

5-2014

Social Work and Chaplain Perspectives in Offering Long Term Care Bereavement Support

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Recommended Citation

Tvedt, Laura S., "Social Work and Chaplain Perspectives in Offering Long Term Care Bereavement Support" (2014). *Master of Social Work Clinical Research Papers*. Paper 397.
http://sophia.stkate.edu/msw_papers/397

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Social Work and Chaplain Perspectives in Offering
Long Term Care Bereavement Support

By

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MSW Clinical Research Paper

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

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

Abstract

Currently, more than 1.4 million people are considered long term care residents in the United States and one in five deaths happen in long term care facilities (Nursing Home Statistics, 2013). The purpose of this study will be to understand the types of grief and loss experienced by family members, as well as gain awareness of bereavement support systems in long term care facilities, what the support systems entail and what, if any, the barriers are to providing support. The research design was qualitative research with interviews. This design was chosen due to the exploratory nature of the research question. The researcher interviewed eight subjects; five social workers and three chaplains. The interview was a semi-structured format, guided by a set of questions. The researcher used a grounded theory-based approach to analyze the transcripts of the discussions. The qualitative interviews reflect the lack of bereavement services provided to families whose loved one has passed away in a long term care facility. Respondents feel there is a greater need for these services. They also feel there isn't sufficient time to invest in the support services and that they lack funding. There are many common needs during bereavement. While some experience different types of grief, they all need some form of support to cope with their loss. Long term care facilities should have a relationship with bereaved individuals when their loved one dies. Data suggests there is a need for bereavement services that offer different types of supports in long term care settings but there are barriers that influence program development and accessibility.

Acknowledgements

I thank God for the strength, endurance and blessing to accomplish this research paper.

I thank Jessica Toft, Ph.D., LISW (Chair) for being my personal cheer leader. It was your enthusiasm and encouragement that propelled my paper to completion. I thank Heather Kittok and Amanda Thooft (Committee Members) for taking precious time to read my drafts, offer suggestions and invest in me personally. I am forever in your debt.

To my classmates, AS1, I will miss you forever. We were partners in crime, had inside jokes during class which made the long hours tolerable, and were a constant support during our struggles and victories.

I thank my Mom, Karen Anderson, for talking to me late at night to ensure I didn't fall asleep on the way home from school. Thank you for being supportive and listening when I struggled. I want to thank my other "mom", Faye Carroll, for stepping in and filling the gap when I needed childcare or when the kids needed a ride. You both took pressure off of Joel and I. We love you!

To my sweet, precious children-Jaden, Gabriel, Ashlyn, Zachary and Ava... you jumped up and down when I was accepted into grad school, you cheered when I had break, you waited up to get a good-night kiss, you cooked and cleaned and supported me with every hug. It was difficult being away from you and I look forward to not ever missing another concert or program. I look forward to your homework time because it won't be mine! And, I look forward to just being with you and just concentrating on you. You are amazing and I love you all more than words can say!

Finally, I dedicate this paper to my one and only true love, Joel Tvedt. You have been my pillar of strength, my constant support and advocate for homework time. You stepped up to the plate and we were a team with the common goal of winning. We've won. Game over!

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Introduction

The elderly population is growing each day with the gradual retirement of the baby boomer generation. It is estimated that by 2026, the population of Americans ages 65 and older will double to 71.5 million (Bercovitz, 2008). By 2020, 12 million older Americans will need long-term health care (Nursing Home Statistics, 2013). Currently, more than 1.4 million people are considered long term care residents in the United States and one in five deaths happen in long term care facilities (Nursing Home Statistics, 2013).

Many families struggle to understand their grief after the death of a loved one and would benefit from bereavement support. While grief is a natural response to loss, it is different for everyone. It is relationally specific and can last various amounts of time. Sometimes families start their bereavement process as soon as a diagnosis is given or when their loved one enters a long term care facility; they also face grief before and after their loved one passes away (Buglass, 2010). Smith and Segal (2013) describe grief as being the emotional suffering which is felt when someone you love has been taken away.

Even though grief is a normal process, family members may still be struggling with grief and loss many months after their loved one has passed away. Some of the common symptoms of grief include shock and disbelief, sadness, guilt, anger, fear and physical symptoms (Smith & Segal, 2013). Family members may have difficulty with memories of their loved one being in extreme pain, or of the difficult physical status preceding the death. It is not uncommon to experience depression, grief and anger during bereavement (Holtslander & McMillan, 2011).

Mental and physical stressors impact family members before and after the death of loved ones and quite often they become depressed (Boerner & Schulz, 2004). Family members spend time in the care facility while trying to provide sufficient support and care for a dying family member. While this is considered invaluable to other family members, many will be hit with intense and difficult emotions during the bereavement process (Holtslander & McMillan, 2011). Depression and psychological distress, according to Chentsova-Dutton et al. (2002), may cease in intensity after the first year of bereavement. The psychological stressors peak shortly before and shortly after the death of a family member. Depression can be experienced by each family member; it is not limited by a particular relationship (Chentsova-Dutton et al. (2002).

The purpose of this study will be to understand the types of grief and loss experienced by family members, as well as gain awareness of bereavement support systems in long term care facilities, what the support systems entail and what, if any, the barriers are to providing support.

Literature Review

The Centers for Disease Control and Protection (2013) report there are 16,100 nursing homes in the United States. The total number of licensed beds for occupancy is 1.7 million with an average occupancy of 86% with a typical length of stay being 835 days. The Centers for Disease Control and Protection (2013) report the average age of a nursing resident is 76 years of age. In order to understand the ways in which long term care facilities approach support for this many families after a death of a loved one, we must understand the nature of grief.

Definition of Grief

Grief is a very normal process for families whose member has died. In fact, family members may still be struggling with grief and loss many months after their loved one has passed away. Family members may have difficulty with memories of their loved one being in extreme pain or of the great loss of physical status preceding the death. Depression, grief and even anger are common and may be strong, especially amongst bereaved caregivers (Holtslander & McMillan, 2011).

The definitions of grief and bereavement may be hard to differentiate. Grief is a natural response to loss. It is defined as emotional suffering felt when someone you love is taken away; the more significant the loss, the more powerful the grief will be (Smith & Segal, 2013). Bereavement is defined as a loss of someone with great meaning, and grief is a response to bereavement (Stroebe, Hansson, Stroebe & Schut, 2001). Bereavement is the natural period of mourning. Time spent in bereavement or the level of anguish suffered while grieving, varies from person to person (Smith & Segal, 2013).

Stroebe et al. (2001) define the terms more intricately as:

Bereavement, the objective situation of having lost someone significant, is an event that typically occurs with increasing frequency across the life span, with people having to face the death of parents, siblings, partners, friends, or even their own children. The intense distress associated with bereavement is termed *grief*. This is defined as a primarily emotional (affective) reaction to the loss of a loved one through death. (p. 1)

Patterns of Grief

In a study done by Chentsova-Dutton (2002), there seemed to be a natural pattern to the grief process. Findings reported the intensity of grief was the highest at two

months and the lowest at one year post-death. This study revealed that persons grieving experienced the need to cry, had persons or things remind them of their loved one and believed that no one could take the place of their loved one. These feelings diminished significantly by 13 months post-death. Finally, this study revealed spouses and adult children had the same likelihood of experiencing anxiety, stress, grief and depression (Chentsova-Dutton et al, 2002).

Grief and Role of Family Members

Grief may be experienced in a particular way based on the person's role within the family and relationship to the person who has died.

When loved ones are in a long term care facility, family members are often the overseers of physical care. Being involved in their care involves many things. Quite often, family members are designated as a health care power of attorney or a financial power of attorney (Keefe & Fancey, 2000). Not only is there stress handling the daily details of finances and health decisions, family members are asked to come into long term care facilities for meetings regarding their loved one. This adds to the unspoken expectation of needing to visit as often as possible to let your loved one know they haven't been forgotten. Keefe and Fancey (2000) report 45% of adult children visit their parent(s) at least once a week.

Providing personal comforts and care differ from physical care. Keefe and Fancey (2000) explain personal comforts as doing extra special things. This could include ideas such as, buying treats such as, cookies and candies, providing personal items such as, lotions and flowers and bringing home-cooked meals. Families do these special things in order to enhance their loved one's quality of life (Keefe & Fancey, 2000).

Grief and Depression

Family members of loved ones often are subjected to incredible stressors before and after the death of their loved one. Mental and physical stressors surround the family member and quite often they become depressed (Boerner & Schulz, 2004). Being the supportive family member adds to the stress of being able to provide sufficient time needed to attend to loved ones needs in facilities. Many family members will be hit with intense and difficult emotions during the bereavement process (Holtslander & McMillan, 2011).

When the responsibility of caregiving ends, usually it is because the loved one has passed away. This adds to an already highly stressful situation since the family's responsibilities now include funeral arrangements and legal paperwork. (Chentsova-Dutton et al, 2002). A common outcome of bereavement is depression (Boerner, Schulz & Horowitz, 2004). Holtslander and McMillan (2011) interviewed family members three months into bereavement and found that a considerable amount of them had depressive symptoms. Kissane (1994) reported that one-fourth of adult children and one-third of spouses of a deceased love one experienced psychological distress while adjusting to bereavement. One-fourth of bereaved family members met the criteria for Major Depressive Episodes during their first three years of bereavement (Chentsova-Dutton et al, 2002).

Chentsova-Dutton et al. (2002) reported depression and psychological distress may cease in intensity after the first year of bereavement. The psychological stressors peak shortly before and shortly after the death of a family member. Depression can be experienced by each family member; it is not limited by relationship.

Forms of Grief

Forms of grief vary in type and by person. These include: anticipatory grief, complicated grief, delayed grief and the absence of grief. Some of the common symptoms of grief include shock and disbelief, sadness, guilt, anger, fear and physical symptoms. Working through these phases, although in no certain order, will hopefully lead to acceptance (Smith & Segal, 2013).

Anticipatory Grief. Family members can enter into an anticipatory grief process. They anticipate the death of their loved one if they are ill and need coping strategies to help navigate successfully through the process. Lewis and McBride (2004) report “anticipatory grief is as important as the grieving that takes place after the death of a loved one, but family members are unable to take on the roles involved in bereavement because the loved one is still alive” (p. 45). It is important for family members to find a balance with their responsibilities and their personal emotional and physical health. It is essential to take time for self-care (Simon, 2008).

The symptoms of anticipatory grief can be emotionally and physically draining. Simon (2008) reports symptoms can include appetite changes, nausea, fatigue, sleep changes and headaches. Emotional symptoms include anger, guilt, a feeling of being overwhelmed, sadness, fear, denial and anxiety. Simon (2008) also reported spiritual beliefs may change. They could become helpful in processing grief or they could hinder the healing process by the anger evoked (Simon, 2008). With all the emotions during anticipatory grief, family members may take advantage of the opportunity to say their “good-byes” (Lewis & McBride, 2004).

Coping with anticipatory grief is possible. Simon (2008) suggested family members take time to cry and talk with others. Also, it's helpful to say a proper "good-bye" and express the unspoken to resolve any family issues. Having friends, family and clergy nearby could provide pivotal emotional support (Simon, 2008).

Complicated Grief. Another form of grief is complicated or chronic grief. It differs from normal grief. Hawton (2007) reported it to look like a chronic state of mourning. This person may be seen in a stuck mourning period with continuous persistent and disruptive pining over their loved one. Those with complicated grief have a difficult time accepting the death. Sometimes there is a bitterness related to the death (Hawton, 2007).

Complicated grief is only experienced by a minority of people. A study done by Bonanno et al. (2002) report testing "205 bereaved spouses who were tested prior to the death of their spouse, then at six- and 18-months post-loss, this demonstrated that nearly 16% of their sample showed a pattern of chronic grief" (p. 40). The complicated grief is characterized by elevated levels of depression and grief at six and 18 months post-loss (Bonanno et al., 2002).

Delayed Grief and Improved Functioning. Delayed grief is grief that has been postponed Middleton Et al. (1993). For example, someone might delay grief of their parent if they are heavily involved with the surviving parent's needs. Some people believe delayed grief will eventually turn into depression (Bonanno et al, 2002). A study done by Middleton Et al. (1993) reported 76% of bereavement researchers and clinicians believe delayed grief was an authentic phenomenon. Experiencing delayed grief can lead to improved function if the stress of the situation has come to a conclusion. For

example, if a family member spends much of their time and energy at a care facility with their dying loved one, there may be relief when the suffering ends and they aren't committed to being at the facility anymore. This leads to the thought that persons may actually have a decrease in depression if they are relieved their loved one is gone (Bonanno et al, 2002).

Absence of Grief. Absence of grief is defined as having no signs of grief in the bereaved person after a major loss; it is as if the death did not happen (Bonanno & Kaltman, 2001). Although uncommon, people have had an absence of grief. While typically maladaptive, a study by (Bonanno et al, 2002) reported bereavement theorists' encouraged direct treatment for emotional pain and loss. However, bereaved individuals may not exhibit signs of distress or depression implying their resilience was a product of their own mental resources (Bonanno & Kaltman, 2001).

Needs of the Grieving

Death was an expected daily event in the early 20th century. Many communities and families had set rituals in their schedules for the anticipated daily deaths of friends, neighbors and loved ones (Thompson & Oliver, 2008). The poor house accommodated some of the geriatric population. Eventually, those establishments evolved into nursing homes without clear policy (Thompson & Oliver, 2008). Since there were limited resources to help the aging, poor and disabled, abuse and neglect fell rampant on certain facilities (Thompson & Oliver, 2008). The federal government recognized this problem by implementing the 1987 Omnibus Reconciliation Act (OBRA). OBRA mandates that all nursing homes promote the psychological and physical functioning of residents. By maintaining this standard, resident care has improved outcomes for residents.

Contemporary cultural norms do not accept death as a part of life (Hottensen, 2013). Any death can be traumatic and there are few resources to help bereaved individuals cope (Berzoff & Silverman, 2004). According to the National Institute of Mental Health, 6.7% of adults experience a major depressive disorder. They report that women are 70% higher to experience depression verses a male (National Institute of Mental Health). Individuals at high risk for grief may benefit by early and prompt interventions which may minimize consequences of grief (Cooley, 1992). Unfortunately, families with loved ones in long-term care facilities will most likely be offered little to no support during their bereavement period (Snyder, Ellison, & Neidig, 2002). Families may be unprepared for change and may not know where to turn for help (Snyder, Ellison, & Neidig, 2002).

Karolyn Anderson represents a rural community grief support group. She is quoted by identifying two common needs of the grieving: permission to grieve and to be understood. These are common needs that grieving families or individuals collectively share with one another. The following quotes are from Ms. Anderson on July 21, 2013:

“Permission to grieve is probably the number one need of the grieving. We do such a poor job of even talking about grief. I recently read a survey of 1500 people asking them how long they thought the grief and loss process was supposed to last and the common response was two weeks. Um, well in fact grief and loss is a lifetime process. The second common need is the need to be understood. Um, the need to talk and express what they want to express without feeling judged.

Bereavement Interventions and Coping Resources

Bereavement support for coping can look different from one agency to the next. For example, Foliart, Clausen and Siljstrom (2001) suggested periodic telephone calls, educational brochures, and cards for the anniversary of the death, home visits, grief workshops, support groups and individual counseling sessions. Not all agencies offer comprehensive bereavement support services. If they do, most agencies do not charge an extra fee for the services (Foliart, Clausen & Siljstrom, 2001).

Bereavement interventions play a significant role for families. Vacha-Hasse (2013) report family members need help resolving their grief to help diminish the chances of experiencing negative health responses and complicated grief. Addressing the needs of grieving family members is important in the healing process after the death of their beloved family member (Thirsk & Moules, 2012). There are a variety of ways that this grief could be addressed.

Chaplain and spiritual care. Families and residents benefit from their chaplain's honest informational support and accommodation to behaviors and rituals surrounding bereavement. "The essence of the chaplain's role is to be fully present in relation to the emotional and spiritual realities of life's crises and passages" (Hodgson, Segal, Weidinger & Linde, 2004, p. 50). The chaplain is in a unique position to offer a listening ear without judgment. The chaplain is able to reflect gently and with reverence. This could be the start to openness and the start of healthy grieving. Having a chaplain involved, this offers "the relief of being completely heard, understood and honored" (Hodgson, Segal, Weidinger & Linde, 2004, p. 50).

Support groups. Coping with loss and the adjustment that comes after the loved one's death can be aided by a beneficial support group (Mather, Good, Cavenagh, & Ravenscroft, 2008). The groups can vary in structure, demographics and purpose. For example, grief and loss groups facilitated at a religious institution may look different than grief and loss groups facilitated at the local community mental health center. Bonanno and colleagues (2002) stipulate that it isn't the type of group that is the predictor of success but rather the type of group that works best for the individual bereaved.

Family and Individual Focused Grief Therapy. A study done by Kissane, Lichtenthal, and Zaider (2007) utilized the Family Focused Grief Therapy (FFGT) Model which classifies family members according to their relational functioning. This model nurtures resiliency by using family-centered care or keeping the family members and their needs a priority. Resilience is defined as "a dynamic process encompassing positive adaptation within the context of significant adversity" (Luthar, Cicchetti, & Becker, 2000). By offering preventative FFGT during palliative care and continuing into bereavement for families at risk of a morbid outcome, this study reported potential success in ameliorating the suffering associated with various forms of pathological grief (Kissane, Lichtenthal & Zaider, 2007).

Coping Resources. There are several simple coping strategies facilities can implement during the bereavement process. A study done by Agnew et al. (2011) reported effective support interventions such as, an anniversary card, follow-up contact, bereavement booklet and a condolence letter. Other timely interventions suggested were memorial events and various styles of support groups (Agnew et al. (2011).

Cultural Considerations. Social workers and/or chaplains need to be sensitive to cultural practices surrounding death while meeting the needs of the survivors (Fauri, Ettner & Kovacs, 2000). There may be ceremonial rites and rituals, behavioral manifestations, throwing of flowers or lowering of flags and organ donation. Research surrounding death and culture has been limited in Western societies. Because of these limitations, hands-on social workers or chaplains need to embrace cultural diversity and become educated (Hawton, 2007).

Recommended Aspects of Bereavement Programs

The National Hospice and Palliative Care Organization (NHPCO) published a draft of standards which define practices for bereavement programs. The NHPCO suggested programs last for 13 months (Foliant, Clausen & Siljeström, 2001). A study done by Hultman, Reder and Dahlin (2008) also suggested the bereavement care plan be implemented for at least 13 months. The study also suggested that the care plan reflect individual needs by conducting a bereavement risk assessment shortly before or after the death of a loved one (Hultman, Reder & Dahlin, 2008).

Availability of Bereavement Groups at Long Term Care Facilities

While many agencies offer bereavement support services, there is a clear lack of services offered through long term care (LTC) facilities (Vacha-Haase, 2013). A study done by Murphy, Hanrahan, and Luchins (1997), reported there are limited grief and bereavement services for families of residents in long term care settings. This same study reported on a telephone survey of 121 nursing homes. Ninety percent of long term care facilities revealed they did not provide bereavement related services or referrals for counseling after the death of a resident (Fauri, Ettner & Kovacs, 2000). In a search in

SocIndex of the terms, “bereavement”, “services”, and “long-term care”, only 15 studies were evident. In a second search of “bereavement”, “services”, and “hospice”, 145 studies were found. There are no state or federal standards guiding the type of services provided, thus allowing agencies to provide minimal support (Foliart, Clausen & Siljeström, 2001). This also means that when there is support, there is often variability in the types of services offered (Demmer, 2003).

Current Barriers of Bereavement Support Programs in Long Term Care Facilities

There are several barriers affecting support programs in long term care facilities. Family members may look to the long term care facility as a support system for the family during the bereavement period. A study done by Demmer (2003) reported the top three obstacles in the delivery of bereavement services as lack of time, funding pressures and lack of staff. Other obstacles reported were lack of interest, lack of organizational support and staff or volunteer burnout (Demmer, 2003).

Participants of support groups find it difficult to hear and support others in their own grief. Steiner (2005) reported bereaved individuals find it hard to listen to others' stories. Also, these individuals may not be ready for a group-type setting or may feel friends and family won't act as caring if attending a support group (Steiner, 2005).

A study done Steiner (2005) reported:

Closed grief support groups experience overall low attendance given the number of offerings and extensive publicity. Attendance varies considerably according to age of participants, group location, homogeneity of the community, and relationship of bereaved with the agency providing the group. The results of

this study indicated there are significant numbers of bereaved who view attending a support group as a sign of weakness. (p. 41)

Research Question

Long term care facilities should have a relationship with bereaved individuals when their loved one dies. There are many common needs during bereavement. While some experience different types of grief, they all need some form of support to cope with their loss. Therefore the research question is: Is there a need for bereavement services that offer different types of supports in long term care settings and what are the barriers that influence program development and accessibility?

Conceptual Framework

The conceptual frameworks identified for this research project are Dual Process Model and Ecological Systems Theory. Both theories relate to bereavement services offered in long term care settings.

Dual Process Model

The dual process model of coping with bereavement signifies the intricacy of emotions, loss and restoration processes (Buglass, 2010). In this model, the bereaved is described as an individual who needs to cope with the occurrence of death. They also will experience lifestyle changes that result from it due to coping with both loss and restoration-oriented factors (Buglass, 2010). Families of long term care residents have to create a new normalcy through the bereavement processes. Bereavement support systems in facilities may start the process of both grieving and restoration (Stroebe & Schut, 1999).

There are four parts to the dual process model to be aware of. The first is that feelings and activities following bereavement can be divided into loss and restoration (Stroebe & Schut, 1999). The second is that both of these activities are important for recovering from bereavement (Stroebe & Schut, 1999). The third part is that it is normal to move back forth between loss and restoration (Stroebe & Schut, 1999). For example, one might be establishing new roles or relationships while breaking bonds and ties of the deceased (Buglass, 2010). The final part includes activities surrounding grief work such as denial or avoidance of restoration activities. Restoration activities could include doing new things, changing roles and acknowledging a new identity (Stroebe & Schut, 1999).

Ecological Systems Theory

The ecological systems theory provides a viewpoint in understanding human behavior in the social environment (Forte, 2007). Bronfenbrenner's (1979) theory of ecological systems asserts that individuals are impacted by family and external factors. Within the ecological system, the micro level includes the ways that individual families cope with bereavement. For example, some families may cope by going to therapy or others may cope using their support systems which are close to them. In this micro system setting, the direct environment includes family, friends, classmates, teachers, neighbors and other people who have a direct contact (Bronfenbrenner, 1979). His theory states that we are not just ordinary beneficiaries, but we contribute to the experiences we have when interacting with people in the micro system environment (Bronfenbrenner, 1979).

The mezzo system definition per Bronfenbrenner (1979) identifies those relationships within a community that address how bereavement support is addressed.

This could include church support groups, community support groups, county public health agency support groups and bereavement support in long term care facilities.

Within the long term care setting, bereavement services and groups offer ways to address grief and loss.

The macro level of Brofenbrenner (1979) includes things such as government policies and the relative freedoms permitted government, cultural values, the economy, etc. Looking at the macro system and identifying how bereavement support is facilitated, mandated and funded within a specific long term care setting or state helps administrators and facilitators understand the possible barriers to providing services. Possible opposition in offering bereavement support in long term care settings could come from ideas such as lack of funding, undesignated employee hours and lack of training.

Methods

Research Design

The research design was qualitative research with interviews. This design was chosen due to the exploratory nature of the research question.

Sample

Social workers, with BSW and MSW level licensure, along with facility chaplains employed in a number of sister facilities in central Minnesota have been interviewed for this qualitative research project in long term care facilities. This is a convenience sample of social workers and chaplains employed by a non-profit corporation which owns and operates 12 nursing homes in the state of Minnesota. The researcher aimed to recruit 15 social workers and chaplains. When data collection ended, eight participants were interviewed.

Protection of Human Subjects

Recruitment Process. The researcher gained consent from the corporation's Executive Director to email and interview employees (See Appendix A). The researcher is currently employed by this organization and had access to the email addresses of all employees of the corporation. The researcher does not work in the same facility, supervise or have power over any of the potential interviewees. Prior to interviewing, potential respondents were contacted via email (See Appendix B) asking if they would be interested in being a part of a research study which considered the perspectives of social workers and chaplains regarding having bereavement groups offered in long term care facilities. They were informed that their employer would not who had participated in the research and what the responses were. If interested, the researcher asked the participant to call to set up an interview time. This ensured the interviews were completely voluntary. Once the respondent had made contact with the researcher and agreed to an interview, a second email was sent with the Consent Form (See Appendix C) and Interview Questions (see Appendix D) attached. Next, the researcher and respondent met in a confidential office at their place of employment. While the confidentiality of the meeting could not be guaranteed at their site of employment, the confidentiality of content could be guaranteed. Before the interview took place, the researcher thanked the interviewee for participating in this study by giving a \$10 Target gift card. Next, the consent was reviewed with the respondent (see Appendix C). They were informed that the interview would last approximately 30-45 minutes and would be transcribed by this researcher. They were assured of confidentiality and the only person with access to the transcript would be the researcher. Any identifying information was changed so as to

protect the identity of the respondent. Also, they were informed that the findings would be disseminated in a written research paper and through an oral presentation at the end of May, 2014. The informed consent form was developed from a template approved by the University of Saint Thomas Institutional Review Board (IRB) for expedited level review with the final version being approved by the IRB.

Data Collection Instrument and Process

The interview was a semi-structured format, guided by a set of questions that was preapproved by the IRB (see Appendix D for interview guide). The questions were developed in an open ended fashion so as to encourage honest feedback, unhindered by the interviewer.

The questions were developed as a result of questions that arose from the literature and addressed various aspects of social work bereavement practice in long term care settings. Furthermore, the questions were approved by committee members who have experience working with older adults in long term care settings. The questions began generally, investigating the role of the social worker or chaplain. Next, questions were asked identifying bereavement follow-up care provided to residents and families. Also, questions were asked to help identify reasons bereavement follow-up care was not provided and if so, what were the barriers. Next, if bereavement services were in place, this researcher asked about the types of services and interventions that were offered and what had been found as the most effective practice. Finally, questions were asked exploring the measurement of success in interventions and the strengths and weaknesses of the bereavement care program.

Although the questions were used as a guide to the semi-structured interview, the respondent addressed any of the questions in natural discourse. After the interview was completed, the researcher transcribed the interview verbatim (see Appendix D).

Data Analysis

After completing the interview, the interview transcript was analyzed after it was typed by the researcher. The researcher used a grounded theory-based approach to analyze the transcripts of the discussions. The first analysis of the transcripts employed open coding which result in descriptive codes that remain very close to the exact meaning of the text. The second analysis of the transcripts resulted in a more clarified and consistent use of codes. The final reading of the transcripts revealed more interpretive patterns and frequencies of codes. The recurring codes were grouped into themes, which required three or more instances of common coding, and the results are disseminated in the findings section of the research paper (Berg, 2009).

Findings

This qualitative study sought to understand the types of grief and loss experienced by family members, as well as gain awareness of bereavement support systems in long term care facilities. This study also explores what the support systems entail and what, if any, are the barriers to providing support. In order to gain this knowledge, five social workers and three chaplains agreed to be interviewed. Of the eight facilities interviewed, they had a total of 353 deaths last year. This averages out to 44 deaths per facility. Clearly, bereavement of family members is a common issue that professionals witness.

Responsibility for Contact

Facilities differ on who initiates contact during or after a resident's dying. Four of the facilities had nursing initiate contact, three had chaplains and one reports "anyone" can call the family. This is described by the following:

"In most cases nursing will contact family. Our nursing staff, usually the RN Clinical Coordinator, has the most up-to-date/timely information about a resident's condition and if they see a rapid decline, will call the family in."

"Our facility really tries to be as supportive as possible during the final hours. It's reasonable, though, that sometimes we can't gauge when a passing is likely to occur. So I'd say in most events of passing, it is our chaplain who initiates contact. He keeps a detailed record of visits and really tends to be able to develop a relationship with most families."

It is interesting that facilities have different criteria for who initiates contact. Nursing is always available and involved with the resident and family, however, chaplains have a bond with families, as well. It is important for families to hear and see the sympathy of the staff involved in their loved one's care.

Grief Support Needs

Respondents were asked to identify the top three needs of a person after their loved one dies. Having *emotional support* and *tools for coping* were the most common, with *hope* and *permission to grieve* being the next most common.

Emotional support. Emotional support was required for those loved ones who were closest to the deceased. A couple respondents said:

"Emotional support helps them through the thoughts of who do we call now, what is next....if they have never gone through the steps. In the longer term....having some

kind of support network. Who that comes from? Family or friends or whoever to have that ongoing support. If people don't have that, they just struggle more with their grief."

"When families are hurting so much, sometimes they just need someone to sit with them. And not necessarily say anything. Having a physical presence is sometimes what their spirit needs, not words. And it's okay to ask families what would help them the most. Sometimes we just don't know them well enough. Some like to talk or pray or sing. But being that solid emotional support is vital."

Respondents identified the importance of emotional support. Though it may look different to some, it is still important. Asking families what they need if it's not evident is an effective way to start supporting them. They will struggle in their grief if they do not have an emotional support system in place.

Tools for coping. Coping skills are important for families as they navigate their new-found grief. Family members rely on whatever coping skill is the most effective at the time of need. Copings skills vary from person to person. A couple respondents said:

"When family members experience loss, they turn to their coping skills for survival. What that looks like, I'm not always sure. Quite often it's how we're brought up. How have our parents raised us? How has the community responded in times of loss and grief? Tools can look different for many."

"Coping skills are the very essence to our survival. If you think about the early days 1800's or even the early 1900's, death was everywhere. There were plagues and sickness and poor medical treatment with a lack of pharmaceuticals. I think families dealt

with grief way more often than we do nowadays. Families cope in various ways. I think innately they cope with what's effective for their soul."

The coping skills people use do not necessarily fit into box. They are different for everyone. Maybe their inner spirit works to identify how to survive their loss like their ancestors before them.

Hope. Having hope was also identified as a need for those loved ones who were closest to the deceased. Hope is sometimes the only thing they have to cling to in their greatest hour of need. The definition hope varies from person to person. A couple respondents said:

"Companionship, someone who is supportive. Another need is a sense of hope; hope for the future. Hope that their loved one can find peace in the afterlife. Families who are religious take great comfort in their faith but even those without faith have some kind of framework that they hope that their loved one is at peace. Some of them say they don't exist anymore. Some way to understand that their mind that things are okay. So I think that need for hope is important. What I see the most is telling people try not to fight the grieving process. It is normal. Sometimes they are mad at God or at their mom for dying. I just want to help them understand that is normal to have those feelings and that sometimes our body uses laughter at weird times to process grief."

"I have noticed that families who have hope, do better than some. It's not necessarily religious hope but spiritual hope. There is a difference. Holding on to a belief for an afterlife makes the grieving process a little more bearable. We have songs of hope,

poems of hope and bible scriptures with hope that we read with family. It's a soothing time for them as they come to grips with their loss."

Hope has been identified as being a soothing force for those who grieve. It is something family members can cling to in their loss. Hope can be quiet with reflection or loud with laughter; it is a belief that enables loss to not be forever.

Permission to grieve. Having permission to grieve is the final need identified for those loved ones who were closest to the deceased. Grief needs to be normalized. Society has done a great job with putting a number on how many days someone is allowed to grieve. Even places of employment are very specific on who is able to utilize bereavement days off. A couple respondents said:

"Permission to grieve. Umm, is probably number one. We do such a poor job of even talking about grief. I recently read a survey of 1500 people asking them how long they thought the grief and loss process was supposed to last and the common response was two weeks. Well in fact grief and loss is a lifetime process. It's those first few years that are typically the hardest. The first year is about the first of everything. It's the first Christmas, the first birthday, the first anniversary, the first anniversary of the death. The second year tends to be the loneliest because everyone else has moved on with their lives and they are no longer recognizing the loss of the first year."

"People can be stoic when it comes to grief. It would be interesting to know if that was how they grew up. People need to know it's okay to grieve. It's a long process and if they give themselves permission, then hopefully they can come out on the other end okay."

Not having permission adds to the already bottled up emotions. They can only stay bottled up for some time before they explode. It could come to a devastatingly end.”

Allowing family members to say “Good-bye” to loved one encourages permission to grieve. Honoring them with memories and a service can be a tool used for coping. Encouraging their spiritual outlet will leave them with a feeling of hope.

Bereavement Follow-up

Present in job description. Chaplains and social workers were asked to look through their job description to see if it included bereavement follow-up care. All five of the social workers interviewed did not have bereavement follow-up listed in their job description; each of the three chaplains did. Two of the social workers responded with:

“I honestly didn’t know if it was listed. I looked it up and there wasn’t anything mentioned specifically using that kind of terminology.....support for residents but not specifically bereavement.”

“It’s not listed explicitly in my job description. It could be implied, for example the purpose of the social work position states: ‘The purpose of this position is to identify the social, emotional and psychological strengths and needs of the residents and develop a plan of care to meet their needs....’ It’s briefly touched on.”

Staff may be uncertain of what their responsibility is in bereavement follow-up if it is not in their job description. Chaplains believe it is naturally part of their job description and other staff may step back if they feel it is the chaplain’s role.

Services offered. When respondents were asked if bereavement services should be offered in long term care facilities, seven of the eight interviewed agreed it should.

The only respondent who reported “no” said:

“No. I feel that we provide support leading up to the loved one passing. Once they pass, the social worker could make recommendations to have them contact someone from a church, support group or therapist for the additional support needed.”

Respondents in favor of providing services said:

“I think services should be offered to families and staff. A lot of times staff gets very close to someone who lives in a facility long-term. Our facility also is a Christian organization, and I think our mission would naturally include spiritual and emotional support to grieving families.”

“I think it’s an important part of grief follow-up. It would help families touch base with others as a check-in type. People may be more reclusive and not utilize the support if it’s offered but I feel that most, if not all, of the folks who would take advantage of the support would come out healthier, emotionally, in the end.”

When most of the respondents believed in the bereavement supportive services, it is interesting that only one felt the relationship should be terminated immediately after the death. Could it be that singled out respondent has never experienced personal grief?

Training and resources. Having enough training, money and time during the day to meet the needs of residents and their families is difficult. Respondents were asked if their job duties allowed them enough time to spend with families. Of the eight interviewed, four social workers said, “no,” one social worker said, “yes” and all three chaplains said, “yes”. Having money budgeted for bereavement support services is important. All five social workers report they do not have money in their budget for services, yet, all three chaplains agree they have money budgeted to provide support services.

Five of the eight respondents reported that there isn't staff training to support grieving family members. The other three reported there were periodic in-services. The following quotes help support this data. One social worker said,

“There isn't formal training. Some of the nurses have a good sense and they have experience and training along the way on grief counseling. They at least can help them step through the process and would be able to tell if someone is looking like they aren't handling it well that they would come to me or the social worker and we could get them some extra help.”

Another respondent stated:

“I'm not aware of any formal training for staff members in teaching them how to deal with grieving families. It's more either you have that skill or you don't. A lot of the staff, frontline staff, they've gotten to know the resident and the family so well that it becomes a network. They become close and it changes from staff and client to friend and friend, so to speak. So some are amazing at doing that and some people it scares them so it's easier to avoid talking about it and they don't know what to say. Some of the people go with their gut feeling and usually their gut feeling is spot-on. It's those people who have typically been in long term care for a long time. They just figure out that part. It would be nice if there was more training in that respect.”

Clearly there is a lack of formal training but not a lack of desire to learn. Respondents reported staff had some skills and that skills developed over time from experience.

Bereavement Services

After a resident dies, most bereavement services do not continue past the funeral. Of the eight interviewed, six responded that support services ended at the funeral. All five social worker respondents did not know whose responsibility it was to facilitate bereavement services and all three chaplains reported it was their responsibility. One chaplain reports he provides a book and a phone call at the three month mark. The second chaplain respondent who provides a quality bereavement program reported his facility has one year of bereavement services in place. This protocol was reported as:

“We try to have a staff member attend the funeral or visitation. I leave a card out so the staff can sign it. After about two weeks, I mail that to the family. Then we hold a memorial service about 8 times per year. All the families are invited to attend to remember their loved one. Then we spend time with the families after the memorial service drinking coffee. Usually the families have had several weeks for things to slow down and have a lot of the stresses over with. They are in the routine of trying to get the pile of paperwork completed that comes with a death of a loved one. Families like the time after the memorial service to visit with each other. Now we’re starting to send out some educational material. The social workers are looking for books and materials. We are finding that people need something at the 1 month mark, the 3 month, 6 month and 9 month mark. So we’re look at material that can keep them on track and to remind them that there is someone with them in their journey. A lot of people say that after a month or two that it seems like the world has forgotten.”

The protocol followed by this facility could be duplicated in other facilities with the proper supports in place. When families are feeling like “the world has forgotten”, it

could mean all the difference in their emotional healing to know they have an ally, a friend who has not forgotten their pain.

Facility Strengths and Weaknesses

Strengths. Respondents reported strengths such as close relationships, spiritual value and quality attention at time of death. These strengths are supported by the following data.

Close relationships. Respondents reported close relationships as one of their strengths. Staff report they are able to build relationships with family over time and it's this type of support that helps during the bereavement period. Staff are able to empathize with families. It is evidenced by the following quotes:

“Our staff is open and eager to learn. We are very caring. Our facility is very comfy and has a homey feel to it. Families feel comfortable talking with staff because they can tell that staff personally care about the resident and family.”

“Being a small-town facility, we have the opportunity to develop relationships with families and family members that continue on into the community. I think it makes a difference when running into them at the coffee shop and saying hi...making that connection.”

“We have a tight-knit group of staff at our facility that work well to develop relationships with each other and with our resident and families. Our facility portrays a genuine love for Jesus that we hope to spread to others.”

Close-knit relationships are found to be a key element in facilities offering emotional support during their bereavement time. If staff have enough time to develop relationships with family members, they are able to empathize and give authentic support. These relationships offer emotional support during a difficult time.

Spiritual value. Respondents reported spiritual care as a strength. This was not surprising since the interviews took place in Christian non-profit agencies. This is expressed by the following quotes from respondents:

“Our mission is to spread the word and love for Jesus Christ through our ministry that we offer in our facility.”

“Most people respond to some form of love of God or spiritual care during rough times. We have an edge on providing that since it’s essentially our duty.”

“The incredible value of spiritual care cannot be overlooked during times of grief. It has been what has carried multitudes of people through the ages during their times of loss.”

The fall back for support is spiritual care and has been for a very long time. Respondents stress the importance of it and the value it holds.

Quality attention. Respondents identified quality attention as one of their strengths. Quality attention can look different from one person to the next. Nursing, social workers and chaplains have different roles within the dying process. Support can come from any staff person for families. This is evidenced by the following quote:

“The compassion. The staff that are there are very compassionate people. There’s immediate attention at the time of death. The nursing staff is in and out, aides. I’m there. The social worker is there. The time we’ve spent together has given us a chance to get to know the family really well. In a small town, a lot of the staff even know some of the family members so that’s a big plus. And I think the fact that it’s Christ centered or spiritually centered that brings in a whole new dimension that God is there and most of the families have a church background.”

Weaknesses. Respondents reported weakness such as not having enough resources, bereavement services that are not extended to staff and that there were no contact or ties with following the family after their loved one passes, nor the time needed to do so. This is evidenced by the following data:

Lack of resources. Quite often where funding lacks, so does the support. Respondents believe if their budget was increased, it could potentially help with bereavement support services such as support groups, educational training and follow-up. This is evidenced by the following quotes:

“Money. If there is no money, things don’t happen usually. We know in our heart of hearts how rich and encouraging the support program could be, but without money, it’s just a dream.”

“We have actually talked about this very subject. Budgeting in non-profit agencies can be difficult. Some months we’re in the red. When staff are being asked to go home early to save on clocked-in hours, it’s difficult to think past that because that staff person is also suffering...her paycheck is suffering.”

“Sometimes money doesn’t need to be there for a support group. I know we struggle with our finances but quite possibly, we maybe could fundraise. It’s an interesting possibility.”

The hearts of the respondents were thoughtful and wished there was an easier answer but typically it does come down to the very dollar. The respondents reported budget concerns which unfortunately eat at the possibility of potential support services.

Staff perspective on possible support services. Respondents described support services would be welcomed by family and staff. This is supported by the following quotes:

“It could be more comprehensive and we could have services for staff as well.”

“It would be nice if the support services were extended to family and our facility staff. Staff sometimes grieve as much as families do.”

“In a perfect world we would have an incredible support system in place. This would be very difficult to pull off in this economy and with how life goes on and has gotten more complicated...busier. But, I believe our staff and the families of those we serve, would be empowered.”

If support services were in place, respondents feel that staff would take advantage of the services offered. With how busy life has gotten, respondents feel that staff would take advantage of services already in place.

Lack of time and follow-up. Respondents reported their follow-up support services are weak and needing improvement. This is shown by the following two quotes:

“Follow-up is a weakness. Your questions made me think. The follow-up doesn’t go beyond the memorial service which is about 4-6 weeks after the death. They are kind of on their own. We have no natural ties. Like in a church there would be ongoing care. Or a doctor, they’d continue to see some of the family members. As a nursing home we wouldn’t have any natural ties to continue working with them once their loved one is gone. I think another weakness is there is no contact with families who don’t choose to use our services. They are invited to the memorial service but if they don’t come, we really don’t have any contact with them. So we don’t know how they are doing.”

“There is a great need. We could have a grief group all year long but the chaplain’s schedule doesn’t permit.”

Follow-up and ties to community and families are weak. Respondents believe there is a great need in this area. Training and time for training would be beneficial.

Effectiveness and Recommendations

Measuring the effectiveness and seeking recommendations for a bereavement program is difficult if program measures are not in place. Without knowing the effectiveness of a program, it is difficult to make recommendations. Based on the limited feedback provided by the respondents, the following quotes give suggestions for measuring effectiveness and recommendations for improvement of bereavement programs.

Effectiveness:

“Right now it seems pretty difficult to objectively measure effectiveness.”

Sometimes we get a thank you letter from family members thanking our facility for caring for the resident and for kindness during the end of life process. These get posted up on the employee bulletin board.”

“It’s hard to figure out if we’re doing a good job or not. I would like to see what other facilities are doing, too.”

“We don’t know how they are doing. There is no way to gauge in knowing how we’re doing or to be evaluated and we don’t get feedback from families. I think it would be a good idea to contact people at a year to ask how they are and what was helpful or not helpful or what we could have done better.”

Respondents felt a strong desire, an authentic wanting-to-know, about how families were doing and adjusting. They acknowledged no measurement device and agreed it would be helpful to know how they were impacting others or where they could improve in their service to others.

Recommendations:

“None at this time. Maybe encouraging a more specific budget for these services.”

“It makes it more genuine if you have someone with experience with loss and ‘I’ve been there, done that. I’ve lost a loved one as well’ that adds some genuine components to it. Making sure it is a listening period compared to being dominated by one individual that whole go around the circle and share, rather it being dominated. Having a quality program includes having a space where people feel comfortable and have some of that personal experience. I don’t know if someone who has more formal

training would be as effective as someone who has experience and is informal. It could be just as effective.”

“If two or three more others from our community would partner with our facility to host a grief group, it might be more successful with word of mouth. Also, it might help community members see the nursing home as a positive structure in society versus ‘just a place to die’.”

“I think that folks who may have a loved one needing long term care would be less intimidated by the nursing home atmosphere and they’d already observe how the home was run. It would be a good experience. It might not be for years down the road. Stereotypically, nursing homes are scary places for people to come. Even to just walk in the door it’s scary. So to give them a reason to just walk through the door would help with that feeling of scary. Providing a public place for that, a lot of people are looking for grief support groups out there; so providing the space might be a good advertising aspect.”

Respondents felt that having personal experience with loss would seem more appropriate than coming from someone who had none. They also thought “word of mouth” would prove significant in growing a bereavement support program if members from their community would host the event. This would also help to de-stereotype the nursing facility as a scary place.

Overall, the qualitative interviews reflect the lack of bereavement services provided to families whose loved one has passed away in a long term care facility. Respondents felt there is a greater need for these services. They also believed that there

was not sufficient time to invest in the support services and that they lack funding. Many respondents stated that staff were not formally trained to support grieving family members and that social workers did not have that responsibility written into their job description. The overall response was in favor of bereavement support services in theory, but with questions about how it would be done, and what measurement to use to analyze its effectiveness.

Discussion

There are many common needs during bereavement. Anderson (2013) reported families and individuals need permission to grieve and to be understood. While some experience different types of grief, they all need some form of support to cope with their loss. It can be argued that long term care facilities should have a relationship with bereaved individuals when their loved one dies. After all, the staff at these facilities have been direct care providers and have served in the role of pseudo family members. The data from this research suggests that there is a need for bereavement services that offer different types of supports in long term care settings, but that there are barriers that influence program development and accessibility.

If a chaplain is available, he or she initiates contact with family post-death. Families and residents benefit from their chaplain's honest informational support and accommodation to behaviors and rituals surrounding bereavement. "The essence of the chaplain's role is to be fully present in relation to the emotional and spiritual realities of life's crises and passages" (Hodgson, Segal, Weidinger & Linde, 2004, p. 50).

Coping with loss and the adjustment that comes after the loved one's death can be aided by a beneficial support group (Mather, Good, Cavenagh, & Ravenscroft, 2008). The National Hospice and Palliative Care Organization (NHPCO) published a draft of standards which define practices for bereavement programs. The NHPCO suggested programs last for 13 months (Foliart, Clausen & Siljestrom, 2001). A study done by Hultman, Reder and Dahlin (2008) also suggested the bereavement care plan be implemented for at least 13 months.

With no state or federal standards guiding the type of bereavement services provided, agencies are allowed to provide minimal support (Foliart, Clausen & Siljestrom, 2001). While some agencies offer bereavement support services, there is a clear lack of services offered through long term care (LTC) facilities (Vacha-Haase, 2013). A study done by Murphy, Hanrahan, and Luchins (1997), reported there are limited grief and bereavement services for families of residents in long term care settings.

Bereavement services and follow-up care may look different to each agency. In a study done by Chentsova-Dutton (2002), there seemed to be a natural pattern to the grief process. Findings reported the intensity of grief was the highest at two months and the lowest at one year post death for example, Foliart, Clausen and Siljestrom (2001) suggested periodic telephone calls, educational brochures, and cards for the anniversary of the death, home visits, grief workshops, support groups and individual counseling sessions. A study done by Agnew et al. (2011) reported effective support interventions such as, an anniversary card, follow-up contact, bereavement booklet and a condolence letter.

Facilities have both strengths and weakness. A study done by Demmer (2003) reported the top three obstacles in the delivery of bereavement services as lack of time, funding pressures and lack of staff. Other obstacles reported were lack of interest, lack of organizational support and staff or volunteer burnout (Demmer, 2003). Addressing the needs of grieving family members is important in the healing process after the death of their beloved family member (Thirsk & Moules, 2012).

Implications for Practice, Policy and Research

Practice. The findings from this study provide implications for clinical social workers in the practice setting. Social workers need to be able to identify types of grief and loss and natural stages of change. For example, if someone has been experiencing intense grief for an extended period of time, they may be experiencing complicated grief and would need to be referred to a therapist for further intervention. Social workers also need to be aware of the needs of resident and family members and to have a knowledge base on how to approach and offer support to different types of grieving individuals. Social workers can work in a partnership with facility chaplains to co-create grief support groups which extend a hand to the community. By bringing in community members, it helps break down the barriers caused by stereotypical perceptions of nursing homes.

Policy. Bereavement support would benefit by having a policy in place. Funding is one of the barriers that deter facilities from providing bereavement support. If legislation would earmark money towards a bereavement support budget, facilities may be able to set support measures in place. It is always a possibility that insurance companies would change policy to allow for bereavement services with the proper lobbying.

Research. Implications for further research could suggest different strategies in helping families cope with the stress, loss and pain associated with death. It would be beneficial to research effectiveness of bereavement support not only for family members, but for staff members who experience grief when the residents they work with pass away. With data suggesting lack of funding, research comparing quality bereavement programs verses none at all and the impact of providing support on the psychological well-being, may impact legislation or state and federal funding.

Next, to research and expand the knowledge base for family members emotionally processing a loved one's death. Are there different pieces of their emotional response to death that are being missed which could impact their future psychological health? If so, what are those pieces and how do social workers help fill in that gap?

Finally, it would be interesting to research the official roles between chaplains and social workers; with hospice involved and without hospice involved. Coping and grieving during the bereavement process takes unknown energy at all different levels depending on the person. It behooves social workers to become educated on the grief and loss process and support to better enable successful client relationships and outcomes.

The extent of this research can suggest the possible effectiveness on a micro, mezzo and macro level. If the community and facility employees come together with the proper bereavement training, it is possible they might find a grant opportunity to fund bereavement support services together.

Strengths and Limitations

There are a many strengths of using qualitative research methods. Interviewing long term care social workers and chaplains was beneficial to this study because they

held the greatest insight into facilitating bereavement support. They are at the front lines during crisis and post-crisis and are better able to assess needs of the grieving due to their experience. They also experience the pressures and influences of the larger environment which play a role in whether long term care facilities offer bereavement support or not. And, they offer in-depth information of complex questions and offer a more comprehensive and holistic answer. In this way, interviews allowed for amplification of the previous research and also allowed for unexpected findings that the researcher did not anticipate.

The limitations of this qualitative research method included a restrictive sample with lack of diversity. The sample was derived from a single corporation which employs many employees at different locations within Minnesota; it lacks a diverse geographical population. With allotted time and resources, a broader sample to interview would better gauge the need and effectiveness of bereavement support.

Conclusion

Grieving humans have many circumstances and needs in common. Humans need to be understood and validated. Common grieving needs and the universality of grief and loss are in essence a basic human need. Pain and loss before a death and after a death may be equally painful but the grieving is different, like a parallel bar. Pain before a loved one dies can be the torture of seeing them suffer. Loss of relationship is also difficult. Having the person close at hand, but not being able to have relational conversation, emotional support or physical touch is just as difficult. The qualitative data reflects the lack of bereavement services provided to families and it supports that there is a greater need for these services. Bereavement staff need sufficient time and resources to

invest in the support services. If trainings were provided and resources made available, it would enhance the richness of staff education and family members would benefit.

References

- Agnew A., Manktelow, R., Haynes, T. & Jones, J. (2011). Bereavement assessment practice in hospice settings: Challenges for palliative care social workers. *British Journal of Social Work*, 41, 111-130.
- Berg, B., (2009) Qualitative research methods for the social sciences. 7th ed. ed. Boston, MA: Allyn & Bacon
- Bercovitz, A., Decker, F., Jones, A., & Remsburg, R. (2008). End-of-life care in nursing homes: 2004 national nursing home survey. *National Health Statistics Report*, Number 9
- Boerner, K., Schulz, R., & Horowitz, A. (2004). Positive aspects of caregiving and adaptation to bereavement. *Psychology and Aging*, 19(4), 668-675.
- Bonanno, G. A., Lehman, D. R., Tweed, R. G., Haring, M., Wortman, C. B., Sonnega, J., et al. (2002). Resilience to loss and chronic grief: A prospective study from preloss to 18-months postloss. *Journal of Personality & Social Psychology*, 83(5), 1150-1164. doi:10.1037//0022-3514.83.5.1150
- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychological Journal*, 32(7), 513-531.
- Buglass, E. (2010). Grief and bereavement theories. *Nursing Standard*, 24, 44+. Retrieved from http://go.galegroup.com.ezproxy.stthomas.edu/ps/i.do?id=GALE%7CA230415628&v=2.1&u=clie_stthomas&it=r&p=ITOF&sw=w&asid=7ae672600b7ec0e561cb389c6a9fe9cd
- Centers for Disease Control and Protection. (2013). *Nursing home stats*. Retrieved from <http://www.cdc.gov/nchs/fastats/nursingh.htm>
- Chentsova-Dutton, Y., Shucler, S., Hutchin, S., Strause, L., Burns, K., Dunn, L., et al. (2002). Depression and grief reactions in hospice caregivers: From pre-death to 1 year afterwards. *Journal of Affective Disorders*, 69(1-3), 53-60. doi:[http://dx.doi.org.ezproxy.stthomas.edu/10.1016/S0165-0327\(00\)00368-2](http://dx.doi.org.ezproxy.stthomas.edu/10.1016/S0165-0327(00)00368-2)
- Demmer, C. (2003). A national survey of hospice bereavement services. *Omega: Journal of Death & Dying*, 47(4), 327-341. Retrieved from <http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=sih&AN=12942100&site=ehost-live>
- Fauri, D. P., Ettner, B., & Kovacs, P. J. (2000). Bereavement services in acute care settings. *Death Studies*, 24(1), 51-64. doi:10.1080/074811800200694

- Foliant, D. E., Clausen, M., & Siljeström, C. (2001). Bereavement practices among California hospices: Results of a statewide survey. *Death Studies, 25*(5), 461-467. doi:10.1080/074811801750257545
- Forte, J., Barrett, A., & Campbell, M. (1996). Patterns of social connectedness and shared grief work: A symbolic interactionist perspective. *Social Work with Groups, 19*(1), 29-51.
- Fulton, R. (2003). Anticipatory mourning: a critique of the concept. *Mortality, 8*(4), 342-351. doi:10.080/13576270310001613392
- Hawton, K. (2007). Complicated grief after bereavement: Psychological interventions may be effective. *Bmj, 334*, 962-963.
- Hodgson, N., Segal, S., Weidinger, M., & B., Linde (2004). Bering there: Contributions of the nurse, social worker, and chaplain during and after a death. *Funerals and Memorial Practices, Summer*, 47-52.
- Holtslander, L. F., & McMillan, S. C. (2011, 01; 2013/10). Depressive symptoms, grief, and complicated grief among family caregivers of patients with advanced cancer three months into bereavement.38, 60+. Retrieved from http://go.galegroup.com.ezproxy.stthomas.edu/ps/i.do?id=GALE%7CA248662149&v=2.1&u=clie_stthomas&it=r&p=HRCA&sw=w&asid=19465863c375a9f9635655e9511d84e0
- Hottensen, D. (2013). Bereavement: Caring for families and friends after a patient dies. *Omega: Journal of Death & Dying, 67*(1), 121-126. doi:10.2190/OM.67.1-2.n
- Hultman, T., Keene Reder, E. A., & Dahlin, C. M. (2008). Improving psychological and psychiatric aspects of palliative care: The national consensus project and the national quality forum preferred practices for palliative and hospice care. *Omega: Journal of Death & Dying, 57*(4), 323-339. doi:10.2190/OM.57.4.a
- Keefe, J., & Fancey, P. (2000). The Care Continues: Responsibility for Elderly Relatives Before and After Admission to a Long Term Care Facility. *Family Relations, 49*(3), 235-244.
- Keith Hawton. (2007). *British Medical Journal, 334*(7601), 962-963.
- Kissane, D., Lichtenthal, W. G., & Zaider, T. (2007). Family care before and after bereavement. *Omega: Journal of Death & Dying, 56*(1), 21-32. doi:10.2190/OM.56.1.c
- Lewis, I. D., & McBride, M. (2004). Anticipatory grief and chronicity: Elders and families in racial/ethnic minority groups. *Geriatric Nursing, 25*(1), 44-47. doi:<http://dx.doi.org.ezproxy.stthomas.edu/10.1016/j.gerinurse.2003.11.014>

- Middleton, W., Burnett, P., Raphael, B., & Martinek, N. (1996). The bereavement response: A cluster analysis. *British Journal of Psychiatry*, *169*, 167-171.
- Nursing Home Statistics*. (2013). Retrieved October 02, 2013, from American Association of Justice: <http://www.justice.org/cps/rde/justice/hs.xsl/3005.htm>
- Simon, J. L. (2008). Anticipatory grief: Recognition and coping. *Journal of Palliative Medicine*, *11*(9), 1280-1281. doi:10.1089/jpm.2008.9824
- Smith, M., & Segal, J. *Coping with grief and loss*. Retrieved July/10, 2013, from http://helpguide.org/mental/grief/_loss.htm
- Steiner, C. S. (2005). Grief support groups used by few-Are bereavement needs being met? *Journal of Social Work in end-of-life and Palliative Care*, 1-26.
- Stroebe, M., & Schut, H. (1999). The dual process model of coping with bereavement: Rationale and description. *Death Studies*, *23*(3), 197-224. doi:10.1080/074811899201046
- Thompson, S., & Oliver, D (2008). A new model for long-term care: Balancing palliative and restorative care delivery. *Journal of Housing for the Elderly*, *22*(3), 169-194.
- Thirsk, L., & Moules, N. (2012). Considerations for grief interventions: Eras for witnessing with families. *Journal of Death and Dying*, *65*(2).
- Vacha-Hasse, T. (2013). The "We Care" program for long-term care: Providing family members with support following the death of a loved one. *Omega*, *67*(1-2), 221-226.

Appendix A

October 17, 2013

Dear Ms. Tvedt,

We at _____ give permission to recruit Social Workers and/or Chaplains to be respondents in your research project. We understand that you would like to recruit these participants to interview regarding their perspectives of bereavement groups in long term care facilities. We understand the interviews will be confidential and that participants will not have access to the data nor will they be pressured to participate. We understand you will be contacting participants via telephone or email to set up a time for interviewing during their lunch hour in a private room or at a private location after their scheduled work day is over. We request that a final report be sent to us once it is complete.

Sincerely,

Appendix B

1-06-14

Dear Long Term Care Provider,

My name is Laura Tvedt. I'm a graduate student at St. Catherine University/University of St. Thomas School of Social Work. I'm conducting a research project to explore bereavement support programs in long term care facilities. I currently work in a rehab and long term care facility. I talk with families everyday who might be experiencing grief or coming to terms with their ailing loved one.

There is little research addressing bereavement care in long term care facilities. Most of the research I have found has been linked with certain age groups or diagnosis. This is a topic I feel that could benefit facilities by having a little more exposure to the needs of the grieving. With the proper training, social workers will be best armed with the information that will support bereavement care.

If interested, please call me at 320-336-9557 to set up an interview time. You may also email me at tvedt7@q.com. I will be meeting with you in a public library of your choosing to maintain confidentiality. I will also be asking 19 questions and the interview should last 30-45 minutes. For participating, each respondent will receive a \$10 Target gift card. If you are interested or have any questions about this project, please feel free to call or email me.

Sincerely,

Laura Tvedt, BA, LSW

Appendix C

UNIVERSITY OF ST. THOMAS

Bereavement Care in Long Term Care Facilities

544647-1

I am conducting a study about bereavement services in long term care facilities. I invite you to participate in this research. You were selected as a possible participant because you work in a long term care facility as part of the _____group of facilities in which I am a social worker. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Laura Tvedt, LSW, a graduate student at the School of Social Work, St. Catherine University/University of St. Thomas and supervised by Jessica Toft, Ph.D., LICSW.

Background Information:

The purpose of this study is to examine bereavement availability in long term care facilities, who provides it and what the strengths and weaknesses are in facility bereavement programs. Little research has been done specifically addressing bereavement in long term care facilities. And as you are aware, when residents pass, their families are sometimes left without support.

Procedures:

If you agree to be in this study, I will ask you to do the following things: Meet with me for 30-45 minutes at a local library of your choosing. I will be asking you 19 questions and your response to these questions will be audiotaped. The non-identifiable information will be disseminated in a research paper and presented at The University of St. Thomas in front of a public audience. Any identifying information will be removed from quotes in the published and presented research.

Risks and Benefits of Being in the Study:

This study has minimal risks. I will be asking questions about your agency's performance regarding bereavement care. However, I will not mention in my paper or presentation the name of your agency and your employer will not know you have participated in the research. Your employer has agreed to participate in the study and has asked for the final report, but also acknowledges that they will not know, nor will ask about who has participated.

The study has no direct benefits.

Compensation:

You will receive payment: A \$10 Target gift card.

Confidentiality:

The records of this study will be kept confidential. In any sort of report I publish, I will not include information that will make it possible to identify you in any way. The types of records I will create include paper transcripts and signed consent form which I will keep in a locked filing cabinet and electronic records of the transcripts which will be stored on a password protected computer file. Only the researcher will have access to the data. The data will be destroyed May 15, 2014.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with _____ or the University of St. Thomas. If you decide to participate, you are free to withdraw at any time up to one week after the interview. Should you decide to withdraw before this time, any data collected about you will not be used in this study. You are also free to skip any questions I may ask. One week after the study, any data collected will be included in the study.

Contacts and Questions

My name is Laura Tvedt. You may ask any questions you have now. If you have questions later, you may contact me at 320-336-9557 or my advisor, Jessica Toft, Ph.D., LISW at jetoft@stthomas.edu. You may also contact the University of St. Thomas Institutional Review Board at 651-962-5341 with any questions or concerns.

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

Statement of Consent:

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

Signature of Study Participant

Date

Print Name of Study Participant

Signature of Researcher

Date

Appendix D

Interview Questions

1. Can you describe your role at the agency? ___ Social Worker ___ Chaplain
2. About how many residents died in your facility last year?
3. After a resident dies, who is in charge of initiating contact with family?
4. What type of follow-up is done for family or residents in your facility?
5. How long do you stay involved with a family after someone dies?
6. From your experience, what are the top 3 needs of a person after their loved one dies?
7. What types of bereavement services are offered for families?
8. How long have these services been in place?
9. Who facilitates these services?
10. Are staff trained to support grieving family members? If so, how?
11. Do you feel your job duties allow you enough time to dedicate yourself to families in bereavement?
12. Is bereavement follow-up care listed in your job description?
13. How are bereavement services paid for? Do you know if your agency has a budget for bereavement follow-up care?
14. What strengths do you see in your bereavement program?
15. What weakness do you see in your bereavement program?
16. Do you think bereavement services should be offered in a long term care facility? Why?
17. How do (would) you measure its effectiveness?
18. Do you have recommendations for improvement of bereavement services?
19. In your opinion, if your agency offered a quality bereavement program, do you feel more people would come once your reputation was built?