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Hospice Social Workers in the Death with Dignity Process

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Walden University

College of Social and Behavioral Sciences

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Lisa Carter

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Walden University
2021

Abstract

Hospice Social Workers in the Death with Dignity Process

by

Lisa Carter

MS, Capella University, 2004

BA, University of Puget Sound, 1995

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Human Services

Walden University

November 2021

Abstract

Hospice social workers are in an ethical conundrum due to the contrast between honoring clients' self-determined life closure and hospice organization prescribed non-participation in requests for physician-assisted death. The National Hospice and Palliative Care Association and the International Hospice and Palliative Care Association have issued position statements that the hospice philosophy of care is to provide comfort and reduce suffering, not to hasten death. Social workers are bound by a code of ethics to honor patient choice in end-of-life decisions. This generic qualitative study gives voice to hospice social workers in the Pacific Northwest regarding their motivations and responses to such patient requests considering the organizational policy of non-participation in physician-assisted death. The research was guided by self-determination theory of intrinsic and extrinsic motivators of behavior and decision making. Through one-on-one semi-structured interviews, data were collected from 10 hospice social workers who have received patient requests for physician-assisted death. Data were analyzed through content analysis by coding and categorizing using an inductive approach. Findings indicate that hospice social workers are unclear about organizational policy regarding non-participation and how much support they can offer patients. Social workers also reported feeling lack of education regarding Death with Dignity legislation and how their organization supports them following patient completion of the process. This study can impact social change by raising awareness of the ethical conundrum placed on hospices regarding patient choice at the end of life.

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Dedication

This dissertation is dedicated to hospice social workers who follow the calling to walk alongside their patients at the most difficult time of life. Those who do so with a smile and an open heart, who continually fight for social justice, who work hard despite limited resources and support. This is also dedicated to my parents and my sons. I would not have gotten through this journey without your encouragement, steadfast faith in my abilities, and understanding and patience. Your love and support have made this journey worthwhile. Mom and Dad, you especially deserve my utmost gratitude. I would never have had to confidence to continue on without your support.

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I would like to acknowledge my friends and family who have cheered me on and coached me through my writing, formatting, and tears. My hospice colleagues have given me the support, encouragement, and motivation to persevere. To my hospice patients present and past, who have taught me more about life than I could have ever imagined. I also want to acknowledge my dissertation chair and committee. Dr. Barbara Benoliel, I would never have finished this without your unwavering support and positive motivation. My long road to completed dissertation has been challenging beyond what I ever imagined, but you never gave up on me. Dr. Tracey Phillips, I thank you for your expertise and skill in assessing my methods and writing. Your feedback has been invaluable to me. Walden University has been a positive and motivating experience for me, and I am forever grateful for the overall support and giving me the drive to finish strong.

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Chapter 1: Introduction to the Study

Introduction

Hospice social workers in Washington State have been adjusting to patients requesting legal physician-assisted death since 2009 (Campbell & Black, 2014). Death with Dignity in Washington state requires specific eligibility criteria be met before a participating physician can prescribe the lethal medication ("How to Access and Use Death with Dignity Laws," 2015). Patients must be at least 18 years of age, have a physician-certified terminal prognosis of 6 months or less, and be of sound mind ("How to Access and Use Death with Dignity Laws," 2015). The process includes a verbal request, waiting period, second verbal request, written request, and waiting period, and then a prescription can be written and filled ("How to Access and Use Death with Dignity Laws," 2015). Participation by physicians and pharmacists is voluntary (Death with Dignity Acts, 2017). Hospice and palliative care social workers are bound by a code of ethics as directed by the National Association of Social Workers (NASW) to support self-determined life closure, provide advocacy in end-of-life decisions, and refer patients to resources in line with their requests and needs (Bailey, 2015). Patients must seek assistance from their physician; however, many physicians do not discuss advanced care planning at the end of life with their patients, opting to refer to hospice and palliative care nurses or social workers (Fulmer et al., 2018; Snyder et al., 2012).

Many hospice organizations adopt a stance of non-participation where they will not actively advocate or participate in a patient's request for physician-assisted death but will not impede their efforts either (Campbell & Cox, 2011; Washington State Hospital

Association, 2015). Research found that hospice social workers felt an ethical dilemma between professional standards and hospice philosophy (Hedberg & New, 2017; Norton & Miller, 2012). The position of the National Hospice and Palliative Care Association (NHPCO; 2015) states, “Hospice is not ‘giving up,’ nor is it a form of euthanasia or physician-assisted suicide” (p. 1). With Oregon’s similar Death with Dignity statute, social workers there have found difficulty understanding their role in the process since 1997 (Norton & Miller, 2012). Twenty seven percent of the hospice workforce is social workers impacted by this issue (Green, 2015). With this research, I sought to understand how hospice social workers in Washington State understand their role amidst the above circumstances.

Background to the Study

The NASW Standards for Social Work Practice in Palliative and End of Life Care state that social workers are tasked with advocating for a patient’s right to self-determined life closure through education, counseling, community referral, and advocacy with other health professionals (Bailey, 2015). Norton and Miller (2012) discovered a conflict between non-participation in physician-assisted death and advocating for self-determined life closure as an emerging theme in their qualitative study of hospice social workers in Oregon 15 years after the policy was enacted. Similar themes of ethical conflict were cited by hospice professionals from nursing and social work in Washington where professionals felt they were abandoning their patients by not being able to advocate for them through the Death with Dignity process due to policy restrictions by the hospice organization they represent (Campbell & Black, 2014). While Campbell and

Black (2014) focused on the social worker’s impression of the personal values of the patients they serve, my research focused on the values of the social workers and how they address organizational constraints when faced with a patient request for physician-assisted death. Before legalization of physician-assisted death in Canada, hospice volunteers and community members were surveyed regarding the prospect of legalizing physician-assisted death, and findings showed the majority of participants from both groups were for legalization but would opt for hospice and palliative care for themselves (Claxton-Oldfield & Miller, 2014). Another finding was that 20% of the hospice volunteers cited an experience where a patient had asked about physician-assisted death, and they felt ill-prepared to address this, further stating that they would like training on how to handle these conversations (Claxton-Oldfield & Miller, 2014). Although the aforementioned research regarding the lack of hospice support for patients choosing Death with Dignity illuminates important findings, I have found no research that has examined social workers’ perspectives regarding their professional ethical conflict. Given such, further research is warranted that could examine hospice social workers’ self-determination and ethics related to physician-assisted death and their perceived role in the Death with Dignity Process.

One comprehensive cancer center implemented a Death with Dignity protocol that has demonstrated how this process was executed in a multidisciplinary clinical setting (Loggers et al., 2013). Seattle Cancer Care Alliance, which includes three major medical centers, began the process of determining patients’ preferences and needs regarding end-of-life decisions in 2009. As of 2011, they noted 114 patient inquiries: 44 chose not to proceed, 30 initiated the process but died of natural causes, and 40 completed the process of dying via lethal prescription (Loggers et al., 2013). Loggers et al. (2013) further reported that no staff is required to participate in the program, and once a patient requests to explore the Death with Dignity process, they are then referred to a patient advocate (a licensed social worker) who initiates the protocol. The social worker coordinates all aspects of the process including at least two in-person meetings with the patient and encourages family participation. The process includes psychological evaluations, anticipatory grief counseling, and legacy support. In their retrospective data review, they found 54% of those who initiated the Death with Dignity process enrolled in hospice care. However, there were no specific data gathered regarding the impact of the social worker's role (Loggers et al., 2013). With social work being a hospice mandated by the Centers for Medicare and Medicaid Services (2015), there should be data on the effectiveness of the social worker's role in end-of-life care.

Problem Statement

Death with dignity has come to be synonymous with physician-assisted death (Guo & Jacelon, 2014). Eight states and the District of Columbia have now enacted Death with Dignity Acts, with Oregon and Washington being the first two in the United States (Death with Dignity States, 2019, n.d., Guo & Jacelon, 2014). Many terminally ill patients who choose Death with Dignity to end their lives were enrolled in hospice care, with Oregon reporting 88% and Washington reporting 81% (Campbell & Black, 2014; Hedberg & New, 2017). Hospice organizations, however, take a nonparticipation stance on the Death with Dignity issue, meaning, they neither support nor admonish those who choose to participate (Campbell & Black, 2014; Campbell & Cox, 2011; Gerson et al., 2019; Norton & Miller, 2012). The National Hospice and Palliative Care Organization (NHPCO) Key Hospice Messages (2015) state the philosophy of hospice is to provide end of life care to terminally ill patients to minimize suffering to aid them in living as fully as possible. The problem is patients have a legal right to choose physician-assisted death; however, overall hospice administrators are not taking part in completely supporting all end-of-life choices, making it a dilemma for social workers in their role of supporting clients (Stein et al., 2017). I have not found studies that provide clear insight to the attitudes, motivations, or thoughts of hospice social workers specifically related to physician-assisted death and how organizational policy affects their practice.

Purpose of Study

The purpose of this generic qualitative study was to understand the experiences, beliefs, and values of hospice social workers in Washington State regarding Death with Dignity and perspectives on the organizational policy of non-participation in patient requests for physician-assisted death. The role of the hospice social worker regarding Death with Dignity is unclear, and to understand how hospice social workers currently view their role and identify their views on possible changes needed, further research was needed. Participants included hospice social workers in Washington State employed by Joint Commission-certified hospice organizations. The goal of the research was to understand the experiences of hospice social workers and how they respond internally and externally to patient requests for Death with Dignity. This research also explored how social workers understand organizational policy regarding Death with Dignity and how that affects their interactions with patients.

Research Questions

The research question for this study was what are the experiences of hospice social workers dealing with personal and professional ethics of managing their role for their clients in Death with Dignity (DWD)? Also, there were sub-questions that arose:

- How do they perceive the ethical conflict between supporting self-determined life closure and non-participation in DWD?
- What education and support do they receive from their organization regarding DWD?
- How do personal beliefs and values influence their response to requests for DWD?
- How does employer policy related to participation in DWD influence their personal beliefs regarding supporting a patient's right to self-determined life closure?

Framework

The theoretical framework for this study was self-determination theory (Ryan, 2012, Ryan & Deci, 2020). Self-determination theory states humans need competence, autonomy, and relatedness (Ryan, 2012, Ryan & Deci, 2020). Social contexts affect motivation to meet these needs and can lead to controlled motivation, or conformity to certain behaviors despite the lack of meeting the basic needs (Ryan, 2012). Norton and Miller (2012) cited the problem of lack of clarification of the role of the hospice social worker regarding Death with Dignity in Oregon. They interviewed a focus group of nine hospice social workers with more than 15 years of professional experience and found three themes emerge: patient values of Death with Dignity, organizational policy, and the role of the hospice social worker (Norton & Miller, 2012). They concluded that Oregon hospice social workers' experience demonstrated continued confusion as to their role of how to support patients who request Death with Dignity despite employer policy of non-participation and patient self-determination and resolve to pursue physician-assisted death (Norton & Miller, 2012). Self-determination theory applies to this research in that the hospice social workers are being externally influenced by organizational policy but express a need to meet patient needs, which is what I researched further by asking more about internal influences and how social workers assimilate such into practice. This is an example of autonomous versus controlled motivation where social workers feel a sense of independence in practice but also have organizational pressure to conform to specific rules (Deci & Ryan, 2012).

Nature of Study

The present research is generic qualitative in nature (Sloan & Bowe, 2014). This approach allowed me to explore the texts of the experience of the hospice social workers through their words (Sloan & Bowe, 2014; Wilke, 2002). An inductive content analysis approach was used to collect and analyze data collected through open-ended, unstructured interviews with 10 participants. Inductive content analysis was appropriate for this study, as I have found little information to explain the lived experience of hospice social workers regarding physician-assisted death (Vasimoradi et al., 2013; Westefeld et.al., 2013). Data collection and analysis occurred concurrently as I immersed myself in the data to gain a true understanding of the phenomenon (Vasimoradi et al., 2013). The inductive approach calls for open coding of data and then organization into categories; however, a unit of measure is suggested such as themes or frequently used words (Elo et al., 2014). Microsoft Word Translate was used to transcribe all audio interviews, and all coding was completed manually. Data were collected from face-to-face, one-on-one interviews to gather a complete description of the lived experience. Face-to-face interviews afforded the opportunity to keep the interaction focused on the phenomenon to gather relevant data (Englander, 2012).

The target population for this study was hospice social workers in Washington State employed by a Joint Commission Certified hospice organization. Social workers with less than 1 year of post graduate experience were excluded. Sampling included all available genders, religious beliefs, ethnicities, and ages. Each participant had at least one experience with a patient who has requested information on physician-assisted death. Volunteers were sought from several different hospice organizations that meet the above criteria. Sample criteria were based on the focus of the study being limited to the experience of the hospice social workers with experience specific to the Pacific Northwest. Ten participants interviewed for several reasons. One is that spending more time with fewer participants helped to gain a deep understanding of their experiences (Robinson, 2014). Also, qualitative studies in physician-assisted death have had large samples, such as Campbell and Cox (2011) who asked over 500 nurses a set of open-ended questions via a mailed questionnaire. Their responses were limited in that there was no opportunity for discussion or clarification and emergent themes were not explored (Campbell & Cox, 2011).

Definition of Terms

Definitions of important terminology for the present study are in this section.

Advanced care planning: Decisions about what medical interventions a patient would like if they were unable to speak for themselves (National Hospice and Palliative Care Organization, 2016).

Conscientious objection: The right of individual health care professionals to decline participation in requests for Death with Dignity despite organizational policy and state law allowing the practice (Petrillo et al., 2017).

Death with Dignity: Legislation regarding the request for lethal prescriptions from a licensed physician by a terminally ill patient (Washington State Department of Health, 2015).

Euthanasia: The act of deliberately ending the life of another person to relieve suffering (Euthanasia and Assisted Suicide – NHS Choices, 2014).

Hospice: A philosophy of care to provide comfort to people with life-limiting or terminal illness (CHI – Franciscan Health, 2016).

Hospice social worker: A social worker that provides a psychosocial assessment of hospice patients regarding goals of care, strengths of patient and family, coping styles, care needs, advanced care planning, and bereavement risk (National Association of Social Workers Workforce Studies, 2010).

Non-participation: The position of a hospice organization to neither actively participate nor prevent a hospice patient from requesting DWD intervention (Jablonski et al., 2012).

Passive euthanasia: Withdrawal of life-sustaining medical treatment such as artificial feeding or breathing methods (Garrard & Wilkinson, 2005).

Physician-assisted death: A general term for physician prescription for life-terminating medications for a terminally ill patient (Starks et al., 2016).

Assumptions, Limitations, Scope, Delimitations

This research was based on the assumptions that hospice social workers have the education, knowledge, and desire to work with terminally ill patients under the hospice philosophy of care; answer questions honestly and comprehensively during the interviews; and are aware of current Death with Dignity legislation in their local area.

This study was conducted with 10 hospice social workers who currently practice in the Pacific Northwest. The hospice social workers were employed by a hospice organization that practices non-participation with DWD. The small sample size was a limitation; however, this was by design to keep the data manageable and to gather a rich perspective from participants (Golasfshani, 2003). Data were self-reported by participants and were taken at face value with the assumption that they reported their experiences truthfully (van Manen, 2014). A delimitation was that this study focused on personal insights of the hospice social workers regarding the specific situation of patients who request DWD. Participants were limited to hospice social workers in the Pacific Northwest who have more than 1 year of experience with direct patient care. This sample was purposeful to keep the study focused and to stay within the scope of social work and not hospice in general.

Significance and Social Change Implications

This research contributed to the understanding of the role of the hospice social worker by focusing on the perspectives of those currently practicing and encountering requests for physician-assisted death. This research is significant as it addressed the unique perspective of the professionals who have direct contact with terminally ill patients who are facing making end of life choices (Westefeld et al., 2013). The result of this study provides an opportunity for hospice social workers to understand their role and advocate for changes in how requests for physician-assisted death can be addressed by hospice organizations. Findings also illuminated the position social workers are in advocating for self-determined life closure amidst constraints imposed by organizational policy (Campbell & Black, 2014). Results also allow social workers to open dialogue with the organizations they work for about their beliefs, values, and concerns related to physician-assisted suicide, thus giving social workers a voice in evaluating and writing the organizational policy regarding this issue. This issue is important, considering some states allow professionals to opt out of participating in work that is inconsistent with their personal beliefs or faith, including Washington State and Oregon regarding their Death with Dignity statutes (Campbell & Cox, 2011). Implications for social change are attention to the role of social workers in end-of-life decisions, possible changes to organizational policy, and attention to this issue by other states who are considering similar legislation.

Summary

Hospice social workers are part of a multi-disciplinary team to provide comfort-focused care to terminally ill patients. The philosophy of hospice care is to neither lengthen or hasten death and provide comfort to the patient and family (Key Hospice Messages, 2015). While the role of the social worker is not stated in DWD legislation, the hospice social worker is compelled to assist with advanced care planning, where requests for DWD are likely to arise (Miller et al., 2006). Many hospice organizations in Washington State opt for non-participation in DWD, creating a challenge for hospice social workers to determine their role in assisting the patient with end-of-life plans and open discussions about options (Campbell & Black, 2014).

Chapter 2: Literature Review

Introduction

This chapter reviews the literature on hospice social work, organizational support styles in healthcare, physician-assisted death in the United States, Canada, and Europe, and healthcare workers' preparedness for implementation of physician-assisted death legislation. Position statements from local, national, and international professional organizations for hospice and discipline specific groups are also reviewed. The objective of this literature review is to gain an understanding of what is known and understood about physician-assisted death in the healthcare profession, specifically, hospice and social work. This helped to develop the planned study of hospice social workers and how they assist patients who request physician-assisted death. An understanding of the hospice philosophy of care also contributed to the understanding of this problem.

Hospice is an elective program focused on symptom management with comfort as a goal for terminally ill patients (NHPCO, 2016). Less than half of all deaths in the United States are supported by hospice services (NHPCO, 2012). Hospice accreditation began in the United States in 1984 after decade long campaign to allow people to have the option to die in their homes (History of Hospice Care, 2016). This movement was referred to as Death with Dignity; however, today, Death with Dignity refers to the legislation in Washington State to allow physician-assisted death (NHPCO, 2012). The evolution of hospice care in the United States has led to increased awareness of death and dying in America, increased regulatory mandates from the Centers for Medicare and Medicaid Services, and improved symptom management for the terminally ill (History of

Hospice Care, 2016). Continuing research into how hospice works and serves people and motivations behind providing service will help hospice to continue to change and meet the needs of the terminally ill.

Literature Search Strategy

My search for literature began with the Walden University and Capella University libraries and expanded from there to the following databases: Academic Search Complete, Google Scholar, LexisNexis Academic, Medline, ProQuest Medical, ProQuest Nursing and Allied Health, PsycARTICLES, PsycINFO, PubMed, SAGE Journals, SocINDEX, and US Department of Health and Human Services. Keywords searched the above databases include: physician-assisted death, death with dignity, death with dignity legislation, death with dignity and hospice, physician-assisted death and hospice, physician-assisted death and social work, role of social work in death with dignity, hospice providers in Washington State, National Hospice and Palliative Care Organization, position statement on physician-assisted death, social work attitudes on death with dignity, and international issues in physician-assisted death. References are drawn from entire works and excerpts of works cited primarily within the past 5 years.

Theoretical Foundation

Self-determination theory explains the dynamic between intrinsic motivation and biological and environmental influences (Deci & Ryan, 2012). Biological influences are non-social influences, or those that are genetic, while environmental influences are social factors such as relationships, observations, or physical factors in the environment (Deci & Ryan, 2012). Intrinsic motivation is inherent and develops naturally through the integration of said influences, which play a role in learning and development (Deci & Ryan, 2012; Ryan, 2012). The basis for this theory is that individuals have an inherent need for competence, autonomy, and relatedness and internalize environmental influences to become autonomous or intrinsic motivation (Deci & Ryan, 2012; Gagne & Deci, 2005). When applied to hospice social workers in a professional role, the dynamic between intrinsic and extrinsic motivation plays a role in how they serve their patients' requests and needs (Westefeld et al., 2013). Confusion can arise within the social worker when faced with requests from patients that contrast with their scope of practice or organizational policy and values (Norton & Miller, 2012). Self-determination theory is applied to different areas such as education, sports and fitness, well-being, psychotherapy, healthcare, organizational management, and environment (Self Determination Theory, 2017). This is a metatheory developed over several years including six mini-theories of cognitive evaluation theory, organismic integration theory, causality orientations theory, basic psychological needs theory, goal contents theory, and relationships motivation theory, all of which will be explained below (Deci & Ryan, 2000; Ryan & Deci, 1985, 2000).

Causality orientations theory posits people tend to gravitate toward situations and relationships that regulate behavior in various ways, such as where they have an interest in what is occurring, find reward, gains, and approval, and produce some anxiety about competence (Deci & Ryan, 2000). People want a challenge while feeling supported and encouraged (Ryan & Deci, 2000). Goal contents theory is the duality of intrinsic and extrinsic goals where a person has both innate motivation and motivation from external sources such as peers, loved ones, or performance expectations from an employer (Ryan & Deci, 2000). Close personal relationships that are positive and high quality fill the basic needs of relatedness, competence, and autonomy, or relationship motivation theory (Ryan & Deci, 2000). This suggests people with good friends, family attachments, and supportive co-workers will have healthy psychological development and function (Deci & Ryan, 2000; Ryan & Deci, 2000). This research focused on cognitive evaluation theory, organismic integration theory, and causality orientations theory. Taken as a whole, these three aspects of self-determination theory make up intrinsic motivation, extrinsic motivation, and adaptability in the organized environment (Deci & Ryan, 2000).

Cognitive evaluation theory suggests that autonomy and feelings of competence drive intrinsic motivation, thereby creating a desire to work at a higher level and work in more challenging situations (Gagne & Deci, 2005). Further, extrinsic rewards undermined intrinsic motivation and autonomy in the workplace, leading to decreased performance and motivation to work at a high level (Gagne & Deci, 2005). When extrinsic motivation becomes autonomous, performance increases with managerial support of autonomy (Gagne & Deci, 2005). Adaptability in the organized environment has to do with how people adapt to their work environment based on basic psychological needs (Olafsen et al., 2016). If their basic psychological needs of autonomy, competence, and relatedness will be met in the organizational setting, performance, attendance, and level of performance will improve (Olafsen et al., 2016).

Gagne and Deci (2005) explained that controlled versus volitional motivation creates a sense of pressure to conform to behavior according to prescribed values, meaning that social workers who value self-determined life closure may find conflict in themselves when asked to stifle a patient's request for physician-assisted death. Further, relationships between employee functioning and demands versus resources lead to satisfaction or frustration (Trepanier et al., 2015). Work environments that support employee needs have more productive and engaged workers; if work environments have more demands than resources, work quality declines with employee energy depletion (Tremanier et al., 2015). These results were found with nurses who were employed by a major medical center and demonstrate self-determination theory in the workplace as fitting and important. Tremanier et al. (2015) concluded demand and resources in employment drive the employees' motivation, meaning when workers feel supported, they are satisfied and engaged; when there is more demand for results without support, they are less engaged and feel more negative about their job. Manager support is important in employee motivation as well, as evidenced by somatization by employees and need for managerial intervention (Williams et al., 2014). Managers who provide emotional support to employees find greater employee engagement and decreased absenteeism, while managers who are less directly involved with their employees find increased sick calls, higher employee turnover, and emotional depletion (Williams et al., 2014). In a similar study, Olafsen et al. (2015) found monetary compensation played little role in employee intrinsic motivation; rather, managerial support was the main factor in determining employee self-regulation and motivation. Further, Olafsen (2017) studied employee mindfulness related to managerial support. She concluded that need support and need satisfaction play a role in the mindfulness of employees regarding job performance (Olafsen, 2017). Employees are motivated by supportive managers to approach their job duties with mindfulness, meaning they perform at a high level because they are motivated to do so with positive support (Olafsen, 2017). This research examined this from the voices of the hospice social workers to understand how extrinsic and intrinsic motivation affects their response to requests for physician-assisted death in the face of the organizational policy of non-participation. Understanding more about the hospice social worker and their professional role will build a strong foundation to understand their motivation.

The Hospice Social Worker

Hospice social workers can be distinguished from other areas of social work, as they serve the terminally ill specifically; however, they also provide counseling for individuals, families, and couples facing the loss of a family member or loved one (National Association of Social Workers, 2010). These professionals have a diverse skill set including navigation of the medical system, advocacy, mediation, community education, non-medical symptom management, education of patient and families on the hospice philosophy of care, and participation with the hospice interdisciplinary team (National Association of Social Workers, 2010). Hospice social workers have cited several challenges with integrating to the interdisciplinary team over the years of hospice care in the United States (Oliver & Peck, 2006). Challenges with collaboration with other team members, lack of field experience in a team environment in social work education, high caseloads, and administrative processes are the reasons many social workers report difficulty with feeling relevant in the hospice realm (Oliver & Peck, 2006). Issues of caseload size, lack of education on change or updated Conditions of Participation from the Centers for Medicare and Medicaid (CMS), and lack of support from administrators have been cited by hospice social workers as needs for ongoing education within the organizational setting (Weisenfluh & Csikai, 2013).

Conflict within the hospice interdisciplinary team as reported by social workers was caused by a misunderstanding of roles, the leadership of the team, and psychosocial needs superseded by physical symptoms (Green, 2017). Social workers are viewed by other hospice disciplines as the bridge between team members when conflict arises (Green, 2017). Social workers report blurring of roles in this regard between the conflict, the social worker, and the team leadership (Green, 2017). Hospice social workers are skilled at meeting psychosocial needs of patients, but not physical or medical needs; conversely, other disciplines demonstrate confidence in meeting psychosocial needs of patients in the absence of the social worker (Day, 2012). Social workers report that they feel influenced by previous positive or negative experiences with the interdisciplinary team, organizational policy, and conflict as a catalyst for change (Green, 2017). Leadership styles are also important in considering how conflict is addressed in an interdisciplinary setting since many leadership roles in healthcare have no social work background (Green, 2017). This leads to the misunderstanding of roles and has an impact on the social worker’s perceived importance to the team (Green, 2017). Despite these issues, many hospice social workers report positive job satisfaction due to the nature of autonomy, professional self-direction, and personal values about comfort at the end of life (Cieslak et al., 2014; Whitebird et al., 2013).

Measuring outcomes of hospice social work have not been studied in recent literature (Alcide & Potocky, 2015). In their literature review on empirically tested hospice social work interventions, Alcide and Potocky (2015) were able to identify five studies that met strict criteria of an evidence-based intervention designed for the hospice population. This number was narrowed from a pool of over 600 articles, with only 70 peer reviewed (Alcide & Potocky, 2015). Results indicated that there are few evidence-based interventions for hospice population employed by hospice social workers about key factors of quality of life, concluding that social workers likely use evidence-based interventions such as solution-focused therapy, cognitive behavioral therapy, dignity therapy, or mindfulness, but these have not been studied for effectiveness in the hospice realm (Alcide & Potocky, 2015). Washington et al. (2012) noted social work intervention with hospice patients enhanced problem-solving skills, development of supportive relationships, and confidence and control over their situation with caregivers of hospice patients.

Efforts to create measurable outcomes for hospice social work have been cited as minimal in the academic literature due to efforts by the World Health Organization promoting a paradigm shift in American health care toward Inter-Professional Collaboration (Blacker et al., 2016). Historically, healthcare settings have been plagued by *turf wars* due to role overlap, misperceptions of the role of each discipline, and the perceived hierarchy within the interdisciplinary team (Blacker et al., 2016). Blacker et al. (2016) suggest outcome measures be developed to understand the role of hospice social workers as part of the interdisciplinary team, with change starting with social work educators. This change will demonstrate the importance of social work on the hospice team and raise awareness of their role with an emphasis on the outcomes produced by their intervention (Blacker et al., 2016). Perceived hierarchy in medical settings contributes to poor communication between disciplines and can negatively affect patient outcomes due to poor understanding of the patient’s wishes, needs, or decision-making process (Lancaster et al., 2015). Physicians are the unofficial leaders of the care team, followed by nurses, then support personnel such as social workers and care assistants, which fosters a disconnect between disciplines leading to professionals practicing autonomously instead of collaboratively (Lancaster et al., 2015). Patient safety is of the utmost importance and directly informs outcomes; therefore, working harmoniously within the different professions can lead to greater patient satisfaction, enhanced safety, and better compliance (Lancaster et al., 2015). Social workers tend to be lower in the perceived hierarchy and therefore do not always inject their expertise into a patient’s situation completely. However, with a different perspective on how to interact with other disciplines and a mutual respect for each contribution, social workers can contribute more significantly to the patient's overall experience (Lancaster et al., 2015).

Life review has been a recognized intervention for hospice social workers with adults approaching the end of life; however, the scope and frequency varies due to several factors (Csikai & Weisenfluh, 2012). Hospice social workers often engage patients in life review to assist them with a reconciliation of life events and to find peace before the end of life; however, there is no standardized method for this therapeutic intervention (Csikai & Weisenfluh, 2012). In a survey of over 300 hospice social workers nationwide, the scope and frequency of this type of intervention varied greatly depending on caseload size, length of stay, and acuity of patients (Csikai & Weisnefluh, 2012). Some studies noted patients who were engaged in life review intervention demonstrated improved mood, less hopelessness at the end of life, and greater interest in activities and social interaction (Glass et al., 2006; Hopko et al., 2003; Serrano et al., 2004). Measuring the outcome of this intervention is challenging without a standardized implementation and therefore, contributes to the lack of literature on hospice social work outcomes (Csikai & Weisnefluh, 2012). This is compounded by regulatory changes related to hospice practice for all professions including social work (Weisenfluh & Csikai, 2013). The Centers for Medicare and Medicaid Service (CMS) (2008) issued regulatory changes regarding hospice social work practice and who could be employed as a hospice social worker (Weisnefluh, & Csikai, 2013). Since then, each year, Conditions of Participation as a certified hospice provider have included updated regulations regarding social work practice and oversight including scope and frequency of social work intervention, documentation requirements, and accountability for bereavement services (Weisenfluh & Csikai, 2013). Despite these regulations, there are no directives for what interventions are required or how they are delivered, which leads to the greater issue of lack of measurement of hospice social work outcomes (Weisnefluh & Csikai, 2013). Likewise, the issue of lack of literature on hospice social work involvement with Death with Dignity requests by patients contributes to the problem of lack of requirement of interdisciplinary assessment of patients who request physician-assisted death (Campbell & Black, 2014).

Death with Dignity Legislation

Death with Dignity (DWD) legislation in Washington State was enacted in 2009 by a voter referendum stating terminally ill adults over the age of 18 can legally request lethal prescriptions from participating physicians with the intent to end their lives (Washington State Legislature, 2009). This legislation is modeled after the Death with Dignity Act in Oregon passed in 1997 (Campbell & Black, 2014). According to the Washington State Department of Health (n.d.), the process includes an initial request, in writing, from the patient to their physician for a lethal prescription. The physician must certify the patient as terminally ill with a life expectancy of 6 months or less. After a 15-day waiting period, an oral request must be made to the physician who then can write the prescription or the lethal doses of medication. Once the patient receives the prescription, the pharmacist may fill the medication in 72 hours. Once the patient receives the medications, they may self-administer in their own time. There are reporting requirements for both the physician and the pharmacist once their respective roles have been completed. They have 30 days to file required paperwork with the Washington State Registrar (Death with Dignity Act: Washington State Department of Health, n.d.).

The United States now has eight states as well as the District of Columbia with physician-assisted death legislation (Death with Dignity Acts, 2017). Oregon, Washington, California, Colorado, and Vermont have all passed voter referendums, while Montana had a Supreme Court ruling stating that physician-assisted death is not illegal they have not enacted any legislation (Death with Dignity Acts, 2017). Multiple other states have considered the matter in legislative sessions in 2016 but have yet to present any ballot measures to voters (Death with Dignity Acts, 2017).

Internationally, Canada is the most recent country to allow physician-assisted death which was changed by the Supreme Court of Canada decision in 2015 (Abraho et al., 2016). The decision was delayed until the next year to allow for localities to write legislation, and organizations to develop policies (Abraho et al., 2016). Vancouver Island has seen hospice and palliative care providers integrate medical aid in dying (MAID) into their programs if patients meet certain criteria such as multiple hospitalizations, patient preference, and length of time receiving hospice services (Robertson et al., 2017). Of the 76 MAID deaths on Vancouver Island in the first 6 months of legalization, nine were patients receiving hospice services and had the support of the hospice provider (Robertson et al., 2017).

Switzerland, Belgium, Luxembourg, England and Wales, The Netherlands, and Columbia all have a legal version of physician-assisted death (Assisted Suicide Laws Around the World, 2016). The Netherlands, Belgium, Luxembourg, and Columbia allow not only physician-assisted death but active euthanasia as well (Death with Dignity Acts, 2017). Patients do not have to self-administer lethal prescriptions themselves, but they do have to consent to the doctor administering on their behalf (Assisted Suicide Laws Around the World, 2016). In the Netherlands, an explicit patient request is not documented before euthanasia, with declining rates of these deaths between 2005 and 2010 (Onwuteaka-Philipsen, 2012). The number of patients who died as a result of passive euthanasia was more than active euthanasia, and seventy percent of those were denied active euthanasia requests (Onwuteaka-Philipsen, 2012). In 2010, only two to eight percent of deaths in the nation were as a result of some form of physician-assisted death (Onwuteaka-Philipsen, 2012).

Emanuel, et al. (2016) reviewed data from all countries with legal physician-assisted death and found these types of deaths remain rare and primarily are a result of a cancer diagnosis. Western Europe has seen continued interest in the legalization of physician-assisted death since the 1940's, while interest has plateaued in the United States since the 1990's (Emanuel et al., 2016). Public polls of laypersons show that the majority of those polled were interested in end-of-life options other than comfort care, while most physicians polled reported opposition to all forms of physician-assisted death (Emanuel et al., 2016). This information contrasts with physicians in Ontario, Canada who reported agreement with providing increased options for end-of-life care including physician-assisted death, but unwillingness to actively participate (Landry et al., 2015). The United States has reported that less than one percent of deaths are physician-assisted, while in Europe this is closer to eight percent (Emanuel et al., 2016). In both the United States and Europe, over seventy percent of these deaths were due to terminal cancer. However, quality of life is the reason most often cited in the United States, while pain is the reason most often cited in Europe (Emanuel et al., 2016). In all areas where physician-assisted death is legal over eighty percent of those requesting assistance are white, highly educated, male cancer patients (Emanuel et al., 2016).

The International Association for Hospice and Palliative Care’s official position statement is that in countries where physician-assisted death or euthanasia is legal, hospice and palliative care providers and professionals should not be required to offer or provide physician-assisted death or euthanasia services (De Lima et al., 2017). Further, any country considering legalization of physician-assisted death should not do so until it has verified that universal access to hospice and palliative care services are established (De Lima et al., 2017). Researchers in the United Kingdom have worked to identify continued areas of research that are needed in relation to the issue of physician-assisted death. They surveyed health and social work professionals, lobbyists, researchers, patients, and caregivers to find out what areas of concern are most prevalent (Rogers et al., 2016). Out of several themes identified, two were the role of clinicians and internal and external influences for the desire to seek such services (Rogers et al., 2016). Several of the top themes that were identified by participants were psychosocial in nature, such as care burden of choosing physician-assisted suicide, quality of life factors, dignity at the end of life, alternative pathways to symptom control and alleviation of suffering, and understanding why certain groups of people are more prone to requesting physician-assisted death (Rogers et al., 2016).

Ethical Considerations in Physician-Assisted Death

In 2006, Miller, Hedlund, and Soule explored how hospice professionals meet patient's need to discuss end of life options, specifically related to Oregon's Death with Dignity Act. One noted theme that arose from professional conversations with patients was ethics and restricted conversations. The role of the social worker specifically is not explained in the DWD legislation, but social workers are part of the professional team that treats patients at the end of life which should imply that they require education on issues surrounding physician-assisted death (Miller et al., 2006). After 11 years of DWD in Oregon at the time of this study, social workers were reporting their education regarding the legislation were gained from experience with patients, workshops, and academic institutions in both formal and informal settings. They also reported that they felt an ethical conundrum between the organizational policy of non-participation in DWD, and professional code of ethics mandating advocacy for patients' right to self-determined life closure (Miller et al., 2006).

Since implementation in Washington, ethical considerations have been raised for hospice organizations within the state, and for other municipalities considering similar legislation (Campbell & Black, 2014). Social workers are bound by a code of ethics laid out by the NASW (2015) regarding supporting patient's rights to self-determined life closure. Recent literature addresses ethics from an organizational and individual perspective both in Washington and Oregon (Campbell & Black, 2014; Campbell & Cox, 2012; Jablonski et al., 2012). Eighty to ninety percent of patients who choose DWD in Oregon and Washington were enrolled in hospice care. However, most hospice organizations do not actively participate in the process with their patients (Campbell & Black, 2011; Campbell & Cox, 2014; Jablonski et al., 2012). This nonparticipation is due to the hospice philosophy as stated by the NHPCO that hospice is comfort measures, not euthanasia (Key Hospice Messages, 2015). With this philosophy adopted by hospice organizations across the country, hospice social workers have difficulty understanding their role when a patient state they wish to consider DWD as an end-of-life option (Norton & Miller, 2012). Norton and Miller (2012) noted a lack of research related to hospice social workers experiences with a patient request for hastened death. Researchers chose a sample of 9 hospice social workers who were participating in a larger study and created a focus group. This sample was chosen based on years of experience with hospice and represented several hospice providers in Oregon from varying rural and urban locations (Norton & Miller, 2012). Emerging themes included differing values surrounding Oregon's Death with Dignity Act (ODDA), policy implications, and defining the role of the hospice social worker regarding ODDA (Norton & Miller, 2012). The researchers assert that the role of the hospice social worker is evolving and will continue to do so concerning ODDA (Norton & Miller, 2012). Clear policy needs to be offered due to the conflict between hospice provider's directives to staff not to discuss ODDA versus professional guidelines to offer support and education to patients in this regard (Norton & Miller, 2012).

Similar issues reflected by Westefeld, et al. (2012) regarding ethical considerations for including more professions in the DWD process. Important considerations are patient autonomy, self-determination, the right to free choice, dignity, and mental competence. Further, they suggest training programs for human service professionals to understand the legislation, multicultural issues regarding views of death, dying, and suffering, and language that defines the role of those who interface with patients who choose physician-assisted death (Westefeld et al., 2012). Hospice professionals report lack of education and preparedness for DWD regarding both the legislation and organizational policies from their employers (Clymin et al., 2012; Jablonski, et al., 2012). In this two-part study by Jablonski, et al. (2012) of hospice nurses, less than 10 percent of the nurse's received education on DWD legislation in Washington and only 13 percent were aware that there is no interdisciplinary evaluation required for patients requesting DWD. Sixty percent of respondents erroneously believed that only hospice patients could request DWD, and 41 percent were not aware of their employers' policies regarding patient requests for DWD. They concluded that nurses did not understand how uninformed they were. Personal views of the DWD Act were split, and nurses reported conflict between professional ethics and personal views of DWD. About ¼ of the nurses whose employers had a policy of non-participation in DWD was not sure if they would be reprimanded if they were to discuss DWD with patients who request it. Likewise, about the same percentage of nurses did not know if they could lose their nursing license if they declined to assist a patient who requested DWD. Researchers concluded that there were disparities in the nursing profession regarding professional ethics and employer policy. They also concluded that nurses need education on the DWD Act and how their professional organization views the legislation and their role in that (Clymin et al., 2012).

Ethical dilemmas in hospice social work were explored in situations that do not involve DWD and findings suggest that hospice social workers struggle with the conflict between personal values and family decision-making, personal values and agency policy, and personal values and professional standards of practice (Dennis et al., 2014). Hospice social workers report value in being truthful in interactions, even when conveying information that families or patients have stated they do not want to discuss, such as telling the patient they are dying (Dennis et al., 2014). Some social workers reported a willingness to defy agency policy in certain situations if it meant a positive outcome for the patient ensuring autonomy, while some social workers felt that they had a responsibility to yield to other disciplines even if it violated their personal and professional values (Dennis et al., 2014). While social workers reported a strong sense of advocacy for patient autonomy, they did note that they do not feel like an important part of the interdisciplinary team and find that collaboration about ethical issues takes place on an informal level with colleagues and team members (Dennis et al., 2014). Ethical issues can arise based on the subjectivity of policy or legislation (Gerson et al., 2016). In a survey of hospice physicians, nurses, social workers, and chaplains regarding hastened death in hospice patients, blurred boundaries between symptom management and suffering were noted to contribute to the interpretation of desired suicide (Gerson et al., 2016). Researchers concluded that hospice professionals reconciled patient suicide based on differing interpretations of physician-assisted death legislation and organizational policy (Gerson et al., 2016). Hospice social workers in California were surveyed regarding their preparedness for discussing physician-assisted death, and while there was no formal education provided to them, they felt a level of comfort in adding this option to end of life discussions (Brennan & Kinney, 2017).

End of Life Planning

Physicians have reported discomfort with discussions about end of life and advanced care planning (Snyder et al., 2012). Physicians self-report comfort with discussing advanced care planning, but only engage in these discussions with less than half of their patients (Snyder et al., 2012). Based on data from Oregon after 14 years of legalized physician-assisted death, opposition from the medical community remains even with physicians and other health professionals having a conscientious objection option (Prokopetz, & Lehmann, 2012). These issues are not limited to the United States, as in Canada when physician-assisted death was considered for legalization; many health care professionals were unclear about what end of life treatments was legal (Marcoux et al., 2015). While professionals knew lethal prescriptions were illegal, they were not knowledgeable about the legality of withdrawing life-sustaining treatment, or palliative sedation at the end of life; further, physicians and other professionals lack of knowledge can lead to misinformation to patients considering their end-of-life options (Marcoux et al., 2015; Prokopetz, & Lehmann, 2012; Snyder et al., 2012). Since 2015, physician-assisted death has become legal in Canada. However, regulatory bodies and professional organizations have no frame of reference for creating policies regarding responses to patient requests (Landry et al., 2015). Allied Health Professionals in Canada reported their favor a patient with amyotrophic lateral sclerosis (ALS) choice for physician-assisted death, but few reported comfort with prescribing lethal medications in favor of referrals to mental health evaluation and then third-party involvement to see patients through the process (Abrahao et al., 2016). Respondents in this survey further indicated that they are for a formal training module on the physician-assisted death process to enable them to take a more active role with confidence (Abrahao et al., 2016). Nurse practitioners are now allowed to prescribe lethal medications in Canada, but a study conducted before that change focused on nurses and how they determine a patient's desire for death (Wright et al., 2017). Nurses indicated their concern about assessing the difference between the desire for death based on acute symptoms versus the desire to actively end their lives based on long-term suffering (Wright et al., 2017). Emerging themes from this study demonstrated that some patient's state phrases such as "please kill me," or "let me die" in the midst of poor symptom control or acute anxiety, but then once symptoms are managed, they do not express these words (Wright et al., 2017).

After a scan of the international landscape of physician-assisted death and euthanasia, sources show that the United States and Canada have stricter limitations on how physician-assisted death is implemented. Some European countries allow for euthanasia to be decided by a surrogate decision maker (Hendry et al., 2012; Landry, Foreman, & Kekewich, 2015). Switzerland palliative care physicians report conflict between requests from patients and lack of training about how to respond to such (Gamondi et al., 2017). In a qualitative study of 23 Swiss palliative care physicians Gamondi, Borasio, Oliver, Preston, and Payne (2017) concluded that physicians were interested in collaborating with the right to die organizations to learn more about their role impacts patient decision making at the end of life. However, the physicians cite ethical conflict between palliative care philosophy and honoring patient autonomy (Gamondi et al., 2017).

Seattle Cancer Care Alliance (SCCA) recognized this gap and was able to form a Death with Dignity Program at their cancer center. An evaluative study by the program creators showed success in that patients and staff can express their views without reproach (Loggers et al., 2013). SCCA can allow patient requests for physician-assisted death with the option for their providers to opt out and allow for a different physician, social worker, or nurse to discuss the issue and assess for appropriateness. A multi-disciplinary approach is taken for all requests including social work, chaplain, nurse, and physician, each providing their professional expertise to determine if the patient is mentally competent, physically capable of self-administration of the medication, and within 6 months of the end of life (Loggers et al., 2013). In this model, the social worker is the lead in determining appropriateness for the Death with Dignity process. Once mental competence is established, the medical team determines medical prognosis. There are a minimum three visits with the social worker for assessment of appropriateness for continuing with the process of obtaining a lethal prescription (Loggers et al., 2013). SCCA has demonstrated how a multidisciplinary approach can work successfully while allowing professionals to exercise their right to conscientious objection to DWD.

The state of California recently legalized physician-assisted death; however, before implementation, a conference was offered to healthcare professionals to prepare them for how to respond to the new legislation (Petrillo et al., 2017). Learning from Oregon and Washington, California public health officials gathered a panel of healthcare professionals from all three states to educate and prepare healthcare organizations to rewrite policies, train their professionals, and to encourage allowance of conscientious objection (Petrillo et al., 2017). Other areas with legalized physician-assisted death have not prepared their constituencies for the transition to new legislation (Petrillo, et al., 2017).

Braverman, Marcus, Wakim, et al. (2017) found health care professionals in one health system reported comfort with physician-assisted death and that terminology or use of word suicide had no bearing on level of a professional's comfort with the concept. The majority of the 221 respondents cited patient-centered rights and personal suffering as reasons for supporting physician-assisted death, but the majority was against active euthanasia (Braverman et al., 2017). They report their findings as an indication of changing attitudes of health care workers, particularly physicians as they made up greater than half the sample (Braverman et al., 2017). This report contrasts with the position statement by the American College of Physicians that physician-assisted death is not legalized further and that physicians should not be willing to participate in such requests from patients (Sulmasy & Mueller, 2017).

Currently, social workers, in general, do not play a significant role in end-of-life planning before terminal illness (Norton & Miller, 2012), however, one study shows that this is changing. Stein, Cagle, and Christ (2017) surveyed over 400 social workers employed in the hospice, palliative care, and similar fields and found that over 90% regularly conduct discussions around advance care planning, often taking the lead in these discussions. In hospice and palliative care settings, the social worker is the professional responsible for initiating advance care planning discussions, however, in oncology settings, the social worker has little to no role in this (Stein, Cagle, & Christ, 2017). The social worker has the knowledge and education to lead these discussions, however, due to the medical model of care in most health systems, they are not part of the process in helping patients to determine their advance care plans (Westefeld et al., 2013). Once the patient is enrolled in hospice care, the nurse, social worker, and at times chaplain, all contribute to the discussion of end-of-life planning (National Association of

Social Workers Workforce Studies, 2010). Kwon, et al. (2014) surveyed social work students about their comfort level discussing end of life issues with clients. These students demonstrated positive attitudes and comfort in discussing pain management, advance directives, and self-determination in life closure, including physician-assisted death, which led to the conclusion that social workers value a patient's right to make autonomous decisions about their end-of-life care (Kwon et al., 2014).

McCormick, et al. (2014) noted the need for specialized ethics education for medical social workers in a hospital, medical clinics, nursing facilities, and hospices due to specific ethical dilemmas that arise as a result of physical illness. Noting that ethics in end of life or terminal or chronic illness are not directly taught in social work curricula, finding time away from practice to attend continuing education sessions, and that offerings are taught by non-social work professionals, this group of practitioners developed a continuing education program on medical social work ethics (McCormick et al., 2014). They propose bioethics training for all social workers in medical settings with a case study structure to ensure understanding of the physical issues patients is dealing with affecting their decision-making and to assess perceived suffering (McCormick et al., 2014). The focus on decisional capacity and ethical decision-making in the medical setting to ensure that social workers understand patient autonomy considering decisional capacity versus surrogate decision makers (McCormick et al., 2014).

Methodology

The proposed research will be a generic qualitative study of the experience of hospice social workers. More specifically, interpretive methods based on the question of how people make meaning of and interpret their experiences will be used (Bradbury-Jones et al., 2017). These perceptions and responses cannot be measured or controlled in quantitative research but must be studied differently in a more natural environment (Matua & Van Der Wal, 2015). Generic qualitative methods involve an inductive approach and leads to thematic and categorical analysis based on semi-structured interviews (Kahlke, 2014). By exploring the perceptions and attitudes of social workers based on their current practice and relevant issues, rich data can be uncovered about their professional decision-making, interactions with patients, and their experiences in situations they have encountered.

Extensive review of the literature demonstrates different methodologies used to study physician-assisted death, ethics, hospice, and the interdisciplinary team. Data sources vary depending on the study for example, Norton and Miller (2014) completed interviews with hospice social workers after completing a quantitative survey study of those participants seeking qualitative data to compliment the survey data gathered to give more depth to the experience of the social workers. They had a focus group of nine hospice social workers and asked them open ended questions regarding their understanding of Oregon’s Death with Dignity Act based on the quantitative data gathered from surveys of hundreds of hospice social workers (Norton & Miller, 2014). After a preliminary analysis and refined coding, three themes were identified as values about physician-assisted death, organizational policy, and the role of the hospice social worker (Norton & Miller, 2014). Researchers were able to uncover that patient values as reported by the social workers emerged more than the social workers personal values.

The proposed research will be more directed at the personal values of the hospice social workers and how that may affect their responses to patients. While Norton and Miller (2014) described the patient experience through the experience of the social worker; the proposed research will interpret the experience of the social worker, not the patient.

A cross-sectional survey based on a validated questionnaire gathered data from Canadian healthcare professionals regarding their understanding of legal end-of-life practices (Marcoux et al., 2015). This gave statistical data to be interpreted from hundreds of professionals who responded to 6 patient scenarios about weather their request for end-of-life care was legal; however, this was limited to their current knowledge, without discussion about the scenario presented (Marcoux et al., 2015). This study provided important data but presented participants with fictitious scenarios. The proposed research will focus on the social workers' actual experience and ask them to share, not only the details of the experience, but what that meant to them, their motivation for how they participated, and the impact that experience has had on their current and future practice.

Chan, et al. (2014) researched the lived experience of students in Malaysia with mobile learning in public and private school. They decided on a hermeneutic phenomenological approach as the existing research in that area focused on demographics and usage profiles of mobile learning devices (Chan et al., 2014). The gap in research identified was lack of understanding of student experience with this type of learning with most of the research focusing on learning outcomes or who is using mobile learning (Chan et al., 2014). The methodological approach of hermeneutic phenomenology was chosen to capture the subconscious phenomenon in order to understand the lived experience through language, or the telling of their experiences (Chan et al., 2014). Researchers studying Arab English teaching candidates working to pass their credentialing exam used hermeneutic phenomenology to interpret the experiences of fourth year English teaching students preparing for the exam (Al-Issa et al., 2016). This study explored the students experience with taking the credentialing exam and their reflection on what they would do differently to prepare if they were to re-take the exam with researchers analyzing through a "'micro' lens that leads to better knowing the 'macro' experience," (Al-Issa et al., 2016, pp. 853). Immersion in the transcribed interviews provided with an inductive approach due to lack of prior knowledge of the experiences of the Arab English students (Al-Issa et al., 2016). This allowed researchers to extrapolate rich information regarding the lived experience of the students with exam preparation and how that information helps them to make decisions for future exams (Al-Issa et al., 2016). The proposed research will take a similar approach to learn from the social workers' experience how they would approach physician-assisted death based on past patient interactions.

Key aspects of qualitative research are experience and meaning (Crowder et al., 1997). For interpretive research, the experiences of the participants are explored, but how they interpret and make meaning of that experience is described (Liu, 2016). For this proposed research, hospice social workers will be asked to describe an experience with patient related physician-assisted death in order to understand their experience and reveal themes that may exist. Further, the goal of this research is not to determine causality, but to understand the meaning of the experiences of hospice social workers (Englander, 2012). A generic qualitative approach helps to understand the human factors of the issue being studied and is an appropriate method to discuss experiences participants have already had, leading to a deeper description of the phenomena. Researchers can take a first person look at human experience and discover what it is like to experience the phenomena being studied. Therefore, generic qualitative is the appropriate method for the proposed study. Further description of the specific interpretation will be discussed in chapter three.

Summary

Review of the literature of physician-assisted death proved challenging due to the limited number of academic studies related specifically to social work, hospice, and legislation. Due to the controversial nature of physician-assisted death, there are many commentaries, editorial, and opinion pieces that offer anecdotal examples of the impact of this option at the end of life. Considering this, many articles and studies shed light on the impact legalized physician-assisted death has on healthcare professionals with evidence of acceptance, misunderstanding, fear, and ethical concerns. The literature review makes evident that healthcare workers are conflicted in their responsibility to the patient who has decision-making capacity regarding end-of-life options and self-determined life closure.

Chapter 3 explains my approach and methodology. Generic qualitative is appropriate for this study as I strive to understand, not explain, or interpret the lived experience of hospice social workers. Qualitative exploration states that our human experience is full of meaning and we experience life before we can explain it with language (Adams, 2014; van Manen, 2014). This approach enabled me to engage hospice social workers in a conversation about their experience with Death with Dignity on a deeper level and record their thoughts, feelings, and experience.

Chapter 3: Research Method

Introduction

This research explored how personal values, ethics, and organizational policy affect how hospice social workers respond to patient requests for Death with Dignity in Washington State through interviews with hospice social workers by allowing them to share, in their own words, through semi-structured interviews, how they professionally respond to such requests and how they feel about the influences they face when a patient requests assistance. This chapter explains the methodology I used to choose a sample, collect, and analyze data, and interpret findings.

Purpose of the Study

Now that physician-assisted death is legal in several states in the United States, hospice organizations are driven by their stated purpose of allowing for natural death by way of symptom management (National Hospice and Palliative Care Organization, 2015). This creates a conflict between the hospice philosophy of care and the professional directive of supporting self-determined life closure (National Association of Social Workers, 2008). The purpose of this generic qualitative study was to explore the experience of hospice social workers in how they respond to patient requests for Death with Dignity in Washington State. This was in the context of organizational policy restricting open conversations with patients regarding physician-assisted death. An additional purpose was how the social workers beliefs, values, and code of ethics influence their response to patient requests.

Research Design and Approach

The present research was qualitative in nature with a generic approach (see Kahlke, 2014). The methodology was determined by the nature of the research question. The personal experiences of participants are not quantitative in nature and understanding data in the form of language warrants qualitative, phenomenological approach (Moustakas, 1994). Generic qualitative research involves interpretation, not explanation (Weber, 1897). I sought to understand how hospice social workers make sense of their experiences with Death with Dignity and their motivations for their responses. This approach allowed me to explore the experience of the hospice social workers through their words (Wilke, 2002; Sloane et al., 2014). A generic qualitative approach is appropriate for this research, as this method is interpretive as well as descriptive with a major role for language, conversation, and narrative in the collection and analysis of data (van Manen, 2011). Moustakas (1994) advised the voices of participants can be recorded without influence, thus understanding the true voice of hospice social workers. This approach was appropriate for my research question, as I sought to understand the lived experience of the hospice social workers and their stated internal and external influences regarding Death with Dignity. Their stories were told in their words and analyzed through the lens of self-determination theory (Deci & Ryan, 2012). The analysis was conducted concurrently with data collection to identify emerging themes, which is appropriate to this research of a situation that is not measurable (Jones et al., 2012). Dennis et al. (2014) designed a study on ethical decision making of hospice social workers through the theoretical lens of external influence from the organization and professional ethics. This approach yielded information from the social workers about their professional experiences that created ethical dilemmas according to their professional code of ethics, organizational policy, and family dynamics (Dennis et al., 2014). By allowing social workers to provide their experience in their words, researchers were able to interpret data through descriptive coding and thematic analysis (Dennis et al., 2014). This approach not only gleaned in-depth information from the social workers but provided vast data to be able to conclude the phenomenon of hospice social work ethical dilemmas (Dennis et al., 2014).

Population

I interviewed a purposeful sample of hospice social workers with at least one year of experience currently employed by a Medicare certified hospice provider in Washington State. I accepted both men and women of all ages, but with a master’s degree or higher with at least 1 year of professional experience. I had a population of varied ages and service areas (i.e., urban, rural, inpatient, and care facility).

Setting and Sample

I planned to recruit participants through a proposed partnership with a single hospice provider in Washington State; however, this proved difficult due to the COVID-19 pandemic. The next option was to network through social media via a hospice social workers Facebook page. All social workers were employed by various hospice organizations and followed a similar policy regarding non-participation in Death with Dignity. I asked demographic questions such as level of education and years of professional experience as the only criteria for determining appropriateness for participating in my research. My goal of no more than 15 participants related to the methodology of qualitative data collection and collecting in-depth information from fewer participants (Brandbury-Jones et al., 2017; Fusch & Ness, 2015). Saturation was also important to consider when collecting data and deciding when the data have revealed all there is to show through interviews (Fusch & Ness, 2015). Data collection and analysis were concurrent, and saturation was evident through this process, which drove the number of participants needed.

Holdsworth (2015) interviewed 44 participants for a qualitative study over 2 years and was able to glean rich information regarding the experiences of family caregivers of hospice patients who had already passed away. The large sample size was manageable for that study as Holdsworth had time to conduct a high number of interviews, but also to allow for bereavement time before the interviews. The researcher only met with each participant once, whereas I followed up with each participant via email with an opportunity to review their responses in written transcript form. More than one meeting gave clarity to responses and helped to gain a full understanding of the lived experience and allowed reflection time after the first interview leading to a deeper reflection from participants (Robinson, 2014). Norton and Miller (2012) sampled nine social workers and discovered several themes and were able to follow up their in-person interviews to clarify responses and focus the conversation on emerging themes. This allowed for a rich discussion on the issue of physician-assisted death and for results to reflect their experience from a holistic viewpoint (Robinson, 2014).

Sources of Data

The participants and their stories were the sources of data collected. Semi-structured interviews were voice recorded and transcribed. I developed a set of questions to guide the conversation and allow for elaboration from participants. Each interview lasted for 20 to 45 minutes in a setting of the participants' choice via Zoom video where there was privacy to allow for anonymity and uninterrupted time. Responses were analyzed and coded immediately following the interview and the analysis guided the next interview. Participants were given an opportunity to review their transcribed interview and provide feedback on corrections or clarification via email within 2 weeks of their interview (see Van Manen, 2014).

Validity

Validity of qualitative research has been debated by many researchers as far as relevance (Maxwell, 2013). For this current research, researcher bias was a threat to validity due to my professional experience as a hospice social worker with the phenomenon being studied. I, however, had no pre-existing goals or conceptions of what the data would show, just a curiosity of how others have experienced similar situations. Maxwell (2013) has described this issue of researcher subjectivity as either positive or negative. As a social worker, I am confident in my values and beliefs as directed by my professional code of ethics and strongly believe that all social workers can develop their unique values and can respect the views of others without personal insult or judgment (Bailey, 2015). To increase validity, I had a follow up member check with each participant, gathered rich data through intensive interviews, and had participants validate their responses through review of transcripts of interviews (Maxwell, 2013; Wilcke, 2002).

Reliability

Reliability in qualitative research includes clear documentation of procedures, data, methods, and results (Golafshani, 2003). Regarding data collection, analysis, and reporting, all aspects of the method are to be clear and organized, especially given that data collection and analysis will be concurrent (Elo, et al., 2014). Participants were greeted and asked to review consent form before induction of interviews. They were also reminded of their right to withdraw from the study at any time. Interviews were audio recorded, transcribed, and then reviewed by each participant. The process was recorded in my notes and journaling throughout the study and organized the data. Data are stored on a password-protected electronic file. The analysis was hand coded and organized into themes.

Auditing was conducted by me with dissertation committee members to function as process auditors to align data collected with journaled notes and coded responses (Golafshani, 2003). This will ensure that any person reviewing my research will be able to follow the methods and process for ensuring reliable data. Recruitment of participants included a flyer to explain the problem, purpose of study, and clear information about the voluntary nature of participation in the study. Emphasis was placed on the nonjudgmental nature of the interviews and confidentiality in all aspects of the study. Social workers were informed of the time commitment and expectations of both them and me as a researcher. Those who were interested were asked to email me with questions and to further discuss the voluntary nature of participation.

Data Collection Procedure

After Institutional Review Board (IRB) approval (# 10-21-20-0133009), participants were recruited and provided information on the study and informed consent. Once consent was received, interviews were scheduled. Interviews were one-on-one, semi-structured, and lasted 20 minutes to 1 hour in a location of the participants' choosing via Zoom video to protect anonymity. Interviews were audio recorded and transcribed using Microsoft Word Translate. Participants were asked to volunteer time for a second interview after they review the transcription of their first interview to give them an opportunity to add to their thoughts. None of the participants asked to add to their interview after review. Pseudonyms were attached to their interview for purposes of clarification and second interviews, but personal information was not reported or had a bearing on the analysis of the data. Data will be safeguarded for 5 years and then destroyed.

No more than two interviews per day were conducted to allow me time to reflect and analyze data thoroughly. Limiting the number of interviews in one day also allowed for any changes to questions that needed to be made based on participant responses and understanding. This led to each interview being different from the next, but the same guiding questions were used as outlined in the research questions section (see Appendix A for complete protocol). Participants were allowed to withdraw at any time or to decline to answer any or all the questions in the interview. They were reminded of their contribution to the body of knowledge and thanked for their participation. Data have been stored electronically on a password protected computer and external drive. Handwritten data were scanned into an electronic database and then shredded.

Data Analysis Procedure

Data analysis was concurrent with data collection as I immersed myself in the data to gain a true understanding of the phenomenon (Vasimoradi et al., 2013). The inductive approach called for open coding of data and then organization into categories; however, a unit of measure is suggested such as themes or frequently used words (Elo et al., 2014). I read the interview transcripts, listened to the recordings, and reviewed my notes taken during the interviews and created contiguous data that was categorized using open coding, based on identified similarities, differences, and relationships between emerging concepts (Maxwell, 2013; Vasimoradi et al., 2013). Manual coding was completed after a layout of the text data was transcribed (Saldana, 2016). Initially, pre-coding included highlighting quotes or phrases that stand out (Saldana, 2016). First cycle coding included descriptive and in vivo coding in order to categorize the data as well as use the participants own words as codes, depending on what was discovered in the interview transcripts (Saldana, 2016). Code mapping helped to determine if second cycle coding was of value with the data by organizing codes (Saldana, 2016). Re-visiting the first cycle coding helped to determine the need for further coding is of value to analyze the data (Saldana, 2016).

Interviews were transcribed and printed to organize data to include a word frequency analysis to catch any themes that my open coding may have overlooked or missed. After each subsequent interview, this process was followed. Once initial interviews were complete, the data were compiled to see what major themes were evident, where there were differences, and what questions needed to be asked in follow up interviews (Moustakas, 1994).

Data were reviewed in relation to pre-coding based on common themes identified in the literature and my goals of the study and problem statement to draw conclusions about what the data were demonstrating (Maxwell, 2013). To determine themes and deciding what is important, a holistic, selective, and detailed approach to the data was taken. I considered each interview as a whole and determined the major theme from each one as a whole, then I read each one selectively based on common themes from most or all interviews, then I looked in more detail at the interview responses by question to see where underlying themes may be in relation to the specific questions asked (see van Manen, 2014). Themes were then categorized and presented in tables to simplify the results and interpretations based on the above process, major themes, selective, themes, and detailed themes per question.

Ethical Considerations

Ethics are at the forefront of any research plan and were taken into serious consideration in my research. The nature of the research was revealed to the participants at the recruiting stage to ensure all had a comprehensive understanding of the subject nature of the interviews and to make sure they could contribute based on their experience (Moustakas, 1994; van Manen, 2014). The issue of this research is controversial, even in the face of legality of physician-assisted death, and discussion of this could have caused undue stress or conflict for participants; therefore, it was important to provide transparency, and a clear understanding of the voluntary nature of participating, with the option to end participation at any time. This study was reviewed by the IRB, and any ethical concerns were addressed fully by me. Safeguarding of the data, confidentiality of information in analysis, and reporting were considered throughout the study. I ensured that data would be clean prior to reporting while removing any identifying factors; however, there were some aspects of data collected such as specific workplace that could identify a participant, in which case, they were redacted prior to reporting (Kaiser, 2009).

Summary

In Chapter 3, I have discussed my proposed research method and details about planned participant recruitment, interviews, data collection and analysis, and ethics. I conducted a quality research study based on known and accepted qualitative methodology. Further, I conducted in-depth interviews to learn the authentic stories of hospice social workers to glean the most meaningful data possible. The utmost integrity was given to the participants and the data to ensure valid and reliable results. My dissertation committee was consulted throughout the process to maintain focus and high quality and academic rigor.

Chapter 4 Results

Introduction

The purpose of this study was to understand the experiences, beliefs, and values of hospice social workers in the Pacific Northwest when working with patients requesting Death with Dignity. The key factors I explored were perspectives on organizational policy of non-participation. The research questions I asked were: How do they perceive the ethical conflict between supporting self-determined life closure and non-participation with DWD? What education and support do they receive from their organization regarding DWD? How do personal beliefs and values influence their response to requests for DWD? How does employer policy related to participation in DWD influence their personal beliefs regarding supporting a patient’s right to self-determined life closure?

The results of this generic qualitative study are included in this chapter and answer the above-mentioned research questions regarding social workers experiences with DWD. This chapter describes the data collection methods, procedures, and analyses. Participant interview protocol, data management, and analysis is discussed and presented. I describe coding methods including open coding with an inductive approach with first and second cycle coding. During each cycle of coding, comparisons were made to discover emerging themes. The chapter concludes with a summary of findings per theme and research question.

Recruitment and Setting

I recruited participants from a closed, private Facebook page for hospice social workers in the Pacific Northwest. Permission was obtained from the page administrator to post my flyer seeking volunteers. The page is by invitation only for the purpose of sharing resources, stress relief, emotional support, networking, and educational opportunities. Specific employers or names of co-workers not members of the group are not shared or discussed. The page description is as follows:

A safe space to promote and invite discussion among friends. This is a closed group, unable to be searched. Feel free to invite others you feel may benefit.

Participants for this study are from different agencies in the Pacific Northwest, both faith-based and non-faith based. Some members are more active with posting; others just observe and post sporadically. The setting for this research study was in a location of the participants' choosing via video conference. I advised each participant to use a setting that they felt was private on their end and assured them that I was in a private setting as well.

Demographics

All participants in the study were currently employed social workers at a hospice organization in the Pacific Northwest. All had minimum Master of Social Work degree with post-graduate experience ranging from 3 to 27 years. All participants but one was employed at a faith-based organization. All participants have had at least one experience with a patient who asked about Death with Dignity while enrolled in hospice care. Other demographics were not specifically explored.

Data Collection

I collected data by conducting one-on-one semi-structured interviews with 10 participants between the dates of October 1, 2020, and February 20, 2021. All interviews were held via Zoom Meeting due to restrictions on in-person interaction secondary to COVID-19 community spread. Participants were in their own homes or their parked vehicles for the interviews. Each was asked if they were in a private setting prior to the start of the interview. I reviewed informed consent with each participant and offered an opportunity for questions. Each participant had been emailed informed consent prior to scheduling the interviews with an email reply giving consent. Interviews were audio recorded only, then transcribed using Microsoft Word Transcription. Transcripts were then emailed to each participant for member checking. None had any corrections or clarification from participants. Each interview lasted from 15 to 35 minutes. Transcripts were saved on a password protected flash drive as well as printed out for data analysis.

I followed the data collection plan described in Chapter 3; however, there was one question I added after the first two interviews based on responses given. Participants 1 and 2 offered an independent response that prompted me to add a question for the remaining eight participants. When I asked the participants to describe a situation where a patient asked about DWD, the first two participants offered, “I go farther than I should,” both with the same verbiage. Based on this, with subsequent interviews I specifically asked if the participants ever go farther than they should when discussing DWD with patients. There were no unusual circumstances in any of the interviews and no changes to transcripts after member-checking.

Data Analysis

I explored the experiences and thoughts of hospice social workers for this study. I reviewed the transcribed interviews one by one, then question by question. I started with open coding to glean first impressions of the data and any concepts that were apparent. Then, I began first cycle in vivo coding assigning phrases to the data from each response to the interview questions to keep the data rooted in the actual words of the participants. I cross referenced in vivo codes with initial open codes and discovered consistency with the emerging concepts. Next, I began second cycle coding categorizing into concepts. These concepts reflected the participants' experiences based on the research question and sub-questions. Table 1 shows the organization of categories and concepts.

Table 1

Example of Coding Process

Code	Category	Theme
Not allowed No role Policy Barrier Personal values Go further	Challenges	Challenges in supporting patients' choices
Listening Informal Vague Policy	Communication	Communication with team and patients
Department of Health Nonprofit organization Policy	Policy barrier	Organization barriers to honoring patient choice

The four concepts frame the experience of the hospice social workers when faced with requests for DWD. These highlight their reported challenges, communication issues, resources, and issue of patient choice. These concepts will be discussed further in Chapter 5.

Evidence of Trustworthiness

Credibility

I saved audio recordings from all interviews and handwritten notes taken during the interviews. I used the established interview protocol with all participants and added one question after the first two interviews that I asked each subsequent participant. I sent follow up emails to each participant for member checking with no changes made to any of the transcripts.

Transferability

I used thick description of my procedures, recruitment, and setting so that the study procedures are transferable to other settings. I chose purposive sampling in keeping with the nature of the research; however, my procedures show rigor in how and where I recruited representative of the population and adherence to the interview protocol for each interview. Participants were identified and qualified for the study because of their education and work experience. I recruited participants with the knowledge and experience to answer my research questions. Analysis was driven by the narrative nature of the data, and I reviewed the transcribed interviews with the audio recordings to verify accuracy.

Dependability

I created an audit trail outlining the recruitment, informed consent, and data collection procedures. I also have the audio recordings, transcribed interviews, and handwritten notes saved for review if requested. I also coded manually and kept all notes and written thoughts with the audit trail. All components of this research have been scanned into a password protected flash drive and original written and printed notes and transcriptions have been shredded.

Confirmability

Confirmability in a qualitative study is the confirmation that the data and analysis reflect the participants true experiences and words rather than the researchers bias (Anney, 2014). Data analysis and coding using direct quotes from interview transcripts ensured that the participants' experiences were reported. Regular auditing was completed during the research process with regular discussion and reflection with my committee chair and reflective journaling. This helped to minimize researcher bias throughout the entire procedure, thereby maximizing confirmability.

Results

My results reflect the experiences and views of hospice social workers who have had a patient ask about Death with Dignity. I developed four sub questions to further delve into the social workers experiences regarding self-determined life closure, organizational support and education, personal values, and organizational policy. Open coding led me to organize commonly used words and phrases and in vivo coding to categories. Code mapping organized the codes and narrow them to themes. Each interview was reviewed individually and coded, then those codes compared to each other and categorized from there.

Themes and Study Results

Theme 1: Challenges in Supporting Patients' Choices

Participants reported several challenges when discussing DWD with patients and families. The main challenges were organizational policy of non-participation in DWD, not being free to educate on DWD legislation and the process, not having a role in the patient's end of life experience when they choose DWD and feeling there is a barrier for patients to exercise true self-determined life closure. Different participants shared the following statements:

"The patient was deemed suicidal by the hospice nurse because they had said something about having pills to end it and the nurse freaked out. So, I went out and met with him and his wife and his family. They already had everything in place, but they had not talked to the team about it because they were afraid, they would stop him."

"I had to explain to the patient that working for (agency name redacted) we can't be involved in that particular process, but we can support them up to the end but after they have taken the prescriptions, but because of that they didn't want our support."

"I tell him that as a social worker working with my Catholic hospice organization that I can't assist him in getting information or getting the medication."

"It took her a couple of months to ask about it, but she didn't want anyone to know. I had this spiel about reminding people that we are a Catholic organization and so as an organization we could not support it."

"In any other circumstance we'd stand right by the bedside if needed. There were like, if we are hospice, we should be there for support."

“We’re not supposed to discuss it openly with them”

Another challenge that was highlighted was lack of access to resources to refer patients to. Some social workers reported being unable to suggest outside resources. When asked what resources they were allowed to refer to, they all reported the local department of health. When asked what resources they wish they could refer to, they all cited the same nonprofit organization that actively assists patients with DWD.

To summarize this theme, the participants reported challenges in communication are the restrictions on how much they can discuss with patients, not having a role in the process with patients, feeling a barrier for patients in finding support in their end-of-life journey. The above responses were elicited from several of the interview questions across all participants.

Theme 2: Communication with Team and Patients

All participants reported issues with communication both with patient interactions and at an organizational level, both regarding policy and team communication. Several participants stated their main role in DWD in patient interactions is informal listening to their concerns, thoughts, and feelings. Others reported vague policy directives from the organization they work for. Several different participants’ comments included:

“We’re not supposed to put the exact wording in the chart. We just talk about it in team meeting.”

“We have an opportunity in our biweekly IDG meetings. I have a really supportive group and managers.”

"I don't know if there is a formal process for communication. I just talk to my nurses informally."

"I was just handed a policy without much education or explanation."

"It's not really talked about formally."

"I remember being given a policy that we don't participate in DWD, but that's it."

These responses were categorized based on the interview question, "What education and support do you receive from your organization regarding DWD?." Some social workers felt supported by their teams and managers; others did not feel this level of support and reported more informal support from co-workers and professional peers.

Theme 3: Organizational Barriers to Honoring Patient Choice

The theme of patient choice emerged from responses based several interview questions. Participants were asked about their views regarding true self-determined life closure when they are not able to support a patient who choses DWD and how they wish they could respond to patient requests for DWD if they were able to talk freely about it. They were also asked, based on their experience if hospice is a barrier to self-determined life closure. These responses include:

"I have an incredibly hard time with the fact that we're not able to be as candid as we want with it."

"I feel like we're sort of doing it with one hand tied behind our back."

"I could have found providers for people who would have been willing to walk them through the process."

Further, when asked if hospice is a barrier to patients seeking DWD, most participants stated that it is a barrier, with a few stating it is not.

“I help more than policy allows,”

“It is a barrier because they need resources,”

“It is not a barrier because people find a way to do it.”

These responses prompted the question, “Do you feel you go farther than you should when discussing DWD?” Responses included:

“I probably go farther than I should,”

“I discuss what the patient wants to talk about, not what the policy tells me to,”

“I try not to go further, but I know I do.”

All participants reported either deliberately discussing DWD in more detail than their organizational policy allows or feeling that the issue is nebulous enough to inadvertently discuss the issue more than they should. My central research question was what the experiences of hospice social workers are dealing with personal and professional ethics of managing their role for clients in Death with Dignity. My four sub-questions will be answered in this section.

Sub-Question 1

I asked how social workers perceive the ethical conflict between supporting self-determined life closure and non-participation in DWD. All participants offered that they do not believe the policy of non-participation allows for true self-determined life closure due to their inability to truly educate patients, not being able to offer presence at the time of death, causing those patients to be disenfranchised from true hospice support, and putting up barriers to support. These responses highlighted responses to the interview question asking if they wish they could respond differently to the patients. All participants expressed a desire to be free to educate patients and families instead of not discussing the issue at all. Another common response was the desire to be free to offer emotional support in the decision-making process the patient was experiencing.

Sub-Question 2

I also asked what education and support the social workers receive from the organization they work for regarding DWD. All participants reported being given a written policy stating they were not to discuss the issue when patients ask about it. A common addition to that response was that the issue was gray, and they were unclear if they were allowed to offer resources for further education and support. Some social workers felt they were stretching the confines of the policy by referring to other organizations to help patients find information and support to follow through with their request. Other responses included those social workers were unclear about how much they are to document in the patient record regarding when the patient asks or how much the social worker has interacted with them about it. Only 2 social workers shared that they add the conversation to the patient plan of care, the rest of the participants indicated that they engage in informal communication with the interdisciplinary team about a patient’s preference or inquiry. Several participants stated they had to be vague in documentation or had to be careful how they discussed it in a formal team meeting for fear of violating policy.

Despite all participants working for organizations that endorsed non-participation policies, all but one had a patient complete the DWD process. Two participants shared that they felt comfortable debriefing with their team in a formal meeting, however, the rest of the participants sough informal support from a team member or manager in a one-on-one setting. None of the participants had a formal process for them to rely on for support if they experienced a DWD patient following through with the process. Of the participants that reported having a patient complete the DWD process, none had direct participation in the process and were not present at the time of death. A few participants were available off the patients' property and immediately entered the home following the death to support the patients' loved ones.

Sub-Question 3

Another question I asked was how personal beliefs and values influence their responses to requests for DWD. Each participant was made aware that they did not have to disclose their personal beliefs on DWD, however, all shared their personal view and how they respond to patients. Two participants had experienced a patient suicide prior to DWD legislation being enacted. They shared that this helped shape their view on the issue and they are glad it is now an option. This prior experience does affect their current response to patients when asked about DWD. Two other participants expressed that they do not believe DWD is necessary when hospice support is available to allow for a peaceful natural death. Most of the participants were willing to discuss DWD despite a policy directing them not to. All participants expressed that patient choice is more important than their own personal beliefs and if they were allowed to discuss DWD further with patients they would do so to honor this. All participants expressed those patients need information regardless of the participants own personal values.

Sub-Question 4

Finally, I asked how employer policy of non-participation in DWD influences their personal beliefs regarding supporting self-determined life closure. All participants shared that they do not feel non-participation policies affect self-determined life closure as many hospice patients are able to seek DWD and complete the process, however, all but two participants felt that hospice could be a barrier to seeking support and education regarding patient options for life closure. Therefore, patients can seek out and complete DWD while receiving hospice care, however, the participants shared they wish they could offer more direct support.

Summary

I reviewed the experiences of hospice social workers being asked about DWD by patients in Chapter 4. All participants shared their interpretation of organizational policy surrounding their role in discussing DWD, specific situations they have had with patients, ways they either follow or stretch the policy to meet patient needs, and the resources they offer to patients in these discussions. The emergent themes highlight the issues they cited as challenging with patients and the hospice organization. My findings inform the needs of social workers in clarification of their role, their feelings about patient choice and needs, and clarity of how to communicate within their organization to ensure patient choice is honored. Chapter 5 is a discussion of the interpretation of the findings as well as study limitations, recommendations, and implications for social change.

Chapter 5: Discussion, Conclusion, and Recommendations

Introduction

I conducted the generic qualitative study to answer the main research question: What are the experiences of hospice social workers dealing with personal and professional ethics of managing their role for their clients in Death with Dignity? Participants in the study were hospice social workers providing direct care to terminally ill patients and are employed by a hospice organization in the Pacific Northwest. I interviewed participants in semi-structured one-on-one sessions through the lens of self-determination theory. The purpose was to determine the experiences, thoughts, values, and beliefs of hospice social workers who work under policies of non-participation in DWD.

My findings highlight that the hospice social workers have challenges in following organizational policy regarding non-participation. The evidence from the analysis of the data indicate challenges are due to missing education or guidance from management, unclear boundaries on what can be discussed, feeling that patients' options are not being fully offered, and feeling that they are not able to fully support patients' and families near or at the time of death. This is consistent with findings in a similar study showing that hospice professionals have experienced patient deaths that were self-inflicted due to a patient's lack of knowledge or support for medical aid in dying (Gerson et al., 2020). In this chapter, I present an interpretation of findings, limitations of the study, recommendations for future research, and implications for social change.

Interpretation of Findings

Findings from this study suggest these social workers experience professional or role drift due to their stretching the limit of their organizational policy of non-participation in DWD and their report of feeling constrained by that policy in providing their full social work potential in their role at hospice. Specht and Courtney (1995) began researching how social workers began pushing the limits of their intended mission. They further stated that social workers have become an “agent of the state” in that they are held to stricter guidelines creating ethical dilemmas pushing them to practice beyond their role (Specht & Courtney, 1995, p. 126). Bolin et al. (2009) studied the ethical dilemmas of social workers in relation to the organizations and policies guiding their practice. Their findings showed a positive relationship between lack of organizational support and social work job satisfaction (Bolin, et al., 2009). This means their sense of duty to their clients outweighed their loyalty to the organization or policies. My findings also show that social workers valued their patients’ needs more than strictly following the policy as they reported providing more support to patients who ask about DWD than their policy allows. While the current study did not address job satisfaction, there are similarities to the social workers’ perceptions of lack of support or education about the non-participation policy as an influence over their role drift. One study on nurses’ job satisfaction in relation to perceived organizational support and ethical climate showed nurses leaving the profession early as they have unclear ethical guidelines based on organizational policy (Abou Hashish, 2015).

Findings from the current study showed social workers respect and honor patient choice even when it contrasts with their own personal values regarding DWD. Comacho and Huver (2020) found similar results when they interviewed hospice social workers in California. Social workers reported their own religious beliefs did not accept DWD for themselves, but that did not hinder their support for a patient who decides to do so (Comacho & Huver, 2020). They also found that those same social workers felt a lack of organizational support and need for more education on the legislation, policy, and procedures relating to DWD (Comacho & Huver, 2020). A review of the literature by Gerson et al. (2019) looked at 30 studies regarding hastened death in hospice and palliative care. They concluded that improved communication is needed between hospice professionals and a clearer role for hospice and palliative care professionals (Gerson et al., 2019). This supports the findings of the current study that hospice social workers are not clear on their boundaries and that clear communication from their managers and organizations is needed.

My findings also are like the findings of Evans's (2012, 2020) study of organizational policy interpretation and how there is subjectivity and variation in how social workers perceive their role within the constraints of policy as well as employing discretion in meeting patient needs. Discretion is defined as professional creativity in solving patient problems that stretch the boundaries of organizational policy (Evans, 2020). Social workers in Canada were found to go rogue when there were unclear policies regarding practice and behavior (Weinberg & Taylor, 2019). Weinberg and Taylor (2019) defined rogue social workers as those who bend rules to ensure patients' needs are met with fewer barriers. This is similar to my findings of social workers who shared that they went further than policy allows in talking with patients about DWD.

The theoretical foundation of self-determination theory is consistent with my findings as well, as social workers shared motivations both from the organizational policy and their own values and beliefs. Deci and Ryan (2012) theorized that people will either conform with policy or be motivated by their personal convictions if it is in the interest of the patient. They further found that people can be intrinsically motivated while being extrinsically moderated by factors such as law, policy, or guidelines (Ryan & Deci, 2020). Social workers are tasked with the role of promoting self-determination while being influenced by it as well (Ackerman, 2021). They must empower their patients without bias and walk a fine line between their own values and the choices of the patient (Ackerman, 2021). Based on my results, the hospice social workers in this study were motivated by both organizational policy and their personal values and beliefs, leading to a conflict of how to act but they reported that the needs of the patient were more important than strictly following all aspects of the non-participation policy.

This unique group of social workers demonstrated that they experience role drift and have both intrinsic and extrinsic motivators for how they deal with patient requests for DWD. While they report confusion over how to interpret non-participation policy, they were clear in their position that patient choice is of the utmost importance regardless of policy or their own personal values. The hospice philosophy of honoring self-determined life closure was somewhat of a blurred line for most of the social workers as some reported hospice as a barrier to DWD and some did not. This lends further credence to the unclear policies leading to varying behavior by social workers (Weinberg & Taylor, 2019).

Limitations of the Study

The purpose of my study was to understand the experiences, beliefs, and values of hospice social workers regarding Death with Dignity and perspectives on the organizational policy of non-participation in patient requests for physician-assisted death. One limitation to my study was the focus on just the social work discipline and the regional setting of only the Pacific Northwest. Because of this limitation, results may not be able to be generalized to other disciplines across hospice care or in other regions that provide hospice care. Another limitation was that all participants were female and only one non-faith-based hospice experience was represented. This also leads to limited generalization across all hospice providers and all hospice social workers based on gender and experience.

Another limitation is my conduction of the study amidst the COVID-19 global pandemic. Hospice social workers were under different stressors than usual due to differing working conditions related to the pandemic. Recruitment was affected as hospice organizations were limited in their ability to provide care in general and unable to partner with me to provide participants. Recruitment was done solely online through Facebook and limited my ability to reach a wider participant pool. While this study is within the requirements for a sound generic qualitative study, more participants would have been desirable to be able to yield more generalizable results.

Recommendations

This study has shed light on the dilemma hospice social workers face when dealing with self-determined life closure involving DWD. Since DWD legislation was enacted, hospice providers have held the position of non-participation. In the case of the hospice social workers interviewed for this study, there has been little education or discussion from hospice organizations to their employees about how to deal with patient requests for DWD. Norton and Miller (2014) found similar results when they interviewed hospice nurses in Oregon with the participants reporting confusion about how they were supposed to respond to patients.

Review of the literature showed few studies that directly addressed DWD and how hospice professionals respond or feel about these requests amidst the directive of non-participation. With this in mind, a recommendation for continued research is interviewing other disciplines who provide direct hospice care to see if they face similar conflict as the social workers in my research. Another recommendation is to interview hospice leaders and management to see if they experience any conflict about how to educate and support their employees. A question to ask is where does the confusion originate? Does it start at the organizational level? Is it at the national professional organizational level? Answering these questions will shed more light on this issue and help to determine what changes can be made or to strengthen the resolve of the hospice philosophy of care to continue promoting natural death without medically assisted death.

Implications

Confidence in how to deal with patient choice and providing support at the end of life is important for hospice social workers. The findings of this study show that attention should be paid to the needs of hospice social workers to have education and support surrounding issues of DWD. One implication for social change is opening a dialogue between hospice leadership and employees that directly addresses the discomfort, ambiguity, and importance of the choices of patients regardless of organizational policy. Social workers should feel free to openly discuss issues that affect patient care especially when said issues are legal choices a patient can make. Another implication is the need to educate the hospice community about DWD and give them tools to support their professionals. Even if policies of non-participation do not change, the change that is needed is education, understanding, and emotional support for the direct care professionals, leaders, and patients and families.

Currently, one of the objectives of hospice care is to support self-determined life closure. With more options available to terminally ill patients, hospice professionals need to be prepared to have discussions with patients about those options. I am not suggesting the hospice philosophy should be changed, but that hospice providers need to be able to be open and informed for the needs of their patients and families. An implication because of this would be enabling hospice professionals to make direct referrals to resources for patients seeking DWD. This could allow for confidence and satisfaction that the patient has received the help they are seeking. This could lead to removing barriers to self-determined life closure that the hospice social workers in this study cited.

Conclusion

This study has highlighted the experiences of hospice social workers in how they deal with requests for DWD. Prior research has not addressed this issue directly with any discipline within hospice. With much of the literature focusing on the patient experience, the prescribing physicians, and a few studies of hospice nurses, little is known about how hospice professionals who provide direct care are experiencing this issue. This study has shown that the hospice social workers who participated experienced confusion about their role, organizational policy, insecurity about how they follow organizational policy, and barriers to self-determined life closure. This study’s findings provide opportunity to create an open dialogue about the need for clarity of non-participation policies, organizational support for dealing with the personal and professional implications of patient requests for DWD, and ability of hospice social workers to provide more direct support to patients.

As medical innovation provides more opportunities for healing, so too does the need for innovative options for life closure. The hospice tradition has been to allow for comfort and natural death. But just as healing and recovery from illness has evolved, the needs of the terminally ill have changed necessitating a need for changing interventions. Will there be a paradigm shift in the hospice philosophy of care? Perhaps over time, but for now, with the results of this study, the change needed is an open dialogue between hospice organizations and their staff. Death with Dignity as a legal patient choice does not necessarily need to be promoted by hospice organizations, but it does need to be clearly understood and acknowledged as a choice for patients. As the participants in this study have shared, patient choice is of the utmost importance and should be honored.

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Appendix A: Interview Protocol

Opening script:

My name is Lisa Carter, and I am working on my doctoral study with Walden University. Like you, I work full time as a hospice social worker and am aware that you are busy and will respect your time. Thank you for volunteering your time and experience. First, I would like to remind you that participation is voluntary, and you may withdraw your participation at any time during this interview or after. If any questions make you uncomfortable, or you decline to answer just let me know and we can move on. This interview will take about 30 minutes. Your participation is confidential, and I will assign you a number that is associated with your responses, but not your name or any other identifying information. I want this to feel more like a discussion than a formal interview. This interview is being audio recorded, but again, your confidentiality is of the utmost importance. All recordings and identifying information will be kept secure electronically via password locked flash drive. Nothing is being stored in the cloud or on any server. Thank you for reviewing and completing the informed consent form. Would you like to review that again before we start?

Interview Questions:

1. How long have your worked as a hospice social worker?
2. What is your highest level of education?
3. Have you had a patient ask you about Death with Dignity? If so, describe this situation:
4. How do you explain your role to the patient regarding Death with Dignity?
5. Do you offer education on where the patient can find support?
6. Have you had a patient that has completed the Death with Dignity process?
7. For patients of yours that have completed the Death with Dignity process, what was your role in that process?
8. Did you have an opportunity to debrief with anyone from your organization?
9. Did you receive education from your employer about Death with Dignity? If so, please describe:
10. Do you have a point of contact to discuss any concerns you have regarding an experience you have with a patient who explores Death with Dignity?
11. What personal values or beliefs do you have that you feel influence your interactions with patients who request Death with Dignity?
12. Does the policy of "non-participation" at your organization influence how you respond to requests for information about Death with Dignity?
13. Do you feel you would like to be able to respond differently or have a different role in that process with your patients?
14. How do you feel the term "self-determined life closure" fits into the policy of non-participation in Death with Dignity?
15. Is there anything you would like to discuss further or any other information you would like to share?

Closing Script:

Thank you for your time. Your views and feelings are important to our field. I will be sending you a transcript of our interview via email for your review within the next two weeks. Please feel free to make any clarifications or expand on any of your responses and send back to me. If you have any concerns moving forward, please let me know. Again, thank you for your time.

Appendix B; Recruitment Flyer

Seeking Hospice Social Workers for 30-minute interview

I am a doctoral student at Walden University working to learn about the experiences of hospice social workers and Death with Dignity. With choices for end-of-life care changing, hospice social workers are facing sometimes difficult conversations with patients and families. I want to learn from you, how you address these conversations, where you find support, both professionally and emotionally, and what your thoughts are about support that is needed for social workers moving forward.

These questions are important to help give hospice social workers a stronger voice in how patients are supported and honored with their decisions at the end of life. Social workers are in a unique position to make positive outcomes for patients and families and your experiences matter!

- Participation is strictly voluntary and there is no incentive to do so
- Interviews will be 30 minutes or less
- Contact will be via video conference or telephone (whichever is most convenient for you) at a time that is convenient for you as well
- All interviews will be audio recorded (no video will be recorded)
- Participation is strictly confidential and all identifying information will be kept secure
- One follow-up email will be sent to you to verify the information you have provided in the interview

If interested in participating, or have questions about this important study please contact me via email at: