

2015

# The effect of mindfulness practice on the personal and professional lives of hospice bereavement counselors

Heather R. Floyd-Haupt

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Heather Rose Floyd-Haupt  
The Effect of Mindfulness Practice  
on the Personal and Professional  
Lives of Hospice Bereavement  
Counselors

### **ABSTRACT**

This exploratory study was conducted to examine the perceptions of hospice bereavement counselors' and how mindfulness practices impact their work with bereaved clients.

Additionally, this study looked at the self-defined practices of participants and collected rich narratives of their personal and professional experiences with mindfulness.

Using interviews with hospice bereavement counselors, this investigation found that all of the 10 participants described that mindfulness provided them with enhanced awareness through the use of self-nurturing rituals. These exercises helped all participants in three areas: to quiet the mind, improve physical awareness, and to serve as inspiration in their work.

The study concluded that mindfulness strengthens hospice bereavement counselors personally and in turn enhances their professional work with the bereaved. In addition, mindfulness practices were reported to improve emotional regulation both for counselors and their clients. Over half of participants also stated that mindfulness has allowed them to be in the present moment of now, when asked about their sense of time. Therefore, this study suggests the potential for further research on the impact of mindfulness for bereavement work, hospice care, and for social workers from other fields to utilize mindfulness as a method to improve the personal and professional experience of counseling work.

**THE EFFECT OF MINDFULNESS PRACTICE ON THE PERSONAL AND  
PROFESSIONAL LIVES OF HOSPICE BEREAVEMENT COUNSELORS**

A project based upon an independent investigation,  
submitted in partial fulfillment of the requirements  
for the degree of Master of Social Work

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2015

## ACKNOWLEDGEMENTS

I am tremendously grateful to the immense support I received in the accomplishment of completing this independent research study. The contributions of many people are honored here with great respect and great acknowledgement. First, I am tremendously appreciative for the outstanding support from my thesis advisor, Daniel O'Donnell. I feel especially fortunate for your continuous encouragement and dedication in helping me through this process. I am honored to have been able to receive your wisdom and steadfast advocacy for me and my research project; you went above and beyond! I hope that you will continue to teach and or advise as there are many who will benefit from your expertise in research.

Thank you to my beautiful mother, Laura Day Floyd (passed forward January 21, 2010), who provided me with a meditation and spiritual practice from a very young age. Thank you for allowing me to share mindfulness with you in your dying process. I dedicate this accomplishment and my commitment to finishing graduate school in social work to you.

Thank you to my close friend Lesley Lambert who supported me through many moments of wanting to give up. You bolster and inspire me now and always. Also, a tremendous thanks to Catherine Chipman who has facilitated my mother's wishes for me, been a great friend, and ally whether I am near or far.

Lastly, thank you to Cooley-Dickinson VNA and Hospice team, especially Pat Riggs and Mary Stanton, for an incredible journey in my final year of field placement. It has been so influential in my budding career in social work. In addition, thanks to my participants from other hospice agencies for the amazing work you do with the bereaved.

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## **Chapter 1**

### **Introduction**

The purpose of this research study is to explore the ways in which hospice bereavement counselors perceive their mindfulness practices as influencing the services they provide to families and caregivers. In this examination I will review relevant research on investigations using mindfulness, existing theories of death and the grieving process, research regarding hospice care, and mechanisms of coping with death for both hospice patients and their families. Additionally, I will reference research that has investigated what grief counselors draw upon from personal experiences and practices that guide their professional work.

Practitioners of mindfulness in modern society have a range of conceptualizations about what mindfulness practice entails and implementation (Brown, Ryan, & Creswell, 2007). The roots of this concept come from Theravada Buddhist language of Pali and translated by a British linguistic scholar who defined mindfulness as “the active watchful mind” (Ryhs Davids, 1900, p. 152).

Since the term was coined in the 19<sup>th</sup> century, mindfulness definitions have expanded both in operational definitions with research and in how individuals describe their personal disciplines. It has gained considerable attention in the fields of medicine and mental health across the last several decades. Jon Kabat-Zinn’s Mindfulness Based Stress Reduction (MBSR), has been the most widely researched mindfulness practice as an intervention for patients coping

with the physical and psychological ailments. He defines mindfulness as “paying attention in a particular way: on purpose, in the present moment, and non-judgmentally...it is an intentional appreciation for the present moment through observing both the internal and external experience” (Kabat-Zinn, 1994, p. 53). MBSR has also been used to manage the symptoms of patients who have a terminal illness such as cancer (Shennan, Payne, & Fenlon, 2010). The majority of research on mindfulness practices has investigated how clients and patients can benefit from this intervention but there has been little examination of how mindfulness can benefit grief counselors and its impact on their service delivery.

Investigations that examine Eastern concepts on death and the grieving process assert that it is much like how people adapt to loss throughout their lives (Goldsworthy, 2005). These studies provide ideas for coping with death that connect to mindfulness: being “in the present moment” (Kabat-Zinn, 1994, p.152) and being able to gradually let go of a loved one’s passing.

My own experiences with mindfulness practice and coping with dying and loss have had a significant influence on my interest and motivation in these areas. From a very young age I have practiced meditation and engaged in Eastern spiritual practices. I have no formal mindfulness or meditation training, but have participated in mindfulness practices in various therapy groups and informal workshops. I have experienced these practices as having helped me in difficult times in my life and strengthened by ability to self-regulate when experiencing cognitive, emotional, and physical ailments.

In the three previous years before entering graduate school for social I lost my mother to stomach cancer, my father to a stroke, and a very close long-time friend to brain cancer. I actively participated in their dying process and facilitated mindfulness practices with each as a relaxation technique to ease the emotional turmoil that each of us experienced. I used deep

breathing, guided verbal imagery meditations, and song and prayer with each of them. I witnessed how soothed and calm each became during these exercises and this gave me a greater appreciation for how beneficial mindfulness may be in the face of physical and emotional suffering.

In my second year field placement doing hospice work, I counseled patients and their families on home visits, and I provided individual and group counseling to bereaved clients. In each setting, I utilized mindfulness and witnessed the therapeutic impact of this practice. In both my personal and professional experiences, I have experienced the benefits of mindfulness with death and dying.

I found helping the bereaved to be difficult work due, in part, intense emotions experienced by the grieving family members. Often they believed that there would be no end to their grief. In these situations, my personal mindfulness practice would help me to tease apart their pain from my own and help me to relax. While the research base remains limited, studies have found that self-care and personal experiences with loss appear to improve grief counselors' ability to work with bereaved clients (Becvar, 2003; Ober et al, 2012).

In this exploratory investigation, I will examine the personal self-defined mindfulness practices of hospice bereavement counselors and the perceptions of how their experience with mindfulness has an impact on their work. The goal is to look at the benefits this exercise has had for clinicians and clients as well as gather insight that will inform the potential for grief counselors who do not currently utilize mindfulness to benefit their personal and professional lives.



## **Chapter 2**

### **Literature Review**

The purpose of this study is to explore the ways in which hospice bereavement counselors perceive their mindfulness practices as influencing the services they provide to families and caregivers. Thus, this literature review will cover a discussion of mindfulness definitions and applications, a description of hospice care including perceptions of what hospice provides and bereavement services, coping with caring for the terminally ill, and review theoretical literature of coping with death. I will review studies on hospice care, methods and theories of coping with death, and evidence of the benefit that mindfulness can provide for the bereaved.

#### **Mindfulness**

Mindfulness practice has been used to help practitioners treat a variety of conditions. The origin of the word “mindfulness” comes from Thomas William Ryhs Davids who was a scholar of the Indo-Aryan language Pali. This is the oldest scripture recorded of the Buddhist language and was used in the tradition of Theravada Buddhism. In his book *Buddhist Suttas*, Ryhs Davids (1900) translates the Pali words “sammā-sati [as] right mindfulness; the active watchful mind” (p. 152). Modern mindfulness typically involves guided direction that focuses practitioners’ attention on the present moment. Brown, Ryan, and Creswell (2007) reviewed a

broad collection of contemporary mindfulness practices and noted that practitioners interpret the concept of mindfulness to be broad in its practice and implementation. Some practitioners see it as “a development of awareness skills involving attention to one’s own breath while peripherally being aware of the body” (Rapgay & Bytrisky, 2009), some as an instructed experience (Wayment & Bauer, 2008), and others as a spiritual discipline (Bruce & Davies, 2005). Kabat-Zinn (1994), founder of Mindfulness Based Stress Reduction (MBSR), defined mindfulness as “paying attention in a particular way: on purpose, in the present moment, and non-judgmentally...it is an intentional appreciation for the present moment through observing both the internal and external experience” (p. 53).

Unique to the practice of mindfulness is that it is a gentle exercise that is not about changing or ameliorating a feeling state. Instead, it is an exercise of breath, mind, and body that leads to acceptance and greater awareness of one’s unique internal and external experience. Such elements of mindfulness relate to Maslow’s (1943) hierarchy of human needs (i.e., physiological, safety, love/belonging, esteem, and self-actualization). Linehan (1993), developer of Dialectical Behavior Therapy, uses the concept of the dialectic, a metaphysical system arising from an individual’s recognition of an objective reality paired with the personal perceptions of external objects. It is this dialectic space that allows a detached reality that is uniquely perceived by an individual, that mindfulness practice is intended to evoke in its practitioners.

## **Hospice**

**Description of care.** Hospice support, either at a patient’s home or at a care facility, is a service aimed at providing care for people who are living with a life-limiting illness. Its core service delivery is comfort over curative care. Hospice involves an interdisciplinary team of physicians, nurses, home health aides, therapists, social workers, volunteers, spiritual counselors,

and bereavement counselors. Patients themselves, or their healthcare proxy (often family members), elect hospice care when they choose to no longer use curative treatment. Hospice care strives to address the physical, social, emotional, and spiritual needs of actively dying patients as well as the grieving process of their families.

*Services.* Hospice functions include pain management, the provision of medications and equipment, education for family about proper care, and addressing the psychological, social, and spiritual needs for patients and their families. In the National Hospice and Palliative Care Organization's (NHPCO) 2014 report titled, *NHPCO's Facts & Figures on Hospice* the organization described bereavement services in the US. Ninety-two percent of agencies offer some level of bereavement services to the community, those grieving that lost a loved one not on said hospice (2014). In addition, for each hospice patient represented an average of 1.9 family members who received bereavement services. Hospice agencies provided bereavement care for surviving family and friends up to a year after a loved one's death. Hospice bereavement services within that year may include condolence calls, mailings with educational info about the grieving process, especially around anniversaries or holidays, as well as support groups and individual counseling.

### **Coping with Death and Loss**

A tendency in Western culture is for people to intellectualize and make sense or meaning out of things that are painful, unknown, and mysterious (Sherman, 2000). In contrast, the fundamental Eastern views on death and dying are quite different than perspectives in the US. In the most basic sense, Eastern views of death emphasize both acceptance of death and *being* with death. Using this lens, we can conceptualize the paradoxical nature of life and death, intimacy and distance, past and future, and the spaces of grasping and letting go (Bruce & Davies, 2005,

Black & Rubinstein, 2013). Research on mindfulness in this review suggests that the practice has the potential to balance the contradictions of caring for life and ultimately releasing it.

Attachment theory (Bowlby, 1980), task theory (Worden, 1991), stages-of-death (Kubler-Ross, 1970), social learning (Murray, 2001), constructivist (Neimeyer, 1999), and existential (Yalom, 1980) theories all provide explanations and perspectives on how people adapt to losing another to death. However, these theories incorporate stages of acceptance, emotional anguish, adjustment, isolation, hope, and letting go which may be applied to the experience of death anticipation. These stages are not linear per se, and one stage is not in complete isolation from another. These theories offer explanation to how people grieve another's death; however, they can also be seen in a person who is dying.

Black and Rubenstein (2013) interviewed 34 family sets 6 and 10 months after the death of a family member to explore the concept of mindfulness in hospice care. The sets consisted of a widow or widower and at least 2 biological children. They explored participants' primary reactions to their losses by asking about their coping and whether they perceived any shifts of relationships between surviving family members (Black & Rubenstein, 2013).

The investigation found that such family systems were pushed into "living in the present in its fullness" (Black & Rubinstein, 2013). Black and Rubenstein (2013) found that when death is seen as a Zen concept it infuses families with space to explore the value of the present moment in contrast to Western cultural norms of independence and self-reliance, which seem to often push Americans into experiences of isolation and regret. Their study found that family systems which utilized mindfulness were infused with the potential for healing, solidarity, and an increased sense of self-awareness that assisted them in coping with death and dying. In addition,

exploring “existential questions about life, death, and intimacy” (Black & Rubenstein, 2013) provided these participants with a Zen perspective that was helpful in processing their grief.

### **Benefits of mindfulness**

Mindfulness practice integrates both a sense of control or mastery and a space for hope through descriptive imagery. Many mindfulness studies have focused on MBSR, the most widely studied mindfulness practice. Traditional MBSR involves an 8-week regimen of weekly two and a half hour sessions in addition to one full day training and daily home assignments (Kabat-Zinn, 1996). Shennan (2010) conducted a meta-analysis of the effect of mindfulness-based interventions on illness trajectory in cancer and found beneficial shifts in a range of emotional elements, including: reduced stress and anxiety, improved relaxation, and sleep. Other benefits were physical improvements with “sexual difficulties, physiological arousal, and immune function” (Shennan, 2010). Other beneficial effects on emotions included a reduction in anxiety, increased mood stability, and decreased depression. Shennan (2010) noted that the literature lacked qualitative studies which could beneficially explicate “the underlying mechanisms of mindfulness” (p. 693).

**Mindfulness for patients with terminal illnesses.** The common perception of bereavement counseling is that clinicians only work with family members after a patient dies. However, hospice bereavement counselors may also have the opportunity to provide services prior to the death of the patient. Bereavement counselors can offer help to hospice patients with terminal illnesses who may be struggling with uncertainty in the anticipation of death in a manner similar to their loved ones’ anticipatory grief. It is helpful to explore the experience of hospice patients and how they cope in order to inform how bereavement counselors may support their ability to help their family members through their process of grieving.

Methods for patients to cope with the process of dying have been investigated using a cohort of clients who are facing death; provide further illumination for the usefulness of hospice treatment interventions. Qualitative methods offer insight into both unique experience and common trends among this population. Renz, Schuett, Bueche, Cerny, and Strasser (2012) summarized the findings of their study in identifying the pendulum of ontogenesis in the experience of dying; from emotional turmoil, and the struggle to accept the inevitable, to discovering meaning and coping with the transition to come. Other studies supported this finding. Sand, Olsson, and Strang (2009) and Schroepfer, Noh, and Kavanaugh (2009) explored viewing death from a transitional perspective rather than as an end. In both studies, clients reported that this viewpoint provided them with a sense of control of their internal emotional experiences. These types of interventions can be characterized as offering opportunities and introducing alternatives to patients coping with the dying process (Sand et al, 2009; Schroepfer et al, 2009). These methods are some ways that both practitioners caring for patients and hospice bereavement counselors can use to strengthen the ego and provide a sense of mastery for bereaved clients as well. Sand et al. (2009) and Schroepfer et al.'s (2009) found that patients facing death from incurable illnesses reported that community, involvement, and hope provided them with both freedom and armor when facing death (2009). Family and caregivers can also benefit from socialization opportunities such as those provided in hospice bereavement support groups.

### **Hospice bereavement counselors and mindfulness**

Hospice bereavement counselors work with families during some of the most delicate times in their lives. It is important when working with terminally ill clients and their families for clinicians and hospice workers to be sensitive to the unique needs that individuals bring to the

therapeutic space. While this applies for all healing practices, it is especially important when working with people who are faced with multiple stressors that include tremendous medical, psychological, and social changes in their lives. Mindfulness is a practice that does not use aggressive measures. It is a gentle exercise of recognizing the present moment and experiencing awareness of both inner and outer realities. Mindfulness practice has been shown to have an impact on hospice caregivers, and helped family members of hospice patients cope. And, the specific practice of Mindfulness Based Stress Reduction (MBSR) has benefitted patients with life limiting illnesses (Black & Rubenstein, 2013).

The goal of bereavement counseling is to provide support to family, friends, and caregivers who have lost a loved one by meeting them at their particular point in their grieving process. In meeting this goal and enhancing service delivery to the bereaved, bereavement counselors may experience great benefit in using mindfulness practice as a self-care method. Bereavement counselors may empower clients by providing them with mindfulness techniques. Mindfulness practices provide clients with the opportunity to experience greater agency. It has been shown that having a sense of agency through daily activities that enhance mental outlook is also indicative of providing one with a sense of control, therefore assisting with a person's ability to cope with the process of dying (Schroepfer et al, 2009).

Becvar (2003) interviewed therapists about their bereavement work with families. In addition to the exploration of how therapists perceived benefits to their clients, Becvar (2003) also inquired about cognitive strategies that bolstered them in their work. The data indicated that self-reflection about losses in their own lives helped them to serve their clients (Becvar, 2003). In addition, the study found that therapists' "focus on self-care as well as client care, has

the potential to not only increase their effectiveness, but also enhance their own well-being” (Becvar, 2003, p. 469).

**Personal experiences of clinicians.** Bruce and Davies (2005) studied hospice workers at a Zen hospice center who used mindfulness as “meditation in action.” Bruce and Davies (2005) defined this as not only the traditional form of sitting meditation, but as mindfulness meditation in their daily activities and in serving their clients. Their research found that these clinicians were shown to have a greater appreciation for the points of stress and exhaustion in their work as important places of connection with clients. Bruce and Davies (2005) proposed that “mindfulness fosters openness and supports letting go, and [creates] space for whatever is happening in attending to the living and dying process.” They also found that their personal practice bolstered their capacity to support a patient’s unique process of dying and their personal relationship with the patient (Bruce & Davies, 2005, p. 342).

Ober, Granello, and Wheaton (2012) investigated the competencies of grief counselors in a mixed methods study which was measured by comparing participants’ ( $n = 369$ ) personal and professional experiences with grief with formal training. They investigated three areas of grief counselors’ experience, including: their perceptions of their counseling competencies, their personal experiences with grief and any professional training in grief counseling (Ober et al, 2012). In general, the majority of participants reported minimal formal training for their work. Despite participants responses reflecting that they had less competence in formal training, the personal knowledge and life experience that they bring to their work was shown to be the strongest source of their competence. Participants reported that their personal competencies surpassed their conceptual skills and training in grief counseling (Ober et al, 2012). Grief counselors’ perceptions of personal competencies were evaluated using other questions not



limited to their training or professional experience. These questions covered topics such as “self-care, sense of humor, spirituality, and the ability to articulate a personal philosophy of death and grief” (Ober et al, 2012, p. 155). The study found that grief counselors’ perceptions of confidence in their work is related to attending to their individual needs, which they reported made them more available for their clients (Ober et al, 2012).

Cwierniewicz (2007) conducted qualitative interviews of psychotherapists about the importance of grief and loss in crisis-oriented psychotherapy. Participants were asked to describe their own experiences of grief and loss and to reflect on the effect these experiences had on their work with clients. They were also asked to identify the recommended coping strategies they encouraged clients to use in coping with grief and loss. The recommended coping strategies were of a type that assisted clients in facing their pain rather than avoiding it (Cwierniewicz, 2007). Psychotherapists cited the importance of addressing grief and loss which, if “not dealt with tends to resurface and create additional crises in the future” (Cwierniewicz, 2007, p. 72).

This study focuses on how hospice bereavement counselors perceive their mindfulness practices to influence the services they provide families and caregivers. Learning more about the practices they utilize and how they perceive these practices as contributing to their work is instrumental in developing a fuller understanding of the potential benefits of mindfulness in the work of bereavement counselors. Helping the bereaved can be difficult work as clinicians face the intense emotions of their clients, who often perceive that there will be no end to their grief. In order to effectively support patients and their families in the dying and grief process, clinicians must develop their understanding of these experiences. To this end, clinicians have benefited from a variety of theoretical approaches min understanding the topic of death, coping with dying, and even the process of grieving (Bowlby, 1980; Kubler-Ross, 1970; Murray, 2001;

Neimeyer, 1999; Worden, 1991; & Yalom, 1980). However, the emphasis of these concepts is on perspective and process, not a particular practice such as mindfulness. In addition to theoretical knowledge, research suggests that self-care and personal experiences with loss improve grief counselors' ability to work with bereaved clients (Becvar, 2003; & Ober et al, 2012). It is important to consider not only the theories clinicians can integrate into their work with clients, but also the methods clinicians may use to self-support as they support their clients. Mindfulness has the potential to be a valuable resource of self-care for grief counselors to manage their own emotional reactions to work with bereaved clients.

The term mindfulness originated from a scholar of the Buddhist language, Pali, who coined the word mindfulness from "the active watchful mind" (Ryhs Davids, 1900, p.152). In modern society, mindfulness practitioners have varied conceptualizations of its practice and use (Brown et al, 2007). The concept was expounded upon by Jon Kabat-Zinn, the founder of MBSR and Marsha Linehan, the founder of DBT and has been applied to medical and therapeutic interventions. MBSR has been the most widely researched mindfulness practice as an intervention for patients coping with the physical and psychological symptoms who have a terminal illness such as cancer (Shennan, 2010).

Research on how families and caregivers cope with death and loss has shown that traditional Western cultural norms, such as self-reliance or stoicism, increase experiences of isolation and regret in those who hew to them (Black & Rubenstein, 2013). Other research that supports this finding shows that viewing death from a transitional perspective, rather than an end, helped families to have solidarity and more awareness of their emotional experiences (Sand, et al, 2009; & Schroepfer, et al, 2009). Eastern concepts on death describe the experience as one of holding on and letting go, much like people adapt to loss throughout their lives (Goldsworthy,

2005). These studies suggest that people coping with death and loss may benefit from alternative methods for coping with death that connect to mindfulness: being “in the present moment” (Kabat-Zinn, 1994, p.152) and being able to gradually let go of a loved one’s passing.

There is little research on how bereavement counselors perceive the impact of their mindfulness practices has on their service delivery. One study explored workers at a Zen hospice who use mindfulness. Bruce and Davies (2005) found that “mindfulness fosters openness and supports letting go, and [creates] space for whatever is happening in attending to the living and dying process” p. 1329). Existing studies about hospice work and mindfulness, suggest effective interventions for bereavement counselors such as physical awareness of the breath, letting go of physical sensations and “internal mental chatter,” (Bruce & Davies, 2005, p. 1331), and shifting perspective to “allow [one] to be deeply with [their] experience, rather than identify with it or overlay it with conscious or unconscious commentary” (Shennan, 2010, p. 682).

## **Summary**

The literature reviewed reveals a gap in our knowledge about the mindfulness practices bereavement counselors’ use and how they perceive these practices influence their work. This study contributes to the field of bereavement counseling because it investigates the personal and professional use of mindfulness and how counselors’ perceive it to influence their work. Understanding the practices and perceptions of how mindfulness impacts grief work has the potential to inform not only bereavement work, but also how other therapists and or social workers can benefit personally and thus benefit therapeutic experience for their clients. This study explores the question: In what ways do bereavement counselors perceive their mindfulness practices as influencing the services they provide to families and caregivers?

## **Chapter 3**

### **Methodology**

The purpose of this empirical study was to investigate how hospice bereavement counselors perceive their mindfulness practices as influencing the services they provide to families and caregivers. The utilization of open-ended and semi-structured interviews allowed for a greater range of personal perceptual experiences that was gathered from participants. This study used a qualitative exploratory research design. Phenomenological interviews were conducted with hospice bereavement counselors to investigate their perceptions of how their mindfulness practices might affect the work they do with the bereaved. Lastly, by focusing on the perceptions of hospice bereavement counselors use of mindfulness, this research inquiry addressed a gap in the literature on mindfulness, hospice, care for the terminally ill, and ultimately care for the bereaved.

This study used Kabat-Zinn's (1994) definition of mindfulness practice to describe the independent variable. Kabat-Zinn (1994) defined mindfulness as "paying attention in a particular way: on purpose, in the present moment, and non-judgmentally...it is an intentional appreciation for the present moment through observing both the internal and external experience" (p. 53). Mindfulness was operationalized to the specific behaviors practitioners use. They included: focused breathing, centering, attention to the present moment, and other related exercises that were identified by participants to be of personal, intentional practice. The following descriptions

of these specific behaviors were defined by the researcher based on anecdotal experience and by Jon Kabat-Zinn (1994).

The use of breath is a central exercise to mindfulness practice as Kabat-Zinn (1994) teaches. Focusing on the quality, such as deep or shallow breathing, counting the seconds of inhalation and exhalation, and or practicing what is called, belly breath, and are examples of breathing practices. Belly breath is identified as breathing in air at first to the belly, then to the lungs, followed by breathing out the air in the belly and then through the lungs.

Centering is a figurative concept that follows the literal translation, such as adjusting to a central point. Another definition is to arrive at a place in the body in which awareness of a person's inner and outer perceptions are in tune, or balanced. The idea of centering is to come to a neutral or center point where distractions or preoccupations of the mind and senses are reduced and less distracted.

Attention to the present moment is a practice when a person minimizes their distractions of the past or previous moments, as well as those yet to come. Not worrying about the past or the future is part of the practice of having attention in the present moment. One method that helps bring attention to the present moment is having an awareness of when a person's thoughts begin to wander, noticing this cognitive digression, and redirecting the mind to what is happening in a person's current reality.

### **Dependent variable**

The dependent variable of this study was how hospice bereavement counselors perceive their mindfulness practices to affect the services they provide for families, caregivers, and friends of a deceased hospice patient.

## Sample

This study sampled 10 hospice bereavement counselors who were over the age of 18 and identified as using mindfulness practices. Originally, this study sought to obtain 12-15 participants; however, due to limitations in the size of the population the sample, only 10 participants were interviewed. Participants were recruited through several means: direct contact through the researcher's relationship with a bereavement coordinators group, flyers, and purposive, snow-ball sampling as some participants informed others about the study. The majority of participants were drawn from the Bereavement Coordinators of Western New England group which has 42 members. Of these members, only 23 were affiliated directly with hospice agencies. A further sample restriction resulted from the researcher's attempts to avoid bias or conflict of interest. Participants were not used from the colleagues at the hospice agency of the researcher's field practicum. Prospective participants from the bereavement coordinators group were contacted by phone and or email (often both) to 20 of the hospice grief counselors. In addition to these recruiting measures, the researcher made a flyer for advertisement and both emailed and had them posted at hospice agencies. Another effort was facilitated by participants who expressed excitement about this study and referred me to their colleagues. Despite the limited sample size, this investigation can still inform further research on the topic of how hospice bereavement counselors and their mindfulness practices influence the services they provide to families and caregivers.

Inclusion criteria for the study were bereavement counselors who were currently or previously affiliated with a hospice agency and who self-identified as users of mindfulness or elements of mindfulness practice. Participants did not need to have specific training in mindfulness, licensure, or an academic area of expertise for inclusion in this study. These

hospice bereavement counselors were either currently or previously employed, full-time, part-time, per diem, or provided volunteer service. Exclusion criteria were bereavement counselors who are not affiliated with a hospice agency or do not self-identify as using mindfulness practices. The sample did not exclude participants based on age, sexual orientation, religion, gender, class, culture, or nationality.

This study has limited generalizability due to using a qualitative research method and the small sample size. In using a qualitative design, this study sought a rich narrative to explore the personal experiences of hospice bereavement counselors. The nature of qualitative research allows for greater understanding of the participants' experiences because of the in-depth nature of the interviews; however, the time requirements of this type of interviewing limits the number of interviews a researcher may obtain. In addition, participants in this study represented the demographics of the region, but did not substantially represent the demographics of the wider American society. The region's population consists of mostly white, and middle to upper class persons, making the external validity of this study low.

### **Data Collection Methods**

Data was gathered using open-ended questions that explored participants' perceptions of the effect of mindfulness practice(s) on services they provide to the bereaved (see Appendix A). Questions explored how mindfulness practices facilitated their ability to provide the bereaved with specific services, including coping, support, relaxation, acceptance and spiritual or emotional healing. Approval by the Human Subjects Research Board at the Smith College School for Social Work was obtained prior to data collection (see Appendix B). A consent form was completed by participants before interviews and any questions or concerns were addressed by the researcher at the time of the interview (see Appendix C). Also, participants were asked if

they could be contacted in the future as the researcher conducted data analysis if more questions or clarifications were deemed necessary. All of the participants consented.

Interviews were conducted in-person to facilitate the focus of both participant and researcher. Data collection occurred at a time agreed upon between the researcher and each participant. During the informed consent process, participants were informed that they could opt out of the study at any time and for any reason, but no participants exercised this right.

A flexible, semi-structured interview format using open-ended interview questions was conducted. These questions will be followed up with exploratory questions allowing for clarification of participants' response meaning and intention. Participants' responses were recorded using a voice recorder. The researcher transcribed all of the interviews which maximized familiarity with the content and aided theme development. Interviews were recorded using the researcher's password-protected smart phone using the *Sound Recorder* phone application. This application was selected after discussion with other researchers and the research advisor based on ease of use, quality of recording, and confidentiality and security requirements. The audio recordings were transferred to the researcher's password-protected computer via cabling and were then deleted from the phone.

### **Interview Questions**

This study used a phenomenological methodology to investigate the subjective inner perspectives of people who facilitate the process of grief for the bereaved through the lens of mindfulness practice. Interviews were conducted using questions that generated by the researcher which were intended to capture the in-depth experiences of participants. Questions were developed to enable hospice bereavement counselors to reflect on the intersections of their self-defined mindfulness practice with their reflections on the effect these practices may have on



their work with bereaved clients (see Appendix A). An example of a question included in the interview is: *Would you describe for me an experience in which you used elements of mindfulness practice; deep breathing, tracking physical sensations in the body, and or utilizing relaxing imagery?*

### **Ethical Issues and Limitations of the Study**

Ethical considerations and limitations in qualitative research center on the use of the researcher as the primary instrument of data collection. In conducting qualitative research, it is critical that the researcher reflect on how personal attitudes, values, and biases influence the impartiality of the data collection process. In this study, the researcher's familiarity with concepts of meditation and mindfulness influenced the note-taking. This became apparent during transcription process. The researcher recognized that some participants would use a term or concept in their response and the researcher failed to ask them to further define such concepts to attend to the larger audience. Also, the researcher seemed to over-identify with particular participants' experience or perspective. In addition, the researcher recognized that she became overwhelmed at times due to the length of the interview and frustration with participant responses that did not match the intent of the question.

The researcher's personal experience was a salient source of bias in this study. Specifically, the researcher recently lost both parents and a close friend to cancer. In addition to the direct experience of loss, the researcher facilitated guided mindfulness practices with each of the deceased persons and perceived that these practices had positive effects on all involved. Also, the researcher continues to use meditation and mindfulness practices for personal edification.

Each of these personal experiences skewed the collection and interpretation of the data. To address this, the researcher maintained an ongoing consideration of ethical principles throughout the course of the study to minimize the effect on the study. Also, in order to reduce the effect of positionality on this study, the researcher used reflexivity and an iterative process that involved planning, interviewing, analyzing, and reflecting with every interview. Throughout the data collection phase, the researcher constantly compared newly collected data to previously collected data to support reliability, validity, and reflexivity.

As previously noted, the use of a qualitative methodology did not provide generalizable results due to non-probability sampling. An additional limitation of this study was the lack of representativeness of the sample frame. However, the benefits of qualitative research included increased understanding of personal experience by a data gathering technique that allowed for greater understanding of participant phenomenology. Qualitative interviews supported participants' responses that allow them to express the breadth and depth of their experiences. While theoretical saturation was sought in order to ensure the meaningfulness of the results, this cannot be assured because the sample size was smaller than desired. To address limitations in validity and reliability, the researcher used interventions to ensure accurate understanding and interpretation of participants' responses. These interventions included: peer debriefing, member checking (reflecting participants' responses back to them), and the use of a daily audit journal. The record included a list of daily actions and interviews so that the researcher was not required to rely solely on memory to account for the study process.

### **Data Analysis**

The study utilized a number of techniques to analyze qualitative data. These included: collecting data, documenting the process, organizing and categorizing concepts, capturing

themes and patterns, thinking about the potential for alternative explanations, and reporting the results of the study (Willet, 2014). Willett (2014) outlined four stages for qualitative analysis that were used in this study: recognition, clarification, elaboration, and coding. In the first interview the researcher reflected on themes that emerged and interpreted whether they were similar to the domains outlined in the initial proposal for this study. Over the course of the remaining interviews the researcher compared the initial elements to new themes and began to anticipate other trends that might surface. As these domains developed, a code book divided by each interview question was written to sort through the findings.

### **Hypothesis**

The hypothesis of this study is that bereavement counselors perceive their mindfulness practices as beneficial to the services they provide to families and caregivers by infusing the therapeutic relationship with their personal practices.

## **Chapter 4**

### **Findings**

This study examined how hospice bereavement counselors perceive their mindfulness practices affect the services they provide to families and caregivers. The research sought to learn more about the ways in which mindfulness practice, or elements of mindfulness practice influence bereavement counselors' service delivery.

An inclusion criterion to participate in this study was bereavement counselors who identified using elements of mindfulness such as: focused breathing, centering, and attention to the present moment. Other exercises were also described as being part of participant's self-defined mindfulness practice. Participants were asked to reflect on their practices and describe how they perceive these practices have impacted their work with bereavement counseling. Participants' perceptions were explored using a series of questions designed to identify their definitions of mindfulness, and describe their particular mindfulness and an experience in which they used mindfulness. In addition, participants were asked to describe their perception of the effect of their own mindfulness practices on their service delivery to bereaved clients.

The findings of this study are divided by five sections by the questions: 1. Participants' definitions, 2. Self-defined mindfulness practices of personal life, 4. Description of an experience in which they used mindfulness or elements of the practice directly, 3. & 5. Bereavement

counselors’ perceptions of the impact their mindfulness practices and experiences have on their work with clients; and 6. Participants’ descriptions of how mindfulness has impacted their sense of the past, present, and future. Sections 3 & 5 were combined due to the similarity of the questions and that participants answered them likewise or flip flopped. The lack of specificity and clarification of these questions was recognized by the researcher post hoc when examining the data.

Table 1: Categories by Question

Themes	<i>n</i>
Definition	
Awareness	10
Mechanisms	10
Practices	
Self- nurturing rituals	10
Quieting the mind	10
Physical Awareness	10
Sources of Inspiration	10
Impact on work	
Personal strengthens professional practice	10
Self-care	6
Awareness	4
Connection	10
Experiences	
Emotional Regulation	10
Sense of time	
Being in the now	6
Progression of time	4

### **Definitions of Mindfulness**

**Awareness.** The superordinate theme of mindfulness definitions provided by all 10 participants was awareness. Awareness is the paying attention to an immediate experience. Two participants described mindfulness as “paying attention.” Awareness can also refer to paying attention to what is happening on cognitive, emotional, physical, and or even spiritual levels.

Noticing thoughts, feelings, sensations from the body, and recognizing spiritual connection are all examples of what a person can be aware of. Participants described awareness as a variety of conditions. For instance, two participants described what they attend to as the body, mind, and spirit. In another example, two others referred to awareness as a process of reflection.

**Mechanisms.** Hospice bereavement counselors included in their definition of mindfulness the mechanisms or methods that they perceive to contribute to their awareness. All 10 participants described practices of how it is that they become aware. “Being in the present moment is reached through practicing my ability to detach myself from the event, the reaction to the event, and how I respond. I stop, I pause, I reflect.”

Many of the participants referred to elements of Kabat-Zinn’s (1994) definition of mindfulness “paying attention in a particular way: on purpose, in the present moment, and non-judgmentally...it is an intentional appreciation for the present moment through observing both the internal and external experience” (p. 53). Similar to the responses of the participants in this study, Kabat-Zinn’s (1994) definition goes beyond a simple description of what mindfulness is and integrates the mechanisms of how to practice. Nine participants mentioned the words present moment, echoing the core of Kabat-Zinn’s (1994) definition. Being in the present moment is a state in which a person is striving to not think of or attend to the past or the future. The present moment can also be described as flashes of time, from one instant to the next. In general participants described that mindfulness is the mechanism that has the most direct link as to how it is they reach a heightened consciousness or awareness. These principle mechanisms described by participants in Question 1 informed the answers to Question 2: What are your mindfulness practices or what elements of mindfulness do you integrate into your personal life?

## **Hospice Bereavement Counselors' Practices**

**Self-nurturing rituals.** The practices most used by participants reflected the theme self-nurturing rituals. These practices provide them with physical, emotional, and spiritual wellbeing. Question two asked participants to describe the practices they use in their personal lives. The routines they described have provided them with comfort, empowerment, and sustenance in both their private and professional lives.

Participants described a variety of rituals; the frequency of use ranged from sporadic to routine. However, whether used occasionally or regularly, the self-nurturing behaviors appeared to reflect the importance of taking time to relish the current moment by being aware of internal and external experiences. Participants reported that their practices provided them with awareness of their self-care resources. By paying attention to their own needs, they improved their ability to attain sustenance independently. There were three subthemes of self-nurturing rituals that participants described: quieting the mind, physical awareness, and sources of inspiration (see Table 1).

***Quieting the mind.*** All of the participants in this study reported using an exercise that involved quieting the mind. For seven, this was meditation. Mindfulness is known as a type of meditation so many of the participants used these words synonymously. However, this ritual was further elaborated upon by three participants' who referred to religious and spiritual meditation such as Transcendental Meditation (TM), Vedasya meditation practices, and also Catholic and Quaker meditation. "Personally, I've been a meditating for 40 years, I started with TM meditation, and it is only recently that I have begun to let go of the TM and begin more of the mindfulness meditation."

Four participants said that they have used quieting the mind as a preparation ritual. They have used their mindfulness practices in the morning in preparation for the day, and before going into a counseling session.

Before I meet with clients I will always try to be calm before sessions. If I'm not, I will take in my surroundings by smell or my senses. I will ask God or ask the universe that I hope something will come out of my mouth that will be helpful. It helps inspiration come to me, and I do this so that it is about their needs, not my own.

This participant used multiple types of self-nurturing rituals that provided her with awareness of her emotional state, a sense of empowerment through use of prayer, and the sustenance of hope.

The self-nurturing ritual of letting go is one of detaching from thoughts, experiences, and distractions for two participants. One participant calls it emptying.

Letting go; I mean that is such a phrase we use in hospice work. Letting go is happening every moment, whether one is dying or not, we are letting go. It connects to a leaf I have, that suffering is caused by not letting go.

This participant eloquently narrated the role of letting go in hospice work and described the relationship of attachment to pain. Bereavement work is about helping family and caregivers let go, and facilitating the detachment after the loss of a loved one. I think that the practice of letting go is an important ritual that bereavement counselors can share with their clients.

***Physical awareness.*** In order to quiet the mind all participants of this study used an element of physical awareness. Physical awareness is paying attention to both the internal and external stimuli. Utilizing the techniques participants described to quiet the mind, redirecting of



their cognitive attention or thoughts, was also done by focusing on either the inner physical experience or the outer occurrences and often many of them combined the two.

Paying attention to the breath is the action of concentrating on the speed, quality, and rhythm of breathing. To do this, four participants described their mindfulness practice as including the use of breathing techniques. Two participants described a technique they use as *square breathing*:

I can be anxious about the depth of emotion I face in this work with people dying. I was taught square breathing. In for 4 counts, hold for 4, breathe out 4, and pause for 4 seconds before breathing in again.

Counting breaths enabled this participant with awareness of her physical sensations. This strategy supported self-restoration and self-regulation of emotions of panic, anxiety, and overwhelm.

Half of the sample described noticing their bodies and paying attention to physical sensations, including what they hear, taste, see, feel and express, e.g., sing. These important practices helped participants redirect their awareness from their thoughts and become attune to an inner awareness. Two participants described using a body scan technique. This technique involves closing the eyes, noticing the breath, and focusing on each body part individually; starting with the feet and gradually reaching the head.

One participant described a unique way in which she practices being physically aware of the body. The method she described is variably called authentic movement or contemplative dance. She characterized the process as one that integrates use of the body, or external experience, with seeing from an inner lens; an internal awareness.

Four participants described using nature to heighten their physical awareness through sensations such as sight among others. Participants identified varied experiences that included physical activities such as gardening or the use of a labyrinth and visual experiences including viewing the sky and or mountains. Participants reported that these experiences have increased their sense of strength or support and self-nurturance. The process of focusing on the sensations provided by external stimuli enabled participants to balance their experiences of their internal cognitions and emotions.

***Sources of inspiration.*** Utilizing sources of inspiration (see Table 1) is another self-nurturing ritual that many participants said that they integrate into their mindfulness practice. These sources of inspiration include: music, sound, religious practices of prayer, and literature.

Five participants reported that sound and music are sources of inspiration for them. One has a Tibetan bowl that she uses at the start and end of bereavement groups she facilitates and thinks this is a source of inspiration both for her, and for the group. Two participants reported that the use of singing is an essential aspect of their self-nurturing rituals. For one participant, this involves singing in a choir. Another stated, “I play music. I play the coronet. It is very focusing for me. I also sing a form of Jewish music which is Nigun; it is a melodic incantation of prayer.” Song and music are useful ways that these participants stay connected to their breath. These mechanisms integrate both the internal sensation of listening, as well as the external projection of their voice.

In song, silence, and prayer, some participants ( $n = 4$ ) described that their religious practice is part of their mindfulness rituals. Two participants described that they use the Catholic religion of their upbringing and prayer. “I say the Hail Mary a lot in the car and usually before I have a session. It brings across the birth of Christ, the incarnation and power of women, and of

life and death.” Offering up the pain of her clients to Mother Mary is how another counselor is able to maintain emotional separation with her clients. All participants who illustrated the use of prayer and religion reported that these self-nurturing disciplines have bolstered them in their delivery of bereavement services.

Most participants illustrated that their rituals have provided them with an awareness of their own self-care resources. The participants described that by paying attention to their needs with the use of mindfulness, they have strengthened their own individual abilities to care for themselves independently. Three participants stated that their independent mindfulness practices are not separated from the setting of their hospice work. Their practice of mindfulness rituals is consistent across their private lives and service delivery to the bereaved. This suggests that for at least some bereavement counselors, mindfulness is integrated into their work with clients.

### **Perceptions of Effect of Mindfulness on Work with Clients**

**Combining the findings.** Questions three and five of the interview are combined in this section of data findings. The intention behind question three, “How do you perceive mindfulness to affect your work with bereavement counseling?” was to inquire about the personal mindfulness practices that participants had described in question two and how they affect their work. The aim of question five, “How do you believe your work with the bereaved has been influenced by your experiences with mindfulness based practices?” was to gain greater insight into how bereavement counselors perceive the effect of specific and separate experiences described in question four on their work.. However, the questions are similar enough that many participants responded in a similar fashion to both questions or appeared to answer the intention of the question to which they were not currently responding. This confounding issue was

recognized during post hoc analysis of the data. Failing to clarify these questions more specifically resulted in overlapping responses and this is a limitation of this study.

**The impact of practices and experiences on bereavement counseling.** All participants shared that their mindfulness practices improved their personal self-care, awareness, and the connection they had with bereaved clients. The mechanisms and tools of mindfulness that they use personally and professionally contribute both to their connection with themselves and the relationships they have with their clients.

*Self-care.* Six participants reflected on how their practices have helped them directly. From those, the ability to “be present” ( $n = 4$ ) is a self-nurturing ritual they use for themselves. One participant described the practice as “I will use mindfulness myself; take a deep breath, get grounded, and come back so that I can be present.” Another counselor explained, “Mindfulness has allowed me to do this work a lot longer. In my ability to be present, I don’t seem to burn out, so it seems to be working.” One participant expressed that mindfulness has helped her be able to do bereavement work for 19 years. She also described doing silent prayer, alone each morning to bring her a sense of relaxation. She stated that preparation for the day in solitude and silence has helped her to mark the “threshold in between the time with the self and the time with connecting with others.”

*Awareness.* Paying attention and noticing what is going on in their minds, with their emotions, and or in their bodies ( $n = 4$ ) is a tool that practitioners described as useful to staying present. “I will use mindfulness myself; take a deep breath, get grounded, come back, and just notice the relational component.” Another participant notices her internal cognitive awareness, “I am aware that I don’t have to solve their problems. I’m just sort of a compassionate vessel in the process.” One bereavement counselor described the benefit of being physically attentive.

“So noticing how open or closed I was sitting, or my posture, and learning how to be open to them without overwhelming them. This has to do with mirroring; what’s going on with them.” She started with her breath, a primary mechanism of mindfulness, and then attended to the position of her body. She noted that by practicing awareness of her physical state, she was able to reconnect with the self and attend to her nonverbal communication in client interactions.

Another participant described working with a woman who was really shut down; not communicating and not responding verbally in their individual work. This bereavement counselor used the practice of awareness and expanding her attention with a client to find a creative alternative from her traditional approaches.

The mindfulness piece was being able in the moment to think, *“I could use a little help here, she could use a little help here, and what I generally do really isn’t working me.”* I thought, *“Can I think of something else?”* So what I asked her was something about, “As a child what did you do? Did you like to draw?” I had some art materials and we sat in the big room and I brought out paper and collage things...and wow, it was the most dramatic use of art therapy! She drew and talked!

In the act of stepping back cognitively and pausing to reflect, she found a way to make connection with her client despite the time-limited nature of their interactions.

**Connection.** All participants described the benefits of using mindfulness as a method of making connections and bonds with individuals and groups. One participant reflected upon the value of connection in her work, “When I went to school for counseling psychology, my classic line is it took me two and half years and \$10k to learn that it is relationship that heals.” This participant added that the connection supported by the use of mindfulness also strengthened the therapeutic bond.

You can be an intuitive person, a very highly trained person, a kind and compassionate person, but there is a whole other level of connection and invitation that comes through a mindfulness practice.

*Listening.* Sharing and witnessing the experience of someone else's pain was a method of connection for two participants. According to one participant, making connection is about quieting her own mind to infuse the therapeutic relationship with the space for her client(s) to express their pain and for her to sit with that pain.

Another participant shared, "It contributes to my ability to be attentive and be a better listener in my groups. It is something that I think helps everyone relax." The benefit for group participants is that they have the opportunity to mirror the receptivity of listening that this participant models.

*Teaching.* Six participants said that mindfulness has helped them to connect with clients with providing them resources. "It helps a lot, because I can pass that stuff on to them. The more we learn about ourselves, the better." Another counselor described combining mindfulness with Reiki, a healing energy practice. She shared speaking with a client about having greater awareness of her soul. "At the end she said, 'I'm going to pay more attention to how I see my soul.'" In this example the participant connected a healing art with mindfulness.

Offering encouraging words and suggestions help to name the grief experience for clients were also reported ( $n = 3$ ). One counselor described this connection in detail. "I use mindfulness to charge the situation, to define the situation and help them define the situation. Meet them where they are at." Allowing the space for her work to be both client-centered and collaborative, this counselor makes connection and provides her clients to also become more connected to themselves and what they are experiencing.

Naming the experience of grief and loss with clients strengthens trust in the therapeutic relationship as stated by one participant. “Sometimes I will say to clients, ‘I know it is hard for you right now, but even if you can say that the moment is good, that’s a step to tolerating the pain behind it.’” She reflected that helping bereaved clients in building their capacity to endure the pain of their loss is a gradual process.

Participants reported that they found mindfulness to be helpful and beneficial to their clients. Participants also found that formal education about mindfulness practice for clients, suggestions for use, and encouragement, strengthened the connections that they had with their clients.

### **Narrative of an Experience in which Bereavement Counselors used Mindfulness**

When asked to describe an experience in which they used mindfulness, participants responded in two ways. Five participants described a single personal or professional experience using mindfulness. The other five clients identified routine and repeated practices that they do independently and or with clients ( $n = 5$ ). All participants described that their experience(s) facilitated emotional regulation (see Table 1) for either themselves and or their clients.

All participants expanded upon the mindfulness practices that they do both personally and professionally in their responses. One said, “I always think about keeping my feet on the floor and putting my hand to my abdomen.” Another said, “Sometimes with hospice patients that I see I will make other connections such as hug and cry with them.” A third participant said, “I stay grounded in my body as opposed to my mind.” These participants described important moments of closeness and connection with themselves and with their clients. By using both physical touch and physical awareness, their mindfulness practices elicit a particular intimacy that further quiets their minds.

**A personal and or professional mindfulness experience.** The four participants who described a single experience were the most detailed both in story content and in how they illustrated emotional shifts in themselves and or with their clients. This is important, because it was the researcher's intent in question number four to have participants describe a single experience.

Using mindfulness for anxiety was described as personally helpful for emotional regulation by one participant, as she described her experience with testifying before senate sub-committees on gun regulation. Surrounded by a large number of people who opposed the gun regulation she was advocating for and waiting for quite a long time, her self-nurturing practice helped to regulate her own emotions. "I was also helping two people who were victims of gun violence. I had to stay grounded with my emotions and with being aware of my own breath; up until I was reading my statement." She was able to be effective in delivering her statement by staying present with her inner experience and with surroundings.

One participant shared an experience she had with a hospice patient who she would visit with everyday and use a variety of mechanisms and rituals. She witnessed the impact the mindfulness practices had with this patient as comforting her anxiety. "Then we would see some changes in her breathing where, when she was agitated, she would then switch into a restful sleep." The predominant theme of this participant's experience in helping with the dying process of this client is connection. She did this by being with her, sharing in her experience, coming consistently, and even witnessing the moments of pain and the moments of peace.

Doing mindfulness with this hospice patient was about focusing on creating a space for her that was peaceful and meditative and allowing her to be that person with that mediation practice up into the moment of her death. "It was beautiful. It was truly beautiful. It was quite



moving to everybody...She became an embodiment of peace; very rare. I have never experienced it before”.

The reciprocal nature of this participant’s mindfulness rituals not only provided her client with ease and relaxation, but also gave her the opportunity to see the powerful impact mindfulness can have with other hospice patients.

**Experiences with routine mindfulness rituals.** Five participants elaborated on the routine mechanisms of the mindfulness practices they do and not a singular experience of their mindfulness rituals. One participant reported that in, “Deep breathing; I always think about keeping my feet on the floor. But I have also done where I count in my head; in 5 seconds, out 5 seconds; to keep those the same. I’ve found it really helpful.” This practice is one that she returns to again and again. Another participant shared that her mindfulness practice has helped her with behavior change as she used to have a phobia of being around others.

Participants who identified routine practices that they use and not just one specific experience ( $n = 5$ ) described rituals that help them to feel connected both to themselves and to their clients. One participant described the use of sound that brings comfort to both patients at the hospice where she works, as well as providing peacefulness for her. “I frequently play this small harp that I have. I find that music or just the gentle strumming of the strings brings a sense of great relaxation to me, and the person dying.”

Another counselor who also works at an inpatient hospice unit expresses how it is that she has learned to cope with being around so much pain around her. Her ritual is one that is protective for her and creates a boundary which separates the suffering of others from being absorbed by her. “I pretend that what they have told me goes into a river. There is a river between us, I visualize that what they are saying is going into this river, and not into me. I’m

able to let it go.” Utilizing visualization, religious practice, and letting go are interwoven in this participant’s self-ritual discipline. It also is representative of how using both elements of mindfulness definitions such as paying attention, in this case to the visualization, as well as self-defined mindfulness practices can be integrated and used together.

### **Perceptions of the relationship of mindfulness and time.**

All participants responded to how mindfulness has provided them with an enhanced perception of time and offered them perspective. Participants reflected on the progression of time throughout their lives in general ( $n = 4$ ), others spoke about the concept of time itself ( $n = 2$ ) and some participants replied to both of these themes ( $n = 4$ ). All participants referred to being optimistic, open, and or trusting of time, especially what time will bring them in the future.

**Mindfulness in my life.** For the four participants who answered this question within the context of the progression of time (see Table 1), their responses are about how mindfulness has had an impact on their life experience. “If I were more tuned into the mindfulness and practicing as I do now, I think that would have made a huge difference on my past.” These participants did not so much express regret, as they were engaging in an introspective process while answering this question.

I think in the past; I don’t think I was as conscious of being part of the process. I think know I feel in some ways that I can be more present, because I have a tool to be present, and do this work a lot longer in the future.

Participants expressed gratitude and inspiration for their self-nurturing rituals over time. One participant said that they do not tend to focus on the future, “I think that I am more accepting now. I expect something great will come, because so many things have turned out that way. And it does. A good word for it is trust.”

**A mindfulness approach to time.** Participants referenced the approach of being in the present moment of now (see Table 1). Two hospice bereavement counselors' responses were philosophical in nature as they spoke directly about how to think about time from a mindfulness perspective. One elaborated on how mindfulness has given them perspective "about resting in the "I don't know for sure."” This participant used a quote by Rainer Maria Rilke in which one line reads, "Live the questions now" (1987, p. 48).

Rilke speaks to how this participant said she sees the future. Time through the lens of mindfulness, she said, "It is being open, and curious."

The other participant speaking about time as a concept also used literary references to express their perspective. "Life is all a dream. Shakespeare knew that." They also shared the insight they gathered from T.S. Elliot's 4 Quartets. In her own words she shared, "Time is an illusion."

**Impact and approach to time using mindfulness lens.** Four participants had reflections both about how mindfulness has changed their lives over time, as well as contributed to a theoretical understanding of time and the present moment of now. One participant's response was that mindfulness has changed her sense of time compared to other people. She also said that her philosophical perspective of the concept of now as being the only time. "I stay open to experiences; it is a practice. I have awareness that this day is the moment I have. Who knows? It could be my last." The work of hospice bereavement service and mindfulness are combined in her statement and illustrate the transitory quality of she has had in her life experience; not knowing when life will end reflects the futility in preoccupying the mind with the future.

Another participant responded similarly to this question about the sense of time as being in the now; the present experience. “Mindfulness influences my approach to life in the moment. My sense of now is about gratitude and remembering to open up your heart to beauty, go outside; appreciate where and what is around you.” He explained that part of his approach is inspired by a favorite poem. The poem reflects this participant’s approach and understanding of time; a *carpe diem* inspiration to being present in the moment and to live it fully.

Another participant reflected on how mindfulness has changed her life in comparison to the past and of how her mindfulness practices are like a companion in her sense of time. She described her belief that mindfulness is a mechanism to hold multiple perceptions of time; uncertainty as well as trust for the past, present, and future. “As I look back on the past, I recognize that I was much more reactive to changes and part of my reactions was the resistance I encountered in myself.” Reflecting on how she reacted to stressful situations before using mindfulness practice, she recognized that mindfulness has given her a new perspective on how she can react to difficult circumstances. “It means so much to me right now to see the power of creating an intention and the power of creating an invitation in how you create it and the difference in terms of what that opens your life up to.” Acceptance and optimism were presented in this participant’s perception of time. The personification of mindfulness as a partner in her sense of the past, present, and future is a unique and creative metaphor. Having a “companion,” this participant described that it has allowed her to hold multiple contradictory feelings in both her personal and professional lives.

The answers from all participants about how mindfulness has affected their sense of the past, present, and future, responded that it has regulated the emotions that come up around time across their life experiences and in their theories about what time is.

## **Chapter 5**

### **Discussion**

This study explored the perceptions of bereavement counselors' mindfulness practices on the work they do with families and caregivers. Participants were asked questions about what they define mindfulness to be and how they practice this discipline. In addition they were asked to reflect upon how mindfulness has affected their service delivery; drawing from experiences they have had with the practice. Lastly, participants were asked to describe how mindfulness has affected their sense of time. The findings in this study emphasized the positive effect that mindfulness has on the personal and professional lives of bereavement counselors, improving their connection with clients and providing them with a practice that they can share with the bereaved. Participants noted a variety of mechanisms that they use in order to heighten their awareness and be in the present moment. The findings also highlight participant's descriptions of using mindfulness mechanisms directly with their bereaved clients, and for two participants, with hospice patients directly.

In the next section, the findings of this study will be discussed in comparison to the existing literature. Subsequently the strengths and limitations of this study will be examined, followed by the implications that this investigation has for clinical social work and further research.

## **Examination of Study's Findings to Existing Literature**

This study was conducted because there is currently little research on the effect of mindfulness on the work with dying and loss. Most of the current research on mindfulness and dying focuses on MBSR as an effective intervention to alleviate physical and emotional symptomatology with cancer patients (Shennan, 2010). Literature that focuses on mindfulness as an intervention for family and caregivers coping with death and loss is limited (Black & Rubenstein, 2013). This study focused on exploring the perceptions of bereavement counselors about the benefits mindfulness provides them and their work. There is a lack of qualitative research in the field of hospice bereavement counseling and the data points of this study contribute to other literature on coping with death and dying.

**The concept and practice of mindfulness.** The source of the word mindfulness was coined by the British Pali language scholar, Thomas William Ryhs Davids (1900) who called it, “the active watchful mind” (p, 152). Development of this concept in the 20<sup>th</sup> century as Brown, Ryan, and Creswell (2007) found in their review of the contemporary meaning is that it is the understanding of mindfulness is broad both in its definition and in its practice.

This was congruent in how participants described what mindfulness is to them and how they practice it. All participants in this study included the idea of awareness in their definitions of mindfulness. This finding is similar to the findings in Rapgay and Bytrisky (2009) which summarized the general perceptions of how clinicians view mindfulness as “a development of awareness skills involving attention to one’s own breath while peripherally being aware of the body” (p. 159).

While the participants’ in this study defined mindfulness in a manner consistent with previous research and literature, the mechanisms each described were unique to their individual

practice. Many used elements of Jon-Kabat Zinn's (1994) approach to mindfulness "as an intentional appreciation[s] for the present moment through observing both the internal and external experience" (p. 53). Similar to MBSR, Kabat-Zinn's (1994) eight week course in mindfulness applying being present by inner and outer awareness, participants reported on how they quiet their mind, draw attention to the physical (breath, body, walking, and natural sources).

Different from the reviewed literature on how mindfulness is practiced, five participants in this study elaborated on how they do mindfulness with descriptions of self-nurturing rituals that provide them with sources of inspiration. They reported that music and sound, as well as prayer, and personal religious practices were incorporated into both personal and professional domains. The use of instruments was also described by some, including, a coronet, a Tibetan bowl, and a harp. Other participants described using the sound of their voice for both singing in a choir, and singing devotional Nigun Jewish songs.

The self-defined mindfulness practices identified by participants in this study deviate from the concept of mindfulness used in the majority of current research and suggest alternative methods to practice actively watching the mind ["the active watchful mind" (Ryhs Davids, 1900, p. 152)]. Participants of this study contributed greater insight into how mindfulness practice can be done.

**Coping with death and dying.** There exist a breadth of theories on how people adapt to death and loss. Clinicians and grief counselors have applied many theoretical approaches in their work with the bereaved and even the terminally ill (Bowlby, 1980; Kubler-Ross, 1970; Murray, 2001; Neimeyer, 1999; Worden, 1991; & Yalom, 1980). Some common themes across these theories include stages of adjustment: acceptance, emotional turmoil, hope, isolation, and letting go.

The subordinate themes of adjustment and detachment of these theories were developed to encompass participants' descriptions of what mindfulness is and how it helps them in their personal and professional lives. All participants defined mindfulness as awareness and described the mechanisms of how mindfulness is done. Nine participants described the mindfulness mechanism as being in the present moment. The data point of being present and not dwelling in the past or the future presents mindfulness as an exercise of continual adjustment and detachment which supports previous theories on coping with death. As one participant noted her mindfulness as a practice of is a self-nurturing ritual of detachment, "Letting go; I mean that is such a phrase we use in hospice work. Letting go is happening every moment, whether one is dying or not, we are letting go, [and] suffering is not letting go." This participant described that her sense of time and letting go is part of her mindfulness practice.

#### **Benefits of mindfulness.**

*For patients.* Shennan (2010) conducted a meta-analysis of literature on mindfulness for cancer patients; MBSR being the most widely researched. The benefits found across the research reviewed included: "improved relaxation and sleep, decreased stress and anxiety, and other physical benefits such as with libido and immunity" (p. 693). This was congruent in the findings in this study that mindfulness contributes to emotional regulation. Other research on mindfulness for terminally ill patients has shown that mindfulness can provide an enhanced perspective of death as a transition, not an end, offering them another resource for coping emotionally (Sand et al, 2009; Schroepfer et al, 2009).

For a few participants of this study who often work with hospice patients in addition to their bereavement work described similar effects. One hospice bereavement counselor who visited with a patient for many days before her death described doing a range of mindfulness



relaxation exercises such as reading poetry, and deep breathing. “Then we would see some changes in her breathing where she was agitated, she would switch into a restful sleep.” The participant reported that over the course of this patient’s dying process, the participant observed the patient’s consistent response to mindfulness practice included alleviation of her anxiety and provision of great relaxation. “She became an embodiment of peace; very rare. I never experienced it before.” The mindfulness practices that this participant facilitated not only benefitted the patient, but also provided a greater perspective of death as a transition from agitated to at peace, similar to the findings of Sand et al. (2009) and Schroepfer et al. (2009).

*For families and caregivers.* There is little research on how mindfulness has helped families and caregivers cope. As covered in the literature review, how this population copes with death and loss has demonstrated that Western cultural norms such as self-reliance can perpetuate the grieving process and keep Americans stuck in isolation and regret (Black & Rubenstein, 2013). Goldsworthy (2005) suggests that Eastern concepts of death offer alternative approaches for coping. Kabat-Zinn’s (1994) definition of mindfulness as a state of being “in the present moment,” (p. 152) is one such Eastern alternative.

In this study, participants described how their mindfulness practice influenced their work and also provided stories of how it has helped their clients. Similar to the research, many participants reported that mindfulness was a practice that they did with their clients in order to help them to be present with their sadness and grief. Emotional regulation was described to help not only patients, but hospice bereavement counselors and the bereaved. Connection with bereaved clients through invitation and suggestion, not prescription or advice, was another way participants described the impact of mindfulness on their work. One participant described her work with a client who had become very withdrawn after the loss of her husband.

With her I first just would have her close her eyes, deep breathing, imagining roots going down into the earth and being planted, and then imagining air reaching out through the top of her head, and then I'll do the resourcing which is imagining her peaceful place and feeling that peace and wellbeing. At the end she is remarkably less anxious.

Helping her client to be present and in the moment through the use of mindfulness, this clinician described an enhanced therapeutic alliance. Her client does not have to be alone and can gradually face her grief.

*For bereavement counselors and their clients.* The gap in the literature about bereavement counselors' use and perceptions of mindfulness in their personal and or professional lives, research on mindfulness and hospice work, and investigations about grief counselors was reviewed.

Bruce and Davies (2005) studied caregivers who worked at a Zen hospice center and used mindfulness in their daily activities and with their patients. The participants' use of active mindfulness increased their ability to support a patient's dying process and enhanced their personal relationship with the patient (Bruce & Davies, 2005). Other research on grief therapists suggests that self-care and personal experiences with loss improves their ability to work with bereaved clients (Becvar, 2003; Ober et al., 2012).

Similarly, participants in this study all reported that mindfulness has improved their self-care and also enhanced the quality of the work they do with clients. They reported that the mechanisms of mindfulness both in their personal self-nurturing rituals as well as the practices they do with clients allow them to have a better connection with themselves as well as the relationships they have with their clients. "Mindfulness has allowed me to do this work a lot longer." Another participant expressed that her practice has been able to help her through 19

years of bereavement counseling. Mindfulness provided some participants ( $n = 4$ ) of this study endurance for their work and strength.

*Personal experiences of bereavement counselors.* In contrast to findings in previous research which reported that therapists' perception that awareness of their personal loss helps them to do grief work, (Cwierniewicz, 2007) is that participants did not report that personal loss at all. They did describe other experiences both personally and professionally. One participant depicted how she is able to witness and be in the presence of her clients' loss through using mindfulness to create a boundary that protects her from taking on their suffering.

So what I do is that I pretend that this river flows to Mary, and she takes care of them. I'm able to let it go. At the same time, I pray for them I literally give their pain to Mary. It works for me.

*Connection.* Unique to this study was that all hospice bereavement counselors' described that mindfulness helps them to connect with their clients and improve the therapeutic relationship. They illustrated that by being more connected to themselves they are able to facilitate the connection they have had with clients and provided emotional regulation for them both. "You can be an intuitive person, a very highly trained person, a kind and compassionate person, but there is a whole other level of connection and invitation that comes through a mindfulness practice."

This gap in the literature about connection is central to the purpose of the study, as previous research has not examined how bereavement counselors perceive having a greater attunement to their clients with mindfulness practice. Part of making this connection for two participants is practicing mindful listening. For one clinician, mindfulness has helped her to quiet her mind and listen more. "When I think of myself now and 30 years ago, I'm not as

inclined to state my opinions about things, although I love talking. It is more like the need has vanished.”

Yet another phenomenon was that making connection for six hospice bereavement counselors was through teaching what mindfulness is and sharing accessible exercises with their clients. This study found that using mindfulness exercises, suggestion for use, and encouragement, helped bereavement counselors’ strengthen the connection they had with their clients. “It helps them a lot, because I can pass that stuff on to them.” Another bereavement counselor stated, “I added more information about the research which shows focusing on your breath and coming into the present moment can be helpful to lower your heart rate if you are anxious.”

### **Strengths of this Study**

The strengths of this study was that the qualitative and exploratory design allowed the researcher to collect rich narratives and detailed descriptions of bereavement counselors perceptions of the impact their mindfulness practices have on their work that could not be collected in a quantitative study. As a result of the gap in literature about mindfulness in hospice care and bereavement counseling this project provided a foundation for further research with this population. Most research in the field of mindfulness and the healthcare is limited to Jon Kabat-Zinn’s model (1994), not on self-defined mindfulness practices. Literature is also primarily focused on the benefits for patients with terminal illnesses, not on the clinicians who serve them.

### **Limitations of this Study**

This study has a number of limitations. One is that this study has limited generalizability due to the research method and sample which limits the statistical significance. Additionally, the sample is small for the ideal number of participants in a qualitative study. In addition,

participants in this study represent the demographics of the region, but do not substantially represent the demographics of the wider American society. The region's population consists of mostly white, and middle to upper class persons living in this region making the external validity of this study low. A larger sample and collection from a broader demographic area of participants, would strengthen generalizability and inform further research.

Another limitation is that the interview questions number three and five lacked specificity in the design to capture more exact information, as two of the questions were so similar in wording that participants' answers were flip-flopped between the questions. This is a limitation because questions three and five might have been misunderstood by the participants and the intended inquiry was blurred. Question number four was intended to gather one particular experience, however many participants described routine experiences or multiple ones. The lack of clarity in question number four made it difficult to compare data points and analyze the findings. The study could be improved if the researcher asked more concise and open-ended follow-up questions during the interviews.

### **Implications for Clinical Social Work Practice**

The findings of this study richly contributed to the field of clinical social work because it reveals the perspectives of an under-researched population of bereavement counselors. It gave them a voice to share their mindfulness practices and perceptions of their impact on grief work. Clinicians encounter grief and loss with their clients in the many domains that social workers enter into with their employment. Even if the primary role of a social worker is not with bereavement, they can benefit personally and professionally from the data collected in this investigation. For example, this study supported previous research that clinicians can improve

their self-care by using self-nurturing rituals. These rituals can be seen as tools that support clinicians in being able to effectively work as therapists.

Additionally, participants stated that mindfulness has deepened the connection they have with both themselves and their clients. While clinicians build on their personal sensitivity through professional training, utilizing mindfulness has the potential to substantially enhance their work with clients by strengthening the interpersonal connection.

Clinicians can also integrate the teaching of formal, such as MBSR, or self-defined mindfulness practices with clients, which participants shared were fairly simple and easy to introduce in an accessible manner.

### **Implications for Future Research**

Due to the small sample size as well as the limited diversity of the participants' demographics, further research with a larger number of participants would increase the validity of this study. There were nine women and one man in this study. All identified as white and as having practiced mindfulness for at least 3 years or more. Gathering participants of more diverse backgrounds of gender, age, racially, culturally, socioeconomically and regionally in the United States would be useful to compare for generalizability of this research study.

Another limitation in this study was the lack of specificity and limited number of questions. Although some participants reported that they had received training in mindfulness, such as MBSR, it would benefit this field of research to inquire about formal and informal modes of how they came to learn the practice. While this study examined the experiences of hospice bereavement counselors, it would be interesting to apply the same inquiry to other hospice disciplines such as social workers, chaplains, nurses, home health aides, volunteers, doctors, and other members of the interdisciplinary team. Researching the benefits of teaching loved ones

and caregivers a mindfulness practice and asking what their experiences are could also inform how to improve their experience and avoid caregiver burnout.

Further, although mindfulness and MBSR have been studied with cancer patients and patients with terminal illnesses, a few participants of this study expressed that mindfulness has helped hospice patients. Differing from other samples with terminal diagnoses, hospice patients generally have a more certain prognosis of dying in six months or less, as their doctors have no further treatment for their illnesses. Also, although cancer is a common terminal illness, other chronic conditions such as congestive heart failure (CHF), neurological disorders, and other rare illnesses could be studied to ask in what ways mindfulness can help hospice patients cope with their dying process.

It would also be valuable to understand if a mindfulness practice with hospice patients and their loved ones might have the potential for healing the past and helping both face their anticipatory emotions. This study asked participants how their practices have impacted their sense of time. For two of them, they felt mindfulness has provided them with a perspective of timelessness and a surrendering to the idea of now. Their responses inform future research to look at this perspective with a more specific inquiry of the philosophical experience and understanding of time.

Additionally MBSR has been widely researched for medical and mental health benefits, however there has been no research done with hospice patients by clinicians who are trained in this form of mindfulness. Many of the benefits found have been on physical, mental, and emotional improvements, but not the specific experiences with grief or loss, either with hospice patients or with bereaved. Such further research could inform bereavement counselors and hospice agencies on how to better their service delivery with MBSR training.

## Summary

This study explored the perceptions of bereavement counselors' mindfulness practices on the work they do with families and caregivers. Participants defined their personal practices, narrated the positive impact it has had on their personal and professional lives, shared experiences they have had with clients, and reflected on how mindfulness has affected both time throughout their lives as well and their philosophical view of time. The perceptions of how mindfulness practices of hospice bereavement counselors impact their personal and professional lives are missing from the current literature. It was salient that mindfulness has bolstered their capacity to do bereavement work, improved the relationships they had with their clients, improved their service delivery, and provided them with skills that they can share with both hospice patients and the bereaved.

As mentioned in the literature review Brown, Ryan, and Creswell (2007) reviewed a broad collection of contemporary mindfulness practices and noted that practitioners interpret the concept of mindfulness to be broad in its practice and implementation. This was true in this study as participants self-defined their mindfulness practices beyond formal definitions such as Kabat-Zinn's (1994) MBSR. They explained how they practice awareness by a variety of mechanisms that expand upon mindfulness such as the use of religion, music, sound, and inspirational sources. These self-nurturing rituals contribute to a wider conceptualization of the original definition of mindfulness "the active watchful mind" (Ryhs Davids, 1900, p. 152).

This study was important because it can serve as a foundation for research in the field of mindfulness and hospice bereavement counselors. Also, this study can inform future research into the potential of mindfulness as an intervention for bereaved clients, hospice patients, and grief counseling.



Participants described mindfulness as a tool that is unique from other disciplines in hospice bereavement work and noted that it enhances their personal and professional lives. Using a qualitative design allowed for a deeper look into the experiences of hospice bereavement counselors. Their stories add to the field of death and dying and reveal how mindfulness facilitates coping with loss.

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## **Appendix A**

### **Interview Guide**

- 1.** How do you define mindfulness?
- 2.** What are your mindfulness practices or what elements of mindfulness do you integrate into your personal life?
- 3.** How do you perceive mindfulness to affect your work with bereavement counseling?
- 4.** Would you describe for me an experience in which you used elements of mindfulness practice; deep breathing, tracking physical sensations in the body, and or utilizing relaxing imagery?
- 5.** How do you believe your work with the bereaved has been influenced by your experiences with mindfulness based practices?
- 6.** I'm interested in how mindfulness has impacted your sense of the past, present, and future?  
Could you tell me more about it?

## Appendix B

### HSR Approval Letter



#### School for Social Work

Smith College

Northampton, Massachusetts 01063

T (413) 585-7950 F (413) 585-7994

February 10, 2015

Heather Floyd-Haupt

Dear Heather,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

*Please note the following requirements:*

**Consent Forms:** All subjects should be given a copy of the consent form.

**Maintaining Data:** You must retain all data and other documents for at least three (3) years past completion of the research activity.

*In addition, these requirements may also be applicable:*

**Amendments:** If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

**Renewal:** You are required to apply for renewal of approval every year for as long as the study is active.

**Completion:** You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.

Co-Chair, Human Subjects Review Committee

CC: Daniel O'Donnell, Research Advisor

## Appendix C



### **Informed Consent to participate in a Research Study**

**Smith College School for Social Work • Northampton, MA**

#### **Title of Study:**

**The Perception of Mindfulness Practices of Hospice Bereavement Counselors**

**Investigator(s): Heather Floyd-Haupt XXX.XXX.XXXX**

#### **Introduction**

- You are being asked to be in a research study that focuses on the question: **How do hospice bereavement counselors perceive their mindfulness practice(s) to influence their service delivery to the bereaved?**
- You were selected as a possible participant because you self-identify as practicing mindfulness or elements of this practice.
- We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

#### **Purpose of Study**

- The purpose of the study is to **explore in what ways do hospice bereavement counselors perceive their mindfulness practices as influencing the services they provide to families and caregivers.**
- This study is being conducted as a research requirement for my master's in social work degree.
- Ultimately, this research may be published or presented at professional conferences.

#### **Description of the Study Procedures**

If you agree to be in this study, you will be asked to do the following things: Participate in an in-person or phone interview for 15-50 minutes and you consent for this interview to be audio recorded.

### **Risks/Discomforts of being in this study**

- The study has very low potential risks.

### **Benefits of Being in the Study**

- This study provides the benefit of reflecting upon your mindfulness practice(s), your self-care, and how you provide services to the bereaved. The intention is to provide a therapeutic resource for you with the aim of doing no harm. This study also provides you with an opportunity to express your thoughts and feelings about bereavement counseling and your mindfulness practices.
- Furthermore your participation in this study has the potential to help other bereavement counselors enhance their service delivery to the bereaved.

### **Confidentiality**

- Your participation will be kept confidential, and the records of this study will be kept strictly confidential. If you describe your experiences with information or details about your family history, place of residence, or any other identifiable information, it will be kept confidential. Only the researcher and an interview transcriber will have access to personal information gathered from recorded interviews, and any identifying information will be erased and destroyed upon completion of this research study.
- All research materials including recordings, transcriptions, analyses and consent/assent documents will be stored in a secure location for three years according to federal regulations. In the event that materials are needed beyond this period, they will be kept secured until no longer needed, and then destroyed. All electronically stored data will be password protected during the storage period. We will not include any information in any report we may publish that would make it possible to identify you.

### **Payments/gifts**

- You will not receive any financial payment for your participation.

### **Right to Refuse or Withdraw**

- The decision to participate in this study is entirely up to you. You may refuse to take part in the study at any time (up to the date noted below) without affecting your relationship with the



researchers of this study or Smith College. Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled. You have the right not to answer any single question, as well as to withdraw completely up to the point noted below. If you choose to withdraw, I will not use any of your information collected for this study. You must notify me of your decision to withdraw by email or phone by March 15, 2015. After that date, your information will be part of the thesis, dissertation or final report.

### **Right to Ask Questions and Report Concerns**

- You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, Heather Floyd-Haupt at [hfloydhaupt@smith.edu](mailto:hfloydhaupt@smith.edu) or by telephone at XXX.XXX.XXXX. If you would like a summary of the study results, one will be sent to you once the study is completed. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

### **Consent**

- Your signature below indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above. You will be given a signed and dated copy of this form to keep.

Name of Participant (print): \_\_\_\_\_

Signature of Participant: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of Researcher(s): \_\_\_\_\_ Date: \_\_\_\_\_

#### **1. I agree to be audio recorded for this interview:**

Name of Participant (print): \_\_\_\_\_

Signature of Participant: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of Researcher(s): \_\_\_\_\_ Date: \_\_\_\_\_

#### **2. I agree to be interviewed, but I do not want the interview to be taped:**

Name of Participant (print): \_\_\_\_\_

Signature of Participant: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of Researcher(s): \_\_\_\_\_ Date: \_\_\_\_\_

**Form updated 9/25/13**