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ABSTRACT

This study was conducted with the hope of better understanding the factors that shape social workers' opinions about physician-assisted suicide (PAS). A survey was designed, based on past research, to explore the opinions of social workers regarding PAS depending on the social worker's age, gender, religion, years in the field, state in which they practice, and professional experience with those at the end of life. This study was conducted through an online quantitative survey developed by the authors using mostly questions from a variety of past studies. Fifty-five practicing social workers or social work students over the age of 18 responded.

An analysis of the results indicated that social workers support the use of PAS in the majority of instances. However, support for PAS was significantly less in situations where their involvement would not be legal. Additionally, social workers agreed that education on PAS in social work school is limited. In regards to the role of demographic factors, social workers with more experience in the field and older social workers reported being more comfortable working with patients at the end of life. However, religion was not related to opinions. A factor analysis showed that the survey contained four major factors: rights, religion, law, and personal feelings.

Due to a small sample size, we were unable to analyze the role of gender and state in which one practices. Implications for social work education, policy, and legislation are discussed. Furthermore, study limitations are explored, and recommendations are made for further research.

**SOCIAL WORKERS' ATTITUDES ABOUT
PHYSICIAN-ASSISTED SUICIDE**

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work

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CHAPTER I

Introduction

In the United States, end-of-life choices are of profound importance for many elderly and terminally ill people. One controversial option, physician-assisted suicide (PAS), was legalized in 1997 in Oregon, with the passage of the Oregon Death with Dignity Act (ODDA) (Miller, Harvath, Ganzini, Goy, Delorit, and Jackson, 2004). Cohen, Finn, Boyko, Johnsen, and Wood (1994) define physician-assisted suicide as the, “prescription of medication [e.g., narcotics or barbiturates] or the counseling of an ill patient so he or she may use an overdose to end his or her own life” (p. 90). With the passage of the Oregon act, those who work with patients at the end of life, such as physicians, nurses, psychologists, psychiatrists, and social workers, were also significantly affected. As Miller et al. (2004) highlight, in Oregon hospices, employees were unsure of what their involvement would look like with patients who decided to choose PAS. Since the passage of the ODDA, Vermont and Washington have also legalized PAS through legislation, while Montana has legalized PAS through court order (ProCon.org, 2013). In January of 2014, a court in New Mexico authorized PAS as well, bringing the total number of states to five (Eckhold, 2014). However, a number of states have considered, and continue to debate, legislation related to PAS (Eckhold, 2014). Ultimately, PAS is increasingly in public and professional awareness even if it is not currently legal in many states.

In the future, professionals are considerably more likely to be involved with people considering PAS at the end of their lives. Anticipating the complexity of the issues, a body of

scientific literature explores professionals' opinions on the ethical dilemmas that their potential involvement in PAS may present. In particular, social workers are often involved in providing support to patients and family members during the end-of-life process, and as a result, are an important subset to examine when considering the legalization and implications of PAS. At the same time, the profession of social work emphasizes the importance of preventing suicide, an ethical constraint that could problematize support for PAS among social workers. The governing body of ethics for social workers, The National Association of Social Work (NASW), publishes a Code of Ethics that all social workers are expected to adhere to. In addition, social workers are required to abide by local legislation.

As a result, the PAS issue can place in conflict social workers' concern for the individual, values of autonomy and the prevention of suicide, state laws, and professional ethical standards, and thus requires further exploration. Additionally, research has a role to play in educating legislators and those who work and teach in the field of social work. With the goal of addressing this need for a better understanding of social workers and PAS, we designed a survey to explore the opinions of social workers regarding PAS as they relate to age, gender, religion, years in the field, state in which one practices, and professional experience with those at the end of life. The hope is that this research will help illuminate the opinions of social workers in regards to PAS, with the goal of highlighting areas of need in social work education, policy, research, and legislation.

CHAPTER II

Literature Review

This literature review is made up of nine sections, with the intent of exploring past research on PAS and the growing debate over legalization. It starts by exploring literature on the opinions of the general population, physicians, patients, and caregivers in regards to PAS. It then transitions to analyzing the relationship of hospice and palliative care to PAS, in addition to the role of mental health and mental health assessors. The review then explores the bioethical concerns that shape opinions in the PAS debate, before ending with the role of social workers through social work policy and previous research on social worker opinion. Lastly, the literature review concludes by exploring the limitations of current research on social workers, and the importance of this study.

Popular Opinion

Since the passage of the ODDA in Oregon, discussions and debates on the further legalization of PAS have been playing out in numerous states throughout the United States. As a result, research has been done to explore popular opinion in the US. Allen, Chavez, DeSimone, Howard, Johnson, LaPierre, Montero, and Sanders (2006) compared polls on popular opinion, and found that the number of Americans who supported the legalization of PAS grew from 1947 to 1999, jumping from 37% to 61%. However, they note that, even among the higher support for PAS in 1999, a small minority reported a personal interest in PAS (Allen et al., 2006). Domino (2003) also found that the majority of his survey participants in states throughout the US

supported PAS. While not uniform, the public's attitudes toward PAS are increasingly supportive.

A number of demographic factors have also been found to shape opinions on PAS, religion being an important one. Among the general population, Burdette, Hill, and Moulton (2005) found that:

...conservative Protestants are more opposed to physician-assisted suicide than nonaffiliates. Moderate Protestants and Catholics also express greater opposition to physician-assisted suicide than nonaffiliates; however, it appears that these relationships are explained by other religious factors, namely, church attendance and/or strength of affiliation (p. 90).

Religion also appears to affect specific subsets of the general population. Parks, Zelman, and Wanlass (2010) found that among socially marginalized men (residents of a "substance-abuse recovery program"), those that "reported a higher level of religiosity" were more opposed to PAS (p. 121). Similarly, while Espino, Macias, Wood, Becho, Talamantes, Finley, Hernandez, and Martinez (2010) did not find religiosity to be correlated with Mexican Americans' views on PAS, they did conclude that, similar to previous findings, religion is inversely related to opinions about PAS for non-Hispanic whites.

Minority status within the United States is another contributing factor to opinions on PAS, although more research is needed to further illuminate its role. In regards to ethnic minorities, Butt, Overholser, and Danielson (2005) conclude that European Americans have more positive attitudes towards PAS, when compared to Asian Americans, African Americans, Latin Americans, and others. Burdette et al. (2005) conclude that blacks are less supportive of PAS than whites. However, they note this is "entirely mediated through church attendance" (Burdette et al., 2005, p. 90). Gill and Voss (2005) found that among people with disabilities, African Americans and Latinos were "the least likely" to support PAS (p. 6). However, Espino et

al. (2010) found that older Mexican Americans were more supportive of PAS than their white equivalents.

As it relates to social minorities, Parks et al. (2010) looked at the opinions of socially marginalized men. When they compared their results to a comparable study conducted with the general population, Parks et al. (2010) concluded that the “overall attitudes towards PAS were considerably more negative,” although they acknowledged that this could be in part due to the fact that their participants consisted of proportionately more African Americans, in addition to a much more limited socioeconomic range (p.111-121). Gender has also been found by some to play a role in opinions on PAS. Espino et al. (2010) found that among older Mexican-Americans, males were more likely to be in support of PAS. Gill et al. (2005) found women to be the least supportive of PAS among a group of disabled people. Butt et al. (2003) found no evidence that gender shaped opinions on PAS among college students.

Lastly, the effects of hopelessness, education, social class, and age on PAS have also been explored. Butt et al. (2003) conclude that a “greater reported hopelessness” correlated with more support for PAS. Level of education has also been found to correlate with PAS opinions. Parks et al. (2010) conclude that more formal education relates to an increased support of PAS among socially marginalized men. Domino (2003) also the role of education, and included social class, finding that “better educated, upper class individuals were more favorable [towards PAS] than semi-skilled and unskilled poorly educated lower social class individuals” (p. 199). Additionally, age has also been found to shape opinions on PAS. Butt et al. (2003) found that among undergraduate students, a younger age is correlated with more support for PAS (although the age range among undergraduates tends to be limited). Domino duplicated this finding in his 2003 general population study. Although results do not appear to be fully conclusive, the

research above indicates that among the general population people who identify as religious or as ethnic or social minorities, are more likely to be opposed to PAS. Similarly, those with a more formal education, in addition to those who are younger, are more likely to support PAS. Lastly, research on the role of gender is considerably mixed, although two studies discussed above demonstrated that men were more in favor of PAS. It appears probable that a number of these factors will also contribute to shaping the opinions of those more directly involved in the PAS process, such as professionals and patients.

Role and Opinions of Physicians

In addition to the research on popular opinion, considerable attention has been paid to physicians. Physicians play an integral role as gatekeeper in the process of PAS, as it is their job to write the lethal prescription. As a result, there has been considerable exploration into physicians' opinions on PAS. Cohen et al. (1994) found that physicians in Washington state were divided in their views on PAS, with 50% agreeing that PAS is ethically justified and 39% believing that it is never justified. Craig, Cronin, Eward, Metz, Murray, Rose, and Suess (2007) found similar results in Vermont, noting that 38.2% of physicians agree with legalizing PAS, while 16% believe it should be illegal. They also note that 26% of physicians agreed that legislation is unnecessary. Curlin, Nwodin, Vance, Chin, and Lantos (2008) however found considerably more oppositional opinions when they surveyed physicians throughout the United States, finding that 69% of physicians object to PAS. In the United Kingdom, where PAS is currently illegal, Dickinson, Lancaster, Clark, Ahmedzai, and Noble (2002) explored the opinions of physicians who work specifically in geriatric medicine and intensive care, finding the intensive-care physicians to be more supportive of PAS than their peers in geriatric medicine (Bingham and Kirkup, 2014). Additionally, they note the intensive care doctors expressed a

greater willingness to be involved in PAS, although only a minority (Dickinson et al., 2002). It is evident that the research thus far demonstrates mixed reports of PAS support for physicians.

However, some patterns may be emerging regarding physicians' attitudes towards PAS. Cohen et al. (1994) observed that those physicians with more exposure to terminally ill patients (hematologists and oncologists) were the greatest opponents of PAS (p 93). Craig et al. (2007) and Curlin et al. (1994) duplicated this finding. Dickinson et al. (2002), however, found that physicians who work in geriatric medicine are more opposed than those who work in intensive care. Despite the high level of opposition towards PAS from physicians who work with those close to death, Craig et al. (2007) note that physicians working with patients who had requested PAS were more supportive of legalization than those who had not worked with patients who requested PAS.

A number of demographic variables appear related to PAS attitudes among physicians, many of which are similar to results found for the general population. Using the data collected by Cohen et al. (1994), Hart, Norris, and Lishner (2003) compared opinions of male physicians in a rural practice to female physicians in an urban practice, finding that the rural males were significantly more opposed to PAS than the urban females. However, Craig et al. (2007) found that more male physicians supported legalization than female physicians among physicians within the state of Vermont. Craig et al. (2007) also observed an age difference, noting that retired physicians were more likely to favor PAS legislation. This finding appears to be in opposition to conclusions drawn from the general population that demonstrates increased support among younger people. Similar to the general population, the role of religion was also discovered to be important. Curlin et al. (2008) observed that those "who agree that their religious beliefs influence their practice of medicine" were also more likely to object to PAS

when compared with those who have “low intrinsic religiosity” (p. 115). Similarly, Curry, Schwartz, Gruman, and Blank (2000) also note in their qualitative data analysis that “Declarations by those opposed to PAS based on moral and religious conviction were among the most rhetorically and affectively impassioned” (p. 358). Similarly, religion has also been found to influence nurses’ opinions about PAS. Gielen, Branden, and Broeckaert (2009) conclude that “Attributing more importance to religion...seems to make agreement with...physician assisted suicide less likely” (p. 315).

Curlin et al. (2008) also observed ethnic differences similar to some of those found in the general population, noting that physicians who identified as minorities objected more often than whites. Overall, past research suggests that there are a number of factors that contribute to physicians’ opinions on PAS, among them sex, age, specialty, location, religious beliefs, and experience. Generally, among physicians, there appears to be a decrease in support for PAS among those who are religious, who identify as racial minorities, or who have more experience working with patients with terminal illnesses (hematologists and oncologists). However, physicians who have worked with patients who have requested PAS are found to be more supportive, in addition to those who are retired. The results on gender appear mixed. Given some of the overlap with results from the general population, it is likely that these factors also contribute to shaping the opinions of other professionals, such as social workers, who work closely with the terminally ill.

Patient and Caregiver Opinions

Terminally ill patients, their families, and caregivers are the most dramatically affected by the PAS debate. Emanuel, Fairclough, and Emanuel (2000) surveyed terminally ill patients throughout the United States, finding that in a fictional situation 60.2 % supported PAS, but only

10.6% earnestly considered it for themselves. Among caregivers in Oregon, Ganzini, Beer, and Brouns (2006) found that 50% of family members would support their loved one's request for PAS, while 30% would dispute it: 19% of family members did not have an opinion. However, while caregivers were fairly accurate in predicting their mentally-competent loved one's views on the legalization of PAS, they were "inaccurate in predicting their loved ones' personal interest in obtaining a lethal prescription at the time of the survey, and they did not agree on whether they had actually discussed the patients' individual preferences for PAS" (Ganzini et al., 2006, p. 234).

One again religion plays a prominent role in shaping opinions of the terminally ill, their family members, and caregivers. Ganzini et al. (2006) found that among caregivers of the terminally ill, family members who supported PAS were most often less religious. It is apparent from this research that there is a disconnect between opinions on PAS hypothetically versus personally, and that terminally ill patients and their loved ones are conflicted regarding the possible personal application of PAS, especially for those in states in which it is legal.

Hospice and Palliative Care

Hospice and palliative care play a large role in end of life for many terminally ill patients and their caregivers. As a result, hospice and palliative caregiver's relationship to PAS is tense. Miller, Mesler, and Eggman (2002) gathered social workers' voices on their experiences with PAS in Oregon. They found that social workers highlighted the relationship between hospice, palliative care, and PAS as both important and conflicting, stating that "The option of a lethal prescription may be the biggest disagreement in hospice care since the passage of the Medicare Hospice Benefit in 1982 when programs disagreed on how to pursue reimbursement for care" (Miller et al., 2002, p.55). Curry et al. (2000) found that physicians also recognized the conflict

between palliative care and PAS, many claiming that assertive and effectively managed palliative care should negate the need for PAS, in addition to stating that many physicians are undereducated in pain management, a deficiency that must be remedied. Dickinson et al. (2002) found that physicians in the United Kingdom agreed with the understanding that quality palliative care would make PAS unnecessary.

Berzoff (2008) states that “12-15% of deaths” occur in hospice, a statistic that she argues indicates that end-of-life care is lacking (p. 178). Berzoff (2008) elaborates on The Support Study conducted in 2002, explaining, “A study of cancer patients in ICUs found that 75% had pain, discomfort, anxiety, sleep disturbances, and unsatisfied hunger or thirst. Emotional and spiritual care for families and patients that respects cultures and traditions are essential parts of the dying experience, but are not generally available” (p. 178). From Berzoff’s research, it seems clear that the concerns about insufficient hospice care and pain management are warranted. King and Wolf (1998) elaborate on this, explaining, “This conversation should be about the changes and modifications that are required in the training of health care providers and the delivery of health care services before we can be confident that all patients will have the opportunity to die with dignity” (p. 12). For King and Wolf (1998) the desire is that the discussion about legalizing PAS be tabled until the discrepancies in end-of-life care are remedied.

Social workers elaborated on the conflict between PAS and hospice, stating that one of hospice’s main tenants is the importance of patient-directed care. Many expressed the belief that this gave the patient the right to express an interest in PAS (Miller et al., 2002). However, in conflict with that, hospice also promotes a belief that one should not “hasten or postpone death,” a tenant which is clearly contrary to PAS (Miller et al., 2002, p. 56). Lastly, many hospice agencies that aren’t supportive of PAS fear turning their patients away from receiving services

(Miller et al., 2002). It is apparent that hospices, and the social workers they employ, especially in Oregon, where PAS is legal, are struggling with the importance of both meeting their patient's wishes, and balancing the conflicted nature of PAS and hospice care. Additionally, it is evident that an understanding of social workers' opinions is needed to better address the many conflicts around end-of-life care.

The Role of Psychologists and Psychiatrists and Concerns about Depression

Psychologists and psychiatrists also play an important role in the PAS process, particularly due to the fact that there is considerable debate regarding the reasons motivating a patient to request PAS, but a lack of clarity about how to assess motives. The patients' mental health, particularly their level of depression, is a large concern, given that depression can drive even those who are not terminally ill to suicide. Regarding requests for PAS, Hudson, Kristjanson, Ashby, Schofield, Hudson, Arand, O'Connor, and Street (2006) found depression to be among the top reasons why a person requests PAS. They state, "The most common factors associated with a desire for hastened death appear to be: burden to others, loss of autonomy (and an associated desire to control the circumstances of death), physical symptoms (such as pain), depression and hopelessness, and existential concerns and fear of the future" (Hudson et al., 2006, p. 694). When it comes to implementation, Finlay and George (2011) summarize Ganzini's (2008) finding that "Oregon's Death with Dignity Act may not adequately protect all mentally ill patients" (p. 173). However, Levene and Parker (2011) complicate how the presence of depression should be interpreted, explaining, "Whether it is acceptable to have any level of depression in deaths from euthanasia/PAS is debated because depression does not necessarily make patients incompetent and there is little evidence on whether treatment...will change end-of-life decisions" (p. 210). There are serious concerns about the role mental health issues,

especially depression, play in end-of-life decisions. Ultimately, those with mental health issues are inherently vulnerable when PAS is legalized; however, there is conflict over how vulnerable they really are.

Curry et al. (2000) highlight concerns regarding the role of depression among physicians, many explaining that the role of assessment and treatment is crucial regarding screening for depression. Block and Billings (1995) reach a similar conclusion, stating, “The patient's request for hastened death may be a cry for help in feeling valued, a plea for someone to share in the grief, or a protest against unbearable suffering” (p. 448). Similarly, physicians were unclear about the role of psychiatry in PAS, understanding that a mental health evaluation is important, but unsure of how to best implement it (Curry et al., 2000). Block and Billings (1995), however, state a clear vision for psychiatry, explaining,

Because of the high prevalence of depression in the terminally ill (and especially in terminally ill patients who desire euthanasia or assisted suicide), its treatability, and the difficulty of diagnosis, the psychiatrist should be involved in evaluating all patients who request hastened death. The psychiatrist's role extends through assessment and treatment to a point where either the patient's symptoms have improved or sufficient approaches have been tried to suggest that the depression is not ameliorable (p. 448).

Meanwhile, Sears and Stanton (2001) also envision well-defined roles for psychologists: “Health psychologists can assume four central and compatible roles in PAD: (a) as policy advocates, (b) as educators, (c) as practitioners, and (d) as researchers” (p. 305). Sears and Stanton (2001) suggest that psychologists involve themselves in the development of legislation relating to end of life, educate themselves and others on end-of-life issues, provide informed care to those at the end of life, and support physicians in providing proper end-of-life care.

Despite there being some disagreement about the role of psychiatry and psychology in end-of-life care, Cohen et al. (1994) found psychiatrists to be more in support of PAS than other physicians. DiPasquale and Gluck (2001) also found that the majority of the psychologists and

psychiatrists they surveyed supported PAS. Additionally, they found that a considerable amount of the majority were willing to be involved in PAS, some even if it were illegal (DiPasquale & Gluck, 2001). However, similar to Curry et al.'s findings, DiPasquale and Gluck (2001) express uncertainty regarding the role of psychiatrists and psychologists, particularly the effectiveness of the screening process for those requesting PAS. They explain, "We must make ourselves aware of the potential to be influenced by our personal beliefs and the risk that they might unknowingly or inappropriately affect our assessment results (DiPasquale & Gluck, 2001, p. 505). Ultimately, DiPasquale and Gluck (2001) worry that a mental health worker's personal opinions on PAS could get in the way of an effective assessment for a patient requesting PAS. However, this could be the case for any mental health assessment, as personal beliefs can affect the effectiveness of any evaluation done by a mental health professional.

Sears and Stanton (2001) also highlight the possibility of error in the assessment stage, particularly as it pertains to depression, explaining, "Another concern about PAD [Physician Assisted Dying] is that uncertainty and error may exist in disease diagnosis and prognosis, and in assessment and treatment of conditions such as depression" (p. 304). Levene and Parker (2011) identify another concern regarding the challenges of determining if a patient's mental illness is "motivating" their desire for PAS (p. 210). It is apparent that the process of assessing for a mental illness when determining one's right to PAS is extremely complex and multi-faceted. As a result, the process can easily be complicated by the subjective nature of assessment and the challenges of identifying motivation. In addition, Block and Billings (1995) also express reservations, particularly due to the under-education of mental health workers. They explain, "Further education of patients, physicians, nurses, and social workers practicing in terminal care

settings is needed to counter prevailing beliefs about the normality of depression among patients with terminal illness and its consequent undertreatment” (p. 449).

King, Kim, and Conwell (2000) suggest another need when assessing prospective patients eligible for PAS, a social systems perspective. They advocate that two changes be made to assessments:

First, physicians and mental health professionals who are asked to participate in PAS and PAS evaluations should assess the family system whenever possible and practical. Ideally, family evaluation should include systematic evaluation of both individual and family life cycle processes ...Such a multifaceted assessment is most helpful in identifying instances of abuse or coercion and determining when the family is in need of more extensive intervention to support them through this difficult life cycle transition (King et al., 2000, p. 447-448).

Ultimately, King et al. (2000) focus on the role of the family in the PAS decision, particularly when it comes to elders. Family involvement can be extremely complex, especially if the family disagrees with a patient’s decision. It is apparent that there is considerable apprehension regarding the implementation of PAS due to concerns about mental health and the lack of an effective and valid assessment tool, in addition to the complexity of defining the role of mental health assessor with respect to the relationships between the patient and the family.

Bioethical Concerns

In addition to concern about mental health assessment, there are also considerable bioethical concerns pertaining to the unequal administration of PAS across different types of patients, as well as concerns about self-determination and defining the value of life. Regarding unequal administration, a physician explains, “In our secular, consumerist society, if PAS is made legal, the powerful may use it to promote the genocide of the unwanted or powerless in our society” (Curry et al., 2000, p. 349). Wolf (1996) elaborates on this thought, stating, “Yet the debate over whether to legitimate physician-assisted suicide...is most often about a patient who does not exist—a patient with no gender, race, or insurance status” (p. 282). Wolf’s (1996)

argument can easily be extended to cover other minorities, such as race, gender, sexual identity, and socioeconomic status.

Wolf (1996) chooses to focus on the concerns of women, expressing alarm regarding women's relationship to suicide, in addition to the role of a physician's sexism. Wolf (1996) also talks about gender roles and their effect on a woman's request for PAS, explaining, "...women are expected to adopt self-sacrificing behavior for the sake of the family" (p. 291). Wolf (1996) expresses concern that this could result in women requesting PAS, not because they truly feel it is best for them, but to avoid being a burden to others. Wolf (1996) also expresses concerns about the role of the physician: "When the patient is female and the doctor male, as is true in most medical encounters, the problem is likely to be exacerbated by the background realities and history of male dominance and female subjugation in the broader society" (p. 293). Wolf (1996) fears that this could lead to a physician's increased willingness to help a woman when she requests PAS. Tulloch (2005) comes to a similar conclusion, stating concern about any situation in which "the doctor [is] in the potentially paternalistic position of gatekeeper" (p. 157). Given that the majority of physicians in the United States are white heterosexual males, it can be expected that Wolf's (1996) concern about the history of dominance will also play a role if the patient is a minority of another sort.

For example, King and Wolf (1998) highlight the history of using African Americans as "unconsenting experimental subjects," as observed in the infamous Tuskegee Syphilis Study (p. 7). Ultimately, Wolf (1996) concludes, "[PAS] will inevitably reflect enormous background inequalities and persisting social biases" (p. 307). However, some disagree with this assumption, and even find it demeaning. As one participant with a physical disability stated when asked about perceived vulnerability,

I think it's an insult to the intelligence of the vast majority of people who find themselves in terrible situations and seriously consider PAD [Physician assisted death]. . . . If I was vulnerable to coercion/pressure I would accept that a cure for SCI [spinal cord injury] is not possible and that I will spend the rest of my life in a wheelchair. Clearly I can think for myself and reject these ideas (Hwang, 2005, p. 19).

It is apparent that defining vulnerability in regards to PAS is extremely complex, and potentially demeaning to those identified as “vulnerable.”

In another example of the complexity of outlining vulnerability, Finlay and George (2011) question the racial, socioeconomic, and gendered categories that Battin, van der Heide, and Ganzini (2007) define as vulnerable when reviewing data on the use of PAS and voluntary euthanasia in Oregon and the Netherlands. Battin et al. (2007) reach similar conclusions to Chin et al. (1999), Ganzini et al. (2000), and Sullivan et al. (2000) who conclude from limited research in Oregon that “[PAS] is not elected disproportionately by potentially disadvantaged groups. Additionally, concerns about quality of life and individual autonomy rather than adequate pain control or family or financial burden appear to be primary motivations for patients requesting [PAS]” (as cited by Sears and Stanton, 2001, p. 309). However, Finlay and George (2011) disagree with this conclusion. They state,

Socioeconomic categories are not necessarily a proxy for vulnerability to accessing PAS. The Oregon data demonstrate a greater resort to PAS among better educated and financially affluent persons, particularly those over 65 years of age. This warrants further enquiry to ascertain whether they have vulnerabilities to influence to accessing PAS, which are not adequately addresses (sic) in their healthcare system. More recent research calls into question the conclusion that persons with depression are not being put at risk of PAS (Finlay & George, 2011, p.173).

While the authors (Battin, van der Heide, and Ganzini, 2007) who reviewed the original data conclude that socioeconomically vulnerable people are not at an increased risk from PAS, Finlay and George (2011) “question the validity of this conclusion” due to their differing viewpoint on who is vulnerable (p. 171). For Finlay and George (2011), there is concern that older, wealthier,

and more traditionally educated people are the most vulnerable when it comes to choosing PAS. While they do not speculate on what could cause this vulnerability, it is possible that cultural, political, or familial beliefs could lead to increased utilization of PAS. Ultimately, it is not at all clear from the research which populations the most vulnerable in regards to PAS, especially due to the fact that most investigations thus far are limited to Oregon and, as a result, challenging to generalize to a diverse United States were PAS to become more widespread.

In addition to concerns about vulnerability, there is also an increasing tension between self-determination and risk to oneself. This struggle is apparent in the examination of social work policy that follows. The complexity of defining self-determination and risk only adds to the tension, as both definitions are highly subjective given an individual's viewpoint. Additionally, as highlighted previously, identifying risk is a particularly challenging endeavor, as isolating mental health concerns or social vulnerabilities is also subject to intense debate. Complicating this tension further is the debate about preservation of life. It is apparent that the medical model favors the continuity of life, even if quality of life may appear low. However, defining quality of life is another challenge, as it is also intensely personal. As Dees, Vemooij-Dassen, Dekkers, and van Weel (2010) highlight, determining the point at which suffering has eclipsed a sustainable quality of life is complex. As they explain, "The wealth of motivations and the differences among patients, healthcare professionals, and relatives underlines the fact that unbearable suffering is a profoundly personal and subjective experience. (Dees et al., 2010, p. 350). Ultimately, it is apparent that the decision to end one's life is incredibly multifaceted, individual, and divisive. As a result, the debate over the legalization of PAS is highly complex. Thus, health care professionals, such as social workers, working within such complexity require guidance and support.

Social Work Policy

With the goal of addressing the complexities of health care and mental health treatment, among other ethical concerns, social workers are expected to be familiar with, and follow, the ethical guidelines of the NASW. This is reinforced through the social work education and licensure process. The NASW acts as the governing body for the profession of social work. As part of their role, the NASW releases a Code of Ethics that provides an ethical framework that social workers are expected to follow. As it relates to PAS, the NASW Code of Ethics does not have an explicit position. Therefore, social workers' ethical responsibilities to clients are open to personal interpretation in regards to PAS. Patient self-determination is an area that relates indirectly to PAS decisions. The Code states,

Social workers respect and promote the right of clients to self-determination and assist clients in their efforts to identify and clarify their goals. Social workers may limit clients' right to self-determination when, in the social workers' professional judgment, clients' actions or potential actions pose a serious, foreseeable, and imminent risk to themselves or others. (National Association of Social Workers, 2008)

Ultimately, according to the NASW Code of Ethics, it is up to the social worker to determine whether client's actions, such as the request for PAS, should result in the limitation of self-determination.

The NASW does have an additional handbook to support those working with people at the end of life. The NASW Standards for Palliative and End of Life Care outline expectations for social workers working with those at the end of their life. The NASW Standards state that social workers are "expected to be familiar with the common and complex bioethical considerations and legal issues" that occur at end of life (National Association of Social Workers, 2004, p. 16). This includes PAS. However, they conclude that since issues at the end of life are controversial and value driven, "[the] 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). The NASW also has a policy statement related to client self-determination in end-of-life care, which can be found in *Social Work Speaks*, a collection of NASW policy statements. They reiterate here the same statement regarding not taking a position that is included in the NASW Standards for Palliative and End of Life Care.

However, they also expand on the ethical concerns that social workers should address when exploring end-of-life decisions, such as “the legal parameters...the potential conflict of social work values with those of other health care professionals...the emerging pressures for cost control...the possibility of patients [fearing] becoming a burden...the societal limits on individual self-determination... [and] the necessity to define safeguards to protect individuals and society...” (National Association of Social Workers, 2000, p. 43). Lastly, the NASW also explicitly states that “If legally permissible, it is not inappropriate for a social worker to be present during an assisted suicide if the client requests...” (National Association of Social Workers, 2000, p. 44). In saying this, it appears that the NASW views a social workers’ presence at an illegal assisted suicide to be inappropriate. Overall, in their policy statement the NASW outlines the issues social workers should consider regarding end-of-life decisions, while still refraining from taking a position in the debate.

However, Allen et al. (2006) note that this policy statement is problematic, given that:

...although the NASW policy statement, “Client Self-Determination in End-of-Life Decisions,” observes that social workers may counsel terminally ill clients regarding physician-assisted suicide, this policy is in conflict with most state laws that prohibit social workers from advising their clients in this matter. This policy statement does not provide guidance on when social workers should become involved or under what circumstances and for how long they should intervene in cases involving terminal illness. The policy also neglects to mention that providing advice on physician-assisted suicide constitutes an offense as defined in most state laws. (p. 20)

Overall, while NASW policy provides guidance for social workers, it also offers advice that can conflict with local legislation. It is apparent that there is considerable tension between laws and ethics for practicing social workers. This means that social workers must be well informed about their rights and the law when caring for those at the end of life.

While the NASW does not take a position on PAS, the National Hospice and Palliative Care Organization (NHPCO) does. In their *Commentary and Resolution of Physician Assisted Suicide* the NHPCO states that they don't support legalizing PAS (National Hospice and Palliative Care Organization, n.d.). This is due to the fact that the NHPCO does not see PAS as being congruent with their values that "include universal access to high quality palliative care, fully informed decision-making, mitigation of unwanted suffering, non-abandonment and support for the bereaved" (National Hospice and Palliative Care Organization, n.d., p. 3).

In conclusion, it is apparent that social workers face conflicted policy when it comes to working with PAS. Additionally, while the NASW has released a number of statements to guide social workers, there is still a lack of clarity regarding a social worker's role in the struggle of ethical versus legal.

Previous Research on Social Workers

Similar to physicians, nurses, psychologists, and psychiatrists, social workers are also heavily involved in end-of-life care. Just as there are concerns about the under-education of psychologists and psychiatrists regarding end-of-life care, social workers also face a similar hurdle. Berzoff (2008) summarizes the Kramer, Pacourek, Hoveland-Scafe (2003) study which found that "of 19,223 pages of content in social work textbooks...only a little more than 3%...addressed the end of life" (p.178). In addition, limited research has been done on social workers' opinions and experiences regarding PAS. Within the state of Oregon, where PAS was

legalized in 1997, Miller et al. (2004) found that social workers were more supportive of the ODDA and patients who might utilize PAS than nurses. However, 22% of nurses and social workers were still not comfortable talking about PAS with their patients despite the law (Miller et al., 2004). It is clear that in Oregon, where PAS is legal, a substantial minority of direct care staff are placed in an uncomfortable position.

In South Carolina, a different picture emerges. Manetta and Wells (2001) found social workers' support of PAS to be evenly split. And Kane, Hamlin, and Hawkins (2008) found that social workers had "generally positive attitudes" toward PAS for elderly people. While it appears that social workers have a more favorable view toward PAS than physicians, it is still apparent that PAS is a complicated issue and more research is needed.

Limitations

It is apparent from the research to date that the debate on PAS is currently very active, and showing no signs of going away. Similarly, given the number of states that have considered legalizing PAS, it is also clear that further discussion and understanding of PAS is needed. The field of social work is inextricably tied to the medical system in the United States, as social workers provide for patients and family members in a myriad of different ways, from concrete help with essentials, such as scheduling appointments or securing housing, to more abstract support through different therapeutic modalities. As a result, social workers are an important part of the PAS debate, as it is likely that they will be involved in the lives of a considerable number of terminally ill patients through hospices, hospitals, and other agencies.

Additionally, similar to psychologists or psychiatrists, social workers are often expected to assess patients for the presence of mental illness, another complicating factor in the PAS debate. Ultimately, social workers are far from unfamiliar regarding the ethical dilemmas that

come with serving extremely diverse populations. Understanding this, the NASW attempts to provide guidance. However, it is clear from the previous discussion on NASW policy and the considerable PAS related ethical dilemmas that there is not a clear path for social workers regarding PAS. Similarly, as Berzoff (2008) highlights, social work education on end-of-life care is limited. Additionally, research on social work opinions on PAS, in addition to involvement in the PAS process, is very limited. While some research looking at social workers' opinions and experience regarding PAS has been done (as outlined previously), missing from studies of social workers is data sorting out the impact of various demographic variables.

In conclusion, it is apparent that social workers play an important role in the PAS debate. However, research on social workers is limited, especially in comparison to other professionals who work with those at the end of life, such as physicians. Given the increasing spotlight on PAS regarding a push for legalization in a number of states, it is essential that the opinions of social workers be explored further. With an enhanced understanding of social workers' opinions and the demographic variables that shape these opinions, social work education, practice, and policy can be better informed.

CHAPTER III

Methodology

In this study, we examined the opinions of social workers regarding PAS, with the goal of establishing descriptive data and determining how views were influenced by the demographic data that were also collected, in particular, age, gender, religion, years in the field, state in which one practices, and professional experience with those at the end of life.

Procedure

Data for this survey were collected in partial fulfillment of the requirements of Smith College's School for Social Work masters program in 2013, after approval by the Smith College Human Subjects Review Board. Participants were recruited by email through the authors' connections using snowball sampling. For example, the authors sent requests to friends, family, academic peers, and current and former co-workers asking them to fill out the survey in addition to sending it on by email to those they know who meet the requirements (see Appendix A). In the email, participants were directed by URL to a confidential online survey hosted by SurveyMonkey. Study participants were required to consent before participating and were not compensated for answering the survey. Data were exported from SurveyMonkey and analyzed using Statistical Package for the Social Science (SPSS).

Respondents

This study used non-probability snowball sampling in order to reach participants by email. The criteria for the survey was that participants either be practicing social workers (with

an MSW or BSW), or social work students getting their MSW or BSW. One of the goals of the survey was to understand viewpoints about how the social work education deals with PAS, and as a result, it was important that the participants had attended, or were attending, accredited programs that grant social work degrees. This survey was limited to practicing social workers or social work students, rather than retirees, because research suggests that there is a difference in attitudes toward PAS between those practicing and those who have retired. For example, retired physicians had stronger positive opinions toward PAS than those who were still practicing (Craig et al., 2007). While it is impossible to know if this would generalize to social workers, Craig et al., (2007) speculate that “[PAS] may be more personally relevant to older physicians or that this population has had less experience with recent advances in pain control and palliative care” (403). It is possible that the authors’ concerns could also apply to social workers.

Sample

This study utilized a sample of 55 social workers who completed the survey. Sixty-six participants took the survey, but one dropped out during the screening process, two left the consent form blank, and eight did not answer any questions after the consent form. The mean age of the participants was 37.76 years old, with a range from 20 to 75 years old. Female participants made up 89.1% of the participants, while 7.5% identified as male. Participants who identified as other and wrote in gender queer made up 3.6% of the total. The survey’s participants represented 17 states, with 34.5% interning or practicing in Massachusetts. Participants’ graduation year for their MSW or BSW degree ranged from 1965 to 2015. From the sample of social workers, 47.3% stated they were graduating in 2014 with their BSW or MSW. Similarly, participants indicated that they had been practicing social work for 4 months to 48 years. However, 60% of participants stated that they were still in school for their degree. In regards to religion, 16

different religious affiliations were written in, although 20% of participants identified as Jewish, while another 60% stated that they had no religious affiliation. The three questions used to assess religiosity indicated that participants held complex views regarding the role of religion in their own lives. Respondents who disagreed or strongly disagreed with the statement, “My whole approach to life is based on my religion” made up 60% of the total. However, results were more spread out when participants were asked to indicate their agreement with the statement “My religious beliefs influence my practice of social work.” Participants who agreed or strongly agreed made up 32.7% while 45% disagreed or strongly disagreed. In regards to the statement “I try to carry my religious beliefs over into all facets of life” 29.1% of respondents disagreed, and an additional 29.1% neither agreed nor disagreed. Lastly, participants explained that in their work, 54.5% had not cared for any mentally competent terminally ill patients, while among those who had, the responses ranged from 0 to 1200-1500 patients.

Measures

This study necessitated the development of a survey that would encompass the demographic items, in addition to exploring opinions. A quantitative survey was chosen as many researchers had gathered similar results with this method (Cohen et al., 1994; Craig et al., 2007; Curlin et al., 2008; Hart et al., 2003; Miller et al., 2004), making direct comparisons with the existing literature more direct. However, one qualitative question was included, in the form of a comments section at the end of the survey. Participants responded to 16 questions pertaining to opinions on PAS as well as those measuring religiosity, on a 5-point scale from 1= strongly disagree to 5= strongly agree. The phrase “physician-assisted suicide” was not used in the survey, as it has been demonstrated that this phrase is emotionally charged and can be ambiguous (Cohen et al., 1994; Craig et al., 2007). Instead of using the phrase “physician-assisted suicide,”

the definition utilized by Cohen et al. (1994) was adapted. In addition, a definition for “a lethal dose of medication” was used from Miller et al. (2004). Lastly, Merriam-Webster’s (merriam-webster.com, 2013) medical dictionary’s definition of “mentally competent” was used.

A number of previous surveys used to explore opinions on PAS were integrated after receiving permission from the authors to reproduce or adapt their items. Demographic questions on age in years (item 1) and religious affiliation (item 6), in addition to survey questions were taken from Miller et al. (2004). The survey questions used from Miller et al. (2004) were on immorality (item 12), being present at death under differing circumstances (items 16 and 17), discussing with a patient the option of ending their life under differing circumstances (items 18-21), comfort discussing life ending options with a supervisor or supervision group (item 22), belief that social workers should discuss life ending options (item 23), option of PAS if physical suffering is unbearable (item 25), option of PAS if psychological or spiritual suffering is unbearable (item 26), role of prescribing lethal medications in the care of the mentally competent terminally ill (item 27), and role of providing counseling on the use of lethal medications in the care of the mentally competent terminally ill (item 28). In addition, the formatting of defining phrases was taken from Miller et al. (2004). Similarly, survey questions on the legality of writing a lethal prescription (item 13), and comfort working with a patient who had requested PAS in a state in which it were legal versus illegal (item 14-15) were developed from Craig et al. (2007). To assess a person’s religiosity, questions (items 8-10) were drawn from Curlin et al. (2008) who based their questions on Hoge’s Intrinsic Religious Motivation Scale. Curlin et al. (2008) explains that this scale has been used considerably in past research and as a result is valid. In addition, questions were generated by these researchers to explore the role of the NASW and social work education. The survey used for this study can be found in Appendix B.

CHAPTER IV

Findings

Responses to the demographic items, as well as level of agreement/disagreement with the 20 items measuring attitudes toward PAS, and the three items measuring religious beliefs, were used in the analyses. Means and standard deviations for each of the attitude items, plus the three related to one's religious views, can be found in Table 1.

One-sample *t*-tests comparing each attitude item to a value of 3, the midpoint of the scale, showed that the ratings of 19 of the 20 items differed significantly from the midpoint of the scale. These results suggest that our sample of social workers had strong views related to PAS. (The only item that did not differ significantly from the mean was "19. If it were illegal but my agency supported me, I would feel comfortable discussing with my terminally ill and mentally competent patients the option of ending their lives with a lethal dose of prescription medication.") Among the other 19 items, mean ratings for 16 of them indicated that participants were significantly more likely to agree with the item. Participants were significantly more likely to disagree with three items (Those three items were "20. If it were illegal and my agency did not support me, I would feel comfortable discussing with my terminally ill and mentally competent patients the option of ending their lives with a lethal dose of prescription medication;" "24. During my social work education I learned about the prescription of medication [e.g. narcotics or barbiturates] or the counseling of a terminally ill and mentally competent patient so he or she may use an overdose to end his or her own life;" and "27. Prescribing medication (e.g. narcotics

or barbiturates) for terminally ill and mentally competent patients so they may use an overdose to end their lives should not be a part of the care of those who are terminally ill and mentally competent.”) In general, the response pattern for this analysis indicated a great deal of support among social workers for giving patients PAS options. One-sample *t*-test results for each item can also be found in Table 1.

In order to answer the question of whether experience working with terminally ill patients might influence social workers' attitudes about PAS, participants were divided into two groups, those who indicated that they had experience working with terminally ill patients (no matter how much experience) ($N = 18$) and those who indicated that they did not have experience working with terminally ill patients ($N = 37$). Independent-groups *t*-tests for each attitude item showed only two significant differences. There was a significant difference in the response to "11. I am comfortable working with patients at the end of their lives" ($t(52) = 3.893, p. < .001$, two-tailed). Those who had worked with dying people indicated that they were more comfortable working with patients at the end of their lives ($M = 1.47$) than those who had not worked with dying people ($M = 2.51$). There was also a significant difference in the response to "15. If in my state it were not legal to prescribe a lethal dose of medication to a terminally ill and mentally competent adult who requests it, I would be comfortable working with a patient who had requested a lethal dose of medication" ($t(39.97) = 2.270, p. = .029$, two-tailed). Those who had worked with dying people were more comfortable working with patients who had requested a lethal dose of medication in a state in which it is not legal ($M = 2.11$) than those who had not worked with dying people ($M = 2.78$). Given that 20 attitudinal items were compared, these results indicated little or no impact of experience working with terminally ill people on social workers' attitudes about PAS.

In order to measure the impact of religious views on attitudes toward PAS, participants were divided into two groups, those who did indicate a religious affiliation ($N = 19$) and those who did not ($N = 33$) indicate a religious affiliation. Independent-groups t -tests for each item showed no significant differences between the two groups on any of the 20 items regarding attitudes toward PAS, indicating that, at least in our sample, religious affiliation does not impact social workers' views about PAS.

With the purpose of measuring the impact of age on attitudes toward PAS, participants' ages were correlated with each of the items. Three items were found to be significant. There was a significant correlation in the response to "11. I am comfortable working with patients at the end of their lives" ($r(54) = .33, p < .02$). This implies that older people are more comfortable working with patients at the end of their lives than younger people. There was also a significant correlation in the response to "16. If one of my terminally ill and mentally competent patients received a prescription for a lethal dose of medication from a physician, in a state in which it is legal, and asked me to be present at their death, I would do so" ($r(55) = .36, p < .01$). This suggests that younger people are more comfortable being present at a client's death in a state in which PAS is legal. Lastly, a significant difference in response was found for "17. If one of my terminally ill and mentally competent patients received a prescription for a lethal dose of medication from a physician, in a state in which it is illegal, and asked me to be present at their death, I would do so" ($r(54) = .30, p < .03$). This indicates that younger people are more comfortable being present at a client's death in a state in which PAS is illegal. Ultimately, it appears that while older participants are more comfortable working with patients at the end of their lives, younger respondents are more willing to be present at a death through the use of PAS, legal or illegal.

Another possibility is that participants' attitudes about PAS, particularly their participation in it (however tangentially) might be influenced by whether the actions are legal or not. To investigate this possibility, we compared the pairs of questions that asked participants what they would do in cases where the actions were legal or not (regarding working with a patient who had requested a lethal dose of medication (items 14 and 15), being present at the death of a patient who had requested a lethal dose of medication (items 16 and 17), discussing the option of lethal medication with agency support (items 18 and 19), and discussing the option of lethal medication without agency support (items 20 and 21). Dependent-groups *t*-tests showed that each of the comparisons was significant (for items 14 and 15, $t(54) = -5.57, p < .001$; legal $M = 1.75, SD = .73$; illegal $M = 2.56, SD = 1.14$; for items 16 and 17, $t(53) = -7.32, p < .001$; legal $M = 2.19, SD = 1.10$; illegal $M = 3.31, SD = 1.15$; for items 18 and 19, $t(52) = -6.76, p < .001$; legal $M = 2.06, SD = .95$; illegal $M = 3.02, SD = 1.20$; for items 20 and 21, $t(52) = 6.50, p < .001$; legal $M = 3.55, SD = 1.01$; illegal $M = 2.62, SD = 1.06$), indicating that social workers have more favorable attitudes toward PAS when it is legal than when it is illegal.

Responses to the 23 items on the survey that were answered using the five-point agree/disagree scale, including the items measuring attitudes toward PAS and the items measuring attitudes about religion, were factor analyzed. After inspecting the scree plot, a Maximum Likelihood extraction method with Varimax and Kaiser normalization was chosen so as to produce four factors, each with an eigenvalue greater than 1.5, collectively accounting for over 50% of the variance. Items that loaded with a value greater than .40 and less than -.40 were included in each factor. Those values were chosen because correlations greater than .40 and less than -.40, given our sample size, would be significant. In all, 14 items were included in at least one factor and two items were included in more than one factor.

Factor one accounted for 21.79% of the variance and loaded on items 12, 13, 14, 23, 25, 26, 27, and 28. These items deal with the (perhaps abstract) right to PAS as a part of end-of-life care. In short, this factor seems to be measuring how social workers feel about the issue of PAS and its role in end-of-life care. Factor two accounted for 15.70% of the variance and loaded on items 17, 18, 19, 20, and 21. These items deal with the legal dimension of PAS, a factor found in a previous analysis to contribute to social workers' attitudes toward PAS. Factor three accounted for 9.59 percent of the variance and loaded on items 8, 9, and 10. Clearly this factor relates to a religious dimension measured by the survey. Factor four accounted for 7.5% of the variance and loaded on items 16 and 17. These items are more personal in nature, asking participants to imagine themselves being with a patient at the time of death. In summary, our survey produced four factors representing the dimensions of rights, religion, law, and personal feelings.

All of the analyses suggest that there is a great deal of support for giving patients information about and the right to consider PAS as part of end-of-life care. Some cautions emerged from the comments that participants wrote at the end of the survey. In particular, respondents thought it was important that the patient rather than the social worker initiate the conversation about PAS. Several participants commented on the complexity of the issue and on how difficult and challenging it is to work with dying patients. Additionally, one participant mentioned concerns about ineffective pain management, a concern that was highlighted previously in the existing research. Lastly, another participant noted an additional level of complexity for those working in private practice due to liability.

Table 1

Means, Standard Deviations, and One-Sample t-test Results for Survey Items

Survey Item	Mean	Standard Deviation	One-Sample Results		
			<i>t</i> -value	df	<i>p</i> -value
8. I try to carry my religious beliefs into all facets of life.	3.35	1.20	2.16	53	.036
9. My whole approach to life is based on my religion.	3.75	1.27	4.37	54	.001
10. My religious beliefs influence my practice of social work.	3.35	1.34	1.92	54	.061
11. I am comfortable working with patients at the end of their lives.	2.19	1.03	-5.82	53	.001
12. A physician who writes a prescription that could be used in a lethal amount by a terminally ill, mentally competent patient (in a state in which writing such a prescription is legal) is acting immorally and/or unethically.	4.19	.70	12.40	53	.000
13. The writing of a prescription for a lethal dose of medication repeatedly requested by a mentally competent terminally ill adult with less than six months to live should be legal.	1.80	.81	-10.92	53	.001
14. If in my state it were legal to prescribe a lethal dose of medication to a terminally ill, mentally competent patient who requests it, I would be comfortable working with a patient who had requested a lethal dose of medication.	1.75	.73	-12.82	54	.001
15. If in my state it were not legal to prescribe a lethal dose of medication to a terminally ill, mentally competent patient who requests it, I would be comfortable working with a patient who had requested a lethal dose of medication.	2.56	1.14	-2.85	54	.006
16. If one of my terminally ill, mentally competent patients received a prescription for a lethal dose of medication from a physician, in a state in which it is legal, and asked me to be present at their death, I would do so.	2.18	1.09	-5.57	54	.001
17. If one of my terminally ill, mentally competent patients received a prescription for a lethal dose of medication from a physician, in a state in which it is illegal, and asked me to be present at their death, I would do so.	3.31	1.15	2.02	53	.049
18. If it were legal and my agency supported me, I would feel comfortable discussing with my					

terminally ill and mentally competent patients the option of ending their lives with a lethal dose of prescription medication.	2.07	.95	-7.17	53	.001
19. If it were illegal but my agency supported me, I would feel comfortable discussing with my terminally ill and mentally competent patients the option of ending their lives with a lethal dose of prescription medication.	3.02	1.20	.11	52	.909
20. If it were illegal and my agency did not support me, I would feel comfortable discussing with my terminally ill and mentally competent patients the option of ending their lives with a lethal dose of prescription medication.	3.55	1.08	3.67	52	.001
21. If it were legal but my agency did not support me, I would feel comfortable discussing with my terminally ill and mentally competent patients the option of ending their lives with a lethal dose of prescription medication.	2.67	1.10	-2.23	53	.030
22. I am not comfortable discussing a terminally ill and mentally competent patient's interest in ending his or her life using a lethal dose of prescription medication with my clinical supervisor or peer supervisory group.	4.15	.74	11.44	53	.001
23. I think social workers should discuss options for terminally ill and mentally competent patients to end their lives with a lethal dose of prescription medication.	2.35	.99	-4.79	53	.001
24. During my social work education I learned about the prescription of medication [e.g. narcotics or barbiturates] or the counseling of a terminally ill and mentally competent patient so he or she may use an overdose to end his or her own life.	3.94	1.00	6.95	53	.001
25. Terminally ill and mentally competent patients should have the option of ending their lives with a lethal dose of prescription medication if physical suffering becomes unbearable.	1.52	.67	-16.36	53	.001
26. Terminally ill and mentally competent patients should have the option of ending their lives with a lethal dose of prescription medication if psychological or spiritual suffering becomes unbearable.	2.00	.91	-7.95	51	.001
27. Prescribing medication [e.g. narcotics or barbiturates] for terminally ill and mentally					

competent patients so they may use an overdose to end their lives should not be a part of the care of those who are terminally ill and mentally competent.	3.78	.86	6.64	53	.001
28. Counseling terminally ill and mentally competent patients so they may use an overdose to end their lives should not be a part of the social work care of those who are terminally ill and mentally competent.	3.62	1.10	4.14	52	.001
29. I believe that the NASW Code of Ethics requires that I actively discourage my mentally competent and terminally ill patients from pursuing the option of ending their lives with a lethal dose of prescription medication.	3.36	.79	3.32	52	.002
30. In my social work education I was taught to discourage my terminally ill and mentally competent patients from pursuing the option of ending their lives with a lethal dose of prescription medication.	3.67	.82	5.94	53	.001

CHAPTER V

Discussion

The purpose of this study was to explore the opinions of social workers in regards to PAS, specifically as it relates to demographic factors such as age, gender, religion, years in the field, state in which one practices, and professional experiences with those at the end of life. As discussed in the findings section, a number of factors appear to be related to opinions on PAS for social workers. In regards to overall support for PAS, this research showed that social workers demonstrated a considerable amount of support for PAS, as the majority of the participants agreed with all but four questions. Although there has been limited research on social workers' opinions prior to this study, Miller et al. (2004), Manetta and Wells (2001), and Kane et al. (2008) previously found support for PAS among social workers.

In this study, the majority of the participants disagreed with three of the questions. One of these questions, "27. Prescribing medication (e.g., narcotics or barbiturates) for terminally ill and mentally competent patients so they may use an overdose to end their lives should not be a part of the care of those who are terminally ill and mentally competent," shows support for PAS through disagreement. However, three of the other questions demonstrated hesitations among social workers regarding support for PAS. The first, question 19, which stated, "If it were illegal but my agency supported me, I would feel comfortable discussing with my terminally ill and mentally competent patients the option of ending their lives with a lethal dose of prescription medication" did not differ significantly from the mean, demonstrating that social workers felt

conflicted regarding the legality of PAS. This tension between laws and ethics is also visible in the social work policy discussed earlier. The second, question 20, stated, “If it were illegal and my agency did not support me, I would feel comfortable discussing with my terminally ill and mentally competent patients the option of ending their lives with a lethal dose of prescription medication.” The majority of respondents disagreed, demonstrating again the conflict between legality and ethics, with the additional complication of agency policy.

It is apparent that legality plays a role in shaping social workers’ opinions, with respondents showing more support for exploring PAS with a patient when it is also legal. Worth noting as well is that the NASW does support a social worker discussing PAS with a client in states in which it is both legal and illegal (NASW, 2000, p. 43). However, it is apparent that respondents were either not aware of this or still did not feel comfortable with the potential illegality. It is also possible that the wording of the question effected responses. As Allen (2006) notes, “...providing advice on physician-assisted suicide constitutes an offense as defined in most state laws” (p. 20). As discussed previously, it is apparent that legality and ethics are often in conflict. Where the NASW does draw a line however, is on the presence of social worker during a PAS related death. The NASW states, “If legally permissible, it is not inappropriate for a social worker to be present during an assisted suicide if the client requests the social worker’s presence” (NASW, 2000, p. 44). Survey question 17 relates to this policy. It stated, “If one of my terminally ill, mentally competent patients received a prescription for a lethal dose of medication from a physician, in a state in which it is illegal, and asked me to be present at their death, I would do so.” In agreeing with this question, respondents are going against stated NASW policy. In order to assess for NASW policy understanding, participants responded to question 29, “I believe that the NASW Code of Ethics requires that I actively discourage my mentally competent

and terminally ill patients from pursuing the option of ending their lives with a lethal dose of prescription medication.” Participants demonstrated agreement to this question, although it was not strong on an absolute basis, potentially revealing confusion about NASW policy as it relates to PAS. It is apparent that further research is needed to better gauge social workers’ understanding of NASW policy; however, it is clear that this further emphasizes the conflict between social workers’ ethical choices and legality.

This role of legality was explored further, with a comparison done on the pairs of questions which asked a social worker their opinion if PAS was legal or not (14 and 15, 16 and 17, 18 and 19, and 20 and 21). For each pair, there were significant differences in answers, again demonstrating that social workers demonstrate more support for PAS when it is legal. As Allen (2006) notes, NASW policy does not mention the role of state laws when discussing PAS, however, it appears that social workers are considerably more aware of the role of state legislation than NASW policy is.

The last question the majority of respondents disagreed with was question 24, which read, “During my social work education I learned about the prescription of medication [e.g., narcotics or barbiturates] or the counseling of a terminally ill and mentally competent patient so he or she may use an overdose to end his or her own life.” This limited education about PAS in social work school relates to Berzoff’s (2008) concern that end-of-life education is limited. Additionally, Block and Billings (1995) express concerns regarding the under-education of mental health care workers in terminal care venues. Survey question 30 further examined the intersection of PAS and social work education. Question 30 stated, “In my social work education I was taught to discourage my terminally ill and mentally competent patients from pursuing the option of ending their lives with a lethal dose of prescription medication.” Similar to question 29,

respondents indicated a weak agreement, which potentially further hints at continued confusion about policy views on PAS. This potential confusion fits the comments from several respondents which explored the complexity of the issue and the challenges of working with dying patients. Ultimately, it is apparent that further research is needed in this area to better understand the state of current end-of-life care education, in addition to the discussion of PAS in social work educational programs.

When it comes to the role of demographic factors in shaping opinions, a number of factors played a small role in altering PAS opinions among social workers. Social workers who had prior experience working with terminally ill patients answered only two questions differently, demonstrating that they were more comfortable working with patients at the end of their lives (question 11), in addition to being more comfortable working with a patient who requested PAS in a state in which it was not legal (question 15). Given that only two out of 20 attitude questions were answered differently, it appears that prior experience working with the terminally ill has little to no effect on attitudes toward PAS. It is apparent that more research is needed on the role of previous experience working with terminally ill patients in shaping opinions on PAS for social workers. While previous research on physicians has demonstrated that those who work with more terminally ill patients are less supportive of PAS (Cohen et al., 1994), it is clear that similar research on social workers is lacking.

Similarly, age also played a role in altering answers to a number of the survey questions. Older social workers stated that they were more comfortable working with those at the end of life (question 11), while younger respondents stated a greater willingness to be present at a patient's death in a state in which it was either legal or illegal (questions 16 and 17). While Butt et al. (2003) and Domino (2003) found a younger age to be correlated with increased support for PAS

among the general population, Craig et al. (2007) observed that retired physicians were more likely to support PAS. However, for social workers, it is possible that an increased willingness to be present is related to a number of factors such as education, generational beliefs, or experience in the field. It is highly likely that age relates directly to years in the field. In regard to an increased comfort among older people in working with those at the end of life, it is possible that this comfort is something that comes with experience in the field, although it is apparent that more research is needed to draw any conclusions. Additionally, given that only three of the 20 attitudinal questions showed a difference for age, it is possible that age has little to no effect on attitudes toward PAS among social workers.

Another demographic factor which this study explored is religion. There were no differences found for participants who identified as religious, in comparison to those who did not identify as religious. In regards to previous research, religion has been found to be strongly correlated with opinions on PAS. Burdette et al. (2005), Parks et al. (2010) and Espino et al. (2010) all found increased religiosity to be inversely correlated with support for PAS among the general population. In addition, among physicians, Curlin et al. (2008) and Curry et al. (2000) also found religion to be related to a decrease in support for PAS. Similarly, this relationship was found to exist in the nursing population as well (Gielen et al., 2009). However, previous research on the role of religion in shaping social workers' opinions could not be found. It is possible that limitations in this study prevented the possibility of uncovering a relationship between religion and social workers. However, it is also feasible that this relationship does not exist among social workers. Reasons for the absence of this relationship could have to do with the specifics of a social work education, such as the emphasis on patient directed care or the importance of understanding cultural differences. It is also the case that we grouped together all participants

who indicated any kind of religious orientation, meaning that our religious group was very heterogeneous. It is possible that a larger sample would have yielded a more significant quantity of people who identified as religious, which would have enabled us to group them by type of religious belief and, potentially, given us more meaningful results.

In addition, due to limitations in the sample, this study was unable to look at two demographic factors. In regards to gender, only four men responded to this survey, representing 7.8% of the survey population. Additionally, two people (3.6%) identified as gender queer. Given that the large majority of the survey respondents identified as female, we were unable to look at the possible relationship between gender and opinions on PAS. However, the majority of social workers are female, so this is not surprising. Additionally, in regards to the impact of the state in which they practice, 34.5% of survey participants identified as practicing in Massachusetts, making it challenging to look at the effects on opinion given that a large percentage of survey participants practiced in the same state. Going forward, further research is needed to explore the effects of gender and location on social workers' opinions toward PAS. Additionally, due to the nature of this sample, this survey did not look at the variations in opinion among those who identify as members of oppressed groups. This is also underrepresented in previous research, and would be an important area for future studies to explore.

Lastly, the data were factor analyzed, producing four factors that this survey represented: rights, religion, law, and personal feelings. Law is especially central given the argument over legalization, and it is clear from previous research that the other three factors are often present in the debate on PAS as well. As discussed, literature on the subject has explored, considerably, the role of religion in shaping one's argument. Similarly, the importance of self-determination to the

profession of social work is evident in the NASW Code of Ethics, and dovetails directly with the question of rights. The debate over bioethical concerns, especially vulnerability, also relates directly to the question of rights. In regards to personal feelings, it is apparent from both the bioethical debate and the NASW Code of Ethics that one's subjective definition of a number of important ideas (e.g., vulnerability, self-determination, and quality of life) greatly alters the way in which one develops his or her opinion on PAS.

There are a number of limitations to this study. As mentioned, the survey population was significantly limited by gender and state of practice. Additionally, 60% of the respondents identified as students. As a result, the generalizability of these results is limited, given that a considerable number of the survey participants are female social work students from Massachusetts. Furthermore, the sample was nonrandomized. Also, given that this survey was distributed as optional, it is possible that there is a response bias, with people self selecting in regards to choosing to take the survey. This could alter the results, as those who opt to take surveys are often respondents with the strongest opinions. Additionally, the quantitative nature of this survey limited the nature of the responses.

Reliability is another limitation. While a significant number of the questions were adapted from previous surveys, this survey in its entirety has not been administered previously, and as a result, its reliability is unconfirmed. Similar problems present themselves in regards to validity. While a number of the questions have demonstrated construct validity given their usage in previous surveys, the questions designed solely for this survey have not been demonstrated to be valid.

In regards to researcher bias, the authors were aware of the possible effects of personal opinion on PAS and steps were taken to attempt to avoid the effects of bias. An empirical

method was chosen with this goal in mind, in addition to using survey items from other researchers.

Implications

There are a number of implications from this research that pertain to practice, policy, and further research. This study demonstrates a considerable support for PAS among social workers. However, this support is at odds with an agreement that social work education regarding PAS is extremely limited. It is apparent that this research could be of use to social work schools and educators in helping them develop curriculum on end-of-life issues such as PAS. Additionally, while the increased support for PAS among older participants and those with previous experience with people at the end of life was small, it is important to realize the implications of this finding in education and practice. For example, this research could help inform social work education programs in addition to hiring practices for social workers working with patients at the end of life. It is important that social work educators be aware of the differences that exist among students in regard to opinions on PAS, and that they tailor their education accordingly. Lastly, understanding the role of legality is especially important for social workers, as the majority made clear a preference for being involved in PAS if it were legal. This is especially relevant if clinicians intend to work in a state in which PAS is legal, such as Vermont, Oregon, Washington, Montana, and New Mexico (ProCon.org, 2013) (Eckhold, 2014). Social workers must be educated in a way that enables them to work effectively in such an environment, especially given that legality is often shifting. Similarly, along with legality comes the role of NASW policy.

From this research, it appears that social workers might not fully comprehend PAS related NASW policy. Additionally, as Allen (2006) notes NASW policy is sometimes at odds with state legislation. It is apparent that further discussion of PAS as it relates to NASW policy is

needed to help support social workers and policy makers. Legislators might also benefit from the results of this study as it is possible for them to utilize social workers as advocates for legalization in a debate that is raging in a number of states.

In regards to further research, it is apparent that research on social workers and PAS opinions is extremely limited. While some conclusions can be drawn from this study, it is imperative that this topic be explored further, both with the hopes of validating the results presented here, and examining further areas that were either inconclusive or unexplored in this work. It is especially important that future research continues to examine the conflict between social workers' ethical choices and the role of legality. In addition, research is needed to further illuminate the opinions of those from oppressed groups, particularly as it pertains to the understanding of vulnerability and risk in relation to PAS.

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Appendix A

Recruitment Email

Hi [insert name here],
I hope you're doing well. [tailored introductory hello]
For my thesis at Smith College's School for Social Work, I am working on a project that explores opinions and attitudes towards the prescription of a lethal dose of medication to a terminally ill and mentally competent patient so he or she may end his or her own life.

I am currently looking for study participants, and would greatly appreciate your help.

If you are willing and meet criteria, included at the end of this email is a link to my survey.

In addition, you can help by sending the second portion of my email to those you know who may meet the criteria.

Included below are more details about the survey as well as a link to take it. If you feel comfortable sending it to others, I recommend copying and pasting the information below into a new email.

I very much appreciate your help. Please let me know if you have any questions.

Thank you!
Ann Wheeler

Hello,

My name is Ann Wheeler and I am a student at the Smith College School for Social Work. For my thesis, I am reaching out to social work students who are currently in school for their MSW or BSW, in addition to practicing social workers (with an MSW or BSW). My goal is to better understand opinions about and attitudes toward the prescription of a lethal dose of medication to a terminally ill and mentally competent patient so he or she may end his or her life.

Attached is a link to a survey I have created to explore opinions on this matter. This study is anonymous and participation is optional. The data collected from this study will be used to complete my Master's in Social Work (MSW) Thesis. The results of the study may also be used in publications and presentations. The survey should take you 10-15 minutes and is entirely voluntary. You may exit the survey at any time.

https://www.surveymonkey.com/s/end-of-life_opinions

In addition, I would very much appreciate your help in recruiting others for this survey. If you feel comfortable, please forward this email to those you know who may meet the criteria for my survey.

Feel free to contact me with concerns or questions.

Thank you for your time,
Ann Wheeler
Smith College School for Social Work '14
awheeler@smith.edu
(XXX)-XXX-XXXX

Opinions on End-of-Life Care

Introduction

Thank you for taking the time to complete this survey. The data collected from this study will be used to complete my Master's in Social Work (MSW) Thesis at the Smith College School for Social Work. This study is anonymous and participation is optional. The results of the study may be used in publications and presentations. The survey should take you 10-15 minutes. You may exit at any time.

Thank you for your time.

If you have any questions about the survey, please contact me.

Ann Wheeler

Smith College School for Social Work '14

awheeler@smith.edu

In order to progress through this survey, please use the following navigation buttons.

Click the Next button to continue to the next page.

Click the Previous button to return to the previous page.

Click the Exit the Survey Early button if you need to exit the survey.

Click the Done button to submit your survey.

Opinions on End-of-Life Care

Qualifications

***1. I am participating in this survey because I am age 18 or over, and am a practicing social worker (with an MSW or BSW), or a social work student in school for my MSW or BSW.**

- I Agree
- I Disagree

Opinions on End-of-Life Care

Consent

Consent to Participate in a Research Study

Introduction:

You are being asked to be in a research study which intends to examine what shapes social workers' opinions about the prescription of a lethal dose of medication to terminally ill and mentally competent patients so that they may end their own lives. You were selected as a possible participant because you are either currently a practicing social worker, or you are in school working on your MSW. We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study:

The purpose of the study is to gain a better understanding of the characteristics that shape social workers' opinions about the prescription of a lethal dose of medication to a terminally ill and mentally competent patient so he or she may end his or her life. This study is being conducted as a thesis requirement for my master's in social work degree. Ultimately, this research may be published or presented at professional conferences.

Description of the Study Procedures:

The survey will ask you a series of demographic questions (age, sex, state you practice in, years of experience, year of graduation, number of terminally ill patients you have treated, religious affiliation (if any)). Then we will ask you to indicate your level of agreement with a series of statements related to end-of-life care, using a 5-point scale. Please note that the survey is open to practicing social workers and to social work students, even if you have not had direct experience with end-of-life care.

Risks/Discomforts of Being in this Study:

There are no reasonable foreseeable (or expected) risks. The survey deals with your attitudes about end-of-life care.

Benefits of Being in the Study:

You will be able to share your opinions on a politically relevant subject with important implications in your practice, in addition to possibly gaining insight into your personal feelings about end-of-life care. This research has repercussions for social work practice as it relates to those who are involved in end-of-life care. Also, as the political climate changes (that is, physician-assisted suicide potentially becomes legal in more states), the social work profession will have an important role to play in informing these changes. As a first step, it is important to know what social workers, as professionals, believe about this topic. Also, this study pertains to social work education, and the potential need to address physician-assisted suicide and its role in educational discussions on suicide. In addition, this study could highlight areas of research that need to be explored as it relates to physician-assisted suicide, and the role of social workers. In regard to additional benefits, anyone who is involved in end-of-life care might benefit from the knowledge. Lastly, legislators and voters considering physician-assisted suicide policy would benefit from the research as it will both educate them on the opinions of social workers, and potentially provide allies in the debate.

Confidentiality:

This study is anonymous. We will not be collecting or retaining any information about your identity. The survey website will not forward any identifying information (such as your IP address) to me in order to keep your identity anonymous. I will have no way to tell who has participated.

Payments:

You will not receive any financial payment for your participation.

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Right to Refuse or Withdraw:

The decision to participate in this study is entirely up to you. You may refuse to take part in the study at any time without affecting your relationship with the researchers of this study or Smith College. You have the right not to answer any single question, as well as to exit from the survey at any point during it. However, since I will not know participants' identities, once you submit the survey you will be unable to withdraw.

Right to Ask Questions and Report Concerns:

You have the right to ask questions about this research study and to have those questions answered by me before, during, or after the research. If you have any further questions about the study feel free to contact me at any time using the information on the previous or last page. If you like, a summary of the results of the study will be sent to you. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

Consent:

Your agreement to consent below indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above.

*We encourage participants to print a copy of this consent for their records.

*** 1. Having read the previous material, do you consent to participate?**

- Yes, I agree to the above consent form.
- No, I don't agree to the above consent form.

Opinions on End-of-Life Care

Survey

1. What is your age in years?

2. How do you identify your gender?

Male

Female

Other

3. In what state do you currently intern or practice?

4. In what year did you graduate with your MSW or BSW (If still in school please indicate your predicted graduation year)?

5. For how many years have you been practicing as a licensed social worker (if still in school please put 0)?

6. What is your current religious affiliation (if any)?

7. In your work, about how many mentally competent and terminally ill patients have you cared for through the end of their lives?

For the next four items, please indicate your level of agreement with each statement.

8. I try to carry my religious beliefs over into all facets of life.

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

Opinions on End-of-Life Care

9. My whole approach to life is based on my religion.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

10. My religious beliefs influence my practice of social work.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

11. I am comfortable working with patients at the end of their lives.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

The questions below deal with social workers' beliefs about end of life care. If you have not worked with clients or patients who are terminally ill, we ask that you imagine what you would do or how you would feel in that situation.

In addition, three phrases are used throughout the questionnaire and are defined as follows:

A lethal dose of medication is a dosage of prescribed medication (e.g., narcotics or barbiturates) to be used for the purpose of causing death.

Terminally ill describes a patient who is expected to die from a diagnosed condition within six months.

Mentally competent describes a patient who has sufficient understanding and memory to comprehend in a general way the situation in which they find themselves and the nature, purpose, and consequence of any act or transaction into which they propose to enter.

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12. A physician who writes a prescription that could be used in a lethal amount by a terminally ill, mentally competent patient (in a state in which writing such a prescription is legal) is acting immorally and/or unethically.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

13. The writing of a prescription for a lethal dose of medication repeatedly requested by a mentally competent terminally ill adult with less than six months to live should be legal.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

14. If in my state it were legal to prescribe a lethal dose of medication to a terminally ill and mentally competent adult who requests it, I would be comfortable working with a patient who had requested a lethal dose of medication.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

15. If in my state it were not legal to prescribe a lethal dose of medication to a terminally ill and mentally competent adult who requests it, I would be comfortable working with a patient who had requested a lethal dose of medication.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

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16. If one of my terminally ill and mentally competent patients received a prescription for a lethal dose of medication from a physician, in a state in which it is legal, and asked me to be present at their death, I would do so.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

17. If one of my terminally ill and mentally competent patients received a prescription for a lethal dose of medication from a physician, in a state in which it is illegal, and asked me to be present at their death, I would do so.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

18. If it were legal and my agency supported me, I would feel comfortable discussing with my terminally ill and mentally competent patients the option of ending their lives with a lethal dose of prescription medication.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

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19. If it were illegal but my agency supported me, I would feel comfortable discussing with my terminally ill and mentally competent patients the option of ending their lives with a lethal dose of prescription medication.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

20. If it were illegal and my agency did not support me, I would feel comfortable discussing with my terminally ill and mentally competent patients the option of ending their lives with a lethal dose of prescription medication.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

21. If it were legal but my agency did not support me, I would feel comfortable discussing with my terminally ill and mentally competent patients the option of ending their lives with a lethal dose of prescription medication.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Opinions on End-of-Life Care

22. I am not comfortable discussing a terminally ill and mentally competent patient's interest in ending his or her life using a lethal dose of prescription medication with my clinical supervisor or peer supervisory group.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

23. I think social workers should discuss options for terminally ill and mentally competent patients to end their lives with a lethal dose of prescription medication.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

24. During my social work education I learned about the prescription of medication [e.g. narcotics or barbiturates] or the counseling of a terminally ill and mentally competent patient so he or she may use an overdose to end his or her own life.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

25. Terminally ill and mentally competent patients should have the option of ending their lives with a lethal dose of prescription medication if physical suffering becomes unbearable.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Opinions on End-of-Life Care

26. Terminally ill and mentally competent patients should have the option of ending their lives with a lethal dose of prescription medication if psychological or spiritual suffering becomes unbearable.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

27. Prescribing medication (e.g. narcotics or barbiturates) for terminally ill and mentally competent patients so they may use an overdose to end their lives should not be a part of the care of those who are terminally ill and mentally competent.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

28. Counseling terminally ill and mentally competent patients so that they may use an overdose to end their lives should not be a part of the social work care of those who are terminally ill and mentally competent.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Opinions on End-of-Life Care

29. I believe that the NASW Code of Ethics require that I actively discourage my mentally competent and terminally ill patients from pursuing the option of ending their lives with a lethal dose of prescription medication.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

30. In my social work education I was taught to discourage my terminally ill and mentally competent patients from pursuing the option of ending their lives with a lethal dose of prescription medication.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Opinions on End-of-Life Care

Comments

1. Do you have any additional comments you would like to add?

Opinions on End-of-Life Care

Thank You

Thank you for your time

Ann Wheeler
Smith College School for Social Work '14
awheeler@smith.edu
~~XXXXXXXXXX~~

Appendix C

Approval Letter from the Smith College Human Subjects Review Committee



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

October 17, 2013

Ann Wheeler

Dear Ann,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Debra Hull, Research Advisor

Appendix D

Consent to Participate in a Research Study

Introduction:

You are being asked to be in a research study which intends to examine what shapes social workers' opinions about the prescription of a lethal dose of medication to terminally ill and mentally competent patients so that they may end their own lives. You were selected as a possible participant because you are either currently a practicing social worker, or you are in school working on your MSW. We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study:

The purpose of the study is to gain a better understanding of the characteristics that shape social workers' opinions about the prescription of a lethal dose of medication to a terminally ill and mentally competent patient so he or she may end his or her life. This study is being conducted as a thesis requirement for my master's in social work degree. Ultimately, this research may be published or presented at professional conferences.

Description of the Study Procedures:

The survey will ask you a series of demographic questions (age, sex, state you practice in, years of experience, year of graduation, number of terminally ill patients you have treated, religious affiliation (if any)). Then we will ask you to indicate your level of agreement with a series of statements related to end-of-life care, using a 5-point scale. Please note that the survey is open to practicing social workers and to social work students, even if you have not had direct experience with end-of-life care.

Risks/Discomforts of Being in this Study:

There are no reasonable foreseeable (or expected) risks. The survey deals with your attitudes about end-of-life care.

Benefits of Being in the Study:

You will be able to share your opinions on a politically relevant subject with important implications in your practice, in addition to possibly gaining insight into your personal feelings about end-of-life care. This research has repercussions for social work practice as it relates to those who are involved in end-of-life care. Also, as the political climate changes (that is, physician-assisted suicide potentially becomes legal in more states), the social work profession will have an important role to play in informing these changes. As a first step, it is important to know what social workers, as professionals, believe about this topic. Also, this study pertains to social work education, and the potential need to address physician-assisted suicide and its role in educational discussions on suicide. In addition, this study could highlight areas of research that need to be explored as it relates to physician-assisted suicide, and the role of social workers. In regard to additional benefits, anyone who is involved in end-of-life care might benefit from the knowledge. Lastly, legislators and voters considering physician-assisted suicide policy would

benefit from the research as it will both educate them on the opinions of social workers, and potentially provide allies in the debate.

Confidentiality:

This study is anonymous. We will not be collecting or retaining any information about your identity. The survey website will not forward any identifying information (such as your IP address) to me in order to keep your identity anonymous. I will have no way to tell who has participated.

Payments:

You will not receive any financial payment for your participation.

Right to Refuse or Withdraw:

The decision to participate in this study is entirely up to you. You may refuse to take part in the study at any time without affecting your relationship with the researchers of this study or Smith College. You have the right not to answer any single question, as well as to exit from the survey at any point during it. However, since I will not know participants' identities, once you submit the survey you will be unable to withdraw.

Right to Ask Questions and Report Concerns:

You have the right to ask questions about this research study and to have those questions answered by me before, during, or after the research. If you have any further questions about the study feel free to contact me at any time using the information on the previous or last page. If you like, a summary of the results of the study will be sent to you. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

Consent:

Your agreement to consent below indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above.

*We encourage participants to print a copy of this consent for their records.

***1. Having read the previous material, do you consent to participate?**

- Yes, I agree to the above consent form.
- No, I don't agree to the above consent form.