

# HOW DO CAREGIVERS LEARN? EXPLORING THE INFORMAL LEARNING OF HOSPICE CARE PROFESSIONALS

by

LISA CARAWAY OLIVER

(Under the Direction of Karen E. Watkins)

## ABSTRACT

Hospice care professionals provide care to the dying and support the bereaved. The setting for this study was a privately-owned hospice located in the southeastern United States. Because academia does not typically prepare students for work in end-of-life care, researchers project that in the current healthcare delivery system, there will not be enough trained caregivers (i.e., family or paid professionals) for older adults. This lack of formal education in end-of-life care requires hospice care professionals to learn how to provide care informally. The purpose of this study was to explore the informal learning of hospice care professionals within the context of their emotion work, with the aim of analyzing learning needs and proactively developing professional development interventions to address those needs. Three research questions guided the study: (1) What is the nature of the informal learning described by caregivers?; (2) what type of support is effective for individuals engaged in emotion work?; and (3) what is learned by an action research team exploring the emotion work of individuals who provide emotional support to those experiencing death and bereavement? The study methodology comprised an iterative, cyclical, four-step action research approach: (1) study and plan, (2) take action, (3) collect and analyze evidence, and (4) reflect. The nature of informal learning by hospice care professionals

was organized into three categories: (1) process, (2) perspective, and (3) approach. Co-workers and hospice administrators were cited as providing both effective and ineffective support for individuals engaged in emotion work. The action research team members learned more about themselves as hospice care professionals and about the responsibilities of other non-clinical hospice roles in operating as a team. Significantly, the study found that, within the context of emotion work, the process of informal learning was often typified by a primary emotion quickly followed by a secondary emotion that encouraged a particular approach to a situation. In addition, the study results suggested that hospice support staff meetings, in addition to serving as a formal means of receiving new requirements and educational opportunities, provide a positive, structured routine in what is oftentimes a non-routine setting.

**INDEX WORDS:** Action research, Death and dying, Emotion work, Informal learning, Hospice, Hospice care professionals, Interdisciplinary department teams, Support staff

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by

LISA CARAWAY OLIVER

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LISA CARAWAY OLIVER

Major Professor:	Karen E. Watkins
Committee:	Kathleen DeMarrais Lorilee R. Sandmann

Electronic Version Approved:

Suzanne Barbour  
Dean of the Graduate School  
The University of Georgia  
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## DEDICATION

*To*

*Evelyn, my father's hospice caregiver*

*and*

*The hospice care professionals of United Hospice, the most underpaid, emotionally stretched,  
good-hearted group of people I have ever met.*

*Thank you for allowing me into your world.*

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## CHAPTER 1

### INTRODUCTION

#### **Background**

Sinclair's (2011) study of palliative and hospice care professionals revealed that although an extensive body of literature has evolved exploring the spiritual and existential impact of dying and death, these previous studies have focused predominately on patients and occasionally on family members. Few have centered on the emotion work and informal learning required of hospice care professionals.

Chronic diseases, such as heart disease, cancer, stroke, diabetes, and arthritis, account for 70% of all deaths in the United States and are the leading cause of death and disability (Centers for Disease Control and Prevention [CDC], 2016). While chronic diseases can be controlled, they cannot be cured. Thus, palliative care is usually implemented to treat the discomfort and stress related to chronic illness; it provides relief from distressing symptoms including pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, and problems with sleep. Palliative care also helps individuals work through the side effects of medical treatments.

When a chronic disease has progressed to the point at which an individual has six months or less to live, palliative care expands into hospice care. Hospice is a philosophy of care for the terminally ill that focuses on quality of life until the end-of-life. Hospice care professionals work together with the patient, the caregiver, and the family to provide medical, emotional, and spiritual support. The goal of hospice care is to help people who are dying find peace, comfort, and dignity.

## **Problem Statement**

Typically, the nation's medical schools, nursing schools, schools of social work, and seminaries do not prepare their students to work within the context of hospice or palliative care (Csikai & Raymer, 2005; Institute of Medicine [IOM], 2014; Lloyd-Williams, Cobb, Shiels, Taylor, 2006). Family caregivers—including family members, partners, and close friends—represent a key factor in one's ability to remain in his or her home and community when a disability strikes (Redfoot, Feinberg, & Houser, 2013). Nearly 10 million adult children over the age of 50 care for their aging parents (MetLife Mature Market Institute, 2011).

More than two thirds (68%) of Americans believe they will be able to rely on families to care for them as they become disabled. Unfortunately, due to familial changes in the last generation (e.g., divorce, women working outside of the home, children living farther away from their parents, and families having fewer children) growing numbers of older people are likely to need institutional care (Redfoot et al., 2013). Consequently, many more people will be employed as hospice and palliative care providers.

## **Context**

The setting for this study was a privately owned, for-profit hospice—United Hospice. The organization consists of a 22-bed in-patient facility, which provides 24-hour care, and a home health division that provides hospice care in 22 counties in the state. The in-patient facility is located across the street from a hospital, on the fourth floor of a medical building. The lower three floors of the medical building are home to the hospital's cancer center, where patients receive radiation treatments, infusion therapy, and imaging services.

The mission of United Hospice “is to provide end-of-life care with dignity, grace, and compassion to the patients and families we serve.” The hospice's primary clients are individuals



whose life expectancy is six months or less and their loved ones. Its secondary clients are local hospitals whose patients are ready to be transferred to a nursing care facility but, because the facility is at capacity, are unable to place them in one. Another client of the hospice is pediatric hospitals; the hospice takes over care of the patient once the hospital determines that the patient is terminally ill.

United Hospice is not the most well-appointed hospice; the patient rooms' do not have flat-screen televisions mounted to the wall, nor do the rooms open to a well-tended garden, as they do at hospices in other cities. At this hospice, patients share rooms, and the view outside is through a window looking onto the hospital across the street or at an apartment complex situated next to the medical building. Nevertheless, in relation elements that truly matter in a healthcare facility—cleanliness and care for the patient—United Hospice delivers.

I chose this hospice because it operates in line with both the principles of Dame Cicely Saunders, recognized as the founder of the modern hospice movement (“Dame Cicely Saunders,” n.d.), and the Christian belief that no human life, no matter how wretched, should be denied dignity and love (Strickland, 2009). Not only does United Hospice take in cases other hospices have denied, it also takes in destitute clients.

### **Overview of the Research Design**

The purpose of this study was to explore the informal learning of hospice care professionals within the context of their emotion work, with the aim of analyzing learning needs and proactively developing professional development interventions to address those needs. The questions guiding the study were:

1. What is the nature of the informal learning described by caregivers?
2. What type of support is effective for individuals engaged in emotion work?

3. What is learned by an action research team exploring the emotion work of individuals who provide emotional support to those experiencing death and bereavement?

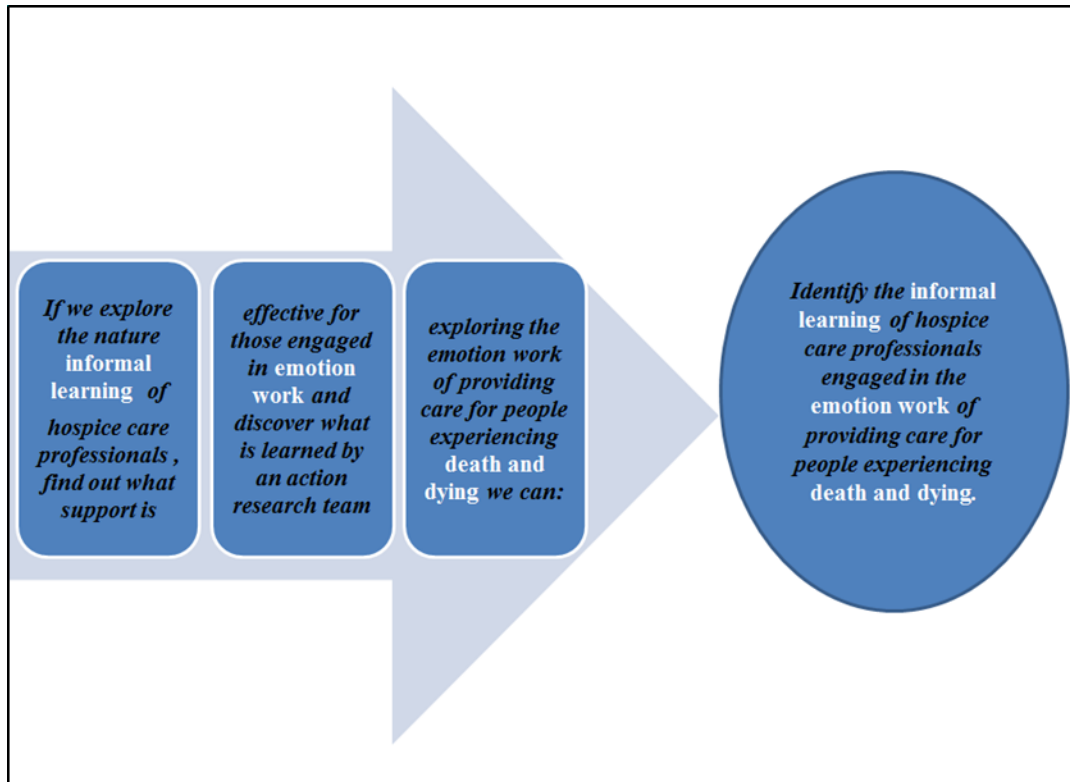
For the purposes of this research, emotion work was defined as the process of “induc[ing] or suppress[ing] feeling in order to sustain the outward countenance that produces the proper state of mind in others” (Hochschild, 1983, p.7). Informal learning was considered a process whereby an activity,

often taking place under non-routine circumstances, using the procedures and responses normally used, fail[s], leading to greater attention to, and awareness of, the tacit hidden, taken-for-granted assumptions, that may help learners rethink situations in which they find themselves, and re-frame their understanding of the kind of learning they might need to undertake. (Marsick & Watkins, 1990, p. 591).

Death was defined per the Uniform Determination of Death Act of 1980: “(1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem” (“The Uniform Determination of Death Act,” 1982).

Dying was considered the process whereby all circulatory, respiratory and brain functions decline until they eventually cease.

Figure 1 illustrates the study’s theoretical framework. The study operated under the assumption that by exploring the informal learning of hospice care professionals and by determining what types of support are effective for those engaged in emotion work around providing care for people experiencing death and dying, one can identify the informal learning of hospice care professionals engaged in this emotion work.



*Figure 1.* Theoretical framework for the study.

The study was designed as a four-step, iterative, cyclical, action research approach to (1) study and plan, (2) take action, (3) collect and analyze evidence, (4) and reflect (Reil, 2010). Twelve hospice care professionals were recruited purposefully to participate in the study. Structured interviews were conducted both individually and as a group, and served as the primary method of data collection, while my position as a participant observer in the hospice provided valuable information as a secondary source. Data sources included critical incident interviews, team meeting minutes, and observation/researcher notes, and data were analyzed using the constant comparative method.

We will all die. According to the CDC, seven out of every ten of us are not going to die instantly, but rather slowly; experiencing a steady decline in health, leading to disability and

eventually, death (CDC, 2016). We may not think much about our future health care needs because currently we are in possession of a great insurance plan that will account for such needs when the time arises. However, “in our current structure of healthcare delivery, there are not enough trained caregivers (family or paid professionals) for older adults” (Bragg & Hansen, 2015, p. 91). One of the reasons for this lack of trained caregivers is that there is no substantive research being conducted on caregivers; virtually none of the literature has examined social supports for hospice workers.

Who is going to be around to properly care for us at our end-of-life? What can be done now to prepare future caregivers with the ability to provide us with the level of care needed to ensure that we have a good death, one where our physical, mental, spiritual, and emotional needs are met? This study provides answers to those questions and offers suggestions for other interventions to prepare current and future caregivers.

### **Organization of Dissertation**

This dissertation is organized into six chapters. Chapter 1 provided the background, problem statement, and context of the study, followed by an overview of the study’s research design. In Chapter 2, I present a review of the literature summarizing the previous research on death and dying, emotion work, and informal learning, as well as demonstrating the need for research regarding hospice care professionals. Chapter 3 provides an in-depth description of the study design, the study participants, data collection methods, and data analysis. In Chapter 4, I describe United Hospice as an organization, the individuals who work there, and the work environment. I also provide background on the action research team and a detailed account of the action research cycles. Chapter 5, presents the research findings, including an examination of the critical incident that triggered learning and how the learning was realized, the types of

support that were effective for individuals engaged in emotion work, and what was learned by an action research team exploring the emotion work of individuals providing emotional support to those experiencing death and bereavement. Chapter 6 discusses the conclusions and implications of the study, and makes recommendations for further research.

## CHAPTER 2

### LITERATURE REVIEW

This literature review provides background for exploring and understanding the informal learning process of hospice care professionals. The review included journal articles, dissertations, and books detailing topics relating to death and dying, emotion work, and informal learning. The data sources used to locate theoretical and empirical literature included Galileo, EBSCOhost, PubMed, Google Scholar, and the National Library of Medicine.

#### **Death and Dying**

Herman Feifel was the first to formally research death and dying, specifically the death attitudes of mentally ill patients (1955) and older adults (1956). Research has since then expanded to include considerations of death anxiety (Templer, 1970), the psychology of death (Kastenbaum & Costa, 1977), and the association of death and dying with religion and faith (Florian & Kravetz, 1983; Thorson & Powell, 1990). In the new millennium, researchers have begun to focus on the quality of death and what it means to have a “good death” (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; Patrick, Engelberg, & Curtis, 2001).

Becker (1973) maintained that individuals are terrorized by the knowledge of their mortality and seek to deny it in various ways. Yet, as Jacobs (2010) and others have argued, death is not the enemy, though many treat it as such. Because most individuals cannot control the exact circumstances of their dying—when they die, where they die, how they die, how people will treat them when they are dying, etc. (Koenig, 2002)—the most common reaction to the thought of dying is fear—“fear of when and how they will eventually die; being abandoned;

becoming undignified in terms of what they do, how they look, how they smell; being a burden to their families physically and financially; dying in pain” (Byock, 1998, p. 208). Because “dying is an experience that nobody can rehearse, most people fear that he or she will be unable to deal with it, or that he or she will be inept in dealing with this ultimate peak of all traumas” (Rayburn, 2008, p. 97). Adults of all ages, including elderly adults, have fears of dying and fears of the unknown (Ciricelli, 2001); indeed, even though they know that preparation for the end-of-life is important, very few are prepared for this reality (Schrader, Nelson, & Eidsness, 2009). This realization of one’s limited time remaining on earth can result in anxiety and an awareness of one’s vulnerability.

### **Death Anxiety**

Nyatanga (2005) referred to death as “the only certainty and arguably the greatest source of anxiety for humanity” (p. 643). Death anxiety or thanatophobia is a state in which people experience negative emotional reactions in recognition of their own mortality (Brady, 2015).

Rayburn (2008) wrote that death anxiety could stem from a concern about practical matters such as:

putting their houses in order, resolving family issues about financial problems that will be caused by their death, emotional trauma of the mourning family, adequate care for their animals, and final disposal or resting place of their physical body after death. (p. 97)

Elisabeth Kübler-Ross, a psychiatrist who revolutionized care of the terminally ill (Noble, 2004), wrote that one of the primary reasons for death anxiety is that “dying nowadays is more gruesome in many ways, namely, more lonely, mechanical, and dehumanized” (Kübler-Ross, 1969, p. 21). Modern hospices are moving away from the clinical setting of hospitals toward a home-like atmosphere for those facing the end-of-life (Rice, 2017). Hospices believe in caring

not only for the patient but also for the family, and hospice care professionals try to address the physical, psychological, and spiritual needs of people at the most vulnerable point of their lives (MacFarquhar, 2016).

There is, however, a scarcity of research on the death anxiety of hospice care professionals. Carr and Merriman (1996) conducted the first study of the death attitudes of hospice personnel. While other studies on the death attitudes of nurses (Payne, Dean, & Kalus, 1998) and death anxiety of social workers (Quinn-Lee, Olson-McBride, & Unterberger, 2014) have been conducted, research on death anxiety has mainly been “restricted to nurses working in hospitals in emergency rooms or oncology units” (Jonasen & O’Beirne, 2015, p. 7). By contrast, how hospice care professionals view their mortality remains a newer venture in this young field (Jonasen & O’Beirne, 2015). While Jonasen and O’Beirne (2015) did conduct a study around the death anxiety of hospice workers, there were limitations regarding a lack of control group and the use of convenience sampling in a single hospice facility.

### **Needs of the Dying and Their Caregivers**

Researchers have identified the holistic (i.e., physical, emotional, social, and spiritual) view of end-of life care as promoted by Dame Cicely Saunders as a contributor to a quality or “good” death. Additional research has been conducted on certain components of a good death, including the physical/pain-management (Steinhauser, Christakis, Clipp, McNeilly, McIntyre, & Tulsky, 2000), emotional (Carlet et al., 2004), social (Christ & Sormanti, 2000; Csikai & Raymer, 2005), and spiritual (Evans & Ume, 2012; Delgado-Guay et al., 2011; Daaleman, Usher, Williams, Rawlings, & Hanson, 2008) needs of the dying and their loved ones. Focus groups have been used to explore end-of-life issues among church congregants and clergy



(Braun & Zir, 2001), and among clinicians and other health care workers (Ablett & Jones, 2007; Alkema, Linton, & Davies, 2008).

For many dying patients, there is much physical, mental, and spiritual suffering (Rees, 1963). There is, however, an ability to control physical pain with medication; therefore, “the greatest need is for a listener who will try to understand and help to relieve the patient’s sense of loneliness and emotional deprivation” (Rees, 1963, p. 927). Hospice care is typically preceded by a period of family caregiving. Family and friends provide personal care (e.g., dressing, feeding, and housework), medical care (e.g., administering medications and changing dressings), and assist with medical decision making and the coordination of care. Yet, recent research suggests a substantial number of caregivers are unprepared for the death of the one for whom they are caring. As Hebert, Prigerson, Schultz, and Arnold (2006) observed, “accepting that death is inevitable does not mean that one is prepared” p. (1166). Steihauser et al. (2001) conducted a study of patients, families, and health care providers to determine what factors are important at end-of-life. They determined that preparedness, or the degree to which the caregiver was ready for the death, was multidimensional, including medical, psychosocial, spiritual, and practical dimensions. Likewise, Herl and Berman (2004) asserted that “family and friends struggle with many challenges—physical, emotional, and spiritual—as their loved one prepares to die” (p. 192).

As an individual’s body is shutting down through the natural end-of-life process, loved ones may become distraught at what this impending death means for them (Evans, 2010). To comprehend the significance of this potential dilemma, I offer a hypothetical vignette that occurs in many hospitals and hospices worldwide. A woman is at the end stage of Alzheimer’s disease, and she refuses to eat or drink. (The refusal of foods and liquids is the natural progression of

end-stage Alzheimer's disease [Lee & Kolasa, 2011]). The woman's husband and two adult children are left to decide whether to begin artificial nutrition and hydration. Because of advancing dementia, patients at the end stage of Alzheimer's disease often do not experience hunger or thirst, and those patients who have poor food and fluid intake become dehydrated and typically do not express pain or discomfort. In some cases, artificial nutrition involves tube feeding, which may cause aspiration pneumonia as a result of the lungs breathing in foreign materials along with the intended nutrients, possibly causing harm and discomfort (Donowitz, 2009). Therefore, while the individual is not indicating that she is hungry, some in the family feel that the dying woman is being starved to death and want her to be tube fed even though tube feeding has its risks.

In this scenario, one child believes that life is valuable in all forms, no matter the quality, and that the mother should have a feeding tube inserted. Evans (2010) described this perspective as "vitalism," the belief that "life's value stems from God and pure biological human life is good no matter what the quality" (p. 4). The other child believes that there is no quality of life lying in bed with a feeding tube that will just prolong an inevitable death. Evans (2010) described this perspective as "conditionalism": "life is only worth living as it meets certain established levels, criteria, or quality" (p. 5).

Lastly, the patient's husband believes that this woman, although incapacitated and expected to die sooner than later, needs to be kept alive because, although she is not the wife of their youth, she is still his wife, and her demise will make him a widower. The man has always identified himself as a husband. Soon he will no longer be able to and therefore questions himself about who he is—an example of spiritual pain. Evans (2010) described this perspective as "instrumentalism": "life is a good to be preserved as a condition of other values" (p. 5).

Unfortunately, the decision about “what to do about mother” usually occurs at mother’s bedside, causing stress (spiritual pain) for all involved, including mother, who is ready to die and probably would welcome her family letting go but feels she must remain alive because her family needs her.

### **Needs of Hospice Care Professionals**

There are perceived rewards of hospice work, such as teamwork and team support, the opportunity to implement the hospice philosophy, and the appreciation of patients and families (DiTullio & MacDonald, 1999). There are also stressors of hospice work (other than those related to the death of the patient) such as administrative problems (Keidel, 2002) and the complex family situations many hospice care professionals must confront in providing hospice care patients (DiTullio & MacDonald, 1999). Specifically, Schaufeli and Enzman (1998) identified two types of work-related stressors faced by people in the helping professions: “job-related stressors, e.g. work overload and time pressure, and client-related stressors, e.g. confrontation with death and dying” (p. 84). Chronic exposure to these stressors may result in what Maslach (1982) identified as “burnout”:

Burnout is a syndrome of emotional exhaustion, depersonalization, and reduced personal accomplishment that can occur among individuals who do “people-work” of some kind.

It is a response to the chronic emotional strain of dealing extensively with other human beings, particularly when they are troubled or having problems. (p. 2)

However, Yang and Mcilpatrick (2001) suggested that hospice work need not necessarily lead to such negative experiences. They argued that “if effective coping strategies are used by hospice workers, caring for the dying could actually be seen as an opportunity for inner growth.

It is important, therefore, to determine which coping strategies are most effective in counteracting the stressful nature of hospice work” (p. 438).

Sardiwalla (2004) identified two categories of coping strategies that can be useful for hospice care professionals: “problem-focused coping strategies to enable the hospice care professional to complete the task-related aspects of the job, and secondly, emotional coping strategies to help the caregiver deal with the terminally ill patient, and facing the death of such a patient” (p. 8). As Jones (2008) noted, “clinical staff members often formulate plans of care for patients. To prevent worker burnout, hospice caregivers must develop a plan of self-care to balance their own needs with the needs of their patients” (p. 125). Table 1 outlines the empirical literature on death and dying.

Table 1

*Empirical Literature on Death and Dying*

Authors	Title	Purpose	Method	Sample	Results	Conclusion	Implications
Abrams, Albury, Crandall, Doka, & Harris (2005)	"The Florida Clergy End-of-Life Education Enhancement Project: A Description and Evaluation"	To mitigate the deteriorating physical and mental effects of futile aggressive care at the end-of-life by educating clergy and faith communities on EOL options, including the possibilities inherent in hospice care, so that clergy and communities might more effectively minister to the dying and bereaved.	Survey	Clergy, lay leaders, and other attendees of faith communities  N = 613	70% of participants who completed both the pre- and post-test reported a higher level of knowledge of end-of-life care on the post-test than they did on the pre-test.	The wide participation of clergy and their enthusiastic response to the program demonstrate that clergy are interested in increasing their knowledge of end-of-life issues.	Clergy and church workers have a deep and abiding ministry in end-of-life care. In many ways, it is the heart of a healing ministry. It is critical for other organizations to offer the support and education clergy need and want to fulfill their ministries.
Braun & Zir (2001)	"Roles for the Church in Improving End-of-Life Care: Perception of Christian Clergy and Laity"	Focus groups were used to explore end-of-life issues among congregants and clergy in Honolulu's multicultural community.	Interviews	Focus groups of clergy and congregants affiliated with Christian churches in Honolulu.  N = 121	Participants identified the components of both a "good death" and "bad death" and the obstacles to achieving a "good death."	Although participants recognized that the subject of death and dying may generate fear among some members and clergy, on the whole they felt that the church could, and should, play a significant role.	Faith communities have a major impact on improving end-of-life care, and pastoral education should include attention to these issues.
Buck & McMillan (2008)	"The Unmet Spiritual Needs of Caregivers of Patients with Advanced Cancer"	To identify the unmet spiritual needs of informal caregivers and explore the relationships between the patient's symptom distress, caregivers' unmet needs, and caregivers' depressive symptomatology at the time of admission to hospice.	Interviews	The sample consisted of caregivers of hospice home care patients with cancer.  N = 110	Caregivers of patients with advanced cancer clearly identify that not all of their needs were being met as they cared for their loved ones. Unmet spiritual needs in this vulnerable population are experienced as a negative stressor on their emotional well-being.	The study concluded that caregivers have specific spiritual needs that are not being met.	Routine assessment of unmet spiritual needs facilitates caring for caregivers.
Carr & Merriam (1996)	"Comparison of Death Attitudes"	To compare and contrast the death attitudes of	Survey	The survey population	As predicted, nurses who work in a hospice	Educational programs designed to help	Since social workers often practice

Authors	Title	Purpose	Method	Sample	Results	Conclusion	Implications
	Among Hospice Workers and Health Care Professionals in Other Settings”	hospice and hospital-based health care professionals.		included registered nurses, licensed practical nurses, social workers, chaplains, and home health aides (certified nursing aides) working in either a hospital or hospice setting.  Hospice n = 106 Hospital n = 76	setting are more comfortable caring for dying patients than nurses in the acute care setting. The hospital nurses more often reported being much less willing to offer to spend time with dying patients and wishing to avoid doing so if it could be arranged. In addition, hospital nurses were much more likely to feel that some to all efforts should be made to keep an imminently dying patient who has a terminal illness alive.	nurses and nurses’ aides become more comfortable with care of the dying could be conducted by social workers.	alongside nurses in both hospice and hospitals, there may be an established relationship that allows for the counseling professional to share knowledge and skills with nurses. Social workers might be excellent facilitators of these kinds of seminars.
Cobb, Dowrick, & Lloyd-Williams (2012)	“What Can We Learn About the Spiritual Needs of Palliative Care Patients from the Research Literature?”	To determine what is known about the spiritual needs of palliative care patients from the evidence presented in published research.	Specialist online databases were interrogated for primary empirical studies of patients with a chronic disease unresponsive to curative treatment. Studies that only used a proxy for the patient or reported expert opinion were excluded. Each study was critically appraised for quality and the strength of its evidence to determine if any data could be pooled.	35 studies were identified, equating to a total of 1,374 patients. Study populations were typically people with advanced-stage cancer, older than 60 years, English- speaking, and with a Christian or Jewish religious affiliation, reflecting the predominance of Anglo-American studies.	Studies fell into two groups: those that investigated the nature of spiritual experience, and those that examined the relationship of spirituality with other phenomena. The evidence was insufficiently homogeneous to pool.	Relevant accounts of what spirituality means for palliative care patients and evidence of how it operates in the lives of people with life-limiting disease can be derived from research. Studies to date are limited by reductive representations of spirituality and the conduct of research by health professionals within health care communities demarcated from disciplines and interpretive traditions of spirituality.	There is a great opportunity for research on the spirituality of end-of-life care. Unfortunately, the health care community is not very open to it.
DiTullio & MacDonald	“The Struggle for the Soul of	To identify those aspects of hospice work that	Interviews	38 hospice workers from a hospice in	The increased work volume and	On the theoretical continuum of	A greater understanding of

Authors	Title	Purpose	Method	Sample	Results	Conclusion	Implications
(1999)	Hospice: Stress, Coping, and Change Among Hospice Workers”	direct-service and middle-management staff considered unique and rewarding, and also to examine those conditions that created problematic levels of stress.		upstate New York.	complexity, and a consequent rise in crisis-driven intervention, were distinct sources of stress. Involved interpersonal factors that participants identified as contributing to a decline in the quality of work relationships. The increasing pace and complexity of delivering hospice care was frequently cited as the cause of faulty communication. Examples of the consequences of inadequate communication on day-to-day operations included lack of planning in filling critically needed open positions, delays in task completion, and role blurring, resulting in unclear work guidelines	strain-stress-burnout, the hospice workers studied generally appeared to be located somewhere between stress and burnout. The coping strategies reported were expressed by these workers as attempts to “keep going.” At the point of the study reported in this article, the participants tended to depict themselves as “still doing the work” but increasingly weary, uninspired, and disenchanted.	stress and coping in hospice will ultimately assist in preserving the health and viability of all professionals dedicated to the service of others.
Feifel, Freilich, & Hermann (1983)	“Death Fear in Dying Heart and Cancer Patients”	To appraise, in a controlled manner, difference between healthy subjects and dying patients on personal fear of death and to investigate differences in personal fear of death between patients dying from heart involvement as against cancer.	Interviews	Individuals from three major groups: 35 with various types of malignancy, 33 with heart disease, and control group of 95 healthy subjects.  N = 163	Terminally ill vs. healthy subjects, well over the 70% in each group denied any fear of death at all. Heart vs. cancer patients, showed no significant differences on the claim to have little conscious fear of death.	Patients close to impending death are markedly more afraid of death on an unconscious level than healthy individuals. Also, the type of disease does not appear to manifest an influencing fear of personal death.	Patients were significantly more afraid of death than the healthy subjects on a nonconscious level although both groups (healthy vs. heart disease or malignancy) disclaimed fear of death on a verbal (conscious) level.
Florian &	“Fear of Personal	To ascertain whether a	Surveys	178 males, ranging	The religious group	This confusion may	Fear of personal

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Kravetz (1983)	Death: Attribution, Structure, and Relation to Religious Belief"	descriptive multi-dimensional measure of conscious fear of personal death differentiates between religious persons and non-religious persons along these facets of this phenomenon to the same extent and in the same direction.		from age 18-30; all Israeli Jews  N = 178	attributed significantly more fear to punishment in the hereafter and significantly less fear to self-annihilation than the less religious groups. Because one aspect of being an observant Jew is believing in one's immortal accountability, this finding is understandable. However, the finding that the moderately religious group expressed significantly more fear of death's consequences to family and friends than the other two groups is not as readily understandable.	have resulted from the use of unidimensional measures of fear of death and relatively coarse measures of religiosity.	death appears to be characterizable in terms of general categories related to the intrapersonal, interpersonal, and transpersonal consequences of death.
Jonasen & O'Beirne (2015)	"Death Anxiety in Hospice Employees"	To measure death anxiety in hospice employees and to determine whether age, gender, and length of time employed in a hospice setting correlated positively or negatively with death anxiety.	Survey	128 employees at a Midwest hospice facility  N = 128	Doctors showed less death anxiety than nurses and administrative staff. Administrative staff scored higher than supervisors and managers. Overall death anxiety was low compared to other hospices.	Non-nurses showed a statistically significant ( $p = .011$ ) difference between death anxiety scores and length of time employed in a hospice. A possible explanation for this discovery was that nurses may be better equipped than non-nurses to face death through training and previous work settings.	Death anxiety could also be low because of effective staff training, efforts to promote employee well-being and aesthetic surroundings within the facility that supports feelings of tranquility.
Lloyd-Williams, Cobb, Shiels, & Taylor (2004)	"How Well Trained Are Clergy in Care of the	To determine the perceptions of clergy on the training they had	Questionnaire	A sample of clergy working in the diocese of	Most clergy believed they possessed adequate liturgical	Suggest that training in care of the dying and the bereaved	There is a great opportunity for end-of-life education in



Authors	Title	Purpose	Method	Sample	Results	Conclusion	Implications
	Dying Patient and Bereavement Support?"	received in supporting the dying patient and the bereaved.		Sheffield was sent a questionnaire to assess what skills and knowledge clergy believed they had in this area, together with areas where they would wish for further training. A subsidiary questionnaire was sent to clergy training colleges to evaluate the teaching offered.  Clergy n = 125  Clergy training colleges n = 21	skills, but 13% felt they possessed none or little skill in pastoral care of the dying. 71% indicated that they would like further training in pastoral care of the dying and 66.3% desired training in care of the bereaved. Of the 50% of training colleges that responded, the number of hours of training on pastoral care of the dying ranged from 6 to 36 hours, and only 26% believed that their training in pastoral support skills was comprehensive.	(including communication skills) should be part of the core curriculum within clergy training colleges and regularly revisited by all those who provide continual ministerial training for clergy.	the clerical community
Mako, Galek, & Poppito (2006)	"Spiritual Pain Among Patients with Advanced Cancer in Palliative Care"	To explore the multi-dimensional nature of spiritual pain in patients with end-stage cancer, in relation to physical pain, symptom severity, and emotional distress.	Interviews	57 patients with advanced-stage cancer in a palliative care hospital were interviewed by chaplains.	Overall, 96% of the patients reported experiencing spiritual pain, but they expressed it in different ways: (1) as an intrapsychic conflict, (2) as interpersonal loss or conflict, or (3) in relation to the divine. Intensity of spiritual pain was correlated with depression but not physical pain or severity of illness. The intensity of spiritual pain did not vary by age, gender, disease course, or religious affiliation.	Given both the universality of spiritual pain and the multifaceted nature of pain, it was proposed that when patients report the experience of pain, more consideration should be given to the complexity of the phenomena and that spiritual pain be considered a contributing factor. Spiritual pain left unaddressed both impedes recovery and contributes to the overall suffering of the patient.	Healthcare professionals should take a broader view of pain management that recognizes the complexities inherent in distinguishing between pain emerging from an underlying biological cause and that stemming from a spiritual or emotional source.
Quinn-Lee, Olson-McBride,	"Burnout and Death Anxiety in	To examine the possible linkages between death	Surveys	Hospice social workers in	Exposure to and understanding the	Understanding of the death process lessens	By better understanding the

Authors	Title	Purpose	Method	Sample	Results	Conclusion	Implications
Unterberger (2014)	Hospice Social Workers”	anxiety and burnout among a group of hospice social workers.		Minnesota and Wisconsin, aged 23 to 44; majority female  N = 290	death process overall decreased death anxiety. However working with a family or patient similar in age and life circumstances and witnessing a patient's pain or symptoms not being controlled or managed will raise anxiety. In terms of burnout, a large workload, difficult issues within a patients' family, and institutional issues impacted level of burnout.	death anxiety, but situations closely related to the social worker may heighten anxiety temporarily. Burnout among hospice social workers has more to do with workload and patients' families than death and dying.	nature of anxiety and burnout, professionals may be able to protect themselves and patients.
Neimeyer, Currier, Coleman, Tomer, & Samuel (2011)	“Confronting Suffering and Death at the End-of-life: The Impact of Religiosity, Psychosocial Factors, and Life Regret Among Hospice Patients”	To attempt to provide an integrative examination of potentially crucial factors in contributing to death anxiety and quality of life in an end-of-life context.	Interviews	Hospice patients, ages 18+ in their final weeks and months of life (prognosis of 3 weeks to 6 months) who could communicate for an interview. Accordingly, the patient sample was diverse in terms of race (35% African American, 65% Caucasian), gender (46% men, 54% women), and age (ranging from 39 to 99 years), with fairly even representation across the major decades of later adulthood: <61 [18%], 61–70 [20%], 71–80	Gender and ethnicity were robust predictors of death avoidance. Men reported greater death anxiety and avoidance than women. African-American patients indicated more death avoidance and escape acceptance than Caucasian participants.	Gender differences and cultural backgrounds of patients should not be ignored at end-of-life.	There are both religious and clinical implications to the study: Scientifically, the study extends research on religious coping in advanced illness and underscores the relevance of situating religiousness in the broader context of personal and social resources and liabilities that collectively configure an individual's response to mortality when it becomes salient. From a clinical standpoint, this research adds to the armamentarium of

Authors	Title	Purpose	Method	Sample	Results	Conclusion	Implications
				[26%], 81–90 [30%], > 90 [6%]; M <sup>1</sup> 473.8, SD <sup>1</sup> 412.4)  N = 153 enrolled in a 2 year study			professionals working with hospice and palliative care populations in general. In addition to playing a role in the assessment of quality of life and fear of death, such scales (or interviews that probe similar content) could prove valuable in identifying patient concerns that complicate the goal of self-determined life closure in the hospice setting.
Payne, Dean, & Kalus (1998)	“A Comparative Study of Death Anxiety in Hospice and Emergency Nurses”	To determine if a nurse's skills and confidence in providing good quality care to dying and bereaved people relates not only to his/her level of experience and training but to personal attributes such as degree of death anxiety.	Questionnaire, followed by short structured interview	Accident and emergency nurses, n = 20  Palliative care nurses, n = 23  N = 43	Results show that hospice nurses have low death anxiety despite spending almost every day with dying patients.	Nurses varied on their ability and/or willingness to reflect on the care provided.	There is a need for an easily accessible and confidential support network with accident and emergency nurses.
Sardiwalla, VandenBerg, & Esterhuyse (2007)	“The Role Of Stressors and Coping Strategies in Burnout Experienced by Hospice Workers”	To determine how the stressor experienced by hospice workers in and outside the working environment as well as coping strategies adopted by them can be used to predict the extent to which they experience burnout.	Questionnaire	Hospice workers, n = 78	Hospice workers do, in fact, experience a high degree of burnout, which affects their work performance and general functioning. Burnout is mainly the result of work-related stressors.	The results obtained indicate that the respondents experienced very high stress levels. This could possibly be attributed to factors such as various stressors outside of the work environment, problems with transport, and insufficient fringe	The present research lends further credence to the fact that the role played by caregivers is often taken for granted by members of society and other health professionals, thus making it more difficult for hospice workers to cope with their jobs.

Authors	Title	Purpose	Method	Sample	Results	Conclusion	Implications
						benefits provided to caregivers, owning the nongovernmental organization status of hospices.	
Thorson & Powell (1990)	"Meanings of Death and Intrinsic Religiosity"	To simplify understandings of relationships between multi-dimensional elements of the fear of death and dying with a uni-dimensional construct of intrinsic religiosity.	Survey	346 individuals, ages 18-88.  N = 346	Respondents who were older and higher in intrinsic religiosity were significantly lower in death anxiety. Both the high and low anxiety group were more concerned about dying than being dead. Primary fears had to do with pain, helplessness, and loss of control concepts.	Death anxiety of lower and intrinsic religious motivation is higher in later life.	The immediate threat of dying for most people is the fear of discomfort.

One of the key findings in the death and dying literature relates to the spiritual concerns of the dying, namely fears that clergy may not be effective in ministering to the dying (Abrams, Albury, Crandall, Doka & Harris, 2005; Braun & Zir, 2001; Lloyd-Williams, Cobb, Shiels, & Taylor, 2004). There is also a fear that the spiritual needs of the dying and their caregivers may not be met by healthcare workers (Buck & McMillian, 2008; Daalman, Usher, Williams, Rawling, & Hansen, 2008; Mako, Galek, & Poppito, 2006).

Another key finding is the discovery of specific death attitudes and anxiety among nurses and terminally ill individuals. Carr and Merriam (1996) determined that hospice nurses, although surrounded by death and the dying throughout their workday, were more comfortable caring for the dying in acute care settings. Feifel, Freilich, and Hermann (1973) conducted research on the fear of dying in heart and cancer patients. During interviews with both healthy subjects and dying patients, the researchers learned that well over 70% of each group denied any fear of death at all. However, patients close to death were markedly more afraid of death on an unconscious level than healthy individuals. The following section of the literature review discusses emotion work, its role in hospice work, and social supports for hospice care professionals.

### **Emotion Work**

The term *emotion work* originated from Hochschild's (1983, 2003) research on flight attendant trainees. Her study revealed that flight attendants are expected to control their true feelings to maintain a pleasant and nurturing environment for the customer. Hochschild (1983) named this social expectation for an individual to manage emotions according to his or her environment "feeling rules." Emotion work refers to "the act of evoking or shaping, as well as suppressing, feelings in oneself" (Hochschild, 1979, p. 266). Building on the work of C. Wright

Mills, Hochschild's (1983) research revealed that people control their emotions in their personal and work life, supporting the notion that the management of feelings and emotional expression (Hunter, 2001) is an important and demanding component of working with people. According to Bolton (2000), "emotion work is part of the everyday social exchange; there are rules that exist to ensure social stability and the well-being of those involved" (p. 582).

The research in emotion work has been conducted in various occupational fields, such as academia (Bellas, 1999), retail (Leidner, 1999), and police work (Johnson et al., 2005); on particular groups such as flight attendants (Hochschild, 1979); nurses (Ablett & Jones, 2007); and professional Black women (Durr & Wingfield, 2011). Emotion work research in healthcare generally and in hospice care specifically has mostly been conducted from a nurse's perspective (Ablett & Jones, 2007; Froggatt, 1998; Gray, 2009, Ingebretsen & Sagbakken, 2016).

### **Emotion Work Involved in Hospice Work**

Taking care of individuals at the end-of-life and their families is an experience rich with meaning (Jones, 2008). Some important tasks can only be accomplished at life's end, and hospice care professionals help facilitate the opportunity for life review, healing, and coming to terms with one's legacy. According to Jones (2008):

Hospice staff regularly experience a wide range of powerful emotions; the mystical space between the physical and spiritual worlds, and the reality of loss and death. End-of-life experiences range from inspiring, graceful processes to difficult, complex situations with layers of longstanding problems, few resources, and the potential for abuse or suicide. (p. 38)

While Ingebretsen and Sagbakken (2016) described hospice nurses as serving a "complex and multifaceted role with large amounts of complex emotional exposures" (p. 1), the same can

be said for all individuals working in the hospice care profession. For example, hospice work with older adults sometimes taps into feelings and unresolved issues from many sources. The emotions of hospice professionals may be evoked regarding parents, grandparents, or other older adults (Jones, 2008).

Most professionals enter hospice work envisioning the ideal death, which often includes the healing of relationships, resolution of regrets, peaceful and pain-free death for clients, and manageable grief for families. However, when the realities of hospice set in (e.g., patients referred too late for needed services, long-standing complicated situations, being the object of misplaced anger or guilt), the hospice professional may begin to feel frustration, self-doubt, and burnout.

Larson (1985) asked 200 hospice workers to anonymously share secret behaviors, thoughts, and feelings related to their work. Larson found that “the demanding and emotionally complicated nature of hospice work can trigger self-doubt and arouse strong emotions that may be embarrassing and sometimes mortifying” (p. 35). The origins of the participants’ secrets ranged from a feeling of a lack of competency (“I don’t know if I’m helping a lot of times” [p. 36]); to anger and hostility (“Sometimes I want to slap a patient—again and again” [p. 37]); to fear (“I’m afraid of walking into a room to talk with someone who might be dying, because I am afraid of finding death” [p. 37]).

While many hospice care professionals cite similar reasons for becoming burned out (Sinclair, 2011), others cite policy and institutional factors, such as increasing time pressure and the resulting loss of opportunity to exercise professional judgment; a sense of organizational and personal fragmentation related to increased volume, diversity, and complexity of work demands; and a rise in the unpredictable, discontinuous, and distracting conditions under which hospice

work is performed (DiTullio & MacDonald, 1999; Keidel, 2002; Payne, 2001; Slocum-Gori, Hemsworth, Chan, Carson, & Kazanjian, 2013; Whitebird, Asche, Thompson, Rossom, & Heinrich, 2013).

### **Social Support**

Many articles have discussed the support of hospice nurses (Abendroth & Flannery, 2006; Ablett & Jones, 2007; Dunn, Otten, & Stephens, 2005; Hammonds & Cadge, 2014) and hospice clergy (Lloyd-Williams, Wright, Cobb, & Shiels, 2004; Rutland-Wallis, 1996). Regarding hospice social workers, previous research has centered on preparation for oncology settings (Kovacs & Bronstein, 1999), social workers' search for identity among an interdisciplinary team (Macdonald, 1991), and burnout and death anxiety of those in the field (Quinn-Lee et al., 2014).

Larson (1985) is the only researcher who has addressed the social support of hospice care professionals as a group. Larsen asserted that the staff support group is an antidote to the stressful effects of hospice work: "a moderately high level of self-disclosure presents the best possibility for enhancing continued openness" (p. 39). The constant exposure to repeated losses, traumas, awareness of their own mortality, and the termination of intense relationships causes compassion fatigue and increased symptoms of anxiety and depression (Keidel, 2002; Showalter, 2010; Whitebird et al., 2013); yet, the literature offers little related social support for hospice workers. The empirical literature on emotion work is outlined in Table 2.



Table 2

*Empirical Literature on Emotion Work*

Author	Title	Purpose	Method	Sample	Results	Conclusion	Implications
Ablett & Jones (2007)	“Resilience and Well-Being in Palliative Care Staff: A Qualitative Study of Hospice Nurses’ Experience of Work”	To describe hospice nurses’ experiences in order to understand the factors that help to promote resilience and mitigate the effects of workplace stress. It also aimed to explore the processes by which nurses continued to work in palliative care and maintain a sense of well-being.	Interviews through purposive referrals.	Palliative care nurses, n = 10	Compared themes to personality constructs. During the analysis, themes emerged relating to the underlying interpersonal factors that influenced the nurses’ decisions to begin and continue working in palliative care, and their attitudes towards life and work. A source of divergence in the data concerns the nurses’ response to change.	The findings illustrate the interpersonal factors that may enable hospice workers to remain resilient and effectively buffer or moderate the stressful effects of working in palliative care. The opportunity for reflective practice may enable staff to acknowledge the emotional impact of working in end-of-life care, and to address their own existential issues.	The findings suggest implications for staff training and support in the factors that promote resilience, particularly hardiness and a strong sense of coherence, could be developed through staff training packages.
Alkema, Davies, & Linton (2008)	“A Study of the Relationship Between Self-Care, Compassion Satisfaction, Compassion Fatigue, and Burnout Among Hospice Professionals”	To explore the relationship between self-care, burnout, compassion fatigue, and compassion satisfaction in hospice care professional (HCP) workers.	Surveys: (1) Professional Quality of Life Assessment (ProQOL-RIII) (2) Self-Care Assessment Worksheet (SCAW)	Hospice care professionals from two hospice agencies in the midwestern United States.  N =37	There was significant $p < .05$ negative correlation between compassion satisfaction and burnout ( $r = -.612$ ) and compassion satisfaction and compassion fatigue ( $r = -.300$ ). Data analysis reveals a strong positive correlation between compassion fatigue and burnout ( $r = .761$ ).	The results of this study indicate a tentative relationship between self-care, compassion fatigue, burnout, and compassion satisfaction.	Hospice care employers can assist, and perhaps require, their workers to take part in holistically focused self-care activities. Related to this, it is also suggested that future research focus specifically on the types of self-care activities that can assist HCPs in managing compassion fatigue and burnout and enhancing compassion satisfaction.
Brotheridge & Grandey (2002)	“Emotional Labor and Burnout:	To employ an emotional labor framework as a	Survey: (1) Emotional labor scale	Job titles of the participants included retail sales clerk, restaurant server, bank	Burnout: The current study did not find significant	Employees reported the highest level of deep acting, measured	Overall, emotion demands are high and emotional autonomy is

Author	Title	Purpose	Method	Sample	Results	Conclusion	Implications
	Comparing Two Perspectives of 'People Work'"	means of explicitly examining the emotional demands of work and the individual styles of responding to these emotional demands, which have been proposed as contributing to employee stress (Hochschild, 1983).	(2) The emotion work requirements scale (3) Emotional labor scale (4) Maslach burnout inventory	teller, accountant, human resource consultant, engineer, construction worker, nurse, and social worker.  N = 238	occupational differences in emotional exhaustion levels. Job-focused emotional labor: Human service workers reported higher levels of all of the emotional work demands—greater duration (24.33 min) of interactions with clients, greater intensity of emotional interactions (2.86), and greater variety (3.48) of emotional demands than those of clerical employees and physical laborers.	as the extent to which employees attempt to modify their internal feelings to be more genuine with clients. In contrast, physical laborers reported higher levels of depersonalization and diminished personal accomplishment relative to human service workers.	low for “people work,” suggesting that workers will report more burnout as argued by Karasek (1979). The fact that these groups reported similar levels of emotional exhaustion suggests that people work may have unusual work demands but that these may act as both stressors and resources for the employees.
Clarke (2006)	“Developing Emotional Intelligence through Workplace Learning: Findings From a Case Study in Healthcare”	To investigate workplace learning in UK hospices that highlights the significance of particular emotional abilities associated with performing caring roles within these work settings.	Case-study approach	Participants from 20 different hospices took part (from a total of 161 hospices in the UK) all from the southeast of England. These were voluntary participants who self-selected in response to an invitation from the researcher that was sent to all the hospices that took part in the initial research. Of these, 67% (14) were involved in education/ training (either as training officers or practitioner/ lecturers), 27% (6) were clinical nurse specialists and 6% (2) identified themselves as service managers. The average length of experience of working in hospices was 5.4 years.	That two key emotional abilities associated with job performance, the ability to manage emotions and the ability to use emotions to facilitate thinking and decision-making, were closely associated with performing a caring role within these hospices. Within these healthcare environments those abilities may be capable of development through informal or workplace learning mechanisms.	Certain emotional abilities associated with the ability conceptualization of emotional intelligence can be developed using workplace or on-the-job learning methods where competences in Emotional Intelligence, alongside the socio-cultural cues that influence emotional display, are likely to be learned and understood within the context of the workplace.	The idea of a reflective practitioner figures significantly as a key component of professional development throughout the healthcare professions.

Author	Title	Purpose	Method	Sample	Results	Conclusion	Implications
N = 22							
Durr & Wingfield (2011)	“Keep Your ‘N’ in Check: African American Women and the Interactive Effects of Etiquette and Emotional Labor”	To situate Black women’s voices and experiences at the center of discussions and research on occupational mobility by examining the interactive effects of manner, behavior, and reaction or etiquette and emotional labor.	Two samples: (1) Group interviews (2) Semi-structured interviews	Two samples: (1) 20 African-American women, college-educated, employed as lower level executives, middle managers, and administrators in public and private organizations, state and city government, and universities. (2) 25 African-American women working in a professional capacity. Study did not indicate levels and type (corporate, government or academia) as first sample.	For professional Black women, the performances that they feel compelled to give are shaped by the ways intersections of race and gender isolate them and place them under greater scrutiny. As they take stock of their work environments and perceive colleagues’ stereotypes, beliefs, and preconceptions, these women learn that, like Michelle Obama, they must repackage themselves in ways that are more palatable to their White co-workers.	Black women co-mingle etiquette and emotion management to gain acceptance and promotions, which strengthens race/ethnic group solidarity.	Results suggest that the challenges of the professional workplace are shaped in important ways by race and gender. Future research should consider whether these social and professional expectations pose the same challenges for Latinas, Black men, Asian-American women, and others. The expected norms, sanctions, and rules of the professional workplace are not neutral, but raced and gendered in ways that may have a different impact on various groups.
Froggett & Hockley (2011)	“Action Research in Palliative Care: Defining an Evaluation Methodology”	To present an account of participatory action research and illustrate the way in which evaluation approaches are integrated within this methodology.	Group interviews, observation and field notes; evaluation questionnaire	Following the death of a resident, reflective debriefing sessions were organized within 10 days of the death with the aim of facilitating learning place alongside the provision of support for staff. Any staff who had cared for/known the resident (including domestics and ancillary staff) attended.	When examining the educational aspect, there was evidence of three different ways of learning; staff were not only “being taught” through the RDBS, for example the constipating effects of analgesics, but there was evidence that “understanding” was being developed.	The specific evaluative methods adopted will reflect the nature and focus of the evaluation being undertaken.	Evaluation processes are integral to action research approaches.
N = 24							
Gray (2009)	“The Emotional Labour of Nursing: Defining and Managing	To identify nurse definitions of emotional labor; the routine aspects of emotional labor in	In-depth and semi-structured interviews  N = 16	Nurses were recruited to the study via the researcher’s attendance at several pre- and post-registration classes held at	The emotional labor between nurses, student nurses, lecturers, patients and clinical staff is a vital	Emotional labor brings added value and sustains a caring environment between nurses and their	Emotional labor brings value to the relationship between patient and nurse. However, it is an

Author	Title	Purpose	Method	Sample	Results	Conclusion	Implications
	Emotions in Nursing Work”	nursing; traditional and modern images of nursing; and gender and professional barriers that involve emotional labor in health work.		a local East London hospital where the research was based and conducted. The majority of participants were female (12 of 16) and ethnically quite diverse (7 described themselves as White, 6 as Black and 3 as Asian). 10 of the student nurses were under 23, and there were 6 qualified nurses in the age range of 30-50 working in a variety of clinical settings such as primary care, children’s oncology and mental health.  N = 16	part of the quality of care that is within the NHS. Emotional labor informs interpersonal relationships and sustains the quality of nurse-patient care.	patients. This gives nurses space to engage with, reflect upon, and manage their own and others’ emotions, which greatly improves practice and the standard of patient-centered care. The findings reported here and elsewhere suggest that emotional labor needs to be made more explicit and codified in order to incorporate it into policy and practice.	individual practice and therefore needs to be integrated into policy and/or practice.
Hackett & Palmer (2010)	An investigation into the Perceived Stressors for Staff Working in the Hospice Service”	To gain a deeper understanding of the perceived stressors in order to identify coaching needs among the hospice staff group.	Interview with focus groups.	People participated in each focus group. All participants were female. Focus group 1 consisted of a mixed group of professionals: three nurses, one occupational therapist, one occupational technical support worker, and one doctor. Focus group 2 consisted of all nursing staff ranging from newly qualified staff to very senior staff.  N = 6 (total)	Five final categories of coaching needs were identified: <ul style="list-style-type: none"> <li>• Demands</li> <li>• Change</li> <li>• Managers’ support</li> <li>• Peer support</li> <li>• Self-care</li> </ul>	The findings indicated the usefulness of a coaching intervention to support staff with self-care strategies.	There is a need for a thorough staff support systems within the organization, including accessible supervision, debriefing, and reflective sessions. The coaching intervention would need to include an educational aspect on the long-term effects of stress on health, and the importance of ‘making time and space for the self’ to manage the ongoing demands that are inherent to working in palliative care. Within the context of coping strategies to manage demands, it is also important to highlight the need for a good work-life

Author	Title	Purpose	Method	Sample	Results	Conclusion	Implications
Hochschild (1983)	"The Managed Heart: The Commercialization of Feeling"	To introduce the idea of emotional labor; how emotional labor required people to "coordinate self and feeling" and disguise the effort involved.	Interviews and observations	Delta Airlines flight attendant trainees and officers of the company, seven supervisors, four advertising agents, and two public relations officials; average age was 35, average years of experience was 11.  N = 123	The worker can become estranged or alienated from an aspect of self-either the body or the margins of the soul-that is used to do the work.	While there is physical labor in pushing carts and mental work when preparing for and organizing emergency landings and evacuations, emotional labor, this kind of labor calls for a coordination of mind and feeling, and it sometimes draws on a source of self that we honor as deep and integral to our individuality.	balance.  The signal function of emotion becomes more important, and the commercial distortion of the managed heart becomes all the more important as a human cost.
Hockley & Froggett (2006)	"The Development of Palliative Care Knowledge in Care Homes for Older People: The Place of Action Research"	To determine if action research, as a research methodology, can be used to develop palliative care knowledge in generalist care settings	Qualitative and quantitative; individual interviews, documentary analysis, observation and keeping field notes; evaluation questionnaire  N = 15	Nurse managers, nursing home owners, GPs, nurses/care staff, relatives of relevant end-of-life care policies and procedures.  N = 15	In care home 1, a number of smaller actions were undertaken: the development of new documentation, the provision of education and training, reflective debriefing sessions following the deaths of residents, the introduction of a resident remembrance book, and the rewriting	Both studies highlighted the importance of doing research and bringing about change in the real world of care homes with all the difficulties of developing end-of-life care in a context that is short-staffed with considerable retention and recruitment problems. Not only did significant change occur, but staff really appreciated being involved and being enabled to take responsibility for sustaining the changes.	Action research is a viable methodology in developing knowledge about palliative care; however, researchers must be (1) sensitive to issues of power, open to the plurality of meanings and interpretations and able to take into account the emotional, social, spiritual, and political dimensions of those with whom they interact; and (2) keeping reflexive field notes to reduce the possibility of bias.
Hopkinson, Hallett, & Luker (2005)	"Everyday Death: How do Nurses Cope"	To find out how newly qualified nurses cope with	Phenomenology	The median age of the participants was 23 years (range 21-44). All	1. The nurses ministered to the needs of the patient and the	Results show that, in order to help nurses, strategies that	There is an opportunity to acknowledge and learn from these multi-

Author	Title	Purpose	Method	Sample	Results	Conclusion	Implications
	With Caring for Dying People in Hospital?"	caring for dying people in acute hospital medical wards.		participants had been practicing as registered nurses for less than 3 years and longer than 2 months (median 12 months). One was a male nurse.  N = 28	needs of other people in the dying situation. In addition, not only did they give care, but they themselves were receiving care. There was a complex multi-person and inter-dependent network of relationships around each dying person. 2. All the nurses' stories contained evidence of their thinking and actions being informed by the learning of new knowledge. However, it was experiential learning that they believed helped them to care for dying people. Most considered their studies to be of little relevance to caring for dying people, and seemed unaware of the way it was supporting their practice. 3. Creating measures of practice was an important way in which the nurses sustained their own well-being in dying situations.	complement those of education and training may need to be adopted.	person, interdependent networks.
Ingebretsen & Sagbakken (2016)	"Hospice Nurses' Emotional Challenges in Their Encounters with the Dying"	The purpose of the study was to explore nurses' emotional challenges when caring for the dying in hospices.	In-depth interviews	Nurses from recruited from two hospices in Denmark.  N = 10	Although all of the nurses said that they experienced emotional challenges or felt emotionally touched during their work, the study found a variety of opinions related to the	Many participants in the study said they had expected themselves as hospice nurses to be "experts" and to master any situation. However, several had reconsidered their	Hospice nursing involves continuous reflection and balancing between meeting the dying as a human being and meeting the dying as a hospice professional.

Author	Title	Purpose	Method	Sample	Results	Conclusion	Implications
					extent to which their emotional reactions should be revealed in their role as a hospice professional. The participants described their emotional challenges as simultaneously draining and enriching experiences leading to personal and professional growth and development.	role, and now considered their professional role to be interwoven with their personal role.	
Johnson, Cooper, Cartwright, Donald, Taylor, & Millet (2005)	"The Experience of Work-related Stress Across Occupations"	To compare the experience of occupational stress across a large and diverse set of occupations.	The measurement tool used is a short stress evaluation tool, which provides information on a number of work-related stressors and stress outcomes.	26 various occupations N = 11,001	6 occupations (ambulance, teachers, social services, customer services – call centers, prison officers, and police) are reporting worse than average scores on each of the factors—physical health, psychological well-being, and job satisfaction (ambulance workers, teachers, social services, customer services – call centers, prison officers).	The finding that physical health, psychological well-being, and job satisfaction are linked was expected and supports existing research in this area (Dewe, 1991). It is, therefore, not surprising that many of the occupations reporting high stress levels are also reporting low levels of job satisfaction.	The premise that emotional labor is an important facet of the experience of occupational stress is supported in that all of the high stress occupations revealed above high levels of emotional labor.
Kovacs & Bronstein (1999)	"Preparation for Oncology Settings: What Hospice Social Workers Say They Need"	To investigate the influence of their formal academic training, informal on-the-job training, and related professional and personal experiences on their preparation for oncology social work.	Survey	108 oncology social workers. N = 108	Despite the value placed on both generalist and specialist training, it was the more specialized training that social workers indicated was inadequate. Social workers also identified a need for interdisciplinary	In addition to graduates' academic and field preparation, findings suggested that continuing education of hospice and other health care social workers dealing with people living with and dying from cancer is important	In terms of practice, hospice social workers need increased knowledge about the medical aspect of their work, including the medical process, terminology, paperwork, etc. Regarding education, there is a need for more specialized knowledge

Author	Title	Purpose	Method	Sample	Results	Conclusion	Implications
					collaboration. A high value was placed on the role family members' and friends' illness prepared them for oncology social work.	for continuing growth and success in this work.	in the classroom. There is also a need to help social workers integrate their personal experiences with loss in their professional work.
Kubler-Ross (1969)	"On Death and Dying: What the Dying Have to Teach Doctors, Nurses, Clergy, and Their Own Families"	To understand and help patients during the terminal phases of illness deal with their anticipations of their own death.	Interviews	Terminally ill patients, the professionals who serve that patient, and the patient's family.	Kubler-Ross' interviews demonstrates the necessity of maintaining communication and providing the patient with a meaningful relationship.	The author makes a useful point in emphasizing how modern "scientific" hospitals provide an atmosphere where emotional sterility may exceed the microbiological.	The needs of the dying include an emotional connection; hospitals would be wise to integrate this type of care in addition to the technological advancements of care.
Larson (1985)	"Helper Secrets: Invisible Stressors in Hospice Work: Staff Support Groups and Networks Are Recommended Antidotes"	To formally investigate hospice-care related helper secrets.	Having hospice workers anonymously share secret thoughts, behaviors, and feelings related to their work on uniform sheets of paper.	200 hospice workers	Hospice workers were experiencing a "fallacy of uniqueness" (i.e., everyone is coping effectively and the individual alone is failing). The guilt and shame is internalized; there is a failure to see that the feeling is not because of an internal flaw, as much as it is the situation the individual confronts.	The antidote for the stressful effects of helper secrets is the staff support group.	Guilty and embarrassing helper secrets, when kept concealed, can corrode from within; when revealed to empathic co-workers, they can strengthen support networks and promote the personal and professional growth of the caregiver.
Papadatou (2009)	"In the Face of Death: Professionals Who Care for the Dying and the Bereaved"	Understanding the relationship between the dying and the caregiver; understanding personal responses to death; how a team organizes itself and develops functional and/or dysfunctional patterns in order to cope with loss and death.	Interviews	Nurses, physicians, psychologists, social workers, chaplains, palliative care specialists, bereavement counselors, and other health care professionals.	Papadatou also surmised that the caregiver's needs sometimes conflicts with the patient's needs.	In caregiving, one does not have to be perfect, just "good enough."	As caregivers, if we are to be of help, we must include death's influence on all of the relationships that surround and are affected by it.
Payne (2001)	"Occupational Stressors and	To investigate the level of burnout	Questionnaires comprising the	Female nurses from 9 hospices.	In general, the level of burnout (characterized	The investigation of problem-focused and	The issues related to burnout and



Author	Title	Purpose	Method	Sample	Results	Conclusion	Implications
	Coping as Determinants of Burnout in Female Hospice Nurses”	among hospice nurses; to ascertain which aspects of nursing work were positively or negatively related to burnout; to examine the relative contributions made by these different variables and to suggest individual and organizational interventions to reduce levels of burnout.	Maslach burnout inventory, nursing stress scale, ways of coping scale, and a demographic information form.	N = 89	by high emotional exhaustion, high depersonalization of patients, and low personal accomplishment) was low. In multiple regression analyses, “death and dying,” “conflict with staff,” and “accepting responsibility” contributed to emotional exhaustion. “Conflict with staff,” “inadequate preparation,” “escape,” and reduced “painful problem solving” contributed to depersonalization. “Inadequate preparation,” “escape,” reduced “positive reappraisal” and fewer professional qualifications contributed to lower levels of personal accomplishment. Overall, stressors made the greatest contribution to burnout, and demographic factors contributed the least.	emotion-focused coping in relation to burnout was oversimplifying the coping-burnout relationship. Suggestions for stress management included staff training in counselling skills, monitoring staff conflict, implementing stress inoculation training to teach appropriate use of coping skills, and monitoring particularly vulnerable groups of hospice staff such as unqualified nursing assistants and qualified nurses in management positions. It was concluded that despite the difficult nature of hospice work, the hospice is a positive environment in which to work.	compassion fatigue really had nothing to do with the hospice work and more so with the administration. This burnout would have been the result of any working environment.
Rowley & Taylor (2011)	“Dying in a Rural Residential Aged Care Facility: An Action Research and Reflection Project to Improve End-of-Life Care to	To examine the ways in which nursing care could be provided that maximized the likelihood of a good death, to identify barriers nurses perceived to prevent optimal end-of-life care to dying	Reflective practice	Hospital employees and relatives of dying patients.  N=22  Hospital employees, n = 14 Relatives of dying patients, n = 8	Participants realized that they needed to focus on staff pain management knowledge deficits, so that early detection of key deficiencies would demonstrate areas for improvement.	Implications of the research demonstrated that it is possible to establish a working relationship with aged care nurses, with no prior knowledge of action research or reflective processes, to	Participants’ insights were based on the premise that they are central characters in their work stories and that through reflection and change strategies, they could be proactive in improving the care they give to people

Author	Title	Purpose	Method	Sample	Results	Conclusion	Implications
	Residents with a Non-Malignant Disease”	residents, and to explore the relationships between nurses and relatives of the dying resident, with the intention of improving care.				influence end-of-life nursing practices.	dying from a non-malignant disease. The action plans they enacted consisted of developing strategies for sharing the issues with their colleagues and raising staff awareness.
Sinclair (2011)	“Impact of Death and Dying on the Personal Lives and Practices of Palliative and Hospice Care Professionals”	To gain insight into how professionals in palliative and hospice care professionals incorporate the nature of mortality into their personal lives and clinical practices.	This ethnographic inquiry used semi-structured interviews and participant observation.	Using purposive sampling, key leaders in palliative and hospice care at five centers across Canada (N = 6) and frontline clinicians (N = 24) involved in end-of-life care in Canada.	Clinical exposure to death and dying taught participants to live in the present, cultivate a spiritual life, reflect on their own mortality, and reflect deeply on the continuity of life.	Although Western society has been described as a “death-denying” culture, the participants felt that their frequent exposure to death and dying was positive, fostering meaning in the present, and curiosity about the continuity of life.	The professionals’ exposure to death and dying allowed them to appreciate life and the present more.
Slocum-Gori, Hemsworth, Chan, Carson, & Kazanjian (2013)	“Understanding Compassion Satisfaction, Compassion Fatigue and Burnout: A Survey of the Hospice” palliative care workforce.	(1) Understand the complex relationships among compassion, satisfaction, compassion fatigue, and burnout within the hospice and palliative care workforce and (2) explore how key practice characteristics practice status, professional affiliation, and principal institution interact with the constructs of compassion satisfaction, compassion fatigue, and burnout.	Self-reported measures of compassion satisfaction, compassion fatigue and burnout.	A national survey of HPC workers comprising clinical, administrative, allied health workers, and volunteers, was completed. Respondents from hospital, community-based and care homes informed the results of the study.  N = 630	Results indicated a significant negative correlation between compassion satisfaction and burnout and between compassion satisfaction and compassion fatigue, and a significant positive correlation between burnout and compassion fatigue.	Results indicated that healthcare systems could increase the prevalence of compassion satisfaction through both policy and institutional level programs to support HPC professionals in their jurisdictions.	Despite awareness of the stress on oncologists and oncology nurses, training programs are lacking the curriculum elements to teach physicians and nurses how to cope with HPC, including the psychosocial needs of the dying patients and their families.
Whitebird,	“Stress,	To better understand	Survey	Hospice workers	Hospice staff reported	Poor mental health	Hospice workers not

Author	Title	Purpose	Method	Sample	Results	Conclusion	Implications
Asche, Thompson, Rossom, & Heinrich (2013)	Burnout, Compassion Fatigue, and Mental Health in Hospice Workers in Minnesota”	how stress affects the mental health of hospice workers in terms of burnout and compassion fatigue and how they cope with these issues.		throughout Minnesota N = 547	high levels of stress, with a small but significant proportion reporting moderate-to-severe symptoms of depression, anxiety, compassion fatigue, and burnout. Staff reported managing their stress through physical activity and social support, suggesting that more opportunities to connect with coworkers and to exercise could help decrease staff burnout.	places staff at risk for burnout and likely contributes to staff leaving hospice care.	getting adequate care is probably resulting in less than adequate care of patient and family members.
Zambrano, Chur-Hansen, & Crawford (2014)	“The Experiences, Coping Mechanisms, and Impact of Death and Dying on Palliative Medicine Specialists”	To explore the experiences, coping mechanisms, and impact of death and dying on palliative medicine specialists when dealing with their patients at the end-of-life.	One-on-one interview data were analyzed thematically. Purposeful sampling was employed for participant recruitment in open-ended, in-depth interviews.	Palliative medicine specialists practicing in one city. N = 7	The analysis of participants’ accounts identified three distinct themes: (1) being with the dying, (2) being affected by death, and dying and (3) adjusting to the impact of death and dying.	Despite the stressors and the potential for burnout and compassion fatigue, these participants employed strategies that enhanced meaning-making and emphasized the rewards of their work.	When there is balance between self-care and care giving, there is a career where the “rewards outweigh the cost” of dealing with death and dying.

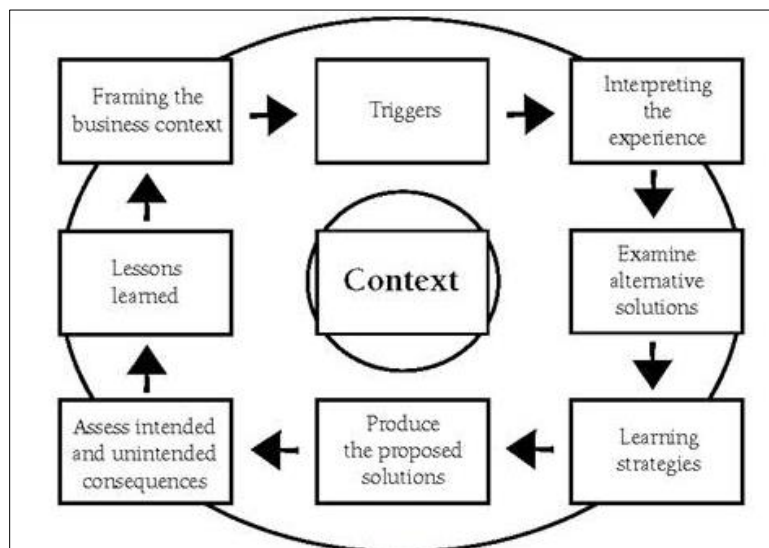
A great deal of the literature involving emotion work has focused on the stress, burnout, and impact of death and dying on the personal lives of hospice care professionals. Larson (1985) referred to these admissions as “helper secrets” and argued that the feelings of embarrassment, inadequacy, and guilt were a result of hospice workers’ unrealistic expectations of themselves. Larson identified that “the most helpful antidote to the stressful effects of helper secrets is the staff support group; when revealed to empathetic coworkers, they can strengthen support networks and promote the professional growth of the caregiver” (p. 40).

### **Informal Learning**

According to Marsick and Watkins’ model, informal learning differs from formal learning “by the degree of control exercised by the learner, the (non-classroom) location, and the predictability of outcomes” (Marsick, Volpe, & Watkins, 1999, p. 88). Incidental learning is a “byproduct of informal learning, taking place in activities such as task accomplishment, interpersonal interaction, sensing the organizational culture, trial-and-error experimentation, or even formal learning” (Marsick & Watkins, 2001, p. 25).

Figure 2 depicts Marsick and Watkins’ (2001) informal learning model: The center represents the belief that learning develops out of everyday encounters, while working and living develops in a given context. A new life experience may offer a challenge, a problem to be solved, or a vision of a future state. The outer circle represents the context within which the experience occurs—the personal, social, business, and cultural context for learning that plays a key role in influencing the way in which people interpret a situation, their choices, the actions they take, and the learning that is affected. The model depicts a progression of meaning making that, in practice, is more often an ebb and flow as people begin to make sense of a situation. With each new insight, they may have to go back and question earlier understandings. The

model is arranged in a circle, but the steps are neither linear nor necessarily sequential. While incidental learning does occur, it is not systematic and may be asynchronous with the need to apply certain knowledge, skills, and abilities.



*Figure 2.* Marsick and Watkins' (2001) informal learning model. Used by permission.

Berg and Chyung (2008) also described informal learning by contrasting it with formal learning:

Formal learning can be likened to riding a bus; the route is preplanned and the same for everyone. Informal learning is more like riding a bike in that the individual determines the route, pace, etc. Informal learning can take a reactive form, where the learning was unplanned but still recognized by the learner retrospectively. (p. 230)

Eraut (2004) described informal learning as “learning that comes closer to the informal end than the formal end of a continuum” (p. 250). He identified three levels of intention: “implicit learning, reactive learning, and deliberative learning” (p. 250). Within each of the levels of intention, Eraut assigned a “time stamp” of past, present, and future thoughts associated

with the level of intention. Similarly, Schugurensky (2000) identified three forms of informal learning distinguished by intentionality and awareness: “(1) self-directed: without the assistance of an educator; (2) incidental: learning that is unintentional but conscious; and (3) socialization: the internalization of values, attitudes, and beliefs that occur during everyday life” (p. 2).

### **How Informal Learning Occurs**

Jarvis and Watts (2012) asserted that disjuncture initiates learning. Disjuncture represents a lack of harmony between a person’s interest and knowledge, and his or her socio-cultural world. The disturbance can be positive, such as when someone wonders if there is a safer way to operate a machine, or negative, such as when a crisis occurs in a routine procedure. Livingstone (2001) wrote:

Much of the most important learning that we do occurs in moments of transition, whether it happens to be a birth, a death, a marriage, a divorce, a transition between careers or locations, or some other major influential event that provokes us into a concentrated period of informal learning. (p. 24)

However, according to Merriam and Clark (1991), the same life event may result in significant learning for one person but not another; that is, the judgment of what is significant is personal and subjective. According to Marsick et al. (1999):

Informal learning usually begins with an internal or external jolt. Sometimes that jolt comes from the external environment such as a lost or changed job or relationship, the demands of new technology, changes in the scope of one’s work or responsibility, or evidence of likely failure in the absence of corrective action. Sometimes that awareness is driven internally, by a person’s capacity to envision the future or to otherwise reappraise his or her focus and direction. Sometimes learning is anticipatory, occurring

because a person wants to prepare for a future event by rehearsing, role-playing, or otherwise previewing the experience. (p. 5)

Every time an individual ventures into a new situation (e.g., starting a new job), he or she is surveying the landscape, looking for contextual cues on what is acceptable and what is not. Even once a new situation becomes routine, if a disjuncture occurs between what is expected and what actually happens, a trigger encourages the individual to make sense out of that experience. As found in this study, hospice care professionals frequently learn informally and incidentally when providing support to the dying and bereaved.

### **Informal Learning in Healthcare**

When asked about her perspective on death education, Hannelore Wass (2004), one of the founders of the thanatology movement, wrote:

Less than a fifth of students in the health professions are offered a full course on death; the rest typically are provided death-related content in a few lectures. This lack of depth dissatisfies teaching faculties and leaves graduates entering their professions inadequately prepared to care for dying people and their families, or to counsel bereaved or suicidal people. (p. 297)

Despite the dramatic growth of knowledge around palliative and bereavement care over the past decades, education remains a major challenge in this field (Papadatou, 2009). Wass and Papadatou's comments suggest that most healthcare professionals learn how to deal with death and dying through informal or incidental means.

Previous studies have explored the nature of informal learning in the workplace (Eraut 1999; Livingstone, 1999), factors and conditions that influence informal learning in the workplace (Berg & Chyung, 2008; Skule, 2004), and learning teams in the workplace

(Livingstone, 1999). Research on informal learning in the workplace has been conducted on working professionals in general (Cheetham & Chivers, 2001) and, for example, in the professions of gaming (Lam, 2011) and aviation industries (Wofford, Ellinger, & Watkins, 2013). However, no studies were found regarding the informal learning of hospice care professionals. Table 3 outlines the empirical literature on informal learning.



Table 3

*Empirical Literature on Informal Learning*

Authors	Title	Purpose	Method	Sample	Results	Conclusion	Implication
E. Ouweneel, Taris, van Zolingen, & Schreurs (2009)	“How Task Characteristics and Social Support Relate to Managerial Learning: Empirical Evidence from Dutch Home Care”	What type of learning makes managers working in the home care sector of the Netherlands most effective?	Qualitative	95 home-care organizations in the Netherlands, with more than 100 employees were requested to participate in the survey; 82 responded. Total response rate was N = 57,963. Researchers only used the questionnaires from managers, taking the respondents down to 1,588.  n = 1,588	Analysis showed that task characteristics and social support had positive effects on informal learning at the workplace. Job control had a stronger positive influence on informal learning at the workplace among managers than did psychological job demands.	Job control and supervisor support had the strongest effects on managers’ informal learning in the workplace.	Receiving support in the workplace was important in improving home-care managers’ learning opportunities at work. Also researchers should invest effort in examining the effects of other workplace-related factors that affect workplace learning. Thus, researchers should study informal on-the-job learning in a broader context, considering other work characteristics (e.g., variety) and personality constructs.
Lam (2011)	“Employees’ Informal Learning and Customer Relationship Skills in a Casino”	To better understand how the informal learning of frontline employees influenced their customer relationship skills in dealing with patrons at gaming tables.	Qualitative; in-depth interviews	Full-time employees as recommended from the 6 casinos.  N = 49	(1) Politeness and caring attitude (2) detecting the emotional status of patrons (3) managing patrons’ emotions at gaming tables (4) self-regulation of emotions	The casino can improve their service encounters with patrons by making better decisions on appropriate tactics, by perfecting the requisite customer relationship skills, and by tactfully applying them to the demands of different service encounters, based on their informal knowledge accumulated over years in their workplace. Nevertheless, given the self-directed nature of informal	It was unfortunate that the researcher could not compare informal learning strategies between casinos or that the casino management had to choose who would participate in the study. Otherwise I thought his research questions were well thought out.

Authors	Title	Purpose	Method	Sample	Results	Conclusion	Implication
						learning (in which the learner determines what, where, and when to learn), the professional service of the casino to manage patron emotions to achieve positive customer experience is often affected by their own interests and motivations.	
Lisboa & Coutinho (2011)	“Informal Learning in Social Networks”	To discern whether the environment can be set up as formal spaces for learning.	Qualitative interviews based on grounded theory	The Orkut social network consisting of 75 communities with 20 or more members.  N = 1,500 (approx.)	The answer was not conclusive; yet, there was strong evidence that collaboration and knowledge sharing can be used as cognitive and social tool.	The researchers were disappointed that e-moderators did not take a “leadership role” in leading community discussions. There was a feeling this lack of leadership role did not allow the community to be a rich space for knowledge sharing and collaboration.	It is important that the e-moderator examines the content of discussions in the forum and provides feedback. Only by doing this can the e-moderator help the group to build up knowledge collaboratively and to apply it in other contexts in their lives.
McLean (2013)	“Public Pedagogy, Private Lives: Self-Help Books and Adult Learning”	To learn how informal adult learning takes place through interaction with products of popular culture.	Qualitative interviews via online chat survey, telephone calls, and email exchanges.	Women over 40 years of age. They were well-educated, with half of them having completed a graduate degree, and all of them having completed some postsecondary education.  N = 12	The results demonstrated that self-help books can be useful for adults engaged in important learning projects.	The critical assessment of self-help literature as a domain at the crossroads of adult education and popular culture should take up at least three challenges: (1) there is a need to review the quality of the advice provided in such books and to assess their pedagogical strategies; (2) to determine whether	Since the emergence of adult education as a specialized field of scholarship and professional practice has taken place at the same time as the dramatic increase in popularity of self-help literature, it would be useful for adult educators to explore the social, cultural, economic, and political changes that have made self-help books so important.

Authors	Title	Purpose	Method	Sample	Results	Conclusion	Implication
						the act of reading self-help books empowers readers to more independently understand and improve their lives, or whether such books actually inculcate an even greater dependency on external sources of computatively expert advice. Third, explore the social, cultural, economic, and political changes that have made self-help books so important in our times.	
Skule (2004)	“Learning Conditions at Work”	To develop a framework to understand and assess the quality of learning environments in the workplace.	Interviews & telephone surveys	Various occupational groups in 11 widely different private and public sector enterprises, 4-8 interviews per enterprise. Interviews were used to formulate an exploratory survey. Survey was given to 1,300 private sector and 200 public sector employees of Norway.  N = 2,500	There is no significant link between formal and informal learning; therefore, they are 2 separate phenomena. Also the amount of participation in informal learning strongly resembles the participation pattern in formal training opportunities.	While this research identified conditions for informal learning, the actual measurement of informal learning taking place was difficult because many were not aware of the informal learning experience.	A framework of this kind is applicable for a wide range of purposes. As the framework may be used to measure the quality of the learning environment, it may be a supportive tool to help authorities verify the quality of work-based learning that is part of such programs.
Wofford, Ellinger, & Watkins (2013)	“Learning on the Fly: Exploring the Informal Learning Process of Aviation Instructors”	To examine the process of informal learning of aviation instructors.	In-depth, multiple semi-structured interviews and document review	Newly certified flight instructors were selected as participants based on a purposeful intensity sampling design to obtain information-rich data to facilitate	The study captured the complexity of the informal learning process for aviation instructors as they faced the daily challenges associated with facilitating their	This study provided a rich, thick description of the complexity of the process of informal learning as it unfolds in a very dynamic, ill-structured, and often	There is a need to continue research to examine how certain characteristics of workers and their work environment influence informal learning.

Authors	Title	Purpose	Method	Sample	Results	Conclusion	Implication
				examination of their individual informal learning process.  N = 10	students' learning, which served as the catalyst for their learning.	spontaneous environment and presents a visual illustration of this process as a non-sequential, ongoing process, often tacit in nature.	

Significant to my study was Wofford, Ellinger, and Watkins' (2013) research on the informal learning process of aviation instructors. They described the informal learning process of newly certified flight instructors as one that "unfolds in a very dynamic, ill-structured, and often spontaneous environment" (p. 93). This environment is very similar to that in which informal learning occurred for the hospice care professionals in my study.

### **Conclusion**

The purpose of this study was to explore the informal learning of hospice care professionals within the context of their emotion work, with the aim of analyzing learning needs and proactively developing professional development interventions to address those needs. Research has identified the work-related stressors faced by people in helping professions (Schaufeli & Enzman, 1998), as well as strategies of how to cope with the stressors of hospice work in particular (DiTullio & MacDonald, 1999; Keidel, 2002). Many articles focus on emotion work in hospice work (Jones, 2008), burnout (Maslach, 1982), and factors of hospice work that can lead to burnout (DiTullio & MacDonald, 1999; Keidel, 2002; Payne, 2001; Slocum-Gori et al., 2013; Whitebird et al., 2013). Research on the social support of hospice care professionals does not address hospice workers but, rather, particular segments such as hospice clergy (Lloyd-Williams et al., 2004; Rutland-Wallis, 1996) and particular situations such as hospice social workers' preparation for oncology settings (Kovacs & Bronstein, 1999).

Larson's (1985) work identifying the hospice-care-related helper secrets is most likely the first piece of research supporting the informal learning process of hospice care professionals. He held that "the inner struggle reflected in many of these secrets can be thought of as a conflict between the hospice workers' self-concept as helpers, and the thoughts, feeling, and behaviors

that are the content of their secrets” (p. 39). Pines, Aronson, and Kafry (1981) identified this phenomenon as the “fallacy of uniqueness” (p. 35).

Larson (1985) claimed that the staff support group is the antidote to the stressful effects of helper secrets. Not only does sharing secrets build intimacy (as cited in Hillix, Harari, & Mohr, 1979), but according to Marsick et al. (1999), informal learning and incidental learning (Marsick & Watkins, 2001) provide support as well. Therefore, the gaps in the literature this study addressed are (1) the coping strategies of hospice care professionals in the context of death and dying, (2) the type of support that is effective for those engaged in emotion work, and (3) the nature of the informal learning process described by caregivers.

## CHAPTER 3

### METHODOLOGY

The purpose of this study was to explore the informal learning of hospice care professionals within the context of their emotion work, with the aim of analyzing learning needs and proactively developing professional development interventions to address those needs.

Three research questions guided the study:

- (1) What is the nature of the informal learning described by caregivers?
- (2) What types of support are effective for those engaged in emotion work?
- (3) What is learned by an action research team exploring the emotion work of individuals who provide emotional support to those experiencing death and bereavement?

This chapter explores the study's methodology, research design, data collection, data analysis, data trustworthiness, and limitations.

#### **Study Design**

This study was developed using action research, a “defined systematic and rigorous inquiry or investigation that explores the nature of problematic events or phenomena” (Stringer, 2007, p. 4). Because action research’s primary purpose is to “provide the means for people to engage in systematic inquiry and investigation to ‘design’ an appropriate way of accomplishing the desired goal and to evaluate its effectiveness” (Springer, 2007, p. 6), it is an appropriate methodology for an intervention in which a process is being modified or for the development of a support group. Evans and Hopkinson (2016) found action research “a clinically reflexive

model aimed at generating knowledge about a social system while simultaneously trying to change it” (p. 1675).

The goal of action research is to address a specific problem within a specific setting, such as a classroom, a workplace, a program, or an organization (Merriam, 2009) in order to create change. Action research is often conducted by “people in the ‘real world’ who are interested in practical solutions to problems and who are interested in social change” (Bogdan & Biklen, 2007, p. 234). The hospice care professionals of United Hospice—administrators, nurses, chaplains, and social workers—are those “people in the real world” who provided a rich context for this action research study. Minkler (2012), who supports the use of action research in hospice and palliative care settings, wrote:

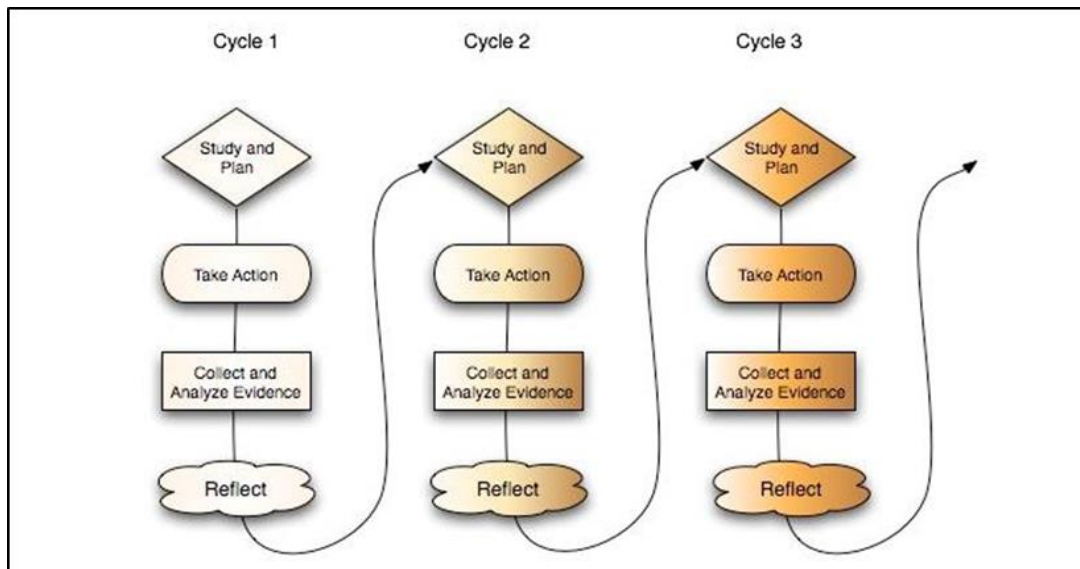
With its attention to “blurring the line” between the researchers moreover, the researched, reducing power imbalances, building individual and community capacity, and using study findings to promote change, action research holds special relevance for fields like palliative care. (p. v)

Action research “includes a wide range of methodologies, grounded in different traditions that express competing philosophical assumptions” (Cassell & Johnson, 2006, p. 786). Because of its diverse use, some scholars have compared action research to the scientific method and “found it wanting in various ways and to varying degrees.” Cassell and Johnson (2006) argued that “assumptions about ontology and epistemology are unavoidable as all research is underpinned by some manifestation of these assumptions” (p. 806).

Generally, action research steps consist of (1) “study and plan”: identify the themes, validate the findings with the action research team, and prioritize themes by order of importance; (2) “take action”: develop and implement a mutually satisfying intervention to address the



prioritized theme; (3) “collect and analyze evidence”: evaluate the effectiveness of the intervention; and (4) “reflect”: consider what can be done to make the implementation more effective (see Figure 3). This iterative, cyclical process allows the research to take shape while it is being performed. Greater understanding of each cycle points the way to improved practice (Riel, 2010).



*Figure 3.* Progressive problem solving with action research. Adapted from Riel, M. (2010).

Understanding action research. Center for Collaborative Action Research, Pepperdine University. Used with permission.

However, action research is not a straightforward process. Stringer (2007) wrote:

As experience will show, action research is not a neat, orderly activity that allows participants to proceed step-by-step to the end of the process. People will find themselves working backward through the routines, repeating the processes, revising the procedures,

rethinking interpretations, leapfrogging steps or stages and sometimes making radical changes in direction. (p. 9)

In this study, initially one intervention was implemented; while it was a popular choice for the action research team, the intervention did not focus on the purpose of the study, the informal learning of hospice care professionals. As a result, the action research team developed a second intervention and implemented them concurrently.

### **Use of Narratives**

The participant interviews were first transcribed then converted into narratives. Merriam (2009) stated that “narratives are effective as qualitative data because a narrative will allow a researcher to understand how people make sense of their lives, delineate the process of meaning-making, and describe how people interpret what they experience” ( p. 14). Also, as Merriam (2009) explained:

stories (or narratives) are how we make sense of our experiences, how we communicate with others, and through which we understand the world around us. The key to this type of qualitative research is the use of stories as data, and more specifically, first person accounts of experience told in story form having a beginning, middle, and end ... First person accounts of experience constitute the narrative “text of the research” approach. Whether the account is in the form of autobiography, life history, interview, journal, letters, or other materials that we collect, the text is analyzed for the meaning it has for its author. (p. 32)

### **Approaching the Potential Study Site**

In October 2014, I met with the United Hospice interdisciplinary department team. Known as IDT, a representative of each hospice discipline (physician, administrator, nurse,

social worker, nurse, pharmacist, chaplain, volunteer coordinator, bereavement coordinator, and others meet weekly with insights to contribute to the care of the patient and loved ones. I introduced myself, explained my study, and gave examples of the mutual benefits of the hospice participating in the research. In January 2015, upon receipt of the University of Georgia's Institutional Review Board (IRB) approval of my research design, I officially began my study at United Hospice. Figure 4 illustrates the overview of the research plan, data collection, and data analysis strategies; each step of the implemented action research process is identified. Within each step of the process, phases are categorized, action steps are identified, outcomes are listed, a timeline is given, and the data collected to evaluate the interventions are described for each phase.









Action Research Process	Phase	Action Steps	Timeline	Data collected to evaluate the intervention
	0	<ul style="list-style-type: none"> <li>Identified a hospice</li> <li>Met with facility director at United Hospice to propose study and introduce the benefits to the hospice</li> <li>Presented study to interdisciplinary department team and received permission to conduct study</li> </ul>	October, 2014	Responses from the interdisciplinary department team during presentation.
	1	<ul style="list-style-type: none"> <li>Study approved by UGA IRB</li> <li>Held kick-off meeting at United Hospice; recruited study participants</li> <li>Interviewed twelve United Hospice hospice care professionals (these participants included the four action research team members)</li> </ul>	January, 2015 to April, 2015	<ul style="list-style-type: none"> <li>Recordings</li> <li>Transcripts</li> </ul>
	2	<ul style="list-style-type: none"> <li>Recorded interviews were transcribed, converted into narratives, and analyzed using Constant Comparative Analysis</li> <li>Presented program evaluation data</li> </ul>	July, 2015	
	3	<ul style="list-style-type: none"> <li>Identify team norms</li> </ul>	August, 2015	List of team norms
	4	<ul style="list-style-type: none"> <li>Continued identifying the norms of a working team</li> <li>Discussed the current process of IDT meetings</li> <li>Develop a revised process of conducting IDT meetings</li> <li>Received permission from the medical director to test a revised way of conducting interdisciplinary department team meetings</li> <li>Shared the news that our current intervention did not align with the goal of the research study and we need to come up with another intervention</li> </ul>	September, 2015	<ul style="list-style-type: none"> <li>Meeting minutes</li> <li>Observations</li> </ul>
	5a	<ul style="list-style-type: none"> <li>Identified what "success" looks like</li> <li>Communicated with IDT members regarding three-week trial run of revised process</li> <li>Conducted the revised interdisciplinary department team protocol for three consecutive interdisciplinary department team meetings</li> </ul>	January, 2016	<ul style="list-style-type: none"> <li>Verbal feedback from IDT members</li> <li>Verbal feedback from action research team members after IDT meeting.</li> <li>Observation</li> <li>Meeting Minutes</li> </ul>
	5b	<ul style="list-style-type: none"> <li>Decided on an intervention</li> <li>Received permission from the medical director begin facilitating hospice wide support staff meetings</li> <li>Developed the support staff meeting agenda</li> <li>Contacted home health support staff to get buy in for the hospice wide support staff meetings</li> <li>Began support services meeting</li> <li>Identified what "success" looks like</li> </ul>	January, 2016 to March, 2016	<ul style="list-style-type: none"> <li>Meeting minutes</li> <li>Observations</li> <li>Recordings</li> </ul>
	6a	<ul style="list-style-type: none"> <li>Discussed feedback received from hospice administration</li> <li>Discussed action research team feedback</li> </ul>	February, 2016	<ul style="list-style-type: none"> <li>Meeting minutes</li> <li>Observations</li> </ul>
	6b	<ul style="list-style-type: none"> <li>Discussed feedback received from support staff meeting participants</li> </ul>	April, 2016	<ul style="list-style-type: none"> <li>Meeting minutes</li> <li>Observations</li> <li>Recordings</li> </ul>
	7a	<ul style="list-style-type: none"> <li>What happened; how did we fall apart as a team?</li> <li>Based upon what happened, what intervention to work on next.</li> </ul>	March, 2016	<ul style="list-style-type: none"> <li>Meeting minutes</li> </ul>
	7b	<ul style="list-style-type: none"> <li>How can we make it better?</li> </ul>	July, 2016	<ul style="list-style-type: none"> <li>Meeting minutes</li> </ul>

Figure 4. Implemented research plan.

## Research Data Collection and Analysis

Below is an audit of how the data were collected and analyzed. Data collected for analysis were obtained in the form of critical incident interviews, final interviews, action research team meeting minutes, and observational notes by the researcher.

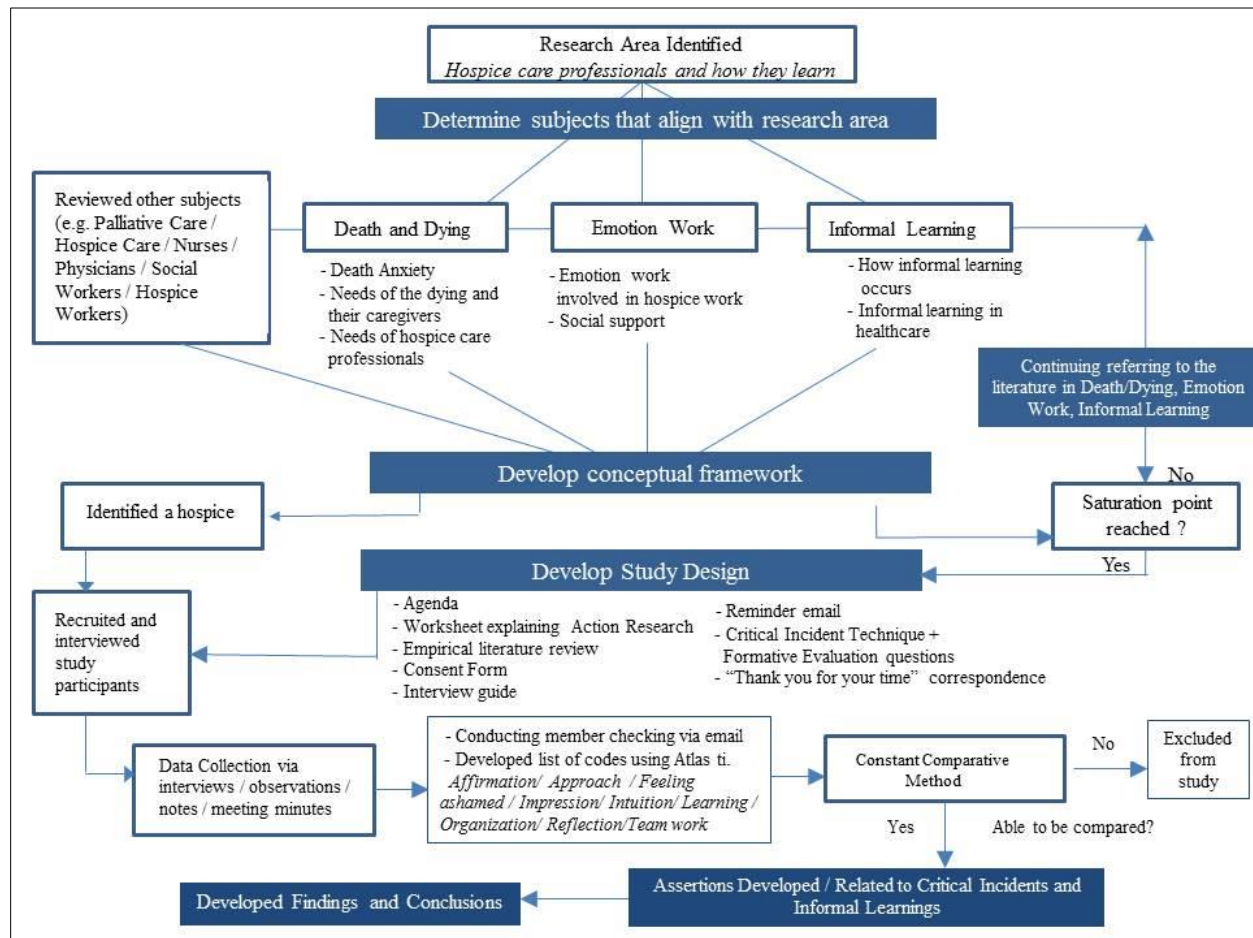


Figure 5. Visual audit trail of the research process.

Figure 5 provides a comprehensive visual audit of the research process. Research began with the determination to study hospice care professionals and how they learn, followed by the decision to frame the conceptual framework of the study around death and dying, emotion work,

and informal learning. While these subjects comprised the foundation of the framework, I also supplemented my research with readings on palliative care, hospice care, and workers employed in those environments. With the theoretical framework complete, and a hospice identified, the study design was developed and hospice employees recruited to participate in the study. Data sources included interviews, observations/notes, and action research team meeting minutes. Once the recorded interviews were member-checked, analysis for themes was conducted using Atlas.ti qualitative data analysis software (version 7.5.11). When more than one theme appeared, constant comparative analysis was used until an assertion was formed. This assertion was then tied to the critical incident as well as the primary and, if applicable, secondary emotion that encouraged the informal learning approach. That information was used to generate study findings and conclusions.

### **Sample Selection**

The sample for this study was a non-probabilistic purposeful selection. Purposeful sampling assumes that the investigator wants to discover, understand, and gain insight; therefore, he or she must select a sample from which the most can be learned (Merriam, 2009). A convenience sample is a nonrandom method of sampling “in which individuals who fit the criteria of a study are identified in any way possible” (Emerson, 2015, p. 165). It is “based on time, money, location, availability of sites or respondents, and so on” (Merriam, 2009, p. 79). Twelve hospice care professionals employed by United Hospice served as the purposeful convenience sample for this study. While all 12 individuals participated in the initial interviews, shortly afterward, five left the organization; between the first and third action research team meetings, two management-level individuals chose not to attend. Of the remaining five hospice care professionals, four were based in the in-patient division, with the remaining individual

based in the home health division of the hospice. The results of the program evaluation were used to change how in-patient division IDT meetings were conducted; therefore, the individual from home health was not included in the development of this intervention. When it was discovered that the intervention did not focus sufficiently on the research purpose—understanding how informal learning within the context of emotion work and death and dying supported staff—the action research team developed a second intervention, this time for support staff from both the in-patient and home health divisions. Unfortunately, I forgot to invite the home health individual to the meeting; however, she did participate in the support staff meetings, as did another newly hired social worker and the chaplain from home health.

### **Study Participants**

Approximately half of the 12 individuals interviewed were 20 to 29 years of age; the oldest was 62. The hospice care employees included the following roles: administrator, facility director, registered nurse (in-patient division), chaplain (in-patient division), bereavement coordinator (in-patient division and home health division), social worker (one in-patient division and two home health division), and volunteer coordinator (in-patient division)/social worker (home health division). Of the 12 individuals interviewed, eight had been employed at United Hospice for one year or less, and of those eight, only one had previous hospice experience. The individuals interviewed was primarily female (10 females, 2 males) with an even racial mix (6 African Americans, 6 Caucasians). The study participants were interviewed twice, once at the beginning of the study and then again at the conclusion of the study.

Table 4 identifies the interviewed hospice care professionals, their role at and tenure with

the hospice, previous hospice experience, divisional affiliation , race and gender, age, whether they participated in the study, and, if they did not, the reason given for not participating.



Table 4

*Hospice Care Professionals Interviewed*

Name*	Role	Tenure with Organization	Affiliated with which United Hospice Division	Race/Gender	Age	Participated in Study?	Reason for Non-Participation
Jim	Director of support services	<1 year	Both in-patient unit and home health	White Male	? >	No	Participant left organization
Suzanne	Social worker	1 year	Home health	Black Female	20-29	Yes	N/A
Carrie	Facility director	3 years	In-patient unit	Black Female	60-69	No	Participant attended the first three meetings; later stated she had scheduling conflicts.
Cindy	Case manager	<1 year	Home health	Black Female	30-39	No	Participant was no longer interested in being in the study
Alicia	Nurse practitioner	<1 year	In-patient unit	Black Female	40-49	No	Participant left organization
Janet	Registered nurse	4 years	In-patient unit	Black Female	40-49	No	Participant left organization
Joe *	Chaplain	<1 year	In-patient unit	White Male	40-49	Yes	N/A
Frieda *	Social worker	1 year	In-patient unit	White Female	20-29	Yes	N/A
Sophia *	Volunteer coordinator/social worker	1 year	Both in-patient unit and home health (as needed)	White Female	20-29	Yes	N/A
Alex *	Bereavement coordinator / chaplain	3 years	Both in-patient unit and home health	White Female	30-39	Yes	N/A
Tasha	Social worker	1 year	Home health	Black Female	20-29	No	Participant left organization
Galina	Administrator	5 years	Both in-patient unit and home health	White Female	60-69	No	Participant believed her presence would hinder the progress of the action research team

Note. \* Action Research team members.

**Action research team members.** Out of the four active action research team members, two were 20 to 29 years of age, one was 30 to 39, and one 40 to 49. The team was majority female (3 females, 1 male), and all were Caucasian. Three members of the team had been at United Hospice for one year or less, with the fourth member entering her third year. None of the four members had previous hospice experience.

### **Data Collection**

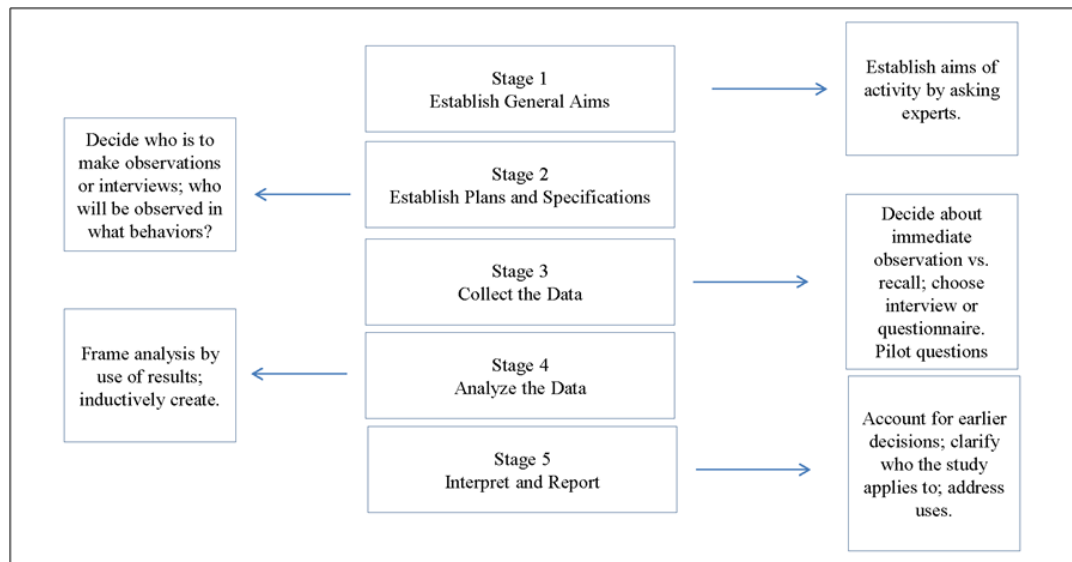
A variety of data collection methods were used for this study exploring the informal learning of hospice care professionals. These included critical incident interviews, researcher observations and notes, team meeting minutes, and closing interviews. Each method is described here, along with the rationale for its inclusion into the study.

#### **Critical Incident Interviews**

The critical incident interview is a technique developed by Colonel John Flanagan and others in the Aviation Psychology Program of the United States Army Air Forces during World War II. The Aviation Psychology Program was established in the summer of 1941 to develop procedures for the selection and classification of air crews. The critical incident interview technique consists of a set of procedures for collecting direct observations of human behavior in such a way that facilitates an understanding of the behaviors' potential usefulness in solving practical problems and developing broad psychological principles (Flanagan, 1954).

According to the critical incident interview technique, respondents are asked to identify events or experiences that were "critical" for some purpose (Kain, 2004). The technique is a proven qualitative research method offering a practical, step-by-step approach to collecting information about human activities and analyzing their significance to the people involved

(deMarrais & Lapan, 2003). Figure 6 illustrates this technique, as adapted from deMarrais and Lapan (2003).



*Figure 6.* Flanagan's critical incident technique (adapted by deMarrais & Lapan, 2003).

Used with permission.

Within healthcare settings, a critical incident comprises an event or circumstance involving a patient, his or her family, or healthcare team that has a substantial effect on the medical outcome of the patient. Victoroff and Hogan (2006), exploring characteristics of effective learning experiences for undergraduate dental students, believed the critical incident interview technique to have value in “capturing a detailed description of the behaviors of the participants in a specific situation, rather than generalizations or opinions, allowing the theory generated from the data be grounded in the actual behaviors of the participants” (p. 125). While reflection and analysis of critical incidents have been widely regarded as valuable learning tools for nurses (Byrne, 2001), its use in palliative care has not received such extensive acceptance

(Charalambous & Papastavrou, 2009; Wohleber, McKittrick, & Davis, 2012). The action research method of inquiry has also not received much acceptance in the palliative care field.

In their book on participatory research in palliative care, Hockley, Froggatt, and Heimerl (2012) wrote of their experience finding action research projects in palliative care:

We have found it difficult to locate many specialist palliative care centres undertaking action research projects. We asked ourselves “why this might be?” It is certainly not the case that the specialty of palliative care is not undertaking research—there is plenty of research into symptom control and the different aspects of end-of-life care from both patients and their families. However, actually researching day-to-day practice within specialist palliative care using an action research approach is much less common. (p. 11)

The critical incident interview technique was used in asking study participants two questions. The first question asked the individual to identify an incident during which the participant, upon later reflection, realized learning had taken place. The second question asked the participant to identify another incident, during which the participant was aware that learning was taking place in the moment. The identification of a critical incident encouraged participants to reflect on experiences in which they believed something was learned while in the moment of the experience or as a result of the experience. The open-ended nature of the questions allowed for the emergence of stories that revealed individuals’ beliefs, values, and assumptions about their work (Wilensky & Hansen, 2001). These narratives in turn offered insights into identifying what supports were of value to the participants (as well as their peers) in their role as hospice care professionals. The outcome of this participatory worldview was the development of an action agenda for reform that, if implemented, could change the work life of not only the research participants but all employees of the hospice. The open-ended interviewing, narrative

design, and participatory worldview contributed to the qualitative nature of the study design (Creswell, 2009).

In addition to the two critical-incident questions, the interview process also entailed two follow up questions:

1. What works well at United Hospice?
2. What can be a challenge working at United Hospice?

The answers to these additional questions formed the basis of the program evaluation portion of the study.

Individual interviews were conducted at a time convenient for study participants. Twenty-four hours before the scheduled meeting time, I sent an email to the study participant, reminding him or her of our meeting and requesting that the member contact me (the researcher), either via email or text, if there was a need to reschedule. Figure 7 shows a sample of the email reminder.

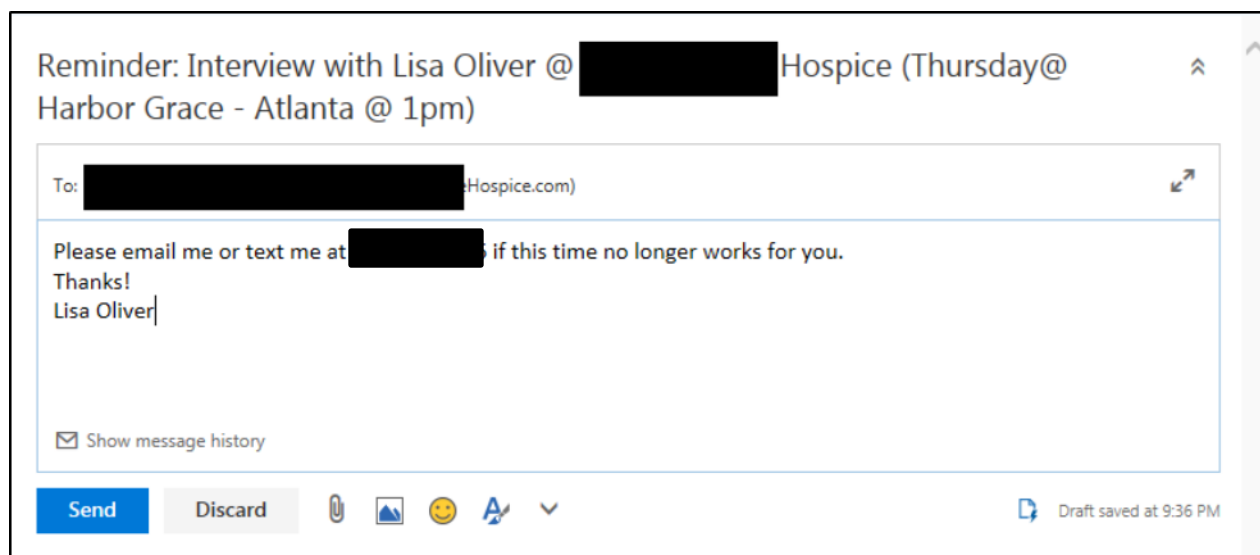


Figure 7. Sample email reminder for study interview.

Table 5 lists the interview questions associated with the critical incident interview technique used in this study. To ensure consistency across interviews, I employed an interview guide, illustrated in Figure 8.

Table 5

*Critical Incident Interview Questions for Hospice Care Professionals*

Question 1	Question 2
<p>In your work with the dying and bereaved, think about a really significant time where you really felt you learned a great deal:</p> <ul style="list-style-type: none"> <li>• Can you walk me through, from the beginning to the end, of this significant time?</li> <li>• What made the learning significant?</li> <li>• Who or what helped you realized this learning?</li> <li>• What was that like for you?</li> </ul>	<p>I wonder if you could think about another time when you were aware of your learning in working with the dying and bereaved:</p> <ul style="list-style-type: none"> <li>• Can you walk me through, from the beginning to the end, of this significant time?</li> <li>• What made the learning significant?</li> <li>• Who or what helped you realized this learning?</li> <li>• What was that like for you?</li> </ul>

All of the interviews lasted approximately one hour. A majority of the interviews were conducted face-to-face, with two conducted via Skype. Each interview began with characterization questions, which asked about the hospice care professional's number of years of experience in his or her profession, the number of years of experience within the context of hospice, and the number of years employed by United Hospice. I then posed the critical incident interview questions. The first asked the individual to recall a significant incident in his or her role as a hospice care professional in which, upon reflection, the individual realized he or she learned something. The second question asked the participant to recall another critical incident as a hospice care professional during which, at the moment, he or she realized learning was occurring.

### Interview Guide

SCRIPT: First, I want to thank you for taking time out of your schedule to speak with me. As I mentioned before, I am a graduate student at the University of Georgia conducting research in fulfillment of requirements for a doctorate in Adult Education. This interview will take about 60 minutes and will include questions regarding your background and role in your organization and how you informally learn to care the dying and bereaved. I would like your permission to audio record this interview so I may accurately document your responses. If at any time during the interview you wish to discontinue the use of the recorder or the interview itself, please let me know. All of your responses are confidential and will be used to develop a better understanding informal learning among hospice care professionals. I would also like to obtain your written consent to participate in this study. I am the primary researcher in the study "How Do Caregivers Learn? Exploring the Informal Learning of Hospice Care Professionals". You and I will both sign the consent form and date each copy, certifying that we agree to continue with this interview. You will receive one copy and I will keep the other, separate from your responses. Your participation in this interview is completely voluntary. If at any time you would like to stop the interview, take a break, return to a previous question, or withdraw your participation, please let me know. Do you have any questions or concerns before we begin? Please take some time to read over and sign the consent form.

[Sign and date consent forms]

[SET PHONE TIMER]

[BEGIN interview]

[TURN ON RECORDER]

*{This is Lisa Oliver, Interviewing (Use a pseudonym) on DATE, Beginning at TIME}*

#### Topic Domain 1: Background

- Lead Question: Tell me about your role in your organization
- Follow Up Questions:
  1. How long have you been a (social worker, nurse, etc.)
  2. How long have you been working with your organization?
  3. What is your educational background?

Prompts: • I am not sure I know what you mean...can you say more? • You said that XYZ....could you explain that? • What did you say then? • What were you thinking at the time? • Give me an example... • Tell me about

Figure 8. Interview guide used for study.

Topic Domain 2: Significant Learning Experience

**Background**

Research shows that many Hospice Care Professionals are graduating from their respective programs with limited education and exposure to death and dying. So, if these individuals are not learning in formal educational settings, they are learning their profession “informally”. I am trying to learn more about how Hospice Care Professionals use informal learning to responds to the needs of the dying and the bereaved. I would like to ask you some questions about a few of your most significant experiences related to this problem. I would also like to ask you about how you interpreted these experiences, and finally what happened.

Shall we begin?

**SIGNIFICANT LEARNING EXPERIENCE**

Lead Question: In your work with the dying and bereaved, think about a really significant time where you really felt you learned a great deal. Can you walk me through, from the beginning to the end, of this significant time? What made the learning significant? Who or what helped you realized this learning?

**FINAL QUESTION**

In light of what you have now talked about, is there anything else you would like to tell me (or you think that I should know) about this problem?

[WRAP-UP and ANSWER any participant questions]

[THANK YOU so much again for agreeing to participate. Please do not hesitate to contact me should you have any questions]

[SPEAK into the recorder: “This ends the current interview” and STOP recorder]

*Figure 8 (continued).* Interview guide used for study.

I also asked study participants two additional questions: (1) What works well at United Hospice? and (2) what can be a challenge working at United Hospice? The answers to these final questions served as the foundation to the evaluation of the program at United Hospice. Normally, within two days after the meeting, I would send the study participant who was interviewed a hand-written note, thanking them for their time.



## **Researcher Observations and Notes**

Following Merriam's (2009) suggestion, I adhered to a three-stage process of collecting data: entry, data collection, and exit. As my lead advisor recommended, I volunteered at the in-patient division of the hospice every Sunday afternoon or Monday evening from April 2015 to May 2016. (While I stopped going to the hospice continuously every Sunday or Monday, I continue to volunteer at United Hospice. I attend the support staff meetings the fourth Thursday of every month, and I put in extra time at the hospice any time there is an infant on the floor of the in-patient unit.) This informal immersion in the system allowed me to engage in participant observations. Springer (2007) wrote that "observation in action research is more ethnographic, enabling an observer to build a picture of the lifeworld of those being observed and an understanding of the way they ordinarily go about their everyday activities" (p. 75). The participant-as-observer is one of four roles that sociologist Raymond L. Gold conceptualized for sociologists conducting field work. Gold (1958) wrote:

Both field worker and informant are aware that theirs is a field relationship. This mutual awareness tends to minimize problems of role-pretending; yet, the role carries with it numerous opportunities for compartmentalizing mistakes and dilemmas which typically bedevil the complete participant. Probably the most frequent use of this role is in community studies, where an observer develops relationships with informants through time, and where he is apt to spend more time and energy participating than observing. At times he observes formally, as in scheduled interview situations; and at other times he observes informally when attending parties, for example. During early stages of his stay in the community, informants may be somewhat uneasy about him in both formal and

informal situations, but their uneasiness is likely to disappear when they learn to trust him and he them. (p. 220)

Gold's participant-as-observer conceptualization held true to my relationship with the employees of the hospice. During my first few visits, I found that, while the environment was very friendly and congenial, the staff kept to themselves. Later, when I came in on Sundays, I was asked if I "got myself something to eat" or if I "want to make myself a plate." Being a participant-observer allowed me to have informal conversations with hospice care professionals employed by United Hospice but not connected with the action research team (e.g., custodians, certified nursing assistants, desk personnel). It also allowed me to speak informally with members of the action research team to get clarification on actions observed while I was volunteering. The information gleaned from the interviews, observations, and subsequent conversations revealed dynamics and mindsets within the organization in general and among the action research team members in particular that needed to be addressed to ensure that subsequent interventions could be sustainable. Marshak (2006) identified these dynamics and mindsets as "covert processes that routinely impact human interactions and can confound our most diligent efforts to accomplish our goals... Covert processes include all out-of-awareness dynamics that occur in human systems, for whatever reasons" (p. 20).

Because of what I learned as a participant-observer, as part of the "pre-step" to the action research cycle, I decided to address the subject of covert processes with the action research team. Schein (2006) wrote that "etiquette, tact, and politeness often require keeping covert things covert" (p. x). However, covert processes can "strongly [influence] the outcomes of a social action, often in a negative way, so it [can] not be simply ignored" (p. 8). Thus, I felt the need to include an information session about covert operations because of what I observed

during my time at the hospice.

I first introduced the action research team to Kaner, Lind, Toldi, Fisk, Berger, and Doyle's (2011) definition of a good discussion: "The goal of a good discussion is to produce more harmony among individually different perspectives—to reconcile the diversity through a process of mutual understanding" (p. 83). I further explained that because of our upbringing and experiences, we all enter situations with a bias, and until these biases are addressed, no organizational change will occur (Kaner et al., 2011). I explained, moreover, that the discomfort of bias can deepen—"even to the point of ruining a group's ability to think together—when participants don't realize that their individual frames of reference are biasing their assessment of the value of one another's contribution" (Kaner et al., 2011, p. 82).

I challenged the group members around their biases, beliefs, assumptions, and values. Marshak (2006) explained that "beliefs, assumptions, and values comprise the broadest array of concepts that order, judge, link, and explain events ... All have the impact of both organizing and limiting your-experience and responses" (p. 23). As noted previously, when conducting the initial interviews, one of the follow-up questions was, "What does not work well at United Hospice?" As a group activity, I wrote all of the responses to that question and posted them on a flip chart-sized sheet of paper. I gave each team member sheets of paper and a pen and asked him or her to write down one of the responses shown and ask, "Why do I feel that way?" As participants answered that question, I requested that they continue asking themselves, "Why do I feel that way?", until the bias they held was revealed. I explained briefly Argyris' (2002) concept of double-loop learning to reinforce an awareness that it is not enough for an individual to acknowledge what he or she believes to be correct in response to the question, "What does not work at United Hospice?"; rather, individuals needed to challenge themselves as to why they felt

the way they did. No one was asked to share his or her answers, as it was not my intent to embarrass anyone. However, I did want to enhance participants' awareness of how biases, beliefs, assumptions, and values can affect how they experience life generally and how they interacted in our meetings specifically.

The action research team's response to the activity was positive—both after the meeting and during the recap at the following meeting. Alex and Joe—both chaplains who, as part of their preparation for the chaplaincy, received clinical pastoral education training—were already aware of how biases could have an effect on ministering to others and believed this was a valuable activity. Likewise, Sophia stated (and all agreed) that holding such biases affects not just work life but “life” in general. As a result of this activity, I suggested that the action research team develop a set of “group norms.” According to Richardson (1999), “having a set of norms—or ground rules—that a group follows encourages behaviors that will help a group do its work and discourages behaviors that interfere with a group's effectiveness” (p. 1). I suggested the team develop group norms for two reasons: (1) nearly everyone interviewed had a negative opinion about the weekly IDT meetings and how they operated; (2) by establishing a set of norms for how we conducted ourselves in our meetings, the members of the action research team could “lead by example” when participating in the IDT meetings, and perhaps the behaviors exhibited would “cross over” to other members of the team, resulting in better behavior at the meetings. Figure 9 depicts the norms for the United Hospice action research team.

**HOSPICE**  
**ACTION RESEARCH TEAM NORMS**  
**December, 2015**

**Communication**

- We will listen to each other carefully for the sense of what each person is saying. We will use reflecting practice by repeating what we thought to understand (outloud) before responding.
- We will not use language that may be offensive to others.
- We will develop meeting minutes and disperse within a reasonable amount of time.

**Under what conditions we will meet**

- We will start every meeting with a short "check-in" to acknowledge where we are physically, mentally, emotionally, and spiritually.
- We will use their professional judgment regarding receiving phone calls and need to step out of the room (E.g. we will stay present and try to keep distractions to minimum.
- We must make every attempt to arrive on time.
- We will be prepared for the meeting. Examples of preparedness includes, but not limited to, emails being read, follow up tasks completed, and being emotionally prepared to get to work.
- We will hold each other accountable with the decisions made.
- We will create a safe sharing space to voice interpersonal concerns.
- We will lay out items for the next meeting prior to ending the current meeting

**How we will interact with each other**

- We will strive to focus on the task at hand so we can be productive.
- We will respect and validate an individual's personal and professional experience

*Figure 9. United Hospice action research team norms.*

## **Meeting Minutes**

I generated minutes after each action research team meeting. Information shared about the meetings included the date, what members were in attendance, the agenda and decisions made concerning agenda topics, any next steps, and the proposed agenda for the next meeting. In addition to providing structure to our action research activities, the meeting minutes kept members current on what was happening within the team and what was expected at the next

session. McNiff and Whitehead (2011) stated that documenting the minutes of staff meetings provides evidence to “show the situation as it unfolds” (p. 106), while Caffarella identified meeting minutes as a “technique of collecting evaluation data” (p. 251).

### **Closing Interviews**

With the interventions implemented, appointments were set up for closing conversations with the action research team members, both as a group and individually. To the group, I asked, “What worked well about our time together?”, “What did not work well about our time together?”, and “What should we have done differently?”

Table 6

#### *Closing Interview Questions for Hospice Care Professionals*

- |  |
|--|
| <ol style="list-style-type: none"> <li>1. Can you talk about a time when you felt supported while dealing with the emotions or the stress of being in your position?             <ol style="list-style-type: none"> <li>a. What happened?</li> <li>b. Who or what helped?</li> </ol> </li> <li>2. The purpose of this study was to explore the informal learning of hospice care professionals within the context of their emotion work, with the aim of analyzing learning needs and proactively developing professional development interventions to address those needs, what have we done that has been helpful in addressing that?</li> <li>3. In your opinion, what still needs to be done to support hospice care professionals and what recommendations would you make going forward?</li> </ol> |
|--|

### **Data Analysis**

Each interview with the 12 United Hospice employees was recorded and then transcribed shortly afterward using Rev.com. As I read the transcripts, I used open coding to categorize the type of environment in which the informal learning occurred. Table 7 shows the type of environment informal learning occurred and the frequency of these occurrences.

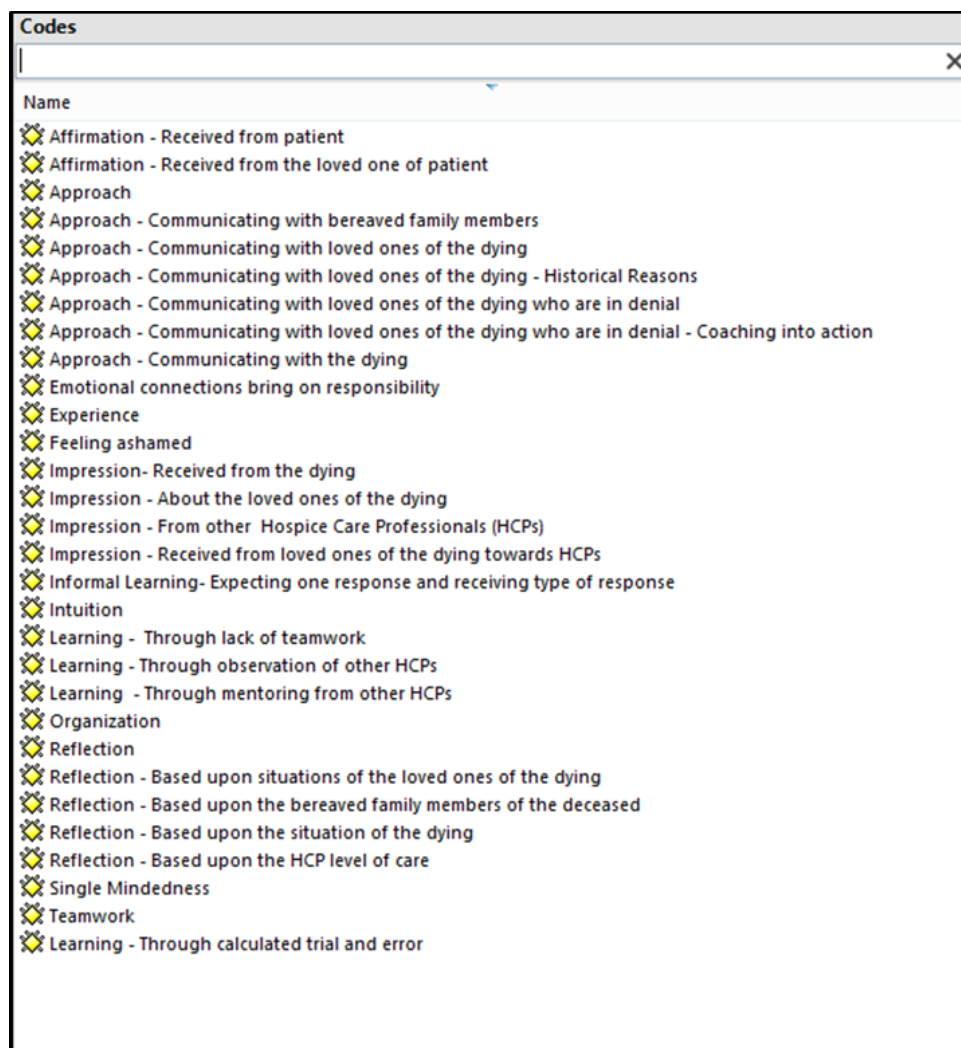
Table 7

*Type of Environment in which Informal Learning Occurred and Frequency of Occurrences*

<b>Type of environment</b>	<b>Frequency</b>
Activity related to working in the hospice	65
Perspectives held by the learner based on experiences	191
Process of working with patients and performing tasks	32
Based upon relationship with patients and social structure	102
Setting and context	114
Strategies on how to communicate/work with patients and loved ones	30

The transcriptions were then converted into data narratives, which are first-person accounts of lived experiences—stories that have a beginning, middle, and end (Merriam, 2009; Patton, 2002). As a research technique, the narrative form is effective as qualitative data because a narrative allows the researcher to “understand how people make sense of their lives, delineate the process of meaning-making, and describe how people interpret what they experience” (Merriam, 2009, p. 14).

I imported the narratives into Atlas.ti, and a narrative analysis was performed using open coding. Figure 10 shows the categories identified.



*Figure 10.* List of codes defined in narratives using the framework of informal learning within the context of emotion work.

As Glaser and Strauss (2009) illustrated in their 1964 study, “The Social Loss of Dying Patients,” one theoretical category related to the care of dying patients is social loss—loss to family and occupation—which clearly affects how nurses care for dying patients. This category of social loss was generated from Glaser and Strauss’s observation that people whom society considered “very important people” received special care in intensive care units, while lower-



class “Negroes” were often neglected in city hospital emergency wards. According to Glaser and Strauss (2009):

Even if the evidence changes (or is different in other hospitals for various other reasons), they can be sure that social loss is a category related to nursing care, and predictions can be made on its basis, that patients who have high social loss will receive better care than those who have low social loss. If this prediction proves incorrect, then one finds out the next structural conditions to negate the relationship. The discovered theoretical relationship lives on until proven theoretically defunct for any class of data, while the life of the accurate evidence that indicated the category may be short. (p. 35)

Glaser and Strauss believed the purpose of the constant comparative method of joint coding and analysis is to:

generate theory that is integrated, consistent, plausible, close to the data and at the same time is in a form clear enough to be readily, if only partially, operationalized for testing in quantitative research ... The method is still dependent on the skill of the researcher analyzing the data and is not designed to guarantee that two researchers working independently with the same data will achieve the same results; it is designed to allow, with discipline, for some of the vagueness and flexibility that aid for creative generation of theory. (p. 114)

In this study, I used the narratives developed from the interviews with the 12 United Hospice employees to perform the constant comparative analysis. Stage 1 of the constant comparative method begins with comparing incidents applicable to each category. Figure 11 illustrates the process of coding an incident for a category and comparing it with previous events in the same and different groups coded in the same category.

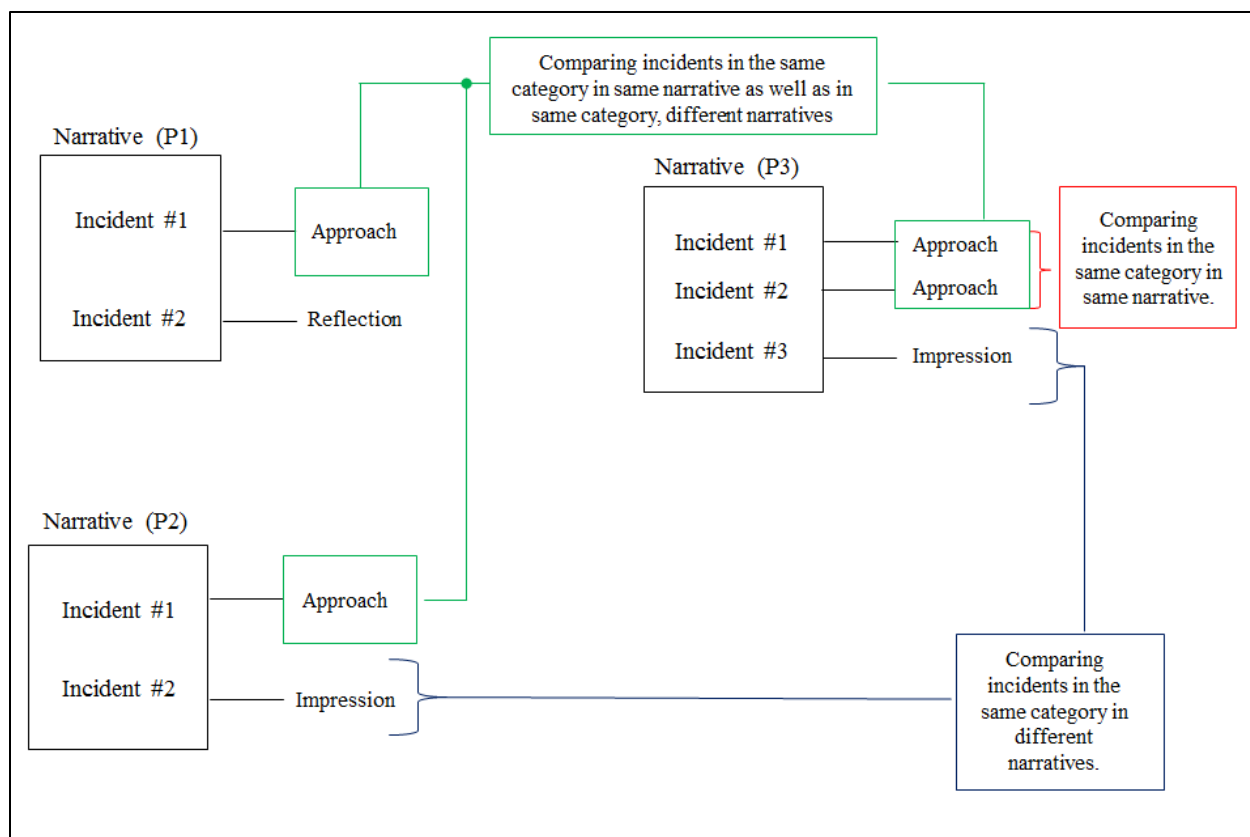


Figure 11. Constant comparative method of qualitative analysis: Stage 1.

The constant comparative method is an iterative and inductive process of reducing the data through constant recoding (Glaser & Strauss, 1967). The method was used to generate a theory from the categories of informal learning previously identified.

During Stage 2, I integrated the categories and their properties. Generally, as the coding continues, the comparisons moves from comparing incidents in the same category in the same narrative and the same category but different narrative to the same category but with a different focus. As the example in Figure 12 illustrates, each category is first broken into the components of the category. By discovering the components assigned to a category and comparing that incident with other incidents with the same category/components, a theory emerges.

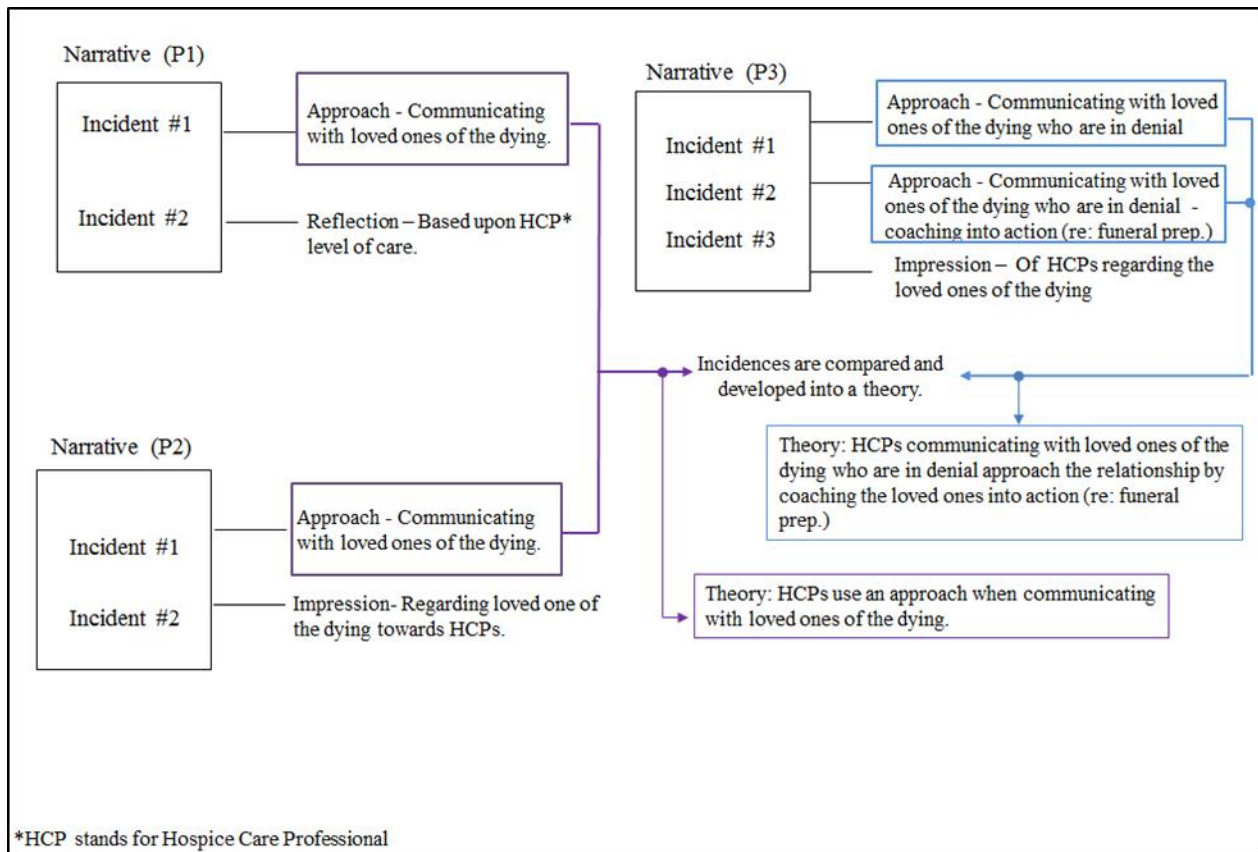


Figure 12. Constant comparative method of qualitative analysis: Stage 2.

Stage 2 required the delimiting of the theory. According to Glaser and Strauss (2009): This delimiting occurs at two levels: the theory and the categories ... First, the theory solidifies, in the sense that major modifications become fewer and fewer as the researcher compares the next incidents of a category to its components. Later, modifications are mainly on the order of clarifying the logic, taking out non-relevant properties, integrating elaborating details of components into the major outline of interrelated categories and reduction occurs when the analyst discovers underlying uniformity in the original set of categories or their properties and then reformulates the theory with a smaller set of higher-level concepts. The second level of delimiting the theory is a reduction in the

original list of categories for coding. As the theory grows, becomes reduced, and increasingly works better for ordering a mass of qualitative data, the analyst becomes committed to it. This allows the researcher to pare down the original list of categories for collecting and coding data, according to the present boundaries of the theory. (p. 121)

The emerging theory from Stage 2 became integrated with other categories of analysis to generate an integrated theory. The reduction of terminology allowed for the integrated theory to be generalized so that it could pertain to healthcare workers, not just hospice care professionals, and all loved ones of patients, not just those who are dying. Glaser and Strauss (2009) also discovered that on “the level of formal theory, [this integrated theory] could even be generalized as a theory of how the social values of professionals affect the impression of their clients” (p. 122).

At the final stage of the process, Stage 3 (see Figure 13), I processed the coded data, a series of memos, and the theory. The discussions in the memos provided the content that generated the categories, which become the major themes of the theory (Glaser & Strauss, 2009), presented later.

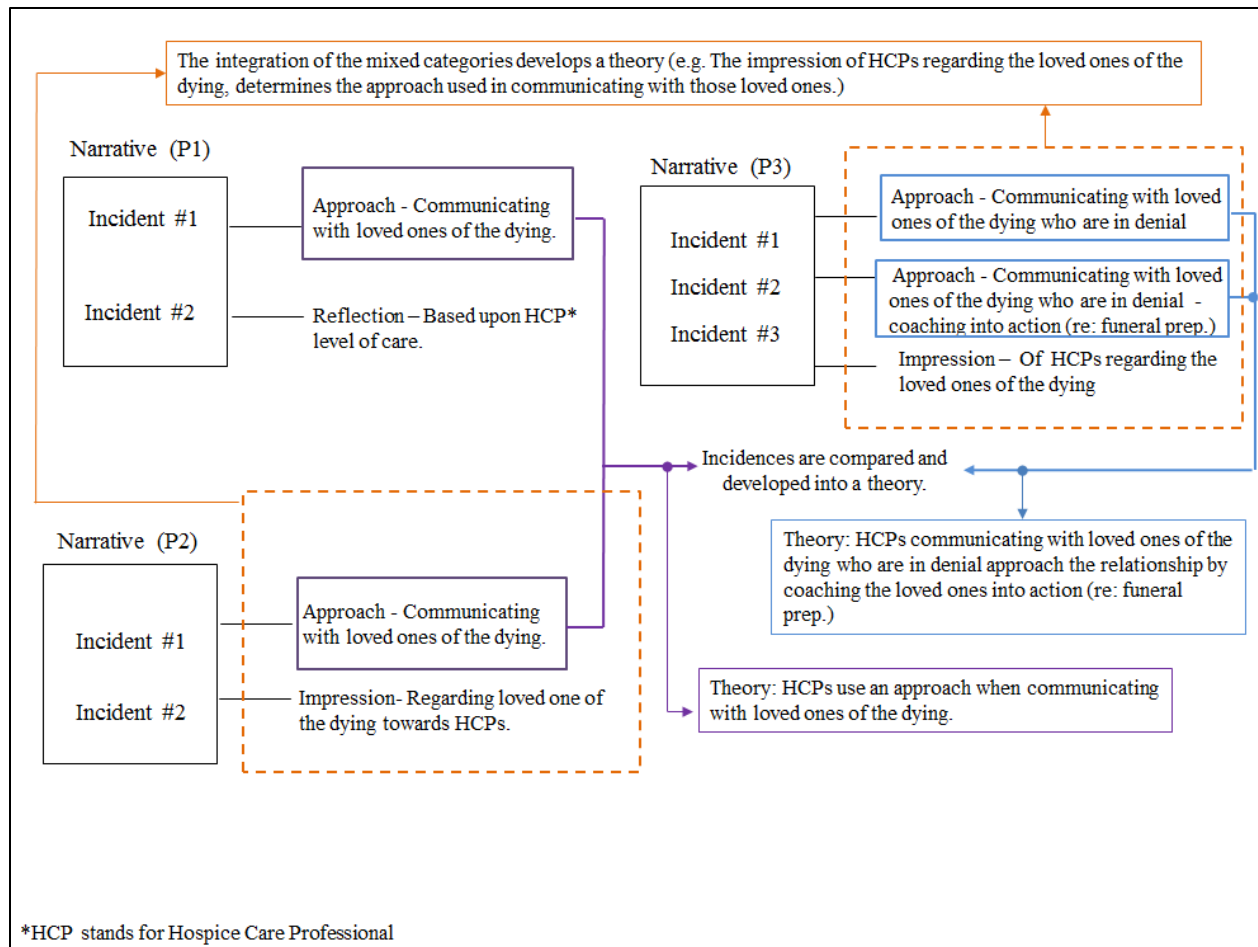


Figure 13. Constant comparative method of qualitative analysis: Stage 3.

### Data Trustworthiness

Stringer (2007) states that “Rigor in action research is based on checks to ensure that the outcomes of the research are trustworthy – that they do not merely reflect the particular perspectives, biases, or worldview of the researcher and they are not based solely on superficial or simplistic analysis of the issues investigated” (p. 57). Checks for trustworthiness are “designed to ensure that researchers have rigorously established the veracity, truthfulness, or validity of the information and analysis that have emerged from the research process” (p. 57).

Guba's (1981) model of trustworthiness of qualitative research was used in this study to ensure reliability and data validity because it is well developed conceptually and has been used with success by qualitative researchers, particularly nurses and educators, for many years (Krefting, 1991). Guba promoted a naturalistic paradigm for inquiry, which he described as one of the many paradigms for arriving at "truth,"

including, for example, the legal paradigm that characterizes courtroom proceedings; the "expert judgment" paradigm that characterizes accreditation site visits, peer review of proposals, and judgments of athletic performance; and the *modus operandi* paradigm (Scriven, 1976); tracing of characteristic causal chains that characterizes forensic pathology and television repair. (p. 76)

### **Member Checking**

Each United Hospice employee who was interviewed was emailed the transcript from the recorded interview to review and, if needed, clarify any part of the interview that was not representative of the idea or ideas being conveyed. Stringer (2007) stated that this action between the researcher and study participant enables participants to "verify that the research adequately represents their perspectives and experiences" (p. 58).

### **Prolonged Engagement in the Field**

At the hospice, my presence was not only in a research capacity but also in a volunteer capacity; whether I was helping to organize and facilitate the hospice's quarterly memorial service or increasing my availability to care for the babies when they arrived in the unit, my presence allowed me to build trust with employees, observe behaviors, and overhear conversations to which I would not have been privy otherwise. Creswell and Miller (2000) asserted that the more a researcher "stays in the field, the more pluralistic perspectives will be

heard from participants and the better the understanding of the context of participant views” (p. 128).

### **Researcher Positionality**

I was raised primarily by my great-great-grandmother, a woman with a third-grade education who worked as a hotel chambermaid, emptying and cleaning the chamber pots of hotel guests in Atlantic City, New Jersey. After many years of working in the city’s hotels, she eventually became a housekeeper for a middle-class family in the nearby town of Margate, approximately six miles away, where she had to catch the bus to work and back six days a week. Although my great-great-grandmother’s working life was physically harder than I could ever imagine, she never seemed discontented about the work. I believed that she figured out early in life that cleaning out chamber pots and people’s houses is the type of job one gets when one is a “colored” girl without an education. She did, however, share with me her discontent with the poor treatment she and those like her received because of differences in race, education, or job position. The value of equality central to my great-great-grandmother’s stories emphasized treating others as one would like to be treated—respectfully, no matter their station in life.

My father died of prostate cancer in 2003. Once Dad began actively dying and home hospice care began, a staff member from the Community Hospice of Maryland named Evelyn was assigned to support our family. Evelyn was a strong, calming figure in our home at a time of great fear and uncertainty. Through this woman’s presence, I realized that one does not have to be famous to make a difference in someone’s life. It was Evelyn’s compassion that made me want to volunteer locally at a hospice. I also realized then that I wanted my own life’s work to make a difference.

I believe that when a person undergoes a conscious experience for the first time, whether pleasant or traumatic, the conditions of that experience will serve as the lens through which all other similar events will be viewed. My mother's death due to a car accident was instant; by contrast, my father's death from cancer was a slow decline that lasted months. My experience with Dad dying was completely different than with Mom dying. With Dad, he and I had time to talk, reminisce, reflect; talk about our regrets and say our goodbyes. With Mom, there was nothing I could do but plan her funeral. Planning a funeral is something I know how to do, having seen it done with others who have died or from television shows and movies. It is a process: You do A, then B, and so on. Experiencing someone dying, however, is an entirely different paradigm. Yes, I have seen dying on television and in the movies, but it is nothing like living through it. At the beginning of my father's actively dying diagnosis, I did not know what to expect and was scared. However, with the assistance of hospice personnel who genuinely listened to my the family's concerns, fully and honestly answering our questions, and educating us on what to expect and what to do about it, I had a more comfortable, though no less sad, experience with dying. Not everyone has had such an experience.

The value of equal respect for all instilled by my great-great-grandmother directed me to this study. In this life, dying is a given. Hospice is an opportunity available to anyone who wants to live, until they die, with emotional, physical, and social support, and without pain. It is my goal to educate people on death and dying so that they do not waste time trying to escape death but rather enjoy life.

As a great-great-granddaughter who adored her "Grandma" and who wants to right the wrongs her great-great-grandmother experienced; as a daughter whose father received excellent care from a hospice care professional; and as a researcher studying the informal learning of



hospice care professionals, I acknowledge the biases I brought to this study. For instance, I was biased in my choice of United Hospice as the site of my study, as this hospice takes on cases that other hospices turn away and accepts destitute clients, giving everyone who comes to that organization for end-of-life care an opportunity to die with dignity and free of pain. I was also biased in my belief that people who do hospice work can do no wrong and that the individuals I worked with at United Hospice as part of this study are the most underpaid, emotionally stretched, good-hearted group of people I have ever met. That said, as I report the qualitative data that I collected and analyzed, I am mindful of reporting the data as it appeared and not colored from what I know about hospice care professionals or the individuals from whom I collected the data.

### **Study Limitations**

While valid and reliable, the results of this study cannot be generalized to all hospice care professionals for several reasons. First, the study's population was limited to one hospice; involving additional organizations might have provided greater heterogeneity of responses. Thus, future research might involve larger samples of hospice care professionals from multiple organizations. Second, the small sample was fairly homogenous regarding gender, thereby limiting the ability to evaluate differences between male and female hospice care professionals. However, despite these limitations, the study clearly indicated the need for further research in the area of informal learning of hospice care professionals.

### **Conclusions**

The purpose of this study was to explore the informal learning of hospice care professionals within the context of their emotion work, with the aim of analyzing learning needs and proactively developing professional development interventions to address those needs. .

While planning and developing the modified process for operating an IDT meeting more effectively and determining how the support staff meetings would function, the action research team became more aware of how they learn informally (both as a group and individually). The greatest gains in awareness occurred when time was taken to reflect formally upon the implementation of an intervention, what worked well, what could have worked better, what went poorly, etc. It took time to develop and build trust among the action research team. Ultimately, the camaraderie that blossomed as a result of this trust expanded into the second intervention, which included all support staff members, not just the action research team members. Though not all of the support staff team members were as engaged as I had hoped, we all learned about each other, more about ourselves, and how certain influences can affect our objectivity.

Volunteering at the hospice allowed for my informal immersion as a participant-observer and offered opportunities for informal conversations with United Hospice care professionals both on and off the action research team. This informal immersion allowed me to observe and overhear some covert behaviors that, if not addressed, would have lessened the likelihood of the intervention's success and sustainability.

Chapter 4 tells the story of United Hospice—the organization, its work environment, and the background on the members of the action research team.

## CHAPTER 4

### UNITED HOSPICE

This chapter tells the story of United Hospice—the community it serves, its organizational structure, its employees, the work dynamic within the organization, and the sense of pride the employees hold for their jobs helping people who are dying to do so with peace, comfort, and dignity, and supporting their loved ones through the bereavement process. The main characters of United Hospice are the hospice care professionals who are part of the interdisciplinary department team but are considered support staff. The individuals in these positions also made up the action research team for this study. The support staff at United Hospice believe that, as non-clinicians (bereavement coordinator, chaplain, social worker, volunteer coordinator), what they bring to the organization is not deemed as important to the administration as what a clinician (medical director, nurse practitioner, nurse) offers.

One character is the hospice administrator, who keeps the organization functioning. Another character is the facility director, who, though part of the administration, does not feel as such, and acts accordingly. Another character who looms large in this story is the hospice's owner, who also serves as its medical director. This person, whether intentionally or not, intimidates those who work under her.

The story begins when a researcher enters the system to conduct a study on how hospice care professionals learn informally. Preliminary interviews with study participants, combined with the researcher's observations and casual conversations with employees, reveal that the hospice lacks infrastructure. Study participants agree with the researcher's assessment and

decide that the first step in implementing some structure is through the weekly IDT meetings. While this assessment does not align with the researcher's study purpose, it means a great deal to the study participants to implement this intervention, so the researcher supports the effort while searching for another intervention that more closely aligns with the study. The medical director initially approves of the restructured IDT meetings only to reject it later, challenging the action research team to provide a reason why they felt the need for the meetings to be restructured. At this point, the team does not act as a team at all; each action research team member present at the meeting capitulates to the medical director, agreeing with her assessment that nothing should change in how IDT meetings are conducted. Later, the action research team discusses this failure to "stick together" and agrees to do so.

The team goes on to implement the intervention that aligned more with the researcher's study—that is, the monthly support staff meeting. This meeting joins the support staffs from both the in-patient facility and home health divisions to educational opportunities, processes, and procedures that could affect the group. It is a significant shift for both entities to meet regularly because, prior to this, the only time the support staff were brought together was to be "called on the carpet." In addition to discussing processes and procedures that may affect the group, each month a support staff member would present a case about an experience involving a hospice situation on which the member wanted feedback. These presentations of the case are regarded as movement to the group; presenters sharing what challenges they experienced allow other group members to see they are not alone in their struggles. As a result, this monthly meeting helps this group evolve from a set of employees from different divisions to a cohesive support staff.

Figure 14 depicts the logic model, which identifies and defines the problem the study addressed. In the column labeled, "Situation," I identify hospice care professionals as the subject

of the study. Because these individuals had limited exposure to the subject of death and dying in their respective educational programs, informal learning was their means for determining how to respond to the needs of the dying and bereaved. I then list the questions that my study answered. Next, in the “Inputs” column, I list the resources used to develop and refine my study. In the column labeled “Outputs,” I identify those activities that were conducted to provide answers to the research questions. Under each activity, I identify the action research cycle with which that activity was aligned. Finally, the “Outcomes-Impact” section identifies the short-, mid-, and long-term outcomes I envisioned for the study.

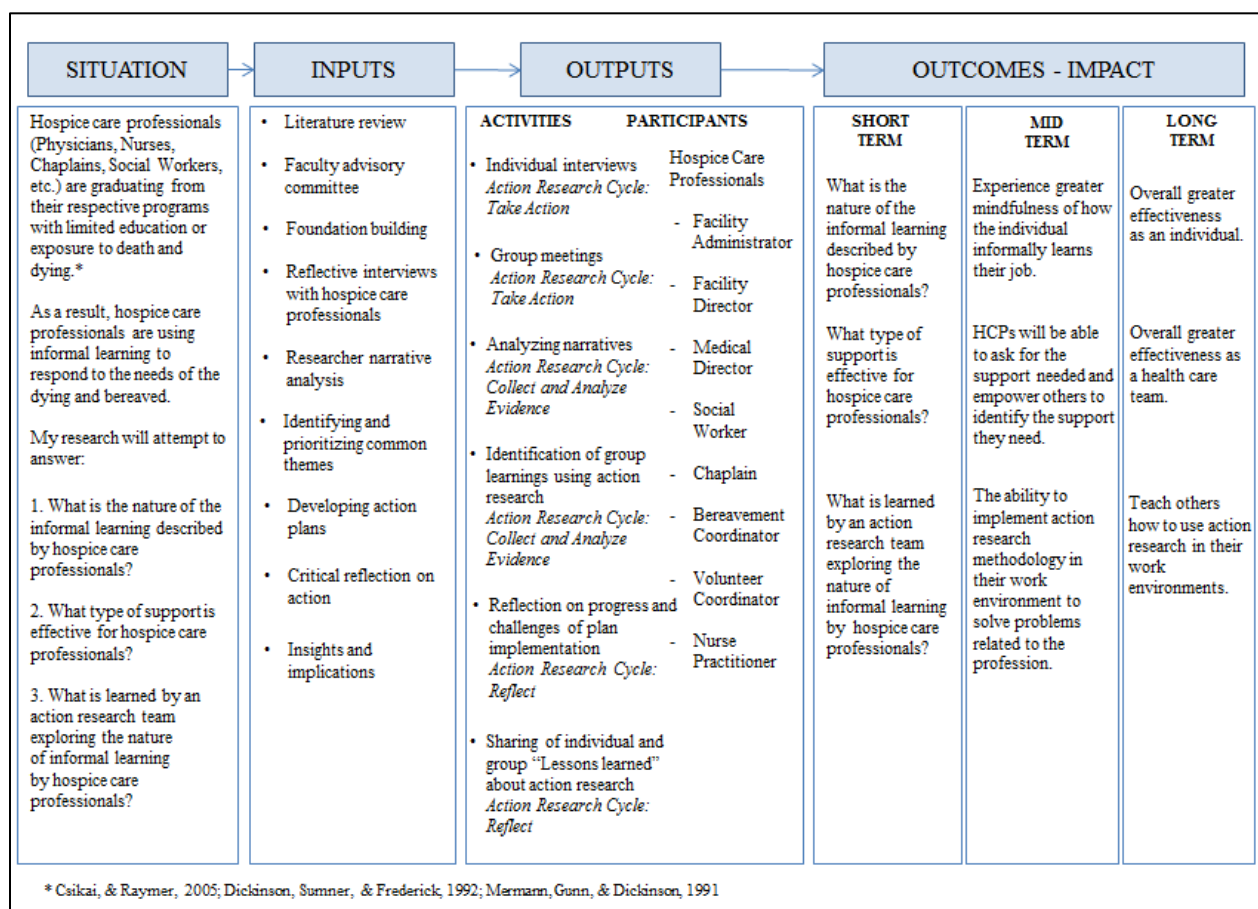


Figure 14. Logic model for the study.

## The Organization

Figure 15 illustrates the organizational chart for United Hospice. At the time of the study, the organization was led by the medical director, who also owned the hospice. During the time I conducted the study, the associate medical director position remained vacant.

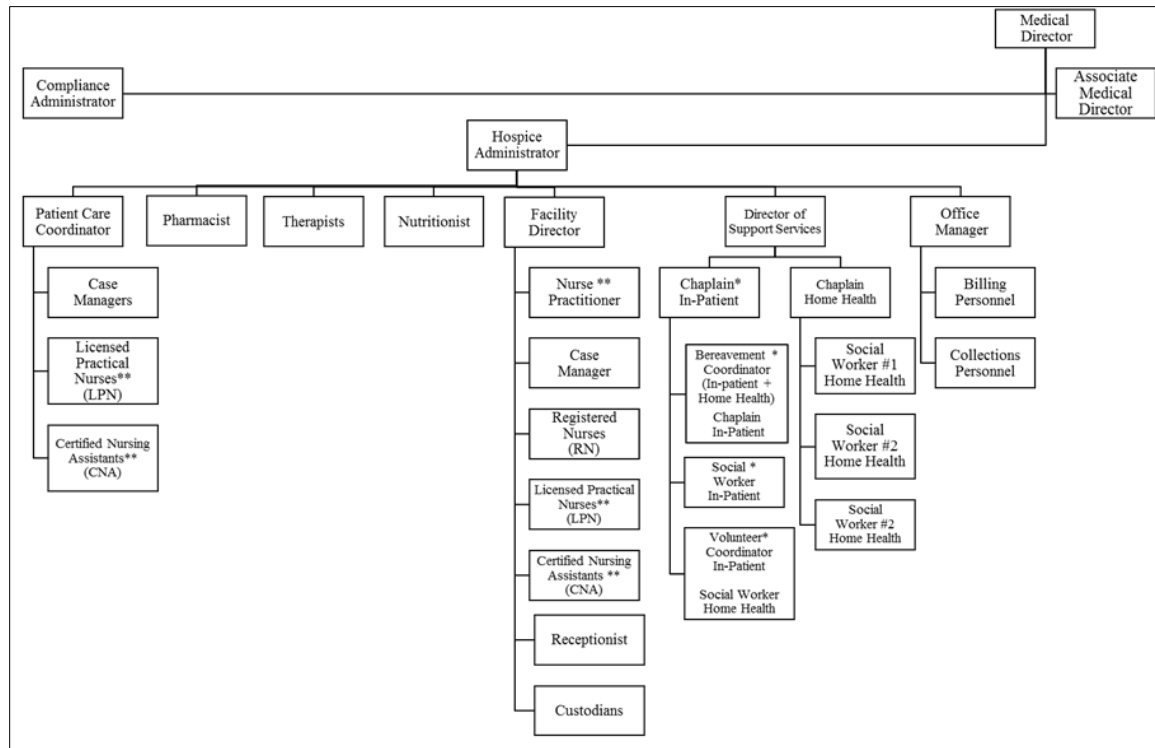


Figure 15. Organizational chart: United Hospice.

Overall operations of the hospice were the responsibility of the hospice administrator. However, this person performed more than administrative work; she did whatever needed to be done in order to keep operations running as smoothly as possible. I knew the administrator to perform an intubation on a patient in the in-patient unit, make home health visits to check on patients, and, when the director of social services decided not to come to work for one week (without explanation)—leaving an enormous caseload for his subordinate to handle—take on

most of the social worker's case load. A few participants, during their interviews, felt strongly that the administrator was the individual who makes United Hospice work well. One social worker stated that Galina, the administrator, made United Hospice work well for her:

Galina is just amazing. I can have anything, and I bring it to her. She gets it done. She's one of those people that she loves this, so she has a passion for it. She's genuine. I can't explain it. I've worked for a ton of different people, but she's the only supervisor, boss—I don't know what her title is—but she's the only person that really genuinely makes me feel comfortable. She wants me to grow with the organization. She's eager to help.

The facility director was responsible for all facility work and for employees with clinical responsibilities in the in-patient division. The director of social services was responsible for the employees with non-clinical responsibilities at both the in-patient and home health divisions. United Hospice displayed a calm, efficient operation as it relates to patients and their loved ones; however, the organization lacked an operational infrastructure in which employees could work efficiently. At the time of the study, there were no written processes developed to explain how certain tasks are to be completed. For instance, regarding the intake of new patients to hospice, there were as many ways that intake was handled as there were hospice care professionals processing the intake. Often, while sitting in a meeting, a side conversation would come up regarding Mrs. Abram,<sup>\*</sup> and how her onboarding sheet (i.e., the document used to complete the patient intake) was missing critical information or that the employee on the evening shift who on-boarded Mr. Dunn forgot to get the next of kin's signature regarding services the hospice will provide. While these missing pieces of information were always found eventually, there was considerable retracing of steps and backtracking involved. However, despite the lack of structure, patients did not suffer or receive lesser care because of it.

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<sup>\*</sup> Pseudonyms have been used to protect the identities of participants.

From my observations, the hospice care professionals at United Hospice extended themselves and used their personal assets to do what needed to be done for patients (e.g., a social worker used her personal vehicle to transport a patient, so the patient could get replacement identification to successfully register for and receive Medicaid) and for each other. This environment of doing what was required for patients, patients' loved ones, and other employees may have contributed to the high attrition rate among its employees. While this type of working environment is not exclusive to United Hospice, this issue is important to address since many hospice programs fail because of insufficient or inadequate development and operational management as well as burnout and compassion fatigue (Wilson & English, 2014).

### **The Work Environment**

The environment of the in-patient unit at United Hospice was communal and familial. (On Sundays, for example, a potluck is held, and just about everyone on staff that day brings a dish and, as time allows, eat an afternoon meal together.) There was evidence that the employees showed concern for United Hospice patients and respected one another. Though I was present at the hospice for only brief periods, I observed numerous acts of care and concern for patients' families as well as toward other employees, even as employees experienced their personal losses.

Upon entering the in-patient unit, there was a table with numerous cards and letters from loved ones of former patients thanking United Hospice for the care provided to their loved ones. Sometimes treats were left in the hospice kitchen from a loved one of a deceased patient for the staff to eat. I personally observed this ritual when a woman brought cupcakes to the nurse's station one Sunday, thanking the nurses for taking wonderful care of her mother.

As with many families, fallouts and misunderstandings develop between people as a



result of the death of a loved one, and, for a time, people fall “out of the family.” Unfortunately, this feeling of being out of the family” affects an employee’s work life. During his interview, for instance, Jim talked about the nepotism that occurred in the organization:

[United Hospice is] a small operation and is run like a mom and pop small business.

There is a perception of nepotism; there's a lot of if you're on this list you're good, if you're not on this, and you know, just, there's a lot of stuff that's very, very frustrating, frankly.

Similarly, Alex described United Hospice as “one big dysfunctional family”:

It is a family, right, and so people do care about each other. People are all in each other's business all the time. There's no boundaries, no boundaries, and very little accountability ... So some things get harped on really hard and then other things just slide and slide and slide because those folks are in the in-crowd. A lot of stuff gets done. A lot of stuff gets done because there's this loyalty. Not everybody has it, right, and someone will get burned out because they don't feel very loved by the family.

In my observations, I noticed at times an air of defensiveness among employees at the hospice—for example, defensiveness about how a procedure was done or not done at intake, or defensiveness over how a decision was made or not made regarding patient placement. In her interview, Alex explained the possible reason for such behavior:

I think that our staff does try to do a good job, but when their actions are critiqued, they feel defensive. Instead of accepting the feedback as a constructive view of how a task could have been done differently, they hear “you're doing it wrong.” They do not want to change. This might make everybody's life easier; instead we defend our territory, our slice of the pie, our office space, our whatever, so we and our friends can be okay, but

we're not thinking about how we all might be happier if we could all come together and talk about things and work out better solutions. I think people are also afraid of failing.

I asked all of the study interviewees as well as some of the people I casually talked to at the site if they had ever been given a job description of their position. The answer was “No.” As a result, there was a level of internal misunderstanding as to what tasks were required, by whom, and what constitutes completeness of job responsibilities. Connor, Egan, Kwilosz, Larson, and Reese (2002) wrote about what could occur in such an environment:

A lack of understanding across disciplines can contribute to role competition, role confusion, and role definition, which can lead to friction within the team and isolation of members, and can impede interdisciplinary collaboration and the development of holistic plans of care. (p. 346)

### **The Clinician vs. the Non-Clinician**

During the initial interviews, most of the non-clinical hospice care professionals—social workers, chaplains, and the volunteer coordinator—felt that the opinion of the clinicians—the nurse, nurse practitioner, facility director (who was trained and had experience as a nurse) far outweighed that of the non-clinician. One social worker explained it this way:

There's a very clear focus on clinical knowledge. I don't think there's really a clear understanding of what a social worker and chaplain's education and background can prepare them for. We have the education and knowledge on certain techniques as to how to approach things, how to have counselling sessions, how to have family meetings, how to do all of that, that expertise can be taken for granted ... Because it is not clinical, it does not matter ... I guess the feeling is that anyone can provide support services or that

support services aren't needed by certain people ... It's disheartening that we [non-clinicians] don't have that voice.

While not excusable, this deference to the opinion of the clinician is understandable.

At United Hospice, individuals in administrative roles—the medical director (a physician), the hospice administrator (a nurse), and the facility director (a nurse)—are clinicians. Yet, not considering the knowledge and expertise of non-clinicians regarding patient care is antithetical to the philosophy of hospice care. The National Hospice and Palliative Care Organization (n.d.) articulates this philosophy as follows:

Hospice addresses the needs and opportunities during the last phase of life by including the individual and family, trained volunteers, caregivers and clinical professionals in the caregiving team. This interdisciplinary approach to care focuses on the individual's physical symptoms and the emotional and spiritual concerns of the patient and family.

### **The Medical Director**

As sole owner of the hospice, the medical director was a business owner, an employer, and a physician. Whether intentional or not, the medical director instilled fear in the hospice care professionals. In casual conversations, action research team members shared stories about dreading the days when IDT meeting occurred; colleagues would mentally psych each other up to prepare for the meetings because, simply put, the meetings could be “brutal.”

I had the opportunity to sit in on an IDT meeting. The purpose of the IDT meeting was to review the census of the hospice; as each patient was presented by the meeting facilitator, everyone at the meeting provided his or her professional input on the physical, mental, emotional, social, and spiritual state of the patient. In this particular meeting, the medical director was not expected to attend so the administrator began the meeting. (According to

protocol, if the medical director was unable to attend or start the meeting on time, meeting facilitation fell to the hospice administrator.) About an hour into the meeting, someone saw the medical director walking toward the conference room and whispered loudly, “Here comes Dr. X.” The stress and tension created when Dr. X. took her place at the conference room table was palpable—as if a five-star general entered a room full of enlisted personnel. The entire atmosphere changed.

### **Overall, Hospice Care Professionals Are Proud of the Organization and what It Represents**

When asked in the pre-intervention interview “What works well at United Hospice?” nearly everyone responded in a manner similar to the following, as recorded in my researcher notes:

What works well is that United is a hospice that gives a lot of unfunded patients the opportunity to die with dignity. We take on really difficult families that seem like the other hospices have found reasons not to take. One of the things that is different about United [from other hospices in the state] is that we try to meet the patient where they are and look at each individual case and provide what's needed.

While this hospice has experienced a number of organizational challenges and a great deal of turnover, its employees were dedicated to the patients, their families, and each other.

### **Action Research Team**

Table 8 identifies the action research team members, followed by a narrative description of each member. These introductory descriptions come directly from the interview data.

Table 8

*Action Research Team of United Hospice*

<b>Name</b>	<b>Role</b>	<b>Tenure with Organization</b>	<b>Affiliated with which United Hospice Division</b>	<b>Race/Gender</b>	<b>Age</b>
Joe	Chaplain	< 1 year	In-patient unit	White male	40-49
Frieda	Social Worker	1 year	In-patient unit	White female	20-29
Sophia	Volunteer Coordinator/Social Worker	1 year	Both In-patient unit and home health (as needed)	White female	20-29
Alex	Bereavement Coordinator / Chaplain	3 years	Both in-patient unit and home health	White female	30-39

**Joe**

Joe was chaplain of the in-patient division of United Hospice. During his studies in clinical pastoral education, Joe served as a chaplain-in-training at both a large general hospital in Atlanta, Georgia, and a smaller regional hospital in the northeast suburbs of Atlanta. Joe's position with United Hospice was his first as a chaplain. At the time of the interview, Joe had been with the organization less than one month.

**Frieda**

Frieda was a social worker in the United Hospice in-patient division. She had five years of experience as a social worker but none as a hospice social worker. At the time of the interview, Frieda had been with the organization for one year.

**Sophia**

Sophia was the volunteer coordinator/social worker at United Hospice, covering the in-patient and home health divisions. This was Sophia's first position working in a hospice. At the time of the interview, she had been with the organization for one year.

## **Alex**

Alex was the bereavement coordinator at United Hospice. She had bereavement coordinator responsibilities for both the in-patient and home health divisions. A chaplain by training, at the time of her interview, Alex had been with United Hospice for three years. This was her first position out of seminary.

### **Action Research Cycles and Planning Phases**

The study was positioned as an iterative, cyclical, action research approach with four steps: (1) study and plan, (2) take action, (3) collect and analyze evidence, and (4) reflect (Riel, 2010). The first cycle involved identifying a hospice site, gaining entry and permission to conduct a study onsite, recruiting study participants, and developing a set of team norms under which to operate.

Applying the constant comparative method, I used the data pertaining to what interviewees considered weaknesses with the United Hospice organization to generate the following findings:

1. There is a need for more structure within the organization.
2. There is a need for education among the hospice care professionals about their roles and responsibilities and about how each professional (e.g., social workers and chaplains) has been formally trained for his or her profession.
3. While hospice is a holistic approach to care for the terminally ill, it seems that at United Hospice the voice of the clinician is valued more than the non-clinician.

These findings were presented to the action research team in order for the members to determine (a) if they agreed with my findings and, if so, (b) which finding(s) they wanted to address, and (c) what type of intervention should be adopted to deal with the issues raised by the

findings. In addition to the three findings I presented, the team identified two more items that needed to be addressed within the hospice: (d) there is a lot of “anxiety” felt by the employees; and (e) some people believe they are unable to handle difficult situations.

### **The Intervention**

The action research team considered five interventions:

1. Begin implementing infrastructure within United Hospice in terms of job responsibilities, processes and procedures.
2. Each discipline of the United Hospice meets with the administrator to discuss “what the task is or is not” within that discipline’s responsibility as it relates to hospice care.
3. Every month, for two hours per session, members of the IDT cross-train with other members to gain an understanding of the tasks and responsibilities of that discipline.
4. Get everyone’s voice “heard at the IDT’s table.”
5. Have a psychiatrist/psychologist conduct seminar(s) with the hospice staff around dealing with anxiety and difficult situations.

Out of the five proposed interventions, the action research team felt most strongly about the first, (“Begin on implementing structure within United Hospice”) and the fourth (“Get everyone’s voice ‘heard at the IDT’s table.’”). However, identifying the means of achieving the first intervention was considered “overwhelming” due to the sheer amount of time it would take to gather the proper amount of data to develop, implement, and evaluate such an intervention. Therefore, after some discussion, it was decided that the fourth intervention was the most attainable by focusing on how the IDT meetings were conducted. Team members described

these meetings as “chaotic,” “disjointed,” and “a mess.” As a group, we decided to meet the second and fourth Thursdays of the month to work on the intervention.

This intervention was chosen to complement the focus of this study—understanding the informal learning of hospice care professionals—and to develop the action research teams’ capacity to continue the action research process on its own by enhancing members’:

- perceived ability to complete at least one full action research problem-solving cycle, with me as researcher being available to guide the process;
- belief that the intervention should be straight-forward, offering the team knowledge and experience to take on the more complex interventions; and,
- desire to implement an intervention that would provide a sense of accomplishment.

Though the action research team felt motivated to take on this work, after consulting with my committee, we concluded that this intervention did not focus sufficiently on the research purpose—learning how informal learning within the context of emotion work and death and dying supported staff. While the action research team and I worked on an intervention to bring structure to the IDT meetings, I continued working on the narratives, identifying the informal learning that occurred within the context of emotion work.

### **Action Research Cycle One: Planning the Study**

Table 9 shows the timeline for action research cycle one.



Table 9

*Action Research Cycle One: Planning the Study*

Stage	Date	Activities
Study and Plan	October 2014	<ul style="list-style-type: none"> <li>• Identified a hospice</li> <li>• Met with facility director at United Hospice to propose study and introduce the benefits to the hospice</li> <li>• Presented study to interdisciplinary department team and received permission to conduct study</li> <li>• Submitted proposal to University of Georgia (UGA) Institution Review Board (IRB) for approval to begin study</li> </ul>
<i>Entry as a participant observer</i>		
Take Action	January 2015	<ul style="list-style-type: none"> <li>• Study approved by UGA IRB</li> </ul>
	April 2015	<ul style="list-style-type: none"> <li>• Held kick-off meeting at United Hospice; recruited study participants</li> <li>• Interviewed 12 United Hospice care professionals (these participants included the four action research team members)</li> <li>• Conducted action research team meetings</li> </ul>
Collect and Analyze Evidence	July 2015	<ul style="list-style-type: none"> <li>• Recorded interviews were transcribed, converted into narratives, and analyzed using constant comparative analysis</li> <li>• Presented program evaluation data</li> </ul>
Reflect	August 2015	<ul style="list-style-type: none"> <li>• Identified team norms</li> </ul>

**Study and Plan**

I gained entrance into the system by calling the hospice and asking to speak with its administrator. Because the administrator was not available, the facility director took the call. After a brief discussion over the phone, the facility director invited me to meet with her. We agreed to a date and time approximately one week later.

At the meeting, I explained the purpose of my research, gave a brief overview of action research, and explained how it could be a “win-win” for both United Hospice and myself. The facility director was excited about the study and invited me to present my proposal at the weekly IDT meeting, since interdisciplinary collaboration is central to the palliative care philosophy, as

identified by the founder of the modern hospice movement, Cecily Saunders (Oliver, Tatum, Kapp, & Wallace, 2010).

Once the facility director introduced me to the IDT meeting participants and described the purpose of my attendance, I was given 10 minutes to propose my study. Nearly everyone was interested in discovering how they learn informally. One nurse in particular was concerned my study would create more work, as they already carried “a heavy load and really don’t have time to answer questions.” The hospice administrator responded that participation would not be mandatory. I concluded my presentation thanking the meeting attendees for their time and explained that before I could proceed with the study, I was required to obtain permission from the University of Georgia’s Institutional Review Board (IRB).

### **Take Action**

In January 2015, the IRB approved the study, and soon after the study at the hospice started with a two-hour kick off meeting. In addition to the familiar faces from the October meeting, there were new faces, including the bereavement coordinator (who was on maternity leave the previous fall), a recently hired nurse practitioner, and a newly hired chaplain. Also invited to the kick-off meeting by the administrator were members of the home health team: two social workers and a case manager.

The administrator invited hospice care professionals from both the in-patient and home health divisions of the hospice to participate in the study’s kick-off presentation. Just before I began the meeting, I handed out a detailed agenda. I started the meeting by introducing myself and my purpose in focusing on United Hospice. I explained the study and the questions the study would explore about informal learning within the context of emotion work and death and dying. I provided handouts as I spoke briefly about the action research process, the proposed

study timeline, and the empirical literature review that underpinned the study. I covered the expectations required of participation and answered any questions or concerns. Once the consent forms were signed and returned, study participants were requested to select two one-hour slots in which they would be available to be interviewed.

In total, 11 individuals signed up to participate in the study. Not all of the invited hospice care professionals decided to take part in the study; consequently, the study was missing a nursing perspective. However, the administrator recruited an individual from the nursing staff to provide that perspective, bringing the total of study participants to twelve.

Not long after my interview with the director of support services, the hospice fired him. Soon after, one of the social workers from home health left the organization as well. I found out about the director and the social worker in a conversation with the social worker for the in-patient division, whom I originally believed had declined participation in the study. I took the opportunity to ask the social worker why she chose not to participate. She told me that when she asked the facility director about participation, she was told that the participants of the study would be managers and individuals who had years of hospice experience; since the social worker was new to the hospice (at the time she had been employed by United Hospice for less than a year), she would be “unable to participate.” As the social worker observed the action research team forming, she found it odd that the newly hired chaplain was on the team, considering this was his first job in a hospice, but she said nothing. I asked the social worker if she was still interested in participating; she said she was, and soon after I interviewed her. This interview with the social worker provided me with a deeper understanding of additional issues within the hospice, since she was very forthright in her opinions about what worked well and what could be challenging working at United Hospice.

## **Tuckman's Stages of Group Development**

While the action research team did experience the stages of Tuckman's (1965) development sequence of forming, storming, norming, and performing in small groups, our sequence did not develop in that order. Ours began with norming.

**Norming.** After sitting in a few of the meetings facilitated by hospice staff and identifying a clear need for norms, I asked the action research team members if they would be interested in developing some group norms around how the team should operate. Group norms, as Cialdini and Trost (1998) explained, are guidelines for acceptable and unacceptable behavior that develop and are informally agreed upon through interactions among group members. All team members agreed that this would be a wonderful idea. The hope was that once the team established a set of norms, those norms would be adopted by the interdisciplinary team as well. As a group, we developed a set of norms, decided on the frequency of our meetings, and developed a process for conducting the meetings. The team also agreed that the norms of the group would be revisited quarterly to determine if revisions were needed.

**Storming.** After the meetings began, I noticed that when the administrator was present, the other members exhibited deference toward any statement she made. At one of the meetings, the administrator offered to recuse herself from the meetings, stating that her presence would not allow others to speak as freely as they may like; however, I asked her to consider staying because her input was vital to the success of whatever the action research team decided to implement. Although she agreed, the administrator never attended another meeting. Later, during our closing conversation, I asked the administrator why she did not attend any more of the action research meetings. Her response: "I knew they would be afraid to talk around me; you wouldn't have an authentic study."

Soon after the administrator stopped attending the meetings, the facility director and the nurse practitioner followed suit. In the second meeting, the facility director received a phone call and left, never to return to the meeting, and while the nurse practitioner came to the second meeting, providing a great deal of input, she did not attend subsequent meetings. It seemed as if the team was falling apart.

I drafted separate emails to the administrator, the facility director, and the nurse practitioner explaining the planned activity for the next meeting and sharing the group's disappointment with their absence. None of the recipients responded to the letter. A copy of this letter is shown in Figure 16. Not long after sending the emails, I learned that the nurse practitioner had submitted her resignation.



Figure 16. Copy of email communication sent to hospice leaders.

While the remaining members of the team decided to move forward in reorganizing the IDT meetings and developing the monthly support staff meeting interventions, we all expressed doubt as to whether we would be successful. We felt that no matter how much time we put into the development of these interventions, unless the administrator approved it, the intervention would not move forward.

**Forming.** The action research team members and I experienced what Marshak (2006) described as “implicit core beliefs, values, and assumptions that keep us the way we are”—for example, “There’s nothing we can do until the people upstairs take action” (p. 110). Alex

realized and pointed out to all of us that this was exactly what was happening, and as a team we made the conscious decision to move forward.

**Performing.** The action research team members continued to learn about biases they brought into personal and professional situations that could impede organizational change (Marshak, 2006). Marshak (2006) asserted that “actions based on one’s own interests are deemed to be political and being political is considered inappropriate behavior in most organizations. However, in reality, people and work groups do consider their own needs and interest when they respond to organizational change initiatives” (p. 25). Historically, emotions have been viewed as the enemy of reason and are to be overcome or suppressed. Although emotions and feelings are an integral part of human life, they are considered anathema in the workplace. Consequently, feelings and emotions related to a change effort tend to be hidden or are expressed only in covert ways (Marshak, 2006). Therefore, the action research team needed to acknowledge and neutralize the overt processes and mindsets that threatened to undermine its organizational change efforts.

### **Collect and Analyze Evidence**

The interviews were recorded with a digital audio recorder and transcribed using the transcription service Rev.com.

**Evaluation data findings.** A formative evaluation was conducted to examine the environment of United Hospice. Formative evaluations are used to examine established programs and assist in their continuous improvement (Patton, 2009). I asked participants to “Tell me about United Hospice as a facility. What works well, and what can be a challenge?”

Regarding United Hospice's strengths, all of the participants interviewed indicated they were proud that, as an organization, the hospice cared for the patient and the patient's loved ones:

- "United tries to meet the patient where they are and look at each individual case and provide what's needed"
- "What works well is that United Hospice is a hospice that gives a lot of unfunded patients the opportunity to die with dignity—because we get a lot of referrals from Central [Hospital] and a lot of them don't have insurance."

Another identified strength of the hospice related to the administration's encouragement of staff to practice self-care. For instance, employees were given 26 days of paid vacation each year. One interviewee shared an instance in which "someone was out and ran out of [personal time off], and they were allowed to go into the negative and build his or her time up."

While everyone interviewed signaled that they were proud of the organization and its reputation of "giv[ing] a lot of unfunded patients the ability die with dignity," some felt that the organization's practice of accepting anyone desiring hospice care was a downfall: "because they take on so many people so far out, so that poses—well, in the home health area—a service delivery challenge. It just poses a problem because they're rushing. They're rushing, and they feel bad doing it."

Another element of United Hospice the interviewees regarded as both a strength and weakness was the organization's comradery and the sense of family among the employees. Some people liked the feeling of belonging that the hospice provided:



I feel like we have a lot of comradery where we can. If there is a challenge with a patient or a personal challenge or even challenges among staff members, we're able to go to somebody. We know who we can go to in confidence and get that third-party opinion. Others, however, felt that the family environment had no place in a hospice.

Another often repeated weakness of the hospice was its lack of infrastructure. Such phrases as “lack of structure,” “no clear defined roles,” and “no clear defined rules” were heard frequently in the interviews. The lack of clear roles with the organization seemed to affect the social support staff.

### **Action Research Cycle Two: Implementation of Two Interventions**

In September 2015, the action research team continued (1) identifying our group norms and (2) addressing the hidden dimensions of organizational change within United Hospice. I shared with the team that while our objective to revise how IDT meetings were conducted was a valuable intervention, it was not sufficient to meet the research purpose of exploring informal learning of hospice care professionals within the context of death and dying, and emotion work. As a result, we needed to come up with another intervention. However, as a team, we could not, at that moment, think of another intervention, but we kept the notion in the back of our collective minds while we continued meeting. Between mid-November 2015 and December 2015, meetings dropped off due to holiday vacations of team members. The team met consistently again beginning in January 2016. At the January meeting, I presented an analysis of the critical incident interviews (see Table 10).

Table 10

*Action Research Cycle Two: Implementation of Two Interventions*

Stage	Date	Activities
Study and Plan	<i>Intervention A:</i> September 2015	<ul style="list-style-type: none"> <li>Continued identifying the norms of a working team</li> <li>Discussed the current process of IDT meetings</li> <li>Developed a revised process of conducting IDT meetings</li> <li>Received permission from the medical director to test a revised way of conducting IDT meetings</li> </ul>
	<i>Intervention B:</i> September 2015-January 2016	<ul style="list-style-type: none"> <li>Shared the news that our current intervention did not align with the goal of the research study and we need to come up with another intervention</li> </ul>
Take Action	<i>Intervention A:</i> January 2016	<ul style="list-style-type: none"> <li>Identified what “success” looks like</li> <li>Communicated with IDT members regarding 3-week trial run of revised process</li> <li>Conducted the revised IDT protocol for 3 consecutive interdisciplinary department team meetings</li> </ul>
	<i>Intervention B:</i> January 2016-March 2016	<ul style="list-style-type: none"> <li>Decided on an intervention</li> <li>Received permission from the medical director to begin facilitating hospice-wide support staff meetings</li> <li>Developed the support staff meeting agenda</li> <li>Contacted home health support staff to get buy in for the hospice-wide support staff meetings</li> <li>Began support services meeting</li> <li>Identified what “success” looks like</li> </ul>
Collect and Analyze Evidence	<i>Intervention A:</i> February 2016	<ul style="list-style-type: none"> <li>Discussed feedback received from hospice administration</li> <li>Discussed action research team feedback</li> </ul>
	<i>Intervention B:</i> April 2016	<ul style="list-style-type: none"> <li>Discussed feedback received from support staff meeting participants</li> </ul>
Reflect	<i>Intervention A:</i> March 2016	<ul style="list-style-type: none"> <li>What happened: How did we fall apart as a team?</li> <li>Based upon what happened, what intervention should we work on next?</li> </ul>
	<i>Intervention B:</i> May 2016-July 2016	<ul style="list-style-type: none"> <li>How can we make support staff meetings better/more effective?</li> </ul>

At the January meeting, I presented to the team how an informal learning approach was triggered when certain emotions were experienced by an individual. The participants expressed considerably more interest in discussing the triggering emotions than the informal learning approaches applied as a result of the emotions. I argue that, due to the emotionally charged nature of hospice work, the hospice care professionals in this study had not taken the time to reflect upon the emotions they experienced while fulfilling their respective duties. For example, as a first time chaplain not yet comfortable in his role, Joe said, “I’m still trying to figure out how to practice pastoral care in this context. I really haven’t developed a strong ‘[hospice] repertoire,’ if you will, yet.” Also, being White, Joe was often anxious about whether non-White families would positively receive him as a messenger of comfort (“I wondered how people would receive me and if they would receive me, if my pastoral care would be seen as authentic and as spiritually present or just seen as kind of another White do-gooder”). Although Joe was aware of the anxiety he felt as a new chaplain who happened to be White, he never thought long enough about it to consider the anxiety a legitimate “fear.”

Days after the September meeting, Alex contacted me with an idea for an intervention. She wrote:

This is for all the chaplains and social work team members. We’ll do case presentations (probably one person presenting a case per meeting) and get feedback from our peers. I think this is going to help our support staff become better practitioners, and help us become better able to articulate what we learn over time through these critical incidents. Alex later explained to the action research team that this sharing among a single discipline of professionals was what she had experienced during her training as a chaplain in her clinical pastoral education (CPE) curriculum. Alex indicated that this exercise, known as a *verbatim*,

“helps analyze significant events that happen in ministry, which was found to be difficult but very helpful.” Silberman (2011) defined a verbatim as:

the primary tool that we use in CPE. In effect, it is a written reconstruction of a conversation that you have with a patient, family member or staff person. You try to incorporate all that was happening including what was said, what you were feeling, noting the pauses in the dialogue, the interruptions and so on. This is then presented either to your Supervisor or your peer group. In recalling the visit and the dynamics of the group, we look at what may have been factors that made the visit go well and those factors that interfered with the visit. This is a primary component of the reflection part of the action-reflection-action learning model. (p. 6)

The verbatim reveals much about the state of the patient, emotionally and spiritually, as well as the CPE student. It is an effective arena for strengthening one’s faith and for acknowledging and discarding unnecessary personal baggage (Knudsen, 2010). Alex and I both saw the benefit to incorporating verbatims into the team’s monthly support staff meetings. We theorized that verbatims would help the hospice support staff become better why do we need to know more and have more studies on informal learning in this context? , allowing them to better articulate what they learned informally over time through these critical incidents.

This combined support group of social workers and chaplains from both divisions made sense for two reasons: (1) organizationally, within the hospice, both the social workers and chaplains were grouped together under “support services,” and (2) in addition to their professional role, hospice chaplains were valued by other IDT members for comfort and aid they offered to team members who experienced team conflict and work-related stress. During her

interview, Alex mentioned “having to provide support to her coworkers who come to her when experiencing team conflict and work related stress.” Like Alex, other chaplains also reported providing day-to-day support for interdisciplinary team members, an informal role added to their list of professional responsibilities (Wittenberg-Lyles, Oliver, Demiris, Baldwin, & Regehr, 2008).

While social workers often play a central role in counseling, case management, and advocacy services for the dying (Christ & Sormanti, 2000), the limited current research and literature on end-of-life care within social work suggests that health care social workers are not as prepared as they need or would like to be in working with end-of-life care issues in their practice (Csikai & Raymer, 2005; Suzanne, personal communication, April 22, 2015). In the small learning community of this study, both the social workers and the chaplains could potentially learn from each other.

The verbatim (which in our meetings we called a “case study presentation”) was part of the monthly support staff meeting. Before, the only time support staff met was when the administrator called a meeting to announce and discuss new regulatory procedures or when “the staff needs to be ‘called on the carpet’ for something” (Alex, personal communication, January 25, 2016).

The week before we began the trial, Alex sent me an email stating, “When I informed the folks [on the] interdisciplinary team about our plans for next week, there was skepticism and curiosity.” Alex described the scene at the IDT meeting: the medical director said she “didn’t really understand” what we meant by revamping the IDT meeting process, so an outline of the plan was shown to her. The administrator seemed a “little thrown off by the formatting” and

seemed to think we were not keeping all the topics from a single discipline together, so the team organized the plan by discipline. Figure 17 depicts the revised format.

**Hospice**  
**Interdisciplinary Department Team (IDT) Meeting Agenda**

1. Reflection (Chaplain) : *The Reflection will be followed by 30-45 seconds of silence to prepare the group for the discussion at hand.*
2. Bereavement Report (Bereavement Coordinator): **a) who died b) family dynamics c) risk level.**
3. Patients Presented (*in the following order, beginning with newest patient*)
  - Nursing**
    - a) Name
    - b) Demographics
    - c) Admit date
    - d) Diagnosis
    - e) Karnofsky score
    - f) Symptoms managed (w/ meds discussion)
    - g) GIP Reason/ need for placement (flows into SW)
  - Social Worker**
    - h) Logistics
    - i) Funeral planning
    - j) Coping (emotional)
  - Chaplain**
    - k) Coping (spiritual)
  - Group**
    - l) Additional resources needed
4. New Referrals

**Hospice Steering Team | 01.06.16, edited 2.2.16**

Figure 17. Revised interdisciplinary department team meeting agenda.

On January 8, 2016, Alex sent out an email to the IDT informing participants about our trial of the new IDT meeting agenda. The email message identified the person (i.e., the

administrator) who chose the individuals making up the team, the name we gave ourselves, what we had been doing over the previous four months, and what we hoped to accomplish. The email also identified why we chose to work on the IDT meetings and highlighted a benefit of adopting this process. This communication followed Gesme and Wiseman's (2010) recommendation around communicating a change within in a healthcare practice. Recipients of the email were asked to give the process three weeks, and at the beginning of the IDT meeting on the fourth week, the team would seek IDT attendees' opinions about what worked and what did not work regarding the new approach. Attached to the email was a copy of the revised IDT meeting format. A copy of the email sent to IDT participants is shown in Figure 18.

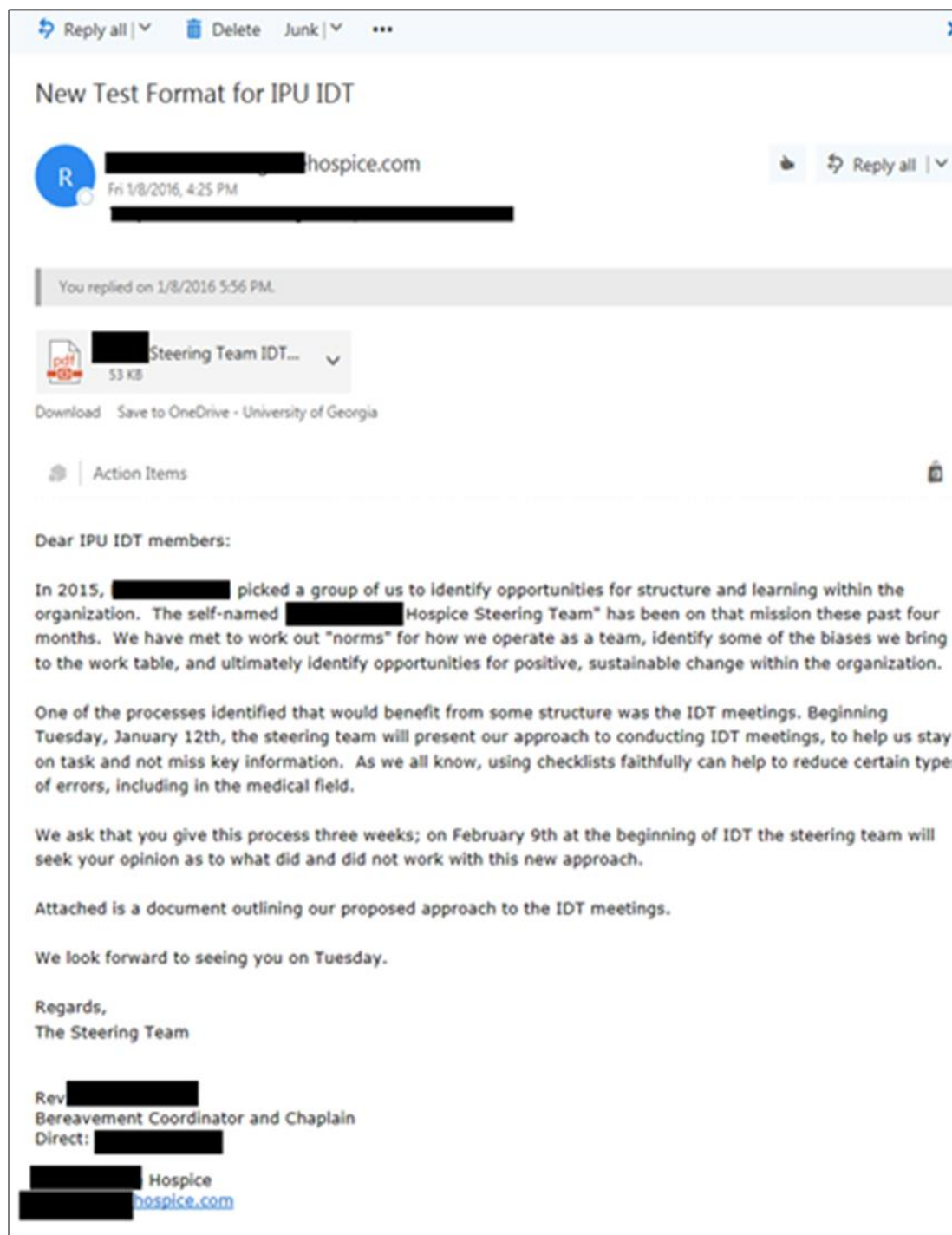


Figure 18. Letter notifying interdisciplinary department team meeting members of three-week trial.



## Take Action

In this phase of the action research cycle, for Intervention A, the revamp of how the IDT meetings are conducted, the action research team identified what success would “look like”: communication with IDT members, with the intention of conducting a three-week trial of a revised IDT process. Regarding Intervention B, the action research team began its first hospice-wide support services meeting, and, similarly, we identified how success would be determined.

**Intervention A: IDT meetings.** With the IDT meetings undergoing a new method of operating, I realized that the action research team had not identified what we defined as “intervention success.” Reaching consensus on such a definition of intervention achievement was very easy, but, by this point, the administrator and the facility director stopped coming to the action research meetings, and the nurse practitioner had left the organization. The only professionals still actively participating in the meeting were all the members of the support staff—those individuals who felt that their voice was not being “heard at the table.” For Intervention A, implementing a more organized process around IDT meetings, we identified success as “all disciplines [are] involved in the meeting; each discipline [is] given a chance to speak even if all that needs to be said regarding a patient is ‘no changes.’”

***Intervention A: Three-week trial run.*** In the three trial IDT meetings, the meeting matched the agenda only about 50% of the time.

*Meeting #1: January 12, 2016.* The first IDT meeting under the revamped agenda went well, until the medical director’s late arrival. When I made an attempt to hand the medical director an outline of the new process, she refused, saying, “I’ve already read it.” Moreover, the medical director chose not to follow our agreed upon plan, and the remainder of the meeting was conducted as determined by the medical director alone. However, the next week while in the

hospice kitchen, a nurse who was present at the IDT (in place of the usual charge nurse) said to me that she liked the new process: “[It] makes the meetings calmer.”

*Meeting #2: January 19, 2016.* During this meeting, the agenda not followed at all. Upon my follow-up with Alex, I was told, “We started late, it was a bad day on the floor.”

*Meeting #2 (Redo): January 26, 2016.* The new meeting procedure was followed, and the action research team members indicated afterward that the meeting “went well” overall. After the meeting, the medical director told Alex that she “liked” the new method conducting the IDT meeting and indicated that, with some modifications, she wanted to adopt it. Her minor modifications were made and the new agenda was in place.

In these monthly staff support meetings, Alex served as facilitator. She also drafted the agenda, mainly because she had experience participating in verbatims and because, as the most senior in-patient staff support member, she had a vision of how an agenda for the meeting should look. I recommended that Alex present first because she had the verbatim experience from the CPE class and would be able to model the example for everyone else to follow. In addition to the case study presentation, other topics related to United Hospice operations, activities, and events (e.g., regulatory procedures, planning the bi-annual memorial service, communication issues, hospice processes) were open for discussion. Once the case study was presented and discussed, I asked the presenters to reflect on what was learned while working on the case and in preparing it for presentation.

The March 2016 presenter presented the case, and the attendees offered their experience and/or thoughts regarding the approach taken and suggested other ways to view the situation presented. Before the end of the meeting, a support person either volunteered or was asked to be the case study presenter at the next meeting, which was to take place in its current form for three

sessions; at the fourth meeting participants in both the IDT and staff support meeting would be asked for their feedback on what worked well and what did not.

*Meeting #3: February 2, 2016.* The agenda for this meeting was not followed at all, and the medical director was not present at the meeting. Because the meeting did not follow the proposed format (no action research team member who attended that meeting could tell me why), the team decided to extend the trial to February 9.

At that time, according to the action research team, what was working successfully with the intervention included the following: (1) the medical director had approved the agenda with slight modifications, and (2) now that the agenda had been distributed, input was being requested from other disciplines about their viewpoints (e.g., as one viewed the agenda and read “spiritual coping,” individuals now thought to seek a chaplain’s perspective on a patient). Before the implementation of the new printed agenda, other disciplines were not considered.

What was not working successfully centered on scenarios when one discipline had the floor to provide their assessment (e.g., nursing) and someone from another discipline wanted to interject something; oftentimes, that discipline was told to “wait their turn.” The action research team members agreed that this was not how the agenda should be interpreted and indicated their intention to explain how it should be interpreted during the feedback session.

I attended the first meeting trial (January 12) and the last meeting trial (February 9). It appeared that the group forgot I was supposed to capture feedback on the revised process at the beginning of the IDT, so I waited my turn. I observed then that the revised agenda was not being used. The conversational process that the revised agenda was developed to eliminate continued.

Toward the end of the meeting, I asked the meeting attendees, “What did you think of the agenda? What worked/what did not work? Would you like to see any changes?”

Clarification was requested from the administrator on how the meeting should progress according to the new agenda. I explained that whoever facilitated the meeting would move down the itinerary by discipline; in turn, each discipline would be given an opportunity to speak.

The medical director stated that the revised agenda was what she “has been doing for over 20 years, and wondered why the group [i.e., the action research team] came up with such an agenda.” The medical director proceeded to ask me if the meeting followed the process that was developed. I responded, “No, it seems the process switches to another patient midway through the agenda.” I pointed out that once the K-scale reading was identified for the patient, the focus switched to the next patient. (K-scale refers to the Karnofsky performance status scale, an assessment tool for functional impairment. The lower the Karnofsky score, the lower the likelihood of survival [Christensen, 2014].) The medical director responded, “If there are no changes with a patient, there is no need for redundancy regarding the patient from week-to-week. If someone has something to say, that person needs to jump in with his or her information.”

At this point, the administrator jumped into the conversation to state that a new process and agenda had been developed because there was a feeling that “not all voices were being heard at the [IDT] table.” Both the medical director and administrator had emphasized that it was important for everyone’s voice to be heard; however, it was up to individuals to make their voice heard.

The medical director asked the two staff support members in attendance if the revised agenda made a difference. Frieda responded, “Yes I have seen people, when realizing other disciplines have yet to speak, be asked their professional opinion on that patient.” Joe responded, “When I have something to say, I will just jump in.”

The medical director noted that everyone sat in the same place every meeting. She

suggested that to get everyone included, instead of sitting in the same seat every meeting, participants should perhaps sit in different seats. At the end of the meeting, the medical director stated that the IDT “did not need a piece of paper to let everyone know how the meeting should proceed.”

**Intervention B: Support staff meetings.** Alex contacted the home health support staff to get their buy-in on this new intervention. Sam, the chaplain, Suzanne, the social worker (whom I was unable to contact for a while) and Carla, a newly hired social worker, thought the monthly support meetings were a great idea. Sam voiced some concern to Alex about my position as an outsider and how my study might supersede the purpose of the support staff meeting. (Alex relayed that concern to me.) The third home health social worker declined to participate formally, but she did attend the meetings from time to time. Between the home health and in-patient support staff, everyone agreed that the third Tuesday of the month at 1 p.m. in the in-patient facility was a convenient time and place to meet.

Our first meeting was held on February 9, 2016. Sam, Suzanne, and Carla from home health and Alex, Joe, Frieda, and Sophia from the in-patient division were in attendance. I was pleasantly surprised to see Suzanne at the meeting, as I had been unable to reach her since the initial interview.

**Meeting #1: February 9, 2016.** The support staff meeting opened, according to the agenda items, with regulatory announcements, learning opportunities, and a discussion of any communication issues. Alex presented the first case study to the group. All members were engaged. I noticed that learning was shared almost immediately. One example of immediate informal learning was a conversation centering on discussing death with people (i.e., the dying, their loved ones, or both) who are in denial about death (coming sooner than later). Sam shared

how he often used a book metaphor to describe someone's life, asking the person how they would write this (final) chapter of "their book." (The implication was that every book has a beginning and an end, and every book has a final chapter—as does life.) Everyone in the room had a "lightbulb moment" of understanding, of how easily a metaphor that everyone knows about can be used to engage with issues that can be so difficult to approach.

***Meeting #2: March 15, 2015.*** This meeting was one of the most emotionally wrought situations I observed during my time at United Hospice. Suzanne did not prepare the case presentation as a hardcopy to hand out; rather, she presented it orally. The case presented was a difficult and traumatic one involving suicide while the patient was on service with the hospice. At the time of the incident, Suzanne was a seasoned social worker but new to United Hospice and hospice generally. Suzanne explained that she was on "great terms" with her patients, especially this particular patient who had been diagnosed with chronic obstructive pulmonary disease (COPD) and was receiving home health hospice care. One day, not long after the social worker left the home of this patient, she received a call from a family member concerned that the patient had locked himself in his room threatening to kill himself. She immediately turned her vehicle around to return to the home but was too late; the patient had committed suicide by shooting himself in the head with a .45 caliber gun. Suzanne said:

He was one of my favorite patients. He's been on services for forever. Complete cognitive person. Great personality. Nice guy. He just had COPD, he couldn't breathe. He just had hard time breathing. He was a hostage in the house for a year, but just because he couldn't breathe, he couldn't move around, he was depressed, miserable.

The trauma for Suzanne occurred both in discovering that the patient had killed himself and in taking responsibility for cleaning the room (for the family member) in which the suicide

occurred. (Once the authorities arrive to remove the deceased, make notes, take pictures, etc., the cleanup becomes the responsibility of whoever owns the property).

Suzanne called the hospice, and immediately Jim and Sam came to the home with cleaning supplies. The three of them worked until early the next morning cleaning that room so the patient's family member would not have to be reminded visually of what occurred. Once the presentation was over, Suzanne thanked Sam and told everyone in attendance how she appreciated Sam being "stalwart the entire time" because she was "a wreck." Suzanne's question at the end of the presentation was simply: "Why didn't anyone HELP, me?" This type of incident was a first for the hospice, after which, according to Suzanne, everyone went on with "business as usual." There was no follow-up, no recap, no meeting to ask if she needed help. That is, while various individuals (mainly Sam) did pull her aside afterward to ask if she was okay, there was no "organization response or follow up" to the incident. As I looked around the room, there were tears in many of the attendees' eyes and sad faces all around. Carla, who was new to the organization, said that it was the first time she had heard of a suicide at United Hospice. The other attendees in the room who were in-patient support staff said that, although they had heard of the incident when it occurred, they had never heard the entire story, nor had they heard the name of the individual involved. People were apologizing to Suzanne, telling her they "had no idea that she had such a horrible experience"; another individual said, "I wish I were there to support you, but I didn't know."

As a result of this case presentation, two new policies were drafted: (1) If a support service staff member, a focused support services meeting will be called within 24 hours of the traumatic event, and (2) if a United Hospice staff member experiences trauma, a care plan will be

created for them, and the bereavement coordinator will check in and find how that staff member is doing in all of the following meetings for a year.

Suzanne apologized to me for “bringing so much emotion to the meeting.” I responded that “there was no need to apologize as your story needed to be heard. Thank you for trusting the group and opening up.” I went on to say that it was important that the individuals in the room felt secure enough to say what they were feeling and felt supported while expressing that feeling.

This was my second time hearing this story; the first time was during the initial interview. When I heard the story the first time, I asked Suzanne, “What did you learn from the incident?” Suzanne responded:

I realized that [I experienced] growth. Had that been when I first started, I probably would've went, "I quit. I can't do it." In that process, I knew that I had grown in hospice social work in particular. I had been through it. I was able to process it and still go on. It was the first [suicide] that the organization had ever experienced. Nobody had ever done that on services. Everybody was shocked. Nobody knew what to do because it never happened before. It was one of those learning processes for the entire organization. Personally, that's something I do now personally for my assessments. For every patient. When I go and visit with them, I ask, "Are you feeling suicidal? Are there any weapons in the home? Do you have a plan? Do you not have a plan?"

***Meeting #3: April 12, 2016.*** This meeting was different because the attendees never got to the case study presentation. We stopped at the “open discussion” item on the agenda. Frieda was really struggling with the medical director’s treatment of her—treatment that she felt could be “savage” and “without warrant.” This statement from Frieda prompted Sam to share a story from his first few years with United Hospice. Sam said the during the first few months, things



were relatively “easy”; though he was working 50- to 60-hour weeks and driving all over the coverage area, he was handling it. (At the time, the hospice only offered home health care, and Sam was the only chaplain.) According to Sam, all of a sudden the grace period was over, and he started getting “slammed” at IDT meetings. He considered these meetings “the worst” because he felt he was never prepared; he kept on getting “zinged” on questions for which he had not prepared. After a while, he started paying attention to all the categories and questions being asked. On the day of the meetings, he would get up at 3 a.m., create a spreadsheet on his computer, containing all of the questions he had jotted down in previous meetings, and then fill in the answers for all of his patients. Sam said “it took a lot out of me, but I felt better going into the team meetings.” He went on to say that this must have been the reason Tasha quit the job because just before she left, “she was getting hit pretty hard in [team meetings].”

This shared insight and experience resonated significantly with a few in the room. I observed three individuals (Frieda, who first initiated the discussion, and two others) reflect silently upon what Sam shared. The two others then confirmed Sam’s experience, stating, “It was just like that when I started.” The informal learning of the shared experience was powerful. Sam, when he first experienced the “grace period, followed by the pressure,” did not think enough of the experience to share it with Alex, who became employed by United Hospice three years later. Alex had a similar experience but also did not think enough of it to share that experience with Sophia, Frieda, and Joe when they all came onboard to the in-patient division. Sophia experienced it but never approached anyone to ask them about what she perceived to be happening. This support staff meeting not only gave Frieda the space to express her concern about what she was experiencing but allowed Sam to share similar encounters and how he dealt with them. Joe, Carla, and Suzanne had yet to experience this pressure. Nevertheless, the shared

insight of how the medical director operated by first giving a new employee a “grace period, followed by the pressure” provided the newer employees with an indicator of what would probably happen in the future.

**Meeting #4: May 10, 2016.** I could see camaraderie developing among the home health and in-patient support staff, as well as a growing awareness that a single role (e.g., social worker) often performs different tasks depending on whether the social worker is in the field (home health) or in the in-patient division.

### **Collect and Analyze Evidence**

**Intervention A.** Because the medical director had effectively vetoed the revised IDT agenda, the action research team convened to determine what intervention to examine next. Unfortunately, the action research team was deflated by the outcomes of the IDT meeting. The lack of administrative support regarding Intervention A had the team wondering if there was even “a point” in attempting another intervention.

Something else occurred during that IDT meeting: The team fell apart. Alex was absent from the meeting due to a family emergency, and Sophia was absent because she was covering for another employee, leaving Frieda and Joe to represent the support staff team and our project, and they were not as passionate as I had expected them to be.

The next day, Alex, Sophia, Joe, and Frieda met to talk about what happened at the IDT meeting. Alex, in our closing conversation, told me about the meeting between the four of them:

I think there were certain ways in which we fell in trying to present [the revised format for an IDT meeting] and carry it out because nobody spoke up for it at the beginning. It felt like only me, so I had a talk with them about it. They said that they agreed ... I hated that Joe felt as though ... you know he was starting to apologize, "I should have said

more." [Alex replied to Joe,] "No, what happened?" I was of the opinion that Joe just kind of went along to get along.

Because there had never been a clear delineation of roles at United Hospice, the group thought we should begin a dialogue among nurses and support staff regarding tasks and expectations between the two roles. Sophia volunteered to approach the administrator about this project and report back at the next meeting.

Alex stated that after the follow-up IDT meeting, perhaps she should have followed up with the medical director regarding our proposed reorganization of the IDT meeting agenda. Alex volunteered to approach the medical director about this intervention and to report back at the next meeting.

On March 31, 2016, I received an email from Sophia on behalf of the entire action research team; the members were "tired and disheartened" by the IDT meeting events, and they just wanted to "hang out with me as a friend, eat lunch with them and come to support staff meeting!" I understood as I was disheartened as well by the change of support for Intervention A.

**Intervention B.** I did not seek feedback on Meeting #4 as scheduled, and I missed the June 14, 2016, meeting due to a work conflict. At the July 12, 2016, meeting, I was able to obtain feedback on what worked and what did not work regarding this intervention. Sam was the first to respond:

Personalities are "jelling" because of the people involved. It is not because we are meeting regularly; it's not because of the meeting but the people at the meeting. Let me tell you, we've come a long way. We are learning to be vulnerable, being open, and trusting. It is not because of this meeting; it is because of the people in this meeting that I

got to know and began to feel like that they understood me, trust me, and work well with me. I like this meeting. I am not sure it is what it is going to be yet; there is an evolution going on.

Frieda shared her perspective:

Before we started meeting on a regular basis, there was not much camaraderie as a support staff ... this is actually quite validating. From a clinical standpoint, a hospital or hospice does not really understand what we do—the “behind the scene” stuff is not obvious to others. This space gives us validity.

The last support staff person to share her feelings about the meeting was Suzanne:

Sometimes working in home health, you don't get to see a lot of people here [i.e., other hospice employees] so you feel kind of separated. This is nice because it bridges the gap and [helps us know] what each other is doing and what you can do to help each other out.

According to the support staff team, what worked regarding this intervention was that a sense of comradery grew among the support staff, with learning occurring between same disciplines (e.g. social work) and the different tasks required between in-patient and home health divisions. Overall, I received positive feedback on this intervention, and it was clear that informal learning occurred in the group. The case studies provided individuals with other perspectives about how to approach situations (e.g., Sam describing end-of-life as a final chapter of a book) and offered a “sanity check” when it was discovered that a case study presented by one support staff member was handled in a manner similar to another staff member.

The one challenge that arose in the meeting related to time management. Alex was receiving feedback that the two hours allotted for the meeting was too long. Although all of the items on the agenda, such as regulatory news, learning opportunities, and communication issues,

were necessary, the case study at the end of the meeting agenda was the most passionately discussed portion of the meeting.

What was not raised during the support staff meeting but was mentioned in the action research team meeting (possibly in an effort not to hurt the feelings of the home health staff) was the issue of disruptions. With the IDT meeting following the support staff meeting, the in-patient unit staff uses the time immediately preceding the support staff meeting to prepare. That was also the time when many people (mainly from home health) casually stopped in to chat, disrupting the work being completed.

Meeting attendees posed a couple of strategies for eliminating this behavior:

1. Make an announcement at the start of the next few support staff meetings asking individuals to meet and socialize in the conference room (or hall) before the meeting.
2. Put up a sign (on a closed door or above an open door) that read “PREPARING FOR MEETING; PLEASE DO NOT DISTURB.”

To relieve the in-patient unit support staff members of the stress of preparing for the IDT meeting immediately before the support staff meeting, the latter meeting date was moved from the second Tuesday to the second Thursday to allow for more preparation for the weekly IDT meetings. I believed that the stress of the upcoming weekly meeting was making participants think that the support staff meeting was too long.

One of the purposes of the support services meetings was to create a “safe space” in which participants could be transparent and candid about their jobs and what processes, procedures, and communication tools could be utilized to make jobs less stressful. Not all support staff members embraced the concept of having a safe space and therefore did not fully

engage with the rest of the group. Presumably it will take more time for these staff members to become fully engaged.

## **Reflection**

**Intervention A.** During my closing conversations, some action research team members gave their opinions as to why Intervention A was not successfully implemented. One team member suggested that it failed because the medical director needed to have “control over everything” and because, as the medical director herself stated in the IDT meeting, she had been conducting these meetings “in the same manner for 20 years,” therefore perceiving no need to change the process. Another individual suggested that the medical director was in “a constant struggle of being a good businessperson, a good doctor, and a good human being.”

There was disappointment throughout the team regarding the failed implementation of the intervention. I got the sense that people were hoping for change but were not surprised when it did not materialize. Alex never did follow up with the medical director regarding our proposed reorganization of the IDT agenda; simply put, it appeared that Alex did not feel comfortable approaching her. Alex gave me her opinion of the medical director’s leadership style: “She doesn't actually have a relationship [with any of the staff]. She just sort of speaks from on high and puts people under the lamplight. There is no relationship there. Everybody is just afraid of her.” That statement highlighted for me why Frieda and Joe did not demonstrate the same amount of passion in the IDT as they did during our action research team meetings. I also believed there were motivations of self-preservation in play. As the researcher, I would not continue on at United Hospice once the study ended; however, Joe, Frieda, and the remaining action research team members who chose to continue working at United Hospice would, potentially, have to receive the wrath of the medical director for standing up for this change.

This scenario reminded me of a passage by Nicolo Machiavelli (1515) about establishing new principalities that are acquired by one's own arms and ability:

It ought to be remembered that there is nothing more difficult to take in hand, more perilous to conduct, or more uncertain in its success, than to take the lead in the introduction of a new order of things. Because the innovator has for enemies all those who have done well under the old conditions, and lukewarm defenders in those who may do well under the new. This coolness arises partly from fear of the opponents, who have the laws on their side, and partly from the incredulity of men, who do not readily believe in new things until they have had a long experience of them. (p. 24)

**Intervention B.** From the very first meeting—when Sam explained how he approached an end-of-life discussion with patients by using the analogy of life as a book and asking a patient how he or she would like the final chapter to read—to the second meeting when Suzanne relived for us the horror she experienced having to deal with the suicide of a patient, and the lack of follow-up support from the organization, to later meetings when Frieda asked the support staff for help in dealing with what she perceived to be the unfair treatment by the medical director, the meetings provided the support staff system with emotional support and a safe space for venting their frustrations. Informal mentoring occurred in these settings, with Joe accompanying Sam on home health visits (for instance). There was greater communication between the support staff regarding regulatory changes, weekend and holiday coverage, continuing education opportunities, and an overall feeling of validation within an organization whose employees felt that the social service expertise they brought to the hospice did not matter.

It was a great disappointment to the action research team that the first intervention to

restructure the IDT meetings was not successful. However, the fellowship that grew as a result of the monthly meetings would not have occurred within a restructured IDT meeting.

### **Summary**

In action research cycle one, the “study and plan” phase of the process moved smoothly. The first hospice I contacted was interested in having a study conducted at its site, and the employees to whom I presented my proposed study were interested to find out about informal learning within the context of death and dying and emotion work.

Approval of the study by the IRB began the “take action” phase. Those who signed up to participate were enthusiastic about learning a new skill and being empowered to make decisions that could directly affect their work life.

With the interviews conducted, the recordings transcribed, and the initial interview content analyzed, the “collect and analyze” phase was fulfilled. The results of the interviews indicated a strong displeasure with how United Hospice operated, findings that were shared with the group. There was a palpable feeling of relief among the participants that they were not alone in their displeasure. As Carrie said, “I’m glad to know I am not the only one that felt this way.” Oddly, no one else responded.

The next couple of meetings, which focused on prioritizing which issue to address first and identifying an intervention, seemed to empower the group. While I attended the meetings to guide and make suggestions, the four study participants who eventually made up the action research team—Alex, Frieda, Joe, and Sophia—actively participated in discussions, gently debating the prioritization of issues to be addressed and ideas for interventions.

In the “reflection” phase of the process, I guided the group in establishing team norms to guide how we would operate among ourselves. The idea was that the action research team would



incorporate these norms in our meetings and would begin to “lead by example” in the IDT meetings. I explained how action research involves everyone who is part of the process taking ownership and responsibility for any change in the process. For example, I explained that if the action research team decided to develop and establish guidelines for how interdisciplinary departmental team meeting attendees were to conduct themselves, more than likely the attempt to establish guidelines would fail because there was no buy-in from the IDT attendees from the beginning.

Action research cycle two began with the tracking of two interventions, Intervention A—the revision of how IDT meetings were conducted—and Intervention B—the establishment of the support staff meetings. The “study and plan” for both interventions proceeded smoothly.

The “take action” phase of the interventions diverged greatly. During Intervention A, we began a three-week trial of the revised IDT meetings. While the trial was in process, Intervention B was taking shape, with the team securing permission from the medical director to hold these meetings, following Alex’s lead in setting the agenda of the meetings, inviting the support staff from the home health division to attend, and holding the meetings.

The “collect and analyze” phase was both bad and good for the team. The rejection of the revised plan for conducting IDT meetings by the medical director was disappointing. On the other hand, the support staff from both the in-patient and home health teams provided an enormous amount of positive feedback on the effectiveness of the group coming together in that manner.

The reflection phase, during which team members looked back at what we did and how we could have made it better, possessed a sanguine quality. Regarding Intervention A, while members were disappointed by its lack of success, no one was surprised by the medical

director's action. Joe said, "We learned a lot, about each other, about how to work as a team and ourselves; there was real value in that." Sophia said, "[The medical director is] the lady who signs the check, she can do what she wants." The feeling of the group was, as Sophia put it, "With you coming it looked like things were going to change, it even felt like things were changing; it sucked that it didn't change, but we fell short, too." Intervention B continued to be a success; although Sophia left United Hospice for other opportunities and there are two new support staff members at the hospice, the meetings are held on Wednesdays now with full support staff participation.

In summary, what was learned informally by individuals was useful, and the system changed slightly, at least in terms of holding more interdisciplinary staff meetings, though the overall culture of the organization has not yet changed to relieve the emotional stress for staff of the organizational inconsistency and ineffectiveness of meetings.

Chapter 5 discusses the specific findings from this study relative to the research purpose and research questions.

## CHAPTER 5

### FINDINGS

The purpose of this study was to explore the informal learning of hospice care professionals within the context of their emotion work, with the aim of analyzing learning needs and proactively developing professional development interventions to address those needs. Three research questions guided the study: (1) What is the nature of the informal learning described by caregivers?; (2) what types of support are effective for those engaged in emotion work?; and (3) what is learned by an action research team exploring the emotion work of those individuals who provide emotional support to those experiencing death and bereavement? This chapter presents the findings that emerged from critical incident interviews, participant observations, and closing interviews with the action research team members and others involved in the interventions. The findings are organized by research question, with themes and sub-themes that emerged during the data analysis.

#### **Overview of Findings**

The nature of informal learning by hospice care professionals can be organized into three categories: (1) process, (2) perspective, and (3) approach. According to the results of the data analysis, “learning from observation” and “learning from trial and error” led to learning that was more process-based and procedural (e.g., learning the difference between general nursing and palliative and hospice nursing or not asking the right questions during intake). Professionals experienced informal learning incidents when they had a closeness with the person dying. That close relationship led the hospice care professional to undergo a change in perspective about his

or her own personal life.

In addition to finding out what type of supports were effective for individuals engaged in emotion work, the data provided examples of support that were not effective for individuals engaged in emotion work. Interviewees cited coworkers and hospice administrators as offering both effective and ineffective supports.

An action research team exploring the emotion work of individuals who provide support to the dying and the bereaved learned more about their role as hospice care professionals as well as the responsibilities of other non-clinicians. The action research team also learned how to operate as a team and how to trust each other. The most important change came in the form of an enhanced awareness that, in this organization, sustainable change came from the top. Table 11 outlines the key findings of this action research study.

Table 11

*Overview of Findings*

Research Question	Findings	Sub-findings
What is the nature of informal learning as described by caregivers?	Learning from observation	<ul style="list-style-type: none"> <li>• Learning from observing how to perform tasks</li> <li>• Learning from observing different family dynamics</li> <li>• Learning how people show their emotions</li> <li>• Learning the difference between general nursing and palliative and hospice nursing</li> </ul>
	Learning from interactions with the dying and the bereaved	<ul style="list-style-type: none"> <li>• Learning from the relationships that form with the dying and bereaved</li> <li>• Learning from the dying</li> </ul>
	Learning "on the fly"	<ul style="list-style-type: none"> <li>• Learning from surprise when one gets an unexpected response</li> </ul>
	Learning from "trial and error"	<ul style="list-style-type: none"> <li>• Not asking the right questions during intake</li> <li>• Learning that not including a spare battery on a pain pump could lead to fatal results</li> <li>• Delayed response</li> <li>• Implementing a bereavement system</li> </ul>
What types of support are effective and ineffective for individuals engaged in emotion work?	Learning from reflection	<ul style="list-style-type: none"> <li>• Sharing stories</li> <li>• Being aware of the situation at all times</li> </ul>
	Types of support that are effective	<ul style="list-style-type: none"> <li>• From coworkers</li> <li>• From hospice administration</li> <li>• From the dying or bereaved being supported</li> <li>• From loved ones</li> <li>• From staff support meetings</li> </ul>
What is learned by an action research team exploring the emotion work of individuals who	Types of support that are not effective	<ul style="list-style-type: none"> <li>• From hospice administration</li> <li>• From coworkers</li> <li>• From lack of infrastructure</li> </ul>
	Learned how to develop trust in each other	<ul style="list-style-type: none"> <li>• Just by having the opportunity to meet</li> <li>• Seeking and giving advice</li> </ul>

Research Question	Findings	Sub-findings
provide emotional support to those experiencing dying and bereavement?	<p>Learned about the roles and responsibilities of other hospice care professionals</p> <p>Learned how the hospice care professionals operate as a team</p> <p>Learned about themselves as hospice care professionals</p>	<ul style="list-style-type: none"> <li>• The difference in the job tasks between social workers in home health and those on the in-patient unit seem unequal on both sides</li> <li>• Case study presentations provided most of the education</li> <li>• Trust in each other grew through the meetings</li> <li>• The team learned about its strengths and weaknesses</li> <li>• How to set boundaries</li> <li>• No one likes it when someone else thinks they can do that person's job</li> </ul>

The informal learning that occurred when observing family dynamics, or when the hospice care professional got an unexpected response from a loved one, or when reflecting upon stories heard was considered a type of learning about how to approach a situation. Effective support for individuals engaged in emotion work was identified as coming from coworkers (e.g., support staff meetings) and the hospice administration. Encounters with the dying and bereaved offering unexpected support for the hospice care professional. One unintended but critical finding in the study was the identification of a general lack of hospice infrastructure, which posed obstacles to the hospice care professionals.

Finally, the learning of the action research team members fell largely within the realm of self-discovery (e.g., learning about trusting each other, learning about themselves as hospice care professionals). The staff support meetings did provide an educational opportunity for the action research team members, as they learned in detail the tasks of their peers.

### **Initial Findings**

My original plan was to have the study participants identify themes within the narratives and then for the entire group to return at a later time to identify and prioritize interventions in line with those themes. However, this approach did not prove productive since no one had time to review the narratives and develop themes. As a result, I identified themes, generated the findings, and presented the findings at the first meeting of the action research team.

I applied Ortony and Turner's (1990) identification of basic emotions to the responses to the critical incident questions, in an effort to identify the informal learning approaches used by study participants in response to the emotions felt. The resulting assertions are found in Table 12.

Table 12

*Informal Learning Approach, Emotion, and Assertion*

Name	Heading	Informal Learning Approach	Emotion	Assertion
Jim	<i>Going with your gut</i>	To respond to an internal feeling inside of self to say something or to perform a gesture (e.g., reaching out to hold someone's hand)	Anxiety	Sometimes the emotion felt when caring for the dying does not make sense to the hospice care professional feeling that emotion.
	<i>Not all families are ready to hear what the patient has to say</i>	To be selective about who is present with the patient when asking the patient, "How are you doing? How are you feeling?" This question is not always asked of the patient with loved ones present: "I don't always do it in front of the family because some people don't understand..."	Wonder	When a hospice care professional is asking a patient the question "How are you doing/feeling?" in the presence of loved ones, he or she may wonder if the patient's response is an honest one or if the patient is presenting a positive outlook so as to not upset those loved ones present.
Suzanne	<i>When put on the spot, you have to use your instinct (or your experience)</i>	To use prior knowledge to answer the question or request of a loved one	Surprise	At times, a hospice care professional may have to use personal experience to respond to a patient or loved ones' inquiry.
	<i>Never again on my watch</i>	To reflect what could be done differently to ensure that a patient suicide could never happen again.	Surprise/Sadness/Guilt	The surprise, sadness, or guilt felt from the unexpected suicide of a patient causes the hospice care professional to reflect on what processes or procedures could have been done differently.
Carrie	<i>Everyone has different responses to death and dying</i>	To observe and engage loved ones to see how they are handling the pending death of the patient.	Surprise/Disgust/Distress	At times, the manner of how loved ones respond to a pending death can surprise and cause distress to a hospice care professional.
	<i>Accepting things you cannot change</i>	To observe and engage patients and loved ones when deciding on how to begin a conversation about end-of-life.	Wonder	At times the hospice care professional's personal outlook can be changed by the dying person's seeming acceptance of her diagnosis.
	<i>Don't look at me like that; I was just doing my job!</i>	To wait and see how a loved one of a former patient responds to seeing you outside of the hospice before you	Surprise/Dejection	A bereaved person seeing a hospice care professional out in public can bring about immediate sense of sadness to that person.



Name	Heading	Informal Learning Approach	Emotion	Assertion
		attempt to greet them.		
	<i>Involve the loved ones</i>	To communicate softly and gently to the loved ones when performing a procedure on a patient.	Interest/Hope	When performing a procedure such as an extubation on a patient, a soft and gentle communicative approach with the loved ones explaining the procedure and the patient's response to what is occurring is recommended. The nurse explaining the extubation process took the mystery out of the procedure and how death was to occur.
	<i>Learn to live life to the fullest</i>	To observe and engage with patients and loved ones	Surprise	At times, the hospice care professional's personal outlook can be changed by the dying person sharing his life lesson learned.
Janet	<i>Sometimes families can be the best teachers</i>	To ask the loved ones of a patient when you are not sure about how to effectively treat the patient	Panic/Anxiety	The feelings of panic and anxiety that may occur when caring for a patient can be lessened by seeking guidance from loved ones on how to effectively care for the patient.
	<i>Hospice care is "learn as you go"</i>	To acknowledge and learn the difference between general nursing care and palliative/hospice care	Surprise	There is often an emotion of surprise when an individual experienced in health care enters a hospice care environment.
Alicia	<i>Rare is the family that is going to come in all on the same page about death</i>	To observe and engage loved ones when deciding on how to begin a conversation about end-of-life	Anticipation	By observing and engaging with loved ones, a hospice care professional can anticipate how to begin a conversation about end-of-life care for the patient.
	<i>Didn't we cover this already?</i>	To observe and engage with patients and loved ones when deciding on how to begin a conversation about end-of-life	Surprise	By observing and engaging with loved ones, a hospice care professional can anticipate how to begin a conversation about end-of-life care for the patient.
Joe	<i>Does it matter to this Black family that I am White?</i>	To "be the ministry of presence"	Fear	In the intimate space of dying and death, barriers that usually separate are broken down.
		To "be the ministry of presence"	Happiness	When a loved one verbally expresses gratitude for the care provided to his or her

Name	Heading	Informal Learning Approach	Emotion	Assertion
				loved one, there is a sense of relief felt by the hospice care professional.
Frieda	<i>Frustrating at the beginning... Very spiritual in the end. Let's call it "ironic."</i>	To keep copious notes when documenting patient care	Redemption	Despite being trained against it, maintaining copious notes can save a hospice care professional from professional disaster.
		To always listen and respond in a manner that is best for the patient	Gratitude/ Redemption	By listening and responding to what best fits a patient's situation and needs
Sophia	<i>Organization and structure is critical</i>	To prioritize hospice tasks in an effort to not become overwhelmed	Anxiety	A disorganized environment can bring about anxiety for some hospice care professionals.
	<i>Overall, we're a team</i>	To assist other hospice care professionals when they look as if they need help	Desire	In most cases, hospice care professionals desire to assist their coworkers who look as if they need help.
	<i>You have to relate to people to succeed</i>	To observe and engage patients and loved ones when deciding on how to begin a conversation about end-of-life	Wonder	Sophia's observation of her patient and his sitter's close relationship made Sophia wonder how she can establish a similar relationship.
	<i>Never forget that the job is about relationships even after the patient dies</i>	To familiarize oneself with the bereaved by reading the deceased's patient chart prior to making a bereavement call	Anxiety	In the case of calling on bereaved loved ones, familiarizing oneself with the deceased's case may lessen the anxiety that may come from making such calls.  The informal learning of how to perform a task or procedure often comes from a more senior employee.
Alex	<i>Not exactly learning on the fly, but...</i>	To observe and listen to the bereaved while trying to apply learned techniques	Anxiety	When counseling the bereaved, observing and listening to them while trying to apply formally learned techniques can bring about anxiety.
	<i>Formal training doesn't prepare you for everything</i>	To try to develop a bereavement program without any knowledge of what would make an effective program	Shame/Distress	Being required to implement a bereavement program without the knowledge or training of what makes an effective program can be a source of shame

Name	Heading	Informal Learning Approach	Emotion	Assertion
				and distress.
	<i>With a father like this, who needs enemies?</i>	To observe and engage with patients and loved ones when deciding on how to begin communication about end-of-life	Surprise/Disgust	When observing familial behaviors not aligned with the hospice care professional's personal values, the individual may feel a sense of surprise or disgust.
Tasha	<i>Death: Maybe if we don't talk about it, it won't happen</i>	To observe and engage with patients and loved ones when deciding on how to begin communication about end-of-life.	Surprise	Hospice care professionals communicating with loved ones of the dying who are in denial approach the relationship by coaching the loved ones into action (e.g., funeral preparation).
	<i>The "miracle" conundrum</i>	To observe and engage patients and loved ones when deciding on how to begin communication about end-of-life	Surprise	Hospice care professionals communicating with loved ones of the dying who are in denial communicate the idea that there is always a "miracle" or a "healing," but it may not be in the package they are seeking.
Galina	<i>Learning can be shitty sometimes</i>	To reflect what could be done differently to ensure a patient suicide could never happen again.	Surprise/Sorrow/Anger	Informal learning sometimes occurs as an unexpected response to a situation as dramatic as suicide, greatly affecting the hospice care professional with feelings of surprise, sorrow, or anger; or it could be as uneventful as learning that a specific document needed to be completed a certain way.

In most cases, it was felt emotion that compelled the participant to approach a situation in a particular manner. Surprise was the most common emotion (i.e., the hospice care professional receiving an unexpected response to a statement or inquiry; surprise at the different medicines, dosing, and jargon used in general nursing and hospice/palliative care; surprise about how some patients are so graceful and accepting of their diagnosis), followed by the fear/anxiety of inadequacy (i.e., of being a hospice chaplain, of effectively caring for a patient, of being able to counsel a family that comes to bereavement counseling).

## **Narratives**

This section comprises the critical incidents of each action research team member as described to me, in the action research team members' own words. In these narratives, the study participants explain incidents that triggered their informal learning.

### **“Does it matter to this Black family that I am a White guy?”**

*Yeah. I wondered how people would receive me, and if they would receive me, if my pastoral care would be seen as authentic and as spiritually present or just seen as kind of another White do-gooder. That was the beautiful thing that I realized in these intimate spaces, that those barriers, those human constructs are broken down in that intimate space, and it just happens.*

*There was a Black family here whose loved one died, an older man, and I really didn't feel like I had a whole lot to offer. I wanted to be present, and I'm still trying to figure out how I practice pastoral care in this context. I really haven't developed a strong [hospice] repertoire yet.*

*I'm still just trying to be the ministry of presence. I'm just saying I haven't worked in hospice before. I've worked in death and dying, so this is my first time*

*working in hospice, so the learning curve is steep, and I'm just beginning now to build resources that will be applicable. Where I don't have to re-create the wheel every day and I find my go-to theology, if you will, so I'm still developing that and how I initiate discourse and create safe space for folks to share, and to open up, and begin creating a meaningful relationship.*

*With this Black family, I don't have a lot of repertoire here, so I'm just trying to be present and I really didn't feel like I was being all that helpful but one of the granddaughters, she appeared maybe 20 years old or so, she came up to me in the hallway after her grandfather had passed, and the family was there for several hours actually. She came to me in the hallway and said something reaffirming: "You've just been really so good. Thank you for all your help." It was really authentic and it shocked me because it seemed so authentic. It was really kind of like I could breathe a little. I could relax a little and those barriers, perhaps that I put up more than anybody else, fall away.*

**"Frustrating at the beginning. Very spiritual in the end. Let's call it 'ironic.'"**

*We had a patient here, let's call him Bob. He was brought up here for pain management, and we got that pain under control very quickly. He was homeless before he got here. He actually had a friend who was also homeless, who stayed here with him but actually provided a lot of care to him. We thought that he—let's call him Larry—we thought that he was really great for Bob. He said that he had to take care of his ex-wife who was on hospice before, this, that, and the other. So we were trying to find a place for him to go, and Larry said that he would be his primary caregiver. So I looked around into low-income housing options. Found some options, but in the meantime, they found their own*

*apartment that was part of a very small, small complex where one of their friends lived as well. First, when Bob got here, it was great, but he had lost his bank card, birth certificate, social security card, basically all of his IDs when he was rushed to Central [the city's general hospital].*

*That's pretty typical, especially if it's an emergency situation and they're trying to do all this stuff. You know, a wallet gets lost. We hear that a lot. You're trying to focus on the care. He was like, "I can't get into my bank account to be able to pay for this before I have my ID," so I had to take him around to get his birth certificate so then he could, on another day, get his driver's license and then another day to the bank. It's not my responsibility. But at the time, there was literally no one else in his support group who could have done it. It was, like, someone had to do it, and I developed a very good relationship with this patient, so I just did it. We eventually got everything squared away. They had this apartment. I asked, "Is everything set up? Is water set up? Is electricity set up?" All these different things. Larry and Bob both responded, "Oh yeah, yeah, yeah, everything's set up."*

*So I drive them there with Jim, who is a supervisor of mine. When we get there, the equipment is being set up and [building maintenance] pull[s] me aside and said, "We really don't think this is a good living situation for any patient on hospice." Jim goes in and assesses the situation. Realizes there's no electricity set up at that time. It was like a Friday afternoon slash evening and John was like, "We've had people who are living under bridges that we provide care to. If this is where they choose to live, this is where they choose to live, you know?" I'm a social worker; he's a seasoned social worker—I'm taking his advice. I'm like, "Okay well let me call [name redacted], and let her know"*

*because she was the admin on call. I let her know and she's like, "It's a step up from where they were before. I think we just need to go with it. This is where they're choosing to live." So that's on a Friday. Monday rolls around; we're getting calls left and right like, from the home health staff: "Where the hell did y'all send these people? I can't believe y'all let them live in this type of situation..."*

*Jim and I are kind of like, you know, we've had some situations where non-social workers can be judgmental of people's places of living. We both saw this place. Is it the Taj Mahal? No. Tuesday rolls around, and we get a call from his home health social worker and she's like, "I don't know what type of situation it was on Friday, but now it's not good. It is not good. Larry's nowhere to be found. Bob has feces all up his back. He hasn't had a bath. There are flies everywhere. The place looks like it's been trashed." I don't know what happened. I let [name redacted] know and she was like, "I really feel like he needs to come up to the in-patient unit," and he could barely care for himself. He couldn't get to the bathroom. He'd had a significant decline over the weekend. [Name redacted] was like, "Well somebody needs to call the medical director and get approval for him to get back up here for in-patient care." And then [name redacted] calls up here and she was just like, "Okay, well I'll just have [name redacted] handle it."*

*In the meantime, it's getting late. We're like, "Where's Bob? What's going on? Why isn't he here yet?" So right before our team meeting at 4, I call [name redacted], and there was miscommunication. [Name redacted] was like, "I was told that basically Frieda put him in this situation, she needs to go down to [name redacted] and have [name redacted] yell at her for having this patient in this situation and that you need to call the medical director to get approval for him to get up here." I wasn't under the*

*understanding that I was supposed to call [name redacted].*

*So I go to the medical director's office immediately. I tell them, "Look, I'm going to be late for team [meeting]." I tell the medical director the situation. She wasn't happy. I was like, "Can he come up here?" She was just like, "I don't know what else to do." And I was like, "Okay, well I'm gonna go get a [certified nursing assistant] and pick him up myself." Because I was like, you know, "I can't get transportation at this time," I just gotta go do it. So I grab a CNA, he jumps in the car with me, we go pick Bob up, and we take him back here. He had a significant decline, and it was very obvious that he and his friends had a huge party that weekend. Tons of drugs were done, all of that. And Larry was nowhere to be found. He had just taken off. And he had about \$800 in cash on him. And that was gone.*

*But I can't physically get him into this car, and that's medical, so that's why I brought a CNA. Oh, no. I didn't bring a CNA, I brought a [licensed practical nurse]. So I get back and the medical director looks him straight in the eye and she goes, "Did you party this weekend?" And he goes, "No." She goes, "Are you sure you didn't party this weekend?" And he just didn't answer. And she thanked me for going and picking him up. And it was somewhat clear to her, had I been told earlier that I needed to handle this, obviously I would have. But there was this whole big thing about Frieda didn't do what she was supposed to do.*

*And in my schooling and my education, I had learned that in a private practice setting, you kind of make the least amount of notes as possible; that way if they're subpoenaed, you're not liable. Especially since I'd been in a private practice counseling setting, and it was more so, if this is subpoenaed because our clients are being brought to*



*court, say in a custody battle, or something else, it doesn't damage them. So I was making very minimal notes about the situation and all that, and my butt wasn't covered.*

*So "a", I learned to always cover my tracks in my notes—put exactly who told me to do what, who I spoke to, all that. But I also learned, because that patient and I had such a good connection that he stayed here 'til he died. I heard that he was on the brink of death, he just had a few more hours or so, the day that he died. Right before I left, I went in there and I told him, "Bob, you've been a really special patient of mine. I just wanted to let you know that I really appreciate the time that we've had," and he actually died right there. He actually waited on me to come. So I also learned in light of all of that and in light of everything you may go through, as long as you hold true to yourself and hold true to your clients and what you know to be true of what you're doing, you're gonna win in the long run. You're going to do what's right for those patients, and you're going to get ... satisfaction out of that. That made it fine. Knowing that he was literally waiting for me.*

*[The nurses, CNAs] were like, "He's been hanging on for so long, I don't know why he doesn't go. I don't know why he doesn't go." So I went in there and he literally [died]. When I went in to tell the nurse, I was like, "He just died on me. You need to go pronounce him." They were all like, "Frieda, he was waiting for you."*

*Frustrating at the beginning. Very spiritual in the end. I guess one word to sum it up is "ironic." You know?*

**“First lesson: Hospice does not equal very end-of-life.”**

*I remember doing my shadowing in social work when I was going with the social workers. I just thought that patients would be actively dying all the time and that their*

*needs would be funeral home funding and grief counseling, not just helping somebody walk through those last months of life. I met Big Daddy, who is actually my patient still in social work. I have two patients still. Big Daddy's still around. Just go in there and seeing somebody posted up in the bed, cooling it. [Big Daddy would say], "What's up, girl?"*

*The second lesson is, patients are having different issues. Yes, having a terminal illness but learning that's not the end-all-be-all for hospice. He has relational issues with his daughter. He's bedbound and has quality of life issues. He has spiritual issues. I'm learning that it's way more than people just come here and they're dying. I had those misconceptions when I came. I even thought that we killed people. You give them some medicine and they're gone, right? No, ma'am. That was one thing.*

*Another thing I learned was I had to learn how to go in and talk to somebody in their most vulnerable moment, meet them where they're at. Not only accept them but open myself and give of myself for them to accept me, too.*

**"Formal training doesn't prepare you for everything."**

*My training as a chaplain was wonderful. It did not train me to be a bereavement coordinator in all of the ways that I needed. It's very good in general, and I did get some good continuing education at the beginning of my time at United Hospice. I had heard early on, and I have some very good advice from my mentors or pastors, the key to good pastoral care is good organization. I appreciate that. That's not my strong suit, but I do try, especially in my job. I try to be organized in my job. But when I came on board there was not a good system for how bereavement was organized. I think what happened was that, now, this is a solved issue now, but what happened at the time was that United*

*Hospice used to be a home health-only hospice. That's why they only had so many patients per year. They only have so many people die per year. They had their chaplain doing bereavement at the same time. He was a chaplain, and he did bereavement.*

*They started having the in-patient division in addition to the home health, and things exploded. There are a lot more deaths from the in-patient than out in the home health hospice—a lot. This overwhelmed the person who was doing bereavement, and all of those old systems did not work. Whatever old systems he had in place did not work and so he cobbled together a much more simplified system that he couldn't maintain. Even though it was simple, it wasn't necessarily giving people the kick that they needed; it just wasn't a good system.*

*So I came onboard and tried to do the best that I could to figure out how to make a better system of organization so that I could get people the care that they needed. It took me a long time to figure that out—like some serious growing pains. I've got some advice from some of my superiors—which was helpful and I wish that I had gotten it earlier—that I have better supervision earlier because my strength is as chaplain and not as the organizer of a huge system or creating from scratch a system.*

*Nobody knew how to do my job when I got there because the person that had previously been in my job they had fired three months beforehand, and so somebody had been doing it in the interim, but he didn't really know how to do it. It wasn't his job. He was just doing it, but he didn't really know what to do at all.*

*For the most part, you set up a system. Oh yeah, that was a huge learning—yes. Yes, you don't know what you don't know. You don't know that there's a better way to do this thing where you can only think of one way to do it.*

*Right. Yeah, I only know how to do this one way that I have imagined. I wish that I had asked more questions earlier on and that I had not been ashamed by what I hadn't been able to come through on. I spent too long being ashamed of what I [could have] done instead of asking for help and how can I do this better. Like what am I doing wrong for this thing that I'm not, like the organizational part, that's not what I'm skilled at. That's not what I've ever been trained for. Why am I so ashamed that I didn't know how to do that?*

## **Summary**

The critical incident narratives for most of the action research team members (i.e., Sophia, Alex, and Joe) that led to informal learning were subtle in nature: learning that to be successful in communicating with the dying and bereaved, one first must be able to relate to the patients and their loved ones; learning that there is no shame in not knowing how to perform a task one has never been trained to do, or finding out that sometimes, the barriers that fall between a profession and a loved one of the dying are the self-constructed. Frieda's critical incident narrative was more direct in its informal learning approach. Despite being taught to "make the least amount of notes as possible," Frieda found that by following that edict, her "butt wasn't covered." So Frieda informally learned "to always cover my tracks in my notes. Put exactly who told me to do what. Who I spoke to, all that."

My initial analysis of these interviews focused on the organizational concerns of the action research team members—how to be effective in performing a task (Joe and Frieda), how to successfully implement a program (Alex), and the need to maintain detailed case notes (Frieda). It occurred to me that these organizational concerns, while not related to death, dying, or emotion work, were creating stress in the already emotionally fraught context of this hospice

setting. The team decided that, as a first step, we needed to relieve some of the organizational stress people were experiencing before looking at additional learning approaches.

### **Research Question One**

The nature of informal learning, as described by caregivers, entailed learning about processes and procedures through observation, being instructed by family members, or by trial and error (see Table 13). Of these, two emotions—happiness and redemption—were not felt until after the informal learning approach proved effective or successful.

Table 13

*The Nature of Informal Learning as Described by Caregivers (N = 7)*

Theme	Sub-theme	Number of Times Mentioned During Closing Interviews
Learning from Observation	• How to perform tasks	4
	• Different family dynamics	2
	• How people show their emotions	2
	• Difference between general nursing and palliative and hospice nursing	1
Learning from interactions with the dying and the bereaved	• Relationships that form with the dying and bereaved	5
	• Learning from the dying	2
Learning "on the fly"	• Not getting the expected response	4
Learning from "trial and error"	• Not asking the right questions during intake	1
	• Not having spare battery	1
	• Delayed response	1
	• Implementing a bereavement system	1
Learning from Reflection	• Sharing stories	2
	• Being aware of the situation at all times	1

### Learning from Observation

Data analysis identified "learning from observation" as the main mode of informal learning among hospice care professionals at United Hospice. Learning from observation occurred in all matters of hospice care: from learning how to perform tasks to observing a patient's family dynamics as a way to determine the most effective way to approach family

concerning patient care. Observation of a person's actions as he or she inquires about a loved one's condition tells the hospice care professional if the loved one is ready to hear the truth. I had an opportunity to observe this action for myself. Once, while sitting in the nurses' station, a woman came in to ask how her loved one was doing. The head nurse said, "Well Mrs. X. is not eating as much, and she is sleeping more"—and the woman began to shake her head as if to say "No" and wave her hand back and forth as if to ward off the words that were being spoken to her. The loved one's actions were evidence to the nurse that she was not prepared to hear what was being said, so the nurse stopped speaking. Finally, learning the difference between general nursing and palliative and hospice nursing came about through observations of differing terminology, medicines, and dosing used in a hospice environment.

### **Learning from the Dying**

Carrie shared a story about a man who never took a vacation his entire life. When the man figured he had amassed enough money to retire and take that vacation, it was too late:

I've had a patient who was quite healthy, and he said to me ... "I need you to live every day to the fullest because I did not. I was striving to make money every day. I worked seven days a week." When he thinks he had enough money saved, he went for a physical. He was going on a world tour. He had cancer. He didn't take any day for himself. He was waiting on this vacation that never happened. He never even enjoyed his money.

Carrie also shared a story about a 75-year-old woman who was dying of breast cancer:

I had an experience with a patient that was actively dying. She was very alert and oriented. I suppose we went there to comfort her, but I had to be the one being comforted. I have never seen anybody so amazing and so ready to talk about death, and so ready to accept what is coming. I was the one crying. It was just so amazing. She was

so prepared. She just threw me off. This lady has lived her life to the fullest, enjoyed every day. She was 75 years old. She had breast cancer. She decided not to get chemo. She continued to live her life. She didn't want to lose her hair. She continued to travel. She did everything she wanted to do until it ravished her body when it came outside. It's just how amazed I was with how she coped with everything. I think she grieved a long time ago about it. She got over that. That really taught me a lot, to understand even for myself how to cope with those things. I ask for the Lord to help me to accept the things that I can't change—how she did.

### **Learning “On the Fly” When Not Getting the Expected Response**

Like most hospices, United Hospice offered bereavement counseling to families and friends of former patients. Care was extended through phone calls, mailings of bereavement literature, individual and group counseling, and semi-annual memorial services. Alex, the bereavement coordinator, had received formal interfaith professional education for ministry in the form of clinical pastoral education (CPE). She also had three years of experience as a chaplain before coming to United Hospice. Still, there were times when her learning occurred on the fly. Alex explained why much of her grief counseling with bereaved individuals could be considered learning on the fly:

You can tell people what's normal from a book, but how do you meet them at the point of their despair? How do you know when to say something or whether to just let the silence ride? You try and you see what happens. You are not just trying stuff. You're always trying what you think is the best thing. You're always trying, like, “this is my best answer ‘right now.’” You're picking up on clues because they are looking at you, or they're not looking at you, or they're exasperated. It's all these things.



Another instance of informal learning that usually occurs on the fly among hospice care professionals is when the social worker, while performing an initial assessment of the services needed by the patient and his or her immediate loved ones, attempts to initiate a conversation with those loved ones regarding final arrangements. Tasha shared a then-recent conversation with the loved one of a home health client:

Social worker: “Do you all have any kind of final arrangements made?”

Loved one: “Like what do you mean?”

Social worker: “Like funeral home, that sort of thing.”

Loved one: “We’re not trying to think about that right now. I don’t want to think about that. We’re not trying to think about that right now. I don’t want to think about that because my grandmother is going to die sooner.”

Tasha quickly had to learn how to respond to this denial of imminent death by coaching the loved ones around making a decision, using phrases such as “Well, this is something you may want to think about” or “At the time of death, the last thing you want to be thinking about is ‘what funeral home are we going to use,’” or by using visual examples such as, “It can be a nightmare if you don’t have that picked out and they just passed, and your grandmother is laying there with [rigor mortis] starting to set in, and you don’t have a funeral home picked out.” The point, Tasha stated, is to meet people where they are, dropping reminders (sometimes subtle, sometimes not, depending on the condition of the patient and her relationship with the family caregivers) at every social work visit.

### **Learning from “Trial and Error”**

A “trial and error” approach to informal learning is used to understand and carry out tasks successfully. Employees are often unwilling to ask for help when it is needed out of fear or a

sense of not wanting to expose oneself as incompetent to perform one's job. Instead, employees engage in some informal learning strategies to learn their jobs.

**Implementing a bereavement system.** As a bereavement coordinator, Alex was responsible for following up with loved ones of deceased individuals who were patients at United Hospice, up to one year after their death. Alex experienced a steep learning curve upon arriving at United Hospice.

Later, after reflecting on the trials and errors of implementing a bereavement program, Alex realized she should not have felt ashamed for needing help in program implementation. Alex never received feedback—neither positive nor negative—on how the implementation was progressing. This lack of feedback led Alex to determine on her own what worked and what was effective regarding the bereavement program, which increased the emotional stress of her job.

### **Learning by Reflection**

The use of shared stories was another method of informal learning at United Hospice. As one example of a shared story, described in Chapter 4, Sam shared his difficulty with the IDT meetings and his strategy for overcoming that difficulty by writing detailed notes in preparation for the meeting. His strategy was to talk as much as he believed he should, “pushing it to the point that I hope I won’t be told to shut up.” Sam, in other words, developed a method of surface acting to help manage the emotional stress of these meetings. Sam’s story also served as a way to address a recurring problem among IDT meeting attendees.

**Be aware of the situation at hand at all times.** The final example of shared stories is one that Galina shared with the staff from time to time to remind them that they are human and therefore make mistakes:

I always tell people that worry about [doing or saying the wrong thing with a patient or loved one], when they are new to hospice, I tell them the story about when I went to do a death pronouncement, and it was Christmas Eve. I was at home with my children. I have four children, and I'm Catholic: Christmas was just a big deal for me. I mean, it's just a big deal. You're wrapping presents, and you're making Christmas cookies, and you're making the house smell great, and we're singing Christmas carols, and the phone went off, and somebody died. I'm like, "Okay, they are close to me. I'll do this one." I jumped in the car and I listened to Christmas carols and I get to this lady's house and it's in one of these, like, a town house where there's two doors and the one door was all decorated. It had a mat—if you stepped on the mat it said, "Ho, ho, ho." It was just wonderful.

I was engulfed in the Christmas spirit, and I rang the doorbell, and the lady opened the door. I said, "Merry Christmas." As soon as I said "Merry Christmas" I thought "stupid idiot." I mean, I said exactly that. I said, "I am so sorry." I said, "I know that this is not a Merry Christmas for you."

She said, "No, it's not." I mean, I had to apologize. We say wrong things to our friends—I mean we just do, you know? We're going to do it because we're human. No, because as soon as I said that I knew that I should not have said it, and I mean the Merry Christmas was shooting out of my mouth and if I could have snatched it back ... All you can do when you do something or say something, and the outcome isn't a good one or you never should have said it in the first place, is apologize. I mean say, "I'm sorry." There's little things that you learn along the way that I hope I'm able to pass on to people.

Many study participants learned procedures informally through observation (e.g., extubation and how to communicate with the loved ones observing the extubation). Some practices were established after a tragedy had occurred (e.g., the forgotten spare battery for the pain pump). In addition to taking on the emotion toll of dealing with death and dying every day, and the misplaced emotions of loved ones of the dying, the hospice care professional's own emotional stress and feelings of insecurities come into play—"Am I implementing this program correctly?"; "Is this the correct process for completing Medicaid 'Request for Payment' forms?"; or "How am I supposed to intelligently and authoritatively speak to a parent about a medical procedure when I am not a clinician?"—and force the hospice care professional to informally identify solutions for completing these tasks.

### **Summary for Research Question One**

In exploring the nature of informal learning of caregivers it was found that at times, a primary emotion triggers a secondary emotion, the latter of which encourages the informal learning approach. Drawing from the critical incidents in this study, the approaches included silent observation, asking for assistance, interaction, trial and error, and reflection. The primary and secondary (when applicable) emotional triggers that encourage an informal learning approach are detailed in Table 14.

Table 14

*The Primary and Secondary Trigger that Encouraged an Informal Learning Approach*

Participant	Incident	Primary Trigger	Secondary Trigger	Learning	How Learned
Jim	<i>Going with your gut</i> While visiting a home health patient	A nagging feeling relating to being told to perform an action	N/A	"To always trust your gut." If you're told to do something, even if it appears to be stupid, do it. There's a reason."	After responding to the nagging feeling related to holding a patient's hand, Jim and the visiting nurse acknowledged sharing an intense spiritual experience with the patient.
Suzanne	<i>When put on the spot, you have to use your instinct (or your experience)</i> Loved one of a dying patient wanted copies of the medical records	In hospice, there is an assumption that death is imminent; there is no need for medical records. This request came as a surprise.	N/A	Suzanne used her prior knowledge to address the request.	Being able to answer an inquiry without formal knowledge of the process may require inferences from prior experience and an ability to relate that knowledge to the current situation.
	<i>Never again on my watch</i> A home health patient committed suicide with a gun that was hidden within reach.	Shock, especially when Suzanne thought progress was being made with this patient, who was a favorite of Suzanne's.	Guilt	Suzanne learned that this experience was not an indictment of her skills; it was the patient's persistence at ending his life.  Now, in conducting patient assessments, Suzanne will ask if the patient is "feeling suicidal" or if there are "any weapons in the home" and whether he/she has "a plan."	Through experiencing the suicide of a patient.  From the patient's daughter, who provided verbal affirmation that Suzanne did everything she was supposed to do.

Participant	Incident	Primary Trigger	Secondary Trigger	Learning	How Learned
Carrie	<i>Everyone has a different point of view and response about dying and death</i>				
	Observing the family members engage in fights with each other during a visit with the actively dying patient.	Surprise. In her previous healthcare occupation as an oncology nurse, this type of behavior was never observed.	Distress	Everyone has a different response to dying and death.	Through interactions and observations with the family of the dying.
	<i>Everyone has a different point of view about and response to dying and death</i>				
	Having dialogue with three sisters who were all undergoing chemotherapy. The sisters would talk about what type of funeral they each would want.	Surprised by the fact that a family could talk and laugh about their final plans, that the sisters were comfortable with that type of conversation.	N/A	Everyone has a different response to dying and death.	Through interactions and observations with the dying
	<i>Accepting things you cannot change</i>				
	Visiting a patient dying of breast cancer.	Shock at seeing the cancer spreading outside the body of the patient.	Wonder	Some patients exhibit a "readiness and acceptance about what was coming."	Through dialogue with the patient
	<i>Don't look at me like that; I was just doing my job!</i>				
	Seeing the son of a former hospice patient outside the hospice	Surprise when the son looked at her then quickly turned away	Hurt	When the bereaved see a hospice care professional, it can bring sad memories to them.	When, outside of the hospice, Carrie prepared to speak to the son of the former hospice patient but the son quickly turned away
	<i>Involve the loved ones</i>				
	Observing a nurse extubating a patient in front of the patient's loved ones.	Amazement	Interest (to learn)	Because the nurse involved the family with the procedure (e.g., telling the family	Through observation, both of how the procedure was performed (by the nurse's constant communication with the loved ones present about the

Participant	Incident	Primary Trigger	Secondary Trigger	Learning	How Learned
				what was going to happen, what to expect, etc.) the family was better able to deal with the death. The nurse took the mystery out of the process of extubation and how death was to occur.	procedure he was performing, and explaining the physical response of the dying patient) and how the family responded to being included in the process
	<i>Learn to live life to the fullest</i>				
	In dialogue with a patient	Surprise	Sorrow	To live life to the fullest	Through the patient relaying the story of how he worked seven days a week to make money to someday retire, only to find out when he finally retired that he was dying
Janet	<i>Sometimes families can be the best teachers</i>				
	Trying to operate a patient's pain pump	Surprise	Anxiety/Fear	Caregivers/family can be valuable resources in the effective care of a patient.	Through the instruction received from the family member about the pain pump's operation and how to get the patient to eat
Alicia	<i>Hospice care is "learn as you go"</i>				
	There are big differences coming from an oncology and HIV/AIDS care environment to the hospice care environment.	Surprise that everything (medication, dosing, lingo, etc.) was different	Interest (to learn)	How to speak to families in a caring way at a hard time because the hospice care professional wants to earn their trust	By observing other hospice care professionals and doing research on the Internet
	<i>Rare is the family that is going to come in all on the same page about death</i>				
	Communicating with loved ones of the dying about what would be best for the	Surprised by the mixed expectations among family members	N/A	It is rare that a family is going to admit a loved one to hospice with everyone being at	Loved ones will keep asking the same questions searching for a word of hope.  By letting the loved one knows that the

Participant	Incident	Primary Trigger	Secondary Trigger	Learning	How Learned
	patient			peace with imminent death.  When loved ones are ready, they will approach hospice care professional with questions AND listen to the answers.	hospice care professional was available; handling a business card. Make sure you seem approachable.
	<i>Didn't we cover this already?</i>				
	Communicating with loved ones of the dying	Non-verbal communication of the loved ones	N/A	Through the mannerisms of loved ones and their differing ways of inquiring about the status of the hospice patient	Through the regular intake of hospice patients and in communicating with the loved ones
Joe	<i>Does it matter to this Black family that I am White?</i>				
	A White chaplain provided comfort to a Black family who had lost a loved one.	Fear of how he was going to be received because he was of a different race	N/A	Those barriers are broken down in that intimate space of dying and death.  By just being the ministry of presence, he was helping the family.	One of the granddaughters of the deceased walked up and said to Joe, "You've just been really so good. Thank you for all your help."
			N/A	At times these barriers are more perception than reality.	One of the granddaughters of the deceased walked up and said to Joe "You've just been really so good. Thank you for all your help."
Frieda	<i>Frustrating at the beginning ... Very spiritual in the end. Let's call it "ironic."</i>				
	In-patient resident	Shock/Disbelief	N/A	Despite what was	Frieda was made out to be the person



Participant	Incident	Primary Trigger	Secondary Trigger	Learning	How Learned
	who was released into home health, but due to neglect had to be re-admitted to in-patient division	Gratitude/Redemption	N/A	<p>taught in school, one needs to take copious notes.</p> <p>"In light of everything you may go through, as long as you hold true to yourself and hold true to your clients and what you know to be true of what you're doing. You're gonna win in the long run. You're going to do what's right for those patients and you're going to get... Satisfaction out of that."</p>	<p>responsible for the lack of care of the patient.</p> <p>The dying patient was "hanging on," not allowing himself to expire for a long time. As soon as Frieda came to the bedside to say goodbye to him, he expired.</p>
Sophia	<i>Organization and structure is critical</i>				
	Organizing self	Feeling overwhelmed	Desire (to get organized)	Unable to function with disorganization	While handling an extra home health case load
	<i>Overall, we're a team</i>				
	Support of other social service support staff	The belief that providing assistance with patients is not outside your job requirements.	N/A	That it is OK to call on and to assist others with their job.	Observing other social service staff employees call on each other
	<i>You have to relate to people to succeed</i>				
	Continuous visits to home health patient, "Big Daddy"	Surprise that some people that are at "end-of-life" in hospice care are not actively dying.	N/A	Patient still had issues related to living (e.g., relationship issues with daughter, spiritual issues, quality of life	Through weekly interactions with the patient.

Participant	Incident	Primary Trigger	Secondary Trigger	Learning	How Learned
		Desire to be able to relate to Big Daddy as his private sitter, Arlette, related to him.	N/A	issues) You must be your genuine self.	Through observation of interactions between Big Daddy and his private sitter, Arlette.
	<i>Never forget that the job is about relationships even after the patient dies</i>				
	Making bereavement calls	Fear; not knowing what to do/say	Desire (to speak appropriately)	One must speak to the bereaved in a different manner than one would in other business calls.	Observation of the bereavement coordinator placing calls; mentoring of Sophia by the bereavement coordinator
Alex	<i>Not exactly learning on the fly, but...</i>				
	Providing bereavement counseling to a group of five sisters	Feeling of not quite knowing what to do	Desire (to be a help to the sisters)	"That there is hope that the most tangled mess with the longest history. Even if it's not coming to 100% resolution, it does have some hope for actual relationship."	"By just 'wading through it'; 'weave through the webs of the spirit.' There are theories learned in books, but it is a lot more intuitive."
	<i>Formal training doesn't prepare you for everything</i>				
	Coming onboard at United Hospice as the bereavement coordinator under the requirement that she design and develop a bereavement program	Despair at not knowing how to design and develop a bereavement program	Shame (for not knowing how to design and develop a bereavement program)	Should have asked superiors to help sooner; that "when you only can imagine one way of doing something, that is the way you choose. There is nothing to be ashamed of not knowing a job task that you have never been trained to perform."	Trial and error of setting up a system for bereavement program

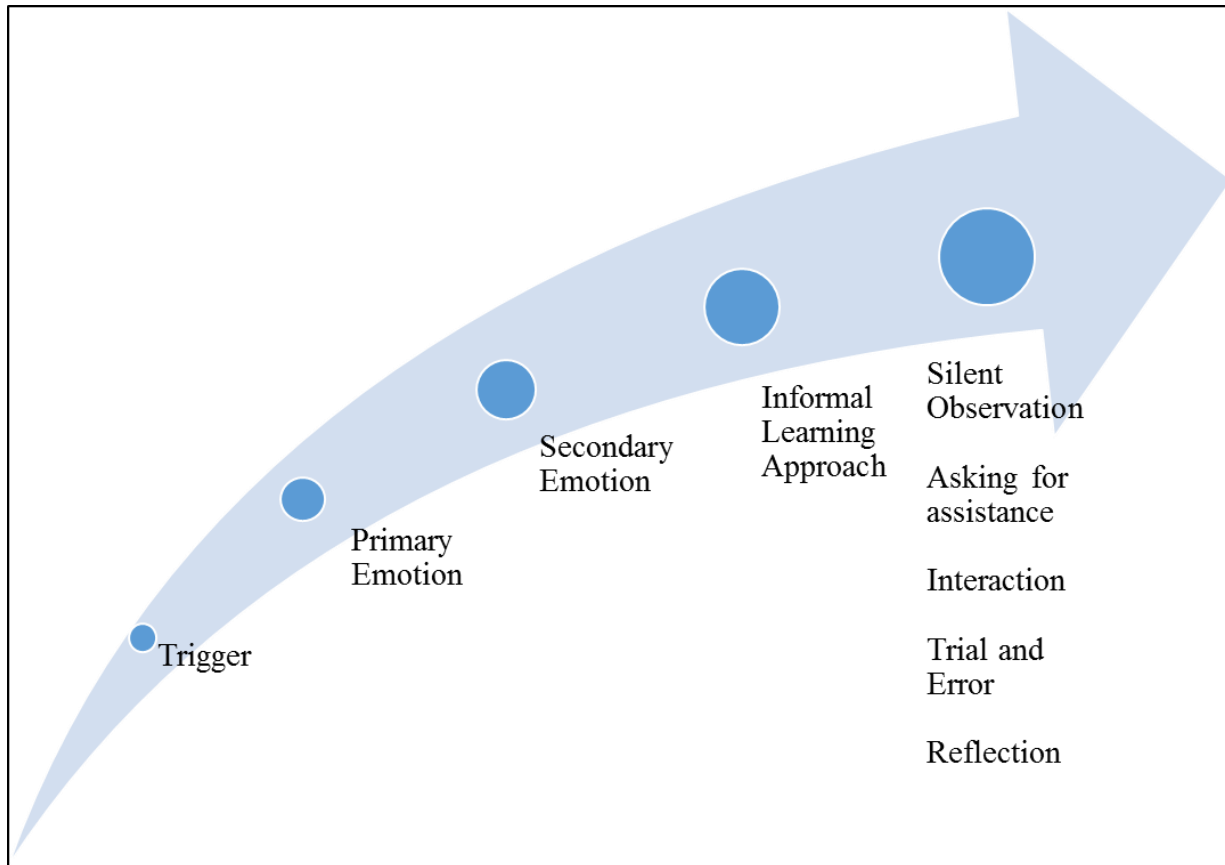
Participant	Incident	Primary Trigger	Secondary Trigger	Learning	How Learned
Tasha	<i>With a father like this, who needs enemies?</i>				
	Home health visits to a heart transplant patient and finding out how neglectful the father is to his son	Surprise at how this parent was treating his child	Disgust	Not everyone had a father like Tasha.	Through stories told to Tasha from the patient, patient's family members, and loved ones
	<i>Death: Maybe if we don't talk about it, it won't happen</i>				
	Speaking with loved ones of the dying about choosing a funeral director	Some loved one's avoid the subject, believing that even thinking about death, will hasten the death of the loved one.	Anxiety (over how Tasha will encourage the loved ones to begin thinking about choosing a funeral director)	There is a need for more education about end-of-life.	Through trying to coach loved ones of the dying in choosing a funeral director
Galina	<i>The "miracle" conundrum</i>				
	Home health case of a 16-year-old boy with a brain tumor	Surprised at the realization that the parent is in denial about the son's condition	Desire (to have the mother realize that there is always a "miracle" or "healing," but it may not be what we are asking for	"You can only give the information, and a person don't have to hear it if they don't want to hear it."	Through discussions with the mother, who believed that "the boy's dying will be a failure on God's part and on her part because she did not pray and/or tithe enough"; and by trying to get the mother to understand that there is always a "miracle" or a "healing," but it may not be what we are asking for.
	Patient with a battery-operated pain pump	Shock	Guilt	Always carry with the equipment a spare battery. Put blame where blame is due.	The patient committing suicide upon hearing the low battery alarm; he feared that the pain and suffering would return when the battery died.

One example of the secondary trigger was the story of Suzanne (“Never again on my watch”), whose home health patient committed suicide with a gun that was hidden within reach. The first emotional response was shock because Suzanne believed that she was making progress with this patient. The second emotion was guilt: Suzanne believed that she had failed to properly access the patient, to perceive that he was suicidal. This feeling of guilt encouraged Suzanne to reflect upon all her interactions with the patient to identify what she had done wrong. In this case, it was the patient’s daughter who helped to lessen Suzanne’s guilt. The daughter told Suzanne, "You know, we did everything we could to help him. He just was resisting. You were amazing. I know I did my part as a daughter."

Another instance of informal learning via a secondary emotional trigger was the case of Janet (“Sometimes families can be the best teachers”), who had difficulty operating the pain pump of a patient she was onboarding. As a hospice nurse with five years of experience, Janet’s first emotion was one of surprise that she could not get the pain pump to function. After trying a couple of different configurations, Janet experienced anxiety over the prospect that the patient would soon be in pain if she did not make the pain pump operational. This anxiety compelled her to seek guidance from someone more knowledgeable than she about operating a pain pump—in this case, a relative. By observing and asking questions of the relative, Janet learned the correct operation of the pump.

My last example of a secondary emotional trigger relates to Alicia (“Hospice care is ‘learn as you go’”). Coming to United Hospice from an oncology and HIV/AIDS care environment, Alicia was surprised that medication, dosing, and jargon used in hospice were different from those used in her previous work environments. Her surprise at these differences

triggered her interest in learning more about hospice care. Alicia’s learning occurred through research on the Internet but also by silently observing other hospice care professionals.



*Figure 19.* The nature of informal learning described by caregivers.

As the data in this study indicated, in emotion work related to death and dying, there are no “hard and fast rules” on how to interact with the dying and their loved ones; rather, there is a great deal of learning “on the fly” through trial and error and by hearing situational stories (either anecdotally or in case study presentations) from other hospice care professionals.

## Research Question Two

When interviewing the action research team members about the supports they received in their role as hospice care professionals, administrators and coworkers provided rich examples of both supports offered and supports lacking. Table 15 presents the themes and sub-themes that emerged during data analysis regarding the types of support that are (and are not) effective for individuals engaged in emotion work.

Table 15

*Types of Support that Are Effective or Ineffective for Individuals Engaged in Emotion Work (N=7)*

Theme	Sub-Theme	Number of times mentioned during interviews
Types of support that are effective	• From coworkers	16
	• From hospice administrators	6
	• From the dying or bereaved being supported	4
	• From loved ones	2
	• From support staff meetings	2
Types of support that are ineffective	• From hospice administrators	4
	• From coworkers	2
	• When the help is not helpful	1
	• Lack of infrastructure	1

### Types of Support Found to Be Effective

Hospice care professionals, especially among the support staff employees, spent a great deal of time providing support to each other around navigating the organization, settling internal disputes, and providing encouragement when feeling overwhelmed. At times, positive support came from the individuals who were initially the recipients of the support.

**Support from coworkers.** Support from coworkers at United Hospice came in the form of guidance and encouragement. The role of guiding those working in the in-patient division often fell to Alex, who had been at United Hospice for three years and was the most senior non-clinical employee in the in-patient division. She often found herself helping her coworkers navigate the United Hospice work environment:

I spend a lot of time trying to help Frieda and Sophia and Joe deal. Right, so I spend a lot of time helping them sort through conflicts, helping them deal with their stress of all this stuff people are putting on them, helping Joe figure out, you know, his boundaries and his job responsibilities.

Encouragement came in various forms for the hospice care professionals at United Hospice. At times, the way in which another coworker performed his or her role that provided encouragement for others. Carrie shared how Joe had made a difference to the unit since he began working at the hospice:

Joe has been helpful. He has occasionally been, when he's not too busy, getting the staff together. Sit down if they need to pray about anything, anything bothering anybody. He's been doing that. There's no chaplain we had that did that. I thought that was very nice. For birthdays, he comes and he gets everybody together, and sometimes he say a poem about [the person], write a poem about the nurse or whatever. He does very, very well. He does a whole lot of stuff that a whole lot of people really don't do. Very fantastic. In the middle of the day, about two in the afternoon, 12-hour shift, he said, "Let's just gather together." We talk, we share. Oh, and if there's a big event or something racial happened that people might be angry about, he brings it up and we address it.

Sophia told of the support she received from Frieda and Joe:

I feel generally supported if I feel overwhelmed or something like that, since I'll wear other hats than just volunteer coordinating lately. Frieda and Joe are always so good about being, like, "You're only one person. Your charts and your visit logs show for what you've done all day."

**Support from the hospice administration.** A few of the hospice care professionals interviewed for this study cited the administration's approval of my project at United Hospice as proof the administration supported its employees. As Carrie stated, "In the beginning when we all got together, I thought we were all on one accord. That was how I felt. I thought I was excited. I thought, 'Okay, something good is going to come out of it.'" In interviews, several hospice care professionals told stories of how administrators, namely Galina, supported their employees when "things get extremely overwhelming." Galina had been known to "swoop in and put barriers in place" or as Galina called it, "[putting] up a shit shield" to relieve an individual of some of his or her workload.

**From the dying or bereaved being supported.** There were times when, unexpectedly, the encouragement came from the dying or bereaved being supported. Joe shared the story about the Black family whose patriarch had died and the granddaughter later telling Joe, "You've just been really so good. Thank you for all your help." Joe was surprised because initially he feared he would be seen as "another White do-gooder," and he also believed that he had nothing to offer that family from a chaplain's perspective.

Joe shared another story of support he had received not only from the bereaved but also from his coworkers. The incident occurred when he was called back into work one night, a few hours after completing a full shift. When Joe received the call, a hospice patient had just died



about 30 minutes earlier, and the family was asking for the spiritual guidance of a chaplain. Joe returned to the hospice to meet with and lead the family in prayer, spending approximately one and a half hours with them. The amount of gratitude the patient's family "blessed him with" (Joe's words), along with the display of gratitude shown by the nurse on duty who requested Joe to return to the hospice, provided him with significant encouragement about how well he performed his role as chaplain.

Joe shared a story from his first days as a United Hospice chaplain when a patient, a native of Cuba, came into the unit. The patient spoke no English, and Joe spoke very little Spanish. Still, Joe felt he needed a way to connect with the patient. The only way he felt he could possibly connect with the patient was through music. Going to his office to get his laptop, he searched Google for music from the Buena Vista Social Club, a well-known Cuban band. Joe set the laptop on the patient's tray table and pressed play on a YouTube video featuring the band. Joe explained:

That's the only [Cuban band] I know, so I went over there and I played it. He's uncomfortable, he's kind of in and out, but when I turned it on and played it his fingers were kind of "tap tap tap," kind of going with the beat.

**Support from loved ones.** Out of the six hospice care professionals interviewed post intervention, only one stated she received support from a loved one. Alex remarked that she received support from her significant other when she reflected upon certain incidents that occurred at the hospice:

I talked to my husband about it last night ... Yeah, I talked to him about a lot of things last night, about a lot of work stuff last night ... processing things. Yeah, we were talking about folks who have anxiety and feel like ... or are having a hard time and feeling really

anxious. I'm like, "I get so anxious all the time." He's like, "You felt anxious for a while." I'm like, "You're right, I did." I had a rough time here at United Hospice about a year and a half, two years ago. Then when he said that, then I sort of reflected some more. When Sam said yesterday that people, when they come here, they get a grace period, but then all the sudden they get thumbed down real hard and back to the wall, a lot—much pressure. That was certainly true for me.

**Support staff meetings.** Support staff meetings proved to be gatherings where both the home health and in-patient unit support staff could compare notes, share a meal, stories, and experiences, and go to each other for help. After one meeting, I made the following notes:

Before the meetings were held there were two entities at United Hospice, the support staff of home health and the support staff of in-patient unit. In the five months since the support staff meetings have been held, there is a cohesiveness and camaraderie among the group. I can actually see and feel the group to be a single entity, the support staff of United Hospice.

During her interview, Sophia echoed my observations about the group's cohesiveness: "I really feel like we could all go out for drinks tonight, you know. I can see you outside of work and not be weird. I hope everybody can feel that supported." Sophia's comment was regarding an incident that occurred during a case study presentation at a staff support meeting. Joe had supported Sophia in her position in the case study and explained to her that she brings much skill and experience to the position. Because she brought a lot "to the table," there was no need to act in a subservient manner when dealing with the administrator.

Suzanne said the support staff meetings helped her to:

feel supported, basically since we met the first time. The first time we all ever got together. When we get in the support services (sic) meeting and Alex asks, "Does anyone have any questions? Does anyone have anything going on?" I can appreciate that because sometimes you do have stuff going on, but you don't know if that's the right time or place to ask those questions, and the fact that we have that opportunity during those meetings is ... I appreciate it.

### **Types of Support Found to Be Ineffective**

When I asked the action research team interviewees for examples of support, I was also offered examples of non-support from hospice care professionals.

**From hospice administration.** Suzanne, whose patient committed suicide, felt she “was not supported by the medical director, the business administrator—no one. No one followed through with her situation.” In a support staff meeting, Suzanne elaborated on the lack of support. She asked the group, “Why didn’t anyone HELP me?” Suzanne said that after the incident had occurred—which was a first for the hospice—everyone went on with “business as usual.” There was no follow-up, no recap, no meeting to ask if she needed help. Although various individuals (mainly the home health chaplain) pulled her aside to ask if she was okay, there was no “company response or follow up” to the incident.

Tasha, a home health social worker who was interviewed during the first round of interviews but left the organization soon afterward for other employment, spoke about the lack of consideration United Hospice had for its home health staff. United Hospice offered home health services in the metropolitan area and its 22 surrounding counties. While the hospice had increased its home health patient intake, it had not increased the home health staff. This required Tasha and other home health staff to both travel further and care for more patients. Tasha

believed that this situation resulted in not providing patients or families the time and attention they deserved:

It just poses a problem because you're rushing. Sometimes I feel like I have to rush to get to the next person because sometimes they are so spread out so that service delivery is a challenge. You're rushing and you feel bad doing it. That can be challenging because you can't give them all of your attention.

At times the hospice care professionals were requested and expected to perform tasks that, if there were standard position descriptions in use, would not fall within the scope of the description. Once, Frieda was ordered by the medical director to contact a parent of a pediatric patient to get permission to perform a particular medical procedure. As a social worker, Frieda had no knowledge of the procedure she was to recommend to this parent, nor did she know about possible complications or side effects, which Frieda was sure the parent would ask about. Having to perform tasks without prior knowledge of how to perform them led Frieda to feel overwhelmed, leading her to conclude, "It's not the job in itself. It's what's put on me."

Two action research team members mentioned the lack of support given by the hospice administration when the "leadership" (i.e., the nurse practitioner, facility director, and administrator) stopped attending the bi-weekly meetings. While I was never able to get the entire action research team to the meeting at the same time, the first few meetings included at least one leadership representative present. I kept all members of the action research team abreast of meeting activities and decisions via the meeting minutes. Carrie said the following about the hospice administration's support:

I think it was going well. Then I felt, at some point, the people I thought would have joined in, would join. I guess I [didn't] know management, higher than I am, would have supported that need for structure.

I thought this an odd statement considering Carrie stopped attending the action research team meetings herself. I sent individual emails to each administrator, facility director, and the nurse practitioner, pleading with them to attend the meetings, that their presence was a morale boost for the other team members (i.e., the bereavement coordinator, chaplain, social worker, and volunteer coordinator). No one ever responded to my requests.

At times, the encouragement came from coworkers when they saw the words and actions of administrators hurt another coworker deeply. Although all hospices are supposed to operate under the framework developed by the International Work Group on Death, Dying and Bereavement (IWG) (Vachon, 2015)—that is, under an interdisciplinary team comprising patients, family members, and professionals, with all disciplines being equal partners without privileging one discipline over another (Buck, 2011, p. 7)—the support staff believed they were not held in as high regard as the clinicians. This incident underscored this belief.

At United Hospice, the IDT meeting began with a report from the bereavement coordinator (Alex). (Historically, the medical director was late for this meeting, always arriving sometime after the bereavement presentation). In this particular session, the medical director entered the room just as Alex was finishing her updates. Upon the medical director's entry, the administrator said, "You are just on time Doctor; we are just finishing up with bereavement." According to Alex, Sophia, and Frieda, that statement "crushed" Alex's spirit.

Immediately after the meeting, Frieda and Sophia approached Alex to comfort her and to lift her spirits. According to Alex, Frieda and Sophia told her:

We didn't think that was very nice. We really value what you do and we know that it's very, very hard. Especially Sophia is like, "I know that it's very, very ... That's it's a whole lot of work that you do and it's very valuable." Frieda said that "Every week when I hear you go through the bereaved families and stuff, it really helps me to let go of taking care of those people when I know that they're in somebody's good hands ... Like it's a good, rich, meaningful information. I know that they're in somebody else's good hands and I know that they're going to be taken care of and I can let go."

While the statement from the administrator to the medical director in front of the IDT members hurt Alex deeply, her coworkers attempted to provide her with encouraging words to assuage that pain.

**From coworkers.** Joe shared a time when a nursing assistant tried unsuccessfully to help when she took over the care the chaplain and the social worker were providing to a grieving family member:

Just last week a younger mother died. That patient's cousin was particularly grieving in very powerful ways which I wanted to honor and give that person space. I'm not going to tell them it's going to be okay and to calm down. They needed that. It's sacred, and you can't get in the way of that. It's a really important part of their grieving process, that initial ... Really important, the deeper they grieve initially, the deeper their grief process will become later on. A social worker was there. A social worker came in to support. She saw that the griever was hyperventilating, and so the social worker was a little concerned and trying to coach her into breathing and taking some deeper breaths, slower breaths. At which point, a nurse assistant jumped in and offered assistance and escorted the griever out of the building, down the elevator, and outside, believing that the griever

needed fresh air. The social worker and I didn't agree that that was the best course of action. Now, she is outside with people walking around and it's not good safe space. It would have been better just to walk down the hall and be in that private room. The case was the [certified nursing assistant] was not “staying in her lane,” if you will. She was assisting with pastoral care and social work responsibilities. Maybe she did, she truly wanted to help.

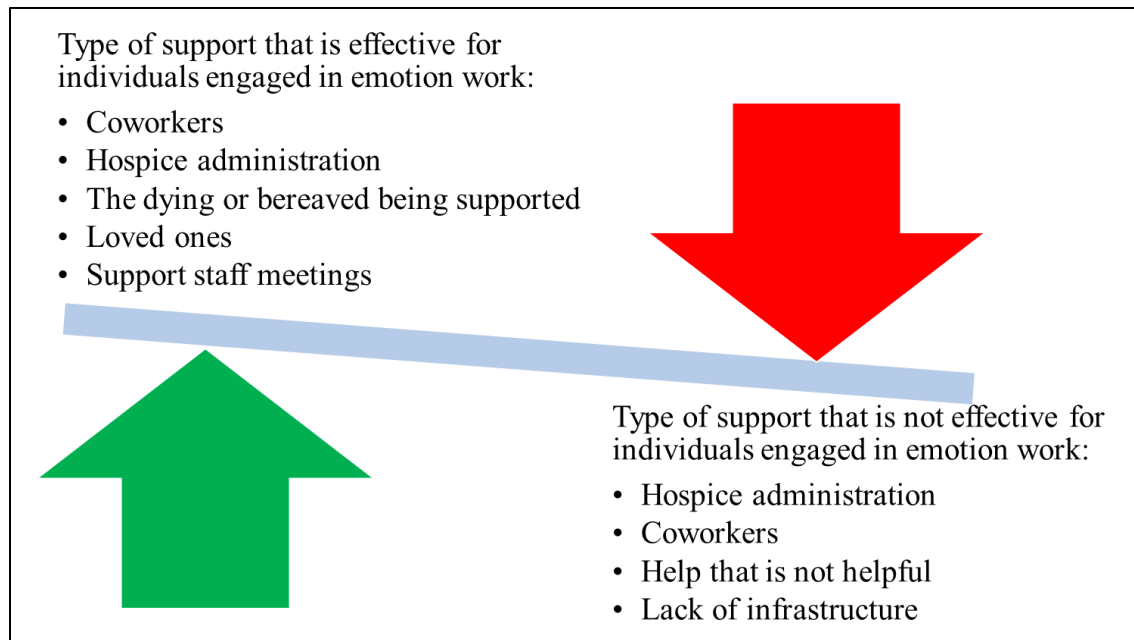
While the nursing assistant probably did want to do something helpful, her interference with the care that was already being provided to the loved one by the chaplain and the social worker was not helpful. Joe later explained that the nursing assistant, by taking the loved one, who was grieving heavily, out of the building, sent the wrong message to everyone in the room—that having a strong reaction to a death is not normal.

Finally, Suzanne shared a story about lack of coworker support. Suzanne felt that her being in the field, as the home health social worker, isolated her from the support her counterparts in the in-patient unit were receiving:

Sometimes I don't feel like I'm supported as well as the social workers that may be in the in-patient unit, just because we don't have interaction with any of the support members during the week, because we're in the field. I'm a home health social worker, so my only interaction is with my patients. I don't really run into any other staff members. When I have an encounter, or something happens, I kind of either have to figure it out myself or I can call them, but they really don't know what's going on. They're not in a particular type of field or they don't even know my patient because we're just doing two separate things.

## **Summary for Research Questions Two**

Overwhelmingly, the hospice care professionals at United Hospice found the greatest amount of effective support among each other. In a couple of cases (i.e., Frieda and Joe), effective support also came in the form of the actions of the dying and words from loved ones of the dying.



*Figure 20.* Types of support that are effective or ineffective for individuals engaged in emotion work.

For Frieda, who was under fire for her decisions related to a patient's care, the fact that her patient, who, according to the nurses, was "hanging on all day," finally expired after Frieda came to his bedside to say goodbye, was her sign of that she made the right choices on his behalf. In the case of Joe, his receiving words of appreciation from the granddaughter of a deceased patient was his sign of support at a time when he believed he did not have much to offer the family. While these supports were unexpected, they were probably the most powerful



sources of support because those actions and words erased any doubt about how capable that hospice care professional was at doing his or her job.

An unexpected but valuable addition to the research was the feedback about what types of support were not effective for individuals engaged in emotion work. Many believed that the hospice administration (i.e., the lack of position descriptions, the way some employees were reprimanded and others were not for the same infraction, the defensive nature of some employees, lack of communication overall, etc.) contributed to the stressful environment, which did not have the infrastructure to support its employees. Earlier I shared the incident involving Joe and the nursing assistant who took over the care of the grieving loved one, while the grieving loved one was already being cared for by the chaplain and the social worker. These instances that the hospice care professionals view as a lack of support for performing their jobs presented an opportunity for the hospice administrators to make some needed changes and also provide education around job responsibilities.

### **Research Question Three**

The data analysis regarding this question was different. When I asked the question about “learning,” the responses were more concrete; there was no theme that needed to be teased out. I asked not only what was learned but how” the learning occurred. Table 16 presents what was learned by the hospice care professional and in what manner the learning occurred.

Table 16

*What Is Learned by an Action Research Team Exploring the Emotion Work of Individuals Who Provide Emotional Support to Those Experiencing Dying and Bereavement? (N = 7)*

What Was Learned?	How Did It Come About?	Number of Times Mentioned During Interviews
Learned how to develop trust in each other	<ul style="list-style-type: none"> <li>• Support staff meeting. (Allowing the support staff the opportunity to meet regularly)</li> <li>• Support staff meeting became a safe space to seek and give advice</li> </ul>	9
Learned about the roles and responsibilities of other hospice care professionals	<ul style="list-style-type: none"> <li>• Participating in staff support meetings</li> <li>• Case study presentations</li> </ul>	6
Learned how well the action research team operated as a team	<ul style="list-style-type: none"> <li>• Through implementation failure of first intervention</li> <li>• Recap of events leading that occurred during first intervention</li> </ul>	3
Learned about themselves as hospice care professionals	<ul style="list-style-type: none"> <li>• Reflection (after events, discussions, case study presentations)</li> </ul>	8
Sustainable change must come from the top	<ul style="list-style-type: none"> <li>• Through implementation failure of first intervention</li> <li>• Recap of events leading that occurred during first intervention</li> </ul>	2

### **Learned How to Develop Trust in Each Other**

This was a unanimous sentiment among the action research team. Beginning with the first meeting when the action research team started, continuing into the monthly support staff meeting, the action research team grew into a unit which relied on and supported each other as hospice care professionals.

**Just by having the opportunity to meet.** Prior to the beginning of each support staff meeting (i.e., a meeting of the support staff of both the home health and in-patient units), everyone in attendance went around the table to “check in”—give a brief description to the group as to where one was mentally, spiritually, emotionally, etc. The purpose of this check-in was to

allow the team members to stop and reflect on what they felt individually as they went into this setting to meet as a group. Alex believed the check-in allowed the support staff to see each other as people with issues outside of work instead of “Julia, the home health social worker”:

I think that there definitely has been growth there and possibilities there and I do think that it has improved things whereas if we didn't have that space it wouldn't. We don't have any other venue where we come together like that ... And that's exactly why you need these forums where we can stop to talk about things because we're going to have issues and we need to understand each other better and sometimes people do slack off, and they just don't do their work. Sometimes there's a legitimate reason, and there's something going on behind the scenes we don't know about.

Alex also believed that everyone, but in particular hospice care professionals, needed regular times of debriefing, support, and time to reflect:

They need content [e.g., what the case studies bring], but they also need space. They need content to get them going and reflect on things and continuing education, but they also just need open space to work things out by talking and being with other people and experiencing silence and stuff.

Since the implementation of the intervention, the monthly support staff meetings had become “safe spaces” for the support staff—from both home health and in-patient units—to come together, have a meal together, share ideas about how to approach a situation, and to ask for advice on how to deal with certain people within the hospice.

## **Learned about the Roles and Responsibilities of Other Hospice Care Professionals**

During the initial interviews with the members of the action research team, participants mentioned more than once that there was not a clear delineation of roles within United Hospice. For most of the support staff, working at United Hospice was their first professional position since completing their respective graduate studies, while for support staff personnel who were seasoned professionals, United Hospice was their first position within the context of hospice itself.

Throughout the case study presentations at support staff meetings, it quickly became apparent that there was not a clear understanding of the tasks or responsibilities other professions performed. One chaplain's case study not only provided the chaplain with the feedback he requested regarding the particular case, but it gave him an opportunity to answer some of the social workers' questions about what a chaplain does when working with the dying or bereaved. Another case study presentation, by Frieda, began a discussion on the different responsibilities that an in-patient unit social worker has to her home health counterpart. Until this support staff meeting intervention and until this case presentation, the in-patient unit and the home health social workers were unaware of the differences in their duties.

**Differences between the tasks of the units seemed unequal to both sides.** Sophia stated that, while the support staff meetings and case study presentations had "built some understanding about sort of the differences between the roles," those roles still seemed unequal:

and that's exactly why you need these forums where we can stop to talk about things because we're going to have issues and we need to understand each other better, and sometimes people do slack off and they just don't do their work. Sometimes there's a legitimate reason, and there's something going on behind the scenes we don't know about.

Sophia believed that if there were greater communication from the administration regarding “what the heck a social worker is supposed to do, there would not be this sense of unfairness, at least on our end.” Alex expressed similar concerns:

It's just hard for some of us up here to understand, and we haven't really been given a good explanation in terms of if they have 20 or 30 patients a piece down there and they only have to make one visit a month, then that's really just one to two visits a day. Assuming that they're working five days a week.

That's really just one to two visits a day and then a phone call, again, once a month. Obviously, there's other legwork to do sometimes, but it just seems ... What are you doing with your time ...

The support staff meetings [have] built some understanding between their roles [i.e., home health and in-patient division] and all the things that they're responsible for, so the jobs, they're obviously not equivalent and, not necessarily, they don't have to be unbalanced, but it's felt, at least by Frieda, that they are unbalanced and I can see her argument ... The feeling in the in-patient unit is that the home health social workers are slacking off, so, therefore, there is not a lot of pity or sympathy for their plight. Instead, they're viewed as kind of favored, whereas Frieda up here is feeling more hemmed in.

Just as Sophia and Alex believed that the in-patient unit staff were “doing more” than the home health staff, Suzanne felt as though, because the in-patient unit had “direct access” to peers and the administration, they were better supported:

I feel like we have a good team here, but it does come to a point where sometimes I don't feel like I'm supported as well as the social workers that may be in the in-patient unit just

because we don't have interaction with any of the support members during the week, because we're in the field.

In my final conversation with Frieda, her concerns centered on “the behind-the-scene issues,” such as the medical director “really harping on funeral homes” (meaning during the IDT meeting, the medical director seemed to put pressure on the social worker to urge the patient or their loved ones to decide on a funeral home that would be called to pick up the deceased once the patient expires). Frieda believed that:

it's one thing that has to resolve itself. One way or another it's going to happen, whether I intervene or not, whereas in other issues it's not going to happen if I don't intervene. So, to me, I should be focusing on other things, like the nursing home placement. Other things like that, that if I don't intervene it's not going to happen.

**Case study presentations provided most of the education.** The case study presentations at the support staff meetings provided an opportunity for attendees to get a firsthand look at an end-of-life scenarios from the perspective of other professions (e.g., a social worker observing the case study presentation of a chaplain) or from the perspective of the same profession but within a different context (e.g., a home health social worker observing the case study presentation of an in-patient unit social worker). For instance, during one case study presentation and subsequent discussion, I found out that the volunteer coordinator/social worker thought that the purpose of the chaplain when visiting a person was to “lay hands on them” [i.e., pray over them]. She had no idea a chaplain conducted a spiritual assessment of the patient or was formally trained beyond seminary to work with people in crisis. During another case presentation, both the home health social worker and the in-patient unit social worker realized

that the intake process for patients was different and that there was different paper work required for home health versus in-patient units.

Remarkably, each group thought the other had greater advantages: the home health social workers believed that the in-patient unit social workers had greater support from the hospice (because “support can be found just by walking into someone’s office”). Suzanne recounted many times when she had been required to make a “judgment call” with no backup or support. When asked why she did not call the administrator (or anyone) for help during those times, Suzanne replied that it was because she did not have interaction with any of the support members during the week, because she was in the field. The only interaction Suzanne had was with her patients, since she did not run into any other home health staff members. If an incident with a patient or within the patient’s household required social work involvement, she had to figure it out herself or call for advice, but she felt that the person from whom she sought advice did not know what was going on. They were not in a particular type of field from which she needed advice, or they did not know the patient because they (i.e., Suzanne as the social worker and whomever she would reach out to) were doing two separate things.

Conversely, the in-patient unit social worker believed that despite the home health social worker being required to do a significant amount of driving to visit patients, that individual had more freedom associated with the position with fewer patients. In addition, because the in-patient social worker was “onsite,” she was required to perform tasks that were not among a social worker’s responsibilities. (For example, the medical director required the in-patient unit social worker to get the permission of a parent of a pediatric patient about a medical procedure that the medical director thought the patient should have.)

During a case study presentation, Joe observed that at times nurses (or certified nursing

assistants) provide the “wrong” spiritual guidance to patients, with, for instance, a certified nursing assistant telling a patient that his or her soul needs to be “saved” before he or she dies. This was a surprise to the chaplain because while he knew nurses were with the patients throughout their shifts, administering medicines, and cleaning, feeding, and at times talking with the patient, it was not until he walked into a room and heard the certified nursing assistant tell a patient his “soul needed to be saved” that he realized “bad theology” was being spread. During his case study, the chaplain asked the group what he should he have done because he was so shocked; he did not know what to do and, therefore, did nothing. (The recommendation was to take the offending person aside and explain that telling a patient that they “have” to do anything before dying could cause spiritual harm to the patient).

### **Learned How Well the Action Research Team Operated as a Team**

Trust and confidence among the group members grew through the meetings. As Joe commented:

With that confidence and trust come much more effective and formal learning in develop[ing] collegiality, cooperation, and where it is much easier to admit shortcomings or have questions or concerns. Yeah! It's much easier to approach that person, and so the day-to-day of working with patients becomes much more fluid and comfortable. Trust grew through our meetings.

I observed this enhanced trust and openness among the in-patient division support staff and between the home health and in-patient support staff. In the support staff meetings, I saw Joe being honest with Sophia about her worth and telling her she should not capitulate to the administrator. In response, Sophia told Joe that she felt as if she owed something to the administrator because the administrator had given her a professional job at United Hospice. In



addition, the home health chaplain shared his story about his first few years with the hospice, how he had taken steps to overcome administrative difficulties.

The greatest growth appeared to have occurred with Carla, a home health social worker hired within the past year. Carla came to the staff support meetings but rarely offered input. After about the fourth or fifth meeting, she became more confident and engaged both in the meeting and with the other support staff members. Alex noticed this change in Carla as well:

I do think that having this opportunity [i.e., for the support staff to meet on a regular basis] has certainly improved things. [Carla] was very human yesterday, especially when we were having our discussion at the end and very relatable, and people were able to be open and talk about things. Not so much especially stuff that related to her, but she was very open, and I think that really did help and I think the fact that we've been trying to build up that space for a few months did help. That couldn't have happened the first time.

Joe added that the support services group members could provide their own sources of informal support: “I feel like when that trust and openness of being able to let down guards, that ... as that is nurtured, built into that is informal support.”

**The team learned about its strengths and weaknesses.** Once I analyzed the transcripts from the first interviews with the action research team members, I identified emerging themes and shared my findings with the action research team. My findings seemed to confirm individuals’ sense that they were not alone in how they felt about what worked well and what did not at United Hospice. This shared feeling seemed to have empowered the group to be more vocal about their concerns related to their work environment. During her closing interview, Sophia recollected the effect of the action research team realizing that most everyone felt the same about the United Hospice environment: “I think [the shared feeling of what does not work

at United Hospice] gave us the backbone to ... figure out what's not working and kind of get ready to 'buck' the system."

This collective sense of "backbone" among the action research team led the members to propose a new approach to conducting the IDT meetings. The action research team spent months determining the components of an efficient and effective IDT meeting. Once an agreed upon meeting process was in place, Alex consulted with and received permission from the medical director to carry out a three-meeting trial of the revised process. At the end of fourth IDT meeting, all in attendance would provide feedback to the action research team about what they liked and what they did not like about the revised process. In an about-face, the medical director challenged the action research team's rationale for revising the process, stating that her "20 years of experience [conducting IDT meetings] stands to reason that she knows what she is doing." The only members of the action research team who were present at the end of the meeting were Frieda, Joe, and Galina (Alex had to leave the session to attend to a family emergency, and Sophia experienced an urgent situation at United Hospice that took her out of the meeting.) The medical director asked both Joe and Frieda if they had a problem with how the meetings were being conducted; however, neither of them spoke up about why we, as the action research team, believed a revision to the IDT meeting was justified.

As Sophia stated, "the system bucked back that day." When the medical director challenged the present members of the action research team as to why there needed to be a revision to a process that she had used for over 20 years, the team collapsed. Alex said: "I think there were certain ways in which we fell in trying to present this and carry it out because nobody spoke up for it at the beginning. It felt like it was only me." Alex later told me that she spoke to

Joe and Frieda about their lack of response to the medical director's inquiry during the IDT meeting and how it was important that as a team they needed to stick together.

At the next support staff meeting, the attendees did not take on a case study but deconstructed what had happened at the fourth and final trial of the revised IDT process. I told those in attendance that while I was disappointed we, as the support staff, were not able to speak to the reasons we felt a revision of the process was necessary, I was more disappointed and shocked that the medical director, who had initially approved the trial, reversed her decision and, moreover, questioned the staff for wanting to revise the process in the first place. Joe felt that he "set the project back" by not being "forthright." When I asked him what had happened, why he did not explain what he believed to be the reason for revamping how the IDT was conducted, he admitted to being caught "off guard" by the medical director's inquiry. I was not surprised by his answer; none of action research team members present had anticipated the medical director's change in attitude regarding the revised process. When Alex asked Frieda why she did not speak up, Frieda explained that she felt she was already the target of the medical director's wrath and did not want to do anything else to "set her off."

We agreed that while the action research team grew stronger as a group in learning where we stood in our collective position, in identifying our needs as a support staff, and in learning to trust each other, our weakness related to our inability to face the medical director and defend "our truth."

### **The Action Research Team Learned about Themselves as Hospice Care Professionals**

The phrase "setting boundaries" was often used during the interviews with the action research team members. During the first interview with Suzanne, she told me that shortly after taking the position at United Hospice, she needed to set boundaries:

I give all my patients my work cell phone number, and if anything is to come up, the families have the okay to call me or text me at any time—that's fine with me. Normally I like to take calls before 5:00, but if it happens to be after that, I will take it. I'll address the concern. Nine times out of 10 for me, I find it to be more effective when I first meet them to get all of their needs, all of their concerns, write it down on paper ... Make sure I handle it before the next time I talk to them so that they don't need to call me for anything in between because it can be very overwhelming.

It took maybe about three months in [the position], and I was just like, "Okay. They can't call me every day. This is too much." Some patients I won't give my cell phone number to because I know that they'll call me every single thing [sic]. I know not to give my cell phone number to some patients from experience. Just experience.

Alex recalled a bereavement counseling situation with a woman whose mother had died. The woman, Alex recalled, had “no boundaries whatsoever”:

I met with her a couple of times, and she just was like trying to treat me like a friend and inviting me to social events. Every time I get her to go see a different counselor [because Alex felt the woman had issues beyond bereavement counseling and beyond Alex's capability], but every time she did, she would throw back at me, “Oh, but I came to hospice to have counseling, I want you to be my counselor, you're who I really want to talk to. I don't want to go to anybody else.” I want to try to cut her off; she liked to call the hospice and was like “telling” on me. I needed help.

Yeah, in that way, it was extreme. It was really extreme. I tried to talk to her for a while and quickly realized that I was way out of my depth ... Even at one point, she's like, “I want to have grief counseling with my sister,” and I was like this is really, like, I

am not cut out for this. I let it happen.

I think that [bereavement counseling] was good for her sister, and it got nowhere with her. Yeah. She would just have kept going forever, forever, and ever and ever.

Yes, until I was finally just like, “I just can’t do this anymore. I’m not helping you.”

Sophia recalled when the director of social services left United Hospice, her role began to change, and she was asked to take on more responsibility. When reflecting on that time just after the director left, Sophia stated, “It’s cool to help folks out and do what you can do, but sometimes you got to take care of yourself ... It’s teaching me to set boundaries.”

It seemed that most of the hospice care professionals were setting boundaries prior to the implementation of any intervention at United Hospice, but not until the intervention occurred and support staff members began to communicate with each other did they realize that “setting boundaries” was a shared valued among all of them.

One pervasive sensitivity among most of the employees I interacted with at United Hospice and all of the action research team members was that no one liked it when someone else thought he or she could do that individual’s job. Very early in my visits to United Hospice, I heard the following rant:

People think to do social work all you need to do is have a kind heart; to be a chaplain, all you need ... is to learn how to pray. There are years of schooling and training that occurs that prepares us as professionals to perform this type of work. I am sure there are misconceptions about nurses, and I am sure they do more than prescribe medication. However, we don’t know—we don’t know because there are no job descriptions.

### Summary for Research Question Three

This intervention resulted, in many ways, in a transformational experience for the action research team. Meeting regularly, both as an action research team and as attendees of the support staff meetings, provided a safe space to seek assistance regarding issues of individual professional concern and allowed for all to learn about the roles and responsibilities of other hospice care professionals.



*Figure 21.* What is learned by an action research team exploring the emotion work of individuals who provide emotional support to those experiencing dying and bereavement?

The case study presentations delivered during the support staff meetings encouraged much reflection—on how the case presenter handled the case, on how meeting attendees would have handled similar situations, on other people’s points of view. There was no other time in the

mostly short tenure of the staff that United Hospice employees were allowed to commune around their experiences as hospice care professionals. These meetings served as constant reminders that each hospice care professional was not alone in the trials and tribulations he or she experienced at a hospice. As a result, there was a visible sense of trust among those who attended the meetings regularly. Trust was exemplified by meeting attendees expressing their feelings about an individual to that individual, resulting in honest dialogue; it was exemplified by the in-patient unit chaplain (who was new to his role) joining the home health chaplain (who had six years of hospice chaplain experience) on home visits. The failure to stick together as a team when challenged by the medical director around the need to reorganize the IDT meetings and the later discussion among the action research team regarding its failure to be united illustrated the importance of functioning as a team. Overall, the support staff from both divisions became closer as a result of the monthly support staff meetings. However, I still wonder if unity would prevail where the group challenged again by the medical director. Finally, with regard to this hospice, the action research team realized that they could only make so much of a difference in their environment; any sustainable change must come from the support of the medical director/owner.

### Summary

The most common emotion experienced by hospice care professionals was surprise. Often this emotion was followed by the secondary emotion that encouraged an informal learning approach. *Regarding the emotions of happiness and redemption, those emotions were not felt until after the informal learning approach proved effective or successful. Much of the learning in emotion work related to death and dying occurs “on the fly” and through trial and error. The support from coworkers was found to be the most effective source of support for hospice care*

*professionals. Hospice administration was found to be an effective source of support and, at times, not an effective source of support for hospice care professionals.*

For the hospice care professionals of United Hospice, learning to have trust in each other was the greatest affect this study had on its participants. Just having a regular, dedicated time to meet and talk about hospice related topics proved beneficial. Learning about the roles, responsibilities and challenges of their peers through the case study presentations was transformative; not only did the hospice care professionals learn about each other's' responsibilities, but they also learned that they shared similar challenges working in hospice.



## CHAPTER 6

### CONCLUSION

The purpose of this action research study was to explore the informal learning of hospice care professionals within the context of their emotion work, with the aim of analyzing learning needs and proactively developing professional development interventions to address those needs. This chapter begins with a discussion of the summary of findings, followed by the significance of the study, conclusion, recommendations for future research and concluding thoughts.

#### **Summary of Findings**

The setting for this study was a privately owned hospice located in the southeastern United States. The questions guiding this study were: (1) What is the nature of the informal learning described by caregivers?; (2) what type of support is effective for individuals engaged in emotion work?; and, (3) what is learned by an action research team exploring the emotion work of individuals who provide emotional support to those experiencing dying and bereavement? The empirical literature on death and dying, emotion work, and informal learning as it relates to hospice care professionals is sparse. This study adds to the body of knowledge in the death and dying empirical literature; the results aligned closely with the research of Payne, Dean, and Kalus (1998), who found that many of the stressors that hospice care professionals face are mainly work-related and affect work performance. Unlike Hockley and Froggatt's (2006) success using action research methodology—which generated a feeling of appreciation among study participants and enabled them to take responsibility for making and sustaining changes regarding palliative care education—this study generated mixed results among the action

research team members. Finally, regarding the findings in the empirical literature around informal learning, this study aligned with Wofford, Ellinger, and Watkins' (2013) research on the learning of aviation instructors. The complexity of the process of informal learning as it unfolded in a very dynamic, ill-structured, and often spontaneous environment was very similar to the environment experienced by the hospice care professionals at United Hospice.

The interviews of 12 hospice care professionals were open-ended, with both narrative and participatory qualities, contributing to a research design that was qualitative in its approach (Creswell, 2009). The interview formats included group discussions and one-on-one interviews, encouraging depth and breadth in answers to the research questions. Data collection methods included critical incident interviews, researcher observations, and notes, team meeting minutes, and closing interviews. Interview transcripts were analyzed using the constant comparative method. By the time the results of the interviews had been developed and an action research team formed, the number of the study participants had shrunk to four. The action research team identified two interventions for implementation: (1) a revamp of how the IDT meetings were conducted and facilitated, and (2) monthly support staff team meetings. Initially, the medical director (who also owned the hospice) approved both interventions; however, shortly afterward, she rescinded approval of the first intervention. The monthly support staff meetings were successful, bringing together support staffs from the separate divisions of the hospice. Once non-existent work relationships formed between workers from different divisions. In one case, a mentoring relationship formed.

In the final interviews, six hospice care professionals were interviewed: the four that made up the action research team and two management-level employees who had stopped attending the meetings but always inquired about how the study was progressing.

The critical incident technique was used to identify when and under what conditions informal learning occurred. Data analysis showed that informal learning among hospice care professionals at United Hospice occurred primarily through observation, learning “on the fly,” and through trial and error. A critical incident always preceded an observation that led to informal learning. That critical incident produced an emotion that compelled the hospice care professional to approach the situation in a particular way; that emotion represented a disjointedness occurring between what was expected and what actually occurred in a particular situation. The hospice care professionals of United Hospice acquired a great deal of informal learning through reflection. For Carrie, Alex, and Galina, it seemed that caring for the dying and bereaved led not only to informal learning through observation but significant internal and spiritual growth through dialogue with the dying and bereaved.

The internal support the hospice care professionals provided to each other was the most effective type of support for the individuals engaged in emotion work at United Hospice. Another type of support—that received from the dying and bereaved, whether via actions or words spoken—made an enormous difference to the hospice care professionals. Responses from the study participants also revealed the types of support that were not effective for individuals engaged in emotion work. Hospice administration and lack of infrastructure were cited as being unsupportive to individuals in emotion work. This was not surprising; Keidel (2002) found hospice administration to be a source of stress for some hospice workers.

Finally, an action research team exploring the emotion work of individuals who provided emotional support to those experiencing dying and bereavement learned a great deal both about themselves as hospice care professionals and as a team of hospice care professionals through reflection. They learned that the inordinate amount of pressure they may have felt in the

interdisciplinary department team meetings was not a product of their imagination but rather a real occurrence experienced by nearly every employee at United Hospice. They learned about their positions and what was expected of them from their coworkers. Individually, the action research team members learned they were not alone in their feelings of anxiety, discontent, satisfaction, etc., that occurred in their work as hospice care professionals.

Perhaps the greatest lesson the action research team learned was the need to support each other. While the incident with the medical director illustrated the need for the team to be united around concerns regarding the hospice administration, I believe the team, along with the other members of the support staff, realized that there were only a few others who understood hospice work and could help navigate issues that occurred as part of a hospice care professional's roles.

### **Significance of the Study**

The results of this study captured and documented the types of informal learning that occurred among hospice care professionals when empowered to implement an effective support intervention. Regularly scheduled support staff meetings served as resources for hospice care professionals wishing to become more proficient in executing hospice related tasks. These meetings reinforced informal learning that aided in the efficiency and retention of employees. This study of how a group of hospice care professionals learned informally is significant in that it serves as the foundation for other studies, including the following.

### **Research in the Area of Informal Learning of Hospice Care Professionals**

The results of this study could act as a foundation for the capacity building of hospice care professionals using informal learning. This study illustrated that the knowledge gained by the hospice care professionals was acquired through informal learning. Due to the lack of end-of-life preparation in the field by the institutions who graduate the physicians, nurses, social

workers, and chaplains who perform hospice work, I believe it would not be difficult to identify and therefore research the many instances of informal learning occurring among hospice care professionals. At the hospice level, effective learning represents a combination of formal training and the awareness of how one learns informally.

### **Research on How Common the Demanding and Emotionally Complex Nature of Hospice Work Triggers Self-Doubts and Arouses Strong Emotions**

Hospice care professionals provide end-of-life care to the dying and support to their loved ones. The element that separates most other vocations from that of the hospice care professional is that the latter faces death every working day. This entails having emotional conversations with patients about what is going to happen when they die, providing spiritual support to both the dying and their loved ones, and holding those needing to be held while they release what can be at times unyielding emotions. I have witnessed hospice care professionals assume the brunt of a loved one's fear, anxiety, and frustration without responding in kind. Hospice care professionals interact daily with the physicality of death and dying (for instance, the smells of decomposition). Study participants shared emotionally complex stories of incidents that occurred well before the death of the loved one but that were now at the center of the bereavement process.

Facing mortality (and all that comes with it) on a daily basis in their work environment aroused strong emotions in the hospice care professionals who participated in this study—including self-doubt. A few participants discussed feelings that revealed how effective they were in their position or if they were executing their tasks correctly. This highlights an opportunity for future research to explore why individuals working in such an emotionally complex environment are so hard on themselves regarding the quality of work they perform on the job.

## **Effectiveness of Hospice Support Staff Meetings**

The implementation of the monthly support staff meetings by the United Hospice action research team served as a formal way for professionals to receive information about new requirements and educational opportunities. The meetings provided a safe space to seek guidance and suggestions about professional situations a support staff member may have been experiencing. They also provided a sense of routine in what was normally a non-routine setting. I deemed the intervention effective because relevant knowledge was shared, and the meetings were self-managed, self-sustaining, and well-attended. However, this was one intervention; it would be examining closely the effectiveness of these meetings.

## **The Impact and Effectiveness of Reflection in Informal Learning**

In addition to providing a scheduled and structured time to meet and a safe space to ask for and receive guidance, the support staff meetings provided the hospice care professionals with space that allowed for different types of reflection. In some situations, it allowed the hospice care professional to return conceptually to a similar experienced event, interpret it, and make meaning (or new meaning) of it. In other situations, the reflective response was to a condition the hospice care professional had yet to experience. Becoming aware of a situation encouraged the hospice care professional to reflect back on the situation presented, thinking about how he or she would respond if the opportunity presented itself. Informal learning had taken place because some knowledge of how to negotiate a situation was within that “inexperienced” hospice care professional. In this study, reflection was essential to deep informal learning—not the informal learning associated with handling everyday job-related tasks, but the deeper, more emotionally based approaches to end-of-life care.

## **The Study Identified How Informal Learning Occurs**

This study illustrated that, in most cases, when the hospice care professional experienced surprise or shock, another secondary emotion soon replaced it. That secondary emotion encouraged an informal learning approach. However, future research should focus on informal learning in the context of end-of-life care because healthcare professionals typically come to the hospice environment with very little theoretical knowledge of the subject, nor are the processes and procedures related to the hospice position formally provided, (e.g., by an on-the-job training program). This study provided strong evidence suggesting that hospice care professionals use informal learning to acquire virtually all of the knowledge needed to provide end-of-life care.

Appropriate training for hospice care professionals will become even more critical in the near future. According to the Pew Research Center, baby boomers account for 79 million people, or 26% of the United States population (Cohn, 2008). By 2030, more than 20% of Americans will be older than 65; a quarter of these will have four or more chronic diseases that will require long-term care or hospice (Boult, 2015; CDCP, 2016).

## **What This Means for Other Scholars of Adult Education and Training**

This study demonstrated that having a moment of positive structure in an otherwise chaotic environment provided great value to the hospice care professionals. More importantly, regularly scheduled sessions of this type also provided a means for less experienced employees to seek guidance from seasoned employees without feeling ashamed or incompetent. In this study, the presentation of personal case studies allowed for all meeting participants to reflect on the case presented, think of how they would have responded in a similar situation and (if applicable), and think about similar cases experienced. Schon (2009) referred to such reflection during a case study presentation as *reflective practice*, which entails considering one's

experience in applying knowledge to practice while being coached by professionals in the discipline. Critical reflection on experiences continues to be an effective technique for professional development (Ferraro, 2000).

In addition, the study demonstrated small ways in which greater efficiency in process and procedures could occur—for example, skills training in preparing Medicaid documents correctly, which would eliminate the time and expense required to backtrack and correct. Retention of employees would likely increase because small gatherings like the support staff meetings provide a resource system, opportunities for hospice-specific informal learning, and validation for the hospice care staff.

The effectiveness of these meetings was confirmed by the way they managed and sustained themselves. No administrator required attendance; yet (except for illness or planned absences) everyone attended. The implementation of an informal professional development model generated at least one mentoring opportunity along with various combinations of informal encouragement and coaching. Though this model was effective for United Hospice because it met the needs of the support staff by responding to the challenges that occurred within the group, this same model could adjusted and implemented for other professions.

## **Conclusions**

Below are the conclusions drawn from the analysis of the data.

### **Critical Incidents of Emotion Work Triggered a Primary Emotion Usually Followed By a Secondary Emotion**

One example of a secondary emotional trigger was found in the story of Suzanne (“Never again on my watch”), whose home health patient committed suicide with a gun that was hidden within reach. Suzanne’s initial emotional reaction was one of shock because she believed that



she was making progress with this patient; the second emotion was one of guilt. Suzanne believed that she had failed to properly assess the patient, missing crucial signs that he was suicidal. This feeling of guilt encouraged Suzanne to reflect upon all of her interactions with the patient to identify which actions she should have handled differently. In this case, it was the patient's daughter who absolved Suzanne of her guilt, telling Suzanne that both did everything they could do as a daughter and a hospice care professional. Another instance of informal learning via a secondary trigger was the case of Janet, ("Sometimes families can be the best teachers"), who had difficulty operating the pain pump of a patient she was onboarding. The surprise of not knowing how to operate the pain pump was followed by a feeling of anxiety that soon, the patient would be experiencing pain. This feeling of anxiety caused Janet to ask the relative for assistance in operating the pump Janet learned the correct operation of the pump from the relative.

My last example of a secondary emotional trigger relates to Alicia ("Hospice care is 'learn as you go'"). When Alicia came to work at United Hospice from working as a nurse in the fields of oncology and HIV/AIDS, she was surprised that the medication, dosing, and jargon used in hospice were different. This surprise prompted her to learn more about hospice care. While Alicia learned much of the differences via the Internet, much of the learning happened by silently observing other hospice care professionals.

### **Creating Routine Informal Learning Structures for Reflection Is Powerful in Non-Routine Environments**

Reflection is a key linkage between emotion work and technical and personal learning. While death from chronic illness follows a routine trajectory (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003), hospice work is far from routine. At any time during the day or night, hospice

care professionals may be required to conduct patient intake, care for patients in residence, communicate with funeral directors for pickup of deceased patients, and prepare the deceased for transport from the hospice. Often, from an emotional standpoint, the loved ones of the dying need to be supported, too. Between the patients, the loved ones, the paperwork, and the tasks required to perform the hospice care professional's job, there is usually little time to reflect on what is occurring on the job, at the job.

The monthly support staff meetings were successful because they provided a regularly scheduled meeting in which to communicate about new processes, procedures, and educational opportunities. Most importantly, it represented a time to meet, share, and reflect—to share with the group challenges that were affecting a person's job, to reflect about another member's challenges, reflect upon people's responses to those challenges, and reflect on their own challenges. Unlike other time spent at the hospice, these meetings allowed the hospice care professionals to think about their peers, themselves, the challenges they faced, and antidotes to the difficult challenges they faced every shift.

### **The Learning Process of Emotion Work Occurs Across the Stages of Dying, Death, and Bereavement**

Analysis of the narratives of the hospice care professionals indicated that loved ones of the dying journeyed through three distinct stages of anguish as it related to their loved one's death (see Figure 22).

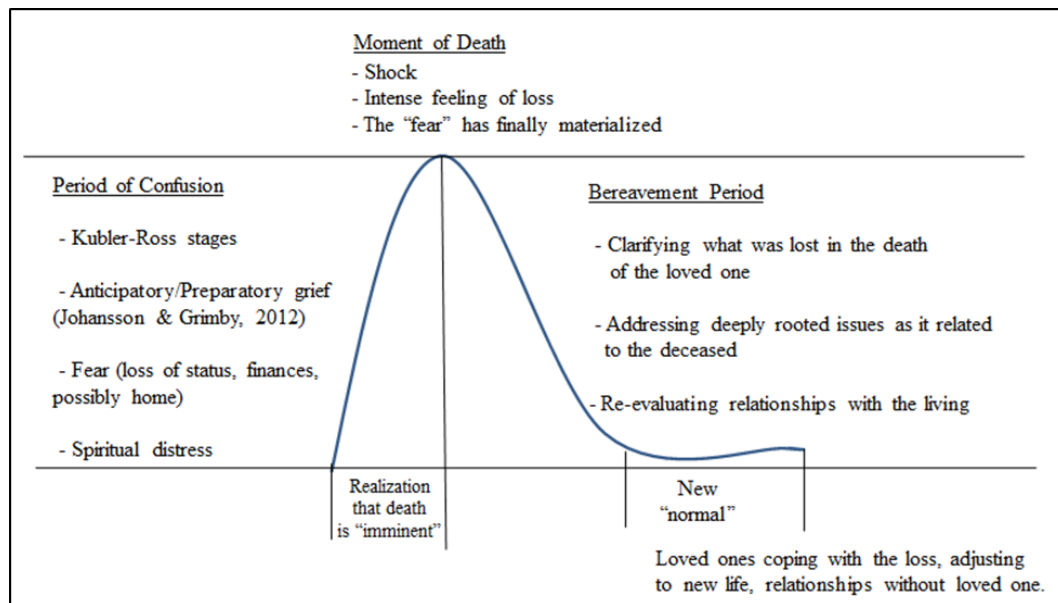


Figure 22. Dying, death, and bereavement trajectory for loved ones of the dying.

**Period of confusion.** During this period, hospice care professionals walk the loved ones through the process of preparing the patient for hospice services. Loved ones may respond in very different ways to a hospice diagnosis. Alicia ("Rare is the family that is going to come in all on the same page about death") illustrated the challenges of communicating with loved ones of the dying on what is best for the patient when not all family members are accepting of imminent death. Suzanne ("When put on the spot, you have to use your instinct (or your experience)") recalled a time when the loved one of a patient wanted copies of the patient's medical records (implying that the previous hospital or the hospice was not providing proper care). Yet, another time, Carrie ("Everyone has a different point of view about dying and death") recalled an incident in which the family began fighting with one another while the matriarch of the family was actively dying. Carrie had to step in, pull the son out of the fight, pull him aside, and ask him *"if he wanted his mother to remember him like that, fighting his family, and carrying on."*

**Moment of death.** When I received the call that my father, who had been under hospice, had expired, I experienced profound shock. I was surprised by that emotion because, after all, my father was in hospice care, and I had been notified earlier that he was “close to the end.” On two occasions during this study, I was on the hospice floor and observed the loved ones’ response when a nurse “pronounced” a patient (i.e., declared the patient deceased). The first occurrence I considered an ordinary response to a loved one’s death; the second filled the halls of the unit with an outpouring of anguish over the loss. At such moments, all the thoughts that were anticipated when the patient was actively dying suddenly became “real,” and the loved ones were forced to move forward to lay their loved one to rest. The hospice care professionals need to be there to support the loved ones when the patient expires, whether to hold them while they cry, pray for and with the family, or counsel loved ones about what it is they are feeling.

**Bereavement period.** I consider the bereavement period to begin when the constant company at the home of the bereaved loved one has ended, and life in many ways returns to the way it was prior to the “period of confusion.” During this period, the individual may gain greater clarity about what the loss represents. It is a process of reassessing, reevaluating, and adjusting to life without the deceased.

Hospices offer bereavement counseling to loved ones up to 13 months post-death. In her narrative, Alex told a story about providing bereavement counseling to five sisters to help them unpack issues around their deceased mother and with each other.

**The “new normal.”** When loved ones returned to the hospice with sweet treats for the staff or a card of thanks for the care the deceased received, I observed them in conversation with the receptionist or a certified nursing assistant regarding how they were “getting along.” This

action on behalf of the loved one was an expression of appreciation for support received during a trying time. In turn, the hospice care professional encouraged the loved one on their progress.

**Why this trajectory is important to learning in emotion work.** Though the literature identified stages of dying, death, and bereavement, there are no references to a trajectory as it relates to the emotion work provided by hospice care professionals at each stage. At times, a hospice care professional may work at each of the stages in the trajectory with three different families during one shift. It would be helpful for the hospice care professional to be aware of this trajectory to understand what loved ones might be experiencing emotionally and thus to better support that person.

This study highlighted the adaptive abilities of the hospice care professionals. Trained in their professions but not for their vocations, these individuals were professionally dedicated in an environment that can be difficult and emotionally challenging.

The study made evident the need for job descriptions in hospice. Interviews uncovered misunderstandings among hospice employees about tasks—procedures used to perform a task, factors that needed to be satisfied in order for a task to be considered complete, and what positions were qualified to carry out the tasks. Lastly, the study demonstrated the potential of empowering individuals to make decisions to better their work life. The administration's support for the implementation of monthly meetings strengthened intra-organizational ties (between in-patient and home-health units), developed mentoring relationships, and provided opportunities for informal learning and reflection to allow them to do their jobs better each time. The study was not designed to provide a generalized overview of hospice facilities, nor was it able to provide a gender balanced perspective of hospice care professionals' experiences.

## Future Research

This study contributed to the understanding of informal learning in a hospice environment by identifying how this learning occurs. However, we need to know more and have more studies on informal learning in the context of end-of-life care because healthcare professionals come to work in a hospice environment with very little theoretical knowledge of the subject, nor are the processes and procedures related to the hospice position formally provided, (i.e. an on-the-job training program). This study provided strong evidence to the theory that hospice care professionals use informal learning to learn virtually everything they need to know about providing end-of-life care.

The issue of providing appropriate training for hospice care providers will become more critical as we reach the year 2030, when, according to the Pew Research Center, baby boomers, those individuals born between 1946 and 1964, account for 79 million people, or 26% of the United States population (*Baby Boomers: The Gloomiest Generation*, 2008). By 2030, more than 20% of Americans will be older than age 65; a quarter will have four or more chronic diseases that will require long term care or hospice (Boult, 2015; *Chronic Disease Overview*, 2016).

More important, regularly scheduled sessions of this type will also provide a means for less experienced employees to seek guidance from seasoned employees without feeling ashamed or incompetent for not knowing. And this research revealed that having a moment of positive structure in an otherwise chaotic environment provides great value. The presentation of personal case studies allows for all meeting participants to reflect on the case presented and think of how they may respond in a similar situation and (if applicable) think about similar cases experienced. This reflection during a case study presentation is what Schon (2009) regarded as reflective

practice. As defined by Schon (2009), reflective practice entailed thinking about considering one's experience in applying knowledge to practice while being coached by professionals in the discipline. Critical reflection upon experience continues to be an effective technique for professional development (Ferraro, 2000).

The effectiveness of these meetings was confirmed by the way they manage and sustain themselves. No administrator requires attendance, yet (except for illness or planned absences) everyone is in attendance. The implementation of an informal professional development model has generated at least one mentoring opportunity and varied combinations of informal encouragement and coaching. While this model was effective for United Hospice because it met the needs of the support staff by responding to the challenges that occur within the group, this same model can be implemented not only in the hospice care industry but adjusted for other professions.

I recommend studies be commissioned to learn about the informal learning within interdisciplinary department teams—the collective soul of any hospice. I believe there is a great opportunity to acquire different perspectives on one's profession as well as other occupations that make up the IDT. Future research should also compare hospice care professionals who work in a hospice with job descriptions and guidance on process and procedures with those who do not have access to such infrastructural elements. Lastly, I would like to see a study conducted over a 10 year period between similar universities; one university that implements a death and dying curriculum in all professions that could potentially work out of hospice—not only future physicians, nurses, social workers, chaplains, and seminarians, but the pharmacists, accountants, business administrators, physical and respiratory therapists, and another university that continues with its present curriculum of how it educates its students. The intent of a study of this type

would be to interview the hospice care professionals who received a death and dying curriculum as part of their matriculation to determine if they felt better prepared to speak with individuals about end-of-life issues.

### **Concluding Thoughts**

To be a leader of change in a system, one must be willing to immerse oneself in that system. Had I not taken the advice of my committee leader, Karen E. Watkins, to volunteer at United Hospice ahead of my study, I would not have earned so quickly the trust and camaraderie of the hospice employees. These relationships allowed me to access and participate more deeply in the internal activities of the hospice. As a result, I experienced my own informal learning.

My team transformed from a group of United Hospice employees involved in a newly action research team to an actual support staff team. Once empowered to make decisions to better their work life, the members began to trust, challenge, and speak truth to each other. In addition to growing into a team, each member developed greater insight into themselves as hospice care professionals.

Death is not going away. It is up to Western society to fully accept death for what it is: a part of life. My hope is that in a move toward accepting death as a part of life,

During this study, it became clearer to me that I did not give attention to many of life's issues until they had the potential to affect me or my loved ones. This was the case with hospice care: Until my father was the recipient of it, hospice was not relevant to me. Similarly, the reader may think these issues of "death and dying, emotion work, and informal learning" are not relevant to his or her life either. But the fact is, death happens to everyone; moreover, according to the Centers for Disease Control and Prevention (2016) only three out of ten of individuals are going to die instantly—the vast majority will require long-term care.



Here is another fact: the nation's medical schools, nursing schools, schools of social work, and seminaries do not prepare their students to work within the context of hospice or palliative care (Csikai & Raymer, 2005; IOM, 2014; Lloyd-Williams, Cobb, Shiels, Taylor, 2006). But as death will happen to all of us, this action research experience illuminated it is important that hospice care professionals have both formal training and informal leaning opportunities to learn how to provide the best end-of-life care possible. This training and awareness could mean the difference between a good death and a bad death for many.

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