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Physician assisted suicide and Midwest social workers: Are they ready?

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By

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

Abstract

Physician assisted suicide (PAS) is explicitly legal in four states, legal by court decision in one, and bills have been introduced in 25 other states including Minnesota, Iowa, and Wisconsin. This quantitative study was designed to understand Midwest, end of life social workers attitudes towards PAS, their preparedness for the implementation of PAS into their practice, and their awareness of PAS legislation where they practice. Sixty-two end of life social workers from Minnesota, Iowa, and Wisconsin completed an anonymous online survey. The results indicate that over half of the participants support PAS legislation and ¼ are neutral or undecided which is consistent with previous research done on social workers from other areas of the country. There are diverse feelings of preparedness with a majority feeling moderately to very prepared and found that their professional values, professional experience, and professional values influence their perceived preparedness. Very few social workers had accurate awareness of PAS legislation in their state and few have attended events to gain education or advocate for their position. Implications for practice emphasize the need for end of life social workers to address and analyze their attitudes, values, and beliefs towards PAS and to become involved on a macro-level in order to provide best care to patients on an individual and systemic level.

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I would like to dedicate this work to Tonia, Mandi, Grandpa Warren, Grandma Mary, Suzette, and Shirley. In your life you gave me so much love that through your death I learned how to love others.

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Brittany Maynard became a household name in the United States in 2014 by sparking a highly controversial debate on national news. Maynard was diagnosed with a brain tumor at the age of 29. She underwent surgery to later discover the tumor had returned and was more aggressive then ever before. She was given a six month prognosis and a recommendation of full brain radiation. Realizing that the radiation would drastically change her quality of life and not cure her condition, Maynard declined and began to prepare for the end of her life. She discovered the probability of unmanageable pain, loss of cognitive and motor function, and personality changes. This is not something she wanted for herself or her family. On November 1, 2014, Brittany Maynard decided to end her life through physician-assisted suicide (PAS) in Portland, Oregon (Firger, 2015). PAS is defined as the "voluntary termination of one's own life by administration of a lethal substance with the direct or indirect assistance of a physician" (MedicineNet, 2012, para. 1). While it is suggested that some research uses the term physician assisted death in attempt to distance the practice from taboo associated with suicide (Federman, 2014), this paper will use PAS to maintain consistent with the bulk of research.

PAS continues to gain government and public attention. In the United States, PAS is explicitly legal in four states, legal by court decision in one, and bills have been introduced in 25 other states (Korchnak, 2015). Advocacy groups and organizations are actively present and attempt to represent the general public opinions on death with dignity laws. Ardelt (2003) summarizes the main supporting and opposing arguments. The supportive argument states that a terminally ill adult should have the right to seek relief from harsh, long term suffering and that their self determination and control over their life and death should be respected and honored. The opposing argument encompasses the ethical and moral burden it places on families, friends, physicians, and other professionals, religious considerations, and the slippery slope concern that if it is allowed for adults it is only a matter of time before that transcends to children and

vulnerable adults. This social challenge is more than a dichotomous argument. Some believe that PAS should be legal, but only under certain circumstances (Erblaum-Zur, 2005). Despite the nuances in the spectrum of beliefs surrounding this issue, Gallup poles indicated that 68% of Americans support PAS (Dugan, 2015).

The PAS movement continues to take legal steps forward and backward. This fluctuation brings about challenges for systems to implement PAS into their education, training, and practice. Having PAS as a medical option affects hospitals, hospice agencies, and their staff. Professionals, including end of life social workers, need to be equipped and feel prepared to have conversations with patients in order to provide education and support around end of life decisions. Furthermore, they need to do so despite their own personal beliefs and values surrounding the topic. An end of life social workers main role is to provide psychological and social support for patients and families (Weisenfluh & Csikai, 2013), hence it is one profession that is highly effected by the passing of PAS laws. Social workers' opinions, perception of preparedness, and ethics and values surrounding PAS have been analyzed in Oregon (Miller, Mesler, & Eggman, 2002), New York (Erblaum-Zur, 2005), Florida (Kane, Hamlin, & Hawkins, 2005), and South Carolina (Manetta & Wells, 2001). The Midwest perspective has been neglected. With PAS bills being introduced in Minnesota, Iowa, and Wisconsin it is important to understand end of life social workers' attitudes towards, perception of preparedness, and awareness of PAS. In gaining this understanding, the social work profession can better prepare its practitioners for the legal implementation of death with dignity laws.

Literature review

The literature review will examine the history of PAS in the United States, end-of-life care in the United States, end-of-life social workers roles and how their attitudes and perception

of preparedness influences their practice. Additionally, the literature review will explore the social worker's position on PAS and how their ethics and professional values interact.

History of PAS Legislation in the United States

In 1906, the first PAS law was introduced in Ohio. Although unsuccessful, it initiated a movement that would take nearly a century for legislation to support. In November of 1994, an act legalizing PAS was passed in Oregon. It was reaffirmed in 1997 after a postponement due to a legal injunction by a 60% to 40% margin (Oregon Department of Human Services, 2013). Ballot Measure 16, The Oregon's Death with Dignity Act (DWDA) allows Oregon residents who are terminally ill, competent adults with a prognosis of 6 months or less to obtain a lethal prescription from their primary physician. The patient's diagnosis and prognosis must be confirmed by a consulting physician and a psychological examination conducted if deemed necessary by the primary physician. The physician must communicate all other options to the patient, recommend they inform their family of their decision, and give guidance on self administration. The patient must first make an oral request to their physician, wait 15 days, make a second oral request, submit a written request (signed by two witness with one not being a relative, beneficiary, or employed by medical facility in charge of their care), and then wait 48 hours before accessing the prescription from the pharmacy (The Oregon Death with Dignity Act, 1994).

The Oregon Public Health Division is mandated to issue a yearly report to the public on information collected on participation in PAS. In 2014, PAS accounted for .3% of statewide deaths, 155 patients received a prescription, and 94 died from ingestion while 37 did not utilize the prescription and died of other causes. 67.6% were 65 plus years, 92.5 were white, 47.6 possessed at least a bachelor's degree, 48% were married, and gender was nearly 50/50. 89.5% of patients died at home and 93% were receiving hospice care with no reported complications

with ingestion. Absence of referrals to the Oregon Medical Board suggests physicians are fulfilling the requirements for PAS.

Dying individuals in Oregon consistently voice that their top three concerns are loss of autonomy, ability to partake in enjoyable life activities, and dignity (Oregon Public Health Division, 2015). Research has suggested that Oregon's DWDA addresses these concerns. Patients who request PAS in Oregon have a higher quality of symptom control and feel more prepared for death (Smith, Goy, Harvath, & Ganzini, 2011). It has similar effects on loved ones of patients with a higher level of acceptance and preparation for the death and no significant difference in depression, grief, or mental health when compared to end of life patients who didn't utilize PAS (Ganzini, Goy, Dobscha, & Prigerson, 2009).

Other states began to follow in Oregon's footsteps. Washington passed Initiative 1000 in November of 2008 by a margin of 58% to 42%. The Washington Death with Dignity Act went into effect in March of 2009 (The Washington Death with Dignity Act, 2008). In 2013, Vermont was next and the first to pass through legislation instead of ballot initiatives. An act relating to patient choice and control at end of life was implemented immediately (Patient Choice at End of Life, 2013). Most recently, the California Senate passed the End of Life Option Act in September of 2015, after the short wait for Governor Jerry Browns signature (B.ABX2-15, 2015). Washington, Vermont, and California's DWDA requirements, policies, timelines, and documentation all mirror Oregon's.

Three west coast and one east coast state made the practice of PAS explicitly legal, in Montana the line is not as clear. Although the courts favored terminally ill patients the right to PAS in Baxter v. Montana (Marker, 2010), its legality is questionable. Like Oregon and the other three states, physicians in Montana can prescribe a lethal prescription for the purpose of death, yet unlike the other states physicians are not protected by law. A physician can use a patient's

request in their defense if charged. After Baxter v. Montana, a bill was proposed to make PAS illegal under all circumstances and three other bills were proposed that would legalized PAS and provided guidelines and implement safe guards. None of the bills passed. In January of 2015, Senator Dick Barrett introduced Montana Death with Dignity Act, but a month later missed the deadline for bill transmittal (H.R. 202, 2015).

The high magnitude of PAS controversy is apparent in New Mexico. In January of 2014, Nan G. Nash a district court judge of New Mexico, ruled that terminally ill patients of the state have a constitutional right to request and receive PAS (*Morris and others v Brandenberg*, 2014). Attorney General, Gary King, quickly appealed this ruling. In August of 2015, the New Mexico Court of Appeals ruled 2 -1 that PAS is illegal and that the legal ramifications of someone who assists another in dying is a fourth degree felony.

End of life care in the United States

Medical care in the United States has evolved and transformed in the last 60 years. The initial benevolent model of physician knows best was replaced with the autonomy model in the 1960's. "The autonomy model starts from the premise that the patient knows what treatment decisions is in line with his or her trues sense of well-being" (Will, 2011, p. 1491). Along with patients taking more control over their medical care, treatment modalities have drastically expanded, and people are living longer than they ever have. As great of advancements that have been made in Western medicine, there comes a point when there is nothing else a physician can do. These changes resulted in a societal need for more comprehensive supportive care and services in end of life. Hospice care was the first to emerge, which focused on providing care to patients with a prognosis of six months left to live. Decades later, palliative care departments in hospitals began to emerge to address the needs of patients who wanted to move towards comfort care and away from medical treatments and advancements.

Hospice

Dr. Cicely Saunders led the modern hospice movement in the 1960's. She established St. Chrisophers Hospice near London during this time and brought her years of experience and wisdom to the United States in a presentation at Yale University after being invited by the Dean of Nursing, Florence Wald. Dr. Saunders emphasized the importance of providing holistic care to dying patients and demonstrated the positive effects through influential photos of patients before and after receiving hospice care. In 1974, Florence Wald established the United State's first hospice in New Haven, Connecticut. It did not take long before the hospice movement began to receive federal support (National Hospice and Palliative Care Organization, 2015). Now, 40 years later, hospice care is still reflective of Saunders and Wald vision of end of life care. Hospice focuses on providing comfort in end of life, not a cure. Thus, the main medical modality is pain and symptom management. Services are available in patients homes, hospitals, residential settings, and nursing homes. It involves an interdisciplinary team to ensure holistic care to the patient and their loved ones. The team consists of physicians, nurses, nursing assistants, chaplains, social workers, bereavement therapists, music therapist, volunteers, and other professionals if deemed necessary (MedicineNet, 2012).

The goal of hospice is to provide the best dying experience possible for patients and their families. The idea of a good death came into the spotlight with Dr. Saunders hospice movement, but dates back much farther. The Bible referenced it many times in the Old Testament, such as, "And he died in a good old age, full of days, riches, and honour" 1 Chronicles 29:28 (King James, Authorized Version). The idea of a good death has evolved from simply acquiring old age and managing physical health and symptoms, but to accruing quality of life with an emphasis on social and psychological needs. Auger (2007) provides a modern definition and characteristics of good and bad death. Good death comes in old age, is pain free, symptoms are managed, the

patients' choices are heard, respected, and implemented, and they die in their home. They die naturally either suddenly or progressively due to a terminal illness. Bad death is essentially the opposite: people dying young, in pain, or individuals spending their last days hooked up to life sustaining treatment, in a hospital, surrounded by strangers. Smith (2000) also identified the importance of choice. He discovered that a good death is one in which patient autonomy and patient and family preferences are met while still upholding the values of the professional care team. Families of lost loved ones emphasized the emotional and social needs and identified that empathic staff that provided "tender loving care" was more influential in a good death than an elegant environment or advanced medical treatment (Munn & Zimmerman, 2006, p. 55).

Palliative care

From the modern hospice movement in the United States came palliative care programs in hospitals and similar institutions in the 1980's. Like hospice, these programs utilize an interdisciplinary team of professionals to provide holistic comfort care to patients in inpatient and outpatient settings. Unlike hospice, not all patients are terminal, but have been diagnosed with a chronic disease. There is a larger emphasis on context interpretation in palliative care than in hospice. Patients and their families commonly need a clearer understanding of their prognoses and treatment options, how to manage symptoms and pain, the up coming choices that will need to be made, and their corresponding emotions (Bern-Klug, Gessert, & Forbes, 2001).

End of life social workers

Social workers were implemented early in hospice care and made a requirement in 1982 when Medicare began to cover costs. Despite this mandate, research shows that social workers' unique perspective, experience, and education have been underutilized (Csikai, 2002). This is partly due to costs and the overlap in roles for social workers and nurses, with an emphasis on the nurses' ability to assess and treat physical symptoms. Fortunately, in the last 20 years much

research has been done on the importance of regular and early social work intervention for patients and their families and how it can lower hospitalization rates (Bushfield, 2005) and contrary to previous beliefs, significantly lower hospice costs (Reese & Raymer, 2004).

Role

The National Association of Social Workers (NASW) has identified that hospice and palliative social workers perform numerous tasks and are responsible for fulfilling many roles. At the core of these responsibilities is the generalist social work holistic approach. The "biopsychosocial assessment guides practice" and that "assessments focus on the goals, needs, and strengths of both the patient and the family caregiver(s)" (NASW, 2010, p. 1). The job functions listed are primarily direct client practice such as counseling, education, mediation, advocacy, providing resources, and support. They also identify the importance and high need of other roles end-of-life social workers embrace such as educator, researcher, administrator, and macro level advocator.

End-of-life social workers and their perception of their roles and duties align with the NASW. A nationwide survey completed by 1,169 palliative and hospice social workers identified their primary roles: to support the patient and family, to communicate their psychosocial needs to members of the interdisciplinary team, to provide relevant resources, and to assess for grief and bereavement issues. A majority of hospice social workers carry a caseload anywhere from 21-50 cases and palliative social workers conduct 1-5 consults a day (Weisenfluh & Csikai, 2013). Similarly, hospice directors have identified that a social workers role in end of life is to provide financial resources, assess for psychosocial problems, and coordinate social support. Additionally, they identified the social workers skill in cultural competency and counseling in areas such as crises intervention, suicidal ideation, denial, anticipatory grief,

anxiety, and bereavement (Reese, 2011). Unfortunately, hospice workers of Oregon are often unsure about their role within PAS (Notron & Miller, 2012).

Establishing a health care directive is an important intervention a palliative and hospice social worker provides when discussing treatment goals with patients and their loved ones. A healthcare directive is a written document that states your health care wishes and gives one the opportunity to appoint an agent to speak on their behalf if they are unable (Minnesota Department of Health, 2010). This is an important legal document that establishes an understanding of goals of care for the interdisciplinary team and health care for the patient moving forward.

Many end-of-life social workers and past research identifies the patient and their family as the unit of care. The social worker and the interdisciplinary team attend to the needs of not just the patient, but the family as well because they are so influential on each other. For example, a family's acceptance of the patient dying often influences how the patient holds on, because they still want to meet the needs of their families (Broom & Kirby, 2012). From the other perspective, if a caregiver can detect that their loved one is uncomfortable and symptoms aren't being managed this can add distress to the caregiver and family (Tilden, Tolle, Drach, & Perrin, 2004). Even when symptoms are being managed, caring for someone who is dying is hard emotionally and physically. End-of-life caregivers are prone to symptoms of depression and anxiety, serious long-term medical problems, and mental decline (Office on Women's Health, 2008). Caregiving involves a lot of balancing between their own lives and that of their loved one and requires a level of death acceptance. The social worker is trained to provide counseling to the unit of care when this is a presenting problem and has shown to relieve caregiver stress and reduce feelings of guilt and worry (Empeno, Raming, Irwin, Nelesen, & Lloyd, 2013). It has been suggested that social workers also are the preferred profession by families for support and

to assist in times of crises (Vosler, 1990). The ability develop such compassionate connections is a unique skill set of social workers. It is the key to empowering, educating, goal setting, and supportive counseling with patients and families to create meaning at end of life (Christ & Blacker, 2005).

Attitudes and perception of preparedness

According to Gwyther et al. (2005) there are required competencies an end-of-life social worker must possess: knowledge, skills, attitudes and values. Attitudes and values should be the first to be addressed and analyzed before moving forward in this area of work and continually self-assessed once in the field. This is an important first step because fear of death, death avoidant attitudes, and recent personal experience with a terminal diagnosis can directly affect feelings of preparedness to do the work, as well as behavior, level of collaboration, and effectiveness of communication of the social worker (Black, 2005). Therefore, it is essential for social workers in this field to be open to death and to work through any personal issues in order to give the best possible care to patients and their loved ones.

Unfortunately, early literature highlights social work students' feelings of under preparedness to assist dying and grieving patients and families. Kramer (1998) assessed second year Master's of Social Work students' perception of preparedness to assist dying patients and their grieving families and the results demonstrate little to somewhat prepared. Reese et al (2005) took it a step further by comparing death anxiety and denial, religious and cultural beliefs, and end of life preferences among social work students, medical students, and community residents. The results indicated a need for training in personal preparedness, death anxiety, and death denial, and that awareness of one's own beliefs is a must in order to respect the beliefs of patients and members of the interdisciplinary team.

Steps have been taken to address this issue and advance the field of end of life social work. Reese (2011) identifies many: Society for Social Work Leadership in Health Care established social work standards in 2000; the Journal of Social Work in End-of-Life & Palliative Care was developed in 2003; Social Work End-of-Life Care Education Project established workshops that encouraged further education in 2005; Social Work in Hospice and Palliative Care was set up in 2008; and post graduate certificate programs specializing in end of life care were established at Smith's College and New York University. Despite these organizational and educational advances, one study found that social workers believe they are qualified to do less than half of the interventions provided within the hospice social worker's scope of practice. (Reese, 2011).

Social workers and physician assisted suicide

When navigating controversial topics social workers can turn to their professional ethics and values to help guide decision-making. Social workers are taught to value the dignity and worth of people, and work to promote their well-being and self-determination. Yet, with no concrete position on PAS within the Code of Ethics and varying and unclear policies in agencies, social workers are left to make their own professional judgments congruent with legislation. This has left social works expressing a range of professional attitudes towards PAS.

Professional values, policy, and the Code of Ethics

The NASW provides ethical guidelines a social worker is expected to follow in their Code of Ethics. The Code of Ethics does not address PAS (NASW, 2008). In their handbook, The NASW Standards for Palliative and End of Life Care, they do not adopt a position.

> "The social workers working in palliative and end of life care are expected to be familiar with the common and complex bioethical considerations and legal issues such as the right to refuse treatment …and physician aid in dying. End of life issues are recognized as

> controversial, because they reflect the varied value systems of different groups. Consequently, NASW does not take a position concerning the morality of end of life decisions, but affirms the right of the individual to determine the level of his or her care" (National Association of Social Workers, 2004, p. 16).

A few years after Oregon's DWDA was established, Miller, Mesler, & Eggman (2002) asked end of life social workers about their direct experience working with PAS. Cardinal values and practice implications came up as two of the overarching themes. The social workers identified self-determination, advocacy, and empowerment as three professional values that influence their attitude and direct practice with patients considering PAS. Erlbaum-Zur (2005) analyzed 312 end of life social workers and their attitudes towards PAS. The findings suggest that the more strongly a social worker felt PAS was consistent with their professional values, the more likely they were to agree with legalization and assisting patients seeking PAS..

Social workers identify similar struggles within their agencies 14 years after the passing of Oregon's DWDA. The lack of clear policy leaves social workers questioning their role in assisting patients with this heavy decision. One social worker voiced fear of being reprimanded if they initiated the conversations. Similarly, another stated their agency policy is the patient must start the conversation (Norton & Miller, 2012). Unfortunately, this controversial topic has been convoluted leaving social workers to rely on their experience, education, judgment, and interpretation of professional values and ethics to help guide their position and practice behavior.

Attitudes, experiences, perception of preparedness, and knowledge

Social workers and PAS have been previously analyzed in states that possess death with dignity laws and states that do not. Six years after Oregon passed their DWDA, a study was conducted that suggest nearly ¾ of hospice social workers support PAS. A majority reported having a conversation with patients about PAS as an option, and 22% stated that they were not

comfortable having such conversations (results were reflective of social workers and nurses comfort level) (Miller et al., 2004). Oregon possesses the highest researched social work support for PAS.

Social workers' attitudes and perception of preparedness in other states and regions of the United States have been studied. A mail survey was utilized with a sample of 312 New York social workers employed in long term care facilities. The findings suggest that attitudes were very diverse with a majority agreeing that under particular circumstances, PAS should be permissible. They did not feel educationally prepared and had minimal involvement in the debate. The findings also suggest that the more experienced the social worker, the more negative their attitude towards PAS. This could be related to the values of the age group and not professional experience. (Erblaum-Zur, 2005). Similarly, 122 hospital social workers from a multitude of southern states completed a mail survey, and the findings indicate that PAS should be permissible in some situations, can be ethical, and social workers would be willing to participate. One fourth of the sample reported requests to discuss these options with patients and families. There was a positive correlation with numbers of years in medical social work and their attitudes towards this end of life issue (Csikai, 1999).

Florida social workers were the only sample in the literature that do feel capable of assisting individuals in end of life decisions and have a moderate knowledge of the resources available. A majority of respondents believed that PAS should be legalized (Kane et al., 2005). Manetta & Wells (2001) took a slightly different approach in South Carolina. They asked 66 social workers to fill out a voluntary questionnaire at a suicide conference that inquired if they favored PAS and if there was a difference in the education or training regarding mental health issues, ethics, or suicide between those that favor and those that do not. The findings suggest that half of the social workers favor while half oppose, subjects that took an ethics course were more

likely to favor, more than half in each group reported taking a course on suicide, and over half of all participants were not aware of their current state policy on physician assisted suicide.

End of life social workers' attitudes, challenges, personal and professional values, along with perceived preparedness has been studied in Oregon and other states where PAS is not a legal end of life option. The results varied across demographic locations. These results may bare reflective of the lack of a general professional position and could also be due to the different cultures within the demographic regions in the United States. It has been suggested that the Midwest is a friendly and conventional region. "The characteristics of this psychological region suggest a place where traditional values, family, and the status quo are important" (Rentfrow et al., 2013, p. 1006). The level of openness to change and differences is significantly lower than any other region. These demographic traits, along with PAS bills being introduced in numerous Midwest states displays a high need to understand end of life social workers and PAS within this area.

Conceptual Framework

This study was designed and conducted through the lens of the NASW's concept of competency (NASW, 2008). Competency is the only ethical principle that is also a core value in the Code of Ethics. The ethical principle of competency is broken down into three sections. The first states that a social work should only practice within the limits of their "education, training, license, certification, consultation received, supervised experience, or other relevant professional experience" (NASW, 2008, p. 8) The second section addresses the necessity for social workers to receive competent education, training, and supervision before integrating a new treatment modality into their practice. The third identifies that the NASW does not address many specific or upcoming areas of practice, it is up to the social worker to utilize their judgment and resources

to provide competent services to clients. The core value takes it one step further identifying the social workers responsibility to share their competency to others in their field.

According to the NASW's concept of competency, social workers should not assist patients who request PAS in decision making and preparing for end of life until they have received an adequate amount of education and training and have access to consultation and supervision. With PAS becoming a larger social issue that society is facing, it is essential that it is addressed in education and post-graduate trainings for social workers and their supervisors. As Gwyther et al. (2005) suggested, it takes more than knowledge and skills to become a competent social worker. Competency can come into question when ones personal values, attitudes, and beliefs conflict with professional responsibility and duties (Black, 2005). Social workers need safe places to learn to adapt to systemic changes that directly affect services to clients.

Methods

This study is a quantitative design that addresses three research questions. These questions are: 1) What are the attitudes of Midwest, end of life social workers toward physician assisted suicide laws? 2) Do they feel prepared to have conversations and assist in decision making with patients that request PAS and why? 3) What is their awareness and involvement in PAS legislation in their state? Descriptive and demographic data were collected and analyzed. Additionally, a qualitative question was utilized to contextualize the other data. The questionnaire utilized to obtain this data can be found in Appendix B.

Research Design

The purpose of the study is to examine Midwest, end of life social workers attitudes, perceived preparation for implementation, and knowledge of PAS. A survey was created by the researcher and was administered using Qualtrics, an online survey software. The survey was distributed in monthly news letters and/or by email to members of multiple organizations:

Minnesota Hospice and Palliative Care, The Hospice Organization and Palliative Experts of Wisconsin, Hospice & Palliative Care Association of Iowa, and Palliative Care End of Life Social Work Listserv. The survey contained demographic questions: gender, age, state, community of agency, type of practice, level of education, and years of experience. It also contained two questions along a Likert scale. They aimed to measure one's level of comfort discussing end of life options with the interdisciplinary team, attitudes toward PAS, and their perceived preparedness to implement PAS into their practice. The other survey questions addressed why the participant feels prepared, classes completed in their education, preferred terminology related to PAS, their knowledge of PAS laws in their state, and their advocacy involvement. Lastly, an open ended question addressed any additional thoughts or feelings one may have concerning PAS.

Sample

The population this study was interested in is Midwest, end of life social workers. Midwest is defined in this study as Iowa, Wisconsin, and Minnesota. All three of these states had PAS bills introduced to legislature in 2015. End of life social workers include those working in hospice and/or palliative care. Minnesota Hospice and Palliative Care, The Hospice Organization and Palliative Experts of Wisconsin, Hospice & Palliative Care Association of Iowa are state wide organizations. Palliative Care End of Life Social Work Listserv is a national and international electronic mailing list. The letter of consent along with the survey was distributed through their membership mailing list.

Protection of Human Subjects

Steps were taken to protect participants. Before the study was conducted, it was reviewed and approved by the Institutional Review Board at St. Catherine University. The organizations distributed the surveys web link, so the researcher never had access to the member's information.

A consent form was presented in Qualtrics and participants must accept before they can access the survey (see Appendix A). The consent form stated the purpose of the study, its voluntary nature, steps taken to ensure confidentiality, and the researcher's contact information. There were no risks or benefits in participation. To protect confidentiality, no identifying information was collected, the survey data were stored in a password protected file on the researchers laptop, and were destroyed after the study was completed.

Data Collection

Data was collected from December of 2015 to January of 2016 utilizing an online survey program called Qualtrics. The survey questions were developed by the researcher, influenced by the literature, and reviewed by the researcher's chair and committee members to increase validity and reliability (see Appendix B for survey questions). The survey is formulated into four sections: 1) demographic information, 2) attitude towards PAS, 3) perception of preparedness and 4) policy awareness and involvement. The demographic information measured gender, age, state and community where they work, type of practice, level of education, classes completed, years of experience, preferred terminology, and level of comfort discussing end of life options with the interdisciplinary team. Attitude toward PAS was operationalized through:

- "What is your attitude toward physician assisted suicide laws" (10) Response options range from 1 (strongly oppose), to 2 (oppose) to 3 (neutral or undecided) to 4 (support) to 5 (strongly support) along a Likert Scale.

The third section measured social workers perception of preparedness for the implementation of PAS into their practice. Perception of preparedness was operationalized through the following:

- "Do you feel prepared to assist patients who request physician assisted suicide and their families in conversation, decision making, and preparing for end of life" (11). Response

options range from 1 (not at all) to 2 (slightly) to 3 (Moderately) to 4 (Very) to 5 (Extremely) on a Likert Scale.

- "What has influenced your level of preparedness" (12). Participants can select as many responses as they wish. Response options are "Professional experience," "Professional values," "Personal experience," "Personal values," "Undergraduate education," "Graduate education," "Doctoral education," "Additional training," "Peer reviewed research," "Agency," "Supervisor," and "Staff."

The fourth section measured policy awareness and involvement. Policy awareness and involvement was operationalized through the following:

- "What is your awareness of the current legal status on physician assisted suicide in your state" (13). Response options are "Illegal," "Illegal, but a bill was introduced in 2015," "Illegal, but a bill was purposed in 2015 and rejected," "Legal by court order," and "Legal."

- "How many events have you attended to inform and/or advocate for your attitude toward physician assisted suicide" (14).

Data Analysis

The collected data were analyzed using the statistical software program, Statistical Package for the Social Sciences (SPSS). Descriptive and inferential statistics were used to analyze data. Descriptive statistics were ran on questions 1, 3-5, 7-9 and 14 in order to describe the demographics of the participants. Frequency distributions were also ran to determine the number of years in end of life care and advocacy events attended along with the samples averages. A Chi-Square was run to discover if there is an association between level of education (7) and class completed (8).

Attitude towards PAS

This survey sought to discover Midwest, end of life social workers attitudes towards PAS laws. A frequency distribution was ran on question 10 to describe the participants attitude. Inferential statistics (Chi-Square) was ran to analyze if there is an association between demographic variables (1, 3-5, 7-9 and 14) and attitude; perception of preparedness (11) and attitude; and knowledge of PAS laws (13) and attitude. A t-Test was ran to discover if there is a difference in PAS attitudes between participants that attended advocacy events for PAS and those who did not (14), Lastly, age (2) and years of experience (6) will be transformed into ordinal variables, a Chi-Square was then ran to determine if there is an association between age (2) and attitude and experience (6) and attitude.

Perception of preparedness

To understand social workers level or preparedness to implement PAS into their practice (11) and what has influenced that perception of preparedness (12) a frequency distribution was ran. A Chi-Square was ran to analyze if there is an association between demographic variables (1, 3-5, 7-9 and 14) and level of preparedness, influences and level of preparedness, knowledge of PAS laws (13) and preparedness, and level of education (7) and influences. A t-Test was ran to discover if there is a difference in level of preparedness between participants that attended advocacy events for PAS and those who did not (14), Lastly, age (2) and years of experience (6) was transformed into ordinal variables, a Chi-Square was then ran to determine if there is an association between age and level or preparedness, age and influences, experience and level of preparedness, and experience and influences.

Policy awareness and involvement

The study aimed to uncover Midwest, end of life social workers policy awareness and involvement in PAS. Descriptive statistics were ran to discover the distribution of participants knowledge of PAS laws in their state (13). A frequency distribution was ran to uncover the

number of advocacy events attended along with the average. A Chi-Square was ran to analyze if there is an association between demographic variables (1, 3-5, 7-9 and 14) and policy awareness; attitude toward PAS laws (10) and policy awareness; and perceived preparedness (11) and policy awareness. Inferential statistics was ran to determine if there is a relationship between years of experience (6) and advocacy events attended (14) and age (2) and advocacy events attended. Lastly, an t-Test was ran to determine if there is a difference in evens attended within demographic variables (3-5, 7-8, and 14), attitude toward PAS laws (10), perception of preparedness (11), and knowledge of PAS laws (13).

Results

Numerous descriptive and inferential statistics were ran to analyze the data. Unfortunately, small category sizes limited the level of description in analysis. Some categories were merged in order to allow for further description: pediatric palliative care and pediatric hospice were combined into pediatric end of life care; in community of practice, suburb was combined with urban; in level of interdisciplinary team comfort, responses of slightly were combined with moderate; and in perceived level of preparedness, responses of extremely were combined with very. Responses to a qualitative question were analyzed to provide a sense of context and perspective to the quantitative data.

Professional demographics

Sixty two Midwest end of life social workers completed the online questionnaire. Demographic characteristics are located in Table 1. The findings in the table show that participants were mostly female (n = 59, 96.70%) and ranged in age from 24 to 64 years (M = 41.20, standard deviation [SD] = 11.13). Participants currently practiced social work in Minnesota (n = 16, 26.20%), Wisconsin (n = 24, 39.30%), or Iowa (n = 21, 34.40%) in a large urban (n = 18, 29%), city (n = 17, 27.40%), town (n = 6, 9.70%), or rural community (n = 21,

33.90%). The sample predominantly worked with adults in hospice (*n* = 49, 79%) and/or palliative care (*n* = 26, 41.90%) with few practicing in pediatric end of life care (*n* = 11, 17.70%). Experience in end of life care ranged from 1 to 26 years (*M* = 7.41, standard deviation [*SD*] = 5.95) with a majority of the sample feeling extremely (*n* = 44, 71%) comfortable having conversations about end of life care options with their interdisciplinary team. Most of the participants had an MSW degree (*n* = 43, 69.40%) and had completed a course in Policy (*n* = 55, 88.70%), Grief and loss (*n* = 31, 50%), Crises intervention (*n* = 24, 38.7%), Suicide prevention and intervention (*n* = 16, 25.8%), Geriatric social work (*n* = 30, 48.40%), and/or Social work in health care (*n* = 30, 48.4%).

Table 1.

Professional Characteristics

	Social Workers (n = 62)	
	M (SD)	
Age	41.20 (11.13)	
Years of Experience	7.41 (5.95)	
	N	%
Gender (*n* = 61)		
Female	59	96.70
Male	2	3.30
Practice Location (*n* = 61)		
Minnesota	16	26.20
Iowa	21	34.40
Wisconsin	24	39.30
Community		
Large Urban	18	29
City	17	27.40
Town	6	9.70
Rural	21	33.90
Type of Practice		
Pediatric end of life care	11	17.70
Adult palliative care	26	41.90
Adult hospice care	49	79

Highest level of education		
BSW	19	30.60
MSW	43	69.40
Course completed		
Policy	55	88.70
Grief and loss	31	50
Crises intervention	24	38.70
Suicide prevention and intervention	16	25.80
Geriatric social work	30	48.40
Social work in health care	30	48.40
Comfortability with interdisciplinary team		
Moderately	5	8
Very	13	21
Extremely	44	71

Note: SD = standard deviation. *Sample sizes vary with missing data

Inferential statistics were ran to discover if there was an association between a participants level of education and selected courses completed: grief and loss (p = .17), crises intervention (p = .44), suicide prevention and intervention (p = .57), geriatric social work (p = .66), and social work in health care (p = .51). Since the p-value is greater than .05 for all listed variables, we fail to reject the null hypothesis. Therefore, this data does not support the research hypothesis that there is a statistically significant association between level of education and selected courses completed. An additional chi-square was ran to discover if there was an association between level of education and completing a policy course. Of participants with a Bachelor's of Social Work (BSW) five (26.3%) had not taken a policy course and 14 (73.7% had. Of participants with a Masters of Social Work (MSW) two (4.7%) had not taken a policy course and 41 (95.3%) had. With a p-value less than .05, taking a course in policy was the only course with a statistically significant association with level of education, χ^2 (1, n = 62) = 6.18, p = .01.

Attitude toward PAS

The ordinal variable "attitude" measured the participant's attitude towards PAS laws. The findings in this study show that 54.10% of the respondents either support (n = 19) or extremely support (n = 14) PAS. These findings can be found in Table 2 along with the participants preferred terminology. The sample predominantly preferred death with dignity (n = 26, 42.60%), physician assisted death (n = 12, 19.70%), or aid in dying (n = 12, 19.70%). In the sample, participants that had an MSW were more likely to have taken a policy course than those with a BSW.

Table 2.

Demographics Distribution of Attitude toward PAS and Preferred Terminology

	N	%
Attitude toward PAS laws (*n = 61)		
Strongly oppose	7	11.50
Oppose	5	8.20
Neutral or undecided	16	26.20
Support	19	31.10
Strongly Support	14	23
Preferred Terminology (*n = 61)		
Physician assisted suicide	8	13.10
Physician assisted death	12	19.70
Aid in dying	12	19.70
Voluntary active euthanasia	3	4.90
Death with dignity	26	42.60

Note: *Sample sizes vary with missing data

Inferential statistics were ran to determine if there was an association between participant's attitude towards PAS and other variables. A chi-square was ran on state where they practice (p = .19), community they practice in (p = 8.23), level of education (p = .38), classes completed such as policy (p = .64), grief and loss (p = .14), crises intervention (p = .55), geriatric social work (p = .27), and social work in health care (p = .40), along with perceived preparedness (p = .12), and if they practice adult palliative care (p = .54), adult hospice (p = .26), or pediatric end of life care (p = .99). Since the p-value is greater than .05 for all listed variables, we fail to

reject the null hypothesis. Therefore, this data does not support the research hypothesis that there is a statistically significant association between attitude towards PAS laws and previously listed variables.

Chi-square was also ran to discover if there was an association between participants attitude towards PAS and taking a course in suicide prevention and intervention. Of all participants who had taken a course in suicide prevention and intervention, one (1.60%) opposed PAS laws, two (3.30%) were neutral or undecided, five (8.20%) support, and eight (13.10%) strongly support. Of all participants who had not taken a course in suicide prevention and intervention, seven (11.50%) participants strongly oppose PAS laws, four (6.60%) oppose, 14 (23%) are neutral or undecided, 14 (23%) support, and six (9.80%) strongly support. In the sample, participants that had taken a course in suicide prevention and intervention were a little more likely than those who had not taken the course to strongly support PAS laws and less likely to oppose or be neutral/undecided. Also, those who had taken the course in suicide prevention and intervention and those that had not were equally likely to support PAS laws. With a *p*-value less than .05, taking a course in suicide prevention and intervention was the only variable with a statistically significant association with attitude towards PAS, χ^2 (1, n = 61) = 11.06, p = .03.

A one way ANOVA was ran to discover is there was a difference in participants who reported attitudes towards PAS as strongly oppose, oppose, neutral or undecided, support, and strongly support in their age (p = .89), years of experience (p = .7), and events attended to educate or advocate for PAS (p = .91). With p-values < .05, we fail to reject the null hypothesis. There is not a statistically significant difference in participants attitude towards PAS and age, years of experience, or events attended.

Perception of preparedness

Table 3 shows participants perceived preparedness to assist patients who request PAS and their families along with factors that have influenced their level of preparedness. The findings in the study show that 10 participants do not feel prepared at all (16.10%), 17 feel slightly prepared (27.40%), 21 feel moderately prepared (33.90%), and 14 feel very prepared (22.60%). The samples level of preparedness was most influenced by professional experience (*n* = 50, 80.60%), professional values (*n* = 42, 67.70%), personal values (*n* = 37, 59.7%), and/or their MSW education (*n* = 21, 33.90%). A few of the other written responses were: *religious beliefs*, *learning from others,* and two different responses naming their lack of experience due to its legality as an influential factor.

Table 3.

Perceived Preparedness and Influential Factors

	N	%
Preparedness		
Not at all	10	16.10
Slightly	17	27.40
Moderately	21	33.90
Very	14	22.60
Influential factors		
Professional experience	50	80.60
Professional values	42	67.70
Personal experience	18	29
Personal values	37	59.70
BSW	8	12.90
MSW	21	33.90
Additional training	11	17.70
Peer reviewed research	5	8.10
Agency	11	18
Supervisor	9	14.50
Staff	12	19.40
Other	6	9.70

Inferential statistics were ran to discover if there was an association between a participants perceived preparedness for the implementation of PAS laws into their practice and state where they practice (p = .13), community they practice in (p = .93), level of education (p = .59), classes completed such as policy (p = .64), suicide prevention and intervention (p = .70), crises intervention (p = .40), geriatric social work (p = .31), and social work in health care (p = .60), and if they practice adult palliative care (p = .53), adult hospice (p = .36), or pediatric end of life care (p = .44). Since the p-value is greater than .05 for all above variables, we fail to reject the null hypothesis. Therefore, this data does not support the research hypothesis that there is a statistically significant association between participants perceived preparedness and previously listed variables.

A chi-square test indicates that taking a course in grief and loss has a statistically significant association with a participants perceived preparedness to implement PAS into their practice, χ^2 (1, n = 62) = 8.80, p = .03. Of all participants that had taken a course in grief and loss, eight (12.90%) felt not at all prepared, four (6.50%) slightly, 12 (19.40%) moderately, and 7 (11.30%) very. Of all participants that had not taken a course in grief and loss, two (3.20%) felt not at all prepared, 13 (21%) slightly, nine (14.50%) moderately, and seven (11.30%) very. In the sample, participants that had taken a course in grief and loss were more likely to feel moderately or not at all prepared, and less likely to feel slightly prepared than participants that had not taken the course. Also, those who had taken the course in grief and loss and those who had not were equally likely to feel very prepared to implement PAS into their practice.

Chi-square was also ran to discover if there was an association between their perceived preparedness and influential factors: personal experience (p = .17), BSW education (p = .20), MSW education (p = .13), additional training (p = .14), peer-reviewed research (p = .75), agency (p = .72), supervisor (p = .50), staff (p = .77), and other (p = .55).). Since the p-value is greater

than .05 for all above influential factors, we fail to reject the null hypothesis. Therefore, this data does not support the research hypothesis that there is a statistically significant association between participant's perceived preparedness and previously listed influential factors.

There were three influential factors that were found to have a statistically significant association with a participants perceived preparedness: professional experience, χ^2 (1, n = 62) = 22.85, p = .00, professional values , χ^2 (1, n = 62) = 8.98, p = .03, and personal values , χ^2 (1, n = 62) = 9.20, p = .03. Participants that found their professional experience and values to influence their perceived preparedness for the implementation of PAS in their practice reported higher levels of preparedness than participants that did not find their professional experience or values to be influential. Participants that found their personal values to influence their perceived preparedness were more likely to report feeling not at all or slightly prepared and much more likely to report very prepared than participants who did not find their personal values to be influential. See Table 4 for detailed chi-square analysis.

Table 4.

Cross Tabulation for Perceived Preparedness and Influential Factors

	Not at all	Slightly	Moderately	Very
Professional Experience				
Was influential				
Count	3	13	20	14
Expected Count	8.1	13.7	16.9	11.3
% within Preparedness	30.0%	76.5%	95.2%	100.0%
% within Professional Experience	6.0%	26.0%	40.0%	28.0%
% of Total	4.8%	21.0%	32.3%	22.6%
Was not influential				
Count	7	4	1	0
Expected Count	1.9	3.3	4.1	2.7
% within Preparedness	70.0%	23.5%	4.8%	0.0%
% within Professional Experience	58.3%	33.3%	8.3%	0.0%
% of Total	11.3%	6.5%	1.6%	0.0%
Professional Values				
Was influential				
Count	4	9	17	12
Expected Count	6.8	11.5	14.2	9.5

% within Preparedness	40.0%	52.9%	81.0%	85.7%
% within Prof. Experience	9.5%	21.4%	40.5%	28.6%
% of Total	6.5%	14.5%	27.4%	19.4%
Was not influential				
Count	6	8	4	2
Expected Count	3.2	5.5	6.8	4.5
% within Preparedness	60.0%	47.1%	19.0%	14.3%
% within Prof. Experience	30.0%	40.0%	20.0%	10.0%
% of Total	9.7%	12.9%	6.5%	3.2%
Personal Values				
Was influential				
Count	6	9	9	13
Expected Count	6.0	10.1	12.5	8.4
% within Preparedness	60.0%	52.9%	42.9%	92.9%
% within Prof. Experience	16.2%	24.3%	24.3%	35.1%
% of Total	9.7%	14.5%	14.5%	21.0%
Was not influential				
Count	4	8	12	1
Expected Count	4.0	6.9	8.5	5.6
% within Preparedness	40.0%	47.1%	57.1%	7.1%
% within Prof. Experience	16.0%	32.0%	48.0%	4.0%
% of Total	6.5%	12.9%	19.4%	1.6%

A one way ANOVA was ran to discover is there was a difference in participants who reported their perceived preparedness for the implementation of PAS as not at all, slightly, moderately, and very in their age (p = .59), years of experience (p = .23), and events attended to educate or advocate for PAS (p = .36). With p-values < .05, we fail to reject the null hypothesis. There is not a statistically significant difference in participants perceived level of preparedness for the implementation of PAS into their practice and age, years of experience, or events attended.

An Independent Samples *T*-test was ran to discover if there was a difference in age and whether certain factors influenced their perceived level of preparedness: professional experience (p = .81), professional values (p = .30), personal experience (p = .75), BSW education (p = .88), MSW education (p = .19), additional training (p = .21), peer reviewed research (p = 74), agency (p = .22), supervisor (p = .88), staff (p = .83), and other (p = .06). Additional Independent

Samples *T*-test were ran to discover if there was a difference in years of experience and whether certain factors influenced their perceived level of preparedness: professional experience (p = .51), professional values (p = .52), personal experience (p = .44), personal values (p = .39), BSW education (p = .89), MSW education (p = .08), additional training (p = .21), peer reviewed research (p = 74), agency (p = .39), supervisor (p = .48), staff (p = .39), and other (p = .95). With p-values greater than .05 we fail to reject the null hypothesis. Therefore there is no statistically significant difference in years of experience or age in whether or not they found certain named factors influential to their perceived level of preparedness.

A final independent samples *T*-test was ran to discover is there was a different in age of participants who found personal values to influence their perceived level of preparedness and those that did not. The participants who found their personal values to be influential had a mean age of 43.7 years old and the participants who did not find their personal values as influential had a mean age of 37.6 years old. The Levene's Test of Equality of Variance for the independent samples T-test is .77. Since .77 is greater than .05, the Levene's Test is not significant. Therefore, the p-value for this T-test is .03. Since the p-value is less than .05, the results of this data are statistically significant. As a result, we reject the null hypothesis. Therefore, there is a difference in age between participants who found their personal values to influence their perceived level of preparedness and those who did not with older participants identifying their personal values as influential.

Policy awareness and involvement

The nominal variable "awareness" measured the participant's immediate awareness of the current legal status of PAS in their state. A majority of the sample was aware that PAS was illegal (n = 37, 59.7%), but only 3 participants had accurate awareness with PAS being illegal, but a bill was introduced in 2015 (4.8%) while some participants did not know (n = 16, 25.8%).

Analysis could not get as descriptive as preferred due to the small number of participants that had accurate awareness. These results can be found in Table 5 along with the number of events participants attended to inform and/or advocate for their attitude toward PAS which ranged from zero to three events (M = 0.34, standard deviation [SD] = .723) with a majority of participants never attending an event (n = 48, 77.40%).

Table 5.

Policy Awareness and Involvement

	n	%
	Social Workers (n = 62)	
	M (SD)	
Events Attended	0.34 (.723)	
Immediate legal awareness		
Illegal	37	59.70
Illegal, but a bill was introduced in 2015	3	4.80
Illegal, but a bill was proposed in 2015 and rejected	6	9.70
Legal	0	0
Legal by court order	0	0
I do not know	16	25.80
Attended event		
No	48	77.40
Yes	14	22.60

Note: SD = standard deviation.

A correlation was ran to show the strength and direction of relationship between events attended and years of professional experience (r = -.11, p =.39) along with events attended and age of participant (r = -.01, p = .99). Both calculated correlations indicated a very weak, negative correlation. With p-values greater than .05 the relationship is not statistically significant. Therefore we fail to reject the null hypothesis. There is not a relationship between events attended and years of professional experience or age of participant.

A oneway ANOVA was ran to discover if there was a difference in events attended to education or advocate for PAS and the state they practice in (p = .38) and the type of community

in which they practice in (p = .74). An Independent samples T-test was ran to discover if there was a difference in events attended and their level of education (p = .87) and whether or not they took a course in policy (p = .37), grief and loss (p = .86), crises intervention (p = .69), suicide prevention and intervention (p = .34), geriatric social work (p = .69), or social work in health care (p = .69). With p-values greater than .05, we fail to reject the null hypothesis. Therefore, there is not a statistically significant difference in events attended by state or community in which they practice, level of education, or whether or not they completed selected social work courses during their education.

Qualitative findings

The survey for this study included one qualitative question about any thoughts or feelings that the questionnaire may have evoked within participants. Thirty-five participants in total responded. Utilizing thematic analysis, five themes emerged: autonomy, suffering, hospice and palliative care, terminology, and lack of awareness. The quotations included were edited for spelling errors.

Autonomy

The first theme that was discovered was an individual's right to autonomy. One responded wrote, *"Death with dignity is a very personal choice for people that are faced with a terminal illness. It is not one way or no way, every individual deserves to know their options related to the dying process."* Other responses implied that PAS should be a situational right,

> *"I feel strongly that individuals have the right to choose to hasten their death in circumstances where they are faced with a progressive, life-limiting illness. I believe that quality of life takes priority over length of life, and that each person has the right to decide what constitutes quality for them."*

Numerous responses suggested that how an individual dies should be their own choice without dictation from the government. *"I also strongly believe in people's right to choose for themselves without government intervention - regardless of the diagnosis."* Similarly, another response elaborated on the other choices the government grants individuals in healthcare.

> *"I think that it is important for people to have a choice in their end-of-life care, and Death with Dignity is part of this and should be an option. I know that it will not be everyone's choice, but I feel they should have that option. In this county, we have many choices for other types of care (abortion, labor methods, treatment of diseases, etc.), why should it be any different on how we die?"*

While some participants reported that it should be a right that is not dictated by government, other responses suggested that the social worker would like to honor patient autonomy, but only if legal. *"If the law allowed, I would prefer to honor the request of individuals who wish to control their own end-of-life processes."*

Suffering

When asked to report any thoughts or feelings the questionnaire evoked, many of participant's responses included aspects of suffering or bad quality of life. Numerous responses suggest it is related to diagnosis, *"certain diagnoses create so much suffering and horrible quality of life."* One participant specifically recognized Alzheimer's as one of these diagnoses.

> *"My internship was with adults with early stage Alzheimer's and their caregivers. Suicide came up often. I know that for myself, personally, I would want the option if I had that diagnosis. Quite frankly it scares me more than any other, it truly is an awful burden to carry and be to others."*

Other responses included how common patient suffering and bad quality of life was in their professional experiences. For some it is common, *"I have witnessed many deaths which have*

been quite difficult, and were not characteristic of the values or the quality of life the patients had previously experienced." For others it was not, *"I realize there are some illnesses that cause symptoms that are very difficult to manage, but I rarely see that in my 15 years of experience with hospice and long-term care."* One response suggested that there are aspects of suffering that a terminal individual can attend to and will miss out on this opportunity if PAS becomes a legal option. *"Suffering is more than just physical and making it legal may not encourage patients to address all aspects of suffering before death."*

Hospice and Palliative Care

The third theme that emerged suggests that hospice and palliative care provide the comfort care needed for a good quality of life in end of life and in death. *"Death with dignity is what hospice provides… Hospice can help people die on their own terms without hastening the natural dying process."* Many responses suggest that education on hospice and palliative care would eliminate the need for PAS and they see this as part of their role as an end of life social worker.

> *"The fear of dying a painful death spurs some individuals to seek an early death. They have not had the benefit of education or experience related to palliative or hospice options. Working within the hospice environment I have learned that medications and holistic measures can provide death in a very peaceful, pain-free and loving environment. I feel my role is to provide education related to all of the options available."*

Some participants reported that they believe PAS is incongruent with comfort care, *"As a hospice worker, I am strongly opposed to physician-assisted suicide. I think a legal law would circumvent the goals of hospice (comfort)."* While others believe it can be consistent, but also the need could be eliminated if hospice and palliative care was more attainable.

"I believe that the expansion of readily accessible palliative and hospice care--with skillful and empathetic providers--would sharply limit the number of individuals interested in such an option. There can be incredible joy and discovery in the final portion of an individual's life that can fundamentally shape them and those they love. Proper care at this stage of life--on medical, psychosocial, and spiritual levels--can help bring great life to the dying process to an extent for many [physician assisted death] PAD would no longer be considered. Nevertheless, it should be an available option and, I believe, can be seen as consistent with extremely compassionate care."

Numerous participants recognized that on rare occasions suffering still persist, but they are able to provide other options to hasten death that abide by legal and ethical practices.

"I have facilitated conversation with patients and loved ones seeking palliative sedation. We have followed ethical protocol at our agency. I have also facilitated conversation and education with staff who care for a patient choosing VSED (voluntary stopping of eating and drinking)."

Terminology

Another theme that was discovered through thematic analysis was the idea that certain terms should or should not be used when naming PAS. The phrase death with dignity and the term suicide both received attention from the participants. Many participants reported that they believe utilizing the term death with dignity suggests that the only dignified death is through PAS. *"People can still die with dignity even without being assisted by a physician with their death."* Another participants elaborated on this concept while also including their thoughts on the using the term suicide.

"I do not like the term death with dignity. In my mind, that implies that other types of death might not have dignity, and I strongly disagree with that thought or implication. I

also do not like using the term suicide when considering this issue because I think suicide should be considered differently in individuals with mental illness versus individuals with terminal illnesses."

Another participant reports they are reluctant to use the term suicide, but unlike the previous response believes that the act should not be considered differently across populations. "*There is much hesitation to use the word "suicide", for numerous and many obvious reasons. However, the act remains suicide, by any other name is still suicide. I believe patients need to be very clear about this objective."*

Lack of awareness

The final theme that emerged was the idea that many respondents have little awareness of PAS legislature and need education and training on PAS if this were to go into effect. One participant reported,

"I realize that there are a lot of things I don't know about this topic. I feel like there may have been a bill introduced in Minnesota, but I am not sure. Working in this line of work, I realize that I need to be aware of what is going on in my state and neighboring states so I am not caught off guard when speaking with families."

Some participants commented on the need to continue these conversations to both gain awareness and question assumptions. *"I really do not know much about it. It is obviously an ethical dilemma, but I feel it is positive that we are increasingly questioning our assumptions about end-of-life and palliative care, wanting to honor choice and dignity."* While another participant recognized their level of unpreparedness, they do not see the necessity in investing time into something that is currently illegal. *"I am not prepared currently. If this would come into law, I would become prepared and gain confidence in supporting patients with their*

choices…No need to prepare and spend a lot of time thinking about something that is currently illegal in my state."

Discussion

The purpose of the study was to understand Midwest, end of life social workers attitudes towards PAS legislation. In this study 54% of participants support PAS, 26% are neutral or undecided, and 20% oppose. This level of support is consistent with prior research done with social workers in South Carolina (Manetta & Wells, 2001). Florida social workers expressed a greater level of support (Kane et al, 2005), but the highest level of researched support resides in Oregon where the practice is legal (Miller et al, 2004). A study was conducted approximately six years after PAS legislation was passed in Oregon and the study suggested that 75% of the sample support PAS (Miller et al., 2004). Perhaps this high level of support is attributed to their education, training, experience, and conversations around PAS.

Although not statistically significant with a *p*-value of .07, there was a trend in data that as years of experience increased so did opposition to PAS. If this study had a larger sample size this difference maybe statistically significant. This is would be consistent with some prior research (Erblaum-Zur, 2005) while also contradictory to other (Csikai, 1999). In a study done with social workers from the southern United States, the results suggested that as their years of experience increased so did their willingness to participate in patients accessing PAS (Csikai, 1999). The trend of years of experience and opposition of PAS was reflected in the qualitative responses. *"I realize there are some illnesses that cause symptoms that are very difficult to manage, but I rarely see that in my 15 years of experience with hospice and long-term care."* A participant with seven years of experience reported that, *"I have witnessed many deaths which have been quite difficult, and were not characteristic of the values or the quality of life the*

patients had previously experienced." Finally, a participant with very little experience voiced that PAS should be legal regardless of diagnosis.

Previous research suggests that half of the social workers who supported PAS would do so only under certain circumstances such as lack of ability to control pain, poor quality of life, or if an ill patient had a poor quality of life that would extend for several years (Csikai, 1999). Support based on circumstances was also reflected in a study of New York social workers (Erblaum-Zur, 2005). The qualitative responses of this study highlight similar qualified support of PAS. Many participants expressed their support for PAS when the patient has a *"progressive, life-limiting illness"* and acknowledged that *"certain diagnoses create so much suffering and horrible quality of life."* One participant mentioned Alzheimer's specifically as a troubling diagnosis that in their experience has a high likelihood of compromised quality of life. While many written responses reflected on palliative care and hospice care being able to alleviate physical, emotional, and spiritual suffering, it was also acknowledged that there are times when this is simply not possible.

Previous literature utilizes an array of terminology to express PAS: physician assisted death, aid in dying, voluntary active euthanasia, and death with dignity. The study sought to understand the preferred term for social workers. The responses were diverse with death with dignity being the preferred term (42%), followed by physician assisted death (20%) and aid in dying (20%), PAS (13%), and lastly voluntary active euthanasia (5%). Although a majority preferred the term death with dignity, some felt so strongly against the term they were compelled to write about it. One participant wrote, *"I don't like the term "death with dignity" at all because it implies any other way of dying is undignified, and that is simply not true."* Other participants had opposing feelings towards using the word suicide. One participant alluded to the idea that suicide is an action not a circumstance hence the term is appropriate. Social workers general

training is "that suicidal ideation is a sign of depression, impaired judgment, or distortion of reality" (Miller, 2000, p. 267). PAS legislation takes steps to ensure the mental and emotional competency of patients who request it. Hence their reality is not distorted, but realistic. A participant spoke to the idea that suicide can happen outside of this context and believes that the term suicide should be reserved for the mentally ill, not terminally ill.

The study also sought out to understand how prepared social workers feel to implement PAS into their practice if legislation was passed in their state, what has influences their level of preparedness The findings in the study suggest that a majority of social workers perceive themselves to be somewhat prepared for the implementation of PAS into their practice. 67% expressed being moderately to very prepared with only 16% feeling not at all prepared. This provides new information when analyzing end of life social workers and PAS. Although the results of Ken et al (2005) suggest that social workers feel capable of having end of life conversations, it was not within the context of PAS.

A majority of participants (81%) viewed their professional experience as a factor that influences their level of perceived preparedness. The results of the study suggest that those that found professional experience as influential had higher levels of perceived preparedness than social workers that did not. Csikai (1999) suggests that experience in end of life care allows social workers the capability to put aside their own biases, fears, and beliefs in order to better serve the needs and requests of their patients. This study suggests that it is the social workers ability to focus on the patient and not themselves and that this ability takes time to develop. Although not statistically significant, there was a trend in the data that suggest that the more experience a social worker has in end of life care the more prepared they feel to the implementation of PAS. The qualitative responses of this study seem to suggest that social workers have seen what hospice and palliative care can do for an individual at end of life, and

even when they support PAS, they do not often see the need because of the success of these services. One social worker response stated, *"Proper care at this stage of life--on medical, psychosocial, and spiritual levels--can help bring great life to the dying process to an extent for many PAD would no longer be considered."* One social worker spoke specifically to her professional experiences within her agency, *"I also think the hospice I work for does an excellent job of providing comfort care."* Lastly, one participant wrote of their past experience of addressing PAS,

> *"I don't get a lot of patients that ask about it, an occasional statement of wishing to die, but with supportive persons around them who listen, these patients typically have their symptoms well managed and can comfortably die naturally and those statements don't tend to persist with good symptom management, emotional and spiritual support."*

These responses suggest that social workers feel prepared for the implementation of PAS because they have experience with the symptoms and reasons why individuals request PAS. More often than not, they are capable of meeting those needs without hastening death.

Another factor that many participants (68%) found as influencing their perceived level of preparedness was their professional values and those that acknowledged professional values as influential had higher levels of perceived preparedness. This is consistent with previous research that suggested that the more strongly a social worker felt PAS aligned with their professional values the more likely their were to support legislation and assist patients around PAS (Erblaum-Zur, 2005). The qualitative data of this study emphasize the value of autonomy and self-determination. One participant believes *"that it is important for people to have a choice in their end-of-life care, and Death with Dignity is part of this and should be an option. I know that it will not be everyone's choice, but I feel they should have that option."* There were numerous, similar responses. One responses spoke to the right to relieve their own suffering, *"people should*

be able to exercise some autonomy over when the struggle and the suffering ends." These results are consistent with a study done with Oregon social workers after the legalization of PAS where social workers identified self-determination, empowerment, and advocacy as professional values that influence their attitudes and practice surrounding PAS (Miller et al, 2002).

The final factor identified by participants (60%) as influencing their level of preparedness was personal values. The results suggest that those that identified personal values as influential factors were more likely to report feeling not at all to slightly prepared and much more likely to feel very prepared. These results also suggest that older participants were more likely to identify personal values as influencing their perceived level of preparedness than younger participants. This speaks to the level of reflection in social work practice; that a social worker's individual values take them to one of two extremes. Their personal values and beliefs are so influential that it either allows them to feel very prepared or not at all and age has allowed them time to understand what their values are and how they effect their practice. One qualitative response spoke to feeling not prepared, *"I am strongly opposed to physician assisted suicide, if this issue were to come up I do not feel I would be able to put my value aside to assist a patient in this process, I would have to refer else where."* There were three other responses that alluded to their inability to work with patients in the context of PAS because of their personal beliefs and values. This is consistent with previous research that suggest that a social workers personal values, attitudes, and experiences directly effect feelings of preparedness to do end of life work (Black, 2005).

Lastly, the study sought out to discover Midwest, end of life social workers' current awareness of PAS legislation in their state and if they are attending events to educate or advocate for their position. The results suggest that while 74% are aware that PAS is illegal, only 5% had accurate awareness of current PAS legislation that bills were introduced in Minnesota, Iowa, and

Wisconsin in 2015. This is consistent with previous research that suggests that a majority of social workers are aware that PAS is illegal in their state (Csikai, 1999), but that over half are unaware of specific state legislation (Manetta & Wells, 2001). The results of this study also suggest that a majority of social workers (77%) have not attended events to educate or advocate for their position on PAS, which is also consistent in a study done with social workers from the south (Erblaum-Zur, 2005). Qualitative responses add context to these findings. One participant expressed,

> *"I realize that there are a lot of things I don't know about this topic. I feel like there may have been a bill introduced in Minnesota, but I am not sure. Working in this line of work, I realize that I need to be aware of what is going on in my state and neighboring states so I am not caught off guard when speaking with families."*

There were numerous other responses that alluded to their lack of awareness and education on the topic.

Implications

There are numerous implications for practice to take away from this study. The first is the vital importance for social workers to have self-awareness regarding their attitudes, values, and beliefs both personally and professionally towards PAS. If PAS becomes a legal option in the Midwest, there will be an array of different beliefs on the issue. In order to meet the hospice goal of providing a good death it is imperative to respect and honor patient autonomy and family preferences while still respecting the different values and beliefs of the interdisciplinary team (Smith, 2000). This can be a challenge when medical providers have the professional values of non-maleficence and beneficence while social workers value relationships, empowerment, and self-determination. Although there is an overlap in the values of justice and autonomy, these values maybe applied differently by each profession and individual. Despite this professional

predicament, end of life social workers in Oregon where PAS is a legal option have recognized that team work is essential in successful delivery of services that allows patients to die how they choose (Miller, 2006).

A second implication is for end of life social workers to understand their role in policy making and the need for their involvement. The results of this study suggest that a majority of Midwest, end of life social workers are not aware of PAS legislation in their state and are not going to events to gain this education or be a professional advocate for their patients. Research suggests that social workers do not identify macro-level work as one of their primary professional roles (Weisenfluh & Csikai, 2013) (Reese, 2011). Furthermore, the NASW (2010) does not list it as a primary job function of end of life social workers, but they do identify the large need and importance of being an advocate for end of life issues and providing education to those who do not possess their experience, knowledge, and insight.

Macro level work should be happening whether a social worker supports or opposes PAS. Numerous qualitative responses from this study alluded to the need to provide more access and education to the general public on hospice and palliative care options and how well these specialties have been shown to handle troublesome end of life issues while providing a good death for patients and their loved ones. Previous research suggests that social workers believe that the United States healthcare system offers inadequate palliative care (Erblaum-Zur, 2005). Therefore, social workers need to go out and provide education on hospice and palliative care services and advocate for the need for improved accessibility and utilization to the general population and legislation.

In a personal conversation with Senator Eaton, the author of Minnesota's Compassionate Care Act, she identified that she would also like assistance from professionals in palliative and hospice care on how to increase utilization of these services. She spoke passionately about her

desire to see the need for PAS as an option decrease because individuals are getting pain and symptom management along with the support necessary to have a peaceful death. Other professionals have voiced similar views. In the fall of 2015, the Minnesota Hospice and Palliative Care Organization hosted a convention on ethical issues for end of life professionals. PAS was the last issue to be discussed, and one of the presenters was a medical doctor with decades of experience who voiced that advocacy organizations have asked him to support PAS legislation. He responded that he would only become a part of the movement if equal attention were paid towards pushing the palliative care and hospice movement forward as well. Therefore, whether a social worker supports PAS or believes that palliative and hospice services provide the means to a good death without PAS, they need to share their experiences, knowledge, and social work lens to others in order to make large systemic change for their patients.

Lastly, there are implications for future research. There have been a limited amount of studies conducted that seeks to understand social workers and PAS. This study provided new information to research by studying Midwest, end of life social workers, preferred terminology, and their perceived preparedness for the implementation of PAS into their practice and what factors have been influential. This study does not address how to prepare end of life social workers if PAS were to become a legal option in their state. Future research should look at social workers from Oregon, Washington, and other states where it is legal to understand what was helpful in preparing them for PAS as a patient option.

Strengths and limitations

There are strengths and limitations to this study. The first limitation is the sample size. There were findings within the study that could have been statistically significant if the sample size would have been larger along with greater generalizability. Ironically, two factors of this study are both a strength and a limitation. The first is choosing a quantitative design. Without

utilizing interviews, the responses are limited due to the lack of contextualizing questions. On the contrary, using a survey allowed a complex issue to be simplified using straightforward questions while also enabling a larger sample size, which was important for this study. The other factor is in the recruitment process. Accessing the sample through national and state wide organizations allows for a range of social workers from different communities, agencies, and hospitals. Their membership to such organizations also speaks to their identification and commitment to end of life work. Utilizing these organizations also limits the study to only participants within the organizations or those connected through them since they were granted permission to snowball the survey. This could threaten the validity of the study and limit the results.

Conclusion

This quantitative study sought out to understand Midwest, end of life social workers and PAS. The results suggest that half of the participants support PAS legislation and feel prepared for the implementation of PAS, yet less than 5% had accurate awareness of current PAS legislation in their state and few had attended an event to educate or advocate for their position. This circles back to the NASW's (2008) value of competency. Despite ones attitude, it is essential that end of life social workers seek out and receive education and training on PAS, get involved on a macro level, and begin to have these conversations amongst professionals and the general public. So if or when PAS becomes legal in the Midwest, end of life social workers are prepared personally and professionally to provide best patient care.

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Appendix A

Consent Form

You are invited to participate in this project because you are a hospice or palliative care social worker. This project is being conducted by N. Rose Gaston, a student in the Masters of Social Work program at St. Catherine University. The purpose of this survey is to gain an understanding of Midwest, end of life social workers attitude towards physician assisted suicide laws, their knowledge and involvement of the laws in their state, and how these factors (along with other demographics and education) influence their perception of preparedness to implement physician assisted suicide into their practice. The survey will take approximately five minutes to complete.

Your responses to this survey will be anonymous and results will be presented in a way that no one will be identifiable. Confidentiality will be maintained to the degree permitted by the technology used. Specifically, no guarantees can be made regarding the interception of data sent via the Internet by any third parties.

Your decision whether or not to participate will not affect your relationships with the researchers, your instructors, or St. Catherine University. If you decided to stop at any time you may do so. You may also skip any item that you do not want to answer. If you have any questions about this project, please contact N. Rose Gaston at gast0007@stthomas.edu. By responding to items on this survey you are giving us your consent to allow us to use your responses for research and educational purposes.

Appendix B

Survey

Physician assisted suicide in this survey is defined by what is practiced in Oregon and other states where it is explicitly legal.

Patient:

- Diagnosed with a terminally illness with a 6 month prognosis by the primary physician and confirmed by a consulting physician
- Resident in the state where the law resides
- Deemed competent by primary physician and/or psychologists or psychiatrist

Primary Physician:

- Must communicate all other options to the patient
- Recommend they inform their family of their decision
- Give guidance on self administration

Timeline

- Patient makes an oral request to primary physician
- Wait 15 days
- Make a second oral request
- Submit a written request (signed by two witness with one not being a relative, beneficiary, or employed by medical facility in charge of their care)
- Wait 48 hours
- Access prescription from the pharmacy

1. Gender?

- Male

- Female

2. How old are you?

3. In what state do you practice social work?

- Minnesota

- Iowa

- Wisconsin

4. What type of community does your social work practice reside?

- Large Urban

- City

- Suburb

- Town

- Rural

5. What type of social work do you practice (select all that apply)?

- Pediatric Palliative Care

- Adult Palliative Care

- Pediatric Hospice

- Adult Hospice

6. How many years have you practiced social work in hospice and/or palliative care?

7. What is you highest level of social work education?

- BSW

- MSW

- DSW

8. Please select all courses (not topics within a course) you completed during you undergraduate, graduate, or doctoral program.

- Policy

- Grief and Loss

- Crises Intervention

- Suicide Prevention and Intervention

- Geriatric Social Work

- Social Work in Health Care

9. How comfortable do you feel having conversations about end of life options with members of your interdisciplinary team?

Likert scale

1 – not at all, 2 – slightly, 3- moderately, 4- very, 5 - extremely

10. What is your attitude toward physician assisted suicide laws?

Likert scale

1- strongly oppose, 2- oppose, 3- neutral or undecided, 4-support, 5-strongly support

11. Do you feel prepared to assist patients who request physician assisted suicide and their families in conversation, decision making, and preparing for end of life?

Likert scale

1 – not at all, 2 – slightly, 3- moderately, 4- very, 5 - extremely

12. What has influenced your level of preparedness? Please select all that apply.

- Professional experience

- Professional values

- Personal experience

- Personal values

- Undergraduate education

- Graduate education

- Doctoral education

- Additional training

- Peer reviewed research

- Agency

- Supervisor

- Staff

- Other (fill in the blank)

13. What is your immediate awareness of the current legal status on physician assisted suicide in your state?

- Illegal

- Illegal, but a bill was introduced in 2015

- Illegal, but a bill was purposed in 2015 and rejected

- Legal by court order

- Legal

- I do not know

14. How many events have you attended to inform and/or advocate for your attitude toward physician assisted suicide?

15. What term do you prefer?

- Physician assisted suicide

- Physician assisted death

- Aid in dying

- Voluntary active euthanasia

- Death with dignity

16. Please share any thoughts and/or feelings this questionnaire may have evoked for you (in one to two paragraphs).