

St. Catherine University

**SOPHIA**

---

Master of Social Work Clinical Research Papers

School of Social Work

---

5-2012

## **Deathbed Visions: Social Workers' Experiences, Perspectives, Therapeutic Responses, and Direction for Practice**

Leslee Curtis

*St. Catherine University*

Follow this and additional works at: [https://sophia.stkate.edu/msw\\_papers](https://sophia.stkate.edu/msw_papers)



Part of the [Social Work Commons](#)

---

### **Recommended Citation**

Curtis, Leslee. (2012). Deathbed Visions: Social Workers' Experiences, Perspectives, Therapeutic Responses, and Direction for Practice. Retrieved from Sophia, the St. Catherine University repository website: [https://sophia.stkate.edu/msw\\_papers/17](https://sophia.stkate.edu/msw_papers/17)

This Clinical research paper is brought to you for free and open access by the School of Social Work at SOPHIA. It has been accepted for inclusion in Master of Social Work Clinical Research Papers by an authorized administrator of SOPHIA. For more information, please contact [amshaw@stkate.edu](mailto:amshaw@stkate.edu).

Deathbed Visions: Social Workers' Experiences, Perspectives, Therapeutic Responses,  
and Direction for Practice

Submitted by Leslee Curtis

May 2012

MSW Clinical Research Paper

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present their findings. This project is neither a Master's thesis nor a dissertation.

School of Social Work  
St. Catherine University & University of St. Thomas  
St. Paul, Minnesota

Committee Members:  
Jessica Toft, PhD, LCSW (chair)  
Carey Winkler, LICSW  
Janet Westlund, LGSW

# DEATHBED VISIONS: SOCIAL WORKERS' EXPERIENCES, PERSPECTIVES, AND THERAPEUTIC RESPONSES

By Leslee Curtis

---

Research Committee:      Chair:      Jessica Toft, PhD, LCSW  
   Members:      Carey Winkler, LICSW  
                        Janet Westlund, LGSW

## **Abstract**

Deathbed Visions (DBVs) are intensely personal, powerful, comforting and even reassuring experiences the dying may encounter just before death occurs. The term DBV is a general label for the broad category of spiritual, mystical, or unexplainable experiences or coincidental occurrences that take place in the arena of death. The dying have reported seeing angels, religious figures, spiritual guides, or deceased loved ones. They may even have control over the timing of their death. Death-related sensory experience (DRSE), end-of-life experience (ELE), and nearing death awareness (NDA) are several terms commonly used to describe the many different experiences people have reported around the time of their death or nearing death experience. DBVs are a neglected source of peace and comfort for the patients and their loved ones. Fear of societal judgments and lack of validation may keep many silent and create confusion. This research explored the experiences, perspectives, and therapeutic responses of social workers and other professional caregivers who work with the terminally ill in the hospice setting.

## **Acknowledgments**

I would like to extend my sincere respect, and appreciation to my research committee chair Jessica Toft, who read through many rough drafts, and provided knowledge and guidance necessary for me to accomplish this project. Her insight and steady support were invaluable to me.

I would also like to express my gratitude and thanks to my committee members, Janet Westlund and Carey Winkler, who graciously agreed to serve on my committee. They offered their expertise and support at critical times during the process. Their editing suggestions and encouragement were so welcomed and meant a lot to me.

I would like to thank my co-classmates for their encouragement, insight, and understanding who have gone through this process with me and helped to keep me motivated.

I would like to thank the participants in this study. They were both personal and professional and provided me with their experiences and perspectives on the topic. They made time in their busy schedules to make themselves available. The help they provided in identifying additional participants was also very much appreciated. I truly admire the compassion, care, and support they offer to their patients and families; this care was evident throughout the interviews.

I would like to thank my husband Cal for his steadfast love, patience, and support as I immersed myself in this project over the last nine long months. I love you more!

I would like to extend my heartfelt gratitude and love to my family for their steady support and encouragement that helped me get through this process.

I would like to thank my co-worker Melissa who has listened to me talk about this project and its challenges over this past year. Her encouragement, support, and friendship have meant the world to me.

Finally, I would like to thank my Dad who passed on to his next chapter in life in 2008. He has always been supportive and I still feel his love every day. I love you Dad.

## **Table of Contents**

Abstract	p. i
Acknowledgments	p. ii
Table of Contents	p. iii
Introduction	p. iv
Literature Review	p. 1
Conceptual Framework	p. 22
Method	p. 25
Findings	p. 29
Discussion	p. 39
References	p. 47
Appendix A	p. 51
Appendix B	p. 55

DEATHBED VISIONS: Social Workers' Experiences, Perspectives, Therapeutic Responses and Directions for Practice

A deathbed vision or DBV is a powerful, comforting experience the dying and their family members often encounter just before death occurs (Willis-Brandon, 2000). The dying will report visions of angels, deceased loved ones, or religious figures, moments, hours, days or even weeks, before actual death takes place. These visions typically lessen the fear of dying and make passing an easier transition for all concerned (Willis-Brandon, 2000).

The term *deathbed vision* is a general label for the broad category of spiritual experiences that take place in the arena of death. They are paranormal experiences that happen to normal people. Death-related visions include such events as near-death experiences (NDE), after-death visitations, and healing visions. Also included are precognitive experiences, dreams, visions, and other premonitions of death that come true (Morse & Perry, 1994). NDE's are defined as the reported memory of all impressions during a special state of consciousness, including awareness of being dead, specific elements such as out of body experience, pleasant feelings, seeing a tunnel, a light, deceased relatives, and/or a life review (Morse, 2004). Nearing Death Awareness (NDA) or DBV's and NDE's are similar, but there are important distinctions. NDE's happen suddenly—as a result of drowning, heart attack, or traffic accident, while NDA or DBV develops in people dying slowly of progressive illnesses, such as cancer, AIDS, or lung disease (Callanan & Kelley, 1992).

NDE's have been more thoroughly researched and will be referenced in this paper for better clarification and interpretation of the deathbed phenomena experiences. This paper will primarily focus on departing visions often called deathbed vision or DBV.

Many diverse racial ethnicities and people of all ages who are nearing death have reported deathbed visions and spiritual experiences. Atwater (2002) conducted one of the

largest studies of this phenomenon with 3,000 respondents. In terms of experiencing this phenomenon, particular racial ethnicities reported experiencing DBVs. Among participants, Caucasian Americans, European and Arabic people predominate at 80%, with 20% being of the African decent (15% African Americans, 5% divided between Kenya, Haiti, and African Canadians). Of the 277 child experiencers, 60% were white, 23% were Latinos, 12% were blacks, and 5% were Asian (Atwater, 2002). Osis (1977) in a pilot study noted that previous religious beliefs did not appear to determine who would have a DBV before dying. Both believers and nonbelievers had powerful DBV's (Willis-Brandon, 2008). The age of experiencers also has not necessarily been a predictor in any individual case either of loss, fear of death, or the hope or expectation of reunion with a deceased person (Kelly, 2001).

There are skeptics who believe that DBV's and NDE's may happen for reasons other than spiritual or mystical beliefs. According to Greyson (1998), there are two major interpretations of deathbed visions: they might be indications of a life to come, or they are the product of hallucinations produced by various psychological or pathological conditions (Greyson, 1998). Few scientists have taken seriously the interpretation of NDE's as evidence for survival, nor have they shown much interest in comparing the strengths and weaknesses of this interpretation with those of other, non-survival explanations (Kelly, 2001). Kelly goes on to say their avoidance seems to stem from the widely prevailing assumption that a scientific view of mind-brain relations makes the hypothesis of survival after death nonsensical (Kelly, 2001). According to Moody (2007), some are convinced that there is life after death because of personal, transcendent, near-death experiences. Others are convinced of it because of their religious faith. And yet

others are just as convinced on personal and philosophical grounds that there is no such thing as an afterlife (Moody, 2007).

A person who has been through an experience of this type has no doubt whatsoever as to its reality and its importance (Moody, 2001). People who have had DBV's or NDE's realize from the very beginning that others would think they are mentally unstable if they were to report their experience, so have resolved to remain silent on the subject or else to reveal their experiences only to some very close relative (Moody, 2001). Regardless of the public's perception or individual reluctance to share their NDE's, death-related visions of all kinds may have the potential to influence our approach to dying patients while supplying them and us as practitioners with spiritual nourishment at a time of great need (Morse, 1994).

It is the purpose of this study to explore the knowledge and experiences of social workers or other health care professionals who may have been exposed to DBV's, to explore their practice approach when working with terminally ill patients, loved ones or their caregivers who have experienced DBV's, and how this issue may have impacted them personally.

## **Literature Review**

This section presents a synopsis of the research on Deathbed Phenomena. This consists of research on what is the Near Death Experience (NDE) and what are Deathbed Visions (DBVs), similarities and differences between them, the historical perspectives that shaped the research, opposing points of view, followed by research on the experiences and perspectives in responding to DBVs from professional caregivers in the hospice and palliative care setting.

### **Near Death Experience**

Raymond Moody first named the near-death experience in 1975. His original definition of the term was ‘any conscious perceptual experience which takes place during a near-death encounter’ (p. 124), which in turn he defined as ‘an event in which a person could very easily die or be killed (and may even be so close as to be believed or pronounced clinically dead) but nonetheless survives, and continues physical life’ (1977, p. 124) as cited in Greyson (1999). Moody later added to that definition the stipulation of a spiritual component: ‘Near-death experiences (NDEs) are profound spiritual events that happen, uninvited, to some individuals at the point of death’ (Moody & Perry, 1988, p.11) as cited in Greyson (1999). Greyson joined Moody by including the transcendental or mystical element in defining the NDE as ‘a profound subjective event with transcendental or mystical elements that many people experience on the threshold of death’ (Greyson, 1994, p. 460) as cited in Greyson (1999).

Moody identified 15 elements that seemed to reoccur in NDE reports: ineffability, hearing oneself pronounced dead, feelings of peace, hearing unusual noises, seeing a dark

tunnel, being out of the body, meeting spiritual beings, encountering a bright light, panoramic life review, a realm where all knowledge exists, cities of light, a realm of bewildered spirits, supernatural rescue, border or limit, and coming back into the body (Moody, 1975). In 1977 Moody later added four recurrent after effects: frustration upon relating the experience to others, broadened or deepened appreciation of life, elimination of fear of death, and corroboration of out-of-body (OBE) visions (Greyson, 2006). Moody noted that no two NDE accounts were precisely the same, that no one element appeared in every narrative, and that the order in which elements appeared varied from one experience to another. He also notes that children's NDEs are similar to those of adults, except that they tend not to include a life review or meetings with deceased friends or relatives (Greyson, 2006).

NDEs happen suddenly as a result of a drowning, heart attack or traffic accident (Callanan & Kelley, 1992) As a consequence of modern resuscitation-techniques NDEs have become more and more frequent and has attracted the interest of many people (Schroter-Kunhardt, 1993). Well-known scientists, psychologists, psychiatrists, medical doctors, parapsychologists, philosophers and scientists of religion began their studies along with the "International Association for Near-Death Studies" (IANDS) founded in 1977 (Schroter-Kunhardt, 1993). Despite extensive research, we still do not know what causes NDEs. Yet they happen to people of every age, religion, and nation (Batey, 2002). Explanation of these experiences has ranged from regarding them as either confusional hallucinations or fabrication, to confirmation of the existence of life after death (Parnia, Waller, Yeates, and Fenwick, 2000). About 8 million American adults, according to a Gallup poll, have had NDEs (Batey, 2002). Another recent study indicates that as many

as 38% to 50% of all patients who clinically come very near to death from any cause may have an NDE (Corcoran, 1988). Sociological, demographic or psychological variables have not been shown to influence the occurrence of an NDE (Schroter-Kunhardt, 1993). Research has shown that people as young as 2 and as old as 100 have had NDEs, 53% of them have occurred in females, 47% in males. Trauma, surgery, combat injury-just about every type of life threat can trigger the phenomenon. Several mothers, for instance, have reported having NDEs during childbirth (Corcoran, 1988). NDEs or OBEs have not been proven to signal any psychopathology; and people with mental diseases do not experience them more frequently than normal human beings. On the contrary, those who have experienced NDEs and OBEs are possibly mentally healthier as a group (Schroter-Kunhardt, 1993).

Schroter-Kunhardt (1993) notes that NDEs are experienced at the moment of real or anticipated death, i.e., before biological death. They are triggered by various situations such as accident, life-threatening illnesses, suicide attempts, operations, or births, which do not influence the content of the NDE. Quite often those who have experienced NDEs are clinically dead, i.e., without heartbeat and respiration. Some NDEs occur during an isoelectric EEG, some others even in the morgue (after giving up resuscitation). This is possible because the definite moment of biological death cannot be exactly determined. Finally up to 37% of Near Death like experiences occur in non-life threatening illnesses or accidents or are not associated with these (Schroter-Kunhardt, 1993).

Schroter-Kunhardt (1993) go on to point out that the contention that death means mere unconsciousness is purely theory, because this can neither be experienced nor verified. The last thing we know from a dying person is his NDE! Only the brain knows

exactly the “point of no return” (p. 222) of biological death. Pictures are the primary language of the brain, representing all somatic and psychic processes. The brain is able to control these pictures effectively (via biofeedback, imagination or autogenetic training). The NDE as a visual experience provides the most objective information about the imminent moment of biological death.

### **Deathbed Visions**

Another deathbed phenomena commonly referred as deathbed visions (DBVs), can be a spiritually transforming experience occurring with the appearance of a messenger beyond the visible observable universe to guide a dying person through the dying process (Ethier, 2005). Death-related sensory experience (DRSE) (Ethier, 2005), deathbed visions (DBVs) (Willis-Brandon, 2000), end-of-life experience (ELE) (Fenwick & Brayne, 2010), and nearing death awareness (NDA) (Callanan & Kelley, 1992) are several terms commonly used to describe the many different experiences people have reported around the time of their death or nearing death experience. Approximately 10% of all dying people are conscious shortly before their deaths, and of these people, it is estimated that 50% to 60% experience deathbed phenomena (Mazzarino-Willett, 2010).

Callanan and Kelley, two hospice nurses, were the first to use the term Near Death Awareness (NDA) in 1992 in their book *Final Gifts*. They reported what NDA might reveal to caregivers, what dying is like, and what is needed in order to die peacefully. NDA may also offer evidence to caregivers that the actual time of death is drawing close (Callanan & Kelley, 1992). Morse (1994) reported people who are near death tell of talking with, or sensing the presence of people, whom we cannot see,

perhaps deceased people they have known and loved. They know often without being told, that they are dying, and may even tell us when their deaths will occur.

DBVs develop slowly in people dying of a progressive illness (Callanan & Kelley, 1992). They are different from a near-death experience, in that their DBV is a manifestation of the dying process from which they will never physically recover (Morse, 1994). People who are experiencing DBVs often have such experiences over time and in a more gradual way. They are not clinically dead; they may undergo no visible or unusual physical change. They still have a pulse and blood pressure, they continue to breathe and most important, they continue to communicate, unlike people who have NDEs (Callanan & Kelley, 1992).

Willis-Brandon (2000) reported that the dying will report visions of angels, deceased loved ones, or religious figures, moments, hours, days or even weeks, before actual death takes place. DBVs happen during wakeful states, dreams, and meditation/prayer as part of the dying process. These visions may lessen the fear of dying and make passing an easier transition for all concerned (Willis-Brandon, 2000). Many of the individuals who have reported these visions were not on medications and were, up to the moment of death, very coherent. Those who were on medications, possibly near death experiencers, have also shared visions similar to those who were not on medications (Willis-Brandon, 2000). According to an end-of-life (ELE) experiences study in a Gloucestershire Nursing Home, conducted in 2006, interviewees agreed that hallucinations evoked confusion and anxiety, whereas ELEs possessed different qualities that focused on inner peace and acceptance of death as well as acting as indicators for nearing death (Brayne, et. al, 2008).

Caregivers and loved ones of the dying report a variety of deathbed experiences. These range according to Kessler (2010) from reports of what they witnessed the dying do or say, such as having a conversation with someone only visible to themselves during the days leading up to the death or at the time of death, seeing angels, preparing themselves for a journey, describing people or beings they are seeing, to sitting up and holding up their arms joyfully at the moment of death. Callanan and Kelley (1992) write that generally patients recognize someone significant from their lives such as a parent, spouse, sibling, or friend who is already dead and report a sense of pleasure, even joyful reunion in seeing that person again. As patients get closer to death, their awareness evolves gently and gradually, as though they are drifting back and forth from a consciousness of this existence to an awareness of the next, intensifying as the patient is nearing death. Callanan and Kelley (1992) state that when dying people begin to have these experiences, they often seem preoccupied, distracted, and perhaps even a little puzzled. They may ask questions, seem glassy-eyed, or appear to be looking through us, as if focused on something beyond. They attempt to share information by using symbolic language to indicate preparation for a journey or change soon to happen. One of the most striking observations that have been made is the vast majority of people reporting both of these experiences say that they have lost all fear of death and have become convinced by the experience that they will survive physical death (Callanan & Kelley, 1992).

Osis (1961) conducted a pilot survey of physicians' and nurses' deathbed observations in the United States during 1959 to 1960. It was the first study of its kind to systematically study deathbed experiences (of terminal and non-terminal patients) utilizing survey methods and statistical evaluations. Respondents described 2,254 death-

related sensory experiences (DRSEs) of terminally ill patients (Ethier, 2005). Osis and Haraldsson (1977) conducted a cross-cultural survey of physicians and nurses in the United States and India. A stratified random sample of 1,708 physicians and nurses in both countries observed that 81% of DRSEs (n=714) were experienced by people with a terminal illness (Ethier, 2005). DRSEs occurred not only to individuals who were aware they were dying but also to individuals who were not aware or had not been told that they were going to die (Barrett, 1926/1986) as cited in Ethier (2005).

The single common element among all reported DRSEs is the seeing of a messenger, a person or heavenly being. Seeing apparitions or human figures was the most frequent phenomenon reported by dying patients- (n= 471) (Osis & Haraldsson, 1977, as cited in Ethier, 2005). Ninety-one percent of identified apparitions were of deceased family members, with 90% of these being close relatives (i.e, mother, spouse, children, sibling, and father, in order of frequency) (Osis & Haraldsson, 1977, as cited in Ethier, 2005). Communication has been reported to take place between the dying individual and the messenger and is verbalized to others. Sixty-five percent of terminally ill patients (n=155) frequently told nurses and physicians the purpose of the apparition. From this communication often comes the knowledge of why the person or heavenly being in the vision is there. “The stated purpose of the apparitions was to aid patients in their transition to another world: ‘to take them away’ (Osis & Haraldsson, 1997, p. 247, as cited in Ethier, 2005). Seventy percent of the dying individuals (n=330) reacted to the apparitions with observable emotions including serenity, peace, and elation (Ethier, 2005). Frequently, accounts of DRSEs describe the dying individual reaching one or both arms out toward the apparition in the dying one’s vision (Barrett, 1926/1986; Osis &

Haraldsson, 1997; Schoenbeck, 1997; Wills-Brandon, 2000, as cited in Ethier, 2005).

This is typically observed among the final actions of the dying individual (Ethier, 2005).

The impact of these experiences on the dying person's loved ones can be profoundly meaningful. According to Willis-Brandon (2000), a Deathbed vision (DBV) is a powerful, comforting experience the dying and their family members often encounter before death occurs. Loved ones may find DBVs extremely comforting. They often report feeling reassured that their loved one would be all right and not alone in their death. Many also conclude their loved one will continue to exist in another realm (Callanan & Kelley, 1992).

Prior research has mainly concentrated on trying to document, define, measure, and interpret these two types of experiences. This next section will review the historical perspectives of Deathbed Visions (DBVs) and Near Death Experiences (NDEs).

### **Historical Perspectives of DBVs and NDEs**

Ancient Greek philosophers posed the question; can we know anything about life after death? They thought the question was ultimately unfathomable and that this particular mystery may be beyond the reach of rational knowledge (Moody, 2007). Moody (2007) contends that they were the first men to apply rational methods to consider the fate of the conscious self upon physical death. He states that these philosophers ventured to the underworld, evoked spirits of the dead, traveled out of their bodies, and studied near-death experiences. Their otherworld adventures helped to lay the foundation and set the agenda for all subsequent, rational thought in the Western world (Moody, 2007). Greeks flocked to oracles of the dead to seek information from departed loved

ones. Or, more commonly, they probably went there because of grief, and hope of reunions (Moody, 2007).

The Bible is the most widely read and discussed book dealing with matters relating to the nature of the spiritual aspect of man and to life after death (Moody, 2001). The Bible, however, has relatively little to say about the events that transpire upon death, or about the precise nature of the after-death world. According to some Biblical scholars, only two passages in the Old Testament speak unequivocally of life after death (Moody, 2001).

The Tibetan Book of the Dead was compiled from the teachings of sages over many centuries in prehistoric Tibet. The book contains a lengthy description of the various stages through which the soul goes after physical death (Moody (2001). Moody (2001) notes that there are striking similarities between the account in this ancient manuscript and the events, which have been related to him by twentieth-century Americans.

Emanuel Swedenborg who lived from 1688 until 1772 was renowned and made respectable contributions in various fields of natural science (Moody, 2001). Later in his life he underwent a religious crisis and began to tell of experiences in which he had purportedly been in communication with spiritual entities from beyond. His later works abound with vivid descriptions of what life after death is like. The correlation between what he writes of some of his spiritual experiences and what those who have come back from close calls with death report is amazing (Moody, 2001).

According to Rogo's (1978) Frances Power Cobbe in 1882 made an effort to systematically study reports of visions of those who had predeceased them by the dying.

Of particular interest were the cases in which the dying had every reason to believe that their visions were of people still alive. She called these “Peak in Darien” experiences, and believed they were evidence that the dying could glimpse another world. Although her accounts opened the dialogue about these experiences, they were rejected by future researchers as lacking adequate scientific validity and breadth.

In the early 20<sup>th</sup> century, James Hyslop tried to make a more comprehensive study of deathbed visions and how they differed from hallucinations. He concluded that deathbed visions were valid and not delusional (Rogo, 1978). Sir William Barrett researched various types of deathbed phenomena and published a book in 1926. In 1961 Dr. Karlis Osis chronicled the observations and visions of doctors and nurses at the bedside of the dying (Rogo, 1978).

It is important to note that research about death and dying occurred primarily out of the public eye until the late 1960s. This avoidance began to change in 1969 when Dr. Elisabeth Kubler-Ross wrote her famous book *On Death and Dying*. Topics related to death and dying became more of a part of the public consciousness, preparing the way for work of Raymond Moody (Greyson, 2010).

In 1975 Moody published *Life After Life*, a book about Near Death Experiences (NDEs), which caught public attention. Medical technology had progressed to the point that more people were being successfully resuscitated and reporting unusual experiences (Greyson, 2010). Although Moody stated in his book that his findings did not prove the existence of an afterlife, it was often given that interpretation by readers (Moody, 1975).

## **Opposing Viewpoints**

Morse (2004) reports many religionists and scientists have examined Near Death Experiences (NDEs), and they have come up with variety of possible explanations. Blackmore (1996) asserts that NDEs are caused by physiological and psychological reactions that are initiated by disturbed brain function either at the point of death or under great stress. Blackmore claims that the tunnel is caused by oxygen starvation, which results in certain inhibitory brain cells to die first; the excitatory cells take longer to die. Blackmore contends that science can also explain those tunnels: Electrical brain scans show that in our last moments, as the brain is deprived of oxygen, cells fire frantically and at random in the part of the brain which govern visions. As oxygen levels drop, the bright light becomes bigger and more immediate, and persons get the sensation of rushing forward into the light. Blackmore claims the similarity of NDEs is because brains behave similarly when they die. She says that people use the evidence from NDEs to bolster their belief in an afterlife. According to Blackmore people are transformed by the NDE because the very experience of being near death, with or without a NDE, is sufficient to make individuals less selfish and more concerned for others. Blackmore contends that NDEs are valid experiences in themselves, only they are happening in the brain and not in the world out there. She considers the NDEs to be like a movie that our brains run at times of extreme traumatic stress. The brain creates endorphins, which can reduce pain and under extreme stress, these large amounts of endorphins produce a dreamlike state of euphoria. Blackmore (1996) suggests that in the end it is probably a matter of personal preference whether to interpret the NDE as a glimpse of the life beyond or the product of the dying brain. Physical explanations:

- The concept of *drugs such as LSD* can give beautiful visions. The effects of LSD have been directly attributed to alterations in the functioning of central monoamine neurotransmitters, especially serotonin (Morse, 2004; Morse et. al, 1989).
- The concept of the *hallucination theory* is that some contend that the dying individual secretes endorphins (a brain and body transmitter substance) that create feelings of elation and pain relief. Endorphins are released under stress including both actual physical trauma and extreme fear, such as the fear of dying. They are known to block pain and to induce feelings of well being, acceptance and even intense pleasure, which might suggest they are responsible for the positive emotional tone of most NDEs (Morse, 2004; Blackmore, 1996).
- The *general anesthesia theory* concept implies that some people who go under general anesthesia can have some of the features of the NDE (Morse, 2004).
- A theory proposed by Karl Jansen, is that a powerful anesthetic name ketamine is released by the body at the time of the NDE and reproduces many of the features that typically accompany NDEs, such as leaving the physical body and meeting beings with higher powers (Morse, 2004; Morse et. al, 1998).
- The *lack of oxygen or excessive carbon dioxide theory* concept contends that brains lacking oxygen or with excessive carbon dioxide produce hallucinations. There may also be a role for carbon dioxide retention, which has long been known to induce strange experiences such as lights, visions, out-of-body and mystical experiences (Morse, 2004; Blackmore, 1996).

- The concept of the *dying brain theory* is that almost all who have NDEs follow a similar path to the light. This experience is the result of the dying brain. The neurotransmitters in the brain are shutting down and creating the same beautiful illusions for all who are near death (Morse, 2004).
- The *temporal lobe theory* concept states that certain features of the NDE occur in a type of epilepsy associated with damage to the right temporal lobe of the brain. In addition, researchers have found that by electrically stimulating this lobe, some elements of the NDE can be mimicked. These include life memories flashing past; leaving one's self behind; feeling a union with the universe and God; and a sudden sense of enlightenment. The limbic system is also sensitive to anoxia and involved in the organization of emotions and memory suggesting a possible link with the life review that sometimes occurs during NDEs (Morse, 2004; Blackmore, 1996).

Psychological explanations:

- The *mental illnesses and organic brain syndrome* concept states people with schizophrenia and organic brain syndromes can have beautiful mental images (Morse, 2004).
- The *birth memory theory* concept states that the late Carl Sagen proposed that the NDE is a memory of birth. As a child is being born, it goes down a tunnel toward a light, and it encounters love and warmth. Therefore, what happens at death is merely a stored memory of the birth (Morse, 2004).

- The *wish fulfillment theory* concept states that some people believe that wonderful NDEs are experienced simply because that is what we want to (or wish to) feel at death (Morse, 2004).
- The *depersonalization theory* concept states that the idea of depersonalization is similar to “wish fulfillment.” When people are faced with the unpleasant reality of death, they attempt to “depersonalize” it by producing pleasant fantasies in order to protect themselves. They “depersonalize” by removing themselves from their own bodies. That is the explanation the theory gives for the experience of floating away from one’s own body (Morse, 2004).
- The concept of the *Darwin theory* contends that the NDE is a deliberate ploy of the human race to help those left behind by death to better adapt to the inevitable ending of their lives. In simplified form, Darwin’s theory of the survival of the fittest means that every species struggles in order to increase its hold on Earth and guarantee the survival of its descendants. That is the foremost primary urge. Hence, the theory holds that the dying is merely generating propaganda asserting that death is not the end (Morse, 2004).

One of the major problems in NDE research is that there is no single agreed upon definition of a NDE (Morse, 2004). For those who have had a NDE, it is often reported as the most important experience of their life and expands their view of self, other humans and the universe. Yet some in our western culture tend to dismiss NDEs as unimportant and irrelevant to life and living (Batey, 2002).

## **Spirituality Interpretations**

Siegel (1981) writes that Anthropological studies of afterlife concepts and the soul's posthumous journey are strikingly similar for all cultures of man. The state of death may have idiosyncratic meanings for different individuals, but the experience of dying involves common elements and themes that are predictable and definable. These elements and themes arise from common structures in the human brain and nervous system to stimulation. The resultant experience, universally accessible, is interpreted by self-referential man as evidence of immortality, but this interpretation is little more than a metaphor to describe a common subjective state of individuals. While satisfied that Western science may explain many elements of life-after-death phenomena, believers in the afterlife, like believers in other paranormal experiences, are nevertheless dubious when anyone dismisses the value of the total experience too readily (Siegel, 1981)

Greyson (1991) reported that Ken Wilbur, a proponent of transpersonal psychology, warned against diagnosing "all non-ordinary states as pathological" (p. 328). Greyson (1991) further noted that psychiatrists had added a code for religious and spiritual problems to highlight their commitment to recognize other sources for transpersonal experience. Near death experiences and deathbed visions all involve experiences that fit the DSM-IV definition of hallucinations but are considered by the experiencers as profoundly spiritual experiences (Greyson & Liester, 2004).

The human condition is bound by the laws of nature: life and death. Each person born into the world will eventually die, and even though each person is aware of this fate, it is still difficult to comprehend. To deal with this inevitability, many turn to religion and spirituality (Reiner, 2007). According to a CBS news poll in 2006 (PollingReport.com,

2007) (as cited in Reiner, 2007), 82% of Americans believe in God, 9% believe in a universal spirit, 8% believe in neither, and 1% is undecided. Ross (1997) found in a small qualitative study that 50% of patients who were terminally ill had spiritual needs, 60% experienced spiritual needs while in the hospital, and 40% needed to find meaning in life events (Reiner, 2007). The Gallup poll reports that between 72% and 83% of Americans believe in Heaven, 21% communicate mentally with someone who has died, 78% believe in angels, and 20% believe in reincarnation (Daniel, n. d.). Willis-Brandon (1999) suggests that many people today fear their own death and have difficulty handling the passing of loved ones. Willis-Brandon argues that society, with its obsession with youth, and dread of aging, has perpetuated the fear of death. She argues that if we can recognize that death is nothing to fear, perhaps we will be able to live life more fully. Being at peace with ourselves allows us to have more compassion for others, our community and planet.

Reiner (2007) writes that religious and spiritual beliefs are thought to affect psychological wellbeing as well as end-of-life decisions. Nakashima and Canada (2005) indicated that in their study of 16 hospice patients, among the core resiliency factors were “empowering relationships with significant others, spiritual beliefs and practices, ability to skillfully confront mortality, and a stable care giving environment” (p. 109). Spiritual and religious beliefs are associated with protecting against depression, despair, hastened death, and suicidal ideation; these beliefs also assist the individual in making sense of the terminal illness, easing emotional burden, and reducing the fear of death. The notion or belief in afterlife, even with a certain degree of uncertainty, sometimes referred to as

“uncertainty comfort,” has been shown to be comforting not only for survivors but also for some hospice patients (McGrath, 2003 as cited in Massoudi, 2010, p. 201).

According to the National Association of Social Workers (2004) standards for palliative and end of life care, Hospice and palliative care social workers have the privilege of supporting individuals and families during some of the most universal and vulnerable life experiences: coping with serious illness, facing one’s mortality, the dying process, and bereavement. These social workers witness, on a daily basis, the struggle to find meaning in the face of serious illness and death. They have a unique opportunity to help people identify, try to answer, and live with core existential questions.

### **Professional Caregiver Perspective**

A pilot study looking into the occurrence of Deathbed Phenomena (DBP) was conducted by the palliative care team at Camden Primary Care Trust in 2003, and an interim study looking at End-of-Life experiences and the dying process in a Gloucestershire Nursing Home as reported by Nurses and Care assistants were asked to consider their clinical practice over the past five years and the incidences of DBP they had experienced. Each person was encouraged to talk freely about their experience of deathbed phenomena and the effect it may have had on them personally and professionally.

Brayne, et al. (2006, 2008) report that all of the participants believed that DBP not only occur, but occur relatively frequently, and were also meaningful for those nearing death and brought comfort to the dying. Several interviewees spoke of DBP as a prognostic indicator for nearing death, which is encapsulated in the language used by patients. They all agreed that DBP are intensely personal and often spiritual experiences

that help patients reconcile with events in their lives and, therefore, to come to terms with their death. Most of the interviewees agreed with the point of view that patients are processing their life and looking towards where they are going, who may be there, or what spiritual aspects of life they are going to have. Interviewees reported that the patients have an urgency to have discussions with family members and repair broken relationships, in order to have good, accepting deaths. The general consensus of the interviewees was that helping patients to become reconciled with their life is an important part of Palliative care work (Brayne, et al. (2006, 2008).

All interviewees referred to dreams as an important part of DBP. These were usually reassuring “waking” dreams-different from normal dreams or nightmares-which helped patients to deal with unresolved issues in their lives. It could be argued that dreams also act as a bridge between the carer and the cared for. Both sets of interviewees agreed that hallucinations evoked confusion and anxiety, whereas DBP possessed different qualities that focused on inner peace and acceptance of death as well as acting as indicators for nearing death (Brayne et el, 2008). Being open minded and telling patients that it is okay to talk about it, that it is normal, and that it happens to many people can be reassuring (Brayne, et. al, 2006, p. 23).

Seven interviewees reported residents who had dementia and confusion became lucid in the last few days of life. This is a DBP that Osis and Haraldsson (1977) drew attention to. The Camden pilot study also confirmed this phenomenon as an important part of some people’s dying process (Brayne, et al., 2008). Another nurse stated that very often before the person dies they will rally round and can open their eyes and have a conversation. One of the interviewees described this phenomenon as a sudden burst of

energy, enabling the resident to communicate to those present for the last time. All the interviewees talked of what might be described as paranormal incidents, such as lights going on and off in the room of a resident who had recently died. Others reported an episode involving a bell sound in the room of a resident who had died (Brayne et.al, 2008).

### **The Importance Of Being Aware Of The Needs Of The Dying Patient**

Kubler-Ross points out “What all of us have to learn is to accept death as part of life. When we have learned this, then maybe we can help our patients learn it, too,” as reported in (Brayne et. al, 2006, p.17). Patients and relatives are reluctant to talk about DBP through fear of ridicule, distress to relatives, appearing crazy, or dismissal, as well as lack of public awareness. Several other reasons given were that patients may not possess the primary language skills to explain what is happening to them, the inadequacy of language itself, the lack of privacy in hospital wards, medical and nursing staff not routinely asking about patients’ experiences, and not wanting to talk about their DBP experience (Brayne, et al., 2006, 2008, and Duffy and Olson, 2007).

Research has shown that empathy and acceptance can encourage continued communication with the professional caregivers and the family. Most patients just want to share their experiences with someone who will understand. Alleviating the patients’ fears by providing a trusting, caring environment can help the dying come to terms with the experience. Family presence may also provide solace and comfort as they die (Corcoran, 1988; Duffy and Olson, 2007).

People experiencing Deathbed Visions (DBVs) often find them comforting and helpful as they prepare to die. DBVs are strongly associated with peaceful deaths. As

they become aware of deceased loved ones, spiritual guides, spiritual figures, or glimpses of an existence after death that are permeated with love and beauty, the dying person may be greatly relieved and no longer fear death. They may be afraid to talk about their experiences or not fully understand them without the support of their caregivers (Callanan & Kelley, 1992).

Willis-Brandon (2000) asserts that DBVs are a neglected source of peace and comfort to all those involved. She states that fear of societal judgments and lack of validation may keep many silent and create confusion. When the dying is free to talk openly about their experiences without being sedated, many families discovered the joy of sharing in deep meaningful ways (Willis-Brandon, 2000). Families, who experienced this or were aware of DBVs, were often comforted as they grieved the loss of their loved one (Callanan & Kelley, 1992).

In a study conducted by Moadel et al. (1999) the authors found that between 25% and 51% of patients who were terminally ill with cancer wanted to have someone with whom they could talk regarding overcoming fears, finding meaning in life, finding spiritual resources, and death and dying (as cited in Reiner, 2007). With individuals seeking answers to questions about death, DBV information often times propels them into resolving their own issues around dying. DBVs can be used for processing grief and developing a sense of spiritual wellness (Willis-Brandon, 2000). DBVs may help people prepare for death by having visions to assist in the review of their lives in a way that leads to a new understanding of the meaning and purpose of their lives (Callanan & Kelley, 1992). Visions witnessed by patients and their caregivers in the active dying stage have guided the end-of-life clinicians on the meaning and significance of deathbed

phenomena (Mazzarino-Willett, 2009).

### **Ways Professional Caregivers Can Help**

Researchers have begun to put together a framework for best practices when working with people who report DBVs. They state that alleviating the patients' fears by providing a trusting, caring environment can help the dying come to terms with the experience. In addition, avoiding judgments about the DBV whether you believe in the phenomenon or not can help the person better control their experience of dying (Corcoran, 1988; Duffy, 2007). Morse correlate the presence of deathbed phenomena as an event of empowerment for the dying, reminding them that they still have purpose; teaching those (family members and clinicians) about end of life, and something to share (Mazzarino-Willett, 2009). Being supportive of the patient holistically, emotionally, and spiritually by active listening creates mutual trust, so the patient can express the tremendous impact the experience has on them (Duffy, 2007).

Mazzarino-Willett (2009) contends that encouragement of venting feelings of loss, fear, anger, guilt, shame, and concern for the unknown has been a staple of hospice care practiced by all visiting clinicians in efforts to assist patients in the acceptance of death and promoting a peaceful passing. Mazzarino-Willett (2009) goes on to state that clinician presence along with a supportive environment can enhance not only the patient/caregiver relationship, but also a discussion of death. If clinicians are diligent in their efforts to introduce the possibility of deathbed visions to patients and their caregivers and the role they play in a peaceful death, perhaps more patients and their caregivers will experience comforting deathbed phenomena and feel less stigma in reporting such phenomena.

## **Conceptual Framework**

The conceptual framework for this paper includes the bio-psycho-social-spiritual-cultural model and the transpersonal theory. Both of these models speak to the spiritual dimension of the person.

### **Bio-Psycho-Social-Spiritual-Cultural Model**

Everyone, according to the Bio-psycho-social-spiritual-cultural model, has a spiritual history. According to Sulmasy (2001), for many persons, this spiritual history unfolds within the context of an explicit religious tradition. But, regardless of how it has unfolded, this spiritual history helps shape who each patient is as a whole person, and when life-threatening illness strikes, it strikes each person in his or her totality (Ramsey, 1970). This totality includes not simply the biological, psychological, and social aspects of the person (Engel, 1992), but also the spiritual aspects of the whole person as well (King, 2000; McKee & Chappel, 1992). This bio-psycho-social-spiritual-cultural model is not a dualism in which a soul accidentally inhabits a body (Sulmasy, 2001). Rather, in this model, the biological, the psychological, the social, the spiritual, and the cultural are all distinct dimensions of the person, and no one aspect can be disaggregated from the whole (Sulmasy, 2001). Our backgrounds and cultures can influence end-of-life experiences, including how we deal with a terminal diagnosis and how we grieve a death. Many elements make up a person's culture-- language, social circumstance, religion and spirituality, sexual orientation and gender. All of these can impact how individuals find meaning and purpose in their living and dying and come to terms with the loss and remembrance of family and loved ones ([hospicefoundation.org](http://hospicefoundation.org)).

Each aspect can be affected differently by a person's history and illness, and each aspect can interact and affect other aspects of the person (Sulmasy, 2001). A major principle of the bio-psycho-social-spiritual-cultural model is that people have a need to allocate meaning and purpose to their lives through their spirituality. Therefore, a social worker that is looking at a person holistically should address a person's spiritual dimension as well. This turns out to be even more imperative as people prepare to die. Deathbed Visions (DBVs) are deeply spiritual experiences that frequently confront preexisting spiritual, religious, and scientific beliefs. Existential inquiry often occurs from these experiences. It logically follows that spiritual care would be a central feature of holistic care for a person who is nearing death.

### **Transpersonal Theory**

According to Washburn (1988) as cited in Smith (1995), the primary objective of transpersonal theory is the integration of spiritual experiences into the larger understanding of the development of the human psyche. He further asserted that transpersonal theory assumes that the ultimate aim of human development is spiritual fulfillment, and thus it is only from the spiritual perspective that human nature can be fully understood. The transpersonal position assumes that everyone has impulses towards an ultimate state and that these impulses are continuous whether or not an individual is aware of them at any given time (Sutich, 1980) as cited in Smith (1995). Reed (1987) as cited in Smith (1995) described these impulses as "a human propensity toward transcendence" (p. 335) as cited in Smith (1995, p. 403) and indicated that this phenomenon is particularly evident as an individual moves closer to death.

Carl Jung proposed that transcendent experience lies within and is accessible to every one, and that the healing and growth stimulated by such experience often make use

of the languages of symbolic imagery and nonverbal experience, which are not reducible to purely rational terms (Kasprow and Scotton, 1999). Transpersonal functioning emerges when identification with personal concern diminishes, and is associated with states of being and modes of knowing arising from connection with levels of reality beyond personal identity (Kasprow and Scotton, 1999).

Included in the transpersonal perspective is the thought that life does not end with the death of the physical body. Redefining one's attitude toward death to formulate a personal death perspective that serves as a comfort rather than a threat often requires the individual to move beyond his or her commonly held beliefs (Smith, 1995). This interactive process of formulating a personal death perspective and a heightened spiritual awareness might be referred to as "transpersonal development" (Wilbur, 1979) as cited in Smith (1995, p. 403), a "propensity toward transcendence" (Reed, 1987) as cited in Smith (1995, p. 403), or a movement "beyond ego" (Walsh & Vaughan, 1980) as cited in Smith (1995, p. 403), concepts compatible with holistic theories of social work.

These experiences according to Furman (2010) have the potential to help the dying and their caregivers to sense a connectedness "to the one Divine mystic consciousness that is composed of the physical and spiritual realms" (p. 109). This can lead to acceptance, comfort and peace as death approaches. Smith (1995) points out that it is a means of alleviating psychosocial distress and of moving toward an integrated transpersonal self that extends beyond the bounds of the physical realm into what is often referred to as the "spiritual" or "transpersonal" (Smith, 1995, p. 404).

## **Method**

### **Research Design**

The purpose of this study was to examine the experiences, perspectives and therapeutic responses of social workers, nurses, nurse's aides, professional caregivers, and chaplains with dying patients and their loved ones, who had experienced or who had witnessed deathbed visions or who had near death awareness in a hospice or palliative care setting. This researcher did not find articles written regarding social workers' experiences with patients who had reported having episodes of deathbed visions. Monette, Sullivan and DeJong (2008) state, that in these situations, "it is most appropriate to use a qualitative research approach which can be exploratory or theory generating" (p. 87). The qualitative research method was chosen to investigate this question due to its exploratory nature with participants.

### **Population Sample**

A non-probability, purposive snowball sample was conducted of social workers, nurses, nurse's aides, professional caregivers, and chaplains that work in a hospice or palliative care settings, who were most likely to have clients who had, or who personally witnessed, deathbed visions, or who had experienced near death awareness. Berg (2009) notes in nonprobability sampling, the investigator does not base his or her sample selection on probability theory. Rather, efforts are undertaken (1) to create a kind of quasi-random sample and (2) to have a clear idea about what larger group or groups the sample may reflect. This sample was drawn from practitioners working in hospices or palliative care settings for their unique experiences of working with dying patients. A nonprobability snowball sample gave the researcher the benefit of having an idea of what a larger group may reflect without having to get an exhaustive list of all professionals working in the hospice and palliative field. According to Berg (2009) the basic strategy

of snowballing involves first identifying several people with relevant characteristics and interviewing them or having them answer a questionnaire. These subjects are then asked for the names (referrals) of other people who possess the same attributes they do—in effect, a chain of subjects driven by the referral of one respondent of another.

Snowballing is sometimes the best way to locate subjects with certain attributes or characteristics necessary in the study (Berg, 2009). A purposive sample was chosen to focus on the actual experiences of the participants in the field.

The sample was limited to eight participants to allow for a more in-depth exploration of the topic. A snowball sample was initiated with an e-mail that was sent out to known colleagues who knew potential participants for an interview. Interested participants were encouraged by their contacts to call or e-mail the researcher to set up an appointment that was convenient for them. A snowball method was used for identifying additional potential interview candidates.

### **Protection of Human Subjects**

The consent form (*Appendix A*), the research question, and the interview questionnaire (*Appendix B*) was reviewed and pre-authorized by the research committee and research professor Jessica Toft (Ph. D) at the University of St. Thomas for approval. The research proposal followed the IRB process established by the University of St. Thomas. Only professionals were interviewed and questions were non-threatening.

Before beginning the interview, participants were given a consent form outlining the purpose and procedures of the study and described steps that were taken to ensure the confidentiality of their participation. The participants were informed that if at any time throughout the interview they wished to skip a question or stop the interview all together

they could do so voluntarily and would not be penalized. They were notified that their participation in the study was confidential and had no direct benefit or risk to them. Their supervisors did not know whether they chose to participate in the interview, unless they chose to share the information. They were informed that the questionnaire was kept confidential and while quotes are used in this study, they were appropriately de-identified where necessary. They were given a copy of the questionnaire and the consent form with contact numbers for the instructor, the University of St. Thomas Institutional Review Board, and the researcher should further questions arise. The participants were told that the interview was recorded and transcribed by the researcher. Transcripts were destroyed on June 15, 2012. The researcher kept their de-identified transcripts for future research purposes. Any publication of results did not include information that would make it possible to identify participants in any way.

### **Data Collection**

The data was collected from four personal interviews, which lasted approximately 30 minutes. The researcher used a semi-standardized interview format and audiotape responses for further transcription. The semi-standardized open-ended questionnaire interview format helped to fully understand the perspectives of social workers, nurses, nurse's aides, professional caregivers, and Chaplains that work with dying patients that may have witnessed deathbed visions or who had experienced near death awareness. Berg (2009) notes this type of interview involves the implementation of a number of predetermined questions and special topics. These questions are typically asked of each interviewee in a systematic and consistent order, but the interviewers are allowed freedom to digress; that is, the interviewers are permitted (in fact, expected) to probe far

beyond the answers to their prepared standardized questions. This method allowed enough flexibility to ask follow up questions to clarify or expand upon the information shared. The interview schedule began with easier non-threatening questions and became more focused on the more important questions for the study. The schedule of questions was tested for validity and reliability by seeking feedback from the research committee. The feedback was favorable and no changes were made to the interview questions. Follow-up questions were asked if clarification was needed or if there was an opportunity for elaboration.

### **Data Analysis**

The questions were first analyzed using open coding to identify common words and themes in a process known as content analysis. Content analysis was a helpful way to interpret the data received from the participants. According to Berg (2009) content analysis is a careful, detailed, systematic examination and interpretation of a particular body of material in an effort to identify patterns, themes, biases, and meanings. Content analysis is typically performed on various forms of human communication (Berg, 2009). Three main themes were developed based on the literature and also reflected in the interviews, which were the experiences, the perspectives, and the therapeutic responses of the participants.

### **Findings**

This research was aimed at exploring deathbed visions or unusual or confusing communications of terminally ill patients in a hospice or palliative care setting. Being in

a hospice or palliative care setting, professionals have a unique opportunity to witness unusual communications and possible deathbed visions of terminally ill patients. Three main themes were created from previous research and the content analysis, which were reflected in the data: experiences, perspectives, and therapeutic responses. *Experiences* comprise the professional title, education, attitude, knowledge, and familiarity of working with terminally ill patients and their loved ones. *Perspectives* refer to the personal points of view of the participants. Lastly, *therapeutic responses* include the various therapies and interventions that may be used with the terminally ill in the active dying stage. The following sections will further illustrate the importance of each of these categories in understanding the phenomena of nearing death awareness, which encompass such things as deathbed visions, visitations by deceased loved ones or spiritual beings, speaking to deceased loved ones who are not visible, or mystical, unexplainable or strange coincidences and occurrences.

### **Participants Demographics and Personal Experience**

The first set of questions in the interviews were designed to look at the participants' professional titles, education and familiarity of working with the terminally ill patient and their loved ones in a hospice or palliative setting. Four participants were each interviewed for one session lasting between 30 and 45 minutes. The participants represented several different settings, roles, and types of experiences in working with the dying and the terminally ill. Of this group two was hospice social workers, one was a registered nurse and one was a licensed practical nurse. One participant worked in an in-patient hospital setting; three participants worked in various settings from in-patient, nursing homes, to private home settings. Their ages ranged from 36 to 55. All of the

participants were female and all of the participants were Caucasian. The number of years spent working in the hospice care setting ranged from 6 months to over 20 years. Prior social work experience includes generalist practice in various settings. Previous experience in non-social work roles includes: education, orthopedic trauma nursing, hospital nursing, and geriatric nursing. One participant volunteered information about her personal experience with the loss of a loved one during the interview despite the fact that there were not direct questions about personal loss, and one participant volunteered information about her own near death experience, which is why she wanted to be a hospice social worker.

### **Participants Unique Experiences and Methods for Care**

The first question was designed to obtain the participants explanations of nearing death awareness. The participants who were nurses gave medical explanations of how they can tell a patient is nearing death such as:

*Respiratory changes, long pauses, short pauses in breathing. When the heart rate increases to 120-130 beats per minute at rest, usually means things are getting pretty close. Maudling of the feet, knees and sometimes also in the fingers. Color changes usually means we are getting into that 24-48 hour time frame. Some people will be really restless or have a burst of energy within a day or so of passing as well. There are a lot of things that we look for and everyone is a little bit different.*

Reducing fears was a common concern for most patients of the participants. This was an interesting finding in that the patients had more fear of the pain they may have versus the act of actual dying.

*There are a large percentage of patients who sign on for hospice, where they have a fear of what is the body going to go through, what am I going to feel. There is a fear of the pain or that transition process. More than fear of what is next.*

All the participants talked about providing education to patients and families surrounding the dying process to help reduce the patient's fears on what to expect.

*Sure, that's the biggest thing is that people don't want to have any pain and that's one of the things that hospice focuses on probably the most, you have all the different aspects of the dying person like their spirituality, emotional, physical comfort. As a nurse we focus mostly on that physical pain and shortness of breath and those types of things. For most people they don't want to have that pain. That is their biggest fear.*

One of the social workers reported her interpretation of when patients start to become less talkative. This may reflect the need to save their energy and strength for when their loved ones come to visit.

*When someone signs on to hospice there has been a terminal diagnosis. Patients aren't always actively dying. There are several transitions. When I start seeing someone transition, it's quite interesting because I often notice things like when patients are quite chatty with me, who want to talk to me, who look forward to me visiting, or at least polite when I visit. I might come in one day and they're not interested in talking to me at all. They don't really want to open their eyes; they're very uninterested, they say, "not now." I start wondering, what am I starting to see here, because that might be something we see when someone is starting to transition. The interesting part is I can call the family and let them know that we are starting to see some transition process and they might be near to death. When the family comes, the patient will open their eyes, they will have a great conversation, and the family doesn't notice anything different. What I have found, and with the literature that I have read, the patient knows they have less energy to spend and they don't want to spend it with me. They want to save their energy for their family. It's interesting because you can see this starting to happen before the loved ones do.*

One participant noted that patients seem to get more internal and reflective the closer they are to dying.

*When patients start going through that transitioning process, when they are getting nearer and nearer to death they start getting more and more internal. Their eyes stay closed a lot more because it saves energy. They become more reflective. Becoming less interested in the physical world.*

One of the participants also spoke about some common features of the dying process that were not considered to be unusual such as, increased restlessness, confusion, and agitation in the pre-active dying phase.

*Some patients start picking at clothing. One of our nurses say that when a patient starts trying to take off their clothes and get naked that they are dying. It's almost like anything that is touching their skin is a nuisance or it doesn't feel good. It's not with all patients, but we've seen some very specific behavior with patients that say, "I don't want this on me, it's not comfortable."*

## **Participants Perspectives of the patient and the loved ones at or near the time of death**

The following are stories shared about dying experiences reported by the participants. This first story is about a young boy who reports seeing lights right before he died. Patients have reported seeing the lights as both calming and comforting.

*I had a little five year old that died at four in the morning two days before Christmas. I went to the home as he was dying and one of the last things that he said to his daddy was, "I see the yites daddy." His dad said I think he is worried about the Christmas tree lights. As I drove away that night I thought no, he saw the lights that people very often see. So at the funeral I went up to the dad and I said I'm sorry I'm so late with this but I think what your son was seeing was the lights that people see as they pass over and his dad said, "OH my Gosh, I bet you are right."*

Participants responded that deathbed visions were considered to be a precursor to death by many professional caregivers. Many caregivers report a sharp decline in bodily vital functions that lead to death right after experiencing a deathbed vision.

*We had a man that took several days for him to die. He was in one of our hospice suites that we had at the time and his wife slept in the next room. For days he saw a lovely lady up in the corner of the room and a small boy kneeling at the foot of his bed. He was Catholic and so was his wife and he believed that the lovely lady was the Virgin Mary and the small boy at the foot of his bed was his brother that died when he was a small boy. I asked the wife how she felt about that and she said, "Ya know, it is very comforting to me to know that when I'm asleep or not here when he dies he has those two comforting visions with him." She was very comforted with the fact that he had someone with him.*

Another participants echoed:

*Patients will sometimes reach up like they are reaching for something. They may be seeing things that I don't. We frequently will have patients that see people that have passed. They will sometimes stare or point and they will sometimes talk with people or they will talk about the children they are seeing. I had a patient about a month ago who*

*looked up as if they were talking to somebody and said, “Not yet, I’m not ready.” It’s like I hear half of a conversation, like they are talking on the phone, you don’t hear the other half. It is very difficult to engage them because they aren’t really present in the physical world necessarily. They’re not quite lucid.*

Two of the participants spoke about sensing and seeing the patient’s energy:

*I believe that there is energy in the body but I had never seen it or felt it. We had one patient, I didn’t really get a chance to get to know him, because he was transitioning in just a couple of days after I had met him. When I went in to see him, he was in that actively dying stage and I sat with him for about two hours and just tried to be that calm presence, keeping a cold cloth on his forehead and holding his hand. It was really interesting, the only way that I can describe it, it was kind of like this bubble that went over him and you could feel this pulsating energy. I couldn’t really see anything but I could feel it. It was just this feeling that once that bubble popped; he was going to be gone. He was just trying to break through it.*

Another participant added:

*I had a patient whose son commented that he could see his mother’s energy. He said, “she is just completely wide open and I can see her energy, it’s just ready to let go.” It was probably hours after that that she passed.*

Several participants reported that some patients could seemingly control the timing of their death.

*We had a patient that passed. All of the family members were there except for one. All of the family members were concerned because the patient’s eyes were still open and they wanted his eyes to be closed. The staff came in and closed his eyes but his eyes would not stay closed. They kept opening. His eyes would not close and it upset a few of the family members. The one family member who was traveling a long distance showed up a few hours later came in saw the patient and the patient’s eyes closed. It was one of those things, it felt like that was his way of saying I waited for you as long as I could and I wanted you to know how important it was for you to be here. Everyone felt really good about it. It was one of those moments where it was like magic where he was able to give that message from beyond.*

Another participant shared:

*There was one gentleman who talked to me pretty often about what he expected to happen at the time of his death. He told me that God was going to come and tell him when it was time for him to go. I said, “Do you really think God is just going to come and tell you?” He said, “Yup, I’m sure of it.” The day that he died it was very evident to me and his family that God came and said it was time to go. He looked up, smiled and went.*

The participants also shared stories that can't necessarily be explained that they have witnessed personally, or those that have been told to them by patients or their caregivers.

*I was called to the home of a young physician who was dying. His wife was concerned because he was so restless and she didn't understand why he was so restless. He was upstairs on the landing and I asked him what he was doing, he said that he was packing because it was time to go and he had his suitcase out. I gave him some Adavan to help him calm down and he went and sat down on the couch. He told his wife that he just wanted to let her know that everything is going to be OK but I'm going away and I don't want you to think that I'm leaving you because I want to and he took a couple of breaths and he died. He knew he was going somewhere else. At the same time she had a net in the kitchen that she had captured a couple of caterpillars and they had formed a chrysalis and right as he took his last breath the chrysalis turned into a butterfly and the wife opened the door and it flew away.*

Some participants felt that these experiences were not distressing or fearful for the patient. One participant reported she had never seen anyone frightened by what they see.

*I think it is almost always comforting to the family members to know that they are going towards something that's reassuring to both. For the dying and the family.*

Another participant felt that those who struggle might be because they do not have a particular belief system, which she admitted might be her bias.

*The only time I've been with someone who is struggling in that regard and this could be my bias, is people who are nonbelievers. It's been my experience that people who really struggle is people who don't have a belief of any sort.*

Another participant echoed:

*A few people who seem to have more trouble at that time and that's usually people who don't have much of a faith base and seem to struggle at the end, but then for whatever reason in those last moments they get real peaceful.*

One of the participants didn't think it mattered if someone had a particular faith belief or not on their particular dying experience.

*People who believe that they are just going to become ashes to ashes and dust to dust are fine with that belief and they are prepared for that belief.*

Another participant felt that religion could sometimes be a barrier at end-of-life.

*I think religious beliefs sometimes can lead to some conflict. It can be bad if someone was Catholic and they didn't believe anymore, and one family member was Christian, and another one may be, you know there can be so many differing religions within the family system, that if one goes away from a religion there is some beliefs that they may not be going to heaven. So, I think that religion can sometimes be a barrier. I've had one patient who was actively dying and a family member was on top of the patient trying to get him to accept Christ, and if he didn't accept Christ he wasn't going to go to heaven. It was a very traumatic experience. It was very traumatic for the nurses and traumatic for the family. The patient was actively dying. He wasn't comfortable and I'm not sure if it was because of the trauma. I don't even know if he understood what was being said, but it was a very traumatic experience. With spirituality I think there is that difference, because it is your belief in that knowing that is not bound by rules, he said, she said, who's right, who's wrong. It's that spiritual belief and I think that is extremely helpful. I think they're not afraid of a faster death; it's more I hear people struggling and more fearful of what's going to happen to my body, and when am I going to go through the transition to that. I've worked with patients who don't have a belief and the process is not a whole lot different. The process is not traumatic. It's there acceptance, this has been a good ride, I don't want it to be over, but I think that fear is more what is going to happen to my body physically.*

### **A Participant's Personal Experience and her Interpretation**

One of the participants shared her personal experience of a dream that she had after her fiancé died: This participant seemed to use this dream, as a bridge between her loved one and herself to let her know he survived death and was okay.

*I lost my fiancé to lung cancer. He was young and we weren't expecting it to go that quickly. Two days after the death, I had a dream that I was in his hospital room along with his family. In my dream he had died and everyone had left the room except for me. The nurse came in and started taking out his IV's, and for some reason she left the room. He opened his eyes looked at me and asked me what is going on. I said to him, "I thought you died and now you are awake?" I couldn't comprehend it. He said, "You know what, I feel great, I feel good. For the first time in a long time I feel really good." The nurse came back in and started unhooking more things and I started saying he's alive, he's alive, don't take him off the IV." She said, "Oh, that happens sometimes, he'll die again," and she left. I woke up and I was a little traumatized and I realized that it felt like he was telling me that I don't know what happened, but I'm good now. I'm OK and you don't have to worry.*

## **Participant's Therapeutic Responses and Approaches to Practice**

It was evident in the interviews that there are many different types of therapeutic responses. Determining what interventions would be the most helpful comes with the experience and knowledge of the medical professionals and the patient. Having another human being to connect with other than a family member may be helpful, as the patient can be really honest and vulnerable, without having to worry about a family member not believing them, or thinking that they are crazy.

*I had one lady that I talked to that didn't have a faith base. She came from a family that had a lot of chemical dependency and a lot of psychosis so she went from a family to a spouse who also had these same issues so she never had a good support system. When she came into our program she really struggled with what was going to happen. She had a lot of anxiety, just a lot of struggling with everything. She had no idea what was going to happen. In hospice, you don't push what your faith or belief is, you go with what the patient is comfortable with and if they want to talk with somebody we do have the spiritual care piece of that. She did actually want to talk about that because no one had ever discussed faith with her at all. She did talk with me a little bit and we also got the spiritual care team involved. It was kind of surprising because the last time that I saw her it was right at her last moments and she was very, very peaceful. She was just relaxed. It seemed like she was able to come to some kind of peace at that point.*

Being a reassuring presence for the patient can bring peace and comfort in the end. All of the participants were sensitive to the dangers of dismissing or ignoring patients' experiences.

*What we try to tell families and what we try to role model for them is to say things like, tell me what that's like for you? (If they see something or they see a loved one who has passed) or tell me more, what is that person doing? Where are they at? Tell me what you see. What's happening at the time? Is it frightening for you? How does it make you feel? I think that is really helpful for the family and friends.*

Participants responded that therapies such as music (sound), aromas (smell), and massage (touch) have very potent natural healing properties that can adjust chemical or other imbalances in the body. Combining these different types of therapies can be highly effective as a non-pharmacological tool in alleviating discomfort associated with the

dimensions of pain. One participant reported some alternative therapies they use that are helpful are aromatherapy, music therapy, massage therapy, guided imagery, mirroring facial responses, and mimicking their speech or speech patterns.

*I try to use some guided imagery to help relieve anxiety and it helps them to relax such as if they were an outdoor person, going up to Duluth, or walking through the woods, going to Florida for vacation spending time on the beach. I try to pull some music therapy in to play music to match their breathing. Music therapy also helps them to reminisce and can spark some memories from different times that were enjoyable in their life. It's really a great experience to watch and be a part of. Massage therapy is a big one. Using essential oils helps with nausea and that type of thing.*

### **Impact of working with the dying on Professional Practice and Life**

All of the participants spoke of how working with the terminally ill has impacted their lives both personally and professionally.

*I think it has really humbled me. You work so hard to get people comfortable, it pulls at your heartstrings. There are people who go through this with such dignity and such grace, it is just amazing watching people go through this and still have a positive attitude about things.*

Another participant reported about her fear of dying.

*It has made me a lot less scared. I really believe, if I didn't believe before I do now. I know there is something. I may not know what it is, but I know there is something and it feels good, whatever it is.*

One participant reported on her views of spirituality and the patient.

*I think before, I was kind of perhaps skeptical. I'm less afraid of death. I struggle when people don't have a belief. I think before, I was more like, well, that's their choice, I mean it still is their choice, but I was just like well whatever. But now I'm like, I wish they had something to hang onto.*

One of the participants reported on the focus of her nursing practice.

*It has helped me to become a better nurse because you really focus on the whole person versus what can I do to fix the one physical thing. It's not so much fixing them as helping them go through the physical process.*

Yet another participant reported on not being judgmental and honoring the patient's experience.

*Keeping in mind that you have to meet the person where they are at, it's very difficult, because I have my beliefs in how I see things and entering that discussion with people I have to be very aware of what's my stuff. I don't want to sway them one way or another. I try to be very mindful of being open to the discussion and not being judgmental and making sure my stuff stays my stuff. It also has made me more aware of the fear that people have of telling their story sometimes. They are afraid that it won't be honored. Some think that people won't believe them or they will think they are having hallucinations. People will always deal with it in their own way.*

### **Final thoughts**

The dying process is an intensely individual experience that requires extreme sensitivity and acceptance from those who provide end-of-life care. This is particularly evident in this final comment by one of the social workers.

*What's really struck me that is important when working with patients, especially when a patient is going through that end of life process, when they are actively dying, if there is something that I see I keep that very private. I may enlist the family to see if they are experiencing anything. I have certainly been around patients' families where a professional caregiver has shared an experience that they either felt something or saw the patient reaching. If the family member didn't see it, it almost feels like they feel, how did you have that intimate experience and I didn't? I always want to investigate what the family members are feeling and what they are going through. I want to make sure that I understand what is going on in the room and being open for them to share what they are experiencing and what they are feeling. I realize that it is a very intimate moment and that it is not necessarily mine to share with the patient. The intimacy is between the patient and the family. They are really doing a lot of very hard work. Emotional work. The family does a lot of hard work after the death, processing and grieving and it should be their moment and their experience, not mine.*

### **Discussion**

The primary interest of this study was to explore the knowledge and understanding about whether social workers and other professional caregivers have had

direct experience with or have had patients or loved ones discuss Near Death Awareness experiences. From those who have had these types of experiences, this researcher hoped to learn how they interpreted and responded to these encounters. Since the research suggested these phenomena happened frequently, it was expected that social workers were often in a position to provide help and support to those who have these experiences.

This research is different than previous studies in that it included interviews with hospice social workers and nurses. The results in this research study reflect their experiences, perspectives, and therapeutic responses. Due to the scarcity of literature found on social workers' experiences and perspectives on deathbed visions and directions for practice, this led to the inclusion of other professional caregivers who work in the hospice care setting.

### **Participants Unique Experiences**

The findings in this research were consistent with the findings found in the literature on deathbed visions or “unexplainable experiences” in patients who were terminally ill. Morse (1994) reported people who are near death tell of talking with, or sensing the presence of people, who we cannot see, perhaps deceased people they have known or loved. Keesler (2010) reports a variety of deathbed experiences ranging from seeing angels, preparing themselves for a journey, describing people they are seeing only visible to themselves, to sitting up and holding up their arms joyfully at the moment of death. The findings included reports of patients reaching their arms out, talking to people that the social worker or the nurse could not see, reports of seeing spiritual figures, packing a suitcase and talking about going on a trip, and seeing deceased loved ones. Also included were stories of synchronous events and coincidental occurrences. Brayne,

et. al, (2008) reported paranormal incidents, such as lights going on and off in the room of a resident who had recently died. Others reported an episode involving a bell sound in the room of a resident who had died.

All of the participants in this study were familiar with the various terms used for “unexplainable experiences” and believed them to be a common occurrence working with the terminally ill who are in the actively dying stage. This corresponds with the findings of Brayne, et. al, (2006) who reported in a pilot study in 2003, that all their participants believed that deathbed visions not only occur, but occur relatively frequently, and were also meaningful and brought comfort for those nearing death.

It is worth noting that the literature review explored the different explanations for Near Death Experiences and Near Death Awareness, but the findings only spoke to the Near Death Awareness experiences.

### **Participants Perspectives of the patient and the loved ones at or near the time of death**

A theme that became apparent in the interviews was the need for more education surrounding Nearing Death Awareness, Deathbed Visions, End-of-Life experiences and other topics related to death and dying with the patients and the loved ones. Kubler-Ross (1969) points out, “What all of us have to learn is to accept death as part of life. When we have learned this, then maybe we can help our patients learn it too,” as reported in (Brayne, et. al, 2006, p. 17).

The findings were comparable with the conceptual framework using the bio-psycho-social-spiritual-cultural model for care (Sulmasy, 2001) and the transpersonal theory (Smith, 1995). All the participants reported in their stories and in their responses

ways in which they practice that incorporates the physical, emotional, spiritual and cultural aspects of each person. One participant reported that it has helped her to become a better nurse because she could really focus on the whole person versus just one aspect of that person.

Sulmasy (2001) states everyone, according to the Bio-psycho-social-spiritual-cultural model, has a spiritual history. One participant felt that it was comforting to the family members to know that they were going towards something. They felt it was reassuring for both the dying and the family. Ramsey (1970) adds, this spiritual history helps shape who each patient is as a whole person, and when life-threatening illness strikes, it strikes each person in his or her totality. Another participant feels she has become less skeptical and is not as afraid of death. In the transpersonal theory Washburn (1988) asserts that the ultimate aim of human development is spiritual fulfillment, and thus it is only from the spiritual perspective that human nature can be fully understood. Still another participant added that if she didn't believe before she does now, because of all of the experiences that she has had with dying patients.

### **Participants Therapeutic Responses and Approaches to Practice**

The nurses who participated spoke about the biological aspects of the dying process, such as medical management for terminal restlessness or agitation, changes in breathing patterns, and color changes of the skin. The roles that care providers play in bringing comfort to patients in the physical process of dying was not something that the literature addressed regarding death bed experiences.

All of the participants talked about meeting the patient where they are. This is mainly a social work term, so it was interesting to find that other disciplines were also

approaching patients in this way. All of the participants spoke about being nonjudgmental and accepting of whatever the patient wanted or needed to help them have a peaceful death. The participants mainly focused on the comfort level of the patient. Be it through pain management, using different therapies, being a calm presence in the room, or just having someone to talk with.

### **Unexpected findings**

A significant finding for this researcher was to be respectful of family members feelings about knowing when to share and when not to share “unexplainable experiences” that the professional may have witnessed or shared with the patient. Family members may feel guilty or cheated that they did not get to have that experience. One participant felt very strongly that these experiences are the patients to share not hers to share. The end of life is a very personal and important part of a family’s life together and care providers should give space to the family to experience it as such. This made a huge impact on this researcher to remember transference and counter transference when working with patients.

Another interesting finding was the confusion regarding the term Near Death Awareness. None of the participants had the same definition and wanted me to clarify for them what exactly I was asking of them. In the literature review there are many different terms (Near Death Awareness, Deathbed Phenomena, Deathbed Visions, and End of Life) that are used with roughly the same meaning. The participants tended to use the term “transitioning,” which seems to describe the same phenomenon as Near Death Awareness experiences.

Lastly, the literature review did not cover job satisfaction, but felt it significant to include that one participant responded that her patients have given her much more than she could ever give them. She said that working with the dying has really humbled her. She also talked about how much she loves her job and couldn't imagine doing anything else.

### **Strengths and Limitations**

Strengths of this study included the nature of the information that was collected, as the phenomenon of Near Death Awareness has not been widely researched. A qualitative approach enabled this researcher to get deep and enriching data from the actual experiences of the participants. The steps taken for the protection of the participants guaranteed their confidentiality, which may have given them the confidence to speak candidly. Lastly, the participants interviewed came from a broad range of education, and disciplines, as well as perspectives, and experiences.

A limitation of this study is that the sample was not representative of the larger population, which makes it difficult to generalize the results to the entire population. The age, sex, race, education, worldview, personal history, and biases of each participant may have had a bearing on how the questions were answered. Time constraints, small sample size, and scope of this project added to the limitations of this research.

The researcher had a bias toward the mystical interpretation of these events due to personal experience. She minimized the risk during the interviews by not commenting or self-disclosing any personal experiences during the interviews. The questions were open ended to allow for a variety of responses.

It was also a limitation that the researcher was unable to interview Chaplains working with grieving and dying patients and their loved ones.

### **Implications for practice**

Raising the level of awareness and acceptance of Near Death Awareness is needed. It is important for social workers to become better skilled in how to recognize and make opportunities available for patients to discuss these experiences in a safe and nonjudgmental way through open-ended questions. Brayne et. al, (2008) report best practices could be achieved by encouraging open and honest discussion about end-of-life experiences within team meetings, as well as by providing focus groups or individual supervision for any members of staff who might have issues or concerns about patients who report end-of-life experiences.

Standardization of the terminology and the definitions would be something to consider. With all of the different acronyms, it was difficult for the participants to understand exactly what I was asking them. They each used different terminology and acronyms such as NDA, DBV, DBP, ELE, etc.

One participant expressed the need for more education surrounding this important topic. According to Bosma, et. al, (2009) it is critical for the social work profession to coherently identify and outline its roles and competencies so that social work practice can be advanced in Hospice and Palliative Care, and adequate education and training be developed and offered to current practitioners and new students. Bosma, et. al, (2009) goes on to say that the lack of a clearly defined identity has contributed to other professionals' confusion about what social workers actually do in Hospice Care, and

consequently, other professions often have inadequate knowledge about the complexity and value of social work practice in this area.

Two issues that were not covered in the literature review is the importance of practicing self-care, doing your own grief work, and debriefing with colleagues would help to avoid burnout while working in this field. Secondly, being aware of transference and counter transference when working with patients and families. Remembering that these experiences are theirs and not the professionals to share.

### **Implications for future research**

Additional studies could be directed toward determining whether caregivers can tell when patients are having hallucinations or if they are having some sort of deathbed vision. Physical, psychological and spiritual viewpoints have historically been viewed as symptoms of the dying brain. Falksen (2011) reports this highlighted the dilemma faced by practioners and the importance of building common knowledge about different types of experiences people may have and how to differentiate what type of response is called for. As found in the literature, Greyson (1991) reported that Ken Wilbur, a proponent of transpersonal psychology, warned against diagnosing “all non-ordinary states as pathological” (p. 328). Greyson (1991) further notes that psychiatrists had added a code for religious and spiritual problems to highlight their commitment to recognize other sources for transpersonal experiences.

Deathbed visions are widely unreported according to the literature. A study would be helpful to determine why patients and professional caregivers don't report them, what could be changed to make it safer to report them, and how to deal with the difficult questions or situations associated with them.

Lastly, a study in cultural competence would be helpful in finding out if professional caregivers are meeting the needs and wishes of all patients at the end of life.

## **Conclusion**

There will always be differences of opinion on deathbed visions. People who have witnessed them or have been privileged to be a part of these “unexplainable occurrences” believe that they happen. Others explain them away as hallucinations or symptoms of a dying brain. As a social worker it is our job to be a calming presence for the patient. Being mindful and open to discussion may help relieve patient fears and give them a nonjudgmental connection with another human being. This may enable the patient to be more willing to report any experiences they are having, which may help them achieve a more peaceful death.

Deathbed visions are an intensely individual experience that requires extreme sensitivity and acceptance no matter what anyone’s beliefs are. It is important to remember that these experiences are the patients’ to share with their family, not ours to share. Debriefing with colleagues is best practice and good self-care, which may help with burn out and team collaboration.

Social workers play an important role in the delivery of Hospice Care. Social workers aim to alleviate suffering and improve the quality of living and dying by addressing the physical, psychological, social, spiritual, and cultural needs at the end-of-life.

## **References**

Atwater, P.M.H. Near-death experience in children. *The Journal of Religion and Psychological Research*, 2002.

- Batey, B. The near-death experience as a call to an expanded consciousness. *The Journal of Religion and Psychical Research*, 2002.
- Berg, B. *Qualitative research methods for the social sciences*. 7th ed. ed. Boston, MA: Allyn & Bacon; 2009.
- Blackmore, SJ. Near-death experiences. *Journal of the Royal Society of Medicine*. February, 1996; 89: 73-76.
- Bosma, H.; Johnston M.; Cadell, S.; et al. Creating social work competencies for practice in hospice palliative care. *Palliative Medicine*. 2010; 24 (79).
- Brayne, S.; Farnham, C.; Fenwick, P. *American Journal of Hospice & Palliative Medicine*. 2006; 23 (1):17-24.
- Brayne, S.; Lovelace H.; Fenwick, P. End-of-life experiences and the dying process in a Gloucestershire nursing home as reported by nurses and care assistants. *American Journal of Hospice & Palliative Medicine*. 2008; 25 (3):195-206.
- Callahan, M.; Kelly, P. *Final gifts*. New York, NY: Bantam Books; 1992.
- Canda, E.; Furman, L. *Spiritual diversity in social work practice*.
- Corcoran, D. Helping patients who've had near-death experiences. *Nursing88*. November, 1988.
- Daniel, T. There is no death. *The Journal of Spirituality and Paranormal Studies*. n. d.
- Duffy, N.; Olson, M. Supporting a patient after a near-death experience. *Nursing2007*. 2007; 37 (4):10/14/2011.
- Engel, GL. How much longer must medicine's science be bound by a seventeenth century world view? *Psychotherapy and Psychosomatics*. 1992; 57 (1-2):3-16.
- Ethier, A. Continuing education credit article: Death-related sensory experiences. *Journal of Pediatric Oncology Nursing*. 2005; 22 (104).
- Falksen, E. Deathbed Phenomena. Clinical Research paper. University of St. Thomas. 2011.
- Fenwick P.; Brayne, S. End-of-life experiences: Reaching out for compassion, communication, and connection-meaning of deathbed visions and coincidences. *American Journal of Hospice & Palliative Medicine*. 2010; 28 (7).
- Furman, L. Grief is a brutal teacher: A social worker's reflections on the importance of spiritual assessment & support during the bereavement process. *Illness, Crisis & Loss*. 2007; 15 (2):99-112.
- Greyson, B. Near-death experiences (from survival of bodily death conference summary). Esalen Center for Theory & Research. . December 6-11, 1998.

- Greyson, B. Hypercapnia and Hypokalemia in near-death experiences. *The Critical Care Forum*. 2010; 14 (3):420.
- Greyson, B. Near-death experiences and spirituality. *Zygon*. 2006; 41 (2).
- Greyson, B. Defining near-death experiences. *Mortality*. 1999; 4 (1).
- Greyson, B. Near-death experiences. *Journal of Near-Death Studies*. 1991; 9 (4).
- Greyson, B.; Leister, MB. Auditory hallucinations following near-death experiences. *Journal of Humanistic Psychology*. 2004; 44 (3):320.
- Kaspro, MC.; Scotton, BW. A review of transpersonal theory & its application to the practice of psychotherapy. *The Journal of Psychotherapy Practice & Research*. 1999; 8: 12-23.
- Kelly, EW. Near-death experiences with reports of meeting deceased people. *Death Studies*. 2001; 25: 229-249.
- Kessler, D. Visions, trips, & crowded rooms!: Five common deathbed experiences. <http://www.examiner.com/trasitions-grief-in-naitional/visions-trips-c...> Updated 2010. Accessed 10/14, 2011.
- King, DE. Faith, spirituality and medicine: Toward the making of a healing practioner. *Pastoral Press*, 2000.
- Kubler-Ross, E. *On death and dying*. New York: Scribner; 1969.
- Massoudi, M. Reflections on dying, our last thought(s), and living a spiritual life. *Journal of Humanistic Psychology*. 2010; 50(197).
- Mazzarino-Willett, A. Deathbed phenomena: Its role in peaceful death & terminal restlessness. *American Journal of Hospice & Palliative Medicine*. 2010; 27 (2):127-133.
- McKee DD.; Chappel, JN. Spirituality and medical practice. *Journal of Family Practice*. 1992; 35 (201):205-208.
- Monette DR.; Sullivan, TJ.; DeJong, CR. *Applied social research: A tool for the human services*. 6th Edition ed. Canada: Brooks/Cole-Thomson Learning; 2005.
- Moody, RA. Near-death experiences in ancient Greek philosophy; the origins of rational inquiry into the afterlife. Academy of Spirituality and Paranormal Studies, Inc. Annual Conference, 2007.
- Moody, RA. *Reflections on life after life*. St. Simon's Island, GA: Mockingbird Books; 1977.
- Moody, RA. *Life after life*. Covington, GA: Mockingbird Books; 1975.
- Moody, RA.; Perry P. *The light beyond*. New York: Bantam; 1988.

Morse, D. Near-death experiences: Modern examination, definition, historical precedents, personal, types, usual stages, cases research, possible explanations. . The Academy of Religion and Psychological Research Proceedings Annual Conference, 2004.

Morse, M.; Perry, P. *Closer to the light: Learning from children's near-death experiences*. London: Souvenir Press Ltd.; 1994.

Nakashima, M.; Canda, ER. Positive dying and resiliency in later life: A qualitative study. *Journal of Aging Studies*. 2005; 19.

National Association of Social Workers. (2004). NASW standards for palliative & end-of-life care. Available at [www.socialworkers.org/practice/bereavement/standards/default.asp](http://www.socialworkers.org/practice/bereavement/standards/default.asp)  
[www.hospicefoundation.org/uploads/hic\\_diversity\\_transcript.pdf](http://www.hospicefoundation.org/uploads/hic_diversity_transcript.pdf)

Osis, K. Deathbed observations by physicians and nurses. Parapsychology Foundation. 1961.

Osis, K. Deathbed observations by physicians and nurses. 1961.

Osis, K.; Haraldsson, E. Deathbed observations by physicians and nurses: A cross cultural survey. *The Journal of the American Society for Psychological Research*. 1977; 71 (3).

Parnia, S.; Waller, DG.; Yeates, R.; Fenwick, P. A qualitative and quantitative study of the incidence features and etiology of near death experiences in cardiac arrest survivors. *Resuscitation*. 2000; 48.

Ramsey, P. The patient as a person. 1970.

Reiner, S. Religious and spiritual beliefs: An avenue to explore end-of-life issues. *ADULTSPAN Journal*. 2007; 6 (2).

Rogo, DS. Research on deathbed experiences: Some contemporary and historical perspectives. *Parapsychology Review*. 1978; 9 (1):20-27.

Schroter-Kunhardt, M. A review of near-death experiences. *Journal of Scientific Exploration*. 1993; 7 (3):219-239.

Siegel, RK. Accounting for 'afterlife' experiences. *Psychology Today*. January, 1981.

Smith, E. Addressing the psychospiritual distress of death as reality: A transpersonal approach. *Social Work*. May, 1995; 40(3).

Sulmasy, D. A biopsychosocial-spiritual model for the care of patients at the end-of-life. *The Gerontologist*. 2002; 42(Special Issue 111).

*Appendix A*

**CONSENT FORM**

Please read this form and ask any questions you may have before agreeing to participate in the study.

Please keep a copy of this form for your records.

<b>Project Name</b>	Hospice Care Providers Experiences of Deathbed Visions and Directions for Practice	<b>IRB Tracking Number</b>	297084-1
<b>General Information Statement about the study:</b>			
I am conducting a study about the experiences, perspectives and therapeutic responses of Social workers and other professional caregivers working with terminally ill patients in a Hospice setting when their dying patients or their loved ones report visions, visitations, confusing messages, or other types of deathbed visions.			
You are invited to participate in this research. You were selected as a possible participant for this study because:			
of your experience working with terminally ill patients and their loved ones. Please read this form and ask any questions you may have before agreeing to be in the study.			
<b>Study is being conducted by:</b>			
		Leslee Curtis	
<b>Research Advisor (if applicable):</b>			
		Jessica Toft	
<b>Department Affiliation:</b>			
		Graduate student at the School of Social Work at the University of St. Thomas	
<b>Background Information</b>			
The purpose of the study is:			
to build knowledge and understanding about whether social workers and other professional caregivers have had direct experience with or have had clients or caregivers discuss confusing communications, unusual visions or experiences near the time of death. From those who have had these types of experiences, the researcher hopes to learn how they interpreted and responded to these encounters. Have they found some responses more helpful than others to their clients' physical and emotional well-being or deaths? How have these encounters affected them as practitioners? There has been little research conducted on this topic, and none found as far as how social workers or other professional caregivers relate to this topic. Since the research suggests these phenomena happen frequently it is likely that social workers are often in a position to provide help and support to those who have these experiences.			
<b>Procedures</b>			
If you agree to be in the study, you will be asked to do the following: <i>State specifically what the subjects will be doing, including if they will be performing any tasks. Include any information about assignment to study groups, length of time for participation, frequency of procedures, audio taping, etc.</i>			
If you agree to be in this study, I will ask you to do the following things: Participate in an audio recorded interview that should last approximately one hour. The data gained from the interview will be used in a class presentation, qualitative research paper, and public presentation at the end of the school year.			

<b>Risks and Benefits of being in the study</b>
The risks involved for participating in the study are:
There are no risks involved in this study
The direct benefits you will receive from participating in the study are:
The direct benefit you will receive for agreeing to participate in this study and for your time commitment is to receive a \$10.00 gift card to Target as a thank you.
<b>Compensation</b>
Details of compensation (if and when disbursement will occur and conditions of compensation) include: <i>Note:</i> In the event that this research activity results in an injury, treatment will be available, including first aid, emergency treatment and follow-up care as needed. Payment for any such treatment must be provided by you or your third party payer if any (such as health insurance, Medicare, etc.).
The \$10.00 Target gift card will be given to each participant after the interview is completed.
<b>Confidentiality</b>
The records of this study will be kept confidential. In any sort of report published, information will not be provided that will make it possible to identify you in any way. The types of records, who will have access to records and when they will be destroyed as a result of this study include:
The records of this study will be kept confidential. In any sort of report I publish, I will not include information that will make it possible to identify you in any way. The types of records I will create and how they will be handled will be listed below. A master list will be kept in a locked file in a secure home office and will also be destroyed by May 31, 2012. It will be kept separate from the other documents generated. All other data will be stored with the only identifying feature being the assigned interview number. Audio recording of the interview will be created; this data will be loaded into the password protected portion of my computer and transcribed into a written format. The interview will then be erased from my recording device. The audio recording of the interview will be stored in the password protected part of my computer and will only be identified by the interview number. This recorded format will be destroyed by May 31, 2012. Written/printed records will have all identifying information removed and will only be identifiable by the assigned interview number. They will be kept in a locked file in my home office. They may include: printed transcripts from the interviews, any notes I may have taken during the interview. One copy of your interview and associated notes may be stored in a locked, secure file for possible future research. After the transcripts have had all identifying information removed, the three members of my research committee and classmates may view the transcript of your interview. These copies will be destroyed by May 31, 2012. Computer files: All data which is stored in my computer will be in the password protected part of my computer and will have all identifying information removed. They will include the notes, transcripts, and audio recordings. The computer will be kept in a secure home office or under my direct care. The transcripts and notes will be stored both in my computer and in written format for future research, but will not

contin any identifying information. This data will also be destroyed when I determine that it is no longer needed for further research.

**Voluntary Nature of the Study**  
 Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with any cooperating agencies or institutions or the University of St. Thomas. If you decide to participate, you are free to withdraw at any time up to and until the date\time specified in the study.  
 You are also free to skip any questions that may be asked unless there is an exception(s) to this rule listed below with its rationale for the exception(s).

Should you decide to withdraw, data collected about you	will NOT be used in the study
---	-------------------------------

**Contacts and Questions**  
 You may contact any of the resources listed below with questions or concerns about the study.

Researcher name	Leslee Curtis
Researcher email	curt3409@stthomas.edu
Researcher phone	763-421-9219
Research Advisor name	Jessica Toft
Research Advisor email	jetoft@stthomas.edu
Research Advisor phone	651-962-5803
UST IRB Office	651.962.5341

**Statement of Consent**  
 I have read the above information. My questions have been answered to my satisfaction and I am at least 18 years old. I consent to participate in the study. By checking the electronic signature box, I am stating that I understand what is being asked of me and I give my full consent to participate in the study.

Signature of Study Participant <input type="checkbox"/> <i>Electronic signature</i>		Date	
Print Name of Study Participant			

Signature of Parent or Guardian (if applicable) <input type="checkbox"/> <i>Electronic Signature</i>		Date	
Print Name of Parent or Guardian (if applicable)			

Signature of Researcher <input checked="" type="checkbox"/> <i>Electronic signature*</i>		Date	
Print Name of Researcher	Leslee Curtis		

\*Electronic signatures certify that:  
 The signatory agrees that he or she is aware of the polities on research involving participants of the University of St. Thomas and will safeguard the rights, dignity and privacy of all participants.

- The information provided in this form is true and accurate.
- The principal investigator will seek and obtain prior approval from the UST IRB office for any substantive modification in the proposal, including but not limited to changes in cooperating investigators/agencies as well as changes in procedures.
- Unexpected or otherwise significant adverse events in the course of this study which may affect the risks and benefits to participation will be reported in writing to the UST IRB office and to the subjects.
- The research will not be initiated and subjects cannot be recruited until final approval is granted.

## *Appendix B*

### **Interview Questions**

**Research Question:** *What are the experiences, perspectives and therapeutic responses of Hospice Providers with dying patients who have reported having Deathbed Visions?*

Q1. What is your professional title?

- Q2. How long have you worked in the Hospice or Palliative care setting?
- Q3. Have you had any additional training or education to work with the terminally ill?
- Q4. How would you explain nearing death visions?
- Q5. How common are these experiences? Can you give me a percentage?
- Q6. Have any patients ever talked with you about their deathbed visions?
- Q7. Have any patients or loved ones ever-expressed fearfulness or have had negative near death experiences?
- Q8. What therapeutic responses have seemed particularly helpful?
- Q9. Can you share some near death experience stories that have either been reported to you or you yourself have witnessed from patients or loved ones?
- Q10. How has working with patients who have had deathbed vision experiences affected you and your practice?
- Q11. Do you think having a spiritual belief make a difference for the dying patient or loved ones in their end of life experiences?
- Q12. Are there any other thoughts or comments you would like to add?