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## **Best Practices of Hospice Social Workers who Work with Families Experiencing Grief and Loss**

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Best Practices of Hospice Social Workers who work with Families Experiencing Grief  
and Loss

Submitted by Bethany L. Butzow  
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.

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## **Abstract**

This qualitative study examined the best practices of hospice social workers who work with patients and families during their hospice journey. Data was collected through semi-structured standardized interviews with hospice social workers currently working in the area. Open coding methods were used to inductively analyze codes in the data and to find common themes from the interviews. Themes that emerged from this study were separated into three categories: family roles and functioning, collaboration among the interdisciplinary team, and the hospice social worker role. Additionally, sub themes that correlated with these three major findings were discussed. The majority of the findings of this study were consistent with previous research. Other themes that were not congruent with previous research were also found, including the physician's lack of education on hospice and the quality of communication among the interdisciplinary team. Implications for this study suggest ideas for future research in this area, with hopes to enhance hospice education, research, and training. Ongoing research in this area has the potential to strengthen an understanding of the hospice philosophy for patients, families, and professionals.

## **Acknowledgments**

The completion of this project could not have been achieved without the ongoing support and encouragement of many important people in my life. For all of you that have been there for me through this experience has meant everything to me. A special thank you to Mike Chovanec, Mike Justin, Jeff Wigren, and Deb Goulet for enhancing my learning, supporting my research, and pushing me to do my best. Your time, energy, wisdom, and experience have been truly invaluable to this project. Thank you to the hospice social workers who donated their time, expertise, and personal experiences. I admire your passion, courage, and empathy that you use everyday to support patients and families through their hospice journey.

To my friends and family who have been put on hold for the last two years while I complete my education, your love, support, and understanding has given me the perseverance to get through many stressful days. A special thank you to Jill and Maddie, your patience, support, and ability to make me laugh means the world to me. Thank you to my graduate girls: Heather, Megan, Natalie, Kelli, Lauren, and Melanie for enduring the stress with me. Thank you Mom, Dad, Ben, and Jenna for your love, support, and understanding through this challenging, yet amazing journey.

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## Introduction

Approximately 21 million adults aged 85 and older will reside in the United States in 2050 (Washington, Oliver, Demiris, Wittenberg, & Shaunfield, 2011). These individuals will most likely have physical and mental limitations that will affect their quality of life and will require long term care (Hooyman & Kiyak, 2008). Currently, 75% of older adults spend the remainder of their lives in hospitals, nursing homes, or hospice (NCHS, 1991; as cited in Hobart, 2001). The hospice movement was introduced in Europe in the 1960s by Dame Cicely Saunders, with the first hospice residence established in Connecticut (Kane, Berstein, Wales, Leibowitz, Kaplan, 1984). Within hospice programs, 40.7% of patients receive hospice services in the privacy of their home, while 22% receive services in a nursing home (Washington, et. al., 2011). The term hospice is defined as *“a facility or program designed to provide a caring environment for meeting the physical and emotional needs of the terminally ill.”* (American Heritage Medical Dictionary, 2007).

In general, hospice provides end of life care for people that have a prognosis of 6 months or less to live (Waldrop & Rinfrette, 2009). Although it must be determined that the patient has 6 months or less to live, the average length of stay in hospice is 59 days (National Hospice and Palliative Care Organization, 2007). In the United States, the median length of stay in hospice declined from 29 days in 1995 to 26 days in 2005 (Teno, Shu, Casarett, Spence, Rhodes & Connor, 2007). Moreover, over 30% of patients admitted to hospice die within 7 days or less (Teno, et. al.).

The purpose of hospice is to support the patient and family's quality of life. Hospice focuses on family and often a family member is a patient's primary caregiver

(McMillan & Mahon, 1994). Moreover, hospice comforts the patient through pain management, music therapy, and massage therapy (Waldrop & Rinfrette, 2009).

Quality of life (QOL) can be observed as an important measure at the end of life (Tang, Aaronson, & Forbes, 2004). QOL refers to aspects of life and human functioning that are considered to be essential to living the fullest life (McMillan & Mahon, 1994). Physical, psychological, spiritual, and social support factors contribute to one's well being (Tang, et. al.). Since QOL is derived from multiple factors, it is important to use distinct QOL instruments to obtain accurate psychological, physical, spiritual, and social support factors (Bretscher, Rumman, Sloan, Kaur, Bartlett, Borckenhagen, & Loprinzi, 1999). For example, reports of physical pain do not correlate with psychological functioning (Bretscher). Research surrounding end of life issues is continually needed to assess and improve QOL in hospice patients.

It is important for the field of social work to be educated and have experience with the dying process to provide effective therapy, support, and guidance for family members during stressful times. In American society, death is often ignored or denied by the patient and family members (Hobart, 2001). It is the social worker's role to educate, normalize, and remove the stigma that surrounds dying. A better understanding of death and a better response by hospice social workers to the needs of family members could result in improved therapies and outcomes for families experiencing grief and loss.

As the baby boom generation ages, the social work field must also change to meet the needs of these patients. The baby boom generation is physically healthier and will live longer lives than their parent's generation, which will increase the need for care in home or in an alternative setting (De Lama, 1993). Social workers will not only need to

effectively treat the patient, but also support the family struggling with grief after the patient has died. Future research could focus more on educating social workers about end-of-life needs and how social workers use psychosocial skills to improve the quality of life of the patient and their family.

This study examined how social workers affiliated with hospice programs within health systems addressed and responded to family reactions during the death of a family member. Through qualitative interviews with clinicians who treat patients and families who have experienced a significant loss, this study aspired to gain insight into the different methods that are used to address death, its impacts on the family, and the techniques used to understand the transformation of the family after a family member has passed away.

## Review of Literature

This review of literature focused on a patient's transition to hospice, the perceived quality of life for patients and caregivers in hospice, the family functioning after a patient has died and a social worker's involvement following the death of a family member.

### *Transition into Hospice*

Washington et. al. (2011) found that patient and family experiences in hospice were divided into three categories, transitioning into hospice, quality of care, and communication. Washington et. al. examined 15 family members through semi structured interviews, which focused on their perspectives on end of life care. Many family members, especially the caregiver responded to the transition to hospice as an emotional decision (Washington, et. al.). According to one wife whose husband entered hospice, "*It just got too bad. I never thought it could get that bad.*" (Washington, et. al. pg.163).

Another aspect of the transition is selecting a hospice program. Family members reported feeling overwhelmed with several hospice facilities within the geographical area (Washington, et. al.). Moreover, many family members did not seek assistance from health care professionals to gather more information about each hospice facility. Lastly, family members reported that transitioning to hospice was practical due to the caregiver's career and family (Washington, et. al.). Although the transition to hospice was emotional, family members reported that it was worth their efforts.

Another aspect of hospice experienced by family members was quality of care. Many family members reported that their loved one was receiving a high quality of care by the hospice staff. On the other hand, one family member reported dissatisfaction with hospice care. Although family members were mostly satisfied with hospice staff, several

family members expressed concerns about staff and patient communication (Washington, et. al., 2011). The concerns surrounding communication between patient and staff focused on cultural differences. Many family members reported that miscommunication was an often occurrence in hospice programs (Washington, et. al.).

Family members reported that communication among hospice staff, caregivers, and external family members was an important aspect of hospice care (Washington, et. al., 2011). The family members expressed that hospice does not have a formal means of communication. Family members reported that they would hear inconsistent messages from the hospice staff regarding their loved one (Washington, et. al.). One family member stated, *“I just hear different things from different people.”* (Washington, et. al. pg. 165).

Waldrop and Rinfrette (2009) found that communication was an important component of the transitioning phase of hospice programs. Waldrop and Rinfrette examined 53 hospice employees, which included nurses, social workers, chaplains, and physicians through qualitative interviews and observation. Researchers observed hospice team meetings and communication regarding the patient and family (Waldrop & Rinfrette). In addition to case communication, hospice staff were continually educated about dying, grief, and loss issues in team meetings. Hospice staff learned how to provide support, both emotional and spiritual, to families (Waldrop & Rinfrette). Furthermore, hospice staff were instructed to provide guidance to families about the dying process, offering them coping methods, and preparing them for approaching death. Other education provided to hospice staff regarded crisis situations, in which the staff would intervene to help minimize family conflict, anger, or anxiety (Waldrop & Rinfrette).

Waldrop and Rinfrette (2009) found that four types of communication were essential for a successful transition to hospice including patient and family, patient-family-physician, patient-family-hospice, and hospice and physician communication. Similar to the previous study, patient and family communication regarding transition to hospice is an important first step in communication. Hospice professionals reported that mutual agreement between the patient and family about hospice is needed (Waldrop & Rinfrette). The family must share an understanding that the patient is given a terminal illness and will have physical and psychological difficulties. For instance, one hospice social worker stated, *“some families understand that death is approaching, cope well, and this becomes a process of bonding and strengthening.”* (Waldrop & Rinfrette, 2009, pg. 572). Communication among family, patient, and physician is important for establishing a clear definition that the patient’s illness is terminal and the prognosis. Most likely, a physician will refer the patient to a hospice program after discussing the prognosis with the patient and family (Waldrop & Rinfrette).

Communication among the patient, family, and hospice staff also is critical for the transition into hospice. Some families already had experience with hospice and are therefore knowledgeable about the process. Hospice professionals reported that other families, however, are not ready for the transition to hospice (Waldrop & Rinfrette, 2009). Hospice staff reported in team meetings that family conflict arises due to little education about hospice. For example, a family member of a patient requests a certain treatment and other family members find the treatment futile (Waldrop & Rinfrette). Moreover, hospice staff report communication among the patient, family, and hospice staff is difficult when the family is uncomfortable about expressing their emotions.

Lastly, hospice staff reported hospice and physician communication is clear regarding a patient's admission. Hospice staff reported communication between the hospice department and physician is essential because physicians must give an order to begin hospice care (Waldrop & Rinfrette). Interestingly, hospice professionals stated the physician's attitude about hospice, either positive or negative, had an impact on the patient's transition into hospice (Waldrop & Rinfrette).

Washington et. al. (2011) and Waldrop and Rinfrette (2009) examined the effectiveness of communication on the transition into hospice. While one study examined the patient and family's feelings about transitioning into hospice, the other study examined the perspectives of hospice professionals on transitioning. Both studies suggest that open communication is essential for a successful transition for all members. Specifically, clear communication and shared understanding among the patient, family, and hospice staff is crucial to providing the highest quality of care.

#### *Quality of Life and Hospice*

Teno, et. al. (2007) found length of stay in hospice is correlated with a positive or negative perception of hospice by patients and family members. Teno et. al. developed the Family Evaluation of Hospice Care (FEHC), which is a survey to measure family perceptions of the quality of end of life care. The FEHC survey was attached to hospital and hospice web sites through the nation and Teno et. al. encouraged hospice professionals to contact family members one to three months after a patient's death to participate in the study. Teno et. al. studied family perspectives. Eighty-seven percent of respondents reported the patient was referred to hospice at the right time, while 11.4% of respondents reported that hospice was initiated too late. If respondents reported that

hospice was initiated at the right time, quality of life (QOL) of the patient was higher. On the other hand, if patients began hospice at a later time, then family members reported a lower satisfaction with quality of care. Moreover, one in five family members who reported a hospice stay of less than a month reported that patients were referred too late, which impacted their view on quality of life.

Tang, et. al. (2004) found patients living with a caregiver reported a lower QOL than those not living with a caregiver. According to Tang et. al., QOL can be conceptualized as an “*individual’s subjective well-being.*” (pg. 114). Well-being can be defined as psychologically, physically, socially, and spiritually healthy (Tang, et. al.). Tang et. al. examined 60 participants with a mean age of 73 years old in two hospice programs over a four month period. Five instruments were used to measure QOL in patients including, McGill Quality of Life Questionnaire (MQOL), Spiritual Well-Being Scale (SWBS), American Pain Society Patient Outcome Questionnaire (APS-POQ), Eastern Cooperative Oncology Group Performance Status Rating (ECOG-PSR), and the Medical Outcomes Study Social Support Survey (MOS-SS) (Tang et. al.). These instruments measured a participant’s QOL, spirituality, pain symptoms, physical performance status, and social support respectively. Participants who reported pain, fatigue, and shortness of breath had a decrease in their QOL (Tang, et. al.). On the other hand, spirituality positively correlated with QOL (Tang, et. al.). Interestingly, Tang et. al. found participants who lived with a caregiver had a diminished sense of QOL compared to participants that did not live with their caregivers. Tang et. al. hypothesized that lower QOL was reported by patients due to their feelings of being a burden to caregivers.

While Tang et. al. (2004) found that patients reported lower QOL scores when residing with a caregiver, Bretscher and colleagues (1999) found caregivers rated hospice patients lower on QOL than the patients rated themselves. Bretscher et. al. examined 16 patients from May 1996 to April 1997. Of these 16 patients, 14 were diagnosed with cancer, 1 had acquired immunodeficiency syndrome (AIDS), and 1 had congestive heart failure (Bretscher, et. al.) Similarly to the Tang et. al. study, Bretscher et. al. used several instruments to measure QOL. Bretscher et. al. examined stress scores associated with physical pain, emotional state, and a patient's perception of spirituality. Moreover, Bretscher et. al. examined Likert Analog Self-Assessment Scale (LASAS). In this assessment, patients and caregivers reported on the patient's overall QOL. QOL of life perceived by caregivers tended to rate the patient's QOL lower than the patients rated themselves (Bretscher, et. al.). Interestingly, the QOL of many patients remained stable over time. This finding is inconsistent with other findings, which suggest patients experience significant suffering throughout hospice (Bretscher, et. al.).

McMillan and Mahon (1994) found caregivers did that perceive patient's QOL increased from the time of admission to the third week. McMillan and Mahon examined 67 patient and caregiver dyads that were being admitted to a hospice program. Similar to the previous studies, the majority of patients were diagnosed with cancer, specifically, lung and prostate cancer (McMillan & Mahon). The Sendera Quality of Life Index (SQLI) was used to measure QOL (McMillan & Mahon). Both patients and caregivers were instructed to complete the questionnaire independently upon admission and on the third week (McMillan & Mahon). When the questionnaire was distributed on the third week, caregivers reported an increased QOL of the patient overtime. Specifically, the

average score of perceived QOL of the patient given by the caregiver was 48.2 at admission and 53.3 at the third week, suggesting a statistically significant change (McMillan & Mahon).

Previous studies have focused on the patient's QOL and the caregiver's perception of the patient's QOL. Interestingly, there were inconsistent perceptions of quality of care overtime. Teno et. al. (2007) found timing of referral and length of stay impacted the QOL in patients and caregivers. In contrast, Tang et. al. (2004) found patients living with a caregiver reported a lower QOL than patients living without a caregiver. Bretscher et. al. (1999) found that caregivers rated patients with a lower QOL, while McMillan and Mahon (1994) found caregivers reported that patients had an increase in QOL from admission to the third week. These studies reaffirm the need for additional research in the area of perceived QOL of caregivers and patients.

#### *Family Functioning after Death*

##### *Spousal.*

Zisook and Shuchter (1991) found following the death of a spouse, widows and widowers reported full depressive episodes during the first year. Following a death, widows and widowers have an increased risk of depressive episodes after 13 months if they have a past history with depression and perceive themselves as being in poor physical health. Zisook and Shuchter examined 350 newly bereaved widows and widowers. Participants were interviewed in their homes and completed the Widowhood Questionnaire (Zisook & Shuchter). The interviews were highly structured and examined the marital relationship, nature of the death, early grief reactions, social support, and present, past, and family history of depression (Zisook & Shuchter). After the interviews,

participants completed Widowhood Questionnaire, which included questions regarding coping methods, changing roles, health, and maintenance of old relationships (Zisook & Shuchter). Two hundred five or 59% of participants stated anticipatory grief before their spouse's death and 51% were still grieving at the seventh month (Zisook & Shuchter). After seven months, 24% of participants met the DSM-III-R criteria for a depressive episode, while 16% of widows and widowers reported a depressive episode at 13 months (Zisook & Shuchter). In a depressive episode, individuals reported feeling sad or empty nearly everyday with diminished pleasure in usually enjoyable activities (DSM-IV-TR, 2000, pg. 168). Zisook and Shuchter found that a history of depression served as the greatest risk of bereavement depression after thirteen months. Moreover, younger widows and widowers were more likely to experience depressive symptoms than older participants. Interestingly, Zisook and Shuchter found no gender differences in the participants. Consistent findings on the equivalence of gender were found (Clayton, Parilla, and Bieri, 1980).

While Zisook and Shuchter (1991) examined depression in widows and widowers, Ott and Lueger (2002) found within the first months of bereavement, overall mental status of widows and widowers parallel individuals seeking outpatient mental health treatment. Ott and Lueger examined 94 widows and 24 widowers from hospice programs, churches, and support groups. The average age of the participants was 60. The participants completed a mental health index (MHI), which measures overall mental health status (Ott & Lueger). A pattern emerged with the means of the MHI, ranging from 55.29 in three months to 61.58 in 24 months (Ott & Lueger). The overall mental

health status of widows and widowers illustrates a gradual improvement over a two year period.

Both studies focused on the mental health status of recent widows and widowers. Zisook and Shucter (1991) examined depressive symptoms of individuals and found grief continued to occur seven months after death. On the other hand, Ott and Lueger (2002) found that although grieving is a process, individuals stabilized over two years. From these studies, it can be assumed grieving is a normal process that parallels other situational mental health needs.

### *Children.*

Cait (2005) found that for adult women, grieving was an evolving process. Cait examined 18 women between the ages of 18 and 45. Among the 18 women, eight experienced a parental death while ten experienced a maternal death (Cait). Cait interviewed participants focusing on the relationship between the deceased parent and the current relationship with the surviving parent. Cait found the shifting of family dynamics was a process of grief. Specifically, the participants reported they experienced changes in role. This included heightened responsibility and being expected to care for the surviving parent. Fourteen women identified a shift in their role within the family, which included supporting their surviving parent and replace the role of the deceased (Cait). Moreover, the participants observed a dramatic shift in role after the death of a primary caregiver than the other caregiver (Cait). Without the primary caregiver, the family must find balance and this is due to the shifting of roles. Participants reported a period of destabilization following the death of a primary caregiver and the participants stabilized the environment by acquiring an additional role (Cait). Interestingly, all of the 14 women

reported that as they transitioned into a more caregiver role, they also adapted this role in other relationships (Cait). In a way, the caregiver role became a part of their identity. The variables of birth order and culture expectations are important indicators of the daughter's role transition. Finally, the majority of participants reported the bond between the surviving parent and daughter strengthened. One participant reflected that although she enjoyed the closeness with the parent, it "*interfered with other friendships and relationships.*" (Cait, pg. 13).

While Cait (2005) examined women who had lost a parent (and their relationship) with the surviving parent, Gray (1987) found both males and females had increased conflicts with the surviving parent reported higher depression scores. Gray examined 50 participants, with 34 females and 16 males. In 31 of participants, their father was deceased. On the other hand, 19 participants had lost their mother (Gray). The participants were interviewed by the researcher and then asked to discuss the research with their parent. The interview consisted of questions relating to the nature of the relationship of both parents and the current relationship between the child and surviving parent (Gray). Personality was also assessed through the differential diagnostic technique (DDT), which is a visual-motor personality test (Gray). Personality can be viewed on a continuum and divided into three categories ranging from aggressive behaviors to passive behaviors (Gray). Throughout the interview, the researcher also asked the participants about being prepared for death, religious beliefs, age of the participant at the time of death, time elapsed since death, and social class (Gray). The Beck Depression Inventory (BDI) was also used to assess depressive symptoms. Twenty percent of participants had a significant score on the BDI (Gray). Social support was also a factor in determining a

higher score on BDI. Children who reported lower social support generally had a higher BDI score (Gray). Interestingly, there was a negative correlation between the surviving parent and suddenness of death (Gray). If children were not prepared for the death of one parent and did not have a strong, trusting relationship with the other parent, then higher depression scores resulted (Gray).

Personality was also related to depression scores (Gray, 1987). Passive and dependent children reported higher depression scores than aggressive or balanced personalities (Gray). Religious beliefs also correlated with lower depression scores than those who did not affiliate with a religion (Gray). Adolescents that were 15 years old and younger reported more depressive symptoms than older at the time of a parent's death (Gray). Finally, there were no significant differences in depression score between sexes. Zisook and Shucter (1991) found similar results in adults that were widowed.

Gray (1987) found children, especially younger children report higher depression scores when there is little social support, an unstable relationship with the surviving parent, a passive personality, and not being prepared for death of a parent. Also, both sexes were equally affected by the death of a parent. Both studies examined the experiences of children that are impacted by parental death. Moreover, both studies stress the importance of stable relationships with the surviving parent.

#### *Social Work Involvement with Death*

Hobart (2001) found older women planning for long term lacked awareness of the social work role in assisting with psychosocial aspects of dying. Hobart examined 12 women through interviews on their experiences with health care directives and end of life decision making. Many of the participants assumed that physicians would make their end

of life decisions, which is incorrect (Hobart). Hobart identified that social workers have a unique role in advanced care planning compared to other disciplines, such as physicians and nurses. Hobart explained social workers have specialized training in empowerment and have the skills to empower individuals to make their own decisions about end of life.

In contrast, Billings and Kolton (1999) found discrepancies between communication, bereavement support after death, and advanced care planning in hospice programs. Billings and Kolton interviewed 38 women and 15 men for a total of 53 participants whose adult relative had recently died in hospice from November 1996 to November 1997. Forty-three percent of participants reported that they were a spouse of the deceased person, 32% identified as children, 6% were parents, and 11% were not relatives, but friends or neighbors (Billings & Kolton). The interview consisted of questions about the relationship between the participant and deceased relative, the date and cause of death, and asked the participant to describe how the family was treated after the relative had died (Billings & Kolton). During the interviews, 17 respondents complained about the lack of communication during and after death (Billings & Kolton). For instance, one participant reflected that hospital staff did not initiate family meetings to discuss the patient's current health status (Billings & Kolton). Participants appreciated when hospital staff would share stories, write cards, or attend the funeral of a patient (Billings & Kolton). Twenty-six percent of respondents, however, initiated contact with physician or nurses (Billings & Kolton). Furthermore, three people did not receive information from the patient's physician about the death (Billings & Kolton).

Lastly, Billings and Kolton (1999) found over half of the participants lacked resources from health professionals about grief support groups or other resources.

According to the participants, the support and guidance from hospital staff was lacking (Billings & Kolton). This finding is consistent with other research, in which half of bereaved spouses had no contact with the physician after death (Tolle, Bascom, Hickam & Benson, 1986). In addition, no participants mentioned the support from social workers or chaplains (Billings & Kolton). Participants also commented that they would have appreciated resources or having a hospital staff call the family after death. For example, *“we wrote to the health center two months after mother died. I would have appreciated someone calling us to see how we were doing”* (Billings & Kolton, pg. 40).

Both of these studies reveal social workers in hospital and hospice settings are rarely recognized or acknowledged. Individuals that participated in the previous studies focused on receiving information from physicians and nurses. Although individuals expressed interest in receiving assistance help from hospital staff, they did not receive any assistance. A consistent message throughout the research is the need for more research on social worker’s role in supporting families during bereavement. Patients and families most likely direct their needs to the physician or nurse. There is a need for continuous communication among the multidisciplinary team. Moreover, according to previous research, when there is clear communication and mutual understanding, patients report a higher QOL at end of life. The social work profession is grounded on education and supporting others. As presented by these previous articles, there is inherent need for additional research in how hospice social workers can effectively support the family through a time of crisis. Family dynamics are constantly shifting to adapt to certain stressors in life, including death. It is the role of social workers to guide family members to helpful and supportive resources that are tailored to the family’s needs. This study

aims to strengthen the research on QOL of patients and families at the end of life by gaining insight through experienced hospice clinicians.

### *Gap in Literature*

The researcher reviewed the University of St. Thomas Library database including Social Work Abstracts, Google Scholar, and Psycinfo. Within these databases, the key words of “family roles”, “family functioning,” and “hospice social work and worker” were used. The researcher identified two gaps in the literature, including the limited information on specific role transformation among family members following a death and the lack of research on hospice social workers who are an integral component of the bereavement process for families. It is hoped that the current research can close these gaps to further understand the family dynamic during the grief process.

### *Summary of Literature Review*

This review of literature illustrated hospice is a difficult transition for many patients and families. Many families are overwhelmed with emotions and do not understand the process of hospice. Previous research has also found inconsistent results in QOL. Patients and caregivers have different perspectives of QOL while in hospice. Specifically, caregivers reported lower QOL of patients while patients reported a higher QOL. Research has also focused on family functioning following a death and has found that grief is a continuous process. Grief was dependent on the stability of the surviving parent and child relationship. Research found children who were younger and had an unstable relationship with their surviving parent were at an increased risk for a depressive episode. Lastly, the literature found social workers were rarely involved with family members following a death. Many families tended to receive information on grief and

support groups through their primary physician or nurse. This study aims to strengthen the previous research through using key concepts in interview questions, specifically examining the role of hospice social workers and their response to assisting families during the grieving process.

## Conceptual Framework

The conceptual framework that was used for this study is the *ecological perspective*. The ecological perspective provides organization to understanding human behavior and the social environment (Forte, 2007). Urie Bronfenbrenner (1979) presented models of human development including mircosystem, mesosystem, and macrosystem, (Forte). The mircosystem, mesosystem, and macrosystem are the foundation of social work practice. The mircosystem consists of the immediate family, school, and neighborhood (Forte). The mesosystem consists of two or more immediate systems, such as school and home (Forte). Lastly, the macrosystem is an umbrella term that consists of the values, laws, and customs of a particular culture. All three systems interact and adapt to human development (Forte).

Within the ecological perspective, family systems theory has gained prominence through research. Families organize in implicit or explicit ways to accomplish certain roles and functions (Hutchinson, 2008). As families organize roles and functions, those roles must have homeostasis. According to family systems theory, family members must have homeostasis to remain stable (Hutchinson). If one family member is not stable, this may affect the other family members. Moreover, there are open and closed systems in family systems (Forte, 2007). Open and close systems can refer to boundaries within relationships (Boss, 1980). In open systems, there is a continuous exchange of energy with the environment (Forte). In a closed system, the boundaries are binding and essentially closed from others (Boss). When boundaries are ambiguous, family dysfunction may occur (Boss).

Role Theory is also a component of the Ecological perspective. In Role Theory, one's society and community assign labels and meaning to family roles. In Western cultures, certain roles are necessary for the family to function in society. These roles include having a breadwinner, leadership in making family decisions, household management, and childrearing (Hutchinson).

This framework is applicable to the current research regarding social worker's perspectives of families during bereavement. First, in the microsystem, family members are directly affected by death and must shift the behaviors, actions, and roles to maintain homeostasis. Second, in the mesosystem, death of a significant family member may impact the person's school or home life. Last, in the macrosystem, culture values and ideas about death are created.

Families are unique, and therefore boundaries vary dramatically; from family to family. It is expected social workers have knowledge and skills to detect the boundary style of families and therefore locate adequate resources and support. Another aspect of family systems theory is the concept of homeostasis, which promotes stability in the family (Hutchinson, 2008). This concept directly relates to the current research. After a crisis, such as a death, families will try to stabilize their environment. One example of regaining stability is the shifting of roles of the surviving family members (Cait, 2005). Through the ecological perspective, emphasizing family systems theory, the researcher considers how boundaries and the family environment are affected by death. The researcher also utilized interview questions based on the conceptual framework.

## **Methodology**

### *Research Design*

The design of the research was exploratory and qualitative. The purpose of this study was to gain a deeper understanding of how hospice social workers respond to families during the grieving process. This qualitative design allowed the researcher to explore the experiences of hospice social workers during assessment, intervention, and treatment. Due to the limited literature on hospice social workers, this study enhanced the existing literature on feelings toward death of families and professionals.

### *Sample*

The population for this sample consisted of hospice social workers currently working with families who have recently experienced a significant loss. The criteria for selecting clinicians to participate in this study focused on being a licensed social worker and having at least one year of experience working in hospice. Participants were recruited through a snowball method. The researcher distributed contact information to committee members and asked them to pass the information to other clinicians who would be interested in participating in this study. The sample size of this study was six participants.

### *Protection of Human Subjects*

For the protection of participants, a consent form was given to potential participants. This consent form was created by the researcher that is based on a template from St. Catherine University/University of St. Thomas (See Appendix A). This consent form consisted of background information of the study, procedures, the risks and benefits of participation, compensation, and confidentiality. Potential participants were given a copy of the consent form and interview questions and were allowed to ask any questions

before deciding to participate in the interviews. Moreover, the participants also signed the consent form to signify an understanding of the study. In this consent form, participants were informed that the interview would be audio taped. The researcher, however, transcribed the interview. The researcher also addressed that the information discussed in the interviews would be kept in a secure file cabinet in the researcher's home. The data would be destroyed on June 1, 2012. Following the discussion of the consent form, potential participants were asked to sign the consent form prior to the interview.

### *Setting*

The researcher conducted interviews at a location that was convenient for the participant. Since hospice social workers are affiliated with a health system, the interviews were conducted at hospitals within the Twin Cities area. Hospitals are large non-profit organizations that serve a diverse population, including patients at end of life. If the participant wished to meet outside of the hospital, the researcher accommodated to participant's preference.

### *Instrument*

The researcher used a semistandardized interview schedule. In semistandardized interviews, the questions generally lie "*between the extremes of the completely standardized and the completely unstandardized interviewing structures*" (Berg, 2009, pg. 107). The researcher asked participants questions in a consistent order; however, the participants had the freedom to divert from the topic at hand. Through a semistandardized interview, the researcher had the ability to adjust questions that are tailored to each participant.

The interview consisted of twelve questions developed by the researcher, which focused on the clinician's demographic information, experience in the field, experience working with families following a loss, the types of support they offer families, and experiences working with other disciplines including physicians and nurses (See Appendix B). The questions were reviewed by the researcher's committee members to increase validity.

### *Data Collection*

To locate participants and gather data, the researcher asked each committee member if they have contact information of two to five potential participants. The committee members gave the names and contact numbers of potential participants. First, the researcher developed a flier that consisted of a brief summary of the study, the length of the interview, location, and the researcher's contact information, stating that the participant should contact researcher if interested in participating. The flier also stated the researcher will follow up with the potential participant if they have not responded within a week. Second, the researcher sent the flier, informed consent, and interview questions with instructions via electronic mail to each committee member. Lastly, each committee member sent this information to two to five qualified hospice social workers. When contacted by potential participants, the researcher used a protocol during the telephone conversation. The researcher reintroduced the study and stated that the interview would last 45-60 minutes. Moreover, the researcher discussed the location of the interview. The interviews were conducted at the participant's workplace. In this follow-up telephone conversation, the researcher asked if the potential subject is interested in participating. If potential subjects were interested in participating, then the researcher asked to schedule a

meeting at their convenience. Audio tapes were used during the interview and the audio tapes were transcribed to find themes within the data.

### *Data Analysis*

The audio taped interviews were transcribed and the data from the transcriptions were used in this study. Content analysis was used to interpret the meaning of the interviews. Content analysis is a technique that identifies and applies meaning to patterns and themes in raw data (Berg, 2009). Through content analysis, themes emerged from the data. Moreover, an inductive approach was used to analyze the data, meaning that specific raw data was used to create codes and to apply those codes to applicable theories, instead of applying existing theories to explain the raw data, as is done in a deductive approach (Berg). The technique of open coding was also used to find patterns within individual interviews. The researcher examined the data line by line to identify repetitious codes. After the initial coding session, the researcher reviewed the codes and applied a systematic label to the codes. Thus, themes in the transcription emerged.

### *Researcher Bias*

In most cases, researcher bias may affect the study's findings in a qualitative analysis. For example, the researcher expected to observe gaps in grief support given to families. Such bias was a matter the researcher addressed to increase the value of the study. The interview questions were reviewed by committee members to avoid leading questions. During the interviews, the researcher elicited personal feelings, which were recorded to enrich the findings of the study.

## **Findings**

The purpose of this paper was to gain a deeper understanding of family functioning during the process of hospice. This study aimed to gain insight into the best practices of hospice social workers through techniques that provide comfort, ease, and peace to the patient and their family through the dying process. Additionally, the study examined the aspects of communication, both positive and negative, among hospice professionals, including physicians, nurses, social workers, chaplains, music therapists, massages therapists, and volunteers.

### *Sample*

Six participants were involved in this study, three of whom were female and three were male. Five participants were employed at a large health system in the Twin Cities metro and one participant was employed at a private hospice setting. All of the interviews were conducted at the office of the participant's respective health system. The participants were all Master level licensed social workers that had over one year experience in a hospice setting. Nine eligible hospice social workers were offered a chance to participate in this study and six accepted. The six interviews were conducted through the end of January 2012 to the beginning of March 2012. All of the participants came with valuable experience working with patients and families during a stressful time. A theme is identified when two or more participants are in agreement surrounding a certain interview question. Throughout this section, quotes from participants were italicized to clarify results. Themes that emanated from this study were separated into three categories: family roles and functioning, collaboration among the interdisciplinary team, and the hospice social worker role.

### ***Family Roles and Functioning***

Participants were asked to describe roles and functioning among family members throughout the hospice process. Participants were also asked to describe homeostasis or lack thereof within family members. Additionally, participants were asked how one views current roles of family members and their interpretation of how grief and loss manifests into family roles. Six themes of viewing family roles were identified by hospice social workers. These included: (1) role and abilities of family members, (2) out of state family members, (3) allowing the patient to be part of the assessment, (4) assessing for homeostasis, (5) assessing for anticipatory grief, and (6) how personality type affects the impact of grief. The researcher found the theme, (7) grief impacting the need to control other tangible objects, which was highlighted by one participant.

### **Roles and Abilities of Family Members**

Three out of six participants identified roles among family members “pop up” during the initial assessment. Moreover, four out of six participants identified that the oldest child usually takes on the organizational role and the other, siblings defer to oldest child. The question that led to this response was, “How do you see the roles and functions of these family members in a hospice care setting?” The following three quotes demonstrate how family roles “pop up” at an initial assessment.

*“It has been amazing to me to see a family gathered and say you know every family member has a role in the family and I don’t know if you have thought about it. And I remember one family member especially saying, “Oh really, we have never thought about it, but she is the caretaker, I’m the legal person, and that’s the financial person. They knew exactly, they clicked them off in the room.” (Case 1, Page 1, Lines 1-8).*

*“In hospice, what I notice is that the stress forms from a result of what is going on. The person dying is really causing people to respond in really distinct ways, in really acute, very short duration, very high pressured, I am the leader of the family. I am the*

*peacekeeper. I am the organizer, all of those things. The roles pop up and people assume those roles.” (Case 2, Page 1, Lines 1-8).*

*“I think there is usually one or two people that like to take the role as the decision maker or helping the patient make the decisions and the others fall into place and usually just stay off to the side lines and try not to get involved.” (Case 3, Page 1, Lines 1-5).*

Four out of six participants identified the oldest son or daughter is determined to be the decision maker of their parent’s wishes and the other children follow through with their decisions. The following quotes will illustrate this finding.

*“It isn’t necessarily the oldest or the daughter. But if the oldest is a daughter and they live nearby, then that’s often going to be the person who takes the brunt of things and at some point even though they want the decision making power, they also get frustrated with siblings.” (Case 4, Page 1, Lines 1-4).*

*“I think being the oldest, you are the organizer and you believe the grief is important but we have to plan the funeral. Who do we contact and make sure we have the details? What are the finances? You go into the take charge role as the oldest.” (Case 5, Page 8, Lines 363-368).*

*“The shifting of roles, people have to take on a much stronger role or leadership role than others would do. Sometimes it is the oldest child who steps to the plate and the other siblings follow and direct everything to the eldest.” (Case 6, Page 1, Lines 72-77).*

*“The decision maker is usually the adult child, oldest son, oldest daughter and sometimes the patient will pick someone that isn’t the oldest and sometimes that can cause trouble. Most of the time it works well and most people fall into that pattern.” (Case 3, Page 1, Lines 12-16).*

Several participants acknowledged and identified that roles often pop up in families during assessment. Additionally, it is usually the oldest adult child that becomes the decision maker or organizer, while the other adult children follow them.

#### Out of State Family Members

Six out of six participants identified the conflicts that may arise from out of state family members. Adult children living out of state can come in without knowledge of the illness progression and may have an agenda to treat their loved one. There was no

question that paralleled this answer; however, it is an important factor. This theme became apparent during the discussion of current roles among families members. The following three quotes illustrate this theme.

*“What has happened over the years is that other adult children have learned that as mom or dad becomes more needy, it is easier not to be in that decision making and controlling role, because you can walk away from the work and that is where some of the resentments come in. A child that lives in Colorado and flies home once a year, it is an easier role than the one who is here and is dealing with the day to day things. And it doesn’t seem to do with the number of children in the family.” (Case 4, Page 1-2, Lines 33-39).*

*“The other sibling might live in California and I had a horrible sibling fight going on between the one here (Minnesota) and the one somewhere else. The one in California believes that they are going to change everything because the ones here are doing it all wrong. This is why I cannot have an agenda.” (Case 1, Page 1-2, Lines 44-56).*

*“This one gets notified when Grandma or Pop is dying and they fly in from out of state with an agenda and they are very complicated people to work with at that point because they have their own issues that they are moving through and we have to be really attentive to those people, they usually have really pointed agendas so we really need to work with them on separate tracks. They don’t know the current situation, so they don’t know what is going on. They haven’t been with the family through the whole process and they are going to show up and redefine the situation.” (Case 2, Page 2, Lines 32-46).*

#### Patient Involvement in Assessment

Two out of six participants identified that it was important for family members to allow the patient to be a part of the hospice journey, including assessment. The question asked to evoke this answer was, “As a hospice social worker, how do you do about assessing current roles of patients and their families?” Although there was not a strong cohesion among all participants, the researcher believed that this theme strengthened the study. The following quotes demonstrate this theme.

*“In a home, you can tell so much. I mean, you know, who sits where? What is the proximity of everyone to the patient? Will they the patient to be a part of the process? Who all of a sudden touches the arm of the patient? What kind of support, nonverbals are*

*going on? And then, who speaks the most? Who is trying to speak for the patient?” Case 1, Page 3, Lines 34-46).*

*“Sometimes people are on their best behavior at an admission and things come out afterwards but I think it’s always interesting to watch where the patient is sitting and does the family want them involved in the process.” (Case 3, Page 2, Lines 44-54).*

Both participants informed the researcher that educating the family about the hospice philosophy can encourage family members to include the patient as much as possible. Both participants reinforced that the patient is the focus of hospice and attending to their needs and wishes.

#### Degree of Homeostasis within Surviving Family Members

Six out of six participants identified that homeostasis or equilibrium is a goal or target that the family strives to reach. The following three quotes illustrate this theme.

*“A family just achieves a new level of equilibrium and then there is another decline. And then the system, the mobile, has to readjust again and I think that is the hardest part emotionally for people. You think you almost got a handle and then it changes again.” (Case 1, Page 5, Lines 174-183).*

*“I would have to say that homeostasis does not come into play. There is a desire for it but it is not out there. Families are usually stressed and I find that homeostasis does not exist for them right now. They are off on a journey, they are out nowhere dealing with things that they have never dealt with and there are no rules or guidance. Homeostasis goes out the window. You move toward what they think homeostasis is, but it is not. It is the goal, the target, but they are pretty far usually.” (Case 2, Page 4, Lines 178-184).*

*“I look at it (homeostasis) as a child mobile and then once a piece is tilted, it is very difficult to get back to that equilibrium and things back in order and in line. It takes a process because of the fact of the influence that person has or had on that family. It may be able to shift back into balance but a lot of times it hasn’t necessarily. The goal would be to get that family back to a place where they can communicate with one another and some stability.” (Case 6, Page 2, Lines 82-88).*

All of the participants stated that when there is a crisis in the family, such as a pending death, there is a pull toward equilibrium. Interestingly, two out of six participants stated that homeostasis can be viewed as a mobile, in which as one piece is shifted, the

others shift as well. The process of the mobile to return to balanced may take a long period of time. This parallels the balance among family members. Furthermore, one out of six participants stated that homeostasis did not exist during hospice. This participant stated that the family is trying to find balance, but does not have the resources to do so.

#### Assessing Grief among Family Members

Three out of six participants identified that personality style impacts their ability to cope during a stressful experience. The interview question that accompanied this theme was, “how do you see the emotions such as grief and loss impacting the roles of family members during the transition into hospice?” The same three participants stated that one’s coping ability is embedded at a very young age. Although the ability to cope with grief can be modified through experience, personality style predicts one’s grieving process. The follow quotes provide evidence of this theme.

*“I think that how we experience grief and loss is directly related to our personality. How did we experience when we were 6 and when we were 18 and 44. I do not think it changes much, I think we each use the same coping skills we used for other things. Some might be more effective than others. I don’t think that really changes. I think it is pretty much built in.” (Case 4, Page 4, Lines 155-160).*

*“I believe that it (coping with grief) has a lot to do with personality. Personality is pretty well set at very young age and I think it gets modified as we get older and learn things about grief. Maybe as we experience grief incidences, we learn what to pay attention too.” (Case 5, Page 7-8, Lines 260-264).*

*“The grief and I believe that is a study of personality types. As people have their individual traits, I believe that the grief moves in an individual way and really affects the people with their own make-up if you will and the grief is the trigger and then they have a response, but the response is within their psychology that they bring to the table so everyone is a little bit different with that.” (Case 2, Page 5, Lines 225-230).*

One out of six participants identified that grief and loss creates a need of control for the person. This could be a potentially important of the grief process. The following quote demonstrates this theme.

*“I think stress tends to come out sideways. Family members tend to get focused on one thing and they try to fix it. The thing going on with their loved one cannot be fixed and they want to do something so it comes out as changing medication or buying a wheelchair cushion, something tangible that they see, feel, this is helping.” (Case 3, Page 4, Lines 113-117).*

The participant continued to state that family members have control over tangible objects, such as medication. Furthermore, this participant has observed many family conferences to discuss each medication change during the hospice process.

### ***Collaboration among the Interdisciplinary Team***

A broad theme that emerged from the analyzed data was the use of communication among hospice professionals. The interview question asked participants to describe their perception of communication among the interdisciplinary team. Two themes were identified: (1) communication among hospice professionals and (2) physician referral. Of six participants, three of them identified the use of phone calls, particularly voicemail to continuously be updated on a patient’s status. All of the participants reported that interdisciplinary team meetings, in which patients are discussed in detail, are essential for a functional hospice. A second theme found regarded the primary physician providing information hospice and bereavement services. Out of six participants, all identified that the primary physician was not well educated on hospice services.

### **Communication among Hospice Professionals**

All of the six participants identified the importance of communication and collaboration among hospice professionals. Three out of six participants acknowledged voicemail as a medium for continuous communication, since hospice work is independent. Out of six participants, six stated that interdisciplinary team meetings were

an integral component of hospice, as patients are discussed in depth by the interdisciplinary team. The following four quotes illustrate this theme.

*“I think the team we have here social worker, registered nurse, music, massage, and chaplain, we are all communicating with each other, either through interdisciplinary team or in between times through voicemail. If they (patient or family) are having an emotional crisis that needs more follow up, then the nurse or other team member will call us. It is really an open communication.” (Case 3, Page 5, Lines 230-235).*

*“It is one of the most exciting pieces of our work because the disciplines are very different and it is unusual the things we have to overcome or take care of to be able to communicate effectively. Our group really effectively communicates. We talk as a company at 8:30 am and 4:30 pm everyday. We have staff meetings on Tuesdays that run for two hours. Thursday mornings we have an interdisciplinary team meeting that lasts about 4 hours and discusses all clients and client changes.” (Case 2, Page 8, Lines 408-416).*

*“It is (hospice) all about the team. We work at trying to communicate well with each other but we often are just alone out there. We are encouraged to do co-visits and talk more after. There aren't as many channels for getting together as I would like but we do work at it and often consult with each other about patients and families on the phone, leave messages, but try to talk directly too. Some nurses are better at it than others.” (Case 1, Page 7, Lines 260-265).*

*“Generally, we do a lot of voicemail and have every two weeks a team meeting where the group medical director, supervisor, home health aide, chaplain, music, massage, registered nurse, and social worker participate in that meeting so there is always lines of communication because knowing what one person sees may be different that another person see and team members need to know the emotional aspect you are dealing with in this family.”(Case 6, Page 3, Lines 170-176).*

All of the participants that stated interdisciplinary team meetings were important to summarize and report those differences in the group. Moreover, three out of the four previous quotes mentioned the importance of voicemail, as hospice professionals visit patients and families individually.

## Physician Referral

Another theme found was the involvement of the primary physician. The interview question that corresponded to this theme was, “Studies have consistently found that families often look first to their primary physician and hospice nurse for information on grief support groups or bereavement counseling, what are your thoughts and feelings about this issue?” All of the participants identified that while physicians make the hospice referral, many are not educated on the hospice philosophy. The following two quotes help strengthen this theme.

*“I do not know if they go to the doctor so much. Sometimes they will ask the nurse and then the nurse will get a social worker in. Sometimes they will ask the nurse about our bereavement services and then the nurse will say talk to your social worker and we will get a call. I don’t think they think the doctor knows much about it.” (Case 1, Page 8, Lines 304-310).*

*“Generally the referral has to come from a physician and then what happens is that a nurse and social worker would go out and evaluate whether or not the person is eligible for hospice. Some families are looking for it on the internet but once they come on the program, the role of the social worker is to educate and inform the family members and to the client as to what is available to assist the client.” (Case 6, Page 4, Lines 340-345).*

Two out of the six participants discussed families researching hospice information on the internet. The following quotes demonstrate this theme.

*“I think it is changing. I just had a client group that got us from the internet. How weird is that? They shopped us out. I think the primary caregivers will usually start from the medical. So if there is a doctor that is comfortable and that is another whole study in itself with palliative care and hospice, then they can direct a family into a hospice organization. We usually walk in, the nurse and social worker as one person and we are hospice. It is very singular. We talk about the services that we bring and we acknowledge that they are stressed out.” (Case 2, Page 10, Lines 453-460).*

*“I think a lot of people are going to the internet but some people aren’t interested in the internet either but I think especially with older adults, they trust their doctor to provide the information. It has to be a doctor referral to start hospice and that keeps that in the corner.” (Case 3, Page 6, Line 191-195).*

Both of these two participants stated the increase in technology is shifting the way patients learn about hospice programs. One of the participants stated that the older generation is obtaining information on hospice through their primary physician, which may slowly shift as younger generations' age.

### ***Hospice Social Worker Role***

All of the participants identified the importance of the social worker within the hospice team. Specifically, all participants reported that their role was to inform, educate, and provide resource referral. Furthermore, three out of the four quotes presented identified the importance of allowing the patient to tell their story. This theme was identified through the interview question, "What are the strengths and limitations of the social worker's role in a hospice setting?" The following four quotes further demonstrate this theme.

*"The education and training. I really believe a strength is the variety of what we do, when I enter a hospice setting, you don't really know what you are going to be doing today and I think that keeps our skills really sharp." (Case 4, Page 7, Lines 345-348).*

*"I think it is providing a lot of times its crisis intervention because a family is coming into a crisis. Its really about providing a sense of calm and presence to hear their story and I think its really important to listen to that story first and that is what I do when I admit someone, I want to hear their story and want to hear where they are at." (Case 3, Page 4-5, Lines 230-234).*

*"Being able to find peace, resolution, and sometimes reconciliation. The strength though is really being able to come to a peaceful end of life with a sense of dignity and comfort." (Case 1, Page 9, Lines 370-373).*

*"The strengths come from the experience, listening to the stories and being able to take clips from the past or quote people share with you. We also network very well with the other hospice programs in the area. There is no competition. We are all working together for the common good." (Case 5, Page 15, Lines 672-678).*

Four out of six participants reported limitations to the hospice social worker role.

Two out of the four participants stated medical vocabulary and language is drastically different than social work. The following two quotes demonstrate this theme.

*“Limitations for sure, medical, starting into this kind of work, you are stepping into medical work. There is a different vocabulary....Theoretically, if I were to start hospice training, you would have to involve a couple semesters of medical stuff.” (Case 2, Page 11-12, Lines 480-483).*

*“I think there is always a limitation not having a medical degree and being in a medical field. Some of the kinds of things I have heard from social workers about working in hospitals is they are kind of off to the side and here do this. But there is less of that sense in hospice.” (Case 4, Page 7, Lines 205-209).*

Two of four participants reported time and large caseload as a limitation in the hospice social work role.

*“The limitation first would be time.” (Case 1, Page 8, Line 152).*

*“I think caseload, we would all love to see our patients every week but it does not happen that way. I think that is the most limiting thing we struggle with. And then that time.” (Case 3, Page 7, Lines 140-142).*

## **Discussion**

This study explored best practices of hospice social workers who work with families through the grief process. Insight was gained through observing and understanding family roles, examining issues with out of state family members, patient involvement in assessment, exploring the degree of homeostasis in family members, assessing how grief impact family members, utilizing the interdisciplinary team, confirming physicians have a lack of understanding about area of hospice, and appreciating a social work lens in hospice. This discussion highlighted the demographics of the sample, a summary of the study's findings and an interpretation of the findings. Moreover, this summary will include researcher reactions, limitations and recommendation for future research, and implications for social work practice.

### *Sample*

The sample was comprised of six hospice social workers that have had more than one year experience in a hospice setting. Three of the participants were female while three were male. The average age of the participants was 58 years old. All of the participants were Caucasian. The participants comprised of seasoned professionals that have many years of experience in a hospice setting. Additionally, five of the participants were currently working at a health system and one had experience in a private hospice setting. This sample represented the perspective of hospice from both genders. However, this sample did not represent the entire hospice social worker population; since ethnicity, age, and hospice setting were not diverse.

### *Summary of Findings*

Three broad themes were identified in this study. These themes included: family roles and functioning, collaboration among the interdisciplinary team, and the hospice social worker role. Under these three broad themes, seven themes were identified. These included: (1) observing and understanding family roles, (2) examining issues with out of state family members, (3) allowing the patient involvement in assessment, (4) degree of homeostasis in family members, (5) utilizing the interdisciplinary team, (6) confirming physicians have a lack of understanding in the area of hospice, and (7) the importance of a social work lens in hospice.

### Roles and Abilities of Family Members

A theme discovered through this study was the likelihood of the oldest daughter or son being in a leadership role of the family. This daughter or son would take on this leadership and organization role and if other siblings were present, they would follow the directions of the eldest sibling. This finding was reflected in the literature, however examined familial roles after death. Cait (2005) found that out of 18 women who experienced a parental or maternal death, 14 women shifted into a caregiver role and supported their surviving parent. Additionally, Cait found that the participants reported a heightened responsibility in the family.

An interesting finding that was not reflected in the literature is that roles of family members tend to “pop up” in an initial hospice assessment. Two out of six participants stated that family members assume divergent roles during a stressful time. It could be speculated that during a crisis, new roles and responsibilities emerge. The participants

emphasized however, that the hospice social worker must directly ask what roles family members hold as roles are often not discussed and just assumed.

#### Out of State Family Members

Another significant finding that emerged in the data was out of state family members coming into the environment with an agenda to treat the patient. Several participants stated that family members residing out of state may be unaware of the progression of the disease and have an image of the patient being well and healthy. This finding was supported by the current research. According to Waldrop and Rinfrette (2009), family conflict may arise due to little education with hospice. Family members that are out of state who are unaware that treatment is being withheld may expect a more aggressive form of treatment. This may spark conflict among family members, which could lead to resentment and feelings of guilt. This finding was heavily emphasized in by all six hospice social workers interviewed. Several participants reported out of state family members are often experiencing complicated grief issues and should work through those issues on an individual basis. The literature did not address this issue, however, stressed the importance of educating family members with an agenda of treatment with the hospice philosophy (Waldrop & Rinfrette). A speculation concerning this strong theme could be the increased mobility of family members due a variety of explanations such as moving away to attend college or to pursue a career. The mobility of family members may be considered a rising issue in area of hospice.

#### Patient Involvement in Assessment

Although two out of six participants identified this theme, the researcher determined its importance to this study. This theme suggests that the patient, to their best

ability, be involved in the hospice assessment. It could be speculated that the other participants did not understand the interview question. The interview question asked about assessing current roles of patients and families. Many of the participants only discussed the roles of family members and did not specify the role of the patient. This theme was briefly reflected in research conducted by Hobart (2001). Hobart emphasized the importance of patients to be involved with their own decisions about end of life. Moreover, social workers have specialized training and skills in empowerment, which should transfer to patients in hospice (Hobart). Depending on the patient's desire to be included, the hospice social worker should educate the hospice transition and more importantly, what to expect in hospice to both the patient and family members.

#### Degree of Homeostasis within Surviving Family Members

A theme that emanated from the participants was the impact of homeostasis or equilibrium in families. All participants reported that homeostasis was a goal that families desired to achieve; however, this was a challenging task. This theme was identified within the literature. Cait (2005) found that as grief evolved, family dynamics also shifted. Moreover, Cait found that family members experienced a period of destabilization following the death of the patient and to stabilize, family members acquired additional roles and responsibilities. Although all of the participants reported that homeostasis was a goal, participants differentiated in how families coped with destabilization. A striking metaphor of homeostasis in a distressed family was presented by one participant. This participant stated that homeostasis can be viewed as a children's mobile, which in when one piece is tilted, the other pieces are also tilted. The stabilization of the mobile is a long process and may take a long period of time. This is

also true of the family system during crisis. Each family member has an effect on one another and regaining a balance among all family members is a difficult process.

#### Assessing Grief among Family Members

Another theme that was found was how family members cope with grief and loss. In this study, the ability to cope was related to personality type. Three of out six participants identified that coping mechanisms are built into personality and individuals grieve in similar ways throughout the life cycle. This finding was not reflected in the research; however, Gray (1987) found that personality was related to depression. Gray found that passive personality traits among family members resulted in higher depression scores. Although this is not directly related to this theme, it is useful in studying how personality types lead to certain behaviors of coping. It also could be understood that as individuals experience grief and loss, their behaviors may change and shift in the future, however, immediate reactions and emotions are embedded in one's personality.

#### Communication among Hospice Professionals

Another key theme that emerged from the study was the importance of communication among the interdisciplinary team. All of the participants reported that voicemail messages and team meetings were essential for hospice to function. Since hospice professionals are meeting with patients and families individually, the use of phone calls and voicemail is inherently important for effective communication. This finding was congruent in the literature. Washington, Oliver, Demiris, Wittenberg, & Shaunfield (2011) found that communication among hospice staff was an important aspect of hospice care. Washington, et. al., however, did not express the importance of voicemail or team meetings. Washington et. al. also found that family members reported

that they would hear inconsistent messages from hospice staff. This finding contradicts current research. Participants in this study reported continuous communication about patient status to lessen the probability of miscommunication.

Waldrop and Rinfrette (2009) found that team meetings were dedicated to education on death and dying issues. In this study, participants reported that education on current research regarding grief and loss was provided in team meetings to enhance the ability of professionals to adopt new techniques to cope with death. Consistent with previous research, this study found participants were educated on different perspectives among team members and how medical, spiritual, and emotional components should be examined in a patient and family.

#### Physician Referral

All participants identified the involvement of the primary physician in the transition to hospice. The primary physician is the referral source to initiate hospice, however, it was reported by all participants that many primary physicians are not well-educated on hospice since it is a separate entity. Once the physician refers the patient to hospice, generally, a registered nurse and social worker educate on the hospice process. This finding was not reflected in the literature, however, Teno, Shu, Casarett, Spence, Rhodes & Connor, (2007) found that primary physicians tend to initiate a hospice referral late, which resulted in short stay in hospice. This was congruent with this study. One participant stated that physicians are often focused on treatment, which causes a late referral to hospice. This could contribute to the short duration that patients are on hospice. According to Teno et. al. 30% of patients are in hospice for seven days or less. Other participants stated that information on hospice could be shifting due to the aging

population. Technology and the use of the internet have impacted the ability to easily access information on hospice. There is no research to support this finding. Current research only explores the idea that patients obtain information on hospice through their primary physician.

### Hospice Social Worker Role

A significant theme that emerged from the study was hospice social work is an integral component of the interdisciplinary team. According to the participants, the role of the hospice social worker is to educate, provide resource referral, and emotional support. This was not congruent to previous literature. Billings and Kolton (1999) found that patients and families did not receive information about grief support groups or other supportive resources. Moreover, if information was presented, it was through a physician or registered nurse. In contrast, this study found most information pertaining to grief and loss issues is through the hospice social worker and nurse. Billing and Kolton (1999) found that no information on hospice was provided by hospice social workers. The discrepancies between the literature and current study could be due to differences in sampling population. While Billings and Kolton interviewed women and men, whose relative recently passed away in a hospice program, the current study examined the perspectives of hospice social workers. The inconsistent results could be due to differing perspectives of who is providing bereavement information. The current research found social workers are involved with the assessment process, which includes educating on the hospice philosophy and bereavement services.

## *Interpretation of Findings*

### Researcher Reactions

The researcher documented any reactions or emotions while conducting the interviews. First, the researcher was surprised to find that hospice social work primarily focuses on problem solving and crisis intervention rather than clinical therapy. Hospice requires a Master's degree in Social Work, signifying a need for a clinical lens on family dynamics, however, the social work role focuses on resource referral and education. Secondly, through the perspective of hospice social workers, the researcher was able to gain professional insight into hospice. The researcher has personal experience with hospice, which increases bias toward the hospice philosophy. Through the interviews with hospice social workers, the researcher gained valuable insight into how social workers utilize skills to meet the needs of each family member. Finally, the researcher was surprised to learn how essential family systems theory is in hospice. The field of social work has a foundation in family systems and it is a lens through which hospice social workers can effectively observe, label, and intervene in family dynamics. In essence, the social workers in hospice go further than resource referral; it involves listening and validating a family member's feelings surrounding death and loss.

### Limitations and Recommendations for Future Research

In future studies, a larger sample size would be desirable to gain different perspectives. To obtain a larger sample size, one may consider having participants that have interviewed give researcher information to other colleagues at the same setting. Moreover, additional time gathering participants could have resulted in a larger sample. This sample included three Caucasian males and three Caucasian females, whose ages

ranged from 53- 62. This sample does tend to be representative of hospice social workers. However, a more diverse sample would be valuable for future research. A diverse sample in age and ethnicity would increase the strength of this study. Strict qualifications for participants could increase the diversity of this study, such as only recruiting participants of a certain age or ethnicity. Due to the qualitative nature of this study, it cannot be generalized to all hospice social workers. In the future, it would be plausible to explore a quantitative study by generating a survey for hospice social workers to complete. Moreover, this study highlighted the perspective of hospice social workers. Future research could examine other perspectives, such as family members, other professionals on the hospice team, or physicians. Finally, the researcher did not have a coding partner to increase the reliability of the themes. Future research should include a coding partner to strengthen the findings.

#### Implications for Social Work

This study holds implications for social work practice, research, and training. As indicated through this study, research is limited in the area of hospice; signifying the need for increased research in this area. The themes of assessing grief among family members, the conflicts that arise from out of state family members and physician referral are further discussed as they are important considerations in the social work field. First, through the theme of assessing grief among family members, hospice social workers should be immediately assessing how patients and family members express grief. Since the length of stay in hospice is usually an estimated 7 days and the relationship between the social worker and family is time sensitive, the social work role must utilize skills in assessing the current situation as well as assessing patient and family member functioning. At

intake, a hospice social worker must examine the entire family unit and determine each member's process of grieving. During an intake, a hospice social worker can consider questions of, "*Have you experienced death in the past? If so, how did you cope with this death?*" Through this theme, hospice social workers need to consider, explore, and have a discussion during assessment on how personality type and past experiences with death impacts a family member's ability to express and cope with death.

Secondly, conflicts arising among out of state family members and family members living in the same area as the patient are important to consider for hospice social workers. This theme was identified by all participants, signifying a need for future research and discussion. Family members living out of state may have feelings of guilt and frustration, since they may have missed opportunities to spend time with the patient. To decrease the tension among out of state family members, the use of technology could be considered to continuously inform and update family members through hospice. The use of technology could be through the medium of the internet, such as Skype and other websites. Further, Skype could be used at assessment, where many decisions for care are being determined. The out of state family members could be educated on the hospice philosophy from a neutral third party, the hospice social worker. The hospice social worker could also address any concerns with out of state family members to ensure their understanding and to ease the transition into hospice for both the patient and family.

Lastly, increased training for primary physicians on the hospice philosophy is needed. The medical model and hospice model can conflict, as the medical model treats the patient for recovery, while the hospice model withholds medical interventions and provides comfort care. This research could encourage hospice training for current

medical students. Since hospice is considered a specialty in medicine, future education and trainings should be directed into the curriculum due to the increasing age of the population. Moreover, through education and training, social workers and other medical professionals can become comfortable with death and learn effective techniques to better serve patients at end of life.

The purpose of this study was to explore best practices of hospice social workers who work with families through issues of grief and loss. There are a number of strengths to mention regarding this study. The qualitative design of this study creative a descriptive picture of participant's feelings toward hospice. The interview structure can also be viewed as a strength in this study. Semi-structured interviewing style allowed flexibility, which gained a deeper understanding of the material. Finally, the participants in this study had years of valuable experience, which enriched the nature of the data. The participants were from several health systems, which also created diverse perspectives.

Major themes of this study include defining role and abilities of family members, examining the impact of out of state family members, the importance of assessing grief at assessment, the degree of homeostasis among family members, communication among the interdisciplinary team, physician referral and need for increased education, and importance of the hospice social work role. Several of these findings were supported in the literature; however, additional research needs to be conducted in this area.

Hospice is a supportive environment that provides physical, emotional, and spiritual support for the patient and family. The mission of hospice is symptom management and to increase quality of life in the patient. This study provides evidence for unique family dynamics and how family members cope with grief. The ability to

acknowledge and validate feelings can establish a sense of hope for the future in families. This study explored the best practices of hospice social workers currently assisting patients and families at end of life. Through this research, hospice social workers were able to voice their experiences and describe the hospice journey. Since limited research has been conducted on hospice in general, it is hoped the current study could spark future research in this area.

As the population ages, more research, education, and training is needed to increase an understanding of hospice. Future generations will be exposed to hospice with their aging parents and will encounter confusion, conflict, and crisis. It is hoped this study can bring forth further education and discussion among physicians, the hospice interdisciplinary team, patients and family members. With continued dedication and research in this area, individuals, including patients, family members, friends, and medical professionals can be accepting of death and promote the idea of dying with dignity and integrity.

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## Appendix A

### **The Impact of Hospice Social Workers on Family Functioning during Bereavement**

#### **RESEARCH INFORMATION AND CONSENT FORM**

##### **Introduction:**

You are invited to participate in a research study investigating the responses of hospice social workers to family members following the death a significant loved one. This study is being conducted by Bethany Butzow, graduate student at the School of Social Work, St. Catherine University/University of St. Thomas and is supervised by research chair, Michael Chavonec, Ph.D., LICSW. You were selected as a possible participant in this research because of your expertise in the area of hospice social work and bereavement. Please read this form and ask questions before you decide whether to participate in the study.

##### **Background Information:**

The purpose of this study is to gain an understanding of how hospice social worker's address and response to family members during grief and bereavement. The research aims to understand techniques used with families and strengths and limitations of bereavement support. Approximately 8-10 people are expected to participate in this research.

##### **Procedures:**

If you decide to participate, you will be asked to do the following things: participate in one audio taped interview that will last one hour. The interview will take place in the hospital where the interviewee is employed. Although the interview will take place in the hospital, a private room will be reserved for the interview process.

##### **Risks and Benefits:**

The study has minimal risks. First, the participant may feel that interview questions may be an invasion of privacy. Second, the researcher will probe for sensitive information through a direct interview. Following the interview, the interviewee will have the choice to have a brief debriefing session, in which the interviewee may ask questions and explain their feelings following the interview. There are no direct benefits to you for participating in this research.

##### **Confidentiality:**

Any information obtained in connection with this research study that could identify you will be kept confidential. In any written reports or publications, no one will be identified or identifiable and only group data will be presented. I will keep the research results in a password protected computer and in a locked file cabinet in my home and only I and my advisor will have access to the records while I work on this project. I will finish analyzing the data by June 1, 2012. I will then destroy all original reports and identifying information that can be linked back to you. The audio data will be destroyed immediately after the interview is transcribed. Transcribed data will be used for educational purposes and will be shredded and discarded by the researcher no later than June 1, 2012.

##### **Voluntary nature of the study:**

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with St. Catherine University in any way. During the interview, participants can refuse to answer any question if they choose. If you decide to participate, you are free to stop at any time without affecting these relationships, and no further data will be collected.

**Contacts and questions:**

If you have any questions, please feel free to contact me, Bethany Butzow. You may ask questions now, or if you have any additional questions later, my faculty advisor, Michael Chavonec. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you may also contact John Schmitt, PhD, Chair of the St. Catherine University Institutional Review Board.

You may keep a copy of this form for your records.

**Statement of Consent:**

You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study at any time and no further data will be collected.

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I consent to participate in the study. I consent to participate in the study and to have my participation audio taped.

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Signature of Participant

Date

---

Signature of Parent, Legal Guardian, or Witness  
(if applicable, otherwise delete this line)

Date

---

Signature of Researcher

Date

Appendix B

Flyer for Hospice Social Workers in Private Setting or Health System Setting

## **Recruiting Hospice Social Workers for a Research Study!!!**

**Support the growth of research on the role of hospice social workers and their impact on patients and families!**

I am interested in your input about how hospice social workers address and respond to family reactions during the death of a family member to gain insight into the different methods used to address death, its impact on family, and techniques used to understand the transformation of the family during the death process.

### **Criteria for Participants:**

**Licensed Social Worker**

**At least 1 year experience in a hospice setting**

**Currently working in a hospice setting, either private or health setting**

### **Time Commitment:**

**1 interview lasting 45-60 minutes**

Please contact Bethany Butzow, graduate student in the School of Social Work at the University of St. Thomas/St. Catherine University, at (612) 708-5963 within one week to further discuss the study. The researcher will make forth an effort to follow up if a response is not heard within a week.

**If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through St. Catherine University at  
(651) 690-7739**

Appendix C

Appendix C

### Interview Questions

Instructions to the respondent: Please review questions prior to the interview. In Section A: Demographic Information, please fill out or circle the appropriate response based on your experience prior to the interview. While reviewing the questions, feel free to write notes, thoughts, or reactions to questions, which will improve the richness of the discussion.

#### Section A: Demographic Information

1. What is your gender?  Male  Female
2. What is your age?
3. Are you a licensed social worker?  Yes  No
4. How many years of experience do you have in the social work field?
  - a) How many years do you have in a hospice setting?
5. In what setting do you have experience with hospice patients and their families?
  - a) Private Agency Setting
  - b) Health System
  - c) Other, if so, please explain, e.g. Palliative care program

#### Section B: Open ended Questions

6. According to Family Systems Theory, family members tend to organize and assign roles to certain members. How do you see the roles and functions of these family members in a hospice care setting?
  - a) Could you give an example of specific roles in a family that you have observed?

- b) Have you observed role changes within the family before and after the patient have passed away? If so, can you please explain.
  - c) Have you observed a family's ability to maintain or regain homeostasis, which is stabilizing the family's organization after a death?
7. As a hospice social worker, how do you go about assessing current roles of patients and their families?
- a) How do you see the emotions such as, grief and loss impacting the roles of family members during the transition into hospice?
8. There is limited research on a social worker's role in hospice. Can you explain how you perceive your role and why it is relevant in hospice?
9. Studies suggest that communication between the patient, family, and professionals is important for a smooth and positive experience in hospice.
- a) What are your thoughts about the strengths and weaknesses of communication between hospice care professionals?
10. Studies have consistently found that families often look first to the primary physician and hospice nurse for information on grief support groups or bereavement counseling.
- a) What are your thoughts or feelings about this issue?
  - b) How frequently have you observed that your role is not being utilized to its fullest potential? How does this affect you?
11. What are the strengths and limitations of the social worker's role in a hospice setting?
12. Is there anything else you would like to share that would be useful for this study?

