Journal of Social Work Education and Practice 6(3) 25-34 www.jswep.in
ISSN: 2456-2068 *July 1, 2021*

Hospice Social Workers: The Personal Death Experience

James Power[1] Amelia Crane[2] Miranda Booker[2]

ABSTRACT: Hospice social workers deal with death and dying on a routine basis. What happens when hospice social workers experience a personal death? This is a question that is not often raised. This study explored how social workers make meaning of personal deaths, given their background in hospice care. These hospice social workers shared their early exposure to death as important life events within their families.

These hospice social workers related the beneficial nature of their profession when dealing with personal death. They saw their training as a "toolbox" when dealing with personal death. Their families often turned to them for advice and guidance. They have both professional and personal "hats" to wear.

The hospice social workers conveyed the importance of support from co-workers during the grieving process. Furthermore, the organizational culture of their hospice employers impacted their ability to deal with their own personal loss.

Keywords: Hospice, end-of-life, bereavement, social work, qualitative research

The hospice movement is a relatively new development in medical care. It began in Britain in the late 1960s. Dame Cicely Saunders is credited with the hospice model known throughout the world today. The hospice movement was started in the United States in the 1970s by Florence Wald (NHPCO.org, 2020). The hospice philosophy model includes caring for an individual on physical, emotional, and spiritual levels. In fact, Medicare requires hospice providers to offer these three dimensions of care in order to receive reimbursement. Hospice teams typically comprise physicians, nurses, social workers, certified nursing assistants, chaplains, bereavement counsellors, and volunteers.

There is a misperception in the wider community that hospice care hastens death. However, hospice care neither slows nor advances the death and dying process. Many people decline hospice care at first because of the perception that hospice care is only for those actively dying. In fact, those who receive hospice care early on have a longer life expectancy, perhaps because of the added services and medical oversight (NHPCO.org 2020).

To qualify for hospice, care a physician must determine that someone has six months or less to live if the disease runs its normal course. One can stay on hospice care after six months if

[1,2&3] *University of Wisconsin Oshkosh*

the physician determines there is a continued decline in a patient's condition due to the terminal diagnosis. Initially, hospice care served those with cancer. However, hospice care now includes individuals with dementia, heart disease, chronic obstructive pulmonary disease, and numerous other terminal illnesses.

Hospice care can be provided in several settings. These include homes, hospitals, nursing homes, assisted living facilities, and hospice houses. The majority of care is provided in homes and nursing homes. This may be heightened in rural communities, given limited access to hospitals and hospice houses. For those individuals who remain under hospice care for a length of time, it is those residing in homes that afford hospice providers a more emotional attachment.

Hospice social workers provide for their patients on a number of levels. Their services are both tangible and intangible. Hospice social workers often spend their days listening to the lives of others. It is not surprising that when a hospice patient dies, it often has a profound impact on hospice social workers. Hospice social workers may deal with these deaths on a variety of levels.

Hospice social workers may rely on their co-workers or employers for emotional support. Some attend rituals such as visitations or funerals to provide a sense of closure. Others may process the death of patients on an individual basis. Regardless of how these hospice social workers internalize the death of their patients, it remains a reality of their chosen profession.

Research questions

It seems natural to assume that hospice social workers must deal with death and dying daily but what happens when a hospice social worker experiences a personal death? This personal death could include a family member or friend. In addition, are these hospice social workers expected to process a personal death in the same manner as a professional death?

Theoretical orientation

Erik Erikson (1950) has been credited with the stages of psychosocial development. It consists of an eight-stage model. His eighth stage, ego integrity vs. despair, relates to this study. This stage is typically associated with older adults. However, this paper asserts that it has implications for people younger than the stereotypical application (Sanville, 2002).

It seems logical that the eighth stage may seem appropriate for hospice patients regardless of age. The task at hand is an assessment of contentment and a sense of a productive life instead of dissatisfaction with life experiences, which results in despair. This paper asserts that when hospice social workers experience a personal death, they may engage in the eighth stage of psychosocial development themselves.

Hospice social workers quite possibly review the life experiences of their departed family member or friend, thus engaging Erikson's eighth stage. This may include taking part in Erikson's eighth stage process of their dying loved one. In addition, family and friends may see the hospice social worker as a resource in assessing the eighth stage following the death of a loved one. This researcher suggests that how the hospice social workers perceive ego integrity, as opposed to despair, may influence their recovery from a personal loss and implications for their professional practice.

Background

This study has taken the novel approach of exploring personal death among hospice social workers. Little is known about this issue. Some might suggest given their profession, hospice

social workers are able to deal with personal death in a more efficient and routine manner. However, hospice social workers often experience a personal death in a manner similar to those without a background in hospice care.

This study examined how these hospice social workers first experienced a personal death, often during childhood, and their reactions. This researcher explored the personal death encountered as a hospice social worker. These hospice social workers shared their stories about the role of family, spirituality, and professional background in the grieving process. Finally, these hospice social workers made some reflections on self-care as professionals and recommendations for new or potential hospice social workers.

There is minimal research examining how hospice work impacts trained caregivers, but there is almost no research into the long-term consequences of how hospice work affects the professional instead of the personal lives of those same trained caregivers (Sinclair, 2011). Some trained hospice caregivers claim that emotions can be dangerous and must be controlled in order to function effectively on both a professional and a personal level (Funk, Peters., & Roger, 2017). The danger is, if emotions of grief and stress are not controlled, then that can lead to burnout, and trained hospice caregivers burnout at a rate of 17.3% (Parola, Coelho, Sandgren, Fernandes, & Apostolo, 2018). When trained hospice caregivers experience a personal loss, they separate their professional and personal identities to cope with the grief (Hogan, 2017). Both identities can be massively affected by the personal loss, but the experiences of death and dying learned through the professional identity can help the personal identity control the grief (Marcella-Brienza & Mennillo, 2015; Sinclair, 2011).

When the trained hospice caregivers are confronted with an incomprehensible personal loss before them, it can become difficult to switch between the professional and the personal identities (Hogan, 2017). While the personal identity grapples with processing the loss of their loved one, the professional identity can take over and evaluate the situation and communicate with the health care staff. Even if a trained hospice caregiver has worked with death and dying for years, it can never truly prepare them for the loss of a loved one (Hogan, 2017).

Once the trained hospice caregiver returns to work, they may find themselves feeling distant from the emotions of their job; some may need to transfer away from patient care in order to avoid the constant reminder of pain, and others may need to leave the profession entirely (Hogan, 2017; Marcella-Brienza & Mennillo, 2015). Some hospice patients or their families under the care of a trained caregiver may believe that this caregiver must be stoic and reliable through the stress of the job, but they are human, and as such, are vulnerable to the complexity of human emotions, especially when it is a personal loss (Hogan, 2017).

Methodology

This study was qualitative in nature. It included eleven semi-structured interviews. The interviews were conducted using an interview guide based on existing literature on this topic. The interview guide was adjusted as the research process unfolded. This study was approved by an Institutional Review Board of a semi-rural university. This Institutional Review Board provided oversight of the research process and informed consent documentation. Adjustments in the research design were approved by this Institutional Review Board.

The eleven semi-structured interviews were conducted at a place of choice of the research

participants. These settings included libraries, coffee houses, and dining establishments. Each of these settings provided some level of privacy.

These interviews were audio-recorded with the research participants' permission. Following the interviews, the audio recordings were transcribed. These interviews were coded by a three-member research team, including the principal investigator, an MSW student, and a BSW student. This research team met to discuss emerging themes. The software program, NVivo, was used to manage the data.

This study used a purposeful sampling method. This researcher sought out research participants from regional hospice providers. A research team member visited each regional hospice provider to identify potential research participants. These hospice providers were given oral and written information about this research study. Every effort was made to identify research participants and enroll them in this study. Ultimately, the individual hospice social workers reached out to the research team via e-mail or telephone. After the initial contact, the researcher and research participant agreed upon a setting and time for the interview.

Sample demographics

The demographic characteristics showed levels of variance between categories, and uniformity in others. Research participants' age fell within the range of 37 and 66, with the average resulting in 50.36 years old. Of the eleven research participants, nine were female (81.8%) and two were male (18.2%). Seven (63.6%) held a Bachelor of Social Work, with three (27.3%) of the seven also holding a Master's in Social work. Four (36.4%) of the research participants held only a Master's, with an additional background in a 4-year educational degree. Five (62.5%) of the research participants held licensures of Certified Social Worker (CSW) and three (37.5%) held Certified Advanced Practice Social Worker (CAPSW). All respondents were married, with one respondent being married twice.

An important note in understanding these demographics is that not all eleven respondents answered each characterizing question. The inclusion of percentages does not reflect overall participants, but instead those who answered the specific demographic being analyzed.

Analysis

This study yielded rich data. This researcher has selected some quotes that best illuminate the themes that developed during the data analysis process. These themes included reasons behind a career in hospice, first experiences with death, a personal death prior to, during, or after working as a hospice social worker, spirituality, self-care, and dealing with death as a part of their occupation, and finally recommendations for social workers.

Reasons for a career in hospice

It is important to note that these social workers entered the field of hospice for a variety of reasons and manners. However, a majority of the social workers referred to their occupation as a "calling". None of the social workers reported extended burnout or compassion fatigue. This may be a reflection of the support from family, co-workers, and the hospice agencies themselves.

One hospice social worker commented:

> *And I think I was in hospice for like two, three weeks and a family member asked what I thought of hospice, "Isn't it depressing?", and I am like, "I love it!"*

Another stated:

> *This is what I am supposed to do, this is my calling. Absolutely, God made this work for me, and I love it.*

First experience with a personal loss

How these hospice social workers experience death is a tenant of this study. It was natural to ask about their first encounter with death and dying. All of these research participants reported a death early in life. These deaths were with family members. The research participants presented with polar experiences. There were families that did not discuss or acknowledge death whereas others had an open dialogue. Whether this discussion or lack thereof influenced their future work as a hospice social worker is uncertain and a determinate factor in practice. However, those families that did discuss death in a family may have better tooled these research participants for a career in hospice care.

One hospice social worker stated a common story about first encounters with death:

> *It was my grandmother on my dad's side that passed away when I was probably in 7th grade. I wasn't there at the time she died. She died at a hospital and it was very closed-discussion in my family. It was, "She passed. Here's the funeral. Here is what we need to do." And the couple next couple days but it wasn't really an opportunity to grieve or talk about it or ask questions. It was a learning experience.*

A polar opposite was an open discourse about death:

> *At a young age, I remember my grandparents dying. The first time someone close to us died I was five. And I came home from kindergarten and I found my mom crying. And she was crying because her grandmother, my great-grandmother, had died. And my mom was very close to her grandmother. So, that was the first time (with a personal death). But in my family, we talked about it a lot. And we have a small family, so when my grandparents passed, it was intimate and supportive of one another.*

Personal loss prior to, during, or after working in hospice

Hospice social workers perhaps deal with death and dying differently from the general population. However, these hospice social workers are people too. Each of these research participants reported a death of a family member or friend prior to, during, or after working as a hospice social worker. All of the research participants reported that their role as a hospice social worker better prepared them for a personal death. Some of them stated they a had "tool box" of resources they and their families could use.

One hospice social worker shared:

> *It's a good memory. And I was so grateful to not be afraid to talk about what was happening to her. Not be able to talk about- or I could talk about the regret. Because I knew with working with people after their loved one dies, as a bereavement coordinator, people have a lot of regrets. Wish they would have said something. Wish they would have apologized. Wish they would have asked their loved one about, "What did this mean when this happened in our relationship?" They live with a lot of mystery afterwards. Because they didn't search for the*

> *answer before their loved one died. I didn't want that experience. I didn't want to leave anything unsaid.*

Another stated:

> *Oh gosh, I don't think I would have been able to do half of what I did, had I not had that background. I don't know how. It was a sad moment. It was immensely helpful.*

It is not uncommon for family and friends to rely on hospice social workers during a personal death. Many of the research participants stated their families saw them as a resource. Advice on advanced planning and funeral arrangements were consistent themes. A majority of them stated they took on this role regardless whether it was of their choosing or not. The results of this study did indicate hospice social workers do experience a personal death differently than non-hospice providers. This is supported by the resources available to them and their roles in their families.

One social worker observed:

> *I remember saying something at the funeral, and she said "You deal with this stuff, you are a social worker, help me get through this," and I remember her saying that, and I thought, well, this is different, this isn't work, this is my life, this is my family here. So, it was unique, I really don't know how I dealt with it.*

Another commented on her role in her family:

> *I think because I had experience with hospice and death and dying with my wife's family, when my mother-in-law died, they looked to me as the social worker. As the "death guy" to help the rest of the family. So, I felt like I played the social worker role in the family because that's what they were looking for. They wanted help with decision making. They wanted my help, "Are we doing this right?" "Are we?" I think I still had my social work hat on at that time.*

Spirituality

The hospice social workers reported issues related to spirituality. Spirituality has always been a component of hospice care. The hospice social workers report the role of spirituality as a coping mechanism for themselves and their patients. Faith in the hospice setting can be a powerful tool for working with patients and their families. Some of these hospice social workers relied on their bereavement counselors or clergy for support in the case of a personal death.

One hospice social worker commented:

> *My belief systems have evolved both spiritually, emotionally, throughout my time in hospice. Grew up more conservative. Definitely became more open. Different traditions, faith traditions…I think, end-of-life has helped me realize that many people believe different things and that's okay.*

Another social worker made this observation:

> *We certainly serve people who have a variety of faith traditions. Some have no faith tradition. But the spiritual part of end-of-life is really important. And it's really an honor and a privilege to be with people at that time. That is a spiritual walk. Even if someone doesn't have a faith tradition. For me that's a precious time with my patients.*

Support from peers and hospice agencies

It is not surprising that some of these hospice social workers reported support from their co-workers and the organizations they work for. The research participants acknowledged the impact of their co-workers and their employers in how they experience a personal death. Most stated the importance of their co-workers and that their co-workers might have a better understanding of the death and dying process given occupational experiences. In addition, the research participants shared their employers were supportive in terms of time-off as well as access to outside resources such as employee assistance programs or counselors. Organizational culture seemed to impact the death and dying process among the hospice social worker when encountering a personal death.

One hospice social worker stated:

> *I think the people who work the closest together tend to watch out for each other. They (hospice employer) gave me time that I needed, it was out of state (the death), and I think our policy is 2 or 3 days for a parent that you can have off, and they definitely allowed me that. I was gone for a week and a half, and I was able to, after the death to go back.*

Another hospice social worker made this observation of support from managers:

> *Our director of nursing does that a lot with people that we know are struggling over a loss (personal), and allowing people time to grieve. We encourage people, our staff, to go to funerals, and to the visitations. In order to process their own loss. So, we encourage and don't discourage that. Those are all ways that we try to support the staff.*

Work and life balance

The issue of self-care was voiced by many. Each of the research participants shared the importance of self-care and preforming for roles in a functional manner. They provided a list of self-care that ranged from exercise, yoga, talking with others, and even their travel commutes to work or between visits. They added that their co-workers and their employers seem to support a self-care plan. It is one thing to promote self-care but to have support from organizational culture is another.

One hospice social worker elaborated:

> *I think you need good self-care, that we talked about, and the long commute that I had mentioned. To unwind before you walk in the door. I've done a good half an hour on the road that I can kind of filter through everything in my head and all the day's events that have happened. And have that all out of my head by hopefully by the time I get home. Some good self-care, and just realizing what you can do in the day and the differences that you have made even though we can't change everything.*

Along with self-care, some of these hospice social workers made mention that an individual might need outside support:

> *I always tell people when you're dealing with the death of a loved one that there's not a right or wrong. If it's keeping you from functioning two weeks from now, where you don't want to get out of bed and you can't go to work then you're dealing with some complicated grief. And that's where you need to reach out for*

> *help. There's going to be worse days than others. There's going to be things like that's normal. But if it affects your daily living on a regular basis where you're not able to perform your job, that's probably when you want to reach and seek out help.*

Dealing with death and dying on a routine basis

It is the nature of the profession that hospice social workers deal with death and dying on a routine basis. Many of these hospice social workers voiced their stories with their patients' journey. Some frankly note that hospice work is hard and challenging. However, stepping back from a death can refocus their energies. They note the importance of their co-workers and their employers in supporting their efforts with personal death despite facing challenging situations on a routine basis.

One such example:

> *It gives us a chance to recognize to take a step back. Every time we meet as a caregiving team, we take a few minutes before our interdisciplinary meeting to review the patients who have died in the past two weeks. And to spend a few minutes reflecting on them and talking about what needs their family members might have. It's like honoring the person, not just moving on.*

Another research participant made this reflection:

> *I think I've learned to be more at peace about death, and less afraid of it as a result of my work in hospice. And that's helped my own grieving, because death is less frightening or scary to me. It's a definite loss, it's sad, and I feel for the person deeply, but you don't have that fear.*

Recommendations to others

The hospice social workers were asked about their recommendations to those new to hospice or considering working in hospice. They openly acknowledged that hospice is not a match for everyone, and this may be noticed in school practicums or early on in their hospice career. Not surprisingly they stressed the role of self-care.

One social worker commented:

> *I think that social workers really need to realize when they're in hospice they need to take care of themselves emotionally…have someone to talk to about what they see. Especially in their own hospice office and personally.*

Another elaborated:

> *I think when people find out what I do for a living, they're like, "Oh, how can you do that?" I think it's dismissed a lot. "How can you work in such an emotional way? And support people?" I just tell people I learn more every day. And really, like, 95% of my job is listening. People just want to be heard. They want to tell the story of their loved one. Just like I'm doing this with you.*

Implications for practice

This study highlights how hospice social workers experience a personal death and its implications on an individual as well as professional level. As noted, there are patterns in how these hospice social workers experience death on a personal level. Early experiences with death and reasons for maintaining a hospice career may influence encounters with a personal death.

On a professional level, approaches to support these hospice social workers with a personal death may reduce burnout and compassion fatigue. This support can be from co-workers, organizations, and formal grief counseling. One must not make the assumption that hospice social workers always know how to navigate a personal death given their profession.

Given this study's findings, the paper contends that Erikson's eighth stage has ramifications for hospice social work practice (1950). Hospice social workers may help or shadow their loved one's experience with their assessment of ego integrity versus despair prior to death. Likewise, after the death of a family member or friend hospice social workers may review the eighth stage retroactively. Erikson's eighth stage illuminates how hospice social workers may make meaning of the personal death experience.

This study has, from the beginning, intended to start the discourse on this vital issue. It brings these experiences out of the darkness. While there has been a continued dialogue on the professional lives of hospice social workers, one must not overlook the unique experiences of hospice workers when they encounter their own personal deaths.

There are some limitations of this study. It was based on a small sample size which is not unusual given the qualitative nature of the study. A quantitative study would be warranted based on the findings of this study. A study that encompassed a more comprehensive geographic area with a more diverse sample of social workers would be beneficial. Identifying research participants can be a challenge in qualitative studies despite diligent efforts.

References

Erikson. E. (1950). *Childhood and society.* W. W. Norton Co.

Funk, L. M., Peters, S., & Roger, K. S. (2017). The emotional labor of personal grief in palliative care: Balancing caring and professional identities. *Qualitative Health Research, 27(14)*. doi:10.1177/1049732317729139

Hogan, L. (2017). Personal grief in the professional world. *Journal of Palliative Medicine, 20(3)*, 33-304. doi:10.1089/jpm.2016.0426

Marcella-Brienza, S. & Mennillo, T. (2015). Back to work: Manager support of nurses with chronic sorrow. *Creative Nursing, 21(4)*. doi:10.1891/1078-4535.21.4.206

NHPCO.org (2020). History of hospice. URL: https://www.nhpco.org/hospice-care-overview/history-of-hospice/

Parola, V., Coelho, A., Sandgren, A., Fernandes, O., & Apostolo, J. (2018). Caring in palliative care: A phenomenological study of nurses' lived experiences. *The Hospice and Palliative Nurses Association, 20(2)*. doi:10.1097/NJH.0000000000000428

Sanville, J. (2002) When therapist and patient are both in Erikson's eighth stage, *Psychoanalytic Inquiry, 22* (4), 626-639, DOI: 10.1080/07351692209349007

Sinclair, S. (2011). Impact of death and dying on the personal lives and practices of palliative and hospice care professionals. *Canadian Medical Association Journal, 183(2).* doi:10.1503/cmaj.100511