

5-2017

Assessing and Addressing Family Caregiver Burden: Palliative Care Social Work Perspective

Taylor Logeais

St. Catherine University, tmlogeais@yahoo.com

Recommended Citation

Logeais, Taylor, "Assessing and Addressing Family Caregiver Burden: Palliative Care Social Work Perspective" (2017). *Master of Social Work Clinical Research Papers*. 764.

http://sophia.stkate.edu/msw_papers/764

This Clinical research paper is brought to you for free and open access by the School of Social Work at SOPHIA. It has been accepted for inclusion in Master of Social Work Clinical Research Papers by an authorized administrator of SOPHIA. For more information, please contact hltompkins@stkate.edu.

Assessing and Addressing Family Caregiver Burden:
Palliative Care Social Work Perspective

by

Taylor M. Logeais, B.A.

MSW Clinical Research Paper

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

Committee Members
Dr. Melissa Lundquist, Ph.D. (Chair)
Caroline White, LICSW
Adine Stokes, LSW

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

Abstract

Social workers employed in end-of-life care settings are in a unique position to engage with family caregivers who are at a heightened risk for experiencing caregiver burden, which can have detrimental impacts on the caregivers' health and wellbeing. Even though the National Association of Social Workers (2004) directs social workers specialized in palliative care to assess the complex needs of and provide helpful interventions to family caregivers, research suggests that this objective often fails to be met. Therefore, the purpose of this study was to examine the ability for palliative care social workers to assess family caregivers for caregiver burden and to address those concerns. Through the use of a qualitative design, five palliative care social workers participated in a semi-structured interview to gain their perspective on their work with family caregivers experiencing caregiver burden. The findings from this study indicated that palliative care social workers view family caregivers as an important recipient of their services. Additionally, the findings highlighted the lack of formal assessment tools used by palliative care social workers to assess for caregiver burden and, instead, described a more observational and conversational approach to assessment. Even though the participants indicated a wide range of intervention methods for caregiver burden, the findings also indicated that there are numerous barriers that often prevent palliative care social workers from employing those interventions. Overall, this study underscores the ways in which palliative care social workers assess and address caregiver burden as well as shedding light on the barriers that often stand in their way.

Acknowledgements

This research project would not be what it is today without the unwavering support, encouragement, and guidance provided by my research committee chair, Dr. Melissa Lundquist. Thank you to my research committee members, Adine Stokes and Caroline White, for their insight and support. A special thanks is also due to my field supervisor, Melissa Schmidt, who exemplifies all that a palliative care social worker can be and so much more. Lastly, thank you to my family and friends without whom none of this would be possible.

Table of Contents

Abstract.....	2
Acknowledgments.....	3
Introduction.....	6
Literature Review.....	7
Family Caregivers.....	7
Definition.....	7
Changing Nature of Family Caregiving.....	7
Caregiver Burden.....	8
Impact of Caregiver Burden.....	9
Physical Health.....	9
Emotional Health.....	10
Financial Hardship.....	11
Terminal Illness.....	13
Caregiver Grief.....	14
Assessment Tools.....	16
Zarit Burden Interview.....	16
Caregiver Strain Index.....	17
Marwit-Meuser Caregiver Grief Inventory.....	17
Palliative Care.....	18
Definition.....	18
Palliative Versus Hospice Care.....	19
Models of Delivery.....	19
Interdisciplinary Team Approach.....	20
Palliative Care Social Work.....	20
Person-in-Environment.....	21
Biopsychosocial Assessment.....	21
Intervention Methods.....	22
Family-Centered Care Model.....	23
Theoretical Understanding.....	23
Family Systems Theory.....	23
Application to Palliative Care.....	24
Barriers to Implementation.....	25
Missed Opportunity.....	25
Experiences of the Family Caregiver.....	25
Perspective of the Palliative Care Social Worker.....	26
Methodology.....	27
Sampling Method.....	27
Questionnaire Design.....	28
Data Collection.....	29
Transcription.....	29
Data Analysis.....	30
Protection of Human Subjects.....	31
Informed Consent.....	31
Confidentiality.....	31
Risks and Benefits.....	32

Findings	32
Unit of Care	32
Patients and Families	32
Caregiver Burden	33
Assessment	34
Observations	34
Conversation	35
Lack of Formal Assessment	35
Efficacy of Assessments	36
Intervention Methods	37
Emotional Support	37
Provision of Resources	37
Psychoeducation	38
Barriers	38
Time Constraints	39
The Hospital Environment	39
Distrust	40
Missing Information	40
Discussion	41
Family-Centered Care Model	41
Defining Caregiver Burden	42
Biopsychosocial Lens	42
Impacts of Caregiver Burden	43
Physical Health	43
Emotional Wellbeing	44
Financial Hardship	45
Approaches to Assessment	45
The Missing Link	46
Interventions for Caregiver Burden	47
Emotional Support	48
Psychoeducation	48
Provision of Resources	48
The Missed Opportunity	49
Barriers to Implementation and Engagement	50
Hospital-Based Barriers	50
Time Constraints	50
The Hospital Environment	51
Caregiver-Based Barriers	52
Implications for Social Work Practice	53
Implications for Future Research	54
Strengths and Limitations	55
Conclusion	55
References	57
Appendix A. Recruitment Email	64
Appendix B. Interview Questions	65
Appendix C. Consent Form	66

Assessing and Addressing Family Caregiver Burden:
Palliative Care Social Work Perspective

In 2013 nearly 40 million family caregivers provided over 37 billion hours of care and support for family members including spouses, children, siblings, and especially aging parents (Reinhard, Feinberg, Choula, & Houser, 2015). Estimates place the economic value of unpaid services supplied by family caregivers over \$470 billion in 2013 alone (Reinhard et al., 2015). In order to measure the experiences of family caregivers, the AARP Public Policy Institute published a profile of caregiving across the United States in 2015. Findings from this study emphasized the financial, emotional, and physical toll of caregiving on those who provide the care. For example, nearly 38 percent of surveyed family caregivers responded that they were highly stressed as a result of the care they had provided for their loved ones (AARP Public Policy Institute, 2015). Furthermore, research suggests that the aforementioned stressors associated with caregiving are heightened significantly when caring for a loved one who is in the process of dying (Waldrop, 2007).

As a result, social workers employed in end-of-life care settings are in a unique position to be able to engage with family caregivers who are at a heightened risk for struggling with the burdens of caregiving. While the National Association of Social Workers (2004) directs social workers specialized in palliative and end-of-life care to assess the complex needs of and provide helpful interventions to family caregivers, research suggests that this objective often fails to be met. According to the AARP Public Policy Institute (2015), only 16 percent of family caregivers reported that either a doctor, nurse, or social worker had asked them what services or resources they may need to care for themselves. Furthermore, one in four caregivers responded that they would find it helpful to have conversations about caring for themselves with a member of the

interdisciplinary care team (AARP Public Policy Institute, 2015). Therefore, the purpose of this study is to assess the ability for social workers, specifically within the setting of palliative care, to assess family caregivers for caregiver burden and, subsequently, to address those concerns.

Literature Review

Family Caregivers

Definition. For the purposes of this study, it is important to begin with a clear definition of those included under the title of family caregiver. The following definition has been adapted from the Family Caregiving Alliance and the National Center on Caregiving (2014): “Any relative, partner, friend or neighbor who has a personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic, life-limiting, or disabling condition. These individuals may live with, or separately from, the person receiving care.”

Individuals not included within this definition are those who are employed by or volunteer with a formal service system. It is upon the aforementioned definition of a family caregiver to which all subsequent references of this title will refer.

Changing nature of family caregiving. As the makeup of the American population has changed dramatically over the past 50 years so to has the experience of family caregivers. One reason for this change is the extensive increase in life expectancy among Americans (Levine, 2008). For example, life expectancy in 1960 averaged 69.7 years, reaching 78.7 years by 2011 (Arias, 2015). As a result, family caregivers are supporting their loved ones for longer lengths of time, which studies currently estimate around four years (AARP Public Policy Institute, 2015). Additionally, family caregivers are now providing more complex nursing and medical skills for their loved ones due to the advancement of technology that now makes this level of care possible outside of a hospital setting (Levine, 2008). In a report by Reinhard, Levine, and Samis (2012),

approximately 46 percent of the 1,677 surveyed family caregivers reported that they perform at least one skilled medical or nursing tasks. Examples of such tasks include medication management, wound care, operating medical equipment, and managing the care recipient's incontinence (Reinhard et al., 2012).

Furthermore, the changing nature of the family structure and the nation's workforce has influenced the development of caregiving. While women still represent the majority of family caregivers as they did historically, they are now also working outside of the home more than in the past (Levine, 2008). As a result, many family caregivers find themselves fulfilling a multitude of roles in their lives. For example, they are parents, partners, friends, employees, and caregivers. Each of these roles comes with a plethora of responsibilities. As a result, family caregivers often find themselves caught between these roles and forced to forsake some of their responsibilities so that they can maintain the level of care needed for their loved one. Overall, family caregivers are now providing care that is more complex over a longer period while trying to maintain employment at the same time, creating a situation where the decision to care for a family member can impact the caregiver in a multitude of ways.

Caregiver burden. With the changing nature of family caregiving, research has shifted its attention to better understanding the effects that such roles and responsibilities have on the quality of life for the family caregiver. One term that has emerged from the literature is that of caregiver burden. According to Given, Kozachik, Collins, DeVoss, and Given (2001), caregiver burden can be defined as the following: "a multidimensional biopsychosocial reaction resulting from an imbalance of care demands relative to caregivers' personal time, social roles, physical and emotional states, financial resources, and formal care resources given the other multiple roles they fulfill" (pgs. 679-680). This concept creates the image of family caregivers being

pulled in different directions as they maintain the responsibilities that come with being a caregiver as well as those that come with their multiple other roles in life such as a parent, an employee, and a friend. For the purposes of this study, the definition purported by Given et al. (2001) will be the model from which caregiver burden is understood because it encompasses a biopsychosocial approach to understanding the various manners in which it can impact the lives of family caregivers.

Impact of caregiver burden. As a result of caregiver burden, the research suggests that the stress of caregiving can negatively impact other areas of the caregiver's life including those of physical health, emotional health, and social concerns especially in the form of financial hardship (Given, Wyatt, Given, Gift, Sherwood, DeVoss, & Rahbar, 2004; Corà, Partinico, Munafò, & Palomba, 2012; Grov, Dahl, Moum, & Fossa, 2005). When an individual finds himself or herself caught between the duty of caring for a family member and caring for his or her own self, the research trends suggest that caregivers often forsake their own health and wellbeing.

Physical health. In terms of the physical health impacts related to caregiving, a recent report found that 22 percent of responding caregivers felt that taking care of a relative has made their health worse than it was before taking on the caregiving role (AARP Public Policy Institute & National Alliance for Caregiving, 2015). Therefore, nearly a quarter of those interviewed believe that their responsibilities as a caregiver have caused their health to decline. Additionally, a quantitative and qualitative study of over 500 caregivers found that those reporting a decline in physical health were also more likely to report that their health decline directly affects their ability to care for their loved one (Evercare, 2006). This finding suggests that not only are the caregivers at risk due to declining health but the care recipient may also be at risk for not

receiving adequate care. Furthermore, respondents reported that the worsening aspects of their physical health fall into the following categories: energy and sleep (87 percent), pain and aching (60 percent), headaches (41 percent), and weight gain or loss (38 percent) (Evercare, 2006).

When addressing the aforementioned physical health concerns among family caregivers, it is also important to discuss why some of these declines might be happening. First, some of the research literature points to the caregiving tasks as a cause of physical health decline. For example, studies suggest that caregivers who assist their loved one with a higher quantity of skilled medical or nursing tasks also experience physical health decline (Evercare, 2006; Reinhard et al., 2012; AARP & NAC, 2015). Second, research also points to the ways in which the time dedicated to caregiving can disrupt a caregiver's ability to partake in preventative and self-care activities that could lower their risk of physical health decline (Evercare, 2006). For example, the report findings from Evercare (2006) indicate that 72 percent of the respondents do not visit their doctors as often as they probably should and 55 percent have missed appointments with their doctor due to the time spent providing care. Therefore, the act of providing care for a loved one can negatively impact the physical health of the family caregiver.

Emotional health. Another response that many family caregivers experience as a result of their caregiving role is that of a decline in their emotional health. According to the national caregiving report developed by the AARP Public Policy Institute (2015), 38 percent of caregivers report that they experience high levels of emotional stress as a result of caring for a family member. As a result of heightened stress, the research literature suggests that family caregivers are at risk for experiencing higher levels of anxiety and depression when compared to non-caregivers (Cora et al., 2012; Given et al., 2004; Grunfeld et al., 2004; Pinquart & Sorensen, 2003). In a meta-analysis of 84 academic articles that address emotional health of caregivers and

non-caregivers, Piquart and Sörensen (2003) found that caregivers experienced higher levels of depression and stress along with lower levels of perceived self-efficacy or one's ability to succeed or accomplish a particular task.

Similar to that of physical health decline, research suggests that the emotional health of family caregivers can become compromised as they become responsible for performing higher numbers of skilled medical and nursing tasks for their loved one. According to Reinhard et al. (2012), family caregiver respondents performing five or more such tasks were more likely to indicate that they have experienced depression (51 percent), being worried about making a mistake (36 percent), and feeling obligated to be highly vigilant in case something goes wrong (51 percent). Each of the aforementioned findings were higher among family caregivers performing five or more tasks than for those responsible for one or two tasks. In addition, the feelings of worry or concern about being vigilant and not making a mistake harken back to Piquart and Sörensen's (2003) finding of lower self-efficacy among family caregivers. For example, a family caregiver who has less confidence in his or her ability to accomplish a task such as those of skilled nursing or medical tasks might be more likely to be concerned about making a mistake or feel the need to be extra vigilant and cautious when caregiving. Therefore, findings of the aforementioned studies suggest that as the number of skilled medical and nursing tasks performed by the family caregiver rises so too does the risk for negative emotional health effects such as stress, depression, and a lowered sense of self-efficacy.

Financial hardship. Similar to any other individual, those who provide care for their loved ones have other roles and responsibilities in their lives outside of caregiving. However, the definition of caregiver burden reflects on the ways in which being a family caregiver can disrupt one's ability to fulfill those other roles and responsibilities. One such role often impacted by

caregiving duties is that of being an employee. According to the AARP Public Policy Institute (2015) findings, 56 percent of respondents reported being a family caregiver as well as being employed full time at 40 hours or more per week. An additional 16 percent of the respondents identified themselves as family caregivers who are also employed between 30 to 39 hours per week. Yet again, the individual finds him or herself in a position where he or she is pulled between two different roles including that of the caregiver and that of the employee.

Overall, in 2013 nearly 40 million family caregivers provided over 37 billion hours of care and support for family members including spouses, children, siblings, and especially aging parents (Reinhard et al., 2015). Estimates place the economic value of unpaid services supplied by family caregivers over \$470 billion in 2013 alone (Reinhard et al., 2015). With this in mind, many caregivers reach a point where they are no longer able to be in both the role of caregiver and employee. As a result, nearly 60 percent of family caregivers have reported at least one change or negative impact on their current employment status such as going in late or leaving work early (49%), requesting a leave of absence (15%), reducing the number of working hours (14%), receiving a warning from a supervisor regarding their attendance (7%), or leaving the workforce (6%) (AARP Public Policy Institute, 2015). Other estimates suggest that approximately 22 percent of retirees made the decision to leave the workforce earlier than they had originally planned because of the demands of family caregiving (Reinhard, Feinberg, Choula, & Houser, 2015). With each of these decisions, family caregivers face the reality of losing money when they leave their employment whether temporarily or permanently as their caregiving services are usually unpaid, which leads to both short-term and long-term financial strain.

When trying to identify family caregivers who might be at an increased risk for employment difficulties and ensuing financial hardship, the number of skilled medical and nursing tasks performed by the family caregiver becomes important once again. According to Reinhard et al. (2012), family caregivers who perform a higher number of such tasks were more likely to report that their employment had been negatively impacted by their caregiving duties. For example, while nine percent of caregivers performing one to two skilled medical or nursing tasks reported negative impacts on their employment, 26 percent of caregivers performing five or more such tasks indicated negative consequences on their employment. Therefore, family caregivers performing a higher quantity of skilled medical or nursing tasks for their loved one may be at a greater risk for experiencing employment disruption and, as a result, financial hardship.

Terminal illness. According to Glajchen (2011), caregiver burden reaches its peak when a care recipient is in the terminal stage of his or her illness. The American Cancer Society (2016) defines a terminal illness or a terminal condition as being an irreversible diagnosis that will result in death within the near future or a state of unconsciousness that is permanent and from which a person would be unlikely to recover. The literature examining family caregivers of those diagnosed with a terminal illness largely echoes this concept. For example, one component of the study performed by Grunfeld et al. (2004) was to examine the psychosocial impacts of providing care for a loved one with a terminal illness. For the study, quantitative data was collected from 89 family caregivers of women diagnosed with advanced stage breast cancer using the Hospital Anxiety and Depression Scale as well as the Zarit Burden Inventory to measure caregiver burden. One of the primary comparisons tested using this data was that of caregiver experiences at the start of both the palliative and the terminal phase of the care recipient's illness.

In terms of the psychological impact on the family caregiver, the study's findings suggest that caregivers experience higher levels of depression (30 percent vs. 9 percent) and burden (mean score of 26.2 versus 19.4) at the start of the terminal phase of the care recipients' illness than indicated at the onset of the palliative phase. Additionally, the findings indicate a similar shift in the occupational impact of caregiving when the care recipient enters a terminal health status. For example, 53 percent of family caregivers reported missing work at the palliative phase of care recipient's illness; whereas, 77 percent experienced missed work due to an inability to continue working regular hours as a result of the care provided during the terminal phase. Overall, the findings suggest that family caregivers of those with terminal stage diagnoses are at a heightened risk for experiencing the biopsychosocial results of caregiver burden.

Caregiver grief. When considering the impact of providing care for a family member in the terminal stage of an illness, it is also important to address the unique grief process experienced by this cohort of family caregivers. Even though the vast majority of research literature addressing the concept of caregiver grief has focused on caregivers of those diagnosed with dementia, the following concepts can also be applied appropriately to those caring for a loved one with a terminal stage illness. Therefore, to understand caregiver grief, two concepts must be further explored – anticipatory grief and ambiguous loss. According to Rolland (2004), anticipatory grief refers to the emotional, physical, and psychological grief response that individuals endure prior to experiencing a particular loss. In other words, this can be described as anticipating and thus grieving a loss before it actually happens. For the family caregiver of a terminal patient, anticipatory grief is common in that the caregiver has an extended amount of time while caring for the patient to experience the grief process before their loved one dies.

In addition, caregiver grief also encompasses the experience of ambiguous loss. According to Boss (2004), an individual can experience ambiguous loss of another person when there is ambiguity or uncertainty surrounding their current state of being or their role in that person's life. Boss (2004) goes on to describe two types of ambiguous loss that are defined as follows. First, ambiguous loss can occur when an individual is physically absent from one's life yet he or she remains psychologically or emotionally present. An example of this experience of loss is that of a parent's loss of a child who has been kidnapped or is missing. The second type of ambiguous loss is one where an individual is still physically present in one's life yet that person is psychologically or emotionally absent. For caregivers of a loved one in the terminal phase of his or her illness, it is this second type of ambiguous loss that is often experienced. For example, as the care recipient's illness progresses through the terminal phase, he or she may start to lose cognition and function, which disrupts his or her ability to fully engage with the caregiver on an emotional level.

Similar to caregiver burden, family caregivers of terminal care recipients also experience psychological effects of caregiver grief (Waldrop, 2007). Through a mixed-methods approach, Waldrop (2007) utilized both a quantitative and qualitative assessment to better understand the grief experiences of family members providing care for a loved one with a terminal illness. Prior to the care recipient's death, respondents experienced what Waldrop defines as a "state of heightened responsiveness" in which the caregiver experienced high levels of anxiety and depression including symptoms of hostility and difficulties with concentration and memory (p. 197). Since the expression of caregiver grief is comparable to that of caregiver burden in terms of psychological wellbeing, it is critical to also address the family caregiver's grief experience in

addition to their perceived burden, especially for those caring for a loved one with a terminal-stage illness.

Assessment tools. As the body of research has grown for understanding the impacts of caregiving on family caregivers, numerous assessment tools have been developed to aid researchers in better identifying those who are experiencing high levels of caregiver burden. Specifically, researchers have attempted to create brief assessments to screen for caregiver burden and the ways in which it can present within a biopsychosocial context so that they could be more easily implemented within settings where practitioners find time spent with family caregivers to be limited. The following subsections describe in further detail three commonly utilized assessment tools for caregiver burden.

Zarit Burden Interview. Within the research literature, one of the most widely used assessment tools for caregiver burden is that of the Zarit Burden Interview (ZBI). Primarily, the scale measures the caregiver's subjective understanding of his or her burden and distress within the context of physical and emotional health as well as social and financial hardships related to caregiving (Zarit, Reever, & Bach-Peterson, 1980). In its original form, ZBI includes a series of 22 questions to which caregivers respond how often they experience a certain feeling regarding their time spent caregiving using a 5-point Likert scale ranging from never to nearly always. Once the responses are tallied, a respondent's score can range between 0 and 88 with higher scores indicating higher levels of burden. Due to the amount of questions, the original ZBI was not intended for use as a screening tool but more so for use within research studies. With this in mind, Bedard, Molloy, Squire, Dubois, Lever, and O'Donnell (2001) developed both a 12-item short-form version and a 4-item screening version of ZBI. Based on the study's findings, both versions produced comparable results to those obtained using the full version. Overall, this

represents a possible assessment tool that could be used for screening sessions with family caregivers when time is limited for a more thorough assessment.

Caregiver Strain Index. Another assessment tool that has been developed to assess caregivers for experiences of burden is that of the Caregiver Strain Index (CSI). The CSI is a 13-item questionnaire to gauge the subjective experiences of caregivers within five domains of caregiver strain including employment, financial, physical, social, and time (Robinson, 1983). To use this tool, a provider asks the series of questions to which the caregiver can respond either “yes” or “no.” If the caregiver responds “yes” to at least seven of the items, then it is considered a positive screen indicating that further assessment would be needed (Sullivan, 2004). Based on a review of this assessment tool, both reliability and construct validity are supported (Robinson, 1983; Sullivan, 2004). Overall, CSI is a brief assessment tool that can be utilized to identify caregiver burden and can be easily administered by a provider in a short amount of time.

Marwit-Meuser Caregiver Grief Inventory. As previously discussed, in order to understand the extent of the ways in which care provision can negatively impact the family caregiver, it is important to also assess for caregiver grief. The most widely known measure of caregiver grief is that of the Marwit-Meuser Caregiver Grief Inventory (MM-CGI). Initially, Marwit and Meuser (2002) developed this assessment tool to measure the grief experiences of family caregivers of a loved one diagnosed with Alzheimer’s disease. The original version of the MM-CGI includes a 50-item scale that assesses for the following three factors that the authors connect to the caregiver’s grief experience: Personal Sacrifice Burden, Heartfelt Sadness and Longing, and Worry and Felt Isolation. Through these factors, MM-CGI assesses for the individual losses perceived by the caregiver in his or her own life as a result of caregiving,

intrapersonal emotional responses of the caregiving experience, and feelings related to the potential loss of other social relationships as a result of caregiving.

Similar to the other assessment tools designed for use with family caregivers, the MM-CGI has also been adapted into a short-form version that has 18 items covering the same three factors from the full-length assessment (Marwit and Meuser, 2005). Even though the research literature originally determined the validity and reliability for MM-CGI assessment of dementia family caregivers, recent research has also found the same validity and reliability when MM-CGI has been used to assess caregiver grief among cancer family caregivers (Marwit and Meuser, 2002; Marwit, Chibnall, Dougherty, Jenkins and Shawgo, 2007). Therefore, the MM-CGI is an appropriate assessment tool for measuring the caregiver grief experience among family caregivers for those with a terminal-stage illness.

Palliative Care

Definition. In order to understand the various dimensions of this study, it is necessary to have a clear definition of palliative care. According to the National Hospice and Palliative Care Organization (n.d.), palliative care encompasses a holistic approach to care that aims to not only medically manage a life-limiting or terminal illness but also to address the social, emotional, and spiritual needs of the patient and his or her family members. While the range of illnesses and conditions attended to by palliative care programs is quite extensive, common diagnoses include cancer, chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF), kidney disease, and Parkinson's disease ("Disease Types," n.d.). In general, palliative care services assist individuals living with the aforementioned illnesses and their family caregivers through pain and symptom management as well as assistance with outlining one's goals of care ("What is palliative care," n.d.). When considering pain and symptom management, palliative care

providers often assist patients with managing shortness of breath, nausea, and difficulty sleeping among many other difficult symptoms (“What is palliative care,” n.d.). Therefore, palliative care can be thought of as a philosophy of care that treats the person as a whole by looking at physical, emotional, and psychological effects of diagnoses on both the patient and their family.

Palliative versus hospice care. Many times palliative care and hospice services are used interchangeably to describe end-of-life care. While both models of care aim to improve the quality of life for those living with chronic or terminal illnesses, palliative care can be understood as the umbrella for end-of-life care under which hospice care fits. One area of distinction between the care models is based on the state of the patient’s health prognosis. Palliative care is available throughout the span of the illness from diagnosis to death; whereas, hospice care is available when the patient’s life expectancy is six months or less (UPMC Palliative and Supportive Institute, 2013). In other words, palliative care services have the opportunity to engage with patients and their family members throughout the continuum of an illness. Therefore, palliative care social workers are in a unique position to be able to work with family caregivers over a potentially longer period of time than their hospice counterparts, which potentially offers more chances to address various needs and concerns as they arise over time.

Models of delivery. There are several settings in which patients and family caregivers may come in contact with palliative care service providers. According to the Center to Advance Palliative Care (“What is palliative care,” n.d.), the most common delivery model occurs within inpatient, hospital settings where the palliative care providers can interact with patients and family caregivers on different levels. When an attending physician would like to remain the primary provider but wants to receive input from the hospital’s palliative care providers, the physician places a consult order for their services. Within this context, the palliative care team is

that of an auxiliary service providing an additional layer of support and guidance for a patient and his or her family members. In situations where patients have elected to receive full comfort care as they are dying, palliative care can take on the role of the primary care provider as they monitor the patient to reduce pain and suffering in an effort to improve the quality rather than the quantity of the patient's life (National Institute on Aging, 2016).

Interdisciplinary team approach. Research suggests that the most effective palliative care program is one that operates with an interdisciplinary team approach to care (Hearn & Higginson, 1998; O'Connor & Fisher, 2011). Instead of relying solely on one discipline, the team dynamic allows care providers to pool their knowledge and expertise in different areas encompassed by the holistic approach to care. The formal team is usually comprised of physicians, nurses, social workers, and chaplains along with additional therapeutic disciplines such as occupational therapists, physical therapists, and nutritionists that may also be included within the care team when their services are required to meet the needs of the patient (The National Consensus Project for Quality Palliative Care, 2013). Through a systematic literature review, Hearn and Higginson (1998) suggested that an interdisciplinary approach to palliative care services is beneficial in that the team dynamic improved the satisfaction of both the patient and his or her family caregivers. Furthermore, the study found that interdisciplinary palliative care teams were better able to identify the needs of the patient and family members and to address such needs by providing access to valuable resources and services.

Palliative care social work. Within the context of this study, it is important to address the role and responsibilities of the palliative care social worker within the interdisciplinary team. In order to do so, it is helpful to better understand some of the practice-guiding principles that

palliative care social workers are called to uphold in their practice with patients and their family caregivers.

Person-in-environment. According to Christ and Blacker (2009), the educational background of social workers as well as their commitment to the Code of Ethics help to define their placement within the interdisciplinary palliative care team. Specifically, the authors point to the ability of the social worker to delve into and better understand the various social and medical systems encompassed within each case. One of underlying principles that supports this aspect of social work practice is that of person-in-environment. According to Kondrat (2013), the person-in-environment principle calls social workers to understand clients and their behaviors within the context of the various environments in which they are involved. Within the context of the family caregiver as the client, the person-in-environment approach allows palliative social workers to conceptualize the various environments in which the caregiver partakes (e.g. home, care recipient's life, place of employment, children's school, etc.) and how these differing roles can potentially impact the caregiver.

Biopsychosocial assessment. As is true in other areas of social work practice, the performance of the biopsychosocial assessment and the utilization of its findings to inform direct client practice is of key importance to work performed by palliative care social workers (National Association of Social Workers, 2010). Specifically, biopsychosocial assessments allow the social worker to view the client as a whole so as to better understand the biological, psychological, and social strengths and challenges experienced by the client (National Association of Social Workers, 2016). Since palliative practice defines the unit of care to be that of the patient and his or her family, palliative care social workers are responsible for conducting

such assessments in a way that capture the various goals, concerns, and needs of the patient and his or her family caregiver (National Association of Social Workers, 2010).

Based on the NASW (2004) standards outlined for palliative care social workers, the following are some of the components that should be covered during such assessments: medical condition, structure of the family, roles and responsibilities of family members, communication and decision making patterns and styles within the family, life cycle stage, faith and spirituality, cultural beliefs and values, goals for palliative treatment, available social supports, as well as mental health functioning. Overall, it is through the findings obtained from biopsychosocial assessments that the palliative care social worker can determine the most effective methods of practice intervention.

Intervention methods. According to the National Consensus Project for Quality Palliative Care (2013), appropriate methods that fall within the scope of palliative care social work practice include the following: understanding and coping with concepts of grief and illness; supporting decision making amongst the patient and family members; discussing the goals for care identified by the patient and the family; providing emotional support; and serving as the mediator in conversations within the family system and between the family system and the rest of the interdisciplinary care team. While each of the aforementioned methods can be directed to either the palliative patient or the family caregiver, the literature surrounding palliative care social work practice also highlights the specific interventions that can be utilized when working specifically with family caregivers. For example, Glajchen (2011) identifies several key social work intervention methods for engaging family caregivers following the completion of a biopsychosocial assessment. The interventions mentioned in the study are as follows: provision of information; psychoeducational interventions; skill training; counseling, emotional support,

and psychotherapy; and facilitation of family meetings. Overall, the palliative care social worker has the ability to assess family caregivers using a dynamic, biopsychosocial approach that can be utilized to inform the directive supportive services that they can offer to family caregivers.

Family-Centered Care Model

Theoretical understanding. The basis of this model lays in the belief that families play a vital role in ensuring the well-being of the patient and that it is necessary to consider the needs and concerns of the family in addition to those of the patient (Institute for Family-Centered Care, n.d.). In practice, this model calls for the following principles to be upheld: dignity and respect for the patient and family members; information sharing between the patient, family, and health care practitioners; encouraged participation of the patient and family members in discussions surrounding the plan of care; and collaboration between patients, families, and the health care providers throughout the delivery of care (Institute for Family-Centered Care, n.d.). One example of how this model has been implemented within a healthcare setting is that of the Caregivers and Professionals Partnership (CAPP) implemented at Mount Sinai Hospital. According to a systematic review of available literature on the program, Dobrof, Zodikoff, Ebenstein, and Phillips (2002) found that the program was an effective strategy for raising awareness of family-centered care specifically through the provision of direct services and education to family caregivers along with the drive to build awareness across the hospital and medical disciplines about the needs and concerns facing family caregivers.

Family systems theory. From a social work perspective, the family systems theory provides a foundation for the principles of family-centered care. Originally defined by Dr. Murray Bowen, the family systems theory attempts to better understand human behavior by viewing the family as a complex, emotional unit (Kerr, 2000). Within the family unit, all of the

family members are thought to be connected emotionally to one another and that connection directly affects family members' feelings, thoughts, and actions (Kerr, 2000). In other words, family members are interdependent upon one another. Similar to that of the family systems theory, the main tenet of the family-centered care model is that of the family as a functional unit. Within a medical context, it is understood that the health and wellbeing of one family member can greatly impact other family members on various levels. Therefore, it is important to take the family as a whole into account when approaching medical care, especially when a family caregiver is involved as the interdependence between family members increases substantially when one takes on the role and responsibilities of providing care for a family member.

Application to palliative care. According to the National Hospice and Palliative Care Organization (n.d.), one of the primary principles that guides the provision of palliative care is that of the family-centered care model. As a result, palliative care programs often consider the unit of care to be that of the family (Glajchen, 2011). Therefore, palliative care providers are called to deliver supportive services not only to the patient but also to his or her family system, which includes the family caregiver. Several studies have illustrated the ways in which this model is uniquely suited for addressing the needs of family members who are caring for a loved one who is dying (Kissane, 1999). In an early application of this model, Kissane (1999) emphasized the importance of the family and its primary role as care providers when a patient is suffering from a chronic or life-threatening illness. Based on this understanding, Kissane (1999) completed a longitudinal study of families involved in palliative care to illustrate that family functioning can be enhanced and improved as a result of incorporating the family-centered care model within the provision of palliative care.

Barriers to implementation. Even though palliative care provision is intrinsically tied to that of family-centered care, studies have found that this model has not been fully implemented within palliative care, especially when conducted in a hospital setting (Kovacs, Hayden Bellin & Fauri, 2006; Hudson, Aranda & Kristjanson, 2004). In a systematic review of available literature covering topics of palliative care, the family-centered care model, and caregiving, Kovacs et al. (2006) suggest that this model has been inconsistently implemented within palliative care based on the finding that many family caregivers of patients receiving palliative care did not receive any support to address their own concerns and needs.

Furthermore, the authors believe that the inability to uphold the part of this practice model focused on care for the family is largely related to the systematic functioning of the hospital system, which focuses primarily on limiting spending and shortening hospital stays, thus not allowing time for such a model to be implemented (Kovacs et al., 2006). Similarly, a systematic review of available literature on family-centered care within the context of palliative care performed by Hudson, Aranda and Kristjanson (2004) suggests that certain health-system based barriers might account for the difficulty in applying this model when working with family members in a palliative care setting. For example, the authors identified insufficient resources such as caregiver-focused educational materials and a healthcare system based on profit and quickly moving patients out of the hospital setting may stand in the way of fully implementing family-centered care.

Missed Opportunity

Experiences of the family caregiver. Not only have studies shown that the theoretical model of family-centered care is difficult to implement within palliative care but research has also shown the ways that family caregivers view the lack of attention placed on their needs,

which many have described as a missed opportunity (Dubus, 2010; Hebert, Copeland, Schulz, Amato & Arnold, 2008; Tabler et al., 2015). By utilizing a singular case study tracking the experience of a spouse caring for her dying husband, Dubus (2010) illustrated the ways in which family caregivers often feel left out of the care planning process and that their personal feelings and concerns fail to be addressed by the interdisciplinary team involved in end-of-life care. Similarly, Hebert et al. (2008) collected data through focus groups comprised of family caregivers of terminally ill patients and found that the caregivers believed that hospital-based social workers were not helpful in preparing them for the death of their loved one.

Furthermore, when identifying areas where they would like additional assistance for meeting their personal needs, the caregivers did not identify social workers as a team member who would be able to provide such services (Hebert et al., 2008). Lastly, Tabler et al. (2015) added to this narrative of the missed opportunity by calling attention to the lack of grief and bereavement support for family caregivers by end-of-life care providers. Through a series of phone interviews conducted with 19 family caregivers, the respondents felt that the providers only indirectly met their personal concerns and needs and that they failed to help them address their own grief and bereavement both before and after the passing of their loved one.

Perspective of the palliative care social worker. Even though palliative care upholds the value of family-centered care, the literature review has found that often times palliative care teams have been unable to assess and address caregiver burden experienced by family caregivers of patients diagnosed with a terminal illness. The literature supports the abilities of the interdisciplinary team and, more specifically, the palliative care social worker to provide the appropriate psychosocial support to family caregivers; however, the narrative of the missed opportunity is too important to ignore. At the same time, previous research mainly addresses this

narrative from the perspective of the family caregiver and does not provide the viewpoint of the social workers tasked with the provision of such care. Therefore, this study aims to fill this gap in the research by giving voice to the palliative care social worker and seeking their opinion on the following research question: to what extent do palliative care social workers feel they are able to assess family caregivers for caregiver burden and to address its effects?

Methodology

In order to best ascertain the voice and opinion of palliative care social workers, I employed a qualitative approach to gathering data. According to Padgett (2008), there are several reasons why this research method best fits with the purpose delineated for this study. First, a qualitative research methodology is useful for exploring topics of which not much is known or the voice of the insider is lacking (Padgett, 2008). As previously discussed, the literature review highlights the gap in research covering the voice of palliative care social workers and their understanding of the ability to assess and address caregiver burden. Additionally, Padgett (2008) describes qualitative research methodology as an approach well-suited for capturing the lived experience of those whose perspective I sought. With this approach, my study engaged palliative care social workers to share how they see their ability to engage with family caregivers from their own perspective.

Sampling Method

The sample population for this study consisted of five palliative care social workers. In order to recruit potential participants for this study, I utilized the snowball sampling method. I selected one palliative care social worker to be the initial participant in this study. In order to find additional participants for the study, I asked the first participant to forward a brief email correspondence that I had prepared (Appendix A) about the study to other palliative care social

workers that may be interested in partaking in the study. The email communication (Appendix A) included a brief synopsis of the study's purpose and objectives as well as my contact information. Additionally, the email correspondence asked potential participants to contact me directly if they were interested in being a part of the study. I informed the first participant that he or she was under no obligation to disseminate the email correspondence.

In order to protect the privacy of potential participants, I did not collect any contact information from the already-recruited participants. Furthermore, the contact between myself and potential participants took place only after approval was granted by the University of St. Thomas Institutional Review Board (IRB) to conduct this study. This recruitment method yielded two additional palliative care social workers following the completion of the first interview. In order to gain a greater sample size, I returned to the University of St. Thomas IRB to amend my sampling method to include the ability for me to send an email to a Listserv of palliative care social workers currently practicing in Minnesota. After this amendment was approved, I sent the same email correspondence (Appendix A) to the Listserv. Two additional palliative care social workers responded to this email and I subsequently completed interviews with these individuals.

Questionnaire Design

I conducted one semi-structured interview with each of the respondents so as to best ascertain the thoughts and opinions of each respondent in his or her own words. I relied heavily on the themes presented in the literature review to inform the process of drafting interview questions. Specifically, the literature review identified a missing opportunity for social workers to engage with family caregivers during end-of-life interventions as evidenced by results of quantitative and qualitative studies. The majority of the questionnaire (Appendix B) included open-ended questions addressing the following topics: the respondent's understanding of

palliative care practice, experiences engaging with family caregivers, assessment tools for caregiver burden, family caregiver interventions, and barriers to such engagement.

Data Collection

During the data collection process, I interviewed each participant during one 45- to 60-minute interview. An appropriate location for each interview was decided upon as a collaboration between each participant and me. As a result, one interview was conducted in-person while the remaining four interviews were conducted over the phone to best fit with the schedule of the interviewees. I did not partake in any follow-up contact with the participants. To collect data for the analysis portion of the study, each respondent was asked if they would provide their consent to an audio recording of the interview. I downloaded the “SuperNote” application on my personal cellular device, which created a downloadable file of the interview. My personal cellular device had a passcode lock function enabled to limit any potential breach of privacy and confidentiality of the audio recording. Within twelve hours following the conclusion of each interview, the audio recording was removed from my personal cellular device and uploaded to my password-protected One Drive account provided through the University of St. Thomas.

Transcription. Using the audio recordings collected, I composed a verbatim transcription of each interview in its entirety. Each transcription was saved to my password-protected One Drive account. I utilized the transcriptions for the subsequent coding process, described in the following section. Upon the completion of each transcription, I permanently deleted the audio files containing the recording of each interview. I will keep the interview transcriptions saved in my One Drive account until they are permanently deleted on May 15, 2017.

Data Analysis

For the purposes of this study, I employed the use of grounded theory in order to analyze the data obtained during the qualitative interviews. According to Padgett (2008), grounded theory involves the use of inductive coding that initially stems from a descriptive retelling of the interview transcript data in a sentence by sentence manner. Therefore, the initial coding, or open coding, is highly descriptive in nature (Padgett, 2008). The process of coding is a multistep task that consists of reading through the codes and consistently refining them so that they move beyond a simple retelling of the details of the quote to describe the underlying meaning. Lastly, I combined all of the codes to look for themes and subthemes found throughout the data.

There are several steps that I took in order to ensure the trustworthiness of the data collected in this study. First, I supported the credibility of this study by having frequent sessions with my research committee Chair where I debriefed about the interview, transcription, and coding processes (Shenton, 2004). During these meetings, I worked closely with my Chair to talk through the ideas and interpretations that I have developed and to start recognizing my own biases that I have brought to the data analysis process (Shenton, 2004). Another step that I took to establish trustworthiness of the data is through a process that Shenton (2004) refers to as reflective commentary. This process involves a reflective process where I take notes on the following: verbal and nonverbal observations during the interview process; thoughts on the interview questions I have asked; themes that appear across the interview transcriptions; the development of the coding utilized for the data analysis; and recognition of any changes I would make should I ever perform a similar study. The aforementioned notes were comprised within a Word document saved to my password-protected One Drive account and will be permanently deleted upon completion of this study on May 15, 2017.

Protection of Human Subjects

Informed consent. At the start of the interview conducted in-person, I gave each participant a consent form (Appendix C). The consent form included the following: brief description of the study's background and purpose, information regarding the study's procedures, possible risks and benefits of the study, confidentiality measures, and contact information for myself and the University of St. Thomas IRB. At this time, I engaged with the participant in a discussion surrounding the details of the informed consent. I asked the participant to describe the informed consent for this study to ensure that the participant understood each of its components. For the phone interviews, a similar process was employed. I provided each participant with the consent form in an email correspondence asking them to review and sign the form if they agreed to participate in the study. At the beginning of each phone interview, I spent time reviewing the informed consent form with each participant, asked several questions to assess their understanding of the forms components, and asked for verbal acknowledgement of their agreement to participate.

Each participant was given a copy of the consent form to keep and was asked to sign an additional copy for me to keep for my records. The interview process proceeded only after obtaining the participant's signature and acknowledgement of his or her informed consent to participate in this study. I will keep the signed informed consent forms from each of the participants in a locked cabinet at my home until I permanently destroy the forms three years after the completion of this project on May 15, 2020.

Confidentiality. In terms of the data collected during the interview process, I took the following steps to protect the participants' confidentiality. First, I used my personal, password-protected iPhone to record each interview. To further protect this data, I uploaded each electronic

audio file to my password-protected One Drive account within 12 hours of an interview's completion. At this time, I also permanently deleted the audio recordings from my iPhone.

Risks and benefits. As the data collection method for this study involved the audio recording of each interview, there was the potential risk that there may be a breach of the participants' confidentiality if the recordings were to be taken from my possession. However, I took the aforementioned steps to reduce this potential risk to the greatest extent possible and no identifying information was collected during the interview process. This study had no benefits for the participants.

Findings

The primary aim of this study was to examine the ability of palliative care social workers to assess and address caregiver burden. Five palliative care social workers participated in the interview process for this study. Through the data analysis process, several themes emerged from the data including: unit of care, defining caregiver burden, approaches to assessment, intervention methods, and barriers to assessing and addressing caregiver burden.

Unit of Care

One of the first themes to present itself within the data was that of the unit of care within the context of palliative care. For the purposes of this study, unit of care is defined as those whom the participants described as being the recipients of their care. This theme emerged in the participants' responses to my questions about the primary objectives of palliative care and the role of the social worker within the interdisciplinary team.

Patients and families. In their responses, the participants continually identified both "patients and their families" when referring to the recipients of their services. When describing the objectives of palliative care, one respondent stated that it is "patient and family support

centered.” One respondent indicated, “The patient and their family are the center of our care plan and their voice is the loudest voice in the room when we are having discussions.” Along the same lines, another respondent defined palliative care as “an extra layer of support for patients who have a serious illness and for their families.”

Caregiver Burden

Through the data analysis process, the theme of caregiver burden emerged. When I asked participants to define caregiver burden, the participants described its various components as well as its impacts on the family caregiver. One respondent stated, “Caregiver burden can be categorized in a spectrum.” Another respondent expanded upon this idea by stating that caregiver burden is a “physical, psychological, spiritual task” that can be “very overwhelming and cause a lot of stress” for the family caregiver. For example, a participant shared the following: “I think about the stress and complicated emotions that comes with taking care of somebody who is either seriously ill or chronically ill.”

One participant stated that caregiver burden involves “constant vigilance and worry” while another participant defined caregiver burden as follows:

So I think about caregivers being burdened not only with the time commitment and the energy commitment that’s required to take care of somebody that’s got a serious illness but I also think about the emotional burden and the emotional requirement to cope and deal with those kinds of emotions and to kind of flex their role within the family system.

In addition, one participant mentioned that family caregivers are often “giving up social and sleep time.” The participants also included the impact on the family caregiver’s finances as part of their definition of caregiver burden. For example, one respondent stated that family caregivers may be “giving up work and money opportunities to fulfill this responsibility.” Another

interviewee similarly described someone struggling with caregiver burden as a family caregiver who was “spending all of their time and energy caring for a loved one” including “having to cut back on their time or having to stop their work altogether.” Furthermore, one participant touched on the effects of caregiver burden in her response to this question: “We see the added stress leading to additional health problems, mental health problems, et cetera for the caregiver.”

Assessment

Another theme present in the data is that of assessment methods utilized by palliative care social workers to identify caregiver burden. This theme was largely derived from the questions that I asked the participants regarding their personal definitions of caregiver burden and triggers that might help them to identify the presence of caregiver burden. Based on the data, this theme breaks down into the following subthemes: observations, conversation, lack of a formal assessment, and the efficacy of their assessments.

Observations. When asked to describe what aspects of the patient or family context that trigger their awareness of caregiver burden, each of the respondents referred to “observations” that they make when visiting with a caregiver. One of the participants described this assessment process as “taking the temperature of the room right when I walk in.” For example, one respondent shared the following:

If I see someone that [...] looks like they dye their hair and I can see their roots are two inches long, or like they look like they’re not showering, just any observations that I see that someone’s not taking care of themselves. That’s my first indication.

Another participant indicated that she “see[s] patients who are here for a number of days, weeks, and their caregiver has not gone home and has really not been attending to their own self care at all.” Furthermore, one interviewee stated that the following observations would alert her to the

presence of caregiver burden: “I also might be worried if people are crying, tearful, and seeming very overwhelmed with everything that’s going on.” Another participant referred to observing the physical condition of the family caregiver in the following quote: “I also would worry if a family member had an injury. You know, they threw out their back after they were helping their mom get up.” Overall, the data outlined the ways in which the participants utilized observations of the family caregiver to inform their assessment for the presence of caregiver burden.

Conversation. Another way in which the respondents referred to their assessment methods was through the use of conversation as a tool for assessing caregiver burden. In this study, conversation is defined as an approach to assessment that is based in an open discussion with the client and does not include the use of a formal assessment tool. For example, one participant stated that her “style as a social worker is more conversational” and indicated that assessments took place “in a conversation.” Another participant went on to describe more of what this conversational approach looked like when she stated, “It takes sitting with someone and just giving them the freedom to talk and building that relationship. So maybe on the third time when you sit down, that’s when they tell you.” Overall, these quotes illustrated the conversational approach that three out of the five respondents included in their assessment methodology for gauging the level of caregiver burden.

Lack of formal assessment. One response that was common across all of the participants related to a lack of formal assessment screening tools for caregiver burden. When asked about their approaches to assessing for caregiver burden, respondents replied that they “do not have any formal assessments,” “specific screening tools,” “specific checklists,” or “structured tools” that they have used in their practice. Four out of the five participants indicated that a formal assessment did not fit with the conversational approach. For example, one respondent stated, “I

am not an assessor.” Another participant stated that she “will not sit in front of somebody with a piece of paper where I am circling numbers or on a computer, or anything like that.” Similarly, one interviewee stated the following:

I think when you connect with a person on a personal level and not so much on a formal level with paper assessments or computers or rigid kind of test taking questions, I think people are willing to open up more.

Efficacy of assessments. When asked how well their approach measures the perceived level of caregiver burden, four out of the five interviewees stated that they felt their informal assessment methods were “appropriate,” “effective” or “constructive.” For example, one respondent said the following: “I feel that I have constructive conversations with almost all of my patients and their family caregivers.” Another interviewee responded similarly when she said that her approach to assessment “serves me well and I think it appropriately gauges people’s level of burden.”

In response to this same question, one of the participants shared a different perspective. She indicated, “there’s a lot of room for improvement” and that she felt that “this isn’t something that we even talk about much, you know, how to assess for caregiver burden.” This same participant continued,

I think it’s really an area of my practice that is lacking for sure. I go off a lot of assumptions and that’s obviously not good. So I think there’s a lot of room for improvement and I think it’s really an area of practice that’s neglected especially in this setting. I think in hospice or homecare there’s more attention to [caregiver burden].

Intervention Methods

During the data analysis process, another theme that emerged from the data was that of intervention methods. Specifically, this data originated from the participants' responses to a question about the types of interventions that they utilize in their practice to address caregiver burden. Within this larger theme, the following subthemes outlined specific interventions commonly identified by the interviewees: emotional support, provision of resources, and psychoeducation.

Emotional support. The first subtheme of emotional support was identified as a common intervention method among all of the participants. For the purposes of this study, emotional support is defined as an intervention method based in empathy and expressed understanding of the emotions involved in caregiver burden. One respondent described this intervention as “offering emotional support and counseling just related to how difficult it can be in that role and to be assuming the care of someone else that you love and care about.” Another respondent added that emotional support involves “providing supportive listening, validation about their feelings, and mirroring the kind of empathy that you have for someone in that situation.” Furthermore, another participant described herself as “a container for their negative feelings” and identified that “15 minutes of venting can be enough to sustain them.”

Provision of resources. An additional subtheme present in the data was that of the provision of resources as an intervention method mentioned by all of the interviewees. In this study, provision of resources is defined as an intervention method whereby a palliative care social worker provides specific referrals to additional services that could be beneficial to the family caregiver such as respite care services and caregiver support groups. One participant referred to finding “additional support” that can be “set up for this family at home so that this

caregiver isn't taking on this magnitude of burden that they're taking on right now." Similarly, another participant stated that she found ways to "get them connected with more supports and more help." Specific resources mentioned by the participants included "resources for caregiver consultation, caregiver support groups, and respite volunteers or other sources of respite." In order to assess for these needs, one respondent asked caregivers the following question, "What kind of resources do you have? Do you want to look into hiring someone else to take your place for a couple hours a week?"

Psychoeducation. When describing their intervention methods for addressing caregiver burden, all of the interviewees described "psychoeducation" as a common intervention used in their practice. In this study, psychoeducation refers to the provision of knowledge and skills that palliative care social workers offer to family caregivers. For example, one respondent said the following:

I think a lot of it comes back to education and if you fully educate the people that are going to be acting as caregiver of the kind of burden that they are going to be taking on, whether it's easy or hard, that they still have the choice and so does the patient to make a decision.

Other participants indicated that psychoeducation extends to "educating them on how your wellbeing and your self-care will reflect onto the patient," "grief and loss," "stress-reduction practices," "information about how an illness may progress," and "basic information about hospice [...] and different kinds of care options."

Barriers

The final theme to emerge from the data was that of barriers that prevent palliative care social workers from assessing and addressing family caregiver burden. Even though the

participants were asked a specific question about barriers as the final question of the interview, it is important to note that each of the interviewees mentioned these barriers at varying points throughout the interview and were not limited to their responses to this final question. As a result, the following subthemes detail the common barriers mentioned by the participants: time constraints, the hospital environment, distrust, and missing information.

Time constraints. All of the study's participants indicated "time" or "time constraints" as a barrier to assessing and addressing caregiver burden. For the purposes of this study, the subtheme of time constraints is defined as the participants' belief that they do not have enough time to engage with family caregivers. One respondent indicated that the "average stay at the hospital is two or three days and you are lucky to get one visit with a caregiver." Another respondent stated that time limitations lead to fewer interventions with family caregivers in the following quote: "I think the amount of time that we have is very limited so the number of interventions that we can successfully put in place from beginning to end are very rare."

The hospital environment. Characteristics of the hospital environment identified that created barriers to their work included descriptions of the hospital as being "uncomfortable," "too sterile," and "not conducive to this work." One participant stated, "The hospital environment is awful. It's uncomfortable." Participants who described the specifics of the hospital setting that are problematic to assessing and addressing caregiver burden talked specifically about the spatial dynamics of hospital rooms. For example, one respondent gave a detailed description of these specifics:

Shared rooms are a disaster, uncomfortable chairs are a disaster, bad lighting, being interrupted. Even when you have a private room with a sign on the door, someone will still walk in on you. So I think the hospital environment is terrible.

Distrust. A subtheme that emerged in the data was that of “distrust” as a barrier to assessing and addressing caregiver burden. For the purposes of this study, distrust is defined as the perceived lack of trust that a family caregiver has in both the medical system as a whole and in the palliative care social worker. Four out of the five respondents remarked on this concept by using terms such as “a lack of trust,” “trust issues,” and a “low level of trust” specifically between the caregiver and the medical system. According to one respondent, a common barrier is that of a family caregiver who is “not wanting to engage in conversations with myself or my team because there’s a distrust within medical systems and they haven’t engaged a lot with the medical system.” Similarly, another participant stated, “A lot of people I meet do not have trust in the system and I’m a part of that system so they don’t have trust in me when they meet me.” In particular, this participant also included that this distrust is connected to the fact that she has “the word social worker attached to my name.”

Missing information. The final subtheme to emerge in the data as a barrier was that of missing information received from the caregiver. In this study, missing information is defined as information that the family caregiver has not shared with the palliative care social worker about his or her experiences of caregiver burden. For example, respondents stated the following: “I can only know what [the caregivers] tell me” and “They don’t want to engage in those intimate conversations.” Another interviewee added, “I also think that if someone isn’t going to tell you something then they aren’t going to tell you something. People can hide whatever they want on a formal assessment or conversational approach.” Furthermore, one participant stated, “There’s almost always something else to the story, something else under the surface – you have to leave room for that even if you’re never going to talk about it.” Overall, missing information about the

caregiving situation and potential experiences with caregiver burden emerged as a subtheme of barriers to engaging with family caregivers.

Discussion

The overarching objective of this study was to gain a better understanding of the ways in which palliative care social workers were able to first assess and then subsequently address concerns of caregiver burden among the family caregivers with whom they come in contact. Based on the data collected in this study, the findings support and expand upon the existing research literature in the following areas: the family-centered care model; defining caregiver burden and its impacts; approaches to assessment of caregiver burden; commonly used interventions for addressing caregiver burden; and the barriers that often impede the palliative care social worker's ability to assess and address caregiver burden.

Family-Centered Care Model

According to the research literature, family-centered care is paramount to the delivery of palliative care services (National Hospice and Palliative Care Organization, n.d.; Glajchen, 2011). One way of determining if this model is upheld in the actual delivery of services is to examine the ways in which palliative care providers defined the principles of palliative care and who they articulated as the unit of care. For example, if the response were to be that the patient was the only focus and recipient of their services, then the model of care would be described more so as patient-centered. More specifically, Robinson, Callister, Berry and Dearing (2008) defined patient-centered care as individualizing the plan of care for each patient and also involving patients in this care plan. While these same principles are also upheld in the delivery of family-centered care, this model goes beyond that of patient-centered care in that it includes the family as an integral part of the unit of care (Institute for Family-Centered Care, n.d).

Based on the findings, it appears that the palliative care social workers interviewed for this study uphold the principle value of family-centered care – the family as the unit of care. This was evident in the fact that all of the interviewees referred to “patients and their families” or “patients and family caregivers” as the focus of palliative care principles and the recipients of such services. Overall, these findings support the role of family-centered care as a principle component of palliative care and suggest that the study’s participants view patients and family caregivers as an integral unit of care.

Defining Caregiver Burden

Based on the findings of this study, the definition of caregiver burden described by the palliative care social workers involved in this study supports that which was defined in the research literature. According to Given et al. (2001), caregiver burden is a “multidimensional biopsychosocial reaction” that results from the impacts that caregiving has on a family caregiver’s “personal time, social roles, physical and emotional states, [and] financial resources” (pgs. 679-680). The findings from this study support both the biopsychosocial underpinnings of caregiver burden as well as the impacts that it can have on various aspects of the family caregiver’s life.

Biopsychosocial lens. According to the definition used for the purposes of this study, caregiver burden is more than just a physical or emotional reaction to the act of caring for a loved one (Given et al., 2001). Instead, it is an all-encompassing reaction that presents as a physical, emotional, and social response to the stress and strain of caregiving. The findings from this study support the biopsychosocial lens that is often applied to the definition of caregiver burden. For example, two of the respondents articulated that caregiver burden exists as a “spectrum” that involves the “whole person.” One of the palliative care social workers went on

to define caregiver burden as a “physical, psychological, spiritual task” – a description that directly encompasses the biopsychosocial lens often used to define caregiver burden across the literature.

Furthermore, the ability to view caregiver burden with this lens directly relates to one of the primary practice skills of palliative care social work, which is the biopsychosocial assessment. In particular, the National Association of Social Workers (2016) calls social workers to conduct biopsychosocial assessments as a way of viewing a client and his or her situation from a holistic perspective that encompasses the biological, psychological, and social strengths and challenges experience by a client. For the palliative care social worker, this task is expanded to include both the patient and the family caregiver. Therefore, the biopsychosocial lens utilized by the participants in this study to define caregiver burden reflects the use of a critical skill of social workers as defined in the literature.

Impacts of caregiver burden. Another component of the caregiver burden definition that emerged from both the findings of this study and the greater review of the literature is that of the variety of impacts that caregiver burden can have on the family caregiver. This includes impacts on the caregiver’s physical and emotional health as well as his or her financial stability (Given et al., 2004; Corà et al., 2012; Grov, Dahl et al., 2005).

Physical health. First, the palliative care social workers interviewed for this study described caregiver burden in terms of how it can impact the physical health of the family caregiver. For example, one of the participants mentioned that she is on the lookout for any kind of “injury” and goes on to share an example of a caregiver who may have “[thrown] out their back after they were helping their mom get up.” This negative impact that the physical acts involved in caregiving can have on the bodily health of a family caregiver is also present in the

literature. Similar to the example in this study's findings, a study of family caregivers performed by Evercare (2006) also indicated that such injuries are common among this cohort with approximately 60 percent of respondents stating that they have more experiences of pain and aching since taking on the role of caregiver.

Additionally, several of the interviewees called attention to "lack of sleep" or "losing sleep time" as a common impact that caregiver burden can have on the physical wellbeing of the family caregiver. This impact of caregiving is also well supported in the literature. According to the study by Evercare (2006), 87 percent of family caregivers reported that they had experienced difficulties sleeping and lower energy levels that they attributed to their role as caregivers. If family caregivers are unable to have enough quality sleep time, long-term impacts to their physical health can include increased risk for more serious physical ailments including diabetes, obesity, and cardiovascular disease (Olson, 2015).

Emotional wellbeing. Findings from this study also draw attention to the effects that caregiver burden can have on the emotional wellbeing of family caregivers. For example, all of the participants in this study addressed the "stress" and feelings of being "overwhelmed" that come with caregiving. In particular, one respondent stated that she pays attention to family caregivers who display emotional responses of "crying" and being "tearful" as potential indicators that the caregiver may be experiencing emotional burden as a result of providing care for a loved one. When reflecting back on the research literature about impacts on emotional wellbeing, these findings are well supported. Numerous studies have shown that family caregivers are at an increased risk for emotional health concerns including anxiety and depression when compared to their non-caregiving counterparts (Cora et al., 2012; Given et al., 2004; Grunfeld et al., 2004; Pinqart & Sorensen, 2003). Overall, findings from this study and

the research suggest the numerous ways in which the emotional wellbeing of family caregivers can be impacted by caregiver burden.

Financial hardship. Another finding to emerge from the data collected in this study was that of the ways in which caregiver burden impacts the “financial resources” of family caregivers. The way in which the participants most often described this effect of caregiver burden was through reflections on the time commitment of caregiving and how it can impact one’s work schedule. For example, one interviewee commented that family caregivers are often “giving up work and money opportunities,” while another participant added that they often “cut back on their time” spent working or have to “stop their work altogether.” These findings suggest that the palliative care social workers involved in this study view interruptions to one’s work schedule and loss of income as potential effects of caregiver burden. In connection to the research literature, these findings are well supported. For example, a study performed by the AARP Public Policy Institute (2015) found that 60 percent of family caregivers report at least one change or negative impact on their work schedule or employment status due to leaving work early or arriving late, reducing work hours, and even quitting their jobs. Overall, findings from this study support the literature in that the act of caregiving can have an impact on any other job held by a family caregiver, which can result in increased financial hardship due to lost wages.

Approaches to Assessment

One of the ways in which the data expands upon the literature is that of the approach that the interviewees use for assessing caregiver burden. A common finding across the data was that none of the participants in this study acknowledged use of a “specific” or “structured” screening tool in their practice. In fact, several of the participants commented that they are unaware of any screening tools and one participant acknowledged that this is an area that “lacks” in her practice.

These findings stand in contrast to previous research literature outlining a variety of assessment tools that have been developed to gauge the level of burden or distress experienced by a family caregiver (Zarit, Reever, & Bach-Peterson, 1980; Robinson, 1983; Bedard et al., 2001; Marwit & Meuser, 2003; Sullivan, 2004). Examples of these tools include the Zarit Burden Interview, the Caregiver Strain Index, and the Marwit-Meuser Caregiver Grief Inventory. Even though the research literature supports the use of such assessment tools to measure caregiver burden, they have not been formally incorporated into the practice of any of the palliative care social workers interviewed for this study.

The missing link. Even though the interviewees indicated a lack of formal assessment tools, the ways in which they define caregiver burden and the observations they make to assess for its presence align closely with items outlined in the Caregiver Strain Index (CSI). For example, the participants mentioned that someone struggling with caregiver burden might be “overwhelmed,” not having enough “sleep time,” suffering from a “physical injury,” needing to “cut back” or “stop working,” facing a “financial burden,” and giving up “social time.” Despite the belief of this study’s participants that they are not using a screening tool, all of the aforementioned indicators are present on the CSI. In fact, they cover eight of the twelve characteristics of caregiver strain that are included on this index (Sullivan, 2004). The only areas not covered specifically by the participants in this study include making family adjustments, experiencing emotional adjustments, finding certain behaviors exhibited by their loved one to be upsetting, and finding certain changes in their loved one to be upsetting (Sullivan, 2004). While the palliative care social workers interviewed for this study state that they are “not using any screening tools,” the findings of this study show that their approach to assessing for caregiver burden may be more closely tied to the use of such a tool or checklist than they are aware.

A possible explanation for this finding may rest in the so-called “practice style” employed by the palliative care social workers who participated in this study. In particular, all of the participants described an observational and conversational approach to the assessment process that could be described as informal. Many participants felt that the use of a formal screening tool was not an appropriate “fit” for this style. Specifically, three out of the five participants related a formal assessment tool to the act of “taking notes,” “circling answers on a paper,” or “being on a computer” when interacting with a family caregiver. In each case, the participant describing these acts did so with the sentiment that this approach was not conducive to their assessment style. However, the findings from this study suggest that the assessments of the interviewees closely mirror the items listed on popular screening tools for measuring caregiver burden. Even though the participants appear to identify a majority of the same indicators of caregiver burden through conversation and observation, it is possible that they do not view the use of a screening tool as a component of their assessment because their approach does not involve checking items on a list or asking a series of specific questions.

Interventions for Caregiver Burden

Another finding from this study that both supports and adds to the existing literature is that of the interventions commonly utilized by palliative care social workers to address caregiver burden. In particular, the literature described the following social work interventions that are often employed within palliative care: provision of information; educational interventions; skill training; counseling, emotional support, and psychotherapy; and facilitation of family meetings (Glajchen, 2011). Based on the response of the palliative care social workers interviewed for this study, there are several areas of crossover among these commonly used interventions.

Emotional support. All of the participants stated that they provide “emotional support” for family caregivers experiencing caregiver burden. The findings added to the literature surrounding emotional support by describing what this intervention looks like when applied to family caregivers experiencing caregiver burden. Specifically, the participants described this intervention as involving skills of active and “supportive listening, validation of their feelings” and the use of “empathy.” One interviewee stated that the palliative care social worker essentially becomes a “container for the negative feelings” experienced by the family caregiver, which is made possible by allowing the caregiver the opportunity to “vent” their frustrations and concerns.

Psychoeducation. One of the interventions described in the literature was that of psychoeducation as being helpful when working with family caregivers facing caregiver burden (Glajchen, 2011). However, a review of the literature did not include a description of the topics that may be most helpful for family caregivers. Based on the findings of this study, the contributing palliative care social workers identified several key areas of education that they believe to be beneficial for burdened caregivers. For example, they listed the following topics as opportunities for educating family caregivers: self-care strategies, grief and loss, disease progression, and available care options. Overall, the findings from this study have added to the existing research by articulating specific areas of psychoeducation that may be implemented in the interventions of palliative care social workers when they engage with burdened family caregivers.

Provision of resources. This study’s findings also brought light to a common palliative care social work intervention that was not clearly defined in the extant literature as an intervention for family caregivers in the context of palliative care. All five of the participants in

this study described the provision of resources as an intervention that they commonly use to address caregiver burden. One possible explanation for this finding is that of the systems lens often employed by social workers, which specifically targets various aspects of the family caregiver's life that could be adding to the stressors of caregiver burden. If the social worker identified an area in the caregiver's system that appears to be lacking support, then the social worker can look for supportive services or resources that would be helpful in that particular system.

For example, the interviewees discussed specific resources that they have found to be helpful for family caregivers experiencing caregiver burden including the following: "caregiver consultation," "caregiver support groups," and "respite volunteers or other sources of respite." Of these resources, the most frequently mentioned in the data was that of respite services, which may relate back to the emphasis that the participants placed on the "loss of personal time" experienced by many family caregivers. Based on the findings from one report, 85 percent of family caregivers are not receiving any form of respite care (AARP Public Policy Institute & National Alliance for Caregiving, 2015). By providing family caregivers with information about respite care, palliative care social workers can make family caregivers more aware of these services and provide education on the benefits that respite care can have on their own health and wellbeing. Overall, the findings from this study expanded upon existing literature by emphasizing the use of resource referral as an appropriate intervention when working with family caregivers experiencing caregiver burden.

The Missed Opportunity

The theme of the missed opportunity was one of the most salient to emerge from the literature. It suggests that the implementation of family-centered care cannot always be fully

implemented within a hospital setting, especially in the context of palliative care and supporting the burdened family caregiver (Kovacs, Hayden Bellin & Fauri, 2006; Hudson, Aranda & Kristjanson, 2004). As a result, studies have shown that family caregivers often felt that their personal needs had not been met and that many of the factors of caregiver burden were never addressed even when they are included as part of the unit of care (Dubus, 2010; Hebert, Copeland, Schulz, Amato & Arnold, 2008; Tabler et al., 2015). One of the ways in which the research attempted to understand this disconnect is by exploring the barriers that prevent the implementation of these supportive services for family caregivers.

Barriers to implementation and engagement. The findings of this study support and expand upon the barriers to implementing family-centered care and to engaging the family caregiver emphasized in the research literature. Specifically, the findings of this study emphasize the hospital-based barriers that are present within the extant literature and add to this discussion by including caregiver-based barriers.

Hospital-based barriers. Throughout the extant literature, several studies pointed to barriers that limit implementation of family-centered care and engagement with family caregivers that originate from the setting of the hospital (Hudson, Aranda & Kristjanson, 2004; Kovacs et al., 2006). The findings in this study indicate two primary barriers relating to the hospital setting – time constraints and the hospital environment.

Time constraints. First, all of the study's participants described "limited time" or "time constraints" as a major barrier to assessing and addressing caregiver burden. One way in which this barrier interferes is due to the lengths of hospital stays, which one participant described as being only "two or three days" during which time she would be "lucky to get one visit with a caregiver." In their systematic review, Hudson, Aranda, and Kristjanson (2004) also indicated

short hospital stays as a barrier to the implementation of family-centered care and described this characteristic as a result of the for-profit nature of many hospitals. According to Weiss and Elixhauser (2014), the average length for a hospital stay in 2012 was 4.5 days with each hospital stay costing an average of \$10,400 per stay. With these figures, it makes sense why a for-profit hospital would need to create a greater turnover as it would be a key indicator of its operating efficiency. However, it does not lend itself to a setting that would allow palliative social workers like those interviewed for this study to be able to have the time to engage with family caregivers and provide appropriate interventions to address caregiver burden.

The hospital environment. Furthermore, the findings from this study build on the conceptualization of hospital-based barriers by also describing the hospital's environment as an impediment to supporting family caregivers experiencing burden. Participants in this study referred specifically to the inability to find private and comfortable spaces within the hospitals where they are employed. One reason why the interviewees may have found a lack of privacy to be an issue relates to the dynamic between the caregiver and his or her loved one. According to Reinhard, Given, Petlick, and Bernis (2008), it is imperative for health care professionals to have discussions regarding the caregiving experience with the family caregiver in a space that is separated from their loved one for whom they are caring. If the family caregiver is in the same room as their loved one, it may be more difficult for them to be open with the palliative care social worker about their fears, concerns, and difficulties. When the hospital setting is unable to provide this privacy and separation, it may be difficult for the palliative care social worker to create an environment where the caregiver can feel safe discussing caregiver burden.

In addition, the inability to find a space that this study's participants deemed to be comfortable for discussions of burden with family caregivers also represents a hospital-based

barrier. For example, one of the palliative care social workers described “bad lighting” and “uncomfortable chairs” as part of this uninviting environment. According to a study performed by Gifford (1988), there is a correlation between communication and both a room’s lighting and décor. The study found that rooms with bright lights tended to stimulate more general communication; whereas, softer lighting fostered more intimate conversation. Additionally, furniture and other room décor deemed to be more comfortable and more “home-like” often encourages conversation that is more intimate. Based on these correlations, the findings from this study suggest that the design of the hospital and rooms where discussions between the palliative care social worker and the family caregiver occur can have a direct impact on the depth of conversation.

Caregiver-based barriers. In addition to the barriers emerging from the hospital setting, the participants in this study also indicated that impediments can derive from the caregiver. In their practice, the interviewees described family caregivers with whom they often work as having a distrust in the medical system, which could result in missing information about the family caregiver’s experience of burden. The participants felt that these barriers prevented them from being able to fully assess and then subsequently intervene to address caregiver burden.

As previously described, four out of the five participants in this study indicated that family caregivers with whom they interact often have “a lack of trust,” “trust issues,” or a “low level of trust” in the medical system. The participants felt that this distrust directly limited their ability to engage with the family caregiver to most effectively assess and address caregiver burden. According to the literature, distrust in the medical system is a common phenomenon in the United States. For example, a study conducted with 961 Americans found that between 20 and 80 percent of all respondents reported distrust in response to each item listed in the Health

Care System scale and found an average score of 31 on a scale ranging from 10 to 50 (Armstrong et al., 2006).

This level of trust has been shown to grow only over time, which is not of great help to the palliative care social worker limited to potentially one visit with a family caregiver during any given hospital stay (Halbert, Armstrong, Gandy, & Shaker, 2006). As a result, it may be more difficult for palliative care social workers to be able to build enough trust within this relationship where the family caregiver can feel comfortable being open about their concerns and struggles with caregiving. As one of the participants stated, these conversations may be too “intimate” when distrust is present, which results in the sharing of only limited information. Overall, distrust in the medical system is a common phenomenon and can have a direct impact on the willingness of the caregiver to engage with health care providers including palliative care social workers.

Implications for Social Work Practice

Based on the findings of this study, there are several ways in which palliative care social work practice can be adapted to ensure the best possible care for family caregivers. First, one of the study’s findings was that of the disconnect regarding the use of formal assessment tools for caregiver burden. While many of the participants stated that they do not use formal assessments, this study found that the participants’ definition of caregiver burden and the observations that they make to assess for caregiver burden closely mirror the individual components of the Caregiver Strain Index (Sullivan, 2004). Therefore, palliative care social workers should seek opportunities to learn more about the available assessment tools for caregiver burden and reflect on the ways in which they fit into their current assessment style. If the idea that a series of specific questions feels “too formal” to the social worker, it is possible that the social worker

could continue to take their observational and conversational approach to assessment while engaging with the caregiver and then fill out the assessment tool following the visit. This approach would allow the social worker to be able to gauge a level of caregiver burden by using an assessment tool that has been tested for reliability and construct validity.

Based on the responses from this study's participants, there are numerous barriers that stand in their way of fully engaging with family caregivers to employ interventions targeting caregiver burden. Therefore, it is important for palliative care social workers to find ways to work through these barriers whenever possible. For example, this study underscores the ways in which the hospital environment can be a barrier to engagement. With this in mind, palliative care social workers can make a concerted effort to find locations in the hospital that might be more welcoming to intimate conversations about caregiver burden. This could also be an impetus for palliative care social workers to advocate for more quiet spaces within their hospitals for the purposes of these meetings. Overall, the identified barriers to engagement included in this study could inspire palliative care social workers to find creative ways to work through these barriers in an effort to better engage with family caregivers.

Implications for Future Research

As previously described, there is limited research that explores the perspective of palliative care social workers when discussing assessment and interventions strategies for family caregiver burden. While this study represents a start to this area of research, it is important that future studies continue to expand on the methods used in this study. For example, it would be beneficial to perform a similar study with a larger group of palliative care social workers in order to gain a better picture of how they approach family caregiver burden in their practice. Since this study highlighted the lack of formal assessment tools used in palliative care social work practice,

future research could focus more on the reasons why these screening tools are not used and to gain insight from social workers as to how such tools could be adapted to better fit their practice styles. Lastly, additional research could further explore the impediments to engaging with family caregivers in a medical setting in hopes of finding strategies for breaking down these barriers.

Strengths and Limitations

With every study, there are certain strengths and limitations to be explored. A strength of this study originates from the gap noted in the extant literature, which is the lack of the palliative care social work perspective. Therefore, the qualitative approach utilized in this study allowed palliative care social workers to add their voice and perspective to the discussion surrounding the ability to engage with family caregivers. At the same time, it is critical to assess the limitations of this study. Due to the limited time frame for conducting this research, I was only able to interview five palliative care social workers. Furthermore, I was only able to interview each participant once for this study so I was unable to ask any questions for follow-up or clarification after the end of the interview with each participant.

Conclusion

According to Rinehard et al. (2008), family caregivers are often referred to as “secondary patients” within the medical lexicon (p. 341). A consequence of this label is that the needs and concerns of the family caregiver are often overlooked. As a result, many family caregivers who are suffering from caregiver burden do not receive adequate support to help them manage the various impacts that caregiving can have on their health and wellbeing. According to the literature, the effects of caregiver burden are even more predominant for those who are providing care for a loved one at the end of life. Therefore, palliative care social workers are in a unique position assess and address caregiver burden when they engage with patients and their family

caregivers. This study utilized a qualitative approach to better understand the palliative care social worker's perspective of their ability to conduct assessments for caregiver burden and to employ appropriate interventions for family caregivers. The findings from this study indicate that palliative care social workers are very familiar with the concept of caregiver burden and actively seek to assess for its presence and to provide supportive interventions when engaging with family caregivers. However, the findings also underscore the presence of barriers that often prevent palliative care social workers from more thoroughly engaging with family caregivers to best address concerns of caregiver burden. Overall, this study illustrates the ways in which palliative care social workers make the concerted effort to engage with family caregivers, especially those experiencing caregiver burden.

References

- AARP Public Policy Institute & National Alliance for Caregiving. (2015). 2015 Report: Caregiving in the U.S. Retrieved from http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf
- American Cancer Society. (2016). Frequently Asked Questions. Retrieved from <http://www.cancer.org/treatment/findingandpayingfortreatment/understandingfinancialandlegalmatters/advancedirectives/advance-directives-faqs>
- Arias, E. (2015). United States Life Tables, 2011. *National Vital Statistics Reports*, 64(11). Retrieved from http://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64_11.pdf
- Armstrong, K., Rose, A., Peters, N., Long, J., McMurphy, S., & Shea, J. (2006). Distrust of the health care system and self-reported health in the United States. *Journal of General Internal Medicine*, 21(4), 292-297.
- Bedard, M., Molloy, D., Squire, L., Dubois, S., Lever, J., & O'Donnell, M. (2001). The Zarit Burden interview a new short version and screening version. *The Gerontologist*, 41(5), 652-657.
- Boss, P. (2004). Ambiguous Loss. In F. Walsh & M. McGoldrick (Eds.), *Living beyond loss: Death in the family* (2nd ed.). New York: W. W. Norton.
- Center to Advance Palliative Care. (2016). Disease Types. Retrieved from <https://getpalliativecare.org/whatis/disease-types/>
- Center to Advance Palliative Care. (2016). What is palliative care? Retrieved from <https://www.capc.org/payers/palliative-care-definitions/>
- Christ, G., & Blacker, S. (2009). Social Work Role in Palliative Care. *Palliative Care with Older Adults*. Retrieved from <http://www.cswe.org/File.aspx?id=24173>

- Cora, A., Partinico, M., Munafo, M., & Palomba, D. (2012). Health risk factors in caregivers of terminal cancer patients: a pilot study. *Cancer Nursing, 35*(1), 38-47.
- Dobrof, J., Zodikoff, B. D., Ebenstein, H., & Phillips, D. (2003). Caregivers and professionals partnership: A hospital based program for family caregivers. *Journal of Gerontological Social Work, 40*(1-2), 23-40.
- Evercare. (2006). Caregivers in Decline: A Close-up Look at the Health Risks of Caring for a Loved One. Retrieved from <http://www.caregiving.org/data/Caregivers%20in%20Decline%20Study-FINAL-lowres.pdf>
- Family Caregiver Alliance and National Center on Caregiving. (2014). Definitions. Retrieved from <https://www.caregiver.org/definitions-0>
- Garlo, K., O'Leary, J. R., Van Ness, P. H., & Fried, T. R. (2010). Caregiver Burden in Caregivers of Older Adults with Advanced Illness. *Journal of the American Geriatrics Society, 58*(12), 2315–2322.
- Georgetown Health Policy Institute. (2005). How do family caregivers fare? Retrieved from <https://hpi.georgetown.edu/agingsociety/pubhtml/caregiver3/caregiver3.html>
- Gifford, R. (1988). Light, décor, arousal, comfort and communication. *Journal of Environmental Psychology, 8*(3), 177-189.
- Given, B., Kozachik, S., Collins, C., DeVoss, D., & Given, C. Caregiver role strain. In Mass, M., Buckwalter, K., Hardy, M., Tripp-Reimer, T., & Specht, J. (Eds), *Nursing Care of Older Adults: Diagnoses, Interventions, and Outcomes* (679-695). St. Louis: Mosby.

- Given, B., Wyatt, G., Given, C., Gift, A., Sherwood, P., DeVoss, D., & Rahbar, M. (2004). Burden and Depression Among Caregivers of Patients with Cancer at the End-of-life. *Oncology Nursing Forum*, *31*(6), 1105–1117. <http://doi.org/10.1188/04.ONF.1105-1117>
- Glajchen, M. (2011). Caregivers in Palliative Care: Roles and Responsibilities. In Altilio, T. & Otis-Green, S. (Eds.), *Oxford Textbook of Palliative Social Work* (223-233). New York: Oxford University Press.
- Grov, E., Dahl, A., Moum, T., Fossa, S. (2005). Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. *Annals of Oncology*, *16*(7), 1185-1191.
- Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C., ... & Glossop, R. (2004). Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal*, *170*(12), 1795-1801.
- Halbert, C., Armstrong, K., Gandy, O., & Shaker, L. (2006). Racial differences in trust in health care providers. *Archives of Internal Medicine*, *166*(8), 896-901.
- Hearn, J., & Higginson, I. (1998). Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature review. *Palliative Medicine*, *12*(5), 317-332.
- Hebert, R. S., Copeland, V. C., Schulz, R., Amato, C. A., & Arnold, R. M. (2008). Preparing family caregivers for the death of a loved one: Implications for hospital social workers. *Journal of Social Work in End-of-Life & Palliative Care*, *4*(4), 269-285.
- Hudson, P. L., Aranda, S., & Kristjanson, L. J. (2004). Meeting the supportive needs of family caregivers in palliative care: Challenges for health professionals. *Journal of Palliative Medicine*, *7*(1), 19-25. doi:10.1089/109662104322737214

Institute for Family-Centered Care. (n.d.). Patient- and Family-Centered Care. Retrieved from

<http://www.ipfcc.org/pdf/CoreConcepts.pdf>

Kerr, M. (2000). One Family's Story: A Primer on Bowen Theory. Retrieved from

<http://www.thebowencenter.org>

Kondrat, M. (2013). Person-in-Environment. *Encyclopedia of Social Work*. Retrieved from

<http://socialwork.oxfordre.com/view/10.1093/acrefore/9780199975839.001.0001/acrefore-9780199975839-e-285>

Kovacs, P. J., Bellin, M. H., & Fauri, D. P. (2006). Family-centered care: A resource for social work in end-of-life and palliative care. *Journal of social work in end-of-life & palliative care*, 2(1), 13-27.

Kissane, D. W. (1999). Importance of family-centred care to palliative medicine. *Japanese journal of clinical oncology*, 29(8), 371-373.

Levine, C. (2008). Family Caregiving. In Crowley, M. (Ed.) *From Birth to Dean and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns* (pp. 63-68). Garrison, NY: The Hastings Center.

Marwit, S., Chibnall, J., Dougherty, R., Jenkins, C., & Shawgo, J. (2008). Assessing pre-death grief in cancer caregivers using the Marwit-Meuser Caregiver Grief Inventory (MM-CGI). *Psycho-Oncology*, 17(3), 300-303.

Marwit, S., & Mesuer, T. (2002). Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. *The Gerontologist*, 42(6), 751-765.

Marwit, S. & Meuser, T. (2005). Development of a short form inventory to assess grief in caregivers of dementia patients. *Death Studies*, 29(3), 191-205.

National Hospice and Palliative Care Organization. (n.d.). An Explanation of Palliative Care.

Retrieved from <http://www.nhpco.org/palliative-care-4>

National Hospice and Palliative Care Organization. (n.d.). Patient and Family-Centered Care.

Retrieved from <http://www.nhpco.org/quality/patient-and-family-centered-care>

National Association of Social Workers. (2004). NASW Standards for Palliative and End of Life Care. Retrieved from <http://www.socialworkers.org/practice/bereavement>

[/standards/standards0504New.pdf](http://www.socialworkers.org/practice/bereavement/standards/standards0504New.pdf)

National Association of Social Workers. (2010). Social Workers in Hospice and Palliative Care: Occupational Profile. Retrieved from

<http://workforce.socialworkers.org/studies/profiles/Hospice.pdf>

National Association of Social Workers. (2016). NASW Standards for Social Work Practice in Health Care Settings. Retrieved from

<https://www.socialworkers.org/practice/standards/naswhealthcarestandards.pdf>

National Institute on Aging. (2016). Providing Comfort at the End of Life. Retrieved from

<https://www.nia.nih.gov/health/publication/end-life-helping-comfort-and-care/providing-comfort-end-life>

Olson, E. (2015). Lack of sleep: Can it make you sick? Retrieved from

<http://www.mayoclinic.org/diseases-conditions/insomnia/expert-answers/lack-of-sleep/faq-20057757>

Padgett, D. (2008). Qualitative methods in social work research (2nd Ed) Thousand Oaks, CA: Sage Publications.

- Pinquart, M., & Sorensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and Aging, 18*(2), 250.
- Reinhard, S. C., Feinberg, L. F., Choula, R., & Houser, A. (2015). Valuing the Invaluable: 2015 Update. *AARP Public Policy Institute, Washington, DC*. Retrieved from <http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>
- Reinhard, S., Given, B., Petlick, N., & Bernis, A. (2008). Supporting Family Caregivers in Providing Care. In Hughes, R. (Ed.) *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*. Rockville, MD: Agency for Healthcare Research and Quality.
- Reinhard, S., Levine, C., & Samis, S. (2012). Home Alone: Family Caregivers Providing Complex Chronic Care. Washington, DC: AARP.
- Robinson, B. (1983). Validation of a caregiver strain index. *Journal of Gerontology, 38*(3), 344-348.
- Robinson, J., Callister, L., Berry, J., & Dearing, K. (2008). Patient-centered care and adherence: Definitions and applications to improve outcomes. *Journal of the American Academy of Nurse Practitioners, 20*(12), 600-607.
- Rolland, J. (2004). Helping Families with Anticipatory Loss and Terminal Illness. In F. Walsh & M. McGoldrick (Eds.), *Living beyond loss: Death in the family* (2nd ed.). New York: W. W. Norton.
- Shenton, A. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information, 22*(2), 63-75.
- Sullivan, M. (2004). Caregiver Strain Index (CSI). *Dermatology Nursing, 16*(4), 385-387.

Tabler, J., Utz, R. L., Ellington, L., Reblin, M., Caserta, M., Clayton, M., & Lund, D. (2015).

Missed Opportunity: Hospice Care and the Family. *Journal of social work in end-of-life & palliative care*, 11(3-4), 224-243.

The National Consensus Project for Quality Palliative Care. (2013). Clinical Practice Guidelines for Quality Palliative Care, 3rd Edition. Retrieved from

https://www.hpna.org/multimedia/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf

UPMC Palliative and Supportive Institute. (2013). The Difference Between Palliative and

Hospice Care. Retrieved from <http://www.upmc.com/Services/palliative-and-supportive-institute/resources/Documents/The%20Difference%20Between%20Palliative%20and%20Hospice%20Care.pdf>

Waldrop, D. (2007). Caregiver grief in terminal illness and bereavement: a mixed-methods study. *Health & Social Work*, 32(3), 197-206.

Weiss, A., & Elixhauser, A. (2014). Overview of Hospital Stays in the United States, 2012.

HCUP Statistical Brief, 180, 1-14.

Zarit, S., Reever, K., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, 20(6), 649-655.

Appendix A

Recruitment Email

To Whom It May Concern:

My name is Taylor Logeais and I am a graduate social work student at the School of Social Work at St. Catherine University and the University of St. Thomas. For my final project, I am conducting a **qualitative research study that explores the ways in which palliative care social workers are able to assess and address caregiver burden.**

I am looking for **Palliative Care Social Workers** who would be interested in being a part of my study. Your participation in this study is **voluntary** and would include **one 45- to 60-minute interview** about your experiences engaging with family caregivers and the ways in which you have been able to assess and address caregiver burden in your position. I will be conducting the interviews between January and February 2017.

If you are interested in learning more about this study, please contact me at **(952)-239-3870** or via email at **loge2865@stthomas.edu**.

Thank you for taking the time to learn a little more about my project and for the consideration of your participation in the study.

Sincerely,
Taylor Logeais

Appendix B

Interview Questions

1. What do you see as the primary objectives of palliative care?
2. Describe your role as a social worker on an interdisciplinary palliative care team.
3. How would you describe caregiver burden?
4. How do you screen for caregiver burden?
5. What is it about the patient and family context that triggers your attention to caregiver burden?
6. To what extent do you believe your assessment process appropriately gauges the level of caregiver burden experienced by the family caregivers you encounter?
7. Based on your formal (or informal) assessment of caregiver burden, in what ways do you intervene to address caregiver burden with the family caregiver?
8. Have you encountered any barriers to assessing and addressing caregiver burden among family caregivers?
 - a. If yes, what are some of the barriers that might prevent you from doing so?

Appendix C

**Consent Form****[974813-1] *Family Caregiver Burden: Palliative Care Social Work Perspective***

You are invited to participate in a research study about the ways in which palliative care social workers are able to assess and address caregiver burden experienced by a patient's family caregiver. I invite you to participate in this research. You were selected as a possible participant because you have experience working as a social work professional within the field of palliative care. You are eligible to participate in this study because you are a palliative care social worker. The following information is provided in order to help you make an informed decision whether or not you would like to participate. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by Taylor Logeais under the direction of her research chair, Dr. Melissa Lundquist from the School of Social Work at the University of St. Thomas and St. Catherine University. This study was approved by the Institutional Review Board at the University of St. Thomas.

Background Information

The purpose of this study is to gain a better understanding of how palliative care social workers assess and address caregiver burden faced by the family caregiver of their patients. Even though palliative care upholds the value of family-centered care, much of the research literature suggests that palliative care teams have been unable to focus on assessing and addressing caregiver burden. The literature supports the abilities of the interdisciplinary team, and more specifically, the palliative care social worker to provide the appropriate psychosocial support to family caregivers; however, the narrative of the missing opportunity is too important to ignore. At the same time, previous research mainly addresses this narrative from the perspective of the family caregiver and does not provide the viewpoint of the social workers tasked with the provision of such care. Therefore, this study aims to fill this gap in the research by giving voice to palliative care social workers and seeking their opinion on the following research question: to what extent do palliative care social workers feel they are able to assess family caregivers for caregiver burden and to subsequently address its effects?

Procedures

If you agree to participate in this study, I will ask you to do the following things: review the informed consent policy and partake in a discussion with me about the policy and acknowledge your consent to participate in the study by signing a copy of this form for me to keep with my records. You will be asked to partake in a 45 to 60-minute interview with me at the time and place of your choosing. There will be approximately eight to ten participants in this study. You will be asked to only complete one interview with me and I will not engage in any follow-up communication with you after the initial procedures have been completed.

Risks and Benefits of Being in the Study

The study has risks. As the data collection method for this study involves the audio recording of each interview, there is the potential risk that there may be a breach of the participants' confidentiality should the recordings be taken from my possession. In order to minimize this risk, I will be recording the interviews on my personal iPhone that is password-protected. The audio file will be uploaded to my password-protected One Drive account within 12 hours of the interview's completion. At this time, the audio file will be permanently deleted from my personal iPhone. All of the audio recordings uploaded and saved to my One Drive account will be permanently deleted upon completion of this study on May 15, 2017.

There are no direct benefits for participating in this study.

Privacy

Your privacy will be protected while you participate in this study. You will have the ability to schedule the time and setting for the 45- to 60-minute interview at a location of your choosing. If at any time there is an interview question that you would not like to answer, please let me know and we will move onto the next questions.

Confidentiality

The records of this study will be kept confidential. In any sort of report I publish, I will not include information that will make it possible to identify you. The types of records I will create include an audio recording of the interview and a Word document containing the verbatim transcript of the interview. The audio recording will be originally stored on my personal, password-protected iPhone and will be uploaded to my password-protected One Drive account within 12 hours of the interview's completion. At this time, the audio file will be permanently deleted from my phone. Similarly, the Word document containing the verbatim transcript of the interview will be uploaded and saved to my password-protected One Drive account. Both the audio files and the verbatim transcriptions will be permanently deleted from my One Drive account upon completion of this project on May 15, 2017.

I will be the only one to have access to both the audio recording and the transcripts of the interview. All signed consent forms will be kept for a minimum of three years upon completion of the study. Institutional Review Board officials at the University of St. Thomas reserve the right to inspect all research records to ensure compliance.

Voluntary Nature of the Study

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with St. Catherine University, the University of St. Thomas, or the School of Social Work. There are no penalties or consequences if you choose not to participate. If you decide to participate, you are free to withdraw at any time without penalty or loss of any benefits to which you are otherwise entitled. Should you decide to withdraw, data collected about you will not be used. You can withdraw by contacting me directly at 952-239-3870 or loge2865@stthomas.edu. You are also free to skip any questions I may ask with no exceptions.

Contacts and Questions

My name is Taylor Logeais. You may ask any questions you have now and any time during or after the research procedures. If you have questions later, you may contact me at (952)-239-3870 or loge2865@stthomas.edu or you may contact my research committee Chair Dr. Melissa Lundquist at 651-962-5813 or lund1429@stthomas.edu. You may also contact the University of St. Thomas Institutional Review Board at 651-962-6035 or muen0526@stthomas.edu with any questions or concerns.

Statement of Consent

I have had a conversation with the researcher about this study and have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I am at least 18 years of age. I give permission to be audio recorded during this study.

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

Signature of Study Participant

Date

Print Name of Study Participant

Signature of Researcher

Date