethnographic observations allow researchers to interpret and then represent cultures in qualitative research reports. In-depth interview methods provide a venue to delve thoroughly into the thoughts, feelings, and perspectives expressed during conversations with hospice volunteers.

The grounded theory method represents the most commonly used approach to qualitative data analysis in health communication research (Beck et al., 2004). The founders of grounded theory developed the method while conducting qualitative health research (Glaser & Strauss, 1967). For example, a book detailing current grounded theory methods was recently published under the direction of four renowned grounded theorists working in schools of nursing (Morse et al., 2009).

Grounded theory offers a conceptualization process involving constant comparison between groups, categories, and themes emerging from the data (Morse, 2009). The grounded theory approach allows the researcher to compare one group, incident, or situation to another by looking for similarities and differences noted during observations (Corbin & Strauss, 2008; Glaser & Strauss, 1967). This grounded theory analysis involved categorization of emergent themes noted from the transcribed interview conversations of new and experienced volunteers with an ultimate goal of contributing to hospice communication theory development.

### **Summary**

Few studies have published empirical research specifically addressing the approaches of patient-centered care or practices of mindfulness in the hospice volunteer context. A thematic analysis of the interview conversations shared during this research may contribute to the field of health communication by providing a specific emphasis on hospice communication. In a study of communication in hospice volunteer training, Worthington (2008) encouraged that “developers

and coordinators of hospice training programs, whether for volunteers or medical professionals, should consider the theoretical and practical contributions that communication research and training can make to their training programs” (p. 33). Based on the findings noted during this analysis, I will conclude this dissertation with practical recruiting and training suggestions to enrich the experiences of future hospice organizations and volunteers.

An introduction and rationale for this study were provided in this chapter. The areas of inquiry revealed in this introductory chapter clarified the focus and objectives of this dissertation project. Next, a literature review is provided in chapter two. Previous hospice volunteer research, an overview of patient-centered care, and a section on the mindfulness approach to healthcare, are provided in chapter two. Chapter three offers an explanation of methodological choices employed during this research and analysis. Themes revealed during analysis of the interview transcripts are discussed in chapter four. Chapter five provides a discussion of implications from the findings in this study. A theoretical model emerging from the thematic analysis of the volunteer interviews is also proposed in chapter five. Finally, chapter five concludes by providing practical recommendations and reflections on future hospice communication research.

## CHAPTER TWO: LITERATURE REVIEW

*“It makes you look at things in your life, you know, and your mortality and all that, and working in the field, I think this opens you up to ... appreciating everyday”*

*(Hospice Volunteer Nineteen).*

An introduction to hospice and palliative care, along with a rationale for this study of hospice volunteer experiences, began in chapter one. A literature review from previous studies, focused specifically on hospice volunteers, appears in chapter two. In this chapter, the details explaining the key concepts of patient-centered care and mindfulness accompany suggestions of potential links to the hospice volunteer experience. Four sections organize this literature review: understanding the role of hospice volunteers, challenges and rewards of maintaining and valuing hospice volunteers, patient-centered care and relationships in the hospice context, and mindfulness in hospice encounters. The four sections discussed in this chapter connect with the areas of inquiry presented in chapter one.

**Understanding the Hospice Volunteer Role**

As explained in Chapter One, hospice volunteers perform a variety of services in support of the hospice organization. Based on research with hospice volunteers and on her own hospice experience, Foster (2002) explained the fundamental role of a hospice volunteer:

Essentially, our job as volunteers is to visit with our patients, to get to know them, and to make their lives brighter in whatever way we can. As I reflect upon the interpersonal qualities of volunteer-patient communication, I realize that *what* the hospice workers and patients talk about is relatively insignificant in establishing the meaning of the hospice experience.

Hospice volunteers provide support in a variety of ways. Support may include visits with patients and families, or performing other tasks such as reading, walking, writing letters, listening to music, or helping with pets. Volunteers also provide support for the families of patients by listening or offering respite so that the family member may complete other tasks or rest. Some volunteers may help with child care, bereavement support programs, fundraising, and/or administrative work (Hospice Foundation of America [HFA], 2011).

While comparing regular hospital volunteers and hospice volunteers, Egbert and Parrott (2003) noted significant differences between hospice volunteers who provide assistance for terminally ill patients and regular hospital volunteers who provide assistance for recovering patients. Egbert and Parrott found that hospice volunteers provided mostly emotional support while hospital volunteers provided more instrumental (physical/task related) support. Since hospice volunteers often focus on social interactions with patients and families, their services help to save time for employed hospice team members by fulfilling emotional support needs (Claxton-Oldfield, S., Hastings, & Claxton-Oldfield, J., 2008). In addition, volunteers serve as a liaison between the health professionals and the patient/family.

Ideally, the services provided by hospice volunteers complement the tasks of the health professionals officially employed by the hospice organization. Hospice nurses have reported generally positive attitudes toward hospice volunteers (Claxton-Oldfield, S., Hastings, & Claxton-Oldfield, J., 2008). The nursing population surveyed by Claxton-Oldfield, S. and colleagues (2008) indicated approval of the tasks typically designated for volunteers, although some nurses disapproved of volunteer participation in physical, hands-on care. The surveyed nurses reported respect for the volunteer role. Claxton-Oldfield and colleagues found that 77% of

the nurses surveyed valued volunteer input regarding patient care and 75% of the nurses surveyed believed that volunteer assistance made nursing work easier.

In addition to assisting the health professionals working for the hospice organization, volunteers often develop special relationships with patients and families. The volunteer often serves as a trustworthy, dependable contact during the final stages of life (Claxton-Oldfield, S., Gosselin, & Claxton-Oldfield, J., 2009). While assessing possible reasons for declining or accepting the services of a hospice volunteer, 89% of participants claimed to desire volunteer assistance if faced with the need for end-of-life care. The primary reasons listed for accepting volunteer assistance included a desire for general support, help with practical needs, and/or a lack of family assistance. The interactions between volunteers and patients/families provide instrumental (e. g., task oriented) support and social support to the patients/families.

Families facing the loss of a loved one may benefit greatly from the opportunity to engage with volunteers. During a survey of family members who had encountered a hospice volunteer while helping a deceased loved one, families reported high overall satisfaction from volunteer support (Claxton-Oldfield, S., Gosselin, Schmidt-Chamberlain, & Claxton-Oldfield, J., 2010). The family members rated the opportunity to take a break from the care of their loved one as the most highly valued service of the hospice volunteer. Family members of previous patients also reported satisfaction with the competency of volunteer services. Results showed that 85% of family members perceived the volunteer as well trained and 95% of family members reported that the volunteer was non-invasive of the privacy of the patient and family. Positive reports from health professionals, patients, and families regarding overall satisfaction with hospice volunteer services reflect positively on hospice volunteer standards.

### **Who Becomes a Hospice Volunteer?**

Similar to research on people who volunteer in general, previous research indicates that hospice palliative care volunteer populations are typically composed of married or widowed, middle-aged to older, white females (Caldwell & Scott, 1994; Claxton-Oldfield, S. & Claxton-Oldfield, J., 2007). Hospice volunteers, similar to volunteers in general, cite their reasons for volunteering as connected to their own values and social motivations. For example, volunteers in general report motivations to help others, to serve those in need, and to make a difference in the lives of others (Claxton-Oldfield, S., et al., 2004; Planalp & Trost, 2009a, b). Palliative care volunteers report a natural motivation to help others and explain that they volunteer because they feel a sense of freedom, of personal agency, and of flexibility (Gurguis-Younger & Grafanaki, 2008). Volunteers in hospice find it personally gratifying, intellectually stimulating, and emotionally meaningful to assist those in need at a critical point in their lives. Many of these volunteers were introduced to hospice through the death of a family member and understand firsthand the value of hospice care, but nearly 20% of volunteers are new to hospice. Volunteers consistently report that helping the terminally ill through hospice is not about dying but about living (HFA, 2011).

**Personality and gender.** Research on personality characteristics of hospice volunteers revealed two particular personality types, extroversion and sensing, attributed to the most effective volunteers (Caldwell & Scott, 1994). Extraverts prefer interactions with others and gain personal energy from those interactions. Individuals high in sensing prefer to interact when they have an understanding of the situation and can verify reality (Quenk, 2000). Extraverted, sensing personality types generally demonstrate a preference for interpersonal contact, open and

forthright communication, social interaction, and a desire to contribute to society by helping others (Caldwell & Scott, 1994).

Personal characteristics of hospice volunteers include “compassion, caring, good listening and communication skills, warmth, flexibility, a sense of humor, being nonjudgmental, respectful, and able to maintain confidentiality” (Claxton-Oldfield & Banzen, 2010, p. 407).

While investigating the personality characteristics of hospice volunteers, Claxton-Oldfield and Banzen compared female hospice volunteers to female populations in general. The study showed that female hospice volunteers scored significantly higher on the traits of agreeableness, extroversion, and openness. Similarly, the female hospice volunteers scored significantly higher on empathic concern and perspective taking; female hospice volunteers scored significantly lower on personal distress than females in general.

Egbert and Parrot (2003) found that hospice volunteers scored higher on empathic concern than regular hospital volunteers. They explain empathic concern as “an emotional response reflected in feelings of sympathy, concern, and involvement” (p. 30). Hospice volunteers exhibited higher empathic tendencies than the general population, as well as populations of other types of healthcare workers. As suggested by Egbert and Parrot, individuals reporting higher levels of empathy may best fit the hospice volunteer role.

Male hospice volunteer populations typically represent a much lower ratio of the entire hospice workforce than the female hospice volunteer population. Hospice volunteer populations usually involve a low ratio of male volunteers. In a study exploring male interest in serving as hospice volunteers, research indicated that only 22% of the men surveyed expressed interest in serving as hospice volunteers (Claxton-Oldfield, S., Guigne, & Claxton-Oldfield, J., 2009). Previous research had showed that 46% of women surveyed expressed interest. This finding

provided support for the perception of hospice/palliative care work as gendered. The authors suggested that regardless of age, men typically lack interest in volunteering in the hospice/palliative care context. The men surveyed explained their lack of interest by claiming that they were too busy and/or that they were concerned about their ability to cope emotionally in the role. Learning about the personality characteristics and the impacts of gender on decisions to serve as a hospice volunteer provides insight into why hospice volunteers enlist and what they expect to encounter during their service experience.

### **Inquiry One**

The roles and tasks fulfilled by hospice volunteers lead to a variety of experiences for the individuals choosing to volunteer. Shaped by a review of previous research on the motivations and characteristics of hospice volunteers, the first general area of inquiry in this research explored the overall experiences of hospice volunteers.

Inquiry One: What are the shared experiences of hospice volunteers as they reflect on their encounters with patients and families?

Exploration of inquiry one assisted in my efforts to learn more about the roles, tasks, motivations, and characteristics of the volunteers participating in this research study.

### **Challenges and Rewards: Maintaining and Valuing Hospice Volunteers**

End-of-life communication involves many complexities “ranging from health status to culture and ethnicity to personal belief systems to family dynamics” (Considine & Miller, 2010, p. 167). Central to the work of hospice volunteers, end-of-life communication poses challenges that inevitably influence the hospice volunteer experience. Planalp and Trost (2009b) revealed insights related to challenges that influence the recruitment, retention, and support of hospice volunteers. The researchers assessed motivations by investigating how volunteers originally

learned of the hospice volunteer role, why individuals chose to volunteer, and why hospice volunteers continued to serve the hospice organization. The participating hospice volunteers were particularly sensitive to the demands of palliative care, the hospice mission, and experiences of death and dying. Most of the hospice volunteers surveyed by Planalp and Trost claimed to have initially started to volunteer based on a desire to help and/or to experience personal growth.

### **Facing Death**

Considine and Miller (2010) noted that the most important issues at end-of-life actually involve concerns about comfort, spirituality, and the significance of life rather than the conventional end-of-life concerns of funeral planning or estate settlement. Focused on the dilemmas and issues of communicating in the hospice context, Planalp and Trost (2008) identified particular challenges faced by hospice volunteers, patients, and their families. Volunteers described their interactions with terminally ill patients as challenging because these patients often express “fear, anger, regret, guilt, remorse, impatience, loss of dignity, confusion, and other negative emotions” (p. 228). Communication skills often devolve as patients near the final stages of life. Hospice volunteers also noted the frustrations associated with communication with the patient when the patient has severe physical and/or mental impairments.

The denial of death represents a common barrier as hospice volunteers attempt to lead and follow during end-of-life conversations with patients and family members (Planalp & Trost, 2008). Difficult conversations and challenging experiences became more manageable when hospice volunteers shifted their focus toward more positive perspectives on dying. For example, volunteers participating in the study by Planalp and Trost discussed dying as a form of relief, an adventure, or as a religious journey. Considine and Miller (2010) discussed the dialectic of

leading versus following for hospice workers addressing discussions regarding spirituality and end-of-life concerns. They found that hospice workers surpassed the dialectic by shifting between leading and following based on situations, timing, or by simply addressing multiple goals and conversations at any given time. Willingness to overcome the challenges associated with helping patients and families during end-of-life processes may reflect volunteer commitment to the hospice organization (Planalp & Trost, 2009b).

### **Feeling Valued and Useful**

Hospice volunteers may continue their volunteer service out of a commitment to the hospice organization (Planalp & Trost, 2009b). In order to sustain volunteer commitment, the volunteers must feel useful and valued by the organization, other hospice team members, and patients/families (Claxton-Oldfield, 2004; Claxton-Oldfield, S., & Claxton-Oldfield, J., 2008). During an examination of the challenges faced by hospice volunteers, four common frustrations emerged including feeling underutilized, feeling helpless due to late placement with a patient, feeling undervalued by medical staff, and feeling unable to offer enough help to patients and families (Claxton-Oldfield, S. & Claxton-Oldfield, J., 2008). Volunteers reported higher levels of satisfaction when they felt like contributing members of the team (Claxton-Oldfield, S. & Claxton-Oldfield, J., 2008). Maintaining volunteer satisfaction remains important for fulfilling the requirements regarding volunteer service in hospice organizations.

It is widely acknowledged that volunteers are absolutely essential members of the hospice palliative care team. A great deal of time, energy, and money is invested in volunteer selection, training, and on-going education. If volunteers leave the program because they feel that they are not being properly utilized or are not valued members of the team, this investment is lost. (p. 125)

Volunteer coordinators may improve feelings of belonging and value for volunteers by educating medical staff about the roles, responsibilities, and training involved with the hospice volunteer position (Claxton-Oldfield, S., & Claxton-Oldfield, J., 2008). The authors suggested including volunteers in hospice team meetings as a way to help volunteers feel like contributing members of the team.

**Feeling valued.** Although hospice volunteers ideally feel valued by other members of the hospice care team, some studies have found that volunteers reported leaving a program due to negative attitudes toward volunteers from nurses and other staff members (Brichacek, 1988; Seibold, Rossi, Berteotti, Soprych, & McQuillan, 1987). While volunteers often reported feeling appreciated and supported, Claxton-Oldfield, S. and Claxton-Oldfield, J. (2004) found that volunteers felt most valued by patients and families and least valued by nurses, doctors, and social workers. Findings from a study on nurses' perceptions of hospice volunteers revealed that the nursing staff valued volunteer contributions, yet nurses regarded all other members of the care team as more valuable (Claxton-Oldfield, S., Hastings, & Claxton-Oldfield, J., 2008). The nurses' perceptions indicated that the perceived value of the volunteer role might increase if nurses and other staff attended informational sessions explaining the volunteer role. Nurses and other hospice staff might value volunteers more highly when educated about volunteer selection/recruitment, training, appropriate roles/responsibilities, ways that volunteers can ease their workloads, and reasons for including volunteers in team meetings (Claxton-Oldfield, S., et al., 2008).

**Feeling useful.** Feeling valued as members of the hospice team may improve commitment to the volunteer role. Feeling useful also surfaces as important since many hospice volunteers become involved due to a desire to help others (Claxton-Oldfield, S. et al., 2004;

Planalp & Trost, 2009a, b). Although most volunteer time involves patient interactions, research has indicated that volunteers may feel more utilized when serving in both administrative and patient oriented roles. On-going communication between volunteer coordinators and volunteers helps to prevent dissatisfaction among volunteers; therefore, service and connection to the organization should continue for volunteers when the volunteer has no particular patient assignment (Claxton-Oldfield, S., & Claxton-Oldfield, J., 2008). For example, consistent communication contact might involve informing the volunteer that new patient referrals are slow and/or suggesting other service capacities for the volunteer (e. g., fundraising, office work).

### **Ethical Dilemmas**

Paid health care professionals typically encounter some form of professional training regarding ethics, but hospice volunteers usually experience only brief exposure to ethics education. While hospice volunteer training may include some ethics topics related to the Health Insurance Portability & Accountability Act (HIPAA), volunteer training programs frequently overlook discussions of actual ethical dilemmas encountered during interpersonal interactions between volunteers, patients, and families (Berry & Planalp, 2009).

While exploring ethical dilemmas mentioned during interviews with hospice volunteers, Berry and Planalp (2009) noted ethics themes such as appropriateness of gifts from patients, concerns about patient care and family issues, challenges related to roles and boundaries for volunteers, and issues related to hastening death and/or choices about suicide. Berry and Planalp suggested ethics training after volunteers have opportunities to encounter ethical issues while working with patients.

Berry and Planalp (2009) mentioned a new realization from their study regarding the “unusual status of volunteers as neither health professionals nor friends” (p. 462). Additional

hospice volunteer training on ethics would focus on negotiating the blurred role of the hospice volunteer as both a representative of the hospice organization and a friend, as recommended by Berry and Planalp. Health professionals rarely receive offers of gifts and professionalism expectations warrant decline of gifts, on the other hand, friends often receive and accept offers of gifts as expressions of friendship. The role ambiguity of hospice volunteers complicates decisions regarding appropriate behavior and ethics as volunteers relate to patients and families.

### **Inquiry Two**

Issues related to facing death, feeling valued and useful, and encountering ethical dilemmas contribute to the hospice volunteer experience. I investigated the similarities and differences between less experienced volunteers and more experienced volunteers by exploring the following area of inquiry in this study:

Inquiry Two: How do new volunteer perspectives compare with perspectives of experienced hospice volunteers?

After considering challenges and rewards that may occur during hospice volunteer service, I considered potential changes in perspective that may occur as volunteers gain increased experience as they continue helping dying patients and their families.

### **Patient-Centered Care and Relationships**

A patient-centered care (PCC) approach extends beyond caring for the physical needs of patients by considering psychological and social factors of the patient and the family (Sparks, et al., 2007). Communicating with a patient-centered approach calls physicians to expand beyond the standard biomedical approach to care by helping patients feel understood, attending to the psychosocial context, expanding patient involvement by enhancing the patient's understanding of their illness (Epstein et al., 2005). Care providers using a PCC approach produce higher

patient satisfaction by listening, assessing, and responding to the patient's level of understanding about their own health condition (Mast, Kindlimann, & Langewitz, 2005; Wanzer, Booth-Butterfield, & Gruber, 2009). Illuminating the deficiencies of the current healthcare system in relation to end-of-life and palliative care, Wittenberg-Lyles, Goldsmith, Ragan, and Sanchez-Reilly (2010) recently outlined the acute need for relational, patient-centered communication between palliative care providers and patients/families. Providers employing a patient-centered communication approach emphasize "the collaborative, reciprocal nature of clinician-patient-family interactions" (p. 244). Providers practicing PCC must thoughtfully adapt and create shared understandings with patients and families.

The goal of PCC involves empowering patients as active participants in their own healthcare (Reynolds, 2009). Providers interested in implementing PCC must exercise strong communication skills, advocate for patients, and address patient needs effectively and safely (Reynolds, 2009; Stewart, 1995). Researchers have linked PCC to higher patient satisfaction ratings, better adherence to health suggestions and prescribed treatments, overall better outcomes, and more cost-effective care (Reynolds, 2009). For example, Wanzer, Booth-Butterfield, and Gruber (2004) found a connection between higher levels of overall satisfaction and improved functional, physical, and biomedical outcomes when following a PCC approach.

Wittenberg-Lyles and colleagues (2010) promoted the PCC approach as a way for palliative care providers to recognize the family caregiver as an additional unit of care. According to their research on family members of chronically ill or dying patients, a need exists for increased support and preparation as patients and families struggle during the final stages of life. Effective communication between healthcare providers, patients, and families becomes especially important during end-of-life care as patients and families wade through difficult

adjustments and plans. The primarily relational and social interactions enacted by hospice volunteers may particularly benefit from a PCC approach.

### **Emotions and Relationships in Hospice Care**

Gurguis-Younger and Grafanaki (2008) identified the theme of emotional resilience as central to the palliative care volunteer experience. The authors discussed emotional resilience as “the product of direct personal experience of pain and loss, as well as exposure to death and dying in the volunteer settings” (p. 19). Palliative care volunteers participating in their study mentioned how the resolution of their own past loss experiences contributed to the emotional resilience often needed during volunteer work. An appreciation for living and relating with others surfaced as a sustaining factor leading to personal growth during the palliative care volunteer experience. The authors also discussed the role of emotional resilience in creating a strong sense of community across the palliative care team. The volunteers suggested the community value of “placing aside their own agendas and focusing on the support of the dying person and his or her family” (p. 21). Volunteers discussed a broadening of their own perspectives as they learned to value their connections with dying patients. The volunteers reported feeling a sense of deeper understanding and meaning in their own lives. Simultaneously, volunteers emphasized the need for preserving some personal and emotional distance in the midst of deep connections with patients and families. The volunteers discussed the challenge of maintaining boundaries and preserving emotional distance while encountering interactions marked by authenticity and compassion (Gurguis-Younger & Grafanaki, 2008).

### **Inquiry Three**

The PCC approach represents a relational perspective for healthcare and communication in the hospice context. Guided by an interest in PCC, I considered the following area of inquiry during this research processes:

Inquiry Three: To what extent, if any, do the experiences of the hospice volunteers reflect a patient-centered care approach?

I explored the role of PCC, emotions, and relationships embedded in the experiences of hospice volunteers during the interview phase of this research.

### **Mindfulness and Communication**

Originally derived from Chinese medicine and Buddhist practice, an interest in the concept of mindfulness among the medical community corresponded with the shift toward a PCC approach (Epstein, 2003; Wood, 2004). Attention and awareness represent the fundamental activities of the consciousness characterizing the concept of mindfulness (Brown, Ryan, Creswell, 2007). Attention involves turning toward or taking notice of some stimulus. Awareness involves a conscious use of one's senses and brain activity. Brown and colleagues assert that "mindfulness concerns a clear awareness of one's inner and outer worlds, including thoughts, emotions, sensations, actions, or surroundings as they exist at any given moment" (p. 213).

Leary and Tate (2007) expand the definition of mindfulness by describing five core components: (a) mindful attention, (b) diminished self-talk, (c) nonjudgment, (d) nondoing, and (e) a particular set of philosophical, ethical, or therapeutic beliefs. Mindful attention involves the use of multiple senses to pay attention to the present experience. Diminished self-talk involves "quieting self-chatter—the running flow of mental commentary, thoughts about the past and future, self-evaluations, judgments, and other extraneous reactions" (p. 251). Nonjudgment

involves the ability to experience the present moment without judging the situation or one's reactions to the situation. The concept of nondoing encourages individuals to release preconceived expectations and to simply allow life to occur naturally. The philosophy promoting mindfulness involves "a variety of personal and social benefits, including reducing negative emotions (and stress), becoming a better person, seeing oneself and the world more accurately, or having spiritual experiences" (p. 252).

The mindfulness approach assumes that compassion and mindfulness reside naturally within human behavior when we fully engage with others and become present to the moment, experience, or conversation (Wood, 2004). Mindfulness involves a "state of mind that permits insight, presence, and reflection" as it "applies equally to cognitive, technical, and interpersonal aspects of medicine, and invites a deeper examination of the process of care" (Epstein, 2003, p. 1).

Although medical training rarely includes any formal education on mindfulness, patients report an appreciation for care providers demonstrating behavior associated with mindfulness practices (Epstein, 2003). For example, patients reported an appreciation for healthcare providers who respond to patients with attentiveness, express an interest in the health concerns discussed by the patients, exhibit overall interest in the personal well-being of patients, and express compassion toward patients (Epstein, 2003). When discussed more broadly in the context of communication, a mindfulness approach can facilitate a commitment to attentive and engaged listening (Wood, 2004). Conducive to the mindfulness approach, the attentive role of hospice volunteers often allows for the formation of special and trusted relationships between volunteers and patients/families (Claxton-Oldfield, S., Gosselin, & Claxton-Oldfield, J., 2009).

### **Authentic Encounters**

During his extensive work on mindfulness, Epstein (2003) identified denial (e. g., denial of bad news, denial of pending death) as the least mindful approach to providing healthcare. In a study of nurses who communicate effectively with patients facing death, Seno (2010) concurred with the importance of accepting death as crucial to improving nursing care during the final stages of a patient's life. Seno explained that a key aspect of authenticity resides in the notion of personally accepting, both as a patient and caregiver, an impending death. Reflecting on death can help people develop a stronger appreciation of living as they become "swayed to live more fully and to help others live fully too" (p. 379). A person may transform from inauthentic to authentic through raised awareness and a willingness to communicate more consciously (Seno, 2010). Seno explained authenticity as a deeply personal quality for an individual but asserted that authentic encounters can also occur when individuals live and practice consciousness each day.

### **Focusing on the Positive**

While describing communication in hospice volunteer-patient relationships, Foster (2002) emphasized a focus on the patient as living rather than dying. Volunteers learned that "contrary to our expectations, very little of our experiences with hospice patients centered on death" (p. 249). Faced with the context of end-of-life care, an ability to shift the focus to living rather than dying suggests an advanced level of consciousness stemming from the hospice volunteer experience.

The narratives of hospice volunteers revealed that stories reflecting on death encounters provided a venue for individuals to contemplate personal emotions/feelings, as well as religious/spiritual perspectives on death (Wittenberg-Lyles, 2006). While Wittenberg-Lyles recognized the common perception of death as an ultimately negative experience, her narrative

analysis revealed a transformed view of death. The narratives of hospice volunteers represented death as a more positive experience for the hospice volunteers largely because volunteers can “witness good deaths. Such deaths, loosely defined in accordance with hospice philosophy, include dying with someone by your side, free of pain, and in a peaceful environment (typically the patient’s home)” (p. 53). The sense-making role of stories, along with the development of a transformed view of death, reflected the introspective and thoughtful approach exercised by the hospice volunteers in her study.

The acknowledgment of death, along with recognition of the preciousness of life, surfaced as important during the palliative care volunteer experiences discussed by Gurguis-Younger and Grafanaki (2008). Their research found that volunteers were “aware of the significance of the here and now and the benefits of simply being there in the moment for patients” (p. 20). Similarly, Seno (2010) noted how nurses considered the importance of just being with patients and families as among the most helpful approach in caring for dying patients. Seno explained that the term *being* “indicates not what the nurse is ‘doing,’ but how she was being in the encounter” (p. 378). The heightened attention on being in the moment with patients may lead palliative care volunteers to view the role as an exploration of themselves and a learning opportunity (Gurguis-Younger & Grafanaki, 2008).

### **Mindfulness in Palliative Care Communication**

A recently proposed model of palliative care communication explained key communication skills by using the acronym of COMFORT (Villagran, Goldsmith, Wittenberg-Lyles, & Baldwin, 2010). The components of the COMFORT model include Communication, Orientation, Mindfulness, Family, Ongoing, Reiterative Messages, and Team as important elements for improving communication between patients, families, and providers. In the context

of this research on the hospice volunteer experience, the two concepts of communication and mindfulness emerged as particularly relevant components.

**COMFORT and communication.** The palliative care communication concepts described by Villagran and colleagues (2010), reflect a perspective that encourages healthcare providers to listen more and to focus on a higher quality, lower quantity of verbal messages. Providers must speak with clear language, occasionally reiterating the message, so that the patient understands the reality of the diagnosis. Villagran and colleagues discussed nonverbal immediacy (e. g., maintaining eye contact, leaning forward, avoiding fidgeting, and nodding agreement/understanding) as essential when delivering bad news to patients. These communication recommendations offered support for suggestions connecting PCC and mindfulness approaches to hospice care situations.

**COMFORT and mindfulness.** Employing the concept of mindfulness, Villagran et al. (2010) recommended that palliative care providers must “be present in medical interactions, physically, psychologically, and emotionally” (p. 227). Mindfulness in healthcare contexts represents a process that providers can utilize while forging interpersonal connections and implementing patient-centered healthcare practices. Providers must consider verbal and nonverbal interactions when practicing mindfulness in healthcare settings. Three aspects contribute to the mindfulness communication component presented by Villigran et al. (2010): reduced self-talk and fewer predetermined scripts, lower levels of prejudgment regarding how interactions may occur along with lower judgment about the patient and family, and adaptability to changes during the interaction.

#### **Inquiry Four**

Mindfulness practices represent a more recent trend toward improving healthcare. Villagran and colleagues (2010) introduced a link between the provision of palliative care and the mindfulness approach in health communication while presenting the COMFORT model. Based on previous research on mindfulness in health communication contexts, I investigated a fourth area of inquiry during this research:

Inquiry Four: To what extent, if any, do the experiences of the hospice volunteers reflect a mindfulness approach?

While exploring the typical roles, tasks, motivations, and characteristics of hospice volunteers I became curious about potential connections between the communication experiences of the hospice volunteers and the practices of mindfulness in healthcare settings.

### **Summary**

First, the review of literature presented in this chapter provided an informative summary to explain the role of hospice volunteers. Second, I discussed challenges, rewards, and emotions associated with relational aspects of volunteering for hospice. While focused on the challenges and rewards of the hospice volunteer experience, I have addressed issues such as facing death, feeling valued by the organization, and ethical dilemmas. Third, I provided a summary of the patient-centered care approach and relational dynamics as potential insights to the hospice/palliative care context. Fourth, I discussed the practice of mindfulness and explored connections to the hospice/palliative care context. Throughout this chapter, I have linked the four central areas of inquiry to the relevant literature. The next chapter explains the methodological processes used in this research project.

## CHAPTER THREE: METHODS

*“People have so much to offer and say and boy you can learn from somebody for a single day, no matter how old they are and no matter how old you are... if you can do that I think the whole world is so open to you” (Volunteer Five).*

Providing an overview of the epistemological assumptions that guide qualitative research, this methods chapter reveals perspectives on ethnographic fieldwork, interview methods, and grounded theory analysis. In-depth interviewing served as the methodological approach guiding this exploration of hospice volunteer experiences with patients and families during the final stages of life. Prior to engaging in interviews with hospice volunteers, a fieldwork project informed my understanding of the hospice volunteer context. This chapter includes description of the research site, an explanation of participant recruitment, an account of the development of the interview guide, and a rationale for analysis decisions.

**Research Site**

After securing approval from the University’s Human Subjects Review Board (Appendix D), I began this qualitative research project with a non-profit hospice organization serving the individuals and families of a midsized city in the Midwest. For the purposes of this study, I refer to the participating hospice organization as Midwest Hospice. Due to an acquaintance with an administrative staff member, I established a collaborative research relationship with the volunteer services team. Following an introductory meeting, the volunteer services director and I communicated frequently regarding plans for the research project.

Midwest Hospice represents the largest hospice service in the region, providing palliative care to a metropolitan population of about 300,000 along with several surrounding counties. Although a majority of Midwest Hospice patients receive in-home care, Midwest Hospice does

provide fully staffed inpatient care at two local facilities. Midwest Hospice serves approximately 230 homecare patients and 110 facility inpatients each month. Midwest Hospice operates with the assistance of approximately 400 employees, with about 300 of the employee serving as nurses and hospice aides. The organization supports about 250 adult volunteers and about 75 teen volunteers.

The director of volunteer services at Midwest Hospice welcomed my attendance and observation of a new volunteer training program. New volunteers must participate in a training course comprised of twenty-seven classroom hours. The training programs involve a total of nine sessions conducted over a period of several weeks. The training sessions are held in a conference room at an inpatient facility serviced by Midwest Hospice. Twenty-one new volunteers attended the training session that I observed. At the initial training session, I declared myself as a participant-observer involved in a dissertation-level research project. Similar to the new volunteer attendees, I witnessed the presentations provided during the training sessions. I also wrote field notes to record important ideas or questions raised during the training sessions.

Ethnographic observations, while not the primary research method discussed in this dissertation project, provided insight regarding the mission and organizational environment of Midwest Hospice. The observations also enriched my understanding of the hospice volunteer experience. The field notes assisted in the development of an interview guide used during the interview phase of this research project, as discussed above. Observations of the volunteer training program assisted in preparations for volunteer interviews by giving me more in-depth perspective of the hospice volunteer experience.

## Epistemological Approach

### Qualitative Methods

Qualitative methods provide a flexible approach for exploring issues in communication research. Corbin and Strauss (2008) discussed several notable advantages attributed to qualitative research methodology. In comparison to quantitative research methods, qualitative work allows for more fluidity and ambiguity when approaching a particular area of inquiry. Qualitative methods remain open to modification and development as the research project progresses. Nonacademic audiences may discover greater accessibility to and understanding of qualitative research as qualitative researchers often report findings in the form of narratives and direct quotations from the research participants.

Qualitative research methods represent a growing methodological tool being used by health communication researchers (Kim, Park, Yoo, & Shen, 2010; Kreps, 2008; Lederman, LeGreco, Schuwerk, & Cripe, 2008). A content analysis of journal articles in *Health Communication*, one of the first communication journals that chronicles the broad view of this area of research and allows readers to see early findings and the current trends in research, revealed that qualitative health communication research has significantly increased over the past two decades (Kim et al., 2010). The increased use of qualitative approaches to health communication research reflects the acceptance that “qualitative research methods introduce in-depth understanding of the phenomena of interest” (Kim et al., 2010).

My epistemological perspective on qualitative research aligns with claims articulated by Corbin and Strauss (2008) who asserted that qualitative research essentially bases theorizing on actual experience rather than testing, surveying, or experimenting. In addition to the explanation of experiences and sense-making processes, qualitative research also involves an understanding

of the importance of locating the experience within a larger context. Qualitative researchers must describe context in connection with the research process because individual responses differ with each varied action or interaction.

### **Ethnographic Fieldwork**

**Participant observations.** Ethnographic observations represent an essential method of data collection in this research approach. The observations gathered during fieldwork assist the researcher in interpreting and representing cultures due to the ability of experiencing firsthand cultural elements such as environments, groups, individuals, rituals, social interactions, and backgrounds (Van Maanen, 1988). The role of participant-observer allows ethnographers to immerse themselves in the worlds of participants in order to gain insight into the meaningful contexts of the participant experience (Emerson, Fretz, & Shaw, 1995). By witnessing firsthand the common affairs of the participants, the ethnographer develops a rich understanding of feelings, experiences, and assumptions not easily accessed through secondhand accounts gained during interviews.

Prior to conducting interviews, I participated as an observer in a training program for new hospice volunteers. My role as participant-observer involved sitting in the training classroom alongside the new hospice volunteers throughout a nine session training program. The training revealed important information that assisted in the later development of the interview guide and in my conversations with volunteers. Participating in the training session enriched my understanding of the hospice organizational climate, the roles and expectations of a hospice volunteer, the challenges and rewards of volunteering for hospice, and some perspective into the motivations inspiring individuals to volunteer for hospice.

The presence of a researcher often raises questions regarding the influence on member behaviors (Van Maanen, 1988). My presence, however, seemed to have minimally influenced the training experience since all participants, including myself, observed the training as primarily passive audience members. My immersion in the training sessions allowed me to see “first-hand and up close how people grapple with uncertainty and confusion, how meanings emerge through talk and collective action, how understanding and interpretations change over time” (Emerson et al., 1995, p. 4). As I advanced through the nine training sessions, I observed the presentation of materials along with the classroom reactions of volunteer trainees as they encountered the information. These observations assisted me in developing an appropriate interview guide that helped facilitate engaged, meaningful conversations with volunteers. Field notes recorded during the observations also helped to prepare me for the interview process.

**Field notes.** The role of participant-observer requires the researcher to carefully record insights while immersed in the research context. A systematic approach to maintaining research field notes helps the researcher to create documents for data analysis (Emerson et al., 1995). Although debates exist about the proper use of field notes and whether note-taking helps or hinders research insight, I viewed field notes as essential for retaining knowledge gained during the observations of the training sessions. Utilizing field notes ensures that ethnographers “hone these skills and that the quality of ethnography will improve with self-conscious attention to how to write field notes” (p. xi). While observing volunteer training sessions, I regularly wrote notes during the presentation of information. Upon leaving the sessions, I typed any handwritten notes and organized the observations into categories (e.g., describing the scene, trainee comments/questions, reflections on organizational climate, interesting themes/ideas mentioned, personal thoughts, and so forth).

The process of taking notes further revealed my dual role as a participant-observer. The act of attending sessions alongside the volunteer trainees reflected the participant role, while taking notes reflected the observer role as someone conducting research. The field notes provided a summary and guide as I developed the primary research area of this dissertation project – the interviews of hospice volunteer experiences.

**Reflexivity and personal choices.** Decisions related to logistics and planning were carefully considered during initial phases of this research project. When given the personal opportunity to offer my own time as a hospice volunteer at the beginning of the project, I was faced with an important personal research choice. As I contemplated options for immersion in the research site, I chose to decline the opportunity to serve as a hospice volunteer during the time of the research project. Volunteering for hospice presents powerful and informative ethnographic research opportunities. I decided, however, that the initial emotional experiences of my own service as a hospice volunteer might have proven overly influential and limited my ability to ask questions and to listen for fresh responses from other volunteers. Rather than reflecting on my personal experience as a hospice volunteer, this project instead focused on the experiences of many hospice volunteers by comparing their responses to a set of interview questions.

### **Recruitment of Participants**

After the observations of the training ended, I met with the director of volunteer services to discuss the interview phase of this research project. The volunteer services staff collaborated to compile two lists of potential interview participants. One list included the names and phone numbers of the twenty-one new volunteers who had just completed the training program. The second list provided the names and phone numbers of forty experienced volunteers serving for at

least two years with Midwest Hospice. In an effort to talk with a variety of interview participants, I requested that the lists of volunteers should include different personality types, ages, backgrounds, and experiences.

In the spring of 2011, I began calling potential participants approximately four months after the conclusion of the new volunteer training sessions. Most of the new volunteers had received volunteer assignments and gained some initial experience with patients during the first four month period. The new volunteers recalled my role as a participant-observer in their training sessions and seemed eager to discuss their first experiences. The more experienced volunteers also welcomed the opportunity to participate in this research with Midwest Hospice.

The director of volunteer services mailed an introductory letter to inform potential participants of this research project and to prepare the volunteers for the phone call. I initiated phone contact to request interview meetings after potential participants had received the letter from Midwest Hospice. As I called potential participants I introduced myself as a student researcher at a local university. After reminding potential participants of the letter from Midwest Hospice, I briefly explained the purpose of this research. I described the research as a project to learn more about communication at hospice organizations and about volunteer experiences. I informed participants that I would be visiting both of the local inpatient facilities and that I welcomed an opportunity to meet with them onsite to talk about their volunteer experiences. If the potential participant indicated a willingness to engage in an interview, I asked about their availability and then offered time slots for meetings at the Midwest Hospice inpatient locations. This approach minimized the time and effort needed from participants to meet with me in person.

The initial phone calls led to interview meetings with a total of thirty volunteers of Midwest Hospice. The ages of participants ranged from approximately forty-five years old to

approximately eighty years old. Seven of the interview participants were male. The list of new volunteers yielded thirteen interview meetings. The new volunteers ( $n = 13$ ) were those who had completed the new volunteer training program witnessed during the ethnographic research from four months prior. The list of more experienced volunteers yielded seventeen interview meetings. The experienced volunteers ( $n = 17$ ) were those who had provided at least two years of hospice volunteer service to Midwest Hospice. The range of service years for the experienced volunteers at Midwest Hospice spanned from two years to twenty years (median = four years of service, mean = seven years of service). The new and experienced volunteers who participated in the interviews proved extremely helpful and accommodating throughout the interview processes. The thirty interview participants in this study were all willing to meet at one of the Midwest Hospice inpatient locations.

### **Interviewing Participants**

**The interview setting.** In some research projects the interviewer may extricate more authentic participant responses when the interview is held at a neutral location, separate from the organization. However, for this particular research project I felt that the organizational setting provided the most logical choice as an interview location. I was not concerned about the influence of the organizational setting on participant responses since the participants were volunteers, and not paid employees. A small meeting room was provided during scheduled times at each of the Midwest Hospice inpatient locations. The meeting rooms included a conference table and chairs for approximately eight individuals. A window with a view of the lawn was available in the meeting rooms. This professional, yet intimate, space provided a safe and familiar environment for the interview process.

Each individual interview participant agreed to visit a Midwest Hospice inpatient location on a certain day and time for the interview meeting. When the participant arrived I greeted them with a handshake while standing at the door. I thanked the participant and invited them to sit with me at the table of the meeting room. Following an explanation of this project and the informed consent document (Appendix E) approved by the Human Subjects Review Board, I asked each participant for permission to record the interview conversation. All participants provided consent for the research project and agreed to the use of a digital recording device. After obtaining the signature of each participant, I started the interview with a warm-up conversation and/or a moment of small talk. I eased into the interview questions with simple inquiries (e. g., How long have you been a volunteer with Hospice? What types of volunteer experiences have you had so far?), then proceeded to more specific questions.

Individual interviews ranged from approximately thirty-five minutes to eight-five minutes with an average interview encounter of fifty minutes. The thirty interviews yielded approximately 1500 minutes (25 hours) of actual recorded interview time. The transcribed interviews totaled more than 750 pages of double-spaced type. The typed interview transcriptions assisted in the systematic analysis of the interviews. In an effort to protect the privacy of the participants and of Midwest Hospice, I was the sole researcher to review the actual transcribed documents.

**Conducting interviews.** Qualitative interviewing “permits an in-depth exploration of a particular topic with a person who has had the relevant experiences” (Charmaz, 2006, p. 25). In-depth interviewing allows the researcher to focus on a narrow spectrum of topics and to explore those topics in detail (Rubin & Rubin, 2005). Effective interview questions can help the researcher extract more detailed descriptions of particular interviewee experiences than

information typically gleaned from everyday conversations; thus, in-depth interviews serve as a powerful and needed complement to participant-observation. The interviewer role focuses on listening, making sensitive observations, and encouraging responses from the interviewee. The use of open-ended, nonjudgmental questions helps the researcher to draw out information from the participant as statements and stories emerge during the interview conversation (Charmaz, 2006). The use of in-depth interviews afforded an opportunity to gain insider knowledge from volunteers at Midwest Hospice.

The development of an interview guide allows the researcher to group topics and questions in an organized way, yet the researcher can ask questions in different ways to different participants (Lindolf & Taylor, 2002). The interview guide included twenty-one questions (Appendix A). I initially formed the interview questions around areas of interest that surfaced while I reviewed hospice literature and observed the new volunteer training program. Although twenty-one questions appeared on the interview guide, not all questions were addressed in every interview. Adherence to an interview guide proved useful and provided a framework for exploring the volunteer experiences in a consistent manner. However, if a researcher adheres too rigidly to the guide they risk stifling the conversation. An open-ended interview approach allows for a more conversational, relaxed tone for dialogue between the interviewer and the participants. As I listened for participant responses during interviews, I asked follow-up questions based on the themes and key ideas of the interview guide (Rubin & Rubin, 2005). The open-ended approach used during the interview process allowed the volunteers to discuss thoughts more freely while I followed the general direction of the interview guide (Charmaz, 2006).

The questions included on the interview guide aimed toward reflective and/or personal volunteer responses on topics such as illness, death, loss, grief, emotions, relationships, and

spirituality. While facilitating the interview process, I realized that some of the questions on the original interview guide elicited minimal responses from participants. In some interviews, certain questions probed toward a deep level of personal reflection not yet considered by the participant (e. g., Q12 “As you reflect on your time as a volunteer, please give me an example of how hospice has helped someone change their views on living and dying”). At times, participants seemed unclear or confused about how to respond to certain interview questions (e. g., Q10 “How would you describe the relationship you have formed with patients and their families”). The sensitive and ambiguous nature of some interview questions further spoke to the importance of an open-ended interview process as a flexible approach to research conversations. Despite the slight modifications to the order and totality of the interview guide during the individual interviews, participants often provided unsolicited insight and perspectives related to the original questions. For example, interview question ten used the term relationship. Some volunteers only addressed this topic when asked directly, while others discussed relationships without specific prompting.

While the original interview guide included twenty-one questions addressing an array of topics, the ultimate focus of this study concentrated on responses to the questions that emerged as particularly relevant regarding patient-centered care, mindfulness, and communication encounters with patients and families. Therefore, I emphasized certain questions and responses during the analysis of the interview transcripts. The emphasized questions appear in bold font (Appendix A). Although the current research avoided an analysis of some interview questions from the original interview guide, these overlooked questions and responses remain available in the transcribed interview conversations. The excluded questions from the interview guide represented ideas beyond the scope of this dissertation. The unused portions of the interview

conversations remain valuable as the responses to the excluded questions address other interesting topics for future research. The adaptable approach of qualitative research allows for decision-making throughout the research process that increases the efficiency and efficacy of the project (Corbin & Strauss, 2008). For example, throughout the project qualitative researchers make decisions such as which questions one should emphasize for a particular analysis. The qualitative methods of grounded theory provided a flexible approach to conducting and analyzing the interviews during this study.

### **Grounded Theory Method**

The grounded theory method of conducting thematic analyses represented the primary analytic tool in this study. In a recent overview explaining the evolution of grounded theory methods, Morse (2009) defined grounded theory as “a way of thinking about data – a process of conceptualization – of theorizing from data, so that the end result is a theory that the scientist produces from data collected by interviewing and observing everyday life” (p. 18). Theory construction occurs as concepts emerge from the data analysis in interpretive research studies. The grounded theory method represents the most frequently used theoretical framework for interpretive health communication research (Beck et al., 2004; Kim, Park, Yoo, & Shen, 2010).

### **Constant Comparison**

This analysis relied on the constant comparison method, a strategy that compares one incident or situation to another by looking for similarities and differences (Corbin & Strauss, 2008; Glaser & Strauss, 1967). Aiming toward the development of new theory, the constant comparison method allows the researcher to work continuously toward redesigning and reintegrating the theoretical notions (Glaser & Strauss, 1967). Ultimately, the themes identified throughout this analysis contributed to the development of a theoretical model describing the

roles of communication, patient-centered care, and mindfulness in the hospice volunteer experience. The theoretical model developed during this analysis is explained in later chapters of this dissertation.

The original proposal of the constant comparative method by Glaser and Strauss (1967) challenged traditional data analysis techniques in which the entire collection and coding of the data set occurred prior to any analysis. The constant comparison strategy compares one incident or situation to another by looking for similarities and differences (Corbin & Strauss, 2008; Glaser & Strauss, 1967).

Grounded theory practitioners maintain the use of rigorous coding schemes, but the constant comparison approach allows researchers to consider and reconsider theoretical ideas while working more closely with the data throughout the data collection process. The relative simplicity of comparing one incident with another incident may perhaps distract from the essential function of the constant comparison method as a way of differentiating between categories or themes (Corbin & Strauss, 2008). Glaser and Strauss (1967) explained four stages of the constant comparison method. The four stages of constant comparison provide a guide as the analyst compares incidents and distinguishes between themes.

**Stage one: Comparing.** The first stage of the constant comparison method involves “comparing incidents applicable to each category” (Glaser & Strauss, 1967, p. 105). As the researcher reviews any given incident, he/she may find that one incident relates to multiple categories or questions. For example, I discovered similar accounts across the interviews when volunteers shared information about experiencing the death of a close relative. Although the volunteer descriptions of losing a close relative seemed like comparable incidents, the accounts appeared in different sections of the interviews based on when the individual participant

responded with the most compelling and relevant information. As I analyzed the interview transcripts, I searched for comparable responses that, perhaps not surprisingly, often derived from quite divergent questions. For example, one volunteer might discuss the death of a loved as an explanation for why they became a hospice volunteer, while another might discuss the death of a loved as they describe the role of emotions in their volunteer work.

**Stage two: Integrating.** The second stage of the constant comparison method involves “integrating categories and their properties” (Glaser & Strauss, 1967, p. 108). The initial comparisons between incidents led to the identification of categorical properties. For example, as I noted the incident of experiencing the death of a close relative in various sections of the overall interviews, I started to notice the broad category of personal loss experiences—a category I had not initially anticipated. Glaser and Strauss (1967) explained that “theory develops, as different categories and their properties tend to become integrated through constant comparisons” (p. 109). The integration between categories and properties thereby drive the analyst to a more in-depth understanding of theoretical concepts. By comparing incidents of personal loss experiences described by participants in this study, I developed a deeper understanding of how personal loss might relate to empathic communication, a concept related to patient-centered care and mindfulness. The category of personal loss experiences emerged during this research and its development can be explained by applying Glaser and Strauss’ integration/delimiting theory.

**Stage three: Delimiting theory.** The third stage, “delimiting the theory” (Glaser & Strauss, 1967, p. 109), aims at streamlining the theoretical concepts so that the analyst avoids feeling overwhelmed by the mounting task of constantly comparing more and more categories and properties. As modifications occur with less frequency during the comparison process, the analyst may note a solidification of the theoretical concepts under development. Later

modifications may simply serve to clarify or explain the concepts with further details. The delimiting process allows the researcher to trim the earlier list of categories to a list of shorter, more salient categories. As fewer new aspects emerge, the analyst reaches the point of theoretical saturation. Although the analyst may notice new aspects after extensive coding and comparisons, theoretical saturation helps determine “when enough is enough” (Stern, 2009, p. 117). For example, as I noted multiple accounts of personal loss shared by participants during various parts of the interviews, I initially started connecting these incidents to individualized and/or more specific properties (e. g., motivated by loss of spouse, controlling emotions due to experience of parent’s death, committed to organization due to good care of relative). The delimiting process occurred as I integrated the properties into sub-categories. Ultimately, the overarching category of personal loss experience emerged as a more solidified description of the comparisons. Rather than assign every reaction to a particular stimulant (e. g., loss of parent as opposed to loss of spouse), I realized that many of these reactions belonged to the category of personal loss experience; this realization might not have occurred outside of an understanding of delimiting theory.

Glaser and Strauss (1967) offered the delimiting stage as an economical view for research “since working within limits forces the analyst to spend his time and effort only on data relevant to his categories” (p. 112). Charmaz (2006) also noted the importance of comparisons in making analytic sense of data. However, Charmaz challenged the idea of theoretical saturation by warning that our own ideas may not match the ideas emerging in the data. Charmaz recommended that analysts remain open to the emergence of new ideas which “may challenge taken-for-granted understandings” (p. 54). For example, as I continuously reviewed the interview transcripts for comparisons, I tried to remain open regarding whether a participant’s

description of the death of a close relative indicated some new direction of categorical properties (i.e., I considered the category of personal loss experience in comparison to incidents of overcoming grief and/or other personal obstacles). The risk of choosing categories based on personal predetermined biases of the researcher seemed worthwhile in relation to the benefits of categories derived from organic, emerging emphases.

**Stage four: Writing theory.** The fourth stage of constant comparison involves actually “writing theory” (Glaser & Strauss, 1967, p. 113). Not until the researcher feels confident about the categories and themes identified with the constant comparison method can the research findings develop into publication. Glaser and Strauss suggested that theory writing may commence when the analysis forms “a systematic substantive theory, that it is a reasonably accurate statement of the matters studied” (p. 113). For example, although the category of personal loss experiences emerged as a notable comparison across incidents during the analysis of interview transcripts, the final description of a new theoretical model does not focus on personal loss as a major theme. The final stage of writing theory represents a challenging phase of the analysis process as it represents the cumulative, final product of a long analytic process. For example, while personal loss experiences surfaced across many of the interviews in my study, the final presentation of a theoretical model emphasizes the role of a focus on others and personal experiences rather than concentrating on personal loss experiences.

### **Coding**

Coding involves a process of “extracting concepts from raw data and developing them in terms of their properties and dimensions” (Corbin and Strauss, 2008, p. 159). In their introductory text on grounded theory, Glaser and Strauss (1967) explained the constant comparative method rather thoroughly, but offered little explanation of the actual analytic coding

process. As the study and use of grounded theory developed in subsequent decades, scholars wrote detailed explanatory guidelines to direct novice researchers using grounded theory analysis. For example, Glaser (1978) wrote a chapter on theoretical coding in which he explained that “the essential relationship between data and theory is a conceptual code...conceptual codes (categories and their properties) which have been generated from the data as indicators, we ‘discover’ a grounded theory” (p. 55). The constant comparison method involves a coding process utilized to organize understandings gained by the researcher as he/she compares incidents and theoretical concepts.

Grounded theorists may employ several analytic strategies while analyzing data. Many qualitative researchers seek ways to develop codes as they analyze data. The development of codes involves the recognition of key concepts that become noticeable as researchers review the data. Charmaz (2006) explained coding as a way to “separate, sort, and synthesize data” (p. 3). Coding allows the researcher to attach labels to parts of data and to recognize fruitful comparisons. Ultimately the use of codes provides the organizational structure analysts need in order to systematically exercise the constant comparison method.

Corbin and Strauss (2008) provided systematic details to guide initial analyses through the coding process. Coding procedures assist the analyst in making sense of the data. Corbin and Strauss noted, however, that the procedures used for analyzing data are not as important as actually identifying the meaning of data. A basic three-step process for initial coding can involve breaking data into manageable pieces, exploring pieces for ideas within, and giving conceptual names to the pieces.

**Open and selective coding.** Glaser (1978) defined the terms open coding and selective coding. The use of open and selective coding allows the analyst to identify the meaning of the

data as they break down, explore, and create conceptual names throughout the analysis process. Open coding involves “coding the data in every way possible” (p. 56), while selective coding occurs after a substantial amount of open coding. Glaser explained open codes and selective codes as *substantive* since they refer to the more concrete, real meanings derived directly from raw data. The use of open and selective coding assists the analyst in the development of core conceptual categories (Charmaz, 2006). The use of memos can be utilized in tandem with open and selective coding as the researcher identifies the meaning of the data throughout the analytic process.

**Memos.** The writing of memos represents an important step in bridging the gap between the coding process and the writing process. Charmaz (2006) asserted that “memo-writing constitutes a crucial method in grounded theory because it prompts you to analyze your data and codes early in the research process” (p. 72). While memo-writing serves analytic purposes, the writing remains informal, may appear simply written or awkward, and may employ overly personal language (Charmaz, 2006; Corbin & Strauss, 2008).

Memos serve as a tool to assist in the coding process. Corbin and Strauss (2008) explained memos as the thinking process of the analyst while working through the data. When analysts note an incident/concept while coding, then the analysts write a memo explaining their thoughts at that point. The use of memos helps analysts in the initial analysis stages after they note concepts. After processing the initial codes, and memos about those codes, analysts eventually move toward the development of more substantial notions of categories and themes. Essentially, delimiting theory is articulated by a process involving the synthesis of open codes, selective codes, and the memos contributing to the development of the codes.

### **Organizing the Analysis**

As I started to organize the interview transcripts from the conversations with volunteers, I sorted the transcribed conversations into two groups identified as either new or experienced volunteers. I moved the transcripts of the new volunteers into a separate file and labeled each volunteer with a lower number (one through thirteen) to indicate that they were in the new volunteer group. I moved the transcripts of the experienced volunteers into a separate file and labeled each volunteer with a higher number (fourteen through thirty) to indicate that they were in the experienced volunteer group. Separating the volunteer transcripts into two distinct groups organized the data, and prepared the transcriptions for comparisons between inexperienced versus experienced volunteers. These volunteer number labels were changed prior to the written report of findings in an effort to protect the identities of participants.

As I prepared to recognize core conceptual categories, I used basic memos to identify open codes connecting parts of the conversations with actual interview questions from the original guide. I searched for key words and ideas addressed by the interview guide as I skimmed through each interview transcript. When a particular question from the interview guide appeared in the interview transcript, I used a memo to indicate the question and number. For example, the label Q11 indicated the section of the transcript that addressed question eleven. I sometimes used an additional memo if I noted an important concept in that section of the transcript. These memos assisted in the analysis process as I constantly compared and revisited the transcripts.

Due to the conversational nature of the interview process, participants sometimes guided the topics and discussions with little prompting from the interviewer. For example, participants sometimes addressed a topic without the raising of a formal question from the interviewer. In these conversational instances, I found that the question labeling part of the memo and code

processes required adjustments. When a participant addressed a particular question from the interview guide without specific solicitation or prompting, I still used a memo to code that section of the transcript with a question number label. For example, when the volunteer initiated a discussion on their views on spirituality, I used a question number memo (Q15) on that section of the transcript even though I had not officially asked the spirituality question.

The application of memos and open coding of interview questions and responses within the interview transcripts provided the organized process of the initial analysis. The basic memos indicated the context of a specific incident (e. g., the section of the interview addressing a certain question) while more detailed memos relied on the initial impressions and descriptions of small or segmented aspects within the observations. The analytic process involved the use of more descriptive memos as I reviewed the interview transcripts in search of segments pertaining to each relevant interview question. These descriptive memos contributed to the later development of themes.

Using descriptive memos and open coding to begin the thematic analysis process, I created a separate analysis document with a page for each relevant question from the interview guide. By focusing on memos and codes for one question at a time, I was able to concentrate on sections of the interviews particularly relevant to the topic of each question. As I reviewed every interview transcript for each separate question, I recorded short descriptions in the analysis document to note my impressions of the meanings emerging from the interviews. For example, question fifteen considered the role of spirituality in the work of hospice volunteers. I concentrated on the segment of each transcript where a basic memo directed my attention to the topic of spirituality. I then used descriptive memos to record my impressions of meaningful segments pertaining to spirituality as they revealed themselves in the data. The memo notes

involved short descriptive statements listed under the question fifteen heading of the analysis document. For example, one memo noted in the analysis document explained spirituality as “important to them, but they do not push it.” Multiple volunteers were associated with this memo as several participants discussed similar views on the role of spirituality in their volunteer work. I utilized the memo method as an approach to open coding for all relevant interview questions and on each transcript explored in this study.

Following the use of descriptive memos then open coding, I utilized selective coding to synthesize the separate sections of the analysis document. While open coding involves an encompassing view of all data undergoing analysis, selective coding condenses the information compiled during open coding so that the analyst can delimit and focus on the total context (Glaser, 1978). The selective coding process leads to the actual thematic analysis so that the researcher can eventually describe overall themes revealed by the entire research process. After using open coding to record descriptive memos under the headings of each separate question contained in the analysis document, I used selective coding to organize the memos.

The selective coding process involved sorting through the memos and open codes in order to group perspectives based on similarities or differences. The constant comparison method allowed for the comparison of one incident or situation to another by looking for similarities and differences (Corbin & Strauss, 2008; Glaser & Strauss, 1967), as discussed above. As I sorted through the memos in the analysis document, I discovered that some notes corresponded easily with other notes. For example, I grouped several memos noted from responses regarding spirituality under a code identified as “strong spirituality.” The strong spirituality code encompassed the following memos: spirituality plays a large role, uses prayer, reads scripture to patients, important to them but they do not push on others, and feeling called to share spirituality.

In contrast, some notes recorded during the review of the transcripts remained as outlying perspectives. For example, the memo of “spirituality plays no role” lacked connection to any other memos under the spirituality heading. However, this outlier provided a contrast to the code of strong spirituality. Therefore, I labeled this outlying memo with the code of “low spirituality”. The process of selective coding allowed for a transition toward the development of categories and themes that might ultimately contribute to the grounded theory revealed by this study.

**Establishing credibility.** Although grounded theorists must apply forms of validity and verification that differ notably from quantitative or objectivist/post-positivist researchers, several aspects remain important for verifying grounded theory. In the formative text on grounded theory, Glaser and Strauss (1967) focused on generation rather than verification. In response to any challenges regarding the credibility and the quality of grounded theory, Corbin and Strauss (2008) offered a set of criteria for judging the quality of research. The criterion discussed by Corbin and Strauss involved issues of fit, applicability/utility, conceptual relevance, contextualization, logic, depth, variation, creativity, sensitivity, and memos as evidence. Glaser (1992) posed his own set of criterion for grounded theory including issues of fit, work, relevance, and modifiability. Charmaz (2006), as well as Denzin and Lincoln (2008), emphasized the importance of grounded theory validation by evaluating the credibility, originality, resonance, and usefulness of a new theory. The development of a criterion set provides the research analyst with a venue for establishing credibility despite challenges or critiques regarding validity in grounded theory research.

The theoretical concepts identified during this thematic analysis aligned with several of the above criterion for credible grounded theory. For example, I aimed to establish a goodness of fit between the actual hospice volunteer context and the theoretical propositions developed

during this analysis. A theoretical model emerged directly from the conversations with the hospice volunteers. Previous interdisciplinary and communication-based literature published about hospice and palliative care settings also assisted in the conceptualization of a theoretical model. This study aimed toward practical application and utility by considering potential uses and benefits of the research findings. The theoretical model developed during my research was designed to resonate with academic audiences as well as members of hospice organizations.

### **Summary**

The systematic, yet flexible, methods of grounded theory aided in the development of credible theory emerging from the data. As suggested in the third stage of the constant comparison method, the process of delimiting the theory (Glaser & Strauss, 1967) aims at streamlining the theoretical concepts so that the analyst avoids feeling overwhelmed by the mounting task of constantly comparing more and more categories and properties. Selective coding helped in the delimiting process as I continued to analyze findings from the interviews.

The thematic analysis, presented in chapter four, provides a descriptive overview of the themes and categories revealed during the selective coding process. While delimiting theory I ultimately transitioned to the final stage of the constant comparison method – writing theory (Glaser & Strauss, 1967). A discussion of thematic findings appears in chapter five as I explain the theoretical model developed while delimiting theory during the final stages of analysis.

## CHAPTER FOUR: THEMATIC ANALYSIS

*“It is so very rewarding to me. When people say to me, ‘I don’t know how you can do that, it must be so hard.’ I always think I get so much more out of this than I put into it”*

*(Volunteer Twenty-Six).*

The grounded theory method described in the previous chapter provided the framework for the thematic analysis of the interview conversations with Midwest Hospice volunteers. The participants in this study offered insightful accounts of their hospice volunteer experiences. Key themes emerged as I analyzed the participant responses. The analysis of the first overall theme explores the motivations of becoming a hospice volunteer in connection with patient-centered care (PCC) and mindfulness. Explanations of the second overall theme consider volunteer experiences and connections to PCC. Descriptions of the third overall theme focus on volunteer experiences and connections to mindfulness. Explanations of the fourth overall theme explore communication dynamics of the hospice volunteer experience. By providing direct quotes and examples from participant interviews, I utilize this chapter to explain four overall themes: 1) Motivations and Hospice Volunteers, 2) Volunteer Experiences and PCC, 3) Volunteer Experiences and Mindfulness, and 4) Communication and the Hospice Volunteer.

**Overall Theme One: Motivations of the Hospice Volunteer**

During the initial phase of the interviews with Midwest Hospice volunteers, I asked an interview question (IQ) exploring their motivations for becoming a hospice volunteer (IQ3). The analysis revealed the expression of similar motivations across both new and experienced volunteers, despite differences regarding length of service to the organization. Most participants mentioned multiple reasons for originally enlisting as a hospice volunteer. Since participants

offered several reasons, their responses sometimes appeared in this analysis under several different themes related to the motivations of the hospice volunteer.

The overall theme of Motivations of the Hospice Volunteer included two subthemes. The first subtheme, Motivations and PCC, included the following categories: a) a desire to give to and connect with others, b) a fulfilling use of time, c) previous work in healthcare, d) recruitment by someone else, and e) sustaining the volunteer. The second subtheme, Motivations and Mindfulness, included the categories of a) an overall good impression of the hospice organization and b) a personal experience influential to the decision of becoming a hospice volunteer. In the next section of this chapter, I describe the subthemes of Motivations and the Hospice Volunteer by providing examples and direct quotations from interview participants.

### **Motivations and PCC**

After initial explorations of the motivations of hospice volunteers, I explored the participant responses for motivations related to patient-centered care (PCC). Prior studies found that hospice volunteers offer service due to a desire to help others, to serve those in need, and to make a difference in the lives of others (Claxton-Oldfield, S., et al., 2004; Planalp & Trost, 2009a, b). The participants in this study reported similar motivations. Responses related to helping, serving others in need, and making a difference all reflected facets of patient-centered care (PCC). PCC involves a consideration of the psychological and social factors of the patient and the family (Sparks et al., 2007). The PCC approach emphasizes the multi-faceted needs of patients by encouraging providers to listen, assess, and then respond with appropriate interpersonal interactions (Mast et al., 2005).

In the next section of this chapter, I explain the Motivations and PCC theme. The Motivations and PCC subtheme involved several categories regarding motivations of becoming a

hospice volunteer: a) a desire to give to and connect with others, b) a fulfilling use of time, c) previous work in healthcare, d) recruitment by someone else, and e) sustaining the volunteer.

**Give and connect with others.** Supporting previous research regarding the reasons for becoming a hospice volunteer, many of the Midwest Hospice volunteers expressed a desire to help others. One volunteer explained a need to “do something with my life other than just go to work and come home and I wanted to do something that I felt that I could help somebody and might make me feel a little bit better” (V6). Volunteering for hospice provided a sense of helping others while also offering a feeling of personal fulfillment.

The idea of preparing for the future by serving others in the present was articulated by a volunteer who explained, “I know we’re all going to die and if I’m ever in that position, I would want somebody to take, you know, take care of me and comfort me and my family” (V19). Another volunteer supported this notion of preparing for one’s own future with a statement about *paying forward*. The idea of paying forward reveals a commitment to the PCC approach because the volunteer obviously values the importance of comforting care.

Volunteers emphasized the importance of the PCC approach in statements reflecting their personal goal of contributing to the lives of others. Several volunteers mentioned a desire to “give back” to patients and to the hospice organization. The motivation to give back to others was often associated with the volunteer’s previous experience with hospice. For example, one volunteer shared their experience of having a parent in hospice care: “My mom was a patient in 1996 and I just felt so much peace here, that I just knew that one day I would give back. And the timing wasn’t right then” (V21). While non-volunteers might also share the desire to help others, to pay forward, or to give back, time constraints or availability often directly impacted the decision to commit to hospice volunteer service.

**Fulfilling use of time.** Previous research on people who volunteer in general, as well as hospice volunteers in particular, typically involve married or widowed, middle-aged to older, white females (Caldwell & Scott, 1994; Claxton-Oldfield, S. & Claxton-Oldfield, J., 2007). A striking majority of the Midwest Hospice volunteers participating in this study met this typical description. The average profile of a hospice volunteer may relate to time and availability. For example, women who are married/widowed, as well as middle-aged to older, may have fewer concerns related to careers, children, or household provisions.

Many of the Midwest Hospice volunteers, including some male participants, mentioned time and availability as a reason for deciding to become a hospice volunteer. As previously noted in a statement by Volunteer 21, individuals may frequently feel motivated to volunteer for hospice but only enlist as volunteers when time allows. Participants mentioned free time and retirement as motivating factors that instigated their enrollment as volunteers. Volunteer Six said, “This came up and I’m getting so sick of being at home and I will take it for something to do” (V6). Volunteering provided a meaningful use of free time for some, as noted by several volunteers who had retired or were no longer employed.

In addition to meaningfully occupying one’s free time, the decision to spend time serving patients and families at Midwest Hospice also reflects a dedication to the goals inherent in the PCC approach, such as meeting the functional, psychological, and social needs of others. One volunteer explained her search for a helpful volunteering role that served others:

I was looking for something to do with my extra time. I wanted a volunteer position where I could really feel helpful, even to just sit on some boards, although I wasn’t on the board at the time. But I wanted to really do something hands-on and feel like I was making a contribution. (V26)

Seeking a meaningful use of time represents a theme mentioned by many volunteers as they explained their motivation for volunteering for hospice. Devoting free time toward the care and service of dying patients and families demonstrates the readiness of hospice volunteers to provide the type of conscientious care reflected by a PCC approach.

**Previous work in healthcare.** Although many hospice volunteers have no previous background in healthcare, several Midwest Hospice volunteers mentioned their prior work experience as influential in the decision to become a hospice volunteer. For example, one volunteer explained their decision to become a volunteer by relating the story of her first hospice encounter:

The first time I heard about hospice I was assistant director of nursing in a home for handicapped adults, mentally retarded handicapped, and we went through a program describing hospice. (V16)

The continued interest in caring for patients reflects on the volunteer's commitment to helping others and focusing on the true needs of patients.

Volunteer Two explained that her background in nursing ultimately led her to volunteer for hospice because she wanted to “nurture and take care of and do more of the hands on” care for patients:

I want to do nursing. I want to do more hands on nursing and you know, I just didn't know what I wanted to do so I did some volunteer work at the museum and I came out here and took the class and I've just... It's like after 30 some years I found what I really want to do in nursing. (V2)

The hospice philosophy impressed Volunteer Two because it aligned with her belief in providing nurturing care.

**Recruitment by someone.** While many volunteers at Midwest Hospice mentioned their own desire to help and nurture others, as expressed by the former nurse above, others suggested that they became involved after someone else recognized their potential to contribute. For example, several volunteers explained that a friend, relative, or acquaintance suggested that they would be a good hospice volunteer. One volunteer narrated the dialogue with a friend who informed and encouraged his participation as a hospice volunteer:

She said “You know, you would be really good at Hospice” and I said “What’s that? I never heard it before.” And she said “Well, essentially this is what they do in Hospice.” I said “Why would I want to do that? I’m not interested in that at all.” She said, “Well, I just thought I would mention it” and as time went on, maybe a year or two ... she was a volunteer. And she said “I’m going to a meeting, do you want to go” and I said “At Hospice?” She said “Yes” and I said “Well, sure. I’ll go along” ... I was curious. (V22)

Volunteer 22 provided an example of how relationships with others led to an interest in volunteering for hospice. The encouraging friend identified the caring capacity of Volunteer 22 as someone who would work well in an empathetic, patient-centered environment. Other volunteers expressed similar encounters with friends, family members, or acquaintances who ultimately recruited them as a hospice volunteer because they exhibited caring qualities.

**Sustaining the volunteer.** While the themes regarding motivations for becoming a hospice volunteer were comparatively similar across new and experienced volunteers, motivations sustaining hospice volunteers evolve over time as volunteers engage in more patient encounters. Experienced volunteers explained the overall rewards of working as a hospice volunteer. Reflective of the PCC approach, experienced volunteers described the act of

comforting patients and families as an intrinsic reward. One experienced volunteer appreciated how the act of caring for others rewards the volunteer:

After doing it for a while...as a volunteer it's very rewarding. You will get much more out of it and you will learn so much from the patients and what they give you is priceless. That's a very warming, rewarding experience...it's hard to explain at times because it's such a special moment that you are sharing with them and their journey. (V15)

The motivation to volunteer stems from a variety of personal and social needs. The motivation and PCC theme included the categories of a) desire to give to and connect with others, b) a fulfilling use of time, c) previous work in healthcare, d) recruitment by someone else, and e) sustaining the volunteer. Each of the categories of the subtheme of Motivations and PCC reflected the patient-centered approach because of the volunteers' desire to contribute time and meaningful assistance by caring for hospice patients and families. The analysis of the reasons for choosing to volunteer at Midwest Hospice also revealed an additional theme of motivation. In the next section of this chapter I introduce the subtheme of Motivations and Mindfulness.

### **Motivations and Mindfulness**

Supporters of the mindfulness approach assume that individuals naturally behave with compassion and thoughtfulness when engaging with others by becoming present to the current moment, experience, or conversation (Wood, 2004). In the next section of this chapter I explain the Motivations and Mindfulness theme by providing examples and direct quotations from interviews with Midwest Hospice volunteers. The Motivations and Mindfulness theme involved the following categories regarding motivations of becoming a hospice volunteer: a) an overall good impression of the hospice organization and b) a personal experience influential to the decision of becoming a hospice volunteer.

**Overall good impression.** While explaining reasons for becoming a Midwest Hospice volunteer, several participants expressed admiration and respect for the quality of service provided by the organization. Medical approaches to mindfulness involve insightful attention to the cognitive, technical, and interpersonal aspects of care-giving (Epstein, 2003). An overall good impression of the organization, articulated by many of the volunteers, indicated insightful contemplation by volunteers as they encountered and evaluated Midwest Hospice prior to their enlistment as a volunteer.

Several volunteers shared stories expressing their appreciation of hospice employees and the care provided by the organization. For example, Volunteer 20 discussed the excellent care of her relative as impressive and influential in her decision to become a hospice volunteer because “the ladies that came to my home, they took very good care of him”. When asked if this positive impression of Midwest Hospice influenced her decision to volunteer, she responded, “Yes, absolutely. When I retired I knew that I would go and volunteer” (V20). Several participants shared similar stories of witnessing impressive hospice care and how such experiences instigated their enlistment as a hospice volunteer.

Volunteers learned to value the hospice organization in a variety of ways. Some volunteers came to respect the organization by reflecting on a personal hospice experience, by growing personally in a support group, by sharing meaningful conversation with an involved friend or relative, or by engaging with reading materials. For example, one participant explained that she became a volunteer because “I had read about the hospice program in England and just felt what an incredibly great thing that was. So I decided I’d become involved” (V27). Another volunteer explained that she was impressed by the organization and “Hearing all the positive things about it and visiting this lady that was my customer for a long time and then my husband

was here” (V23). As expressed by Volunteer 23, in addition to holding an overall good impression of the hospice organization, many volunteers were specifically impressed by the organization due to a personal loss experience.

**Personal experience.** Similar to the mindfulness ideals of valuing insight, presence, and reflection (Epstein, 2003), volunteers sometimes choose to volunteer as part of the reflective process after the death of a close relative or friend. For example, one participant became a volunteer “Because we had such a good experience when my husband was passing on and was in the spring of 2009 and I wanted to repay in some way. I also needed to have a place to use my energy and love” (V1). Similar to the story of Volunteer One, several other participants became volunteers due to their reflective processes after a personal loss.

Several participants shared personal loss stories that involved both positive (e. g., heartwarming) and negative (e. g., devastating) death experiences. Volunteer Five shared her negative death experience during the loss of her father and the reflective process that eventually led to becoming a hospice volunteer:

Well, my dad. Actually, to be quite honest with you, it was such a horrible experience watching him die, he had lung cancer and, you know, of course hospice was absolutely wonderful but...You have to wait for a year before you’re allowed to become a volunteer because someone close to you died, well that’s right on the mark because I was nowhere near ready before that.  
(V5)

The story of Volunteer Five represents the deep level of self-reflection encountered by many volunteers who cite personal loss experiences as the reason for becoming a volunteer. Grounded in the belief that humans deserve more positive and comfortable death experiences, these

volunteers introspectively processed their personal losses and chose to proactively serve in an end-of-life care setting.

### **Overall Theme Two: Volunteer Experiences and Patient Centered Care**

Participants consistently described experiences suggestive of a strong alignment with the philosophies of PCC. Volunteer Two shared that “the inspiring part came from the people here. Everything is patient oriented. It’s not about money and it’s not about ego. I mean, it’s all centered around the patient”. Unaware of the official terminology or theoretical practices of PCC as an approach to care, the perspectives expressed by participants demonstrated the harmony between the hospice volunteer approach and the PCC approach.

Several subthemes of Volunteer Experiences and PCC emerged as participants discussed their experiences as hospice volunteers. First, I identified the subtheme of Personal Beliefs and PCC. This subtheme included the categories of a belief in helping others and a belief that no one should die alone. Second, I identified the subtheme of Focus on Others and included the following categories: a) comforting patients and families, b) shifting the focus away from the self, and c) connecting to others. Third, I identified the subtheme of Relational Encounters that included the categories of a) maintaining distance and b) attachment and friendship. In the next section of this chapter, I describe the three subthemes of Volunteer Experiences and PCC.

#### **Personal Beliefs and PCC**

As the participants discussed their experiences as a hospice volunteer, they often shared opinions and perspectives reflective of their personal beliefs. Aligning with the hospice mission, two categories of Personal Belief and PCC were identified during conversations with volunteers. The goals of hospice involve the provision of “medical, emotional, and spiritual care for terminally ill patients and their families. These services are designed to bring comfort, peace, and

a sense of dignity at a very trying time” (HAA, 2010). The personal beliefs expressed by participants reflected the hospice mission. The analysis revealed two categories of personal beliefs reflective of the PCC philosophy including a belief in helping others and a belief that no one should die alone.

**Belief in helping others.** Many of the participants expressed a belief in the importance of helping others and explained that helping others enriches their own lives. Elaborating on this belief, one volunteer expressed dissatisfaction with a career that does not help others: “I don’t feel like I’m making a difference and I always wanted to feel like I had a job where I was making a difference in either my life or someone else’s life” (V6). The desire to make a difference in the lives of others reflects the connection between volunteer motivations and PCC. The PCC approach encourages healthcare providers to focus on the patient and family by listening and assessing physical, emotional, and social needs of the patient (Mast et al., 2005; Sparks et al., 2007).

Participants in this study frequently expressed an appreciation for the hospice mission of helping others during the difficult final stages of life. For example, one volunteer praised hospice because “they really care about and address the whole person. That is what I was really most impressed with them, and not just the physical aspect of controlling pain, but the entire person is important to them” (V7). Further supporting a belief in helping others by focusing on patients, another volunteer shared a personal perspective that reflects the PCC:

I really do think the focus should be on that person. I look at it as a privilege to be in that space and time. I mean, who am I? If they don’t want it, or if they want whatever they feel like, it’s all about them. I mean, for me, a stranger, to be invited into that room, and

they don't know me. I mean, no, it's definitely about that patient, and if it can comfort them or calm them. It's all about that. (V21)

As identified in the excerpt above, participants viewed helping others as a top priority and a personal privilege.

**No one should die alone.** Volunteers in general frequently cite an overall belief in the importance of helping others (Caldwell & Scott, 1994; Claxton-Oldfield, S., & Claxton-Oldfield, J., 2007). Hospice volunteers demonstrate an especially strong belief in helping others by committing to assist during the final stages of life. Several participants expressed a desire to help because of a belief that no one should die alone. For example, Volunteer 19 asserted that “No one should die alone or miserably or have to suffer” (V19). Several volunteers in this study shared similar beliefs, as expressed by the following story:

I used to always say it's so horrible that people have to die alone and when I worked in the hospital - I wasn't the only one to do this - but we knew that somebody was going to pass and we knew that if we went off shift, nobody was going to be there when they died. So we would just stay so that they wouldn't be alone. And I said to my husband, if anything, I just can do this volunteer work and hopefully I can help them out and I came to interview with (the volunteer staff) and they said “our focus right now is to offer volunteers to our nurses and our staff so that no one has to die alone” and it was like one of these aha moments, you know? That's exactly what I was thinking! (V2)

Personal experiences, such as the story of the nurse in the above excerpt, seemed to bolster the belief that no one should die alone. Participants often developed this belief prior to their affiliation with hospice; the belief that no one should die alone represents another motivation for

becoming a hospice volunteer. For example, Volunteer Five shared the story of helping a neighbor prior to becoming a volunteer:

She had no one and so I took her back and forth to the doctor and the hospital and eventually she died and I thought she would have died alone and I thought no one should ever have to die alone. (V5)

The belief that no one should die alone represents an intense and sensitive form of caring for the final needs of dying patients.

### **Focus on Others**

Stemming from the personal belief in helping others, Focusing on Others emerged as a dominant theme across many of the interviews with Midwest Hospice volunteers. A participant emphasized this point clearly by asserting that “Everybody counts, everybody. No exceptions” (V8). The participants in this study discussed the importance of focusing on others in a variety of ways, such as: a) comforting patients and families, b) shifting the focus away from the self, and c) connecting to others. All three of these categories, broadly labeled as a Focus on Others, directly reflect the goals of the PCC approach.

**Comforting patients and families.** As participants responded to a question about the most important things they had learned as a hospice volunteer (IQ7), many explained that the volunteer experience has increased their understanding of how to comfort and relate to others. A great concern in end-of-life care involves the physical comfort of the dying patient. One volunteer asserted that “What’s important here is that if they’re in pain, that’s taken care of. That’s a priority” (V21). Volunteers primarily care for the emotional and social needs of the patient while recognizing the central concern of reducing suffering.

The ability to perform acts of kindness represents a powerful tool in the hospice volunteer's repertoire. One volunteer described comforting as helping with "the little things" when she shared the following example: "I've learned it doesn't take much to make them happy, little things whether you feed them or take them flowers" (V23). Volunteer 20 said that she simply tries to "smile a lot" because "I want them to feel comfortable with me coming in and out and everything." The desire to comfort the patient surfaced as a central concern across participants.

Several participants mentioned their own use of compassion and empathy during hospice interactions. For example, one volunteer provided an example of comforting a recent patient: "So when she's frustrated, I'm frustrated. When she is in pain and I can't do anything about it it's hard, it's frustrating. I am a little more compassionate than I thought that I could be with strangers" (V5). In this comment, Volunteer Five suggests a feeling of surprise at her own ability to comfort others by thinking with empathy and compassion. Similarly, Volunteer 17 claimed that the volunteer experience leads to having "a lot more compassion and I know more about this whole living and dying process especially at the end-of-life." Expressions of empathy and compassion assist hospice volunteers as they comfort others.

**Shifting the focus away from the self.** As participants discussed the importance of maintaining a focus on others, several volunteers explained that the hospice experience has caused them to focus less on themselves. Some participants discussed the need to put aside your own concerns and to avoid being "hung up" on your own situation. Volunteer 23 explained shifting the focus away from oneself as "a good life skill that you learn. You leave everything wherever it is. You want to put it away and you come in here and help the people." Another volunteer explained their perspective that "it's not about me and whether I believe in God or not,

they do, and if it brings them anything positive, I'd be more than happy" (V2). This comment demonstrates a willingness to set aside personal beliefs, if necessary, in order to maintain a focus on others.

**Connecting to others.** When participants responded to a question about their most memorable experience as a hospice volunteer (IQ5), they often offered a story about a moment of connection with a patient. For example, volunteers shared stories about an encounter with the patient and his/her pet, a memorable shopping trip, an interesting request, or some other special moment of connection with a patient. One volunteer told a story of connecting with a patient's family during the final hours of a patient's life:

It was so sweet because they were holding his hand, it was their father, and stroking his forehead and everything and they said "You can hold his hand, can't you?" and I said "Sure I can do that, that's not a problem" and she just looked at me with big tears and said "Oh there are angels on this earth"...It was probably the nicest thing anybody ever said to me. (V2)

The prevalence of stories about connecting with patients as exemplars of the most memorable experiences reveals the volunteers' perceived importance of connecting to and focusing on others.

### **Relational Encounters**

The theme of focusing on others reflects the relational aspects of volunteering for hospice. Participants described relational encounters with patients and families in various ways. The PCC approach inevitably necessitates a consideration of the provider-patient relationship. Since hospice volunteers often emphasize meeting social needs of patients and families, I explored volunteer perceptions of relational encounters (IQ10). The categories identified under

the theme of Relational Encounters included: a) maintaining distance, and b) attachment and friendship.

**Maintain ing distance.** Several newer volunteers discussed relationships with patients as pleasant interactions. Describing relationships in this way points toward some level of attachment yet maintains a sense of detachment or distance. Interacting with patients and families while maintaining distance may prevent the development of close relationships, as described by Volunteer 19 who said, “I’m not going to say formed relationships because I think you can cross the line.” Despite this claim, Volunteer 19 later contradicted the distance perspective by sharing the story of a patient whom they considered a friend: “it was a rewarding experience because you know we’ve become friends.... I mean, they told me all about their lives.” Other participants disagreed with the idea of becoming friends with patients and strongly supported the importance of keeping a detached or distant relational level:

You don’t tend to make friendships. You call yourself a friend, and you mean that. You know how friends care and respond and try to help, and are there, but not the real let’s share our lives kind of thing. It’s not appropriate. (V27)

Although some participants favored a more detached or strictly professional approach to patient interactions, attachments often occurred.

**Attachments and friendships.** While several participants carefully maintain a distant or detached relationship with patients and families, other participants described instances of feeling a significant attachment to patients and/or families. Volunteers working in home care environments, rather than at care facilities, seemed more likely to demonstrate some level of attachment. For example, one participant shared how “It is a little more personal because you really get to know the families and you can come by, a friend. You go there you know over a

period of months many times so you do get more attached and more involved with the families” (V26). Perhaps unsurprisingly, visiting a patient's home may prove more conducive for developing closer relationships.

The volunteer-patient friendship begins with service but can then evolve into friendship. Volunteer Seven described a current patient as “very thankful for what we do but it has become a good friendship.” Several participants use the word “friend” to describe the types of relationships they have developed as hospice volunteers. Most participants who described their relationships as friendships differentiate between the volunteer-patient friendship and other types of friendships, as noted by Volunteer Five: “I think that if I’d met her under other circumstances I think we probably would have been friends.” The volunteer-patient friendship obviously functions differently than another friendship might due to the care-giving role of the volunteer and the finite nature of time implied by this relationship. Another volunteer described the patient relationship in this way:

I guess we became pretty good friends and I think she kind of depended on me but her memory wasn’t great so I can’t be positive that she remembered me from time to time but I felt like she did and I felt like she was always glad to see me and it was just a very comfortable relationship. (V9)

Similarly, another participant shared the following story of helping the patient and family:

It just meant so much for her, and I was willing to do it, and she was able to do it as long as she had help and a lot of patience. And we just became the best of friends. I just loved her and her husband to pieces. And they reciprocated. (V26)

Participants demonstrated their attachments to patients and families as they shared stories of close relationships they perceived as friendships. The tensions between maintaining relational

distance versus allowing attachments and friendships to develop represents a dynamic set of rewards and challenges for hospice volunteers.

### **Overall Theme Three: Volunteer Experiences and Mindfulness**

Mindfulness requires individuals to exercise an insightful and reflective approach; mindfulness in healthcare and medical settings involves a deeper examination of the care-giving process by investing in cognitive, technical, and interpersonal aspects of medicine (Epstein, 2003). The overall theme of Volunteer Experiences and Mindfulness included three subthemes. The first subtheme, Personal Beliefs and Mindfulness, included the categories of strong spirituality and subtle spirituality. The second subtheme, Reflective Perspectives, included the categories of a) appreciating life, b) altered views on death, c) authentic encounters, and d) emotions and boundaries. The third subtheme, Recognizing Self-Improvement, included categories of noticing personal change and experiencing personal growth. In the next section of this chapter, I describe the three subthemes of Volunteer Experiences and Mindfulness.

#### **Personal Beliefs and Mindfulness**

The hospice philosophy focuses on providing spiritual comfort, yet most hospice organizations avoid direct religious affiliations. Sendor and O'Connor (1997) explained that hospice organizations strive to meet the individual spiritual needs of each patient and “need not be sponsored by a religious organization” (p. 23). Despite a lack of religious affiliation, spirituality inevitably surfaces in the hospice context because religious or spiritual commitment often provides individuals with comfort when facing death (Ardelt & Koenig, 2006). The mindfulness approach, originally evolving from the religious beliefs of Buddhism, concentrates on awareness and living with a sense of consciousness of the self, of other people, of the physical surroundings, and of the state of mind. Although some Midwest Hospice participants denied the

role of spirituality in their work as hospice volunteers, most participants identified a spiritual aspect to their volunteer service. The theme of Personal Beliefs and Mindfulness included categories of strong spirituality and subtle spirituality.

**Strong spirituality.** Many participants responded with immediate confirmation of the spiritual elements involved in their work as hospice volunteers. The volunteers that I categorized as presenting a strong spiritual aspect offered responses that articulated the importance of spirituality or religion. The strong spirituality group described volunteer experiences that incorporated biblical scripture, prayer, and/or overt spiritual moments.

A few participants indicated that spirituality played such a large role in their lives that they felt spiritually led or drawn to serve as a hospice volunteer. One experienced volunteer claimed that “I felt like it’s not just me. I feel like I’m really led at times” (V21). Although the theme of spirituality extends well beyond simple religious affiliations with Christianity, many of the participants discussed spirituality in a Christian context. One volunteer vividly explained the feeling of being led or drawn into hospice service within a Christian context:

I’m a firm believer that I’m representing Christ when I visit the sick or when I take my charge on a ride across town to go to his grief counselor. I’m doing God’s work and so I’m there to represent Jesus and the Sermon on the Mount and everything Christ said in the New Testament or everything God said in the Old Testament. So with that, I just have a pretty strong feeling for that but that’s my role, that’s what I’m on this earth for. (V8)

The use of prayer also indicated a strong spiritual aspect of the hospice volunteer experience. Expressing the opinion that other volunteers shared a strong sense of spirituality, one volunteer connected their volunteer position with their use of personal prayer: “I prayed all summer that I would be accepted as volunteer. Yes, so spirituality for me plays a big part and I

sensed with some of the other women particularly that it does” (V1). Two experienced volunteers discussed the strong spiritual dynamic they felt when visiting a patient during the final hours of life. Volunteer 26 mentioned the incorporation of prayer during final moments with patients:

Well I’m a pray-er. And there are times that I just know people are very close to the end. And honestly I feel like it is such a privilege to sit with them and hold their hand and sit with them and pray because I know that they are so close to being with the lord. (V26)

Similar to the idea expressed by Volunteer 26, another volunteer described the final moments of witnessing a patient’s death as a special, spiritual experience: “when you go into a room, and the patient is ready to find his eternal life, it’s just amazing, the energy” (V21). While spirituality and/or religion obviously impacted several participants, others described the role of spirituality as a more subtle influence in their hospice volunteer experiences.

**Subtle spirituality.** While observing new volunteer training sessions during an earlier phase of this research with Midwest Hospice, I noted a cautious approach to discussions on spirituality. During the interviews many participants reflected an open or flexible sense of spirituality as influential to their role as a hospice volunteer. Some participants seemed hesitant to associate spirituality or religion with the volunteer role, yet these participants did recognize subtle spiritual aspects in their volunteer experiences. Volunteer 27 explained that “I think it’s really there; it just percolates in the background.” Similarly, two other volunteers clarified the more subtle spirituality involved with hospice volunteer work. “I think religion is based on golden rule and leave the world a better place than you found it” (V25). “That doesn’t mean you’re a real religious person. Just maybe a little more aware and yes there is somebody higher up than us that controls everything” (V18). While some participants denied the role of

spirituality in their volunteer experience, most participants admitted that the hospice volunteer role was influenced by a sense of spirituality.

### **Reflective Perspectives**

Mindfulness involves a “state of mind that permits insight, presence, and reflection” (Epstein, 2003). Participant responses reminiscent of the mindfulness approach communicated a heightened sense of awareness and sensitivity as they considered their own thoughts, feelings, and actions related to patient interactions. The Reflective Perspectives theme emerged during this analysis as a dominant aspect of the hospice volunteer experience. Participants offered insightful comments and shared touching stories gained during their experiences with hospice. The responses provided by participants in this study suggested an increased level of introspection due to the hospice volunteer experience. The categories of the Reflective Perspectives theme included: a) appreciating life, b) altered views on death, c) authentic encounters, and d) emotions and boundaries.

**Appreciating life.** Many of the Midwest Hospice volunteers expressed a deeper appreciation of life as a result of their interactions with hospice patients and families. Participants asserted that volunteering for hospice inevitably alters your perspective on your own life:

It can't help but change your perspective on life. Where before, even minor things could be very aggravating but now I think, I am able to walk out of here and get in my car and go on to the next thing, but those people – that's a gift to be able to do that. What they're facing now is not good and I have all the freedom. It really changes your attitude and outlook on life. (V26)

As described in the above comment from Volunteer 26, the dominant theme of Reflective Perspectives was strongly emphasized through multiple participant responses regarding appreciation of life. Volunteers value the daily processes of living as their encounters with hospice patients heighten their awareness of their own mortality.

It makes you look at things in your life you know and your mortality and all that and working in the field, I think this opens you up to... appreciating every day. (V19)

Witnessing the painful aspects of facing end-of-life circumstances seemed to develop feelings of gratitude and compassion that further enhanced their own appreciation of life.

You think about other people's circumstances more and that you think about your own blessings but you realize that there are a lot of people out there hurting and it's so out of their control. (V5)

A greater sense of appreciation reinforced the hospice mission to comfort patients and assist in providing improved quality of life:

Much more sensitive, much more aware of your own mortality, too, and the importance of life as you live it, and that's one of the big things about hospice too, is they truly press you and the volunteers and the staff to remember that people are alive until their death. And so quality of life is just really important. (V27)

In tandem with the category of appreciating life, many participants explained their hospice volunteer experiences as enriching their perspectives on death.

**Altered views on death.** While the process of dying differs based on the patients' circumstances and belief systems, the hospice philosophy encourages a caring, yet forthright view of death. Many of the participants in this study recognized changes regarding their own

views on death. As mentioned in the above category of appreciating life, participants expressed an altered view on dying as they recognized and reflected on their own mortality.

Hospice volunteer service offered perspective on “how fleeting your life is. There are no guarantees” (V21). Reflecting on death helped participants to comprehend “how important your life really is and, you know, that death is a hard thing but when you have a place like Hospice...” (V19). Some participants discussed the hospice organization as a more peaceful place for patients and families to experience death. For example, one volunteer realized that hospice organizations focus on both death and life; “I think there’s a lot of progression when they come here and they’re learning to die and they don’t realize there’s a lot of living that goes on here” (V21). The reflections on death occur as hospice volunteers serve as witnesses to the deaths of others. Seno (2010) explained that reflecting on death could help people develop a stronger appreciation of living and, therefore, become focused on living more fully while helping others to live more fully as well.

One volunteer suggested that the distance of watching the death of a stranger allows for the development of an altered view of dying:

A lot of people, my son included, say “I don’t know how you do that. I just don’t know how you do that” and you just do. I can’t explain it. You just do. It’s not bothersome. It’s not horrible to see somebody pass away you know, because it’s overshadowed by you made a difference. (V2)

As described in the above comment, volunteers learn to witness death differently because they focus on providing comfort as the patient nears the final stages of life. Similarly, another participant explained the difference between witnessing death and the personal loss of a relative.

Because you're exposed to it more, and you can take one step there. It's not your mother or father, so there is a little bit of division that you can separate, kind of look beyond the intimacy of what you're losing. (V21)

Several participants described witnessing death as a special privilege shared with the patients and families who receive hospice care. Volunteer 26 explained that "I still have the privilege of time with them when they're so close to the end of the world and going on to the next" (V26).

Witnessing the death of another seemed to encourage a greater acceptance of death as part of the living process.

Reflecting on death by witnessing death experiences at hospice care facilities and in the homes of hospice patients helped to lessen the fear of dying among some volunteers. One participant shared how her volunteer experience led to a more accepting perspective on her own death:

I've looked at death at least twice and totally scared and fortunately, I've been well for quite a while but I don't think I would be nearly that afraid because of my experience here. (V2)

Another volunteer described the experiences as contributing to a greater acceptance regarding the death of others:

When my mother passed away I was scared to touch her but maybe after I got sick so much and then my brother passed away. So I hadn't had any problem with doing that and you know when you are young, you are scared of death and all of that stuff... I'm not anymore. (V20)

The Midwest Hospice volunteers reflected an overall agreement that the hospice volunteer experience had changed their perspective on death, as described below:

It's a cycle. It's life. But I think you have to keep it in check. Otherwise you're not really going to be of service. I miss people, but you know, I think you have to be strong. (V21)

The views on death articulated by the participants in this study reflect a thoughtful awareness of the importance of authentic encounters as a hospice volunteer.

**Authentic encounters.** The mindfulness approach involves a focus on authenticity with the self and with others. Seno (2010) claimed that authenticity is possible when individuals strive for raised awareness and a willingness to communicate more consciously. Seno explained authentic encounters as occurring when individuals live and practice consciousness each day.

As participants described encounters with patients and families, several volunteers explained the importance of consciousness through mentally preparing to engage and offer presence. The idea of *presence*, emphasized strongly during the new volunteer training phase that I attended during prior research, refers to an authentic engagement with patients who may have minimal levels of interaction and coherence during volunteer visits. Presence also refers to shifting the focus away from the self and giving full attention to meaningful encounters with patients and families. For example, one volunteer explained her commitment to authentic encounters as a desire to “Live in the sacred. That’s what I feel about the hospice. I want to be in the sacred. It’s a sacred moment to be with these people” (V8). Another volunteer shared a strategy learned from a more experienced volunteer:

When she sat in the car, she just kind of got herself ready and cleared her mind before she went in and that just really helped a lot during her telling what she did and also the lady I said, she was very thoughtful too. (V9)

References to strategies that “cleared her mind” and practices that allowed for being “very thoughtful” reflect the philosophies of the mindfulness approach; hospice volunteers strive

toward authentic encounters with patients and families. Participants frequently addressed the idea of authenticity by mentioning sympathy, empathy, or compassion:

You learn to feel a lot of sympathy and to care about where they are, and then that helps you respond to what they need. What you don't do is become too empathetic or too emotionally involved. (V27)

While the above response supported the idea of authentic expressions of sympathy or understanding, Volunteer 27 simultaneously warned against excessive emotional investment.

**Emotions and boundaries.** Recognizing the potential for deep emotional involvement when witnessing the final stages of life, hospice volunteer training encourages hospice volunteers to manage emotions by maintaining boundaries. The challenge of engaging in authentic encounters while maintaining emotional boundaries highlighted the utility of using a mindfulness approach in hospice care. One volunteer boldly asserted that “if a hospice volunteer doesn't have an emotional dynamic to it, they don't deserve to be a hospice volunteer” (V8). For many volunteers, interacting with hospice patients and families unavoidably involves feelings.

One volunteer explained that “You always have to be happy and up. You don't bring anything from the outside in” (V23). When asked if she found that to be difficult, her immediate response was “No.” Despite the expression of emotions inherent in witnessing the death of another, hospice volunteers seem adept at emotion management:

I think that I am very compassionate and I have a lot of empathy for what they're going through, but I don't really know them, I guess I can distance myself somewhat because I don't really know them. And once they leave here, I'll probably never see them again. (V26)

As mentioned earlier in this analysis of altered views on death, a hospice volunteer's management of emotions is facilitated by the separation between themselves and the patients.

One volunteer explained “this is a temporary thing, you know, that I know this person for not very long and I’m going to do what I can to make these days better for them” (V9). By consciously recognizing the separation between caring for patients in the final stages of life and protecting oneself emotionally hospice volunteers maintain appropriate boundaries.

Learning to manage emotional and professional boundaries, an issue all healthcare providers should consider, becomes particularly salient for hospice volunteers. The new hospice volunteer training at Midwest Hospice often addressed the importance of maintaining emotional and professional boundaries. One volunteer in particular exemplified a well-developed understanding of boundary maintenance:

I removed myself somewhat from that emotionally, you know, not totally but I guess in a protective way...some heartache but I kind of know that that’s part of it, that you know, this is what I’m doing and I can’t let it eat at me. I can’t let it be on my mind all the time or I won’t be able to continue. (V9)

A few participants expressed the opinion that emotions should play no role in hospice volunteer service, but most recognized the interwoven emotional dynamic and simply attempted to “keep it in check” (V21) while still engaging in authentic encounters. Managing the tension between engaging emotionally and maintaining boundaries encourages a mindful approach as hospice volunteer experiences help develop a reflective perspective.

### **Recognizing Self-Improvement**

Although most participants primarily emphasized the value of serving others during the challenging final stages of life, several participants articulated stories of their own personal growth and self-improvement since becoming a hospice volunteer. The theme of recognizing self-improvement relates to the introspective awareness of the mindfulness approach.

Recognizing self-improvement involved noticing personal change and experiencing personal growth.

**Personal change and growth.** A key question employed during the interview process explored the idea of personal change (Q6). A few participants felt unclear about how they may have changed since volunteering for hospice service but most participants recognized some form of personal change, as described by Volunteer 22, “So I have changed a whole lot but I can’t really necessarily pin it down exactly... I changed a lot.” Several participants confidently affirmed that the hospice volunteer experience undoubtedly led to personal change. For example, one volunteer said, “I’m probably stronger. It makes you put things in perspective” (V21). Other participants associated personal change with an experience prior to hospice (e. g., loss of a relative or spouse, serious illness). Regardless of when the actual personal change occurred, such thoughtful perspectives of recognizing personal change and growth reflect on the volunteers’ capacity for adopting a mindfulness approach.

Newer volunteers responded with less certainty about personal changes because they still had too few hospice experiences. However, one new volunteer shared that her husband noted a personal change since she started volunteering:

I’m more contented. He always says I’m better when I’m taking care of people that I worry less about my really insignificant troubles and I’m just happier when I got someone to take care of. (V2)

Another volunteer credited the hospice experience with tempering their personal reactions to negative encounters:

I think I have mellowed a lot. I don't let things upset me you know like I used to do and you just take things, you can change them. You can't control them. You have to learn to deal with them and I think I've become more and more like that than I ever was. (V18)

Many participants mentioned that outside acquaintances, unfamiliar with hospice, frequently questioned their hospice service and assumed it was a sad or depressing situation. Quite to the contrary, hospice volunteers participating in this study often mentioned the rewards and self-improvements gained by volunteering for hospice. For example, one volunteer described their satisfaction with hospice volunteer work:

You have your opportunity to share someone's life with them, you know, that has lived through things and they can recount what they have experienced. You know, they are helping and you are learning from it and every single one has made me a better person. (V19)

Many participants in this study recognized hospice volunteer service as a catalyst for self-improvement and as an environment conducive to personal change and growth.

#### **Overall Theme Four: Communication and the Hospice Volunteer**

Researchers of communication and palliative care have articulated the importance of communicating effectively when caring for terminally ill patients and families. Villagran and colleagues (2010) provided the following recommendations for communication in palliative care contexts: 1) reduced self-talk and fewer predetermined scripts, 2) lower levels of prejudgment regarding how interactions may occur along with lower judgment about the patient and family, and 3) adaptability to changes during the interaction. Supporting these communication recommendations, this analysis revealed the theme of Communication and the Hospice Volunteer. The categories of Communication and the Hospice Volunteer Experience included a) listening and learning and b) overcoming communication challenges.

**Listening and learning.** The analysis revealed the importance of listening as a key communication skill for the hospice volunteer. Several participants mentioned listening as a key dynamic of their hospice volunteer experience. One volunteer expressed the simplicity of listening as a general life skill: “It’s such a small world. If you just talk to people and listen, it brings everything together” (V24). Other volunteers also supported the idea that a large part of the hospice volunteer role simply involves listening to patients and families. Volunteer 18 explained that end-of-life care “encompasses the fact that people need to talk to somebody and they can talk and get that out and then discuss it. You know, I think that in itself is a big help.” Several participants supported the opinion that serving as a hospice volunteer is “just knowing that there’s somebody listening” (V16) and “mostly being there and being available to listen when they are ready to talk. It takes a lot of patience” (V7). Volunteer Seven indicated that learning to listen requires patience and learning for the hospice volunteer.

Hospice volunteers must learn to interact effectively in the sometimes awkward encounters that occur when others are facing the final stages of life. One volunteer reflected on the overall communication experience of working as a hospice volunteer:

You have to learn. Your experiences teach you how to greet people and how to begin, just how to begin. Once you’ve been a volunteer for a while, that doesn’t become that much of an issue. It can be an issue, though, for when you’re starting. (V27)

As mentioned in the above statement, communicating in the hospice volunteer context may present unavoidable challenges that are difficult to anticipate in training.

**Overcoming communication challenges.** Communication rewards and challenges surfaced as a notable theme as participants frequently discussed their relational encounters with hospice patients and families. As discussed in previous sections of this analysis, relational

dynamics greatly impact the hospice volunteer experience. For experienced volunteers who remain committed to the hospice volunteer role, the rewards of communicating with patients and families outweigh the challenges. One volunteer emphasized the reward of communicating with patients facing end-of-life circumstances:

People have so much to offer and say and boy you can learn from somebody for a single day, no matter how old they are and no matter how old you are and I have no problem saying, "I'm sorry I don't understand", or "I don't know", or "Would you please explain that to me?", and if you can do that, I think the whole world is so open to you. (V5)

Despite the intrinsic rewards of learning from interactions with others, participants in this study also shared several communication challenges.

One particular challenge of interacting with patients nearing the final stages of life involved an inability to communicate with patients. For example, one volunteer explained that "it was just kind of hard because usually if there's a silence I think I get to fill it, you know. I just try not to do that. So it was a learning experience for me" (V16). Some participants admitted to feelings of frustration stemming from the discomfort associated with interactions when a patient lacks the ability to communicate effectively or remains silent or unconscious:

The hard part is a lot of these people, they don't... you can't understand them or they can't hear you because they're hard of hearing and that's frustrating because you can't communicate with them. So you don't know what they want and sometimes they'll say "Well go talk to so and so. Well what do you talk about?" If they can't hear you, what are you going to say and if they don't understand you and I mean that's why I have such trouble with that part of it, that's why I don't want to go and sit at someone's house and

talk to them or sit in the nursing home and talk to somebody, I'd rather be doing things.

(V6)

The above perspective demonstrated that some hospice volunteers feel uncomfortable when dealing with patients who lack communication skills. However, several participants expressed an ability to overcome the challenges of facing communication barriers in the hospice volunteer context. For example, one volunteer described silence as another form of communication:

Well and then you have the communication of silence, which we find we do especially with extended care. They may be deeply asleep; they may be where they're not going to respond at all. So it's your presence, it may be your hand on their hand or stroking their leg as you take in the silence. So that's a form of communication. (V27)

Although hospice volunteers find ways to overcome the lack of verbal communication, other challenges arise due to the high levels of uncertainty experienced during hospice interactions.

Participants in this study commented on the ambiguous and uncertain nature of interactions in the hospice context. Participants indicated higher levels of communication uncertainty when initiating a new patient encounter. For example, one volunteer explained the challenge of establishing new hospice relationships:

Probably the most difficult part of getting started with a patient or caregiver is what to say. You're given some information, but not a whole lot. You're given the age, what the difficulty is, I always ask that. And if they have family, they usually give us that information. And I ask if they stay in touch, if they're highly involved. But even so, I think that initial communication period is probably one of the hardest. You can go in smiling and say this and that and it could be that smiling is not the very best thing to be doing to people. (V27)

One volunteer emphasized the uncertainty of hospice interactions and recommended that volunteers approach all communication encounters with sensitivity:

You always have to be extremely sensitive the first few times as to what the situation the situation is like and what the person you're dealing with is like, and what is needed.

Sometimes you don't always do it right. (V27)

New volunteers may face higher levels of uncertainty as they adjust to the hospice volunteer role. For example, one newer volunteer articulated feelings of nervousness during an awkward first encounter with a patient:

I was nervous and, in addition to being nervous, you know, I was excited about it also.

I've been trained for it. It's what I want to do. It's what I was willing to do and I was nervous but I was anxious all at the same time and then that happened and that wasn't the greatest way to start out. (V5)

In addition to the uncertainty of interacting with new patients, participants also described uncomfortable encounters with patients and families. For example, several volunteers shared stories of difficult conversations (e. g., a patient shared their fear of death), confrontational family encounters (e. g., a rude or aggressive person), and an uncomfortable environment (e. g., an extremely dirty home, frightening pets, hostile family dynamics).

This analysis focused specifically on communication uncertainties but hospice volunteers also face uncertainties due to functional and physical challenges of patient care, not just communication challenges. For example, one volunteer shared a story of an uncomfortable homecare situation:

There was one time when I had a man who was pretty overweight and he had the lift to help lift him out of the chair, but I was so fearful he was going to fall when going to the bathroom. (V26)

While some encounters of uncertainty revolve around non-communication factors, the need for proper communication may be exacerbated when volunteers experience uncertainty about physical caregiving. Volunteers sometimes encounter uncertainty related to physical care for patients, yet hospice volunteers primarily provide social and emotional support. Amplified by the difficult context of death and illness, communication and uncertainty surfaced as a notable challenge experienced by the hospice volunteers in this study.

### **Summary**

The thoughtful and reflective responses shared by the participants in this study revealed four overall themes revolving around the hospice volunteer experience. The thematic analysis provided in this chapter included the following overall themes: 1) Motivations and Hospice Volunteers, 2) Volunteer Experiences and PCC, 3) Volunteer Experiences and Mindfulness, and 4) Communication and the Hospice Volunteer. The direct quotes and examples extracted from participant interviews provided illustrations of each theme and category. The next chapter will offer a discussion of the themes and categories analyzed in this chapter.

## CHAPTER FIVE: DISCUSSION

*“I’m probably stronger. It makes you put things in perspective... how fleeting your life is. There are no guarantees” (Volunteer Twenty-One).*

Chapter four described the overall themes identified during the analysis of interview conversations with hospice volunteers serving Midwest Hospice.. The overall themes included Motivations of the Hospice Volunteer, Volunteer Experiences and Patient-Centered Care (PCC), Volunteer Experiences and Mindfulness, and Communication and the Hospice Volunteer Experience. The analysis and description of the overall themes assisted in my creation of a model reflecting the role of PCC, mindfulness, and communication in hospice volunteer experiences. This chapter addresses the contributions of the overall themes, sub-themes, and categories in the development of a new theoretical model and provides practical recommendations for recruiting, training, and sustaining hospice volunteers.

**The Heart Model of Hospice Volunteer Experiences**

The converging influences of patient-centered care, mindfulness, and communication noted during this analysis contributed to the development of a new theoretical model of hospice volunteer experiences. Utilizing the findings from the analysis of interviews with Midwest Hospice volunteers, I developed the heart model (Figure 1) to illustrate the motivational and theoretical of points of intersection in the hospice volunteer experience.

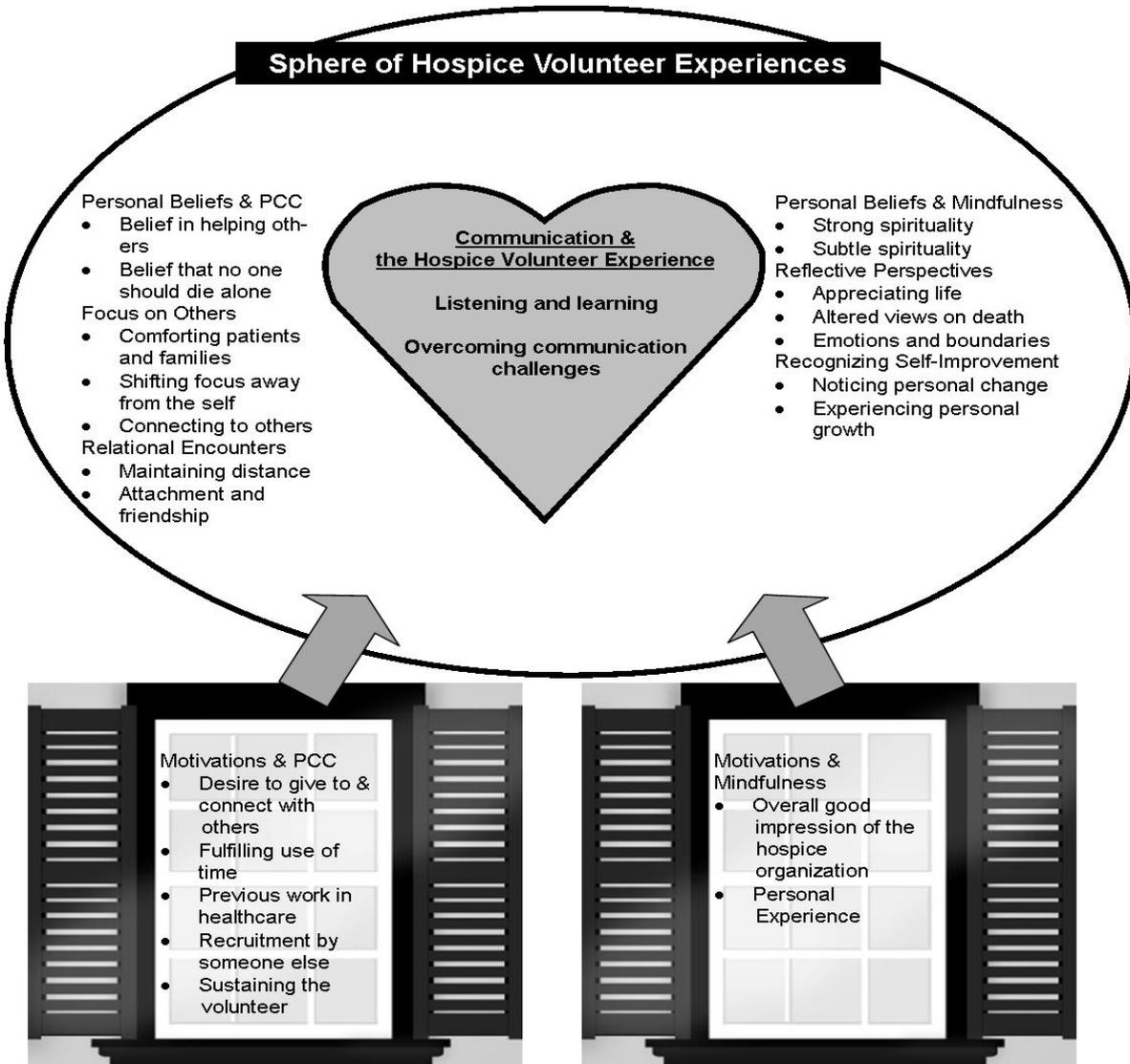


Figure 1: The heart model of hospice volunteer experiences (Cooley, 2011).

This new model illustrates the sphere of hospice volunteer experiences as influenced by the overall themes of PCC and mindfulness. Communication and the hospice volunteer experience serves as the center or heart of hospice volunteer experiences. The two window boxes shown at the base of the model illustrate motivations related to PCC and mindfulness as entry points contributing to the sphere of hospice volunteer experiences. In the next sections of this chapter, I explain the heart model by discussing hospice volunteer experiences and the contributions of the PCC themes. Next, I discuss the contributions of mindfulness themes to the

heart model. Finally, I elaborate on the contributions of communication themes as central to the hospice volunteer experience.

### **Contributions of Patient Centered Care**

The heart model, created after the analysis of Midwest Hospice volunteer interviews, illustrates the notable contributions of PCC as central to the hospice volunteer experience. PCC has been linked to overall better outcomes such as improved patient satisfaction ratings, better patient adherence to recommendations from the healthcare provider, and more cost-effective care (Reynolds, 2009). Previous research in communication and palliative care suggested PCC as instrumental in comforting terminally ill patients and their families (Wittenberg-Lyles et al., 2010). Due to the potential improvements offered by emphasizing PCC in the hospice context, this study explored how hospice volunteers exemplify facets of a PCC approach. Although participants did not officially use the term *patient-centered care*, they did discuss personal beliefs supporting a strong focus on patients and families.

Hospice organizations can emphasize a PCC approach and bolster the value of the hospice volunteer role by highlighting how volunteers help others during the crucial final stages of life. Individuals volunteering for other types of organizations (e. g., homeless shelters, child services, museum docents) also express a desire to help others and offer valuable service. However, the hospice context provides an opportunity for individuals to help those encountering the ultimate challenge of confronting death. The distinct end-of-life experiences inherent in hospice volunteer work distinguish this helping role as an opportunity to assist others within the challenging context of illness and dying. Hospice volunteers in a study by Foster (2002) emphasized the idea that “it’s not about me” (p. 251). Foster explained that hospice volunteers not only help others but must also learn to relinquish preconceived notions and shift their

concerns away from themselves. Previous research suggests that hospice volunteers remain more committed when they feel helpful to and valued by the organization, hospice staff, and patients and families (Claxton-Oldfield, 2004; Claxton-Oldfield, S., & Claxton-Oldfield, J., 2008).

**Relational dialectics.** The PCC approach further contributes to the heart model due to the emphasis volunteers place on relationships. Many of the participants discussed their relationships with patients and families as a form of friendship. However, the friendships described by Midwest Hospice volunteers reflected a tension between the role of caregiver and the traditional role of friend. Similarly, research by Berry and Planalp (2009) suggested a need for training to help volunteers negotiate the unclear boundaries of the volunteer role while functioning in a liminal state as neither an actual friend nor an official health provider.

The dialectical perspective considers tensions, contradictions, shifts, and the overall aspects involved in human communicative relationships (Rawlins, 1992, 2009). In a recent study of hospice workers, Considine and Miller (2010) also explained “dialectical tensions are likely to be particularly apparent in end-of-life interaction, as patients and their families cope with competing forces of connection and separation, of stability and change, of openness and privacy, of life and death (Considine & Miller, 2010, p. 167).

As participants described their hospice relational encounters as friendships, they exposed the dynamic and blurred landscape of friendship. Primarily concerned with the relational context of friendship, Rawlins (2009) stated that “all friendships are affected by social and political forces. In turn, friendships influence all areas of society” (p. 8). The tensions encountered while nurturing hospice relationships during the final stages of life reflects the ubiquitous contradictions discussed when considering the dialectical perspective. For example, the hospice volunteer can be both caregiver and friend despite the sometimes contradictory or shifting nature

between the two roles. The concept of *motion*, a dialectical perspective that assumes relationships are always changing (Rawlins, 2009), applies to the hospice relational context. The declining health and eventual death of the hospice patient guarantee that relationships between hospice volunteers and dying patients remain in constant motion.

*Distance versus attachment*, a dialectic discovered in this analysis of hospice volunteer relationship experiences, involved the tensions and contradictions of maintaining distance during interactions with patients/families as opposed to developing attachments as relationships form between hospice volunteers and patients/families. The dialectic of Distance Versus Attachment impacts the interpretation of the heart model; relational encounters contribute to the heart model by emphasizing the need for maintaining distance and the reward of forming attachments. Contemplating the dialectical perspective proves constructive in the study of hospice volunteer communication as individuals engage in contradictory and changing relationships during the final stages of life.

### **Contributions of Mindfulness**

Participant behaviors and attitudes embodied the mindfulness approach as part of the hospice volunteer experience. Reflective of the mindfulness approach, this analysis revealed the sub-themes of Personal Beliefs, Reflective Perspectives, and Recognizing Self-Improvement. The mindfulness categories of spirituality, appreciating life, altered views on death, authentic encounters, emotions and boundaries, personal change, and personal growth all contributed to the heart model. Hospice organizations can foster mindfulness practices as tools for improving care by enriching the introspective work-lives of volunteers as well as other staff members.

Previous research has connected patient satisfaction and the mindfulness approach. Patients reported an appreciation for healthcare providers who respond to patients with a

mindfulness approach. These patients expressed a desire for attentive care providers who express interest in patient concerns and who express compassion while considering the overall well-being of patients (Epstein, 2003).

Originally derived from the spiritual practices of Chinese medicine and Buddhism, the concept of mindfulness easily connects with spiritual outlooks (Epstein, 2003; Wood, 2004). The notable acknowledgements of spirituality by many participants suggested a straightforward connection between mindfulness and the hospice volunteer experience. While some participants denied the influence of spirituality, most participants claimed subtle or strong spiritual elements as influential in their hospice volunteer service. Caldwell and Scott (1994) also found that a high proportion of hospice volunteers were involved in religious activities; they suggested that spiritual values promote volunteerism by encouraging community engagement and responsibility.

Hospice organizations must carefully manage spiritual conversations. Considine and Miller (2010) emphasized the importance of first understanding a patient's needs since discussions of spirituality can prove helpful or harmful. The positive intentions of spiritual discussions sometimes err toward feelings of judgment or condemnation. The hospice CEO in the study by Considine and Miller stressed the importance of setting clear organizational rules regarding spiritual care. Despite the strong influence of spirituality among Midwest Hospice volunteers, most comprehended the necessity of a sensitive approach to patients who subscribe to different belief systems.

Since mindfulness involves a cognitive perspective permitting "insight, presence, and reflection" (Epstein, 2003, p. 1), the Reflective Perspectives sub-theme further supported the contributions to mindfulness represented in the heart model. Similar to the Midwest Hospice

volunteers, Gurguis-Younger and Grafanaki (2008) noted an enhanced appreciation of living among palliative care volunteers. They suggested that fostering an appreciative perspective may help to sustain hospice volunteers. The hospice volunteers' enhanced propensity to appreciate life suggests that the hospice volunteer experience may deepen the personal sense of reflection, insight, and presence.

Seno (2010) suggested that individuals can form a stronger appreciation for life as they reflect on death. Discussing the importance of accepting death, Epstein (2003) suggested that individuals practicing mindfulness provide better healthcare due to their ability to face and accept death. Participants in this study attributed their improved capacity for experiencing death as an effect of their hospice volunteer work. Despite a common public perception that assumes hospice work involves a dark or depressing environment, the hospice volunteer experience may lead to more healthy and positive views on death. Previous researchers have noted that hospice volunteers altered their initial views (e. g., death as only sad or depressing) to positive or transformed views of death (Planalp & Trost, 2008; Wittenberg-Lyles, 2006). The altered views on death category represented the rewarding and/or enriching aspects of the hospice volunteer experience as central to the heart model.

The necessity of engaging in authentic encounters surfaced as participants asserted the value of being in the moment or present to the situation when administering end of life care. Authenticity, closely related to the mindfulness approach, increases as people raise awareness and communicate more consciously (Seno, 2010). Previous research further supports the essential role of authenticity for hospice volunteers by emphasizing that volunteers can help patients by simply being present to the moment (Caldwell & Scott, 1994; Gurguis-Younger & Grafanaki, 2008). Foster (2002) also highlighted the important role of just "being there" as a

hospice volunteer. The concept of just being with patients and families during authentic encounters reflected the awareness ingrained in the mindfulness approach as central to the hospice volunteer experience.

Emotions and boundaries surfaced as a principal category of the Reflective Perspectives sub-theme. Outlining the mindfulness concept, Wood (2004) explained compassion and mindfulness as natural human behaviors when individuals engage with others and become present to the moment, experience, or conversation. Compassion and empathy, emotions often exhibited by healthcare providers practicing mindfulness, represented a common emotional element mentioned by participants. Egbert and Parrot (2003) suggested that hospice organizations should focus recruitment efforts on empathic individuals because these individuals remain more likely to serve the hospice mission of caring for the patient as a whole person.

While delivering care empathic, compassionate, and comforting caring may positively impact the hospice volunteer, participants discussed the importance of maintaining boundaries. Findings from the current study reinforced previous research by Gurguis-Younger and Grafanaki (2008) as they discussed the challenge of upholding boundaries and preserving emotional distance while maintaining interactions marked by authenticity. As mentioned earlier in this chapter, the tension between experiencing emotion and preserving boundaries reflects the dialectical perspective on communication and relationships. Later in this chapter I will offer recommendations for helping hospice volunteers negotiate these ambiguous situations.

Since mindfulness involves a process of introspection, attentiveness, and self-awareness (Epstein, 2003; Wood, 2004), the sub-theme of Recognizing Self-Improvement indicated further connections between the hospice volunteer experience and mindfulness philosophies. Unsurprisingly, participants noticed personal changes and experienced personal growth as a

result of their time as hospice volunteers. Palliative care volunteers in a previous study viewed the volunteer role as a learning opportunity and a chance for self-exploration as they broadened their own perspectives while coming to value their connections with dying patients (Gurguis-Younger & Grafanaki, 2008). Similar to the participants in the current study, those volunteers also reported a deeper understanding and meaning in their own lives. Internal changes and growth occur naturally as hospice volunteers have opportunities to witness *good deaths*, a term Wittenberg-Lyles (2006) described as involving a peaceful and pain-free experience with someone by the side of the dying patient. The personal changes mentioned by participants, such as feeling stronger, more content, mellow, and better equipped to handle problems, suggested that self-improvement often occurs in the hospice context. Hospice organizations, as recommended in a later section of this chapter, can encourage mindfulness practices to help foster personal growth as a method for sustaining volunteers.

### **Contributions of Communication**

Egbert and Parrot (2003) asserted “there is no better population from which we can learn these communication lessons than hospice volunteers. As providers of social support to terminally ill patients, these laypersons are confronted with difficult communication” (p. 32). For example, the hospice volunteer experience encourages individuals to learn improved listening skills. The emphasis on listening as a crucial task for hospice volunteers surfaced during many of the interviews with Midwest Hospice volunteers. As listed in a later section of this chapter, practicing effective listening skills should be incorporated as a strong aspect of hospice volunteer training programs. Continuing education for experienced volunteers should continuously reinforce listening skills.

While listening represented a dominant theme of hospice volunteer communication, participants also expressed frustration with the deteriorating communication abilities of patients in the final stages of life. Hospice volunteers noted the difficulties associated with communicating when the patient has severe physical and/or mental impairments, including the inability to communicate verbally. In addition to feelings of frustration when patients cannot communicate, hospice volunteers may also encounter difficult conversations due to the end-of-life context. For example, hospice volunteers in a study by Planalp and Trost (2008) discussed communication challenges as patients shared their negative feelings about dying. The communication challenges illuminated the value of communication training among hospice volunteers and highlighted the need for enhanced communication skills throughout hospice organizations. Due to the sensitive nature of caring for terminally ill patients, hospice organizations should address the emotional dynamics of managing frustrations during challenging communication situations.

**Linking communication, PCC, and mindfulness.** Communication represented a central link between PCC and mindfulness while contributing directly to the center of the heart model. Previous research on PCC provided support for the importance of listening, assessing, and then responding to patient concerns (Mast et al., 2005). Additional research regarding the implementation of PCC emphasized the need to use strong communication skills, to advocate for patients, and to appropriately address patient needs (Reynolds, 2009; Stewart, 1995). Mindfulness, as demonstrated by the sub-themes and categories revealed in this analysis, prepares hospice volunteers to communicate more effectively and with a focus on thoughtfully meeting patient needs. Mindfulness approaches can facilitate a commitment to attentive and engaged listening (Wood, 2004).

A key factor in communicating with a focus on patients, listening also serves as a crucial skill for practicing mindfulness. Foster (2002) explained how hospice volunteers increase attentiveness as they realize that “sometimes, being with the patient means becoming comfortable without conversation” (p. 252). For example, Villagran and colleagues (2010) discussed nonverbal immediacy, such as maintaining eye contact, leaning forward, avoiding fidgeting, and nodding agreement/understanding as essential skills in providing patient-centered palliative care. Enacting effective nonverbal behaviors largely depends on listening well and requires the attentive self-awareness infused in the mindfulness approach. The intersections between communication, PCC, and mindfulness converge in the overall hospice volunteer experience. The heart model illustrates this intersection as central to the hospice volunteer experience. Motivations for becoming a hospice volunteer, also representative of PCC and mindfulness approaches, contributed to the center of the heart model.

### **Tapping into Motivations for Recruitment Efforts**

Developing an understanding of hospice volunteer motivations can assist hospice organizations in recruitment efforts. Since federal regulations require hospice organizations to meet a minimum standard of five percent of patient care administered by volunteer service (HFA, 2010), recruiting and maintaining volunteers to serve patient needs remains essential. This section provides an explanation of the motivation themes and discusses the implications of motivations on hospice volunteer recruitment. This analysis contributed to the development of a recommendation list (Appendix B) of organizational practices designed to assist hospice organizations in recruitment efforts.

The current findings, along with previous research, provided support indicating that individuals often choose to become hospice volunteers due to a motivation to make a difference

by helping those in need (Claxton-Oldfield, S. et al., 2004; Planalp & Trost, 2009a, b). A desire for giving to and connecting with others surfaced as a major category within the Motivations and PCC subtheme. The practical implications of understanding hospice volunteers as motivated by helping others should be utilized by hospice organizations when recruiting potential volunteers. Hospice organizations should design messages aimed at capturing the attention of individuals possessing the desire to help and to connect with others. The messages and images used for mailings, newsletters, advertisements, and informational sessions should stimulate interest by tapping into this desire to help. For example, advertisements promoting informational recruitment meetings held at the hospice facilities and at community locations (e. g., libraries and churches) should encourage the attendance of individuals with a marked desire to give to and connect with others. The speakers and materials employed during recruitment meetings should also emphasize the motivation to help others by providing relevant stories and examples of hospice volunteer service.

Motivated by the desire to help others, as well as the desire to find fulfilling uses of personal free time, participants seemed likely to fit the extravert personality type (Caldwell & Scott, 1994; Quenk, 2000). Hospice organizations, therefore, can focus recruitment efforts toward extraverted individuals. Extraverts prefer interacting with others and feel energized by interactions (Quenk, 2000). Analysis along this vein revealed the sub-themes of Focus on Others, Relational Encounters, and Recognizing Self-Improvement. The categories of these sub-themes highlighted the fulfillment gained from interacting with others as hospice volunteers, thereby providing further support for targeting recruitment efforts toward extraverted individuals. By targeting extraverts, hospice organizations can focus recruitment efforts on individuals energized by such interpersonal interactions. These individuals are more likely to enlist as volunteers and

to forge connections with patients/families. Hospice organizations could also utilize current volunteers and other organizational members to encourage extraverted friends, family, and acquaintances to become hospice volunteers. While extraverted personality types may represent a target for hospice volunteer recruitment efforts, it remains important to recognize that other personality types also function well in the volunteer context.

The desire to find fulfilling uses of time emerged as a sub-theme describing a motivation for becoming a hospice volunteer. Previous research revealed the need to feel valued and useful as important to hospice volunteers (Claxton-Oldfield, S., et al., 2004; Planalp & Trost, 2009a, b). Gurguis-Younger and Grafanaki (2008) found that palliative care volunteers reported a sense of freedom, personal agency, and flexibility stemming from their volunteer service; these feelings reflect the personal fulfillment gained when contributing time as a hospice volunteer. Hospice organizations should highlight the rewarding sense of fulfillment experienced by hospice volunteers during recruitment meetings. Sharing the stories of personal fulfillment and meaningful moments encountered by hospice volunteers may help to inspire potential recruits to enlist.

While Planalp and Trost (2009b) found that most hospice volunteers initially started serving hospice due to a desire to help and/or to experience personal growth, the participants in the current study additionally reported commitment to and respect for the hospice organization as a motivation. The motivation of an overall good impression of the organization indicated the importance of presenting an impressive standard of patient-care, along with a positive organizational culture, during recruitment efforts. Hospice organizations should reinforce the organizational mission and high-quality standards of patient care in recruitment and training sessions. For example, when hosting informational recruitment meetings, hospice organizations

can provide information introducing attendees to the impressive service and care options provided by the respective hospice organization. For example, several new volunteers appreciated that Midwest Hospice explained their entire business model and organizational structure during new volunteer training. Hospice organizations might also consider sharing this type of organizational information at recruitment meetings. For example, planners of recruitment meetings might invite guest presentations by the key organizational leaders (e. g., the medical director, the chaplain, the vice president of marketing). By highlighting the positive aspects of their organizational culture, a hospice organization can tap into the motivation of recruits who develop an overall good impression of the organization.

Personal loss experiences, often involving hospice contact, represented another motivation leading participants to become hospice volunteers. Emotional resilience, resulting from personal experiences involving pain, loss, and exposure to death, was attributed as a motivation for palliative care volunteers in a previous study (Gurguis-Younger & Grafanaki, 2008). The emotional resilience that develops after a personal loss experience presents another avenue for recruiting effective hospice volunteers. Hospice organizations should target individuals with relevant personal experiences (e. g., death of a loved one). While hospice organizations may already maintain records tracking key family members following the immediate loss of a patient, hospice organizations should maintain extended contact with the immediate family and also expand efforts to reach less involved family members and friends of patients. One option may involve the distribution of short surveys for any relevant family member or visitor encountered at hospice facilities and at the homes of patients. Although completion of the surveys would be optional, this method of data collection may create a larger database for future contacts. For example, hospice organizations could utilize the extended

database to distribute mailings and/or emails to families and friends of previous patients at the one and two year anniversary of a patient's death. A concentrated effort to maintain contact with individuals who faced personal loss would demonstrate continued concern for those experiencing grief and could result in stronger recruitment efforts and/or enhanced financial donations.

### **Recommendations for Recruitment**

The motivation themes and categories identified in this study facilitated the development of a list of recommendations to assist with hospice recruitment efforts (Appendix B). The recommendations list provides a concise and practical resource to aid hospice organizations interested in tapping into the motivations of potential volunteers. I divided the list into two sections addressing recommendations to use prior to the recruitment meeting and recommendations to use during the meeting. The next section of this chapter explains the rationale for each numbered recommendation on the recruitment list.

**Prior to meetings.** Individuals with a personal loss experience and/or a previous hospice encounter represent prime candidates for becoming hospice volunteers due to their emotional resilience and the motivation to offer meaningful contributions to others (recommendation one). Current volunteers and staff may assist in recruitment efforts; several participants in this study mentioned that they were influenced to become hospice volunteers after a suggestion from someone they knew (recommendation two). This study revealed themes of spirituality as influential in the hospice volunteer experience, therefore contacting potential recruits through religious or spiritual organizations provides a powerful recruitment venue (recommendation three). Further bolstering spirituality as vital to recruitment efforts, Caldwell and Scott (1994) suggested the following:

Because so many of the volunteers were involved in church-related activities, perhaps the best place to let prospective volunteers know about the opportunities afforded them by hospice is through their religious group. When making public presentations, hospice would do well to send someone who is warm, with radiating sympathy and friendliness because these are characteristics of the volunteers themselves. (p. 45)

Since several participants mentioned previous experience working in healthcare as motivating them to become hospice volunteers, individuals with a background in healthcare represent logical recruitment targets to invite to meetings (recommendation four). A previous background in healthcare may lead to a heightened interest in volunteering for hospice, yet the organization must downplay the importance of previous experience during the actual meeting as potential volunteers must not perceive previous healthcare experience as a requirement (recommendation five).

**During meetings.** Since several participants mentioned that they were motivated to volunteer due to an overall good impression of the organization, recruitment meetings should provide impressive details to reflect high-quality care and organizational structure (recommendation six). The content shared at recruitment meetings should strongly emphasize opportunities to help others as a hospice volunteer (recommendation seven). Examples demonstrating the hospice volunteer role as a fulfilling use of time should help to inspire and inform individuals attending recruitment meetings (recommendation eight). By presenting the common characteristics of a typical hospice volunteer, the organization may help empathic and compassionate attendees to recognize their own qualifications and motivations that potentially point toward becoming a hospice volunteer (recommendation nine).

Hospice organizations may improve recruitment efforts by understanding the motivations for enlisting as a hospice volunteer. The recommendation list (Appendix B) provides a tool to guide recruitment efforts. After recruiting motivated hospice volunteers, the organization must consider appropriate approaches to train and sustain hospice volunteers.

### **Training and Sustaining Hospice Volunteers**

Based on the discussions of findings in earlier sections of this chapter, the next section presents suggestions to assist hospice organizations to train and sustain volunteers after the initial recruitment process. The findings regarding communication, PCC, and mindfulness contributed to the list of training recommendations (Appendix C). While the training implications discussed in this section primarily focus on the hospice volunteer experience, many of these recommendations may prove applicable toward training and sustaining other healthcare providers serving in palliative care/hospice settings.

### **Recommendations for Training**

PCC and mindfulness approaches can be encouraged among hospice volunteers by incorporating related concepts into training. For example, Brown and colleagues (2007) affirmed that “mindfulness is considered an inherent capacity of the human organism that can be enhanced through training” (p. 229). Hospice volunteer training can utilize the themes outlined in this analysis, along with general recommendations for PCC and mindfulness practices, in an effort to promote PCC and mindfulness among members of the organization.

Participants in this study consistently related to the dominant theme of a Focus on Others that included a belief in helping others and a belief that no one should die alone. Related to the PCC approach, these beliefs reflect the importance of emphasizing the core values of the hospice mission when training volunteers (recommendation A). Further emphasizing a Focus on Others

and a PCC approach, training should provide strategies for comforting patients and families (recommendation B). Several participants mentioned that the volunteer experience taught them to focus less on the self and more on others. Training should implement strategies to facilitate this shift in focus so that new volunteers quickly adapt to a PCC approach (recommendation C). As an example of a strategy for shifting the focus to others, one participant mentioned her practice of sitting in her car prior to patient visits and saying “let it NOT be about me,” a statement that helped her to center her concerns on the patient and not on herself.

While the Focus on Others theme remains crucially important, training should also address boundaries and emotions in an effort to sustain the healthy emotional involvement of the volunteer. Training should address the management of personal boundaries, including issues such as personal disclosure and becoming overly invested in relationships with patients and families (recommendation D). Emotional expressions, such as the use of empathy and compassion, must be carefully managed so that the volunteer avoids unhealthy attachment to dying patients that may later produce exhaustion or burnout. The Relational Encounters theme involved examples of volunteers developing friendships and attachments to patients and families that prove rewarding. However, training should simultaneously address ways to balance the dialectic of distance versus attachment. While a focus on helping others may inevitably lead to an emotional investment on some level, training should prepare volunteers to manage relationships effectively with patients and families (recommendation E). Appropriateness of relational encounters can increase with training advice that includes discussions of professionalism. For example, volunteers must understand how to determine the suitability of touching during interactions with a patient or family member (e. g., holding a hand or giving a hug).

The dynamics of providing end of life care necessitate training to address issues of spirituality (recommendation F). Spirituality surfaced as influential to most participants as they considered their hospice volunteer service. For example, training should include advice to discourage volunteers from pushing their own specific beliefs on others (e. g., proselytizing or challenging beliefs of others). Training should remind volunteers to respect differences while remaining open to conversations if patients and families broach spiritual topics. While spirituality represents a strong theme in the hospice volunteer experience, training must emphasize that some patients and family members may actively resist any religion or spirituality.

Since the hospice volunteer experience may alter personal views on death, training should prepare volunteers for witnessing the deaths of others by encouraging introspection in the beginning and throughout the hospice volunteer experience (recommendation G). For example, introspective exercises to help new volunteers challenge their previous assumptions about death may help them to comfort others while managing their own emotions. Ongoing training for continuing volunteers should persist with discussions of perspectives on dying to ensure that volunteer experiences remain emotionally stable for the volunteer and therefore helpful to the patients and families. For example, the continuing education of volunteers might include discussion groups facilitated by hospice volunteer coordinators. The discussion groups could provide volunteers with venues for sharing experiences and feelings in an effort to provide volunteers with support from peers and staff.

Effectively serving hospice patients and families requires the volunteer to engage in authentic encounters with those facing death or the loss of a loved one. Training should explain the value of interacting authentically while serving hospice patients and families (recommendation H). Training could include tips for authentic engagement. For example, advice

could address the idea of being present to the moment (e. g., the power of silence or holding a hand) or engaging in sincere and honest encounters (e. g., listening and responding with empathy). Reminding volunteers of the importance of authenticity may improve overall patient satisfaction, but may also prevent the volunteer from feeling a need to pretend or to fake emotions.

As volunteers process the idea of authentic encounters, they may become more introspective. The mindfulness theme of Recognizing Self-Improvement surfaced as a common experience shared by participants. The categories of self-improvement reflected the need for a training component addressing personal change and growth (recommendation I). Addressing the expectation for change and growth may help volunteers to recognize the rewards of volunteering and brace them for their shifting perspectives.

The roles of listening to and facing communication challenges, as discussed in an earlier section of this chapter, emerged as influential factors in the hospice volunteer experience. Hospice organizations should offer basic communication training and skills practice for new and continuing volunteers (recommendation J). Training should focus on listening as an essential function of the hospice volunteer responsibilities. The presentation of case scenarios of hospice encounters, followed closely by tangible advice for improving communication skills, may help to prepare volunteers to communicate more effectively with patients and families. Training could include small group sessions where volunteers can practice role-play scenarios and then receive feedback from the group facilitator. Small group facilitators, ideally qualified in communication instruction, might be equipped with a check-list of communication suggestions to assist in providing feedback to trainees. Research suggests that enhanced communication skills lead to many positive outcomes in healthcare settings such as increased patient satisfaction (Adams,

Smith, Ruffin, 2001), improved patient adherence (DiMatteo, Giordani, Lepper, & Croghan, (2002), and reduced emotional distress among patients (Roter, Hall, Kern, Barker, Cole, & Roca (1995).

As discussed in the literature review and analysis, the communication challenges of hospice volunteers may include frustrations with patients' inability to communicate, uncertainty regarding interactions, difficult conversation topics, uncomfortable settings, among other possibilities. Training should address the potential communication challenges of new and experienced volunteers (recommendation K). By presenting possible scenarios and examples of communication challenges during training, hospice organizations prepare volunteers with appropriate responses. Preparing volunteers for communication challenges may lead to better care for patients and families while preserving the boundaries and emotional reactions of volunteers. Ongoing training for continuing volunteers might also incorporate a section on communication challenges so that experienced volunteers have opportunities to discuss their difficult service encounters and either to seek or to share advice for effectively managing challenges. Providing continuing volunteers with outlets to discuss challenges encountered during their service may help to sustain the well-being and satisfaction of the volunteers. Sustaining volunteers may increase the retention of these valuable members of the organization.

### **Future Research**

This research offered practical insights based on the experiences of Midwest Hospice volunteers and previous hospice research. However, future research should address limitations encountered in this study. Previous research considering hospice/palliative care volunteers provided support for several findings from the current study, yet findings may vary based on the organizational structure, the location, and the volunteer populations of particular hospice

organizations. Future research should consider differences across types of hospice organizations (e. g., small versus large, for-profit versus non-profit, secular versus religious affiliations). For example, examining diversity issues (e. g., the ethnicity and socioeconomic status of hospice volunteers, hospice staff, and hospice patients) may produce divergent findings since the population at Midwest Hospice primarily consisted of white, middle-class volunteers and patients. A further consideration for future studies involves participant selection. The Midwest Hospice volunteers selected to participate in this study may represent exemplary members of the volunteer team. Findings may differ if research involved a survey or interviews of an entire volunteer population since the volunteers not interviewed may express different viewpoints than the exemplary participants.

The heart model and the recommendation lists provided in this chapter might also assist hospice organizations in training paid employees (e. g., nurses, aides, administrators). However, further research must explore the intersecting roles of PCC, mindfulness, and communication among paid hospice employees. For example, researchers should test the transferability of the interview questions used in this study by interviewing employees. Despite the use of an identical interview guide, employee responses will likely differ from volunteer responses.

The recommendation lists provide suggestions for recruiting, training, and sustaining volunteers but should be compared to actual practices already in use by various hospice organizations. For example, Midwest Hospice already utilizes many of the items offered on the recommendation list. Hospice staff coordinating volunteer efforts could offer supportive and/or challenging insights when asked to reflect on the proposed recommendation lists. For example, a future research project might involve interviews with hospice staff working to coordinate the volunteer programs at various hospice organizations. These interviews could explore the

goodness-of-fit and practical utility of the heart model and the recommendation lists presented in this chapter.

### **Conclusion**

The lessons learned by hospice volunteers can also apply to other members of hospice organizations. For example, hospice employees (e. g., nurses, aides, social workers, physicians) can strive toward PCC, mindfulness, and improved communication skills while encountering the challenges and uncertainties inherent during end of life care. Recommendations regarding recruiting, training, and sustaining hospice volunteers may also apply to other health professionals. Egbert and Parrot (2003) asserted that other health professionals can learn from hospice volunteer experiences:

The lessons learned from hospice volunteers will not only benefit the hospice community, but can be applied to health care professionals across disciplines...The experiences of hospice volunteers may become rich sources of information contributing to training programs in empathic listening and the provision of emotional support.” (p. 32)

Understanding the experiences of hospice volunteers and the connections to PCC, mindfulness, and communication contributed to the development of the heart model and practical recommendations for hospice organizations. The lessons learned during this study of hospice volunteer experiences reached beyond the hospice context and extended to the center of the human experience of living and dying.

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## Appendix A

### Volunteer Interview Guide

- Q1. (experienced volunteers) - How long have you been a volunteer with Hospice?  
(new volunteers) - What types of volunteer experiences have you had so far?
- Q2. How many different patients have you volunteered with?
- Q3. Why did you become a hospice volunteer?**
- Q4. (experienced volunteers) - What about this work keeps you volunteering/involved?**
- Q5. What would you consider your most memorable experience as a volunteer?**
- Q5A. (Can you tell me about one of the most gratifying experiences you have had?)**
- Q5B. (Can you tell me about one of your most trying experiences?)**
- Q6. Do you feel you have changed at all since becoming a volunteer? How so?**
- Q7. What do you feel are some of the most important things you have learned?**
- Q8. Please share some examples you've noticed of good communication between volunteers and staff here?
- Q9. How might you improve communication between volunteers and staff? (Do you have any specific suggestions?)
- Q10. How would you describe the relationships you have formed with patients and their families?
- Q11. Have you ever visited with a hospice patient that could not communicate? (ex., deep sleep or coma). What was that like? (Can you tell me about a particular situation?) (How did you feel in that situation?)**
- Q12. As you reflect on your time as a volunteer, please give me an example of how Hospice has helped someone change their views on living and dying.**
- Q13. Would you describe an example of how Hospice has helped you change your views on living and dying?**
- Q14. What role have your emotions played in your work as a Hospice volunteer?**
- Q15. What role does spirituality play in your work as a hospice volunteer? Can you give me a specific example?**
- {TRANSITION STATEMENT: We've been talking a lot about your experiences as a volunteer. Now I'd like to ask a few questions about the actual organization and how it operates...}
- Q16. {Newer} Now that you've actually worked with some patients, what did you find most useful from the training?
- {Older} Looking back over your service as a volunteer, what have you found most useful in the training you have received?
- Q17. In your experience, is Hospice serving diverse types of people in our community? (an example or story?)
- Q18. Under what circumstances have you shared information with people about Hospice care? (for example, what is hospice, what's involved, what to expect, what hospice offers)
- WRAP UP QUESTIONS:
- Q19. Are there any questions you thought I'd ask that we haven't covered?
- Q20. Is there anything else you feel is important for us to know about your experiences as a volunteer?**
- Q21. Do you have any questions for me?

## **Appendix B**

### **Recommendations for Hospice Volunteer Recruitment Meetings**

Prior to Meetings:

- 1) Focus recruitment efforts on individuals with some hospice experience
- 2) Encourage current volunteers and staff to invite friends to recruitment meetings
- 3) Utilize spiritual and religious organizations for potential contacts with potential volunteers
- 4) Direct recruitment efforts toward those with healthcare work experience (e. g., retired nurses)
- 5) Minimize the importance of having a background in healthcare

During Meetings:

- 6) Provide details about the organization (e. g., discuss the quality, staff qualifications, positive outcomes for patients and families, awards or accolades)
- 7) Provide examples of how hospice helps patients and families (e. g., use specific stories including volunteers who have given/donated time and made connections)
- 8) Provide a list of contributions made by volunteers
- 9) Emphasize the characteristics of typical hospice volunteers (e. g., extraverted, caring, compassionate, empathic, good listeners)

## **Appendix C**

### **Recommendation for Training and Sustaining Hospice Volunteers**

- A) Establish the core beliefs of the hospice mission and of the specific hospice organization
- B) Provide strategies for comforting patients and families
- C) Offer tips on how to focus more on others, less on self
- D) Offer advice on managing personal boundaries and emotions
- E) Discuss appropriate relationships
- F) Discuss spirituality, including personal beliefs and respecting differences
- G) Encourage exploration of personal views on death and dying
- H) Explain the importance of authenticity and presence
- I) Encourage reflection on personal perspectives before and after becoming a volunteer
- J) Teach basic listening and communication skills
- K) Discuss communication challenges

## Appendix D

## Human Subjects Review Board Approval



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November 29, 2010

**TO:** Laura Cooley  
COMS

**FROM:** Hillary Harms, Ph.D.  
HSRB Administrator

**RE:** HSRB Project No.: H11D081GE7

**TITLE:** *Organizational Communication: Hospice Volunteer Experiences*

You have met the conditions for approval for your project involving human subjects. **As of November 24, 2010, your project has been granted final approval by the Human Subjects Review Board (HSRB). This approval expires on November 7, 2011.** You may proceed with subject recruitment and data collection.

The final approved version of the consent document(s) is attached. Consistent with federal OHRP guidance to IRBs, **the consent document(s) bearing the HSRB approval/expiration date stamp is the only valid version and you must use copies of the date-stamped document(s) in obtaining consent from research subjects.**

You are responsible to conduct the study as approved by the HSRB and to use only approved forms. If you seek to make any changes in your project activities or procedures (including increases in the number of participants), please send a request for modifications immediately to the HSRB via this office. Please notify me, in writing (or email: [hsrb@bgsu.edu](mailto:hsrb@bgsu.edu)) upon completion of your project.

Good luck with your work. Let me know if this office or the HSRB can be of assistance as your project proceeds.

**Comments/ Modifications:**

Stamped consent documents are coming to you via campus mail.

c: Dr. Lynda Dixon

Research Category: EXPEDITED #7

