

Spring 2018

In-Home Hospice Nursing: Work and Life Experiences Through the Model of Human Occupation (MOHO) Lens

Courtney L. Schauer

Elizabethtown College, schauerc@etown.edu

Follow this and additional works at: <https://jayscholar.etown.edu/otstu>

 Part of the [Occupational Therapy Commons](#)

Recommended Citation

Schauer, Courtney L., "In-Home Hospice Nursing: Work and Life Experiences Through the Model of Human Occupation (MOHO) Lens" (2018). *Occupational Therapy: Student Scholarship & Creative Works*. 1.
<https://jayscholar.etown.edu/otstu/1>

This Student Research Paper is brought to you for free and open access by the Occupational Therapy at JayScholar. It has been accepted for inclusion in Occupational Therapy: Student Scholarship & Creative Works by an authorized administrator of JayScholar. For more information, please contact kralls@etown.edu.

In-Home Hospice Nursing:
Work and Life Experiences Through the Model of Human Occupation (MOHO) Lens

Courtney L. Schauer

Elizabethtown College

Author Note

Courtney Schauer, OTS, Department of Occupational Therapy, Elizabethtown College.

This research was conducted for OT 494: Undergraduate Scholarship Practicum, advised by Dr.

Nancy Carlson-Steadman, OTR/L in Spring, 2018.

Abstract

The purpose of this study was to analyze the daily lives of in-home hospice nurses in order to learn what life experiences, attitudes, and strategies contribute to their abilities in caring for patients who are terminally ill using the Model of Human Occupation (MOHO). Additionally, the study sought to understand how working in hospice care affects the everyday lives of the nurses outside of their workplace. The research questions were, “How do the interests, values, personal causation (motivation), habits, and roles of an in-home hospice nurse affect their occupational performance in caring for the terminally ill?” and “In what ways does working as an in-home hospice nurse affect important habits and life roles performed outside of the workplace?” Participants included three in-home hospice nurses from a common home health agency. Semi-structured interviews using a modified version of the Assessment of Occupational Functioning-Collaborative Version were conducted. Five overarching themes emerged from the data pertaining to the MOHO concepts of volition, habituation, and performance capacity: “A Caregiving Personality,” “Flexibility and Self-Sacrifice in Time Management,” “Value of Patients’ Perspectives,” “Participation in Stress-Relieving Activities,” and “Finding Purpose Outside of Work.” In conclusion, MOHO is well-suited for studying in-home hospice care professionals. Knowledge of how nurses deal with work-related stress can be utilized by OTs to understand their own perceptions of hospice care. More occupation-based studies of hospice professionals would be beneficial as hospice care needs increase with an expanding older adult population.

Introduction

Providing care to hospice patients takes a special kind of person. Hospice is defined as “the concept of care designed to provide comfort and support to patients and their families when a life-limiting illness no longer responds to cure-oriented care” (Martens, 2009, p. 145). Hospice can be delivered in patients’ homes or at inpatient facilities. In-home hospice nurses provide care to a patient while they continue to live at home, whereas inpatient hospice nurses work in a facility such as a hospital, hospice residence, or nursing home where nursing and custodial care is provided 24 hours a day (Martens, 2009). Hospice often includes palliative care. The World Health Organization (2017) describes palliative care as enhancing the quality of life of patients and their families when facing life-threatening illness by focusing on preventing and providing relief for suffering. The main difference between hospice and palliative care is that palliative care can begin at time of diagnosis, while hospice care is provided after curative treatment of a disease is stopped, and it is believed that the person will not survive the illness (Medline Plus, 2016). OTs work in palliative and hospice care; however, there is little literature pertaining to their lived experiences in the workforce. Therefore, a need for occupational therapy research regarding hospice and palliative care therapists is present. This information would provide the profession with the resources necessary to enhance practice skills and/or the mental health and well-being of OTs. On the other hand, the nursing literature contains both quantitative and qualitative studies focused on identifying the needs of nurses and other health care workers in the hospice setting. Studies conducted in the nursing and social work disciplines explore personal characteristics, coping mechanisms, and lifestyle choices that enable health care professionals to remain working in hospice, a field where burnout, professional compassion fatigue, and stress are common.

Hospice serves a growing and diverse population. In 2015, 1, 381,182 Medicare beneficiaries were enrolled in hospice care (National Hospice and Palliative Care Organization, 2016). In terms of demographics, statistics from 2015 reveal that more than half of hospice Medicare beneficiaries were female, and approximately 65% were 80 years of age and older (National Hospice and Palliative Care Organization, 2016). Diagnoses vary and include patients with cancer, dementia, cardiac and circulatory issues, respiratory issues, stroke, and others (National Hospice and Palliative Care Organization, 2016). This diverse and complex population of patients requires specialty care to deal with matters that one encounters at the end of life. According to a 2014 U.S. Bureau of Labor Statistics occupational employment survey, approximately 20,000 occupational therapists and 318,000 registered nurses served on hospice care teams in home health care services and in skilled nursing facilities (U.S. Bureau of Labor Statistics, 2014). Today, there are more than 5,300 hospices located in all 50 states (John Hopkins Medicine, n.d.).

Working in this very emotionally challenging and rewarding setting requires a special skill set and type of person. There is little research on this issue in the occupational therapy literature. The occupation model of practice – the Model of Human Occupation (MOHO) - has the potential to evaluate specific qualities of those who work in hospice. The researcher chose this model because it looks at many different qualities of a person that contribute to occupational performance. This research will use this occupation lens to explore what it takes to be a good hospice health care professional. The research questions are as follows: “How do the interests, values, personal causation (motivation), habits, and roles of an in-home hospice nurse affect their occupational performance in caring for the terminally ill?” and “In what ways does working as

an in-home hospice nurse affect important habits and life roles performed outside of the workplace?”

Literature Review

The literature reviewed for this study focused on studies about nursing and other health care professionals who work in either palliative and hospice care. Similarities between the nature of palliative and hospice care are that professionals in both settings encounter emotionally challenging situations and utilize certain strategies to cope with the emotional demands of their work. For these reasons, research on palliative and hospice professionals was examined. Because OTs work on interdisciplinary teams with other health care professionals in these settings, knowledge from other disciplines is beneficial in facilitating interdisciplinary collaboration. The concepts of the MOHO were also explored in order to best apply the model to in-home hospice care nurses.

Model of Human Occupation (MOHO)

The MOHO is a popular, evidence-based theory used in occupational therapy practice. Occupational therapy is defined as “the therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of enhancing or enabling participation in roles, habits, and routines in home, school, workplace, community, and other settings” (American Occupational Therapy Association [AOTA], 2014, p. S1). The MOHO was created more than 30 years ago, and it facilitates occupation-based interventions used in occupational therapy (Forsyth et al., 2014). It recognizes that there are factors present in one’s life that are separate from the motor, cognitive, and sensory impairments that affect participation in everyday occupations (Forsyth et al., 2014). In other words, the MOHO believes that there are internal and external influences outside of one’s mental and physical abilities that factor into whether he/or she can

successfully participate in desired roles or activities. The concepts of this theory address motivation, patterns of occupation, skilled performance of occupation, and the impact of the environment on occupation (Forsyth et al., 2014). It is a holistic approach which helps an occupational therapy practitioner in understanding personal and environmental factors that are present in a client's life. Utilizing the MOHO to conceptualize the lives of in-home hospice nurses could be beneficial in understanding how they deal with the complexities of caring for patients with terminal illnesses.

Within the MOHO frame, a person is seen as possessing the internal characteristics of volition, habituation, and performance capacities; these elements interact to play a role in engagement in meaningful occupations (Forsyth et al., 2014). Volition refers to one's motivation to participate in certain life roles and activities; it is comprised of three parts: personal causation, which are the thoughts and feelings about personal effectiveness when performing a certain occupation, and values and interests (Forsyth et al., 2014). Habituation refers to how occupations are organized into routines and patterns. Habits are "learned ways of doing things that unfold automatically," and roles provide a cultural script, as well as expectations and responsibilities (Forsyth et al., 2014, p. 508). In different terms, habituation is simply the way in which people organize their lives based on the roles and activities they engage in. The third internal characteristic, performance capacity, is related to the mental and physical skills that enable a person to participate in an occupation (Forsyth et al., 2014). The MOHO deems these internal characteristics highly important to participation in occupations. When looking at in-home hospice nurses specifically, the MOHO could shed light on how one's volition, habituation, and performance capacity influence the care they provide to hospice patients. External to the person, the MOHO emphasizes the importance of the impact of the environment on participation in

occupations. The environment is defined by the model as “the particular physical, social, cultural, economic, and political features within a person’s context that influence the motivation, organization, and performance of occupation” (Forsyth et al., 2014). Within the context of in-home hospice nursing, the environment plays a significant role as the nurses provide care within an individual’s home, vastly different from serving patients in a medical facility. Therefore, the MOHO provides a framework that corresponds with important aspects of in-home hospice nursing.

Although there is no literature that pertains to the use of the MOHO in examining the personal and environmental characteristics that contribute to working as an in-home hospice nurse, Costa and Othero (2012) discuss how palliative care can be integrated into the model itself; they argue that both palliative care and the MOHO are based on client-centered care, and that palliative care can be provided at any point across the lifespan when a catastrophic change in one’s life occurs. Although integrating palliative care into the MOHO is outside of the scope of this study, using it to view the life of someone who provides unique and demanding client-centered care would allow a deeper understanding of how a person provides such care while simultaneously dealing with the complex health and emotional issues surrounding the experience of death. Additionally, nurses who are aware of how the interaction of their own internal factors and their environment influence their performance of providing hospice care may allow them to view their experiences from a new perspective. Knowledge pertaining to nurses’ volition, habituation, and personal causation would benefit occupational therapists, as they also work in the hospice and palliative care field (AOTA, 2015).

Hospice and Palliative Care Workforce

Many branches of the health care profession play a role in the provision of hospice and palliative care. It is typically provided by interdisciplinary teams that are comprised of nurses, therapists, home health aides, bereavement counselors, social workers, spiritual counselors, physicians, and volunteers (National Hospice and Palliative Care Organization, 2016). A study by Kamal et al., (2016) provides a broader understanding of the individuals who work in hospice and palliative care. Their methods included the use of an electronic survey to gather information on the characteristics of the hospice and palliative care workforce in the U.S.; the purpose of the survey was to gather information on the roles and responsibilities, demographics, motivations for entering the field, and future plans of these professionals (Kamal et al., 2016). The respondents included 1,365 physicians (MDs and DOs), nurse practitioners, physician assistants, nurses, social workers, chaplains, and other medical professionals who were members of the American Academy of Hospice and Palliative medicine. Overall, results of the survey showed a workforce that is "...older, predominantly female, and generally with less than 10 years clinical experience in the field" (Kamal et al., 2016, p. 597). Specifically, hospice clinicians were more likely to be over 50 years of age, and clinicians were more likely to be female in both palliative and hospice care (Kamal et al., 2016). In terms of motivation for entering the field, the most common response was "potential for professional growth," followed by "right opportunity/position came along" (Kamal et al., 2016). The authors state a need for guidance and mentorship, work/life balance based on one's stage in life, and managing burnout as ways to retain the clinical workforce in palliative and hospice care (Kamal et al., 2016). Much of the palliative and hospice care literature addresses the mental and emotional health of professionals in the field, showing that research is integral for the management and prevention of the emotional difficulties that derive from continuous encounters with death.

An important concept to consider for the health care professionals that work on hospice and palliative care teams is that of job satisfaction, as they experience death often; additionally, the hospice industry has experienced rapid growth, indicating a need to understand job satisfaction and the work experiences of these professionals (Casarett, Spence, Haskins, & Teno, 2011). Since palliative and hospice care is provided via an interdisciplinary effort, it is essential to understand any differences in perceived levels of job satisfaction amongst these individuals. Little knowledge of job satisfaction in hospice care providers existed prior to their study, so Casarett, Spence, Haskins, and Teno (2011) explored the concept using the Survey of Team Attitudes and Relationships (STAR), which measures job satisfaction; they additionally analyzed variation in job satisfaction between different disciplines within the workforce. Findings revealed significant differences in job satisfaction between disciplines; physicians from the sample were more satisfied with their jobs than nurses, chaplains, social workers, nursing aides, and bereavement counselors; furthermore, nurses and social workers generally measured lowest in job satisfaction, with nurses' satisfaction with their daily work scoring the lowest across all disciplines in the sample (Casarett, et al., 2011). The authors do not offer an explanation as to why nurses working in hospice appear to have lower job satisfaction when compared to other disciplines in this particular sample. This finding shows a necessity for further research into factors that contribute to low job satisfaction in hospice nursing. Tunnah, Jones, and Johnstone (2012) found through anecdotal evidence in their qualitative study that job satisfaction was a determinant of nurses' stress levels. The in-home hospice nurses interviewed in their study discuss "making a difference" as contributing to satisfaction with their work (Tunnah, Jones, & Johnstone, 2012). Therefore, job satisfaction and stress may have a relationship that impacts this workforce.

Stress and Anxiety in Hospice and Palliative Care Nursing

Stress is often associated with the nursing profession. In particular, hospice and palliative care nurses are likely to encounter stressful situations frequently, as they have the unique responsibilities of caring for patients at the end-of-life and addressing needs of patients' families. However, through a review of 16 articles that focused on palliative care nursing, no strong evidence was found which supported that palliative care nurses have higher levels of stress than other disciplines (Peters, Cant, Sellick, et al., 2012). The authors presented this review using three themes: "degrees of stress," "stressors at work," and "mediators of stress" (Peters, Cant, Sellick, et al., 2012). Under the theme of "degrees of stress," the literature review showed that palliative care nurses have not been found to be any more stressed than other nurses, and the authors suggest that palliative care nurses may have developed coping strategies to deal with stress (Peters, Cant, Sellick, et al., 2012). Nurses in other studies have described using coping strategies to deal with the emotional stress that comes with caring for dying patients on a daily basis (Ablett & Jones, 2007; Melvin, 2012; Tunnak, Jones, & Johnstone, 2012; Desbiens & Fillion, 2007; Sardiwalla, VandenBerg, & Esterhuysen et al., 2007). However, Desbiens & Fillion (2007) found that not all coping strategies are beneficial; disengagement strategies including denial, mental and behavioral disengagement, and use of alcohol/and or drugs favored greater emotional distress in their sample of palliative care nurses working in Quebec. Similarly, Sardiwalla, VandenBerg, and Esterhuysen (2007) found that hospice workers using ineffective coping strategies "...tend to report higher levels of emotional exhaustion and depersonalization..." (p. 496). Therefore, utilizing positive coping strategies is important in the emotional health of palliative and hospice care nurses.

Pertaining to the theme of “stressors at work,” the articles reviewed by Peters, Cant, Sellick, et al., (2012) revealed that nurses perceived environmental factors such as poor team communication, factors related to role conflicts, and factors arising from issues with patients and their families as being more stressful than personal distress caused by frequent encounters with dying patients. This finding supports a need for more research into the work environments of palliative and hospice care professionals. Although working with terminally-ill patients is incredibly difficult, other environmental factors play a role in one’s stress. Considering “mediators of stress,” several different coping strategies and coping styles were discussed in the literature reviewed for the study (Peters, Cant, Sellick, et al., 2012). Overall, the articles analyzed suggest that well-trained and experienced palliative care nurses are at less risk for psychological distress or burnout than other nurses because they are better able to utilize methods to deal with stress (Peters, Cant, Sellick, et al., 2012). The literature review provides evidence that the MOHO is a suitable fit for studying the lived experiences of hospice nurses because it emphasizes how environmental and personal characteristics impact their work.

Furthermore, another literature review found that the level of anxiety associated with death in nurses working in hospitals, oncology, renal, hospice care, or community services was not high (Peters, Cant, Payne, et al., 2013). Death anxiety develops when witnessing death, and it causes one to become apprehensive about their own death (Peters, Cant, Payne, et al. 2013). The authors conducted a systematic review of 15 quantitative descriptive survey studies pertaining to nurses’ attitudes toward death. The studies assessed included samples of nurses in general medicine, oncology, emergency/critical care, hospice/palliative care, nephrology; one study of a multidisciplinary staff including nurses was reviewed as well (Peters, Cant, Payne, et al., 2013). Peters, Cant, Payne, et al. (2013) concluded that nurses with positive attitudes toward death were

likely to be more positive towards providing end-of-life care. Also, findings revealed that caring for the dying requires one to understand his/or her own spirituality and personal beliefs about death (Peters, Cant, Payne, et al., 2013). Several studies included in the review from different countries suggest death education courses would be beneficial, especially for nurses under the age of 30 (Peters, Cant, Payne, et al., 2013). Similar to stress, death anxiety can be prevented by education; moreover, one's attitude, personality, and personal beliefs play a role in how one copes with and manages death.

Although Peters, Cant, Sellick, et al. (2012) did not find that hospice and palliative care nurses experience more stress than other nurses, the issue still exists and warrants research to understand causes of stress in this workforce. When looking at stress within hospice, a quantitative study using a modified version of the Nursing Stress Scale (NSS) found differences between in-home hospice and inpatient hospice nurses' perceived stressors, although these differences were not statistically significant (Martens, 2009). For example, results indicated that inpatient hospice nurses held a higher mean perceived stress level in the category of "making a mistake when treating a patient" than in-home nurses, while in-home nurses held a higher mean perceived stress level in the category of "lack of an opportunity to talk openly with other staff members" (Martens, 2009). The author of this study did not attempt to find reasons for these differences (Martens, 2009). Martens (2009) concluded that perceived stress factors vary between individuals, and personality and coping style are important in predicting stress. Peters, Cant, Sellick, et al. (2012) also noted that personal characteristics such as coping style plays a role in the perception of stress. Tunnah, Jones, and Johnstone (2012) studied the experiences and well-being of in-home hospice nurses specifically; analysis of seven interviews of in-home hospice nurses deemed certain stressors, coping strategies, and types of support as important to

the participants. Similar coping strategies are discussed by nurses in Melvin's study of professional compassion fatigue (2012). This concurrence demonstrates that coping strategies are likely used by many hospice and palliative care nurses across various settings.

Martens (2009) found no statistical differences in stressors between in-home and hospice nurses, but differences did exist. Although the nature of their services is basically identical, working in a patient's home adds more levels of complexity to the process of caring for a hospice patient, such as working with and educating family caregivers. Through analysis of opinions of key "thought leaders" in the palliative and hospice nursing field in the United States, themes that represent the complexities accompanying the act of supporting a patient's caregiver emerged (Ellington et al., 2013). Addressing caregiver needs as well as a patient's needs during assessment was deemed highly important, but was not always successful depending on the characteristics of the family (Ellington et al., 2013). For in-home hospice nurses, having communication with, assessing, and training family caregivers in the care of their loved ones is an additional component of their job. Furthermore, family-centered and at-home care requires a nurse to understand different family dynamics and each family member's perspective (Ellington et al., 2013). Nurses who work in patient's home "...have to provide and instruct on care while remaining sensitive to the fact that they are a 'guest' and have been 'invited' into the home" (Ellington et al., 2013, p. 1015). The "thought leaders" surveyed in this study also considered the facilitation of communication by nurses between professionals and the family as important, and they indicated that nurses have the responsibility of preparing and aiding caregivers through the constant changes that occur during the dying stage of life (Ellington et al., 2013). Similarly, White & Gilstrap (2015) found "going with the flow" as a component of in-home hospice care that is integral due to the unpredictability of caring for patients who are dying. Finally, Ellington

et al., (2013) emphasized ongoing and comprehensive education for hospice nurses, and they suggest that concentration on family caregivers needs to be a part of this education.

These articles reveal that while stress and death anxiety are topics of concern for hospice and palliative care nurses, they are not higher in this particular branch of nursing than others. While differences in perceived stressors exist between in-home and inpatient hospice nurses, they are not statistically significant. In-home hospice nurses must consider additional factors when caring for their patients in the patients' homes, which may be the cause for differences in stress between in-home and inpatient nurses. Education, personality, attitudes, and personal beliefs are factors that play a role in one's experiences of stress and anxiety, and the authors of these studies have provided suggestions to limit the extent of these occurrences.

Professional Compassion Fatigue, Burnout, and Compassion Satisfaction

A topic that is common in the literature is professional compassion fatigue (PCF). As cited in Melvin (2012), PCF was termed by Figley (1983) as "a state of tension and preoccupation with the cumulative impact of caring" (p. 606). In other words, PCF is the "cost of caring" for others that professionals can experience, and it can negatively impact their careers (Slocum-Gori, Hemsworth, Chan, Carson, & Kazanjian, 2011). In a descriptive, qualitative study in which six hospice and palliative care nurses were interviewed, the following three themes emerged: risk for professional compassion fatigue in exposure to repeated deaths over extended periods of time, physical and emotional costs of providing end-of-life care, and setting boundaries and using healthy coping strategies (Melvin, 2012). To protect themselves against developing PCF, the nurses interviewed stated the need to put their experiences with caring for the dying into perspective, so as to not let the experiences overcome them (Melvin, 2012). The nurses also reported physical and mental difficulties, such as feeling exhausted or not being able

to feel refreshed after a weekend (Melvin, 2012). Concerning coping strategies, the nurses stated talking with colleagues, reflection, exercise, and supportive peers as methods and supports that enabled their work in palliative and hospice care (Melvin, 2012). This study supported previous research that PCF is a concern for palliative and hospice nurses (Melvin, 2012).

Along with PCF, burnout and compassion satisfaction are topics that are commonly researched in the nursing and palliative care literature. Many studies have looked at how these components affect hospice and palliative care professionals due to the sensitive and emotionally-draining nature of their work. When a professional experiences burnout, he or she may have “emotional exhaustion, depersonalization, and reduction of personal accomplishments” (Jenaro, Flores, & Arias, 2007, p.80). Working with patients who are dying on a daily basis can lead to feelings of hopelessness in hospice professionals; moreover, having a heavy workload, lack of support from co-workers, and believing that one’s efforts do not make a difference in his/or her patients’ lives can contribute to burnout (Alkema, Linton, & Davies, 2008). However, caring for patients at the end of life does not always lead to emotional distress. Compassion satisfaction in healthcare professionals comes from the emotional rewards of caring for others; it is the opposite of compassion fatigue (Slocum-Gori et. al, 2011). Compassion satisfaction is related to witnessing positive change in patients and understanding the impact that hospice care has for them and their families (Alkema, Linton, & Davies, 2008). Radley and Figley (2007) state that having a positive effect, being optimistic, utilizing social resources, and leading a balanced lifestyle contribute to and enhance feelings of compassion satisfaction (as cited in Alkema, Linton, & Davies, 2008). Alkema, Linton, and Davies (2008) investigated the relationship between self-care, compassion satisfaction, compassion fatigue, and burnout in hospice care professionals using the Professional Quality of Life Assessment (PRQOL-RIII), which consists

of the three subscales of compassion satisfaction, burnout, and compassion fatigue, and the Self-Care Assessment Worksheet (SCAW) that measures the degree to which people engage in self-care activities. Data analysis was performed on 37 hospice care professionals' responses to these measures to see if any correlations existed between the subscales of the PRQOL-RIII and the SCAW. Results showed a strong negative correlation between compassion satisfaction and burnout, a negative correlation between compassion satisfaction and compassion fatigue, and a strong positive correlation between compassion fatigue and burnout (Alkema, Linton, & Davies, 2008). The study also revealed that burnout and compassion fatigue were negatively correlated with all aspects of self-care, except physical care, while compassion satisfaction correlated with emotional care, spiritual care, and balance between work and personal life (Alkema, Linton, & Davies, 2008). The findings of this study suggest that performing a collection of self-care activities can help one manage symptoms of burnout and compassion fatigue (Alkema, Linton, & Davies, 2008).

Another study that looked into these concepts found similar findings. Slocum-Gori et al. (2011) measured PCF, compassion satisfaction, and burnout in the hospice and palliative care workforce in Canada. They also used the Professional Quality of Life Scale (ProQOL-RIII) survey, and found a positive correlation between compassion fatigue and burnout, a negative correlation between compassion satisfaction and burnout, and a negative correlation between compassion satisfaction and compassion fatigue in 503 hospice and palliative care workers (Slocum-Gori et al, 2011). Additionally, the authors found that the type of services provided impacted levels of compassion fatigue and burnout, but not compassion satisfaction; for example, the respondents who provided assistance with relief from physical, emotional, and/or spiritual pain or distress to their patients reported significantly higher levels of compassion

fatigue and burnout than those who did not (Slocum-Gori, 2011). This trend was the same for those who provided psychosocial support to patients and/or families and emotional support to other team members (Slocum-Gori, 2011). Pertaining to nursing specifically, nursing had the highest level of compassion fatigue, as well as the highest level of burnout (Slocum-Gori, 2011). This finding could be related to Casarett et al.'s (2011) findings of low job satisfaction in nursing. Considering burnout alone, Sardiwalla, VandenBerg, and Esterhuyse (2007) investigated how stressors experienced by hospice workers and the coping strategies they utilize can be used to predict the extent of burnout using a nonexperimental prospective design. They utilized the Maslach Burnout Inventory to measure levels of burnout, the Experience of Work and Life Circumstances Questionnaire to measure work-related and non-work-related stressors, and the Cope Scale to measure coping strategies; results indicated high levels of burnout in the hospice workers in the sample related to work-related stressors (Sardiwalla, VandenBerg, & Esterhuyse, 2007).

Professional compassion fatigue (PCF) and burnout are concerns for this workforce, as caring for the terminally-ill is a complex and challenging task. Slocum-Gori's (2011) finding that nurses had the highest level of PCF compared to other health care professionals in their sample is pertinent, and further research could shed light on factors contributing to this phenomenon. However, coping strategies can prevent the development of these issues. Working with hospice patients can also lead to compassion satisfaction, showing that health care professionals in this field can have positive experiences in this line of work.

Emotional Challenges and Resilience

Along with stress, PCF, compassion satisfaction, and burnout, it is important to understand the emotional challenges that hospice and palliative care nurses face in their daily

work. Gaining knowledge of how these nurses deal with both their own emotions and patients' emotions can enhance training of the workforce, which in turn may prevent poor outcomes. In a recent study, in-depth interviews with 10 hospice nurses in Denmark were conducted in order to explore the emotional challenges experienced while working with patients; the authors of the study derived four main themes from the data that identify ways in which hospice nurses deal with the emotional challenges presented to them every day. (Ingebretsen & Sagbakken, 2016). The themes represent the benefits of having the ability to control one's own emotions, the use of distancing strategies in terms of "emotional distance" between professional and patient, a personal and professional life balance, and the acceptance of death. The first theme, "emotionally touched," explains the nurses' explanations of being affected by the emotions of their patients while also controlling their own emotions; many stated needing a balance between their own feelings and the feelings of their patient (Ingebretsen & Sagbakken, 2016). The second theme, "identifying and distancing," represents the different ways in which nurses identify with their patients and then distance themselves emotionally from them; the nurses stated needing to create distance as a way to protect themselves from the suffering, and they used certain distancing strategies to do so (Ingebretsen & Sagbakken, 2016). Distancing strategies are similar to coping strategies in the fact that they enable hospice and palliative care nurses to continue working with terminally-ill patients. "Person and profession," another theme described in this study, pertains to the nurses' strong feelings of maintaining a balance between their personal and professional lives (Ingebretsen & Sagbakken, 2016). The final theme, "closeness to death-a reminder of life and death," represents feelings of acceptance of death as a part of life; some of the participants also explain that they feel honored to serve people in the final stage of their lives (Ingebretsen & Sagbakken, 2016).

Dealing with emotional challenges on a daily basis is not as easy task. The people who choose to work in hospice and palliative care must deal with death often, and resilience is needed to remain in the field for a prolonged period of time. Ablett and Jones (2007) interviewed 10 palliative care nurses recruited from a hospice in England to analyze what personal characteristics allowed them to be resilient and maintain well-being in their line of work. Ten themes emerged from the data which related to "...a high degree of commitment and sense of purpose about their work" (Ablett & Jones, 2007, p.737). The nurses interviewed in this study indicated actively choosing to work in palliative care, past personal experiences with death, making a difference, and having awareness of their own spirituality as factors that contributed to their ability to work with terminally-ill patients (Ablett & Jones, 2007). Certain personal factors, such as attitudes toward caregiving, play a significant role in enabling a person to work in the field; other studies have similarly found that individuals will cope with death and manage their feelings in their own ways (Martens, 2009; Peters, Cant Sellick et al., 2012). The Model of Human Occupation (MOHO) states that each person is comprised of volition, habituation, and performance capacity, and the way that these components within a hospice and palliative care nurse interact will determine how resilient they are to emotional challenges they face.

Impact of Death on Hospice and Palliative Care Professionals

Much of the literature reviewed pertains to stress, burnout, and compassion fatigue. However, a topic less addressed is that of how death impacts the lives of hospice and palliative care nurses in a long-term perspective. Experiencing death not only causes short-term problems, such as burnout, but also changes one's perspective on death. Karlsson, Ehnfors, and Ternstedt (2008) interviewed five inpatient hospice nurses from a hospice ward at a university hospital in Sweden two times over the course of 11 years to explore their thoughts, feelings, and attitudes

about working in a hospice ward over a prolonged period of time. When first interviewed, each of the participants held two years of experience in hospice nursing; data analyzed from the first set of interviews was conceptualized as “death as an agent of change” (Karlsson, Ehnfors, & Ternestedt, 2008). This theme was built upon the nurses’ explanations of realizing that they too would die eventually, their reevaluations of their own values and daily lives, and being able to create barriers between themselves and thoughts of death outside of work (Karlsson, Ehnfors, & Ternestedt, 2008). Creating barriers is similar to the process of “distancing” oneself from patients’ feelings to prevent becoming overwhelmed which was described by nurses interviewed in Ingebretsen & Sagbakken’s study of emotional challenges in hospice nurses (2016). Data from a second set of interviews conducted 11 years later was conceptualized as “death as a companion in life;” this theme is comprised of nurses’ descriptions of becoming adapted to death, living in the moment on a deeper level, and feelings of confidence in their abilities to do their work (Karlsson, Ehnfors, & Ternestedt, 2008). Creating barriers between thoughts of death and leisure time was still important to the nurses during the second interviews as well, but the ability to do so had improved over time (Karlsson, Ehnfors, & Ternestedt, 2008). These two themes, both representing different stages in the participants’ careers, show that death impacted the lives of the nurses, as their thoughts concerning death and their values in life changed. Having to actively create a barrier between one’s work life and personal life also constitutes a major impact on life. The nurses’ stated that most of their personal changes derived from their work; therefore, working in hospice for an extended period of time has major impacts on one’s life, although these changes are not necessarily negative (Karlsson, Ehnfors, & Ternestedt, 2008).

Similar evidence was found in Sinclair’s (2011) study, which sought to understand the impact of death and dying on palliative and hospice care professionals including physicians,

nurses, psychologists, and spiritual care providers. In general, participants interviewed in this study reported their exposures to death and dying as a positive thing; their work caused them to reflect upon and accept their own immortality, and it enhanced their sense of spirituality (Sinclair, 2011). Some participants, however, reported on the “ugliness of death,” where witnessing the suffering of a patient and that patient’s family was emotionally difficult for them (Sinclair, 2011). Therefore, professionals working in this field are impacted by the deaths of their patients in negative ways as well, even as the author of the study concluded that, overall, participants labeled death as a meaningful stage of life (Sinclar, 2011). While working in hospice and palliative care is emotionally and mentally challenging, the people who choose to work in the field often are prepared with the skills and personality characteristics needed to do successfully work with terminally ill patients. Palliative care nurses in Ablett and Jones’s (2007) study described choosing to work in palliative nursing as a positive career choice, and those who had worked in the field for a number of years reported hoping to stay in the career. This demonstrates that a certain attitude upon entering the field may determine one’s ability to handle the care of hospice and palliative care patients.

Although emotionally challenging work, the literature suggests that hospice and palliative care professionals change and grow personally through their work with dying patients (Ingebretsen & Sagbakken, 2016; Ablett & Jones, 2007; Karlsson, Ehnfors, & Ternestedt, 2008; & Sinclair, 2011). In a metaphorical analysis of in-home hospice nurses experiences, participants indicated fulfilling “a calling” by working in hospice care, and they “...positioned themselves as different from most others ‘who can’t do it’” (White & Gilstrap, 2015, p. 307). This supports reports from nurses that choosing to work in the field was a positive choice for them (Ablett & Jones, 2007). Another metaphor that emerged in White & Gilstrap’s (2015) study was that of a

“hallowed ground,” which represents the nurses’ gratitude for being able to work with terminally-ill patients and their families. Feeling honored to work with this population motivates professionals to continue working in the field (Ingebretsen & Sagbakken, 2016; White & Gilstrap, 2015). White & Gilstrap also deemed “life lessons” as a metaphor for in-home hospice nursing, where nurses reflected upon their own lives and understood death from a different perspective.

Review of the literature found that PCF, burnout, and compassion fatigue impact hospice and palliative care nurses’ experiences while working with terminally-ill patients. Additionally, nurses perceive stress differently across settings and from their professional peers. Many of the studies found that this line of work impacted the nurses’ lives positively and negatively, but many strategies were found to be used which enabled the nurses to perform their work tasks, as well as embrace and reflect upon how it changed their own lives.

Methods

Participants

Participants in this study included three in-home hospice nurses employed by a home health and hospice care agency in a rural area in Pennsylvania. The inclusion criteria used in this study are as follows: a.) having at least a licensed practical nurse certificate, b.) being 18 years of age or older and c.) working as an in-home hospice nurse. The participants were Caucasian females between the ages of 61-64 years, and they all lived in the rural area in which the home health and hospice agency is located. All participants provide full-time hospice and home health care services within patients’ homes. One participant held a bachelor of science in nursing (BSN) degree, and the other two participants held an associate of science in nursing (ASN) degrees. One of the participants also held a bachelor degree in elementary education and music. All 3

participants were within five years of retirement and were mothers and grandmothers in their personal lives.

Sampling Procedures

Convenience sampling was used to recruit participants. This data collection procedure was chosen because of the researcher's professional connection to the medical director of the hospice program and to ensure that the study could be completed within the given time frame. The medical director reached out to the nursing staff of the agency prior to the study via an informal email to find interested participants, and they were made aware that they were not obligated by the hospice agency to participate. The medical director is not responsible for creating the nurses' schedules or hiring/terminating their positions; therefore, the researcher was not concerned with coercion of the participants. No screening questions were used to determine eligibility for the study, and collaboration with the director of the program ensured that the inclusion criteria were met. Site consent was obtained. After the study received approval from Elizabethtown College's Institutional Review Board, collaboration between the researcher, the program director, and the nurses via telephone communication was used to set up the interviews.

Research Design

This study is qualitative in nature, and semi-structured interviews were conducted which lasted approximately 14-23 minutes each. The interviews were audio-recorded and then transcribed verbatim. The interview guide was created by the researcher using a modified version of the Assessment of Occupational Functioning Collaborative Version (AOF-CV), which is an assessment tool based directly on the MOHO concepts. The researcher modified the assessment to exclude questions that were not relevant to the research questions. The assessment contains a scoring component, but it was not utilized in this study. Probing questions borrowed from the

study “Stress in Hospice Nurses: A Qualitative Study of Their Experiences of Their Work and Wellbeing,” were also added to the interview guide (Tunnah, Jones, & Johnstone, 2012). The probing questions served to prompt the participants to provide further information about a topic. The interviews focused on the hospice aspects of the participants’ jobs, although home health care was mentioned by the participants.

Transcription of the interview data did not involve the participants. General principles of data analysis described by Taylor (2017) were used; active reading of all three interviews and the creation of conceptual labels for sections of data helped to define themes that represented important aspects of the interview material. After analysis took place, the researcher used member-checking to ensure that all themes and interpretations made about the data were true to what the participants originally meant by their responses. Member-checking ensures the accuracy of facts and information gathered in the study by asking the original stakeholders to review the meta-data created by the researcher (Taylor, 2017). If a participant had any concerns, they were asked to reply to the researcher via email or phone within two weeks. None of the participants responded to the member-checking emails.

Results

Five overarching themes emerged from the interview data. These themes represent trends in personal characteristics, interests, values, and roles that were similar amongst the sample of nurses, and they line up theoretically with concepts of the MOHO. As a whole, the themes represent important aspects of the lives of in-home hospice nurses which contribute to their occupational performance.

Theme 1: A Caregiving “Personality”

The nurses each discussed their roles as mothers, grandmothers, and caregivers by emphasizing the importance of these roles and associating them with their interests, values, and habits. Many of the activities they are interested and actively participate in are family-centered. “A Caregiving ‘Personality’” represents the nature of the roles outside of the workplace that the nurses engage in; caregiving is an essential component of the mother and grandmother roles. Specific to occupational therapy terminology, “care of others” is an instrumental activity of daily living (IADL) defined as “arranging, supervising, or providing care for others” (AOTA, 2014, p. S19). The nurses in this study shared that they babysit/and or provide for grandchildren, participate in activities with their grandchildren or are involved with youth organizations, and care for ill family members. These activities all constitute “caring for others.” The nurses articulated that they spend a large component of their time outside of work in these caregiving roles, demonstrating that caregiving is a salient part of their identities.

Participants conveyed the importance of their family through sharing ways in which they care for and interact with family members. For example, Participant #1 shared how taking care of her older relatives outside of work is an interest that she often participates in:

“...caring for older relatives. My mother-in-law, my sister, you know, different people who are sick, is probably what, what I do most...”

Participant #1 did not indicate this act of caregiving as a burden or inconvenience; rather, she conveyed it as a meaningful life role that fills a large amount of her time outside of the workplace. Furthermore, the participants stated that caregiving through their roles as mothers and grandmothers occupied their top interests and was of high importance to them personally.

“I have grandchildren, so I love taking care of grandchildren.” -Participant #1

“I always saw myself in the caregiver role from the time I was 11. There were 7 children in my family, and my mother had to work. So, I made meals, and I took care of the rest of the family. And I always seem to be the caregiver. My mother died young, 52, so all my siblings kind of look at me as the mother. But I always had that role. I was a nurse’s aide, and then I decided that I wanted to be a nurse.” -Participant #3

Participant #2 shared how she believes caring and helping others is a part of who she is. This internal characteristic that she describes is a motivating factor that contributes to the occupations that she chooses to participate in:

“I think it’s pretty much my personality...And whether it was in teaching, nursing, or, you know, I think, it’s my...it’s me.” -Participant #2

Overall, each participant emphasized the importance of family in their lives, and a substantial portion of their interests, values, habits, and roles involved their family. Their career choices to become hospice nurses as well as their devotion to caring and providing for their family members constitutes a caregiving “personality.” In Figure 1, this theme is situated above the person to portray how the caregiving personalities of these nurses influence the occupations and routines they participate in.

Theme 2: Flexibility and Self-Sacrifice in Time-Management

Being in-home health care providers, the nurses interviewed perform their services in patients’ homes. This requires the nurses to travel between patients’ homes throughout the workday to make visits. The agency in which the nurses are employed, located in a rural area, serves people who are spread across a large geographical area. Therefore, much of the day is spent driving. This theme represents the creativity that nurses use to complete their work responsibilities across varying environments and contexts, as well as the time they sacrifice

outside of their shifts to complete documentation. Two of the participants demonstrated flexibility in using the time spent driving on the road to prepare for work and to also complete documentation.

“...my area is a huge geographic area, so I oftentimes have at least half an hour in between visits, uh, I’m driving, and so that is a time to think about the visit I just made, and also, to kind of in my mind to be planning for the next visit.” -Participant #1

“...sometimes because of the circumstances, you can’t finish your computer work, so I usually pull in the parking lot of the fast food place and finish up on my computer.” - Participant #3

The nurses also stated the importance of being flexible with their daily work schedules. On a typical workday, they plan and organize their schedule for the day in the morning at the main office of the hospice agency. There is not a predetermined amount of time to spend with each patient, and the nurses can only estimate how much time they will have to spend there. Therefore, being flexible is essential when navigating through one’s schedule for the day. One nurse shared how she has learned to be more lenient with her schedule:

“Ah, I am a person that likes to stick to the schedule. And sometimes, I know I’m too firm about it.... So, I try not to rush people when I go into their home. And, it doesn't really upset me, I just think, “Okay, now I’m running a little late.” But I don’t give my patients a specific time, it’s like a general time when I’ll get there. But I’m a... rigid time-keeper. I’m still trying to work on that.” -Participant #3

Another participant in the study shared how bi-weekly meetings with the staff affected the layout of her work day. This example shows that flexibility is a required characteristic of this setting:

“Every other week we meet. We had a meeting yesterday. Actually went for 2 hours, and that’s difficult because then we still had to get out. I had an admission to do, I had visits to do, and I had to fit that in... You have to be very flexible.” -Participant #2

The nurses also displayed sacrifice of their own personal time in completing documentation. For each of the participants, the demands of their job often extended into time outside of their work hours, impacting time spent with their families. Working on documentation for work at home demonstrates that their roles as nurses impacted the habits, routines, and roles of their personal lives.

“Yes, so it’s usually... 2-3 hours in the evening, or the wee hours of the morning (laughs) to, to finish up the documentation.” -Participant #1

“But, ummm, negatively, ah, this isn’t hospice, this is nursing in general, that there’s a lot of things that need to be done after your 8-hour shift. Like there’s a lot of computer work and that kind of thing. And, like sometimes my family will say, ‘are you still on that computer?’ And I’ll say, ‘Yeah, I have to get this finished.’ But that’s a negative part of it. That’s the part I don’t like.” -Participant #3

This theme intertwines with Theme 1: “A Caregiving Personality” in the fact that the nurses still provide care for and spend time with their families despite work requirements spilling over into their personal time.

Theme 3: Value of Patient Perspectives

This theme highlights the value which each nurse places on the perspectives and opinions of their patients. “Value of Patient Perspectives” displays the nurses’ ability to learn from and grow personally from their interactions with patients and their families within patient homes. Meeting new patients and learning about them positively impacted the nurses in their own lives.

“And, and trying to be more understanding. I think, uh, seeing...umm, this job, is, is really very helpful when you get to see all kinds of lifestyles, and all kinds of people, personalities, and learning to accept that, I think helps you on a day-to-day basis.” -

Participant #1

“Because you just, just get to know so many people, and there’s wonderful wonderful people, and I don’t think you ever stop learning from people. How they cope, and, just how they see things.” -Participant #1

These statements display the appreciation of meeting new people and understanding and accepting different ways of life. Participant #1 values the lessons from her patients because they help her grow personally. She has learned throughout her career to accept and appreciate different lifestyles. The value in patient perspectives also reveals itself in the nurses’ abilities to keep an open mind when entering patients’ homes.

“But you really don’t know people, like sometimes, unfortunately, we have a pre-formed opinion of people. And then I go into a home and I find out, ‘wow, they’re really a neat person.’” -Participant #3

One participant described the effort she makes to connect with her patients despite having to perform documentation on a laptop while she is visiting them.

“...and most of the time we can chart on our computer while we’re seeing the person, trying not to ignore them and focus on the computer. Because I know some people feel that way, that we’re focused more on that, but I try not to do it. I try to look up, make eye contact, and let them now we’re really listening.” -Participant #3

Participant #3’s efforts to give full attention to her patients despite having to document throughout visits are an example of respecting patients and valuing their

feelings. Through actions like these, the value placed on the patients' perspectives is evident.

Theme 4: Participation in Stress-Relieving Interests

Considering the nature of hospice care, creating a healthy balance between one's work and personal lives is important for mental and emotional health. This theme is defined by the nurses' engagement in interests outside of work that they perceived as stress-relieving and provided enjoyment and entertainment. Participant #1 has a great passion for gardening, and the tasks of planting and weeding contribute to her ability to deal with stress present in her life.

"So...planting something and nurturing something...so, I really think about what I'm doing, and, and umm...use it as a symbol for what I'm dealing with emotionally. So, that's one thing. And then, anything that's an exercise, so whether it's swimming, or walking, or digging something, you know, whatever. I think it's a good stress-reliever." -Participant #1

Participant #2 described how being involved with her family was a way that helped her deal with stress. She attends many of her grandchildren's sporting events. For her, this activity of spending time with family and participating in their interests was enjoyable. Furthermore, she is highly motivated to go to sporting events; this is seen when asked why she enjoys watching her grandchildren play sports: "...it's family and I love my family."

Participant #3 described talking on the phone with friends, going out to lunch with sisters, shopping, going to the movies, and being active with her grandchildren as activities that interest her and provide entertainment. Overall, the three nurses described active

lifestyles outside of work that contribute to a healthy life balance between work and their personal lives.

Theme 5: Finding Purpose Outside of Work

When asked what activities provide a sense of purpose in their lives, the nurses named many activities that were not tied to their work as hospice nurses. This theme is constructed on the idea that the nurses find meaning in activities besides nursing, although their work as hospice nurses certainly provides them with a feeling of purpose. Finding purpose outside of work coincides with the MOHO concept of volition, which is the process by which people are motivated toward and choose activities to engage in. Participating in activities that one values, is interested in, and provides meaning, demonstrates volition.

When asked what gave them a sense of purpose in life, the nurses stated:

“...working with kids in any way, so whether that’s through the church programs, or the 4-H programs. When my kids were younger and in those things, I was real active, umm...but I kind of got away from it, uh, since then, but those kinds of things I think, like helping children give me a sense of purpose.” -Participant #1

“I think working in the church, when I do the music and that, ‘cause it’s, ah, an important part of the service each week...” -Participant #2

“...And as far as outside of work, ah, again, I know I keep saying this, but my family. I was raised in a family of 7, and we were all...still are all very close.” -Participant #3

Through youth programs, playing music in church, and spending time with family, these nurses demonstrate finding purpose in other life roles outside of working as nurses.

Figure 1 graphically represents the five themes of this study by arranging them around a person. This demonstrates the impact that the qualities and characteristics discussed by this

sample of in-home hospice nurses have on their habits, routines, and roles. The themes represent the personal characteristics that contribute to occupational participation and performance, and they help construct the occupational identities of these nurses within their community.

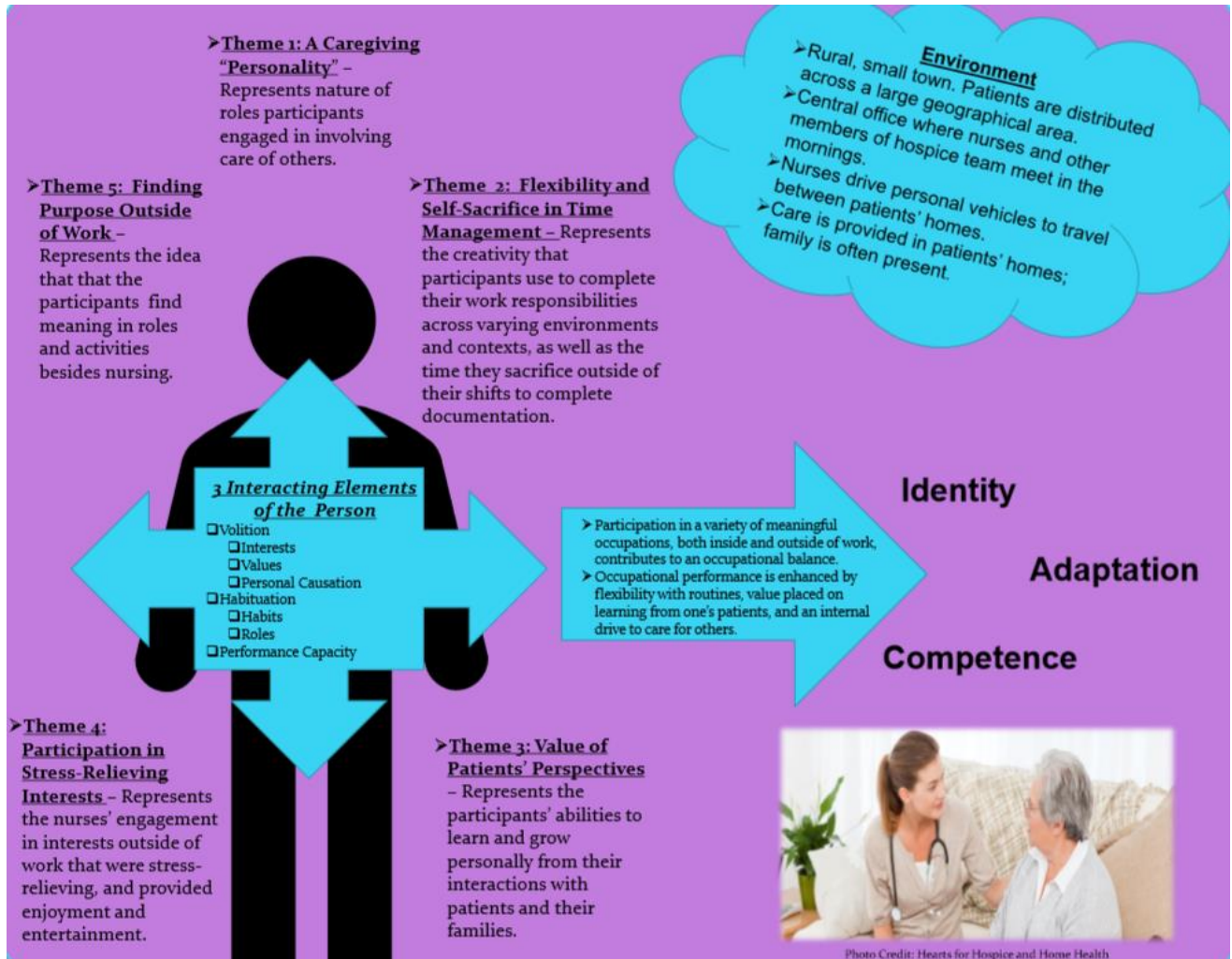


Figure 1: Concept Map of MOHO and Themes

Discussion

Volition, Habituation, and Performance Capacity

The themes of this study are based on the three interacting elements of the person defined by the MOHO: volition, habituation, and performance capacity. In Figure 1, they are arranged around a person to represent their connection to the MOHO concepts and to exemplify their

importance in facilitating participation. The three in-home hospice nurses interviewed reflected on the roles, habits, routines, interests, and values important to them both in their work as hospice nurses and in other meaningful life roles. This study sought to conceptualize a broad view of the work and personal lives of hospice nurses, since many studies in the nursing literature focus only on the challenges associated with the profession. Rather than concentrating solely on the impact of caring for terminally-ill patients on the nurses' personal lives, the MOHO allowed these participants to be conceptualized as whole persons in which their volitions, habituations, and performance capacities interact with their environments to influence performance. Interview data suggests that while documentation impacts daily habits and routines, participation in meaningful occupations is otherwise not hindered by emotional or mental fatigue caused by hospice work in this sample of nurses. This correlates with previous findings that stress and death anxiety is not higher in hospice nursing than in other disciplines (Peters, Cant, Sellick et al., 2012; Peters, Cant, Payne et al., 2013).

The first theme that emerged from interview data, "A Caregiving 'Personality,'" encompasses qualities of participants' habituation, volition, and performance capacity that are associated with caregiving centered-occupations. In terms of habituation, the participants described habits and roles driven by their desire to care for others and spend time with loved ones outside of work. The participants in this study identified themselves as mothers, grandmothers, caregivers, sisters, and friends, indicating that their responsibilities outside of their nursing careers revolve around these life roles. Their daily routines are driven by the meaningful occupations associated with familial roles. When considering volition, interests and values pertaining to friends and family impact activities the participants choose to participate in. Therefore, motivation arises from a desire to pursue occupations involved with caregiving. The

interview data also revealed that the nurses' performance capacities, or their underlying mental and physical abilities to experience occupational performance, enable them to work as hospice nurses (Forsyth et al., 2014). Performance capacity is enhanced by participation in roles outside of work, as they provide meaning, purpose, and balance to the nurses' lives. Similarly, Alkema, Linton, and Davies (2008) found that compassion satisfaction correlated with emotional care, spiritual care, and balance between work and personal life in hospice professionals. Whether the family and work roles of the nurses in this study were chosen because of their caregiving personalities, or if their roles influenced and/or changed their personalities over time is difficult to discern. While it is beyond the scope of this study to determine this relationship, interview data suggest that the inherent qualities present in the participants influenced the caregiving-associated roles they chose to pursue in their lives. Furthermore, participation in these roles over several decades demonstrates a life-long dedication to serving and caring for others, whether it be in the hospice setting or in their personal lives.

The theme "Flexibility and Self-Sacrifice in Time-Management" relates to habituation as the nurses' habits and roles outside of work are impacted by their job responsibilities. The nurses stated that they often complete documentation at home in the evenings, and one participant even described waking up early to document before work. This sacrifice of personal time disrupts routines with friends and family and was reported by all participants. One participant described needing the weekends to "catch up" on household chores because she lacked time on weeknights to complete them. The nurses also spoke about activities they want to participate in but currently do not due to lack of time. All participants are nearing retirement, and they indicated plans for how they plan to spend their time in the future. This shows motivation to engage in certain occupations, but time-restraints have limited their ability to do so currently. Therefore, while

self-sacrifice in time-management has been essential for the nurses to meet the demands of their nursing roles, it has also impeded other meaningful life roles. Additionally, flexibility in schedule-making is an essential characteristic indicated by the nurses that have increased their occupational performance in meeting the demands of a patient population that is distributed over a large geographical area.

The theme “Value of Patient Perspectives” developed from the nurses’ descriptions of how their lives had changed due to experiences with their patients. They strongly value the perspectives and lifestyles of their patients, and they stated that they had grown personally from patient and family interactions within patients’ homes. The ability to learn from and respect the lives of others different from oneself creates satisfaction and gives meaning to the work that the nurses in this study perform. While it is a fact that serving patients with terminal illnesses is mentally and emotionally challenging, the ability to take value from experiences with patients contributes to the ability to remain working as a hospice professional. Personal growth contributes to volition because the interests, values, and personal causation are influenced by life lessons taken away from patient experiences.

“Finding Purpose Outside of Work” encompasses the participants’ reflections of being highly active in activities and interests outside of their jobs that they perceive as stress-relieving. They also stated gaining a sense of purpose from roles other than nursing, which indicates volition to continue engaging in meaningful occupations that are not directly associated with their jobs. The roles that compose the personal lives of the participants contribute to a balance between work and leisure. This theme correlates with Ingebretsen and Sagbakken’s (2016) theme “Person and Profession,” which represents nurses’ feelings of maintaining a balance between their personal and professional lives. Occupational balance is important for anyone; however,

hospice professionals especially benefit mentally, emotionally, and physically from engagement in meaningful, purposeful occupations outside the realm of their careers. Research has shown that burnout and compassion fatigue are curbed by one's ability to find meaning in their life roles. This study demonstrates the positive impacts of participation in a wide variety of occupations on the lives of hospice nurses.

Overall, the themes that emerged from the data reveal that the participants have achieved occupational adaptation in their careers and personal lives. Occupational adaptation is comprised of two essential elements: occupational identity and occupational competence. These concepts of MOHO are influenced by the internal elements of a person and the environments that participation takes place within. Occupational identity is generated from experience and is the sense of who one is (Forsyth et al., 2014). The identity of the in-home hospice nurses derives from their personalities, the interests and values associated with the roles they choose to engage in, and the meaning and purpose they take away from the experiences within their career and in their personal lives. Occupational competence is one's ability to sustain a particular pattern of doing that supports his/or her identity (Forsyth et al., 2014). Results of this study indicate competence because the roles, habits, and routines described by the participants provide them with an occupational balance. The balance between work and other meaningful life roles achieved by these three in-home hospice nurses contributes to their professional and personal identities within their community. Through reflections of their work and life experiences, the nurses showed that their identities, and everything that encompasses who they are as people, are present in the way they provide care to patients and interact with family, friends, and others within the community. Identity, competence, and adaptation are shown in Figure 1 as the results

of the interactions between the internal, personal characteristics (represented by the five main themes) of the nurses and the environments in which their occupations take place in.

Environments of In-Home Hospice Care

The environment is an essential component of the MOHO. The aspects of the environments discussed by this sample of in-home hospice nurses are represented in a cloud; this is meant to portray how all occupations take place within environments, and the particular places, spaces, and people associated with those environments influence occupational performance. Analyzing the experiences of in-home hospice nurses through this occupation-based lens brings attention to the unique work environments where these professionals serve patients. Unlike in other medical settings, in-home services involve continuously changing environments, so adaptation by medical professionals to provide quality care is necessary. Both the physical environment, comprised of objects and spaces, and the social environment, which includes tasks and social groups, impact nurses' participation in hospice care and other meaningful roles (Forsyth et al., 2014). Considering the physical environment, the participants work spaces include the main office where they begin work each day, their personal vehicles used to travel between patients' homes, patients' homes, and the community in which the patients live. Environments within the community such as churches, schools, restaurants, and grocery stores, as well as homes, were named by the participants as locations where they participate in other life roles. In terms of the social environment of their work, the main tasks expected of the nurses pertain to patient care. Social groups include the families and patients the nurses interact with daily, as well as other nurses and health care professionals from the hospice agency. Outside of work, the participants described completing tasks associated with various roles and interacting with family, friends, and community members across a variety of settings.

The agency's main office not only provides the participants of this study with space where they can prepare their daily schedules and gather necessary supplies, but it also allows for interaction with other medical, spiritual, and administrative professionals. Monthly team meetings also take place in the office. The nurses work independently throughout the day, so having a place to speak with others to collaborate on patient care is beneficial to them. Martens (2009) found that in-home hospice nurses perceived "lack of an opportunity to talk openly with other staff members" as more stressful than inpatient hospice nurses in their study; workplace environmental characteristics were not delineated, so the cause of this perceived stressor cannot be determined. Nurses in this study were satisfied with the communication opportunities afforded to them by their workplace and appreciated collaboration with their co-workers, whether it be in the office face-to-face or over the telephone while making house visits. This demonstrates that a central location providing a communication system within home care agencies is needed to support a healthy and efficient workforce.

In-home hospice care is special in this sample of nurses because of the large, rural, geographical area where they are employed. Their patients are dispersed throughout the county; therefore, it is not uncommon for participants to have a 30-45 minute drive between patient homes. Driving time was identified by Participant #1 as a period to gather her thoughts and mentally prepare for her next patient visit. This time is not afforded to nurses working in a hospital or skilled nursing setting. The car itself also serves as a place to complete work responsibilities, as Participant #3 explained pulling over in fast food parking lots to quickly finish documentation on her laptop between patient visits. In this way, the car itself becomes a workplace environment where tasks are completed. The nurses in this study demonstrate creative

and productive use of time while traveling. Comparison studies between home health and inpatient services would shed more light on differences between the two settings.

Serving patients and their families within their own homes allow a health care professional to understand them on a more intimate, personal level. However, one must be aware of how his/or entrance into the family's personal space is received. Ellington et al. (2013) found that family-centered and at-home care requires a nurse to understand different family dynamics and each family member's perspective. Key leaders in the hospice and palliative care industry surveyed in their study stated that nurses who work in patient's home must remain aware that they are a "guest" invited into the patient's home (Ellington et al., 2013). The participants in this study showed that caring for patients in the personal space of their homes gives themselves insight into family dynamics and life styles that are different from their own.

In this study, the small, rural community enhanced the participant's perceptions of how their work as hospice nurses impacted the lives of those they care for. Each nurse stated how their interactions with other community members were positively impacted by their work as hospice nurses. Because of the small size of the population of the area in which the hospice program is located, it is not uncommon for the participants to see patients' family members within the community. Being recognized and remembered by families who they have helped reminds the nurses of the good they do within the community. The nurses shared that they feel their work's importance is validated when a person in the community shows their appreciation by thanking them in places such as the grocery store or at the gas station. In a qualitative study of in-home hospice nurses, Tunnah, Jones, and Johnstone (2012) found that making a difference in the lives of patients contributed to job satisfaction. Similarly, this study found that a small-town

environment contributed to nurses' feelings of fulfillment because they are regularly approached by community members who show gratification for the nurses' care of a family member.

Overall, the environments of this particular hospice and home health agency fostered a sense of occupational identity for the participants within their community and contributed to occupational performance. More studies into the relationships between home health care providers and the communities they live in are necessary to understand the impact that providing in-home care has on the person's identity. This study was conducted in a small community, so there is a lack of an urban perspective on community relationships amongst home health care providers and those they serve.

Assessment – What Does MOHO Bring to the Table?

Current nursing, psychology, psycho-oncology, and social work literature includes both quantitative and qualitative studies of the experiences of hospice nurses. A majority of this research addresses the emotional, physical, and mental challenges experienced by staff. These challenges are caused by caring for patients with terminal illnesses and witnessing death more often than health care professionals outside of the realm of hospice. Therefore, it is essential to assess these issues in the workforce to establish preventative measures to manage work-related stress. Many of the quantitative assessment tools used to assess this population focus on specific issues, such as burnout. However, they do not consider how one's motivation, lifestyle patterns, abilities, and environmental factors interact to influence the experiences and frequencies of these problems.

An example of a quantitative assessment is the Professional Quality of Life Assessment (ProQOL-RIII), which measures factors related to quality of life; it is comprised of three subscales: compassion satisfaction, burnout, and compassion fatigue (Alkema, Linton, & Davies,

2008). Using self-report, caregivers or hospice professionals score themselves in each subscale; scores indicate low, average, or high levels in each category (Alkema, Linton, & Davies, 2008). Example of items on the assessment are “I feel connected to others,” “I like my work as a helper,” and “I feel as though I am experiencing the trauma of someone I have helped” (Stamm, 2010). These items are person-focused, so results of this assessment do not indicate environmental factors that inhibit or enhance compassion satisfaction. Another assessment utilized in the nursing profession, the Nursing Stress Scale (NSS), measures the frequency and sources of stress using a Likert-scale (Martens, 2009). Items on this assessment are situations that can be perceived as stressful by nurses (Martens, 2009). While both of these assessments are extremely useful in understanding specific factors that contribute to compassion fatigue and stress, they do not provide a broad view of the person across different contexts. It is beyond the scope of these assessments to analyze interactions between one’s personal characteristics and the environment. They also do not consider differences across specific work settings, or environmental and social factors outside of nursing.

Many MOHO-based assessment tools would be useful in conceptualizing the lives of professionals who work in hospice care. This study used components of the Assessment of Occupational Functioning Collaborative Version (AOF-CV) to structure interview questions because of the tool’s focus on the internal elements of the person: volition, habituation, and performance capacity. This allowed a deeper understanding of the personal characteristics and strategies used by in-home hospice nurses in managing their careers and lives. Furthermore, knowledge of the values and interests held by these nurses showed motivation for working in this particular field of nursing despite the difficulties that it entails. Another MOHO-based assessment that could be useful in conceptualizing the lives of hospice professionals, the

Occupational Self-Assessment (OSA), analyzes self-perceptions of occupational competence and the impact of the environment on occupational functioning (Asher, 2014). The perceptions of health care professionals' own abilities to work in patients' homes could provide insight on providing client and family-centered care across continuously changing environments. It would also provide professionals with knowledge of strategies to use when caring for someone within his/or her home. Additionally, the Occupational Performance History Interview (OPHI-II), also based on the MOHO, would provide information pertaining to one's occupational identity and competence, environment, and life history (Asher, 2014). Studies have shown that personal experiences can influence one's decision to work in hospice care; for example, Ablett and Jones (2007) found that past personal experiences with death contribute to resilience to emotional and mental stress in hospice. OPHI-II could help researchers shed light on how one's life history, as well as environments, impact working as a hospice health care professional.

Limitations

The participants were all within five years of retirement at the time of their interviews, participated in similar roles outside of the workplace, and worked for the same hospice and home health agency. The homogenous nature of the sample limits transferability of results to professionals working in other practice settings, such as in-home hospice care in an urban community or in an inpatient hospice facility. Caution should also be taken when applying the themes of this study to health care professionals of a different age cohort because life roles change across the lifespan. Another limitation of this study is the lack of researcher triangulation; only one researcher analyzed and coded the interview data. Therefore, the themes discussed offer only a single interpretation of the experiences shared by the participants.

Conclusion

MOHO is well-suited for studying in-home hospice care professionals because it provides a framework for understanding the interaction between one's internal characteristics and the environment. For this study, MOHO provided a framework to conceptualize the interactions between the unique environments of in-home hospice care provided in a small community setting with personal factors of the participants. MOHO highlighted the importance of the nurses' life roles and occupations in their abilities to combat PCF, burnout, and work-related stress. Organizational strategies enabled these nurses to overcome the barrier of time spent documenting. Overall, the nurses in this study achieve occupational performance in their roles as nurses, mothers, grandmothers, sisters, and community members due to motivation embedded in their personality characteristics, values and interests. The balance between professional and personal occupations has contributed to their ability to perform hospice care despite the challenges presented by this field of nursing.

Occupational therapists (OTs) and nurses work together on hospice care teams, so knowledge of how nurses deal with work-related stress can be utilized by OTs to understand their own perceptions of their work experiences in the hospice setting and collaborate more effectively interprofessionally. Nursing has played a role in hospice care for much longer than occupational therapy; therefore, the testimonies of nurses are trustworthy and useful to OTs in enhancing their own abilities to work in hospice care. This study supports the use of an occupation-based model as a framework for analyzing the lives of in-home hospice nurses, and it provides a view of another profession's experiences in a language that OTs are comfortable with.

More occupation-based studies of hospice care professionals, especially occupational therapists, would be beneficial as hospice care needs increase with an expanding older adult population. Further analysis of the impact of environments on professionals working in in-home

hospice care is needed in order to define strategies helpful for interacting with patients and their families.

References

- Ablett, J. R., & Jones, R. S. P. (2007). Resilience and well-being in palliative care staff: A qualitative study of hospice nurses' experience of work. *Psycho-oncology, 16*, 733-740. doi: 10.1002/pon.1130.
- Alkema, K., Linton, J. M., & Davies, R. (2008). A study of the relationship between self-care, compassion satisfaction, compassion fatigue, and burnout among hospice professionals. *Journal of Social Work in End-of-Life & Palliative Care, 4*(2), 101-119. doi: 10.1080/15524250802353934.
- American Occupational Therapy Association. (2015). *Fact sheet: The role of occupational therapy in palliative and hospice care*. Retrieved from www.aota.org.
- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy, 68*(Suppl. 1), S1-S48. <http://dx.doi.org/10.5014/ajot.2014.682006>.
- Asher, I. E. (2014). *Asher's occupational therapy assessment tools: An annotated index*. Bethesda, MD: American Occupational Therapy Association.
- Casarett, D. J., Spence, C., Haskins, M., & Teno, J. (2011). One big happy family? Interdisciplinary variation in job satisfaction among hospice care providers. *Journal of Palliative Medicine, 14*(8), 913-917. doi: 10.1089/jpm.2011.0057.
- Costa, A., & Othero, M. (2012). Palliative care, terminal illness, and the model of human occupation. *Physical & Occupational Therapy in Geriatrics, 30*(4), 316-324. doi: 10.3109/02703181.2012.743205.

Desbiens, J., & Fillion, L. (2007). Coping strategies, emotional outcomes and spiritual quality of life in palliative care nurses. *International Journal of Palliative Nursing*, 13(6), 291-300. doi: 10.12968/ijpm.2007.13.6.23746.

Ellington, L., Cloyes, K., Berry, P., Thomas, N. T., Reblin, M., & Clayton, M. (2013). Complexities for hospice nurses in supporting family caregivers: Opinions from U.S. thought leaders. *Journal of Palliative Medicine*, 16(9), 1013-1019. doi: 10.1089/jpm.2013.0116.

Forsyth, K., Taylor, R. R., Kramer, J. M., Prior, S., Richie, L., Whitehead, J., ...Melton, J. (2014). The model of human occupation. In Schell, B. A. B., Gillen, G., Scaffa, M. E., & E. S. Cohn (Eds.), *Willard & Spackman's Occupational Therapy* (pp. 505-552). Philadelphia: Wolters Kluwer Lippincott Williams & Wilkins.

Ingebretsen, L. P., & Sagbakken, M. (2016). Hospice nurses' emotional challenges in their encounters with the dying. *International Journal of Qualitative Studies on Health and Well-Being*, 11, 1-13. doi: <http://dx.doi.org/10.3402/qhw.v11.31170>.

Jenaro, C., Flores, N., & Arias, B. (2007). Burnout and coping in human service practitioners. *Professional Psychology: Research and Practice*, 38(1), 80-87. doi: 10.1037/0735-7028.38.1.80.

John Hopkins Medicine. (n.d.). Hospice care statistics. *Health Library*. Retrieved from https://www.hopkinsmedicine.org/healthlibrary/test_procedures/urology/hospice_care_statistics_85,P00608.

Kamal, A. H., Bull, J., Wolf, S., Samsa, G.P., Swetz, K. M., Myers, E. R., ... Abernethy, A. P. (2016). Characterizing the hospice and palliative care workforce in the U.S.: Clinician

- demographics and professional responsibilities. *Journal of Pain and Symptom Management*, 51(3), 597-603. doi: <http://dx.doi.org/10.1016/j.jpainsymman.2015.10.016>.
- Karlsson, I. L. K., Ehnfors, M., & Ternstedt, B. M. (2008). Five nurses' experiences of hospice care in a long-term perspective. *Journal of Hospice and Palliative Nursing*, 10(4), 224-232. doi: 10.1097/01.NJH.0000319164.43220.db.
- Martens, M. L. (2009). A comparison of stress factors in home and inpatient hospice nurses. *Journal of Hospice and Palliative Nursing*, 11(3), 144-153. doi: 10.1097/NJH.0b013e3181a1ac87.
- Medline Plus. (2016). What is palliative care? *Medical Encyclopedia*. Retrieved from <https://medlineplus.gov/ency/patientinstructions/000536.htm>.
- Melvin, C. S. (2012). Professional compassion fatigue: What is the true cost of nurses caring for the dying? *International Journal of Palliative Nursing* (18)12, 606-611. doi: 10.12968/ijpn.2012.18.12.606.
- National Hospice and Palliative Care Organization. (2016). Facts and figures: Hospice care in America. *Facts on Hospice and Palliative Care*. Retrieved from https://www.nhpco.org/sites/default/files/public/Statistics_Research/2016_Facts_Figures.pdf.
- Peters, L., Cant, R., Payne, S., O'Connor, M., McDermott, F., Hood, K., ... Shimoinaba, K. (2013). How death anxiety impacts nurses' caring for patients at the end of life: A review of literature. *The Open Nursing Journal*, 7, 14-21. doi: 10.2174/1874434601307010014.
- Peters, L., Cant, R., Sellick, K., O'Connor, M., Lee, S., & Burney, S. (2012). Is work stress in palliative care nurses a cause for concern? A literature review. *International Journal of Palliative Nursing*, 18(11), 561-567. doi: 10.12968/ijpn.2012.18.11.561.

- Sardiwalla, N., VandenBerg, H., & Esterhuyse, K. G. F. (2007). The role of stressors and coping strategies in the burnout experienced by hospice workers. *Cancer Nursing, 30*(6), 488-497. doi:10.1097/01.NCC0000300159.67897.c7.
- 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), 180-187. doi: 10.1503/cmaj.100511.
- Slocum-Gori, S., Hemsworth, D., Chan, W. W., Carson, A., & Kazanjian, A. (2011). Understanding compassion satisfaction, compassion fatigue, and burnout: A survey of the hospice palliative care workforce. *Palliative Medicine, 27*(2), 172-178. doi: 10.1177/0269216311431311.
- Stamm, B. H. (2010). *The concise ProQOL manual, 2nd ed.* Pocatello, ID: ProQOL.org.
- Taylor, R. R. (2017). *Research in occupational therapy: Methods of inquiry for enhancing practice.* Philadelphia, PA: F. A. Davis Company.
- Tunnah, K., Jones, A., & Johnstone, R. (2012). Stress in hospice at home nurses: A qualitative study of their experiences of their work and wellbeing. *International Journal of Palliative Medicine, 18*(6), 283-289. doi: 10.12968/ijpn.2012.18.6.283.
- U.S. Bureau of Labor Statistics (2014). Careers in hospice care. *Career Outlook*. Retrieved from <https://www.bls.gov/careeroutlook/2015/article/hospice.htm#occupations-in-hospice-care>.
- White, Z., & Gilstrap, C. M. (2016). Inside patients' homes: A metaphorical analysis of home hospice nurses' experiences working with dying patients. *Journal of Death and Dying, 72*(4), 302-316. doi: 10.1177/0030222815575282.

World Health Organization. (2017). WHO definition of palliative care. *Cancer*. Retrieved from <http://www.who.int/cancer/palliative/definition/en/>.