

5-2013

# Hospice Social Work Methods and Interventions for Terminally Ill Patients Experiencing Anticipatory Grief

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## Recommended Citation

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Hospice Social Work Methods and Interventions for  
Terminally Ill Patients Experiencing Anticipatory Grief

by

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MSW Clinical Research Paper

Presented to the Faculty of the  
School of Social Work  
St. Catherine University and the University of St. Thomas  
St. Paul, Minnesota  
in Partial fulfillment of the Requirements for the Degree of  
Master of Social Work

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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 the findings of the study. This project is neither a Master's thesis nor a dissertation.

### **Acknowledgements**

The process of this project was particularly challenging, rewarding, and would not be completed without the help, support and patience of many wonderfully intelligent people. Thank you to my committee team of Dr. Karen Carlson, Deborah Goulet, and Joan Stauffer for your time, efforts, and encouragement in this project. Thank you for your willingness to provide your expertise to me. Your advice was used!

The social workers who participated in the interviews were an amazing group of people who have beautiful hearts and passions for this population who are so fragile. Talking with you only inspired me to continue in this profession.

Thank you to my student cohort. If it was not for the late night phone calls, the Thai food, and general debriefing, I would not have survived. You are amazing people.

My family and friends have been nothing but understanding during my education experience. Thank you for allowing me to miss special events so I can be successful in school. Your love and empathetic listening was more helpful than you understand.

A very special thank you goes to my partner, best friend, and editor-at-large, Nate Metcalf and his faithful puppy sidekick Spaghetti. Your love, wisdom, advice, warm hugs, and general distractions kept me grounded and reminded me of who I am and why I love this profession.

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In 2011, there were 2,452,000 deaths in the United States. Of these, 1,029,000 received care from a hospice program (National Hospice and Palliative Care Organization [NHPCO], 2011). Hospice is a program designed to provide palliative care for end-of-life symptoms (Chochinov, 2006) for patients with a terminal diagnosis and a prognosis of six months or less to live. The goal is to provide a comfortable and quality dying experience in a home setting, away from the hospital (Ashford & LeCroy, 2013; NHPCO, 2011). Hospice was created in the 1960s in Great Britain by Dame Cicely Saunders. Her philosophies quickly spread to the United States. In 1982, hospice became a benefit of the Medicare Part A program and can also be covered by most private insurance, Medical Assistance, and HMOs (National Association of Social Workers [NASW], 2004). Hospice involves a multidisciplinary team, whose goal is to provide palliative (comfort care) treatments for the physical, psychological, social, and spiritual symptoms common at the end-of-life (Baker, 2005; Bosma et al., 1991; NHPCO, 2011; Reese & Raymer, 2004; Weisenfluh, 2011). The hospice philosophies include “the belief that each of us has the right to live and die free of pain, with dignity, and that our families should receive the necessary support to allow us to do so” (NASW, 2004, page 11).

In 1982, it became mandatory that a social worker be a part of every interdisciplinary hospice team to facilitate any treatments related to the psychosocial symptoms of hospice patients (Baker, 2005; Harper, 2011; Hultman, Keene, Reder, & Dahlin, 2008). Currently, there are over 700 social workers working for hospice agencies in the United States (Weisenfluh, 2011). They are valuable to a hospice team because they not only address psychosocial concerns, but they also provide an ecological approach to patient care (Bosma et al., 2010; MacDonald, 1991; Reese & Raymer 2004).

Social workers have many tasks in hospice care, including, but not limited to: conducting patient and family end-of-life education; providing resources and referrals for services; planning care with the patient to prepare for advances in the disease; and offering counseling and supportive therapies meant to manage and cope with psychosocial symptoms related to the end-of-life transition (Cagle & Kovacs, 2009; Kramer, 1998; MacDonald, 1991; Reese & Raymer, 2004; Weisenfluh, 2011).

*Anticipatory grief* is the reaction to an expected or anticipated loss (Cheng et al., 2010). Symptoms of anticipatory grief can be physical (sleep changes, appetite changes, headaches), emotional (sadness, anger, self-reproach, anxiety, loneliness, helplessness and numbness), cognitive (disorganization, forgetfulness, and confusion), or spiritual (anger with God, meaning of life, questioning of faith, etc.) (Ashford & LeCroy, 2013; Hultman et al., 2008; Simon, 2008).

Among the psychosocial symptoms experienced by patients with a terminal illness, anticipatory grief is common. Many patients diagnosed with a terminal illness find themselves anticipating the losses that may soon occur. They not only grieve about their diagnosis, but they grieve for their families' future loss (Hultman et al., 2008). They can grieve over their loss of independence and autonomy as the disease progresses. Patients may also grieve the loss of any future goals and dreams (Cheng et al., 2010). Anxieties may develop regarding the dying process and the challenges their families may face in providing care. Patients may wonder what meaning their lives have (Ando, Morita, Okamoto, & Ninosaka, 2008; Ashford & LeCroy, 2013; Hultman et al., 2008).

Because each patient and each family come from different backgrounds, ethnicities, genders, or socioeconomic statuses, they have unique ways of communicating

and relating to themselves and their communities. Therefore, methods and interventions need to be tailored to individual patient needs (Hooyman & Kramer, 2006). Because of the diversity of patients and their needs, the treatment options available for social workers to choose from are unlimited. There is no one-size-fits-all solution to address these needs. Additionally, there is an extremely small number of clinical interventions that have been created specifically for a terminal patient's psychosocial needs (Breitbart et al., 2010; Chochinov et al., 2011). The research on evidenced-based practice is limited with this population (MacDonald, 1991). The purpose of this study is to understand the various available methods and interventions hospice social workers use to assist hospice patients in reducing anticipatory grief. Attention will be paid to the effectiveness of the methods and interventions. The term methods will be used to identify any modality that a person can use to assist a patient. The term intervention will be used to identify a modality used by a clinician.



### **Conceptual Framework**

The conceptual frameworks used for this study are the Lifespan Development Theories and Grief Tasks Models. A lifespan development theory explores changes people experience across stages of their lives. Change is continuous throughout the lifespan. People develop characteristics at a young age, but these characteristics and behaviors may change as time goes on due to influences by their environment (Ashford & LeCroy, 2013). The Lifespan Development Theories attempt to explain the changes people experience over a specific period of their lives.

For the purpose of this project, attention will be paid to the final stages of each Lifespan Development Theory. The end-of-life focus of lifespan development involves finding meaning in one's life and having a feeling of wholeness near the end of it (Hooyman & Kramer, 2006). Important theorists of lifespan development are Erik Erikson and Abram Maslow. Attention will also be given to Elisabeth Kubler-Ross and the stages of dying.

Grief Tasks Models are theories that suggest completion of different tasks in order to resolve grief associated with end-of-life. Once all tasks have been completed, mourning should end. Goals of these theories are for the person to "negotiate a meaningful life" and "to integrate each new loss into a new social context and identity (Hooyman & Kramer, 2006, p. 41). Three theorists who have proposed Grief Task Models are Colin Murray Parkes, Therese Rando, and J. William Worden.

#### **Elisabeth Kubler-Ross and the Stages of Dying**

Some of the best known literature on death and dying comes from psychiatrist Elisabeth Kubler-Ross, who completed a long-term qualitative study on dying patients at

a Chicago research hospital. She identified five different stages that a person goes through while they are in the process of dying. Now a staple of pop-culture reference, the stages are *denial/isolation*, *anger*, *bargaining*, *depression*, and finally, *acceptance* (Ashford & LeCroy, 2013). The final stage, *acceptance*, is a time when meaning can be found in life events, and the impending death is accepted by the patient (Kubler-Ross, 1969). Instead of being happy, joyous, sad, or mournful, this time is peaceful and reflective. In Kubler-Ross's book, *On Death and Dying* (1969), some of the best advice comes from the patients themselves. The advice they gave to clinicians was that the clinicians be present and to listen to what they, the patients, had to say. This undivided attention can provide hope and comfort to patients who may not have been able to express their feelings to others in such a safe and supportive environment (Kubler-Ross, 1969).

### **Erik Erikson and Ego Integrity**

Erik Erikson's Human Development Theory discusses sequential stages of life. Each stage involves biological, social, or cultural issues which a person must face and master before one can move onto the next stage (Ashford & LeCroy, 2013; Haber, 2006). The seventh in a nine-stage sequence deals with *generativity versus stagnation*. The goal is for a person to pass on his or her knowledge to others and to leave a legacy (Haber, 2006). This can be done by reminiscing or storytelling.

Stage eight focuses on *ego integrity versus despair* and is most often associated with those who are older in age (Haber, 2006; Hooyman & Kramer, 2006). The Freudian concept of the ego is a psychological internal structure which helps one adapt to society and its conflicts (Haight, Michel, & Hendrix, 2000). The ego organizes the thoughts and

difficulties that a person may experience in his or her environment. Therefore, a strong ego results in the ability to deal with crisis. Ego integrity involves evaluating a person's life events to find meaning and acceptance of his or her life (Ashford & LeCroy, 2013; Haber, 2006; Haight et al., 2000). The focus of the eighth stage is maintaining identity and self-esteem (Coleman, 1999; Staudinger, 2001). For a hospice patient, maintaining identity and self-esteem involves dignity. A part of emotional comfort is feeling dignified. If one cannot do this, despair may result with feelings of resentment, guilt or anger (Haber, 2006).

### **Abraham Maslow and Self-Actualization**

Abraham Maslow is known in the literature for his Hierarchy of Needs. Like Kubler-Ross's theory, each stage must be completed before moving onto the next. His first four needs were called "deficiency needs" and included physical (i.e. safety and pain relief) and emotional (i.e. love and self-esteem) needs. After these needs are fulfilled, the growth needs can be fostered. These would include needs to find meaning, dignity, and fulfillment in life (Clarke, 2007). The final stage and ultimate goal in Maslow's hierarchy is Self-Actualization (Hooyman & Kramer, 2006; Klunder, 2011). Self-Actualization occurs when people can look back on their lives and feel they have done the best that they could; they can feel their goals have been accomplished (Klunder, 2011).

### **Colin Murray Parkes**

Colin Murray Parkes' model of grief phases includes numbness, pining or protest, disorganization and despair, and realization/reorganization (Bowman, 2012; Hooyman & Kramer, 2006). The first phase involves shock and disbelief followed by the protest phase of grief, where the grieving person may become agitated or become vigilantly attentive to

the possibility that the impending loss may not be true. In the despair phase, sadness, and disorganization occur as the person withdraws from everyday life. Depression, loneliness, or anxiety can occur during this phase as well. Finally, realization or reorganization allows the person to see the impending loss as real. Recovery and acceptance of the loss is possible during this stage (Bowman, 2012).

### **Therese Rando and the R-Process Model**

In the R-Process Model, Therese Rando (1983, 1988) describes guidelines that incorporate all of the different models created for grief phases or tasks. The first phase in the R-process model is to recognize and accept the reality of the loss. This involves the person acknowledging that a loss has or will occur and may not be reversible. The second phase is reacting, experiencing, and/or expressing the pain of the loss. “An active confrontation with the loss-through rage, anger, and the honest expression of sorrow-is widely assumed to be necessary for deliverance from the past, as it requires recognizing all facets of the loss” (Hooyman & Kramer, 2006, p. 44).

The third phase is reminiscing. Reminiscing involves telling stories and memories as a way to keep these experiences alive. It can also be used as a way to find meaning in loss. Relinquishing old attachments is the fourth phase of Rando’s Grief Process Model.

Finally, the last two phases are readjusting and reinvesting.

The challenge is to integrate what has happened and use it to find or construct meaning and to become fuller and larger in one’s being than ever before, even in the face of an apparent diminution of one’s life” (Hooyman & Kramer, 2006, p.49).

### **J. William Worden and Tasks of Mourning**

There are four tasks in J. William Worden’s Tasks of Mourning. In his book *Grief Counseling and Grief Therapy* (2009), he indicates that mourning is the process that

happens after a loss. Grief is the “personal experience of the loss” (p. 37). He uses the term *tasks* instead of “phases” or “stages” because he believes those terms imply a passivity of the griever. “Tasks” implies action and Worden believes that one must address each task in order to adapt to the loss. But, he stresses that these tasks do not have a fixed progression and that tasks can be revisited over time. Some tasks can even be done at the same time as others (Worden, 2009). This model can be applied to anyone experiencing grief including those who may have a terminal illness and/or his or her family or caregiver.

The first task involves accepting the reality of the loss and the second task is to process the grief pain related to the loss. Some people may deny that the loss is real or meaningful. They may keep items related to the loss or claim that the loss is “not a big deal” in order to protect themselves from the pain. One way to help with accepting and processing the loss may be to attend a funeral. This allows the person to see the body of the deceased. Being able to process the pain of the loss involves feeling the pain associated with the loss (Worden, 2009).

Finally, the last two stages involve acceptance and coping. The third task of mourning is adjusting to life without that which was lost. Worden (2009) points out that there are three different kinds of adjustments to deal with: external, internal, and spiritual. External adjustments may mean the person has to take on or learn different roles or skills that they did not have to worry about before the loss. Their sense of self may need to be evaluated after the loss. The results of this evaluation would be an internal adjustment. Finally, the spiritual adjustments help to find meaning and sense of the new life after the loss.

The fourth task is to be able to continue the connection with the loss even after it is gone. This is not to say that the person must keep that loss so present that it stops them from continuing on with his or her own life, but allow the bond of that person, place, or thing to continue in its own way while allowing the griever to proceed with a healthy life.

In summary, the lifespan development theories explore the changes that people may experience at different stages in their life. For terminal patients, each level of change in the stage theories may not be accomplished prior to their death. They may cycle back to different stages in the different theories. Some diagnoses have an extremely short prognosis attached to them. Young cancer patients (especially children or adolescents) may be at an early stage in their hierarchy of development and struggle with entering a new stage in the amount of time they have remaining. However, each patient can strive towards completion of the stage they would wish to complete prior to death and the hospice team can assist as needed.

### Literature Review

The literature reviewed here focuses on the methods and interventions used to combat anticipatory grief. The majority of literature on grief explores bereavement work and grief *after* a loss. Few pieces of literature focus on grief due to *impending* loss. Still fewer articles exist focus on methods and interventions aiming to combat anticipatory loss with terminal patients. Articles were found relating to *chronic* pain and illnesses, but very few for those with *terminal* illnesses. Some of the articles stated the methods and interventions were useful for managing depression and anxiety, also common symptoms at end-of-life. However, anticipatory grief, though common in terminal patients, remains untested and under-scrutinized.

As stated previously, each person comes from a different background with different risks, needs, and strengths. Because of this, different methods and interventions must be considered for each person (Hultman et al., 2008). The literature discusses the importance of allowing the patient and family to experience grief and support in his or her own way. From a strengths-based perspective, the social worker can help the patient and family identify tools they already possess to cope with the anticipatory grief (Hultman et al., 2008).

Spiritual and religious methods are acknowledged as commonly used treatment for grief work. For the purposes of this project, it is understood that spiritual or religious methods usually are provided by the patient's spiritual care coordinator (clergyman, counselor, chaplain, or spiritual leader). The spiritual care coordinator is included in the Medicare hospice program on a needed basis. Specific interventions for cultural or ethnic

groups were *not* included in the literature review, due to the lack of research available. This, however, may be an important topic for future research.

Methods and interventions that may be used by a social worker in a hospice setting and that are discussed below will be:

1. Empathetic Listening and Support
2. Education and Communication
3. Life-review and Reminiscing
4. Grief Therapy
5. Individual Psychotherapy/Cognitive Behavioral Therapy
6. Dignity Therapy
7. Group Therapy
8. Meaning Centered Therapy

### **Empathetic Listening and Support**

The majority of the literature found explains the importance of empathetic listening skills when dealing with grieving hospice patients (Klunder, 2011). This encourages the social worker to support the patient and family in whatever grief they are expressing. Each person's grief journey will be different (Hultman et al., 2008). Providing empathetic listening shows the patient and family that the social worker genuinely cares (Klunder, 2011). Patients and families feel empowered and might be able to say what they are thinking because they are able to express their emotions. This thinking out loud with an empathetic social worker may help patients process the information in a safe environment (Klunder, 2011).



**Education and Communication**

Another method found in the literature stresses the importance for patients and their families to have the information needed in order to understand the illness, possible treatments, and options for care. The information can include what to expect, how to plan for future care needs, and disease progression. The social worker can assist by being a patient advocate or serving as a mediator between the patient and clinicians (Klunder, 2011). In these methods, social workers may fear bringing up taboo subjects with patients, such as the symptoms of the disease, impending death, and funeral planning. A social worker should ask questions about the goals, fears, and worries of the patient. Once a caring and respectful relationship develops between the patient and social worker, communication is able to flow more easily (Klunder, 2011). It is also important for the social worker to meet the patient at the patient's current stage of emotional understanding. Information may need to be clarified.

Information helps encourage self-determination and empowerment in patients (Cagle & Kovacs, 2009). This is especially important because many patients have lost control over so many things as their disease has progressed. Empowering patients to take control, even over the smallest details or events, is important at the end-of-life.

**Life Review/Reminiscing**

The idea of life review is usually associated with psychiatrist Robert Butler (Caldwell, 2005; Staudinger, 2001; Haight et al., 2000), who explains that a life review is where a patient remembers the events of his or her life (Caldwell, 2005) and reflects upon the meaning of them (Staudinger, 2001). Unresolved issues can be remembered, addressed, and possibly resolved (Caldwell, 2005). It can be done in a very formal

structure with predetermined questions or can be unstructured as a normal conversation would be (Haber, 2006). Social workers need to be empathetic listeners and provide support through the evaluation of these memories (Hooyman & Kramer, 2006).

Things to be remembered can relate to roles, historical events, feelings, and experiences from the different phases of life (Haber, 2006). The events can then be reflected upon to find meaning. Life review can also help to pass on knowledge and information to family and the next generation (Haber, 2006) while also bringing the family closer by collectively reminiscing on the patient's life (Caldwell, 2006).

Memorabilia such as photographs, music, and personal items can be used to help elicit memories (Hooyman & Kramer, 2006).

Completed life reviews result in decreased depression, increased life satisfaction, increased psychological well-being and self-esteem, and found meaning or purpose in life, in illness, and in the impending death (Ando et al., 2008; Haber, 2006; Haight et al., 2000; Hultman et al., 2008; Staudinger, 2001). Referring once again to the Lifespan Development Theory, life review has been found to increase ego integrity in persons living in nursing homes by integrating memories with meaning. (Haight et al., 2000).

### **Grief Counseling**

Grief therapy involves "highly trained professionals involving 'specialized techniques of intervention' to address more traumatic, complicated, or chronic grief" (Hooyman & Kramer, 2006, p. 279). The goal of grief therapy is for the patient to find hope. He or she searches for meaning in the difficult situation (Hooyman & Kramer, 2006).

A task to work on during grief counseling would be for the patient to actualize or name the loss or losses. This can be done by allowing the patient to talk about the nature of the loss or feelings of grief related to the loss. This may help the loss to become real for the patient in a safe environment in which they can adequately grieve. The grief symptoms can be supported and normalized by the clinician (Hooyman & Kramer, 2006). Exploring beliefs about death and dying and incorporating experiences, lessons, or spiritual beliefs may assist in helping the patient find meaning in their loss.

Techniques for grief counseling can include using guided imagery, role playing, letter writing, or journaling (Hooyman & Kramer, 2006). Not all techniques of grief therapy have been empirically tested. Ongoing research is needed before they can be shown to be effective (Hooyman & Kramer, 2006).

### **Individual Psychotherapy/Cognitive Behavior Therapy**

Psychotherapy for terminal patients can help with the prevention or management of psychosocial suffering at the end-of-life and help establish a sense of purpose and meaning (Chochinov et al., 2011). It can help with the anticipatory grief related to leaving behind family and losses that come with having a terminal diagnosis. Coping techniques can be evaluated and attempted (Chochinov et al., 2011).

The idea behind Cognitive Behavior Therapy (CBT) is that an outcome behavior (positive or negative) can be created by a chosen reinforcement behavior (Nichols, 2010). CBT can be used to correct bad behavior, increase positive behaviors, or to view a problem in a different light (Nichols, 2010). It may be beneficial for patients who are focusing more on negative thoughts and feelings about themselves or others (Hooyman & Kramer, 2006). There is considerable research showing that CBT is effective for treating

grief, anxiety, and depression in patients with advancing diseases (Hultman et al., 2008; Roy, 2008). An example of a CBT model would be the Rational Emotive Behavioral Therapy (REBT), which focuses on cognitive processes and helps differentiate healthy reactions to loss with unhealthy reactions (Roy, 2008).

### **Dignity Therapy**

At the end-of-life, the threat to dignity is often linked to depression and suffering in terminal patients. The purpose of dignity therapy is to assist the patient in finding meaning and purpose in his or her life by addressing issues he or she most wants to remember, or that have the greatest significance to his or her being (Chochinov et al., 2005). Finding dignity can decrease suffering and distress (Chochinov et al., 2011) and, theoretically, also impact anticipatory grief.

In dignity therapy, the patient reviews his or her life with assistance from a therapist who asks questions based on the empirical model of dignity (Chochinov et al., 2011). Questions on significant events, roles, and accomplishments are asked in order to assist the patient in finding purpose, meaning, pride, and hope in his or her life. Difficult issues, such as the post-death burden to families can be discussed in order to help the patient prepare the family for the difficulty ahead. The interview is semi-structured, in order for the patient to discuss anything he or she wishes (Chochinov et al., 2011). After the session, the therapist records the information and repeats the recorded information back to the patient in subsequent sessions. The patient can make comments or correct any wrong information. In the end, the patient can give the edited and complete transcript to a person of their choosing, as a keepsake (Chochinov et al., 2005).

Dignity therapy is meant to be empathetic, encouraging, hopeful, and respectful (Chochinov et al., 2005). It has been found to increase both dignity, and a sense of purpose and meaning (Ando et al., 2008). In one study conducted by Chochinov et al. (2005), 100 terminally ill patients participated in dignity therapy with their hospice workers. In the end, 76% thought it increased their sense of dignity; 68% thought it increased their sense of purpose; 67% thought it increased their sense of meaning; and 47% thought it increased their will to live. Better yet, 81% of the patients felt dignity therapy would help their family. These statistics are especially important because of the worry patients often feel about the burden of their death upon their family. Another study by Chochinov and his colleagues in 2011 concluded that patients felt their families appreciated them more after dignity therapy. As one person in their study commented,

Mostly I want my family to know that I'm okay with dying and they must move on... [T]he therapy showed me I am not the cancer, I am still in here. I am so grateful for that because I lost myself...it really helped me remember who I am. (Chochinov et al., 2011, p. 760)

### **Group Therapy**

Group therapy has been found to be therapeutic and effective for complicated grief work, such as for those who may develop depression due to grief or who may be suicidal (Roy, 2008). According to Hooyman and Kramer (2006), group and family therapy can be effective because it:

[E]nhances their sense of belonging and affiliation; legitimizes and normalizes their emotions associated with grief; provides chances to express and integrate their experiences; offers opportunities to learn new coping skills from others who have had similar losses; creates a forum for learning and receiving information relevant to the loss and to living beyond it; develops social relationships and supports; allows people to solve their problems with the help of others (p. 331).

Other studies have found group therapy beneficial in reducing psychological and physical distress as well as assisting in increasing coping skills (Breitbart et al., 2010).

### **Meaning-Centered Therapy**

The goal of meaning-centered therapy is just that-to find meaning or purpose in a person's life. (Breitbart et al., 2010; Wong, 2010). "Suffering without meaning will lead to despair and depression" (Wong, 2010, p. 87). Meaning-Centered Therapies are a very positive therapy, focused on hopefulness. This hopefulness can protect patients during difficult times and empower them to get through those times.

Meaning-Centered therapy is a holistic method focused on the mind/body/soul approach. In this therapy, meaning is both individually and socially constructed. The motto of meaning therapy is "meaning is all we need and relationship is all we have" (Wong, 2010, p. 86). This mind/body/soul relationship is the responsibility of the clinician, to encourage rapport and respect during the counseling session. A trustful and respectful relationship can help create an open environment from which the patient can feel liberty to express his or her feelings. Any therapeutic means necessary should be attempted based on the patient's needs and goals.

One strategy for meaning therapy is called PURE and contains four stages: Purpose, Understanding, Responsible action, and Evaluation. The Purpose stage involves finding the motivation in a person's life: What do I want for myself? The Understanding stage involves uncovering the whys of life: Why do I want that for myself? The Responsible action stage creates behavior based upon answers to the first two questions. Examples of these behaviors would be reconciling a relationship or writing an ethical will

or memoir. Finally, the Evaluation stage evaluates the level of satisfaction with the acted upon behavior (Wong, 2010)

A second strategy for meaning therapy is called the meaning-centered ABCDE strategy, and it focuses on negative events of life (Wong, 2010). A stands for Acceptance of the situation experienced. B stands for the Belief in the worth for living. C is the Commitment to goals created. D is the Discovering meaning in life. Finally, E stands for Evaluation of the outcomes (Wong, 2010).

One study conducted by Brietbert et al. (2010) found that meaning-centered group therapy was much more effective in dealing with spiritual and meaning-based needs than regular group therapy, particularly for patients dealing with terminal cancer. Meaning-centered therapy was found to improve the psychosocial symptoms common at the end of life, including depression and anxiety.

With all of the different treatment options, continued research that focuses specifically on interventions for psychosocial symptoms in terminally ill patients will need to be completed. It is important to highlight that hospice also provides support to the family and caregivers of the terminally ill patient. However, this project will focus specifically on the patient. Because much of the literature on interventions focuses on the bereaved, this project will attempt to identify commonly-used methods and interventions by hospice social workers specifically for managing or alleviating anticipatory grief in hospice patients.

## **Methods**

### **Research Design**

The research design for this project is qualitative and exploratory. The purpose of this study is to find commonality in methods and interventions used by hospice social workers in the Twin Cities metro area to assist patients with terminal illness who may be experiencing anticipatory grief. The qualitative design assisted the researcher in gathering information about as many different possible interventions as are available. This method was specifically chosen since a quantitative design may have limited the amount of information the participants could provide. Because the research on evidence-based practice for end-of-life psychosocial symptom interventions is limited, it is hoped this study may further interest in research towards evidence-based practices in end-of-life care.

### **Sample**

The sample taken for this research project is a nonprobability convenience sample. The population is hospice social workers currently working in the Twin Cities metro area. Participating social workers have a social work license and have at least one year of hospice experience. The social workers were recruited via a recruitment email that was sent to their agencies (see Appendix A). The email asked for interested participants to contact the researcher for further information. The email also asked interested participants to pass along the information to any other hospice social workers who may be interested. The researcher originally planned to interview eight to ten participants but was able to collect an exhaustive amount of information after interviewing six participants.



**Protection of Human Subjects**

For the protection of human subjects, the researcher submitted the research proposal to the University of St. Thomas Institutional Review Board (IRB) on December 19<sup>th</sup>, 2012. This included the methods by which the interviews were done and how the researcher would assure privacy to the participants. On January 18<sup>th</sup>, 2013, the IRB requested additional documents including the consent letter, the recruitment email sent to the agencies, and the IRB consent form. After including the proper documents, the researcher resubmitted the study's proposal. On January 24<sup>th</sup>, 2013, the IRB approved the proposal.

The consent form (Appendix B) was given to the participants prior to the interview. This consent form is based on a template created by the University of St. Thomas/St. Catherine University Institutional Review Board. It explained the background of the study, procedures, risks and benefits of participating in the study, confidentiality, and the volunteer status of the participants. Contact information for the researcher and the Clinical Research Committee Chair were also given. The consent form gave possible options for resources in the event the participants felt any negative effects from participating in this study (see Appendix B). They were then allowed to ask any questions they might have had about the study and were given the option to opt out if they felt they could not or did not want to participate. This right or refusal could have been exercised at any time during or after the interview. Colleagues of the researcher were reminded that they were not obligated to participate due to the professional relationship only. The participants were given a copy of the consent form and asked to read it and sign a copy for the researcher, stating that they understood the study.

The participants were informed that the interview would take approximately 30-40 minutes and would be audio-recorded onto the researcher's cell phone. The audio recording was immediately emailed to the researcher after the interview, and the audio recording was then deleted from the researcher's cell phone in the presence of the participant. At a later time, the emailed audio recording was transcribed onto a password-protected Microsoft Word document on the researcher's laptop computer. Participants were asked permission via the consent form to audio-record the interview. Any identifying information from the transcript was deleted. The transcript was seen only by the researcher. To further ensure confidentiality, the transcript will be destroyed at project's end.

#### **Data Collection Instrument and Process**

When the researcher was contacted by interested participants, the researcher confirmed that the subjects met the criteria for the study and then introduced the study's research question and discussed the structure and other conditions of the interview. The interviews lasted 15-30 minutes and took place at the participant's workplace, with special consideration for privacy and confidentiality. The participants were offered an email including the interview survey to preview prior to the interview. An audio recording was used during the interview to allow the researcher to transcribe the dialogue in order to be able to collate and analyze concepts and themes. An unstructured or semi-structured interview was used and participants were encouraged to depart from the interview schedule in order to elaborate on their answers. This allowed the researcher to modify the interview to tailor the needs of the social worker and allow for follow up and clarification where necessary.

The 14 questions (Appendix C) for the interview were based on or inspired by the completed literature review. Initial questions asked about the participants' basic demographics, their licenses and history in hospice work. These questions were posed to gain an understanding of the education level and experience the social workers have. The questions then moved to the participants' role in hospice and an explanation of the purpose of hospice and their role on their own hospice team. Then, questions were asked regarding experiences with anticipatory grief and the physical and psychosocial symptoms related to this grief. The researcher aimed to find commonalities or differences in the definitions or explanations of anticipatory grief. The questions then delved into specific methods or interventions the social worker uses for intervention related to anticipatory loss. Questions about outcomes and evidence to support outcomes were asked about methods and interventions the participants use. Specific methods and interventions addressed in the literature review were then listed to find if the participant was aware of those methods and to find out if he or she had any other methods or interventions to which he or she uses. Finally, the participants were asked what would help them when dealing with patients who may be experiencing anticipatory grief.

### **Data Analysis Technique**

The data analysis was based on grounded theory and inductive processing. After transcription, the raw data were analyzed, line for line, looking for words related to common concepts, in order to find patterns and meaning in the data. Comparing the concepts helped to create the themes for this study. As concepts were found, the researcher repeated analysis of the data to find additional information supporting the concepts identified as well as finding new ones. Concepts were combined to form themes

(Rubin & Babbie, 2014). Themes were focused to clarify meaning. Analysis was completed when the researcher felt concepts and themes were exhausted with information from the data.

### **Findings**

Sixteen agencies were emailed an invitation for eligible social workers to participate. Six eligible social workers volunteered to be participants for this study. The interviews took place January 5<sup>th</sup>, 2013 through January 12<sup>th</sup>, 2013 and were all conducted at the participant's workplace in an area they designated and which provided the interview with confidentiality. One social worker held a bachelor's degree in social work, while five held a master's degree. One participant was a licensed social worker (LSW), two were licensed graduate social workers (LGSW), one was a licensed independent social worker (LISW), and two were licensed independent clinical social workers (LICSW). The years of experience in hospice for the participants ranged from 1 year to 6 years. The majority of the participants received specialized training through continuing education. Two participants received specialized training in grief and loss.

The purpose of this study was to understand the various methods and interventions available and used by Twin Cities hospice social workers for hospice patients experiencing anticipatory grief. The focus was on terminal patients only. Family interventions were not included in the interview schedule, but participants did mention interventions they used for families experiencing anticipatory grief. This study not only provided a list of options given in current research but identified actual methods and interventions used by social workers in the hospice setting.

### **Themes**

From the interviews, themes were identified relating to the study's specific questions about hospice and anticipatory grief. Themes identified in the data analysis were:

- hospice for comfort purposes and the social worker role in supporting patients and families
- anticipatory grief causes and its symptoms
- methods and interventions used by hospice social workers
- methods and interventions unused by social workers
- the signs of benefits
- teamwork and good communication.

**Hospice comfort and the social worker's support.** Participants were asked to explain the purpose of hospice and their role in the agency. All of the participants stated various cares and supports are given to patients and families experiencing terminal illness in order to attain comfort at the end of their lives. Two of the participants stated that the purpose of hospice was to help patients “die well” with support and comfort.

*Hospice is a philosophy of care...with the focus on comfort for people ...who have a disease process that, without further treatment, would probably have six months, best guess, six months or less to live. And so we work as an interdisciplinary team of nurses, social workers, aides, massage and music therapists, volunteers, and others to provide comfort care for the patient and we also see the family as a unit of care. Providing support to them and education to them as well.*

*And then I kind of look at it as a holistic approach because it's not just the physical. It's the spiritual, mental, the emotional. It's really providing that support to the patient as well as the family...*

*Helping people to die well...that's what I had heard about hospice years ago and it makes sense to help people die the way they would like. I always think of the specialty of hospice as pain management, comfort at end-stage illness. But, I think that comfort is the biggest thing, and I think that is the purpose of hospice.*

The participants all identified themselves as the social worker on the interdisciplinary team. The majority of them listed “offering support” as one of their

roles. However, they each had a list of duties they perform on a daily basis. Some of these duties included: educating, providing resources and referrals, being a liaison, etc.

*As you know it can be anything, depending on the needs of the patient or family. So it can simply be emotional support, and it could be acting as a liaison between the different players, getting questions answered, helping with any financial needs, or funeral planning that the patient and family might need. Just about anything else that might pop up.*

**Anticipatory grief causes and symptoms.** All of the participants believed that anticipatory grief was the fear or anxiety over the unknown. The unknown could be about how the death will occur, what the afterlife will be like, how the family will cope or carry on after the patient had died, and if his or her unfinished business will successfully be completed after death. Some participants also mentioned that for patients there may be sadness attached to fear or anxiety of the unknown.

*It's so nice when we have those 95-year old patients who are like "I've lived a great life. I raised a great family. I'm ready to die. I know I am dying because of this prognosis and this diagnosis." And then in other people, it gets kind of hairy.*

*They don't know what the afterlife looks like or what's going to happen to family when they are no longer there to take care of them. Some of those things can cause them more anxiety or more concern about leaving because they don't know how things are going to be handled when they are not there.*

*It's the grief process that comes along with processing what they are facing...maybe some fear, based on the unknown and what to expect; if it will be painful, if it will be peaceful, if it will be long...basically coping with all of those emotions that come with that.*

*Everybody has a period of fear. I always say it's where your beliefs...the rubber hits the road...and we don't know. And I always let people know that even Jesus questioned on the cross. And it's a normal part of the grief process. And when people don't actually have that fear, sometimes I get a little worried...*

This sadness can be grief manifested over the loss of independence, loss of control, and loss of future dreams.

*I think part of what we also see is grief in terms of loss again. Because typically by the time someone goes on hospice they're weaker, they're more fatigued, because they obviously have more physical issues. They maybe can't take a bath on their own or maybe can't even eliminate the waste on their own.*

*I'm thinking of a woman that I was working with about a year ago. And she had had cancer for many years and it had gone into remission and it had come back. I mean it was just up and down, kind of a roller coaster. And you know relatively young, like late 50s. But I remember she had a daughter who got pregnant at the time she was dying...this was going to be her first grandchild and she wasn't going to meet personally, face-to-face, that grandchild.*

Psychosocial symptoms (such as denial of prognosis or impending death, memory loss, stress or worry, fear, or anxiety) related to anticipatory grief may emerge in patients.

*I get calls that people are having behaviors...I would say that at least 90% of the behaviors I see is actually anticipatory grief or other emotional issues going on, that they don't feel heard.*

*You see a lot of it in stress, worry, maybe some non-realistic ideas about what end of life is going to look like...not wanting to hear it...denial, withdrawal, pushing away from family members.*

The participants stated that these symptoms would only increase if anticipatory grief is not managed or becomes uncontrolled in patients. It may also lead to physical symptoms like unmanaged pain or discomfort.

*I just think we see a higher level of all of the things I just mentioned...behaviors, depression, thoughts about taking one's own life...*

Patients may even have difficulty at the end of their life, struggle to die peacefully, and fight until the very end. This kind of death may not allow for closure in patients or families.

*If it's not managed it doesn't allow for the patient and their loved ones to have good closure, a peaceful closure...it can add to the discomfort that a person might feel at the end of life.*



**Methods and interventions used by hospice social workers.** The participants were originally asked what they would use as a method or intervention for anticipatory grief in hospice patients. After this question, the participants were given a list of methods and interventions the researcher had found during the literature review. The methods or interventions most used by the participants were empathetic listening, education and communication, and life review or reminiscing. Within these themes, the participants mention why they use the methods or interventions, what purpose the methods and interventions have, and how they know they are working.

***Empathetic listening skills and validation.*** The majority of the participants commented that empathic listening skills and validation are very common methods they use with patients experiencing anticipatory grief. A few participants described the need for patients to be heard during this time and that a loss of control occurs when illness decreases a patient's independence and choice.

*Empathetic listening skills and support is huge. If a social worker doesn't have that, then we are not in very good water. That is used probably on a daily basis by myself not only with our patients but with their families as well because there is a lot of anticipatory grief in caregivers too.*

*They don't feel heard. And so really this time of life is really about listening. You don't even have to have a whole lot of knowledge about much as long as you are a good listener. Truly. I always say we are called to walk beside people.*

*I think a big piece of it is providing that listening ear. Kind of being companion on the journey, somebody who is going to be there. You know, whether it's going to be a good day or a bad day. If you're pleasant if you're not pleasant. On and on and on. Sometimes it's acknowledging the loss and acknowledging the feelings that result from the loss.*

*I think what I find more than anything is people just want you to listen and validate. They don't necessarily want you to solve the problem because it really, in the end, can't be solved...allowing them to be angry and be sad...*

*Just to be that listening ear a lot of times with that anticipatory grief. They just want to talk through it. They want to vent.*

***Education and communication.*** Education was mentioned by all of the participants as being, not only part of their role as a social worker but a method that they use for patients suffering from anticipatory grief. This education can also help when validating or normalizing a patient's symptoms or feelings. They also mentioned that this education can be used with families who are caring for their loved one. Making sure that the information is communicated with all involved parties, including the interdisciplinary team, may help with managing symptoms of anticipatory grief.

*We do a lot of psycho-education with both families and patients, and through the process, I think there is a normalizing that happens that what they are experiencing is normal for what they are going through. And it's amazing, but I've seen a lot of [it] even in trauma work too, there is a lot of comfort and release that comes from normalizing the experience. That everything is going according to plan.*

*I think the family worries too...I will tell them what I see with other families. That it works out well a lot of the time and how we can help them with how to do things. Tips on how...what are the easiest ways to care somebody.*

*We use "Gone from My Sight" [a book explaining symptoms leading to death] a lot...I find that is helpful not only for families but also for patients.*

*I often will talk to people about how long I've been in hospice and how often...like almost 100% of the time, I see people being comfortable and I'll explain that what I see over and over and over again is, I see people being comfortable. I see people getting tired and weak. And that that being the main things that happened, happens as they get closure.*

*Also enlisting the family to be a support system and educating them [helps] as well. Just because they know their mom is bipolar or schizophrenic doesn't mean that they know how to help them with end of life anticipatory grief...I always put an education piece, too, for the family and the care provider.*

*Education is huge because a lot of times the caregivers at end of life want to be a part of that process and it's just kind of a dance as to how much they are willing to provide...communication is huge too.*

*Life review, reminiscing, dignity therapy, legacy letters.* Five out of the six participants discussed life reviews or reminiscing. The other participant did not bring it up after reading the methods and interventions list. The participants stated that they use life review as a way of gathering information about the patient.

*I begin a life review for my own particular purposes, if a patient is able to communicate with me, as soon as possible. That gives me a lot of information about family, about family dynamics, how well the family functions together, and so forth. So I am really kind of doing it with more of a social work perspective than a life perspective.*

*I use, what I would say [is] a lot of life review and reminiscing, particularly the first time I meet a person. It's like I like to find out who they are. And so that first visit may take a little bit longer just because it's good to kind of get that background. I think in getting that background, it just kind of tells you a lot.*

The participants went on to mention that life reviews or reminiscing is an enjoyable event where the patient can evaluate his or her life. The family can participate as well, and eventually takes over the process of reminiscing as the patient's health declines and may not be able to participate as easily as they once were.

*Periodically, throughout my work with folks there will be a lot of reminiscing, you know. And as the person gets nearer and nearer to death, I think the reminiscing is kind of taken up more by the family...even though that person does not appear to be part of the interaction, I think they are.*

*And I guess I believe that they're hearing everything that is going on. And so, I always encourage that. And I find that people like to- patients like to reminisce. I think in reminiscing, what often happens is that they find purpose in terms of their life and "I wasn't here for no reason" you know...*

*[Life review] brings a sense of closure too...and I think just remembering a person's life and that they have something that is worth passing on gives them a sense of peace and closure as well.*

Three out of the six participants mentioned the use of dignity therapy, ethical wills, or legacy letters in their discussion of life review or reminiscing. All three of the participants discussed the three terms interchangeably as the documentation of a person's

life history and/or the values they see important in that life. The document is written by the interviewer and given to the patient and/or family to enjoy.

*We have a program that we can do and we do like life review and reminiscing as part of social work visits but we also do what [are] called legacy letters in which the patient can kind of outline things in their life that they really want to pass on in writing to people that they are leaving behind: siblings, children, spouses, and then generations to come who haven't even been born yet. So they can know a little more about this patient. I think that's very good with anticipatory grief in general because people feel like they still have a purpose in life. And I think that that's huge. It just gives them purpose. It gives them something that they are leaving behind ...I always feel like the people that agree to do that and do that with me kind of just have a weight lifted.*

*We were trained on the ethical wills so it's taking a person's life values and wisdoms not necessarily stories...but what did they learn from the experiences they had in life and that they would want to pass on to someone and then its typed up and put in the form of a letter and we are working on other forms that can be presented like books and things like that as well... then its presented to the patient or the family as a legacy that they can pass on to future generations.*

*There is a whole dignity project going on and so they are wanting us to identify folks who would benefit from telling their life story which then they would document and give to the patient who would give it to the family. But we haven't had a lot of big takers. Which is kind of interesting too.*

Finally, something worth mentioning is the enjoyment the social workers receive when reminiscing with patients and their families.

*Life review is something I enjoy with our patients because you learn so much and the elderly in general have so much more life experience than we have and have had numerous opportunities that I can never even dream that I am going to have.*

*Those moments of joy are what the life review is about. Because even if you get a little smile or something that makes them happy in the moment, that is what it is about.*

**Methods and interventions unused by participants.** Three interventions were not either heard of or regularly used by the participants in the list of methods and interventions the researcher gave. All of the participants went down the list of methods and interventions the researcher identified in the literature as options. When participants

came across the grief counseling, individual psychotherapy or CBT, only two participants stated it was used in practice.

*Individual psychotherapy is done on a daily basis with our patients. It's just on how deep and on what level...*

*Some CBT, I've used with family and with patients. And again, it can depend on where the patient is with process and it can be helpful with anxiety in particular with some deep breathing or some visualization...I find them really effective especially for in-the-moment types of anxiety and panic that somebody might be dealing with.*

The rest of the participants stated that therapy was not a primary purpose of hospice and that they would feel more comfortable referring outside the agency if a patient needed therapy of any kind.

*I don't think it's my place to diagnose people. I mean, they are at the end of life. They are here because of hospice. Other people might feel differently but, you know, I guess the other piece is that if they do want individual psychotherapy, I would probably be more apt to refer them to someone than actually kind of mix that in with my role...*

*We do not offer that with our hospice...I would refer out...which I do frequently, actually...*

*I have a certification in for The Alzheimer's association. Grief counseling, I don't know if I use [therapy] so much specifically with patients, a lot of time with family, and as you know hospice has bereavement support too.*

Another intervention mentioned in the interview survey and the literature review was support groups. All of the participants stated they do not offer or participate in support groups with patients. Groups are available through some agencies for bereaved families. One participant also stated the difficulty in conducting a support group for terminal patients in one hospice agency that may have different diagnoses or prognoses. Because the patients are coming and going, compounded by frequent mobility issues, there would be no source of continuity or consistency.

*Groups are not offered with any of the hospice agencies interviewed.*

*Groups- we've never done a group with our patients. You know that there are groups out there in the community that people could attend if they wanted to. But I mean, I am thinking too, particularly people who once they are here aren't going out much and even when they are at home or other facilities is kind of hard for them to get places. And I just don't see us doing a group here. I just don't.*

*I do a bereavement group with our bereavement coordinator. Again, I see more value in that for families than the patient themselves (sic).*

The majority of participants had never heard of meaning-centered therapies. The researcher did not go on to explain the idea behind the therapy.

*And meaning-centered therapy? That one I have never heard of.*

*I am wondering if maybe that that term in itself, I don't really use a lot, but I'm assuming that's its therapy focused centered around specific issues or something.*

**Benefits of methods and interventions.** The participants were then asked how they can tell if the methods and interventions they are using are effective. There was a large range of answers, but the general impression was that it brought a sense of peace and calm to patients and their families.

*As you are leaving, they are feeling better. They may even be saying to you, I'm so happy you visited.*

*The mood is different when you walk in and when you leave. The person may be smiling when they weren't smiling before. Some of those different things and, like I said, they verbalize it. "Thank you. I feel better." That kind of thing.*

Patients may feel they are more comfortable to express their thoughts and feelings to others. Others may complete end-of-life tasks or investigate the answers to some of their 'unknowns'. Other participants talked about concrete evidence supporting the benefits of methods and interventions they used.

*Very rarely do we see people in the premonitory, actively dying phase that have fear going into that because usually they are in kind of a sedated state, or just very restful, or even sleeping. But when I can see that we are working through*

*that, we see less stress; less stress on the body, maybe even better pain management...better communication with those around them, with myself, with my care team...maybe some more acceptance, realistic expectations about what the end will look like. We see little things like giving away of things and sharing things with family members that maybe they didn't know about one's life; just really a commitment to leave things behind.*

*Another aspect we sometimes see is reaching out more for spiritual care, like chaplain visits and people wanting to talk about some things that they may have only shared with one other person or no one in their entire life. Wanting to feel like they have some reassurance if they have, like, a faith based background.*

A few of the participants talked about the complexity of each patient and how, despite greatest attempts, a person's anticipatory grief is not managed prior to his or her death. This may be a choice of the patient or family to not deal with their own grief or fears. Despite that, social workers must meet the patient where they are.

**Teamwork and communication.** When asked what they would need, as social workers, to better help them intervene for patients experiencing anticipatory grief, each had a slew of answers. The general themes came out to be teamwork and communication between the team, patient, family, and any other caregivers involved. Good communication can assist in care planning for times of crises and moments when the anticipatory grief is taking control.

*Good communication becomes really super important.*

*I guess the patient being able to express it, talk about it.*

*I think just gathering a lot of the facts...I think that's usually what's missing because that's definitely causing the patient distress, because they know that they have this topic or situation that they need to deal with, but we might not have all the pieces that we need to move forward. So just kind of feeling them out for what they feel, we need to move forward and making (sic) sure you have all of your facts so that you can help develop a plan with them with their involvement.*

The other theme addressed by the participants was teamwork. A supportive and encouraging team helps the social workers to carry the burden of grief placed on them by

patients and families. They can provide support to each other. Team members can also assist by adding their specialized interventions, focused on the anticipatory grief.

*I definitely would encourage spiritual care to get involved and/or bereavement to help with that process so it doesn't all fall on our shoulders. Then encourage the family with that open communication piece...it's not just us social workers (sic) that have to listen to all of that and offer advice or suggestions, but any of the team members can do that. So just making the other team members aware that are involved in that patient care, that this could come up and maybe give them some suggestions or education that comes up when you are not there, and how they can handle it and just work as a team; and again it's not something that has to just fall all on our shoulders to fix.*

*I think it's a team approach. If you are feeling you are doing it all alone, or you are out in left field by yourself trying to put the pieces together, not only are we going to get stressed, but then we are going to bring that stress and anxiety to our patients; so we want to leave that at the door and go in there more positive and upbeat and have them lead the conversation and lead the visits and work through some of that grief. Hopefully before the end comes, they can feel some sense of accomplishment and relief, and not have to be anxious about the dying process.*

*What helps me, presently, is the fact that I have a very supportive care team. I feel like each of the disciplines in our care team is very well represented. That our points of view and our input is all very highly valued.*



## Discussion and Implications

### Theme Interpretations

There are easily identifiable themes to be found in the interviews, beginning with the theme of hospice comfort and the social worker role as a supportive worker. This is expressed by all of the participants. The researcher wanted to have a clear understanding of what the participants' philosophies behind hospice were while understanding how they feel connected in hospice. The concept of offering support is almost unanimous, and that support is later identified by the participants in the various methods and interventions used.

The second theme found in many interviews is that of the causes and symptoms of anticipatory grief. This theme could also be classified as "fear of the unknown", as almost all of the participants discussed a patient's fear regarding the unknowns of their death, future plans, etc.

The methods and interventions that were conducted proved to be another theme. The methods and interventions they discuss most prominently are empathetic listening and validation, education, and life reviews (which also includes reminiscing/dignity therapy/legacy letters). Each participant stressed the importance of empathetic listening. This is a very important theme as it is repeated multiple times by all participants. Simply being companion to a patient's grief and allowing the patient to express his or her feelings in a safe and supportive environment could be the easiest, most effective, and most often used method.

Just as interesting to note, are the methods and interventions *not* used by participants. As stated previously, the participants went down the list of methods and

interventions created by the literature review and some of the participants skipped right down the list to explain only those they have heard of or used in the past. Others went line by line, explaining their knowledge on each. Some said they did not use any form of formalized therapy as it was not their main purpose on the hospice team. A few even said they were not licensed to do therapy. All but two said they would refer out of the agency to a therapist for the patient as needed. Those two participants were both LICSW. Most of the participants had not heard of meaning-centered therapy. The researcher originally intended to explain any method or intervention the participants had not heard of. However, due to time constraints and respect for the participants, the researcher just allowed the participants to say they had not heard of or used a method or intervention such as meaning-centered therapy. Dignity therapy is similar, in that a few of the participants had never heard of it. The participants who discussed life reviews or legacy letters have some knowledge of it and included it when discussing life reviews or reminiscing.

The fourth theme prevalent is the benefits of methods or interventions on anticipatory grief. Common threads were that the participants could tell anticipatory grief was being managed when the patient had peace and calm, were able to have open communication with others, and were able to complete end-of-life tasks or pursue the answers to their “unknowns”.

The final theme revolves around the support necessary for the social workers to maintain care regarding a patient’s anticipatory grief. The common answer deals with teamwork and communication. Some of the participants did not answer this question

directly, prompting this researcher to direct them back to how they, and not the patient, could be helped.

### **Connection with Literature Review**

There are many connections between the findings and the researcher's literature review. First, the participants confirm that the goal for hospice is to provide a comfortable dying experience to patients (Asford & LeCroy, 2013; NHPCO, 2011). The literature review also mentions a focus on supporting the family of the terminal patient. As stated previously, the participants wanted to discuss their methods and interventions with the families who were also experiencing anticipatory grief because this is a support the social workers provide. However, due to the fact that the focus of this study is on terminal patients only, the researcher had to direct the participants to focus specifically on patients.

The participants and literature review both express how many hats the social workers wear in their role on the hospice interdisciplinary team. Many of those hats are discussed in the participant's use of methods and interventions. The participants have also added on other roles, including admission liaisons and bereavement coordinators as part of their job description. The literature review mentions the use of counseling and supportive therapies as social worker tasks. However, the research here did not strongly support this. Only two of the participants (both LICSWs) stated they use therapies in their daily work. The other participants stated they refer outside of the agency for therapy needs.

The literature discusses the symptoms and causes of anticipatory grief in hospice patients. The participants discussed this as well when they talked about the grief related

to the fear of the losses that may occur due to their impending death, including the grief over the loss of independence and control, the loss of dreams and planning (Cheng et al., 2008), and anxieties related to challenges and grief their families may face, both during their disease process, and after death (Hultman et al., 2008). This anticipatory grief may manifest in ways such as anxiety, increased physical symptoms, or pain (Ashford & LeCroy, 2013; Hultman et al., 2008; Simon, 2008). The participants talked about the decrease in these symptoms as evidence that methods and interventions for anticipatory grief are working.

The conceptual framework of this study focuses on the changes people experience over the course of their lives, with a focusing on a person's end-of-life. The strongest connection between the conceptual framework and the findings is found in how the participants can tell the interventions are working with patients. The sense of peace or closure the patients experienced was mentioned by a few of the participants and can also be found in the theorists' conceptual frameworks, including Abraham Maslow (self-actualization) (Clarke, 2007; Klunder, 2011), Colin Murray Parkes (readjusting and reinvesting) (Bowman, 2012), and J. William Worden (accepting and coping) (Worden, 2009).

The participants included in this study validated the literature expressing the importance of empathetic listening skills with patients (Klunder, 2011). This method may be the most important in hospice social work. A few of the participants mention a simplicity in the support offered to terminal patients. Being companion to a person's grief provides a supportive environment in which the patient may be able to express their thoughts and feelings (Klunder, 2011).

The literature review speaks of the importance of education and communication with patients and families, allowing for them to fully understand their illnesses and care plans. The participants talk about how a patient's understanding of their illness can help normalize any feelings or fears he or she may be having. The literature and participants also mention the role of advocate, liaison, and mediator (Klunder, 2011) in the area of education. The health care field is fraught with terms unused by the layperson, and the social worker can assist patients and families in understanding these terms, specificities of the illness, and any treatments.

The literature discusses life review and dignity therapy as separate interventions with their own processes and outcomes. The participants who know of dignity therapy combine them with life review, reminiscing, and legacy letters. The participants talk about involving the family in this intervention, and how it brings them closer together during this process (Caldwell, 2006). A few of the participants mention that the process of reminiscing is taken over by the family as the patient is actively dying and no longer able to participate.

The participants were asked about how they identified the benefits of the methods and interventions they used. Some participants reported a change in their emotional state after using a method or intervention with the patient. Other participants discussed concrete benefits such as pain and stress reduction, better communication, and realistic expectations. This concrete evidence fits with the evidence identified by the literature review on the benefits of various methods and interventions for anticipatory grief.

**Implications for Social Work Practice and Policy**

Any social worker may come into contact with a client who may be experiencing grief and this could include anticipatory grief. Interventions for anticipatory grief can assist social workers in any area of practice as it can affect any person of any culture of any age. Providing social workers with the knowledge base for methods and interventions regarding anticipatory grief will only help the profession provide cares to vulnerable populations.

As stated earlier in this study, hospice care is covered by the Medicare A benefit. Currently, attention has been brought to the cost of health care and Medicare. This is being closely watched by the hospice agencies and advocates. Any changes to the benefit will affect the services provided to patients and families experiencing a terminal illness. While healthcare costs are high, policymakers need to acknowledge the very fragile and sacred time that is end-of-life. Social workers may need to inform policymakers of the importance of this time of life, through research and advocacy for patients.

**Implications for Research**

The purpose of this study is to examine the various methods and interventions hospice social workers use for patients experiencing anticipatory grief. As the literature review expresses, very little research has been aimed specifically at interventions for terminal patients who are anticipating their losses. Continued research can be done to examine the effectiveness of different methods and interventions on anticipatory grief in this population in order to provide social workers with options for evidence based practices. Anticipatory grief can be experienced by other populations, such as those newly diagnosed with a chronic or mental illness or those who have recently become

disabled. Additional research could be focused on any variances of anticipatory grief causes and symptoms in different cultures and specific methods and interventions that can include specific attention to those variances. Additional research can also be done regarding the risks and benefits of using group therapy in the terminal population. The participants mentioned that group therapy is not offered in their hospice programs for various reasons. As the literature review showed, group therapy may be beneficial to those experiencing grief. Additional research may be needed to understand the barriers social workers may have facilitating these groups in a hospice setting.

### **Strengths and Limitations**

**Conceptual framework.** A strength of this study includes the detailed lifespan stage theories. The researcher limited it to the most cited or popular theories. A limitation of this study is that the stage based lifespan development theories have been found to be limited. Instead of being a stage-based development, the research has shown that the lifespan stages are cyclical or even chaotic at times. Because every person's grief process is different, movement between stages is unpredictable. However, a strength of this study is its inclusion of both lifespan development theories and theories related to tasks and processes of grief.

**Number of possible interventions.** An issue that is both a strength and limitation of this study is the amount of available literature on grief interventions. There are many interventions focused on different emotional symptoms, yet very few focus on interventions for anticipatory grief. This made the literature review difficult. The researcher had trouble finding interventions specifically related to anticipatory grief in hospice patients and found an exhaustive amount on grief and loss. The researcher

limited the literature review to include only the most popularly cited interventions. As stated previously, another limitation is that this study did not identify interventions for patients in specific cultural or ethnic groups. Research could be completed focusing on the differences in groups and the effectiveness of interventions with these differences in mind. A strength of this is that this topic may promote future research on specific interventions and their benefits for terminal patients with anticipatory grief.

**Sample.** The sample of participants for this study is hospice social workers with expertise in the field. Insight into positive and negative outcomes of methods and interventions will be very useful. It is, however, limited because the participating social workers are only a sample taken out of the Twin Cities metro area. Different areas of the state, country, or differing schools of social work might have different methods or interventions in which they are trained or specialized.

**Methodology.** This study involves the semi-structured to unstructured interview schedule. The researcher based the interview off of the interview schedule, but allowed the participant to move away from the schedule when necessary. The researcher occasionally failed to reconnect the participant back to the interview schedule. The researcher had intended to explain any interventions the participants may not have understood. This did not happen due to the feeling of time constriction and busy schedules of the participants.



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## Appendices

### Appendix A: Recruitment email

Jolene Metcalf LSW CHPSW

[Date]

Dear [**Organization's Name**]:

My name is Jolene Metcalf and I am an MSW student at the University of St. Thomas and St. Catherine University. I am currently working on my clinical research project and am asking for your social workers' involvement.

Your agency information was obtained from the Minnesota Network of Hospice and Palliative Care website at <http://mnhpc.org/public/find-a-hospice>. Your agency was selected because it is a Twin Cities metro area hospice agency listed under the Minnesota Network of Hospice and Palliative Care organization and employs licensed social workers that might meet criteria for this study.

My clinical research project is focused on hospice social work interventions for anticipatory grief in terminally ill patients. I am looking to interview hospice social workers. The criteria to participate is for participants to be a licensed social worker, to have at least one year of hospice experience, and to currently work in a hospice setting.

If you are willing to have your social workers voluntarily participate in my study, I would ask you to pass the attached email onto them and ask that they contact me by phone or email if interested.

If you, or any hospice social worker you know, may be interested, please contact me, Jolene Metcalf at my email [metc8161@stthomas.edu](mailto:metc8161@stthomas.edu). I will make an effort to contact you within one week to discuss the study.

Thank you for your time

Sincerely,

Jolene Metcalf  
LSW CHPSW

## Appendix B

**CONSENT FORM  
UNIVERSITY OF ST. THOMAS****Hospice Social Work Methods and Interventions for Terminally Ill Patients  
Experiencing Anticipatory Grief**

#395424-1

I am conducting a study about methods and interventions used in hospice social work for anticipatory grief in terminally ill patients. I invite you to participate in this research. You were selected as a possible participant because of your experience as a hospice social worker. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Jolene Metcalf LSW, a graduate student at the School of Social Work, St. Catherine University/University of St. Thomas and supervised by Dr. Karen Carlson, Deborah Goulet LICSW, and Joan Stauffer LICSW.

**Background Information:**

The purpose of this study is to gain knowledge about methods and interventions used by hospice social workers to help patients experiencing anticipatory grief at the end of life.

**Procedures:**

If you agree to be in this study, I will ask you to do the following things: Participate in a 30-40 minute interview regarding methods and interventions for anticipatory grief in hospice patients. The interview will be recorded onto the researcher's cell phone and immediately emailed to the researcher. The audio recording will be deleted in your presence. At a later date, the audio recording will be transcribed onto a password protected Word document. The researcher will then analyze the information and present the findings in May 2013 in a continuing education presentation on the campus of the University of St. Thomas. This presentation will include projects from the graduate social work students who have completed GRSW 682.

**Risks and Benefits of Being in the Study:**

The study has no known risks and the study has no direct benefits. However, if you feel any negative effects of participating in this study, please inform the researcher immediately and the interview will end. Resources for appropriate follow up will be discussed and given to you to pursue independently.

**Compensation:**

There will be no compensation for participating in this study.

**Confidentiality:**

The records of this study will be kept confidential. Research records will be kept on a password protected file on the researcher's computer and any hardcopy information will be kept in a locked drawer at the researcher's home. Findings from the transcript will be presented in May during my presentation. The transcript will be destroyed by January 1, 2014 and the audio recording will be deleted immediately after being emailed to the researcher in your presence.

**Voluntary Nature of the Study:**

Your participation in this study is entirely voluntary. You may skip any questions you do not wish to answer and may stop the interview at any time. Your decision whether or not to participate will not affect your current or future relations with St. Catherine University, the University of St. Thomas, or the School of Social Work. If you decide to participate, you are free to withdraw at any time without penalty. Should you decide to withdraw, data collected about you will be destroyed.

**Contacts and Questions**

My name is Jolene Metcalf. You may ask any questions you have now. If you have questions later, you may contact me at [metc8161@stthomas.edu](mailto:metc8161@stthomas.edu). Feel free to contact Dr. Karen Carlson, at 651-962-5867 or [carl1307@stthomas.edu](mailto:carl1307@stthomas.edu). You may also contact the University of St. Thomas Institutional Review Board at 651-962-5341 with any questions or concerns.

**You will be given a copy of this form to keep for your records.**

**Statement of Consent:**

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study and to be audio recorded. I am at least 18 years of age.

\_\_\_\_\_  
Signature of Study Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Print Name of Study Participant

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Date



## Appendix C

## Survey of Interview Questions

For the purposes of this study, the interviewer understands that the interviewee is a licensed hospice social worker who provides care to patients receiving the hospice benefit and has been working in the hospice field for at least one year.

## Demographics

1. License level
2. Years of hospice experience
3. Specialized training

## Hospice Social Work

1. Can you briefly explain the purpose of hospice?
2. What is your role in the interdisciplinary team?
  - a. Please elaborate.

## Anticipatory Grief

1. In your own words can you define or describe anticipatory grief in hospice patients. Explain if needed.
  - a. What are symptoms of anticipatory grief?
  - b. What causes anticipatory grief?
  - c. What happens if anticipatory grief is not managed?
2. When you care plan for anticipatory grief, what interventions might you attempt?
3. Have you heard of any of the following interventions? If so, can you tell me about its use in your practice?
  - a. Empathetic Listening Skills Support
  - b. Education and Communication
  - c. Life Review/Reminiscing
  - d. Grief Counseling
  - e. Individual Psychotherapy/CBT
  - f. Dignity
  - g. Group
  - h. Meaning-Centered Therapy
4. Strengths and weaknesses of each?
5. How do you know the interventions are effective?
6. What could the profession do to enhance your skills regarding anticipatory grief in hospice patients?
7. Is there anything else you would like to add?