Death with Dignity: Social Worker Perspectives on Ethics and Values

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ABSTRACT

Personal values, individual experiences, and familial bias play a part in the outcome of social worker perspectives on Death with Dignity despite a foundation of professional values and expectations. This research looks at four hospice social workers' opinions. This paper will include background information on Oregon’s Death with Dignity Act ORS 127.800-995 statute and include a summary of hospice and end of life services available. Social workers are asked to use the NASW Code of Ethics to weigh-in on issues surrounding death with dignity and patient rights.

Introduction

Death with Dignity is defined as the process of when a terminally ill adult voluntarily requests a prescription medication to end their life. It is also known as physician-assisted suicide or physician-aid in dying but this research will be using the term Death with Dignity (DwD). In a revolutionary move in 1994, Oregon brought Death with Dignity into daily life as they passed statute: ORS 127.800-995 that allowed patients to legally, and without repercussion to physician or patient, facilitate death through prescriptive means. In 2019, eight other states have passed legislation similar to the ORS 127.800-995 statute. With the prevalence of this issue arising in end-of-life care, questions and concerns regarding ethical impacts begin to emerge. This research is designed to focus on hospice social workers' viewpoints with the Death with Dignity
Act and the ethical considerations surrounding the issue. Throughout the course of the research, the National Association of Social Workers (Workers, N. A. 2008). Code of Ethics and the expectation of social workers that work with end-of-life clients were included. Exploration of how personal values can interfere with providing care for a client interested in DwD is included. Four hospice social workers provided viewpoints and ethical considerations illustrated through interview questions. Results will tie in common responses from questions and discuss their social work ethics and singular values with the issue of DwD. Personal values are highlighted as is the potential interference in regards to advocacy and clear ethics of the social work profession. All Social workers have a responsibility to support choices for end-of-life care options but also have to uphold a code of ethics, manage their personal bias, and assess any potential barrier to providing quality care to patients.

**Literature Review**

Death with Dignity (DwD) is the process that allows terminally ill adults are able to request from their physician, receive from the pharmacist, and take a lethal dose of medication to end-their-life (Death With Dignity. (n.d.). Oregon’s statute came with legal challenges, implications, and repeals that delayed the implementation for three years. (Gaston, N. R., Randall, J. M., & Kiesel, L. R. (2018). The legal challenges continue, but the law was never challenged again. Oregon is going on twenty-one years of uninterrupted challenges. There are eight other states that have legalized Death with Dignity; Washington, Vermont, California, Colorado, Washington, D.C., Hawaii and New Jersey. New Jersey is the newest state that has legalized DwD on August 2019. (Death with Dignity Acts - States That Allow Assisted Death, n.d.)
All eight states that have legalized DwD do not agree with the title of physician-assisted suicide. The term suicide is hurtful for the patients and families that are going to be or have already used DwD. The ORS 127.800-995 statute in Oregon states “Actions taken in accordance with [the Death with Dignity Act] shall not, for any purpose, constitute suicide, assisted suicide, mercy killing or homicide, under the law” (Death With Dignity. (n.d.). The American College of Legal Medicine rejects the term physician-assisted suicide. In 2008 the American Public Health Association made a policy states “We reject the use of inaccurate terms such as “suicide” and “assisted suicide” to refer to the choice of a mentally competent terminally ill patient to seek medications to bring about a peaceful and dignified death.” The American Association of Suicidology also states that “physician aid in dying is not suicide” (Compassion and Choices. n.d).

Though there are different names for the DwD act in each of the states. None of the states use the term “physician-assisted suicide” in their legislation. All the approved jurisdiction for the act has the same requirements and is structured around the first legislature ORS 127.800-995 statute in Oregon in 1994. The criteria for eligibility for DwD remains similar in each state and is as follows:

- Be 18 years or older
- Be a resident of Oregon (or state of legality)
- Have a terminal illness with six months or less to live
- Be mentally competent, i.e. capable of communicating and making healthcare decisions to physicians
- Able to take the medication themselves with no help
- Two physicians sign off stating all the criteria have been met
- Have authorized the first oral request
- Be able to wait fifteen days after making the first oral request before making the second oral request
- After fifteen days of making the second oral request,
- Make a written request witnessed by two individuals. One of the individuals cannot be related to the patient, a physician, or an employee of a health care facility caring for the patient.
The patient has to be educated by both physicians on hospice services as an alternative to the Death with Dignity Act. Both the physicians and pharmacists have to submit a report to the Oregon Public Health Division after the medication is picked up by the patient (Oregon Health Authority. (n.d.). Patients who use Death with Dignity will not have ‘suicide’ as cause of death listed on their death certificates. This allows for the distribution of life insurance and eliminates law enforcement investigations. The patient's physicians record the underlying terminal disease as the cause of death and mark the manner of death “natural” when Death with Dignity is used (Oregon Health Authority. (n.d.).

It is beneficial and important to understand why someone dying of a terminal illness would want to end their life and enact Death with Dignity. It is assumed by people who are not terminally ill to think pain is the number one factor and reason someone would use Death with Dignity. The 2017 Oregon Death with Dignity yearly data summary surveyed residents that used the act and their reasons why they wanted to end their life. Out of 1,275 people that have used Death with Dignity to end their lives, 92% of concerns from users were loss of autonomy, decreasing the ability to participate in activities that made life enjoyable and loss of dignity. Another study was done in 2014 to study patients who were diagnosed with cancer and had six months or less to live. The study examined if pain-related suffering was the number one motive for requesting physicians to assist in death (same as Death with Dignity). The research found that the motive participants desired was to be able to control the circumstances and environmental factors in their death. (Servodidio, C. 2015).

Hospice is the most popular end-of-life care chosen by patients with a terminal illness. Hospice care is a specific kind of care that focuses on the quality of life for people and their caregivers who are experiencing advanced, end-of-life stages. Hospice provides compassionate
care for people in the last phases of their terminal illness so that they may live life as fully and comfortably possible. (American Cancer Society. (n.d.). The goal of hospice is not to facilitate or hasten natural death. Palliative care is a growing field where care is focused around alleviating symptoms such as pain and stress associated with a serious illness. Patients can begin receiving services from palliative care at the same time as treatment (MedlinePlus Medical Encyclopedia. (n.d.). Social workers play an active part in end-of-life care. From education on caregiving, providing support, assisting with legal and final arrangements, and connecting to patients and families to additional resources, social workers walk alongside patients in their final days- a time when DwD may arise as a consideration.

**Social Work Mission, Values and Ethics**

The primary mission of the social work profession is to enhance the well-being and help meet the basic human needs of all people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and/or living in poverty (Jacksonville State University. (n.d.).

The National Association of Social Workers established a Code of Ethics that identifies core values and provides guidelines for practice. It highlights ethical principles that govern social work practice and cement a responsibility to provide all clients with education and services available to them. The ethical principles should be represented and included when a professional is working with the public and private arena (Workers, N. A. 2008). Social workers are bound by the NASW Code of Ethics to ensure clients’ choices are being heard and respected. They are required to work with clients during end-of-life care and are expected and responsible to provide accurate end-of-life education. Social workers should be aware and educated on
hospice, and other end-of-life options; this would include options like Death with Dignity. (Gaston, N. R., Randall, J. M., & Kiesel, L. R. (2018.)

One of the underlying motivations for legalizing DwD is patient choice and autonomy. Social work has built the profession on the ethic of self-determination. “Self-determination- An ethical principle in social work, which recognizes the rights and needs of clients to be free to make their own choices and decisions” (Furlong, M. A. 2003). Self determination empowers clients and patients to have a firm hold on the outcome of their lives- whether positive or negative. Social workers advocate for their clients, so clients are able to feel in control and empowered in their life decisions- and engage in self-determination. Social workers’ role in end-of-life care is to work with patients’ values in life, and the desires they want to pursue.

**Methodology**

Qualitative data interviews were used in the research. Participants are Licensed Social Workers that work in hospice care. Each participant was educated on informed consent and any possible risks before participating in the research. The interviews consisted of ten open-ended questions (see Appendix A). Every participant was given the same ten questions. Half of the participants answered the interview questions online via email. The other half of the participants were interviewed in-person. Secondary data was collected from academic articles, research relating to hospice care, social workers' code of ethics, and the Death with Dignity Act. At the beginning of the research, a literature review was done to gain an in-depth understanding of DwD, ethical issues in social work, and social worker roles. The literature review included 10-15 scholarly articles that were relevant to the research about hospice, Death with Dignity, social work ethics, and social workers’ personal values. Research participants for this research consisted of four hospice social workers. Three of the social workers were from Minnesota and
Wisconsin that do not have DwD legislation. One of the participants lives in Washington, where Death with Dignity is legalized. The researchers looked at similarities and differences between the participant's answers to gain an understanding of social worker perspectives and values.

**Results**

**Knowledge**

When participants were asked about their knowledge on DwD the answers varied. The research acknowledged that geography has an impact on how much social workers know about Death with Dignity, especially in a state where it is legal compared to where it is not. All participants knew that DwD was determined by state legality and that there were different laws and criteria for the states that have DwD legal. The participants all had a general understanding of the law, and there was a general understanding that there is an administration of medication given to end someone's life. The social worker that lived in a state where DwD was legal had significant more knowledge on steps and criteria for utilizing DwD and was able to delineate regulations (Participant D, personal communication, June 6, 2019). Social workers surface knowledge of DwD was evident when not a viable option in their states.

**Opinions**

When participants were asked about their opinions regarding DwD only half expressed that ending your life voluntarily should be a legal choice for all with terminal illnesses. Although all social workers stated choice was a common factor for legalizing, not all agree with having Death with Dignity as a legitimate option. Participants had several concerns with the law that included questions, value judgments, and personal experiences with death itself with participants.
Participants questioned if patients should choose to end their life if given more education on end-of-life options. Concerns were raised with how patients and families are educated on alternative options so that DwD is the final and least desirable choice. One participant was completely against DwD as an option and feels that it society is not valuing life as it should (Participant C, personal communication, May 30, 2019). One participant said, “I do feel Death with Dignity should be available to all, no matter the state they live in” (Participant D, personal communication, June 6, 2019). This participant worked in a state that has DwD. One individual stated, “While I personally believe that all people have the right to make their own choices, I believe that it would not be necessary if more people were aware of other end-of-life options including palliative care” (Participant B, personal communication, May 7, 2019). This seems to mimic the opinions of the other participants who were focused on education regarding hospice and palliative care.

Influences

Participants were asked what they think a families’ role should be with DwD. Half of the participants mention the word “legacy.” When asked to describe what legacy means for a client, a participant said, “When someone dies, and other people look back on that person's life. The joy that person brought to the world, and also the way they lived their lives by, physician-assisted-suicide can affect families and friend's opinions of that person after they have died, that person using Death with Dignity should understand that” (Participant A, personal communication, May 14, 2019). One participant was completely against DwD as an option and feels that it society is not valuing life as it should (Participant C, personal communication, May 30, 2019). Another participant said that roles are to support and be involved in decision making (Participant B, personal communication, May 7, 2019). All participants were in an agreement
that family support is vital for someone using DwD or any end-of-life-care options. Social worker participants shared personal stories of family member deaths that influence their opinion of DwD, end-of-life care, and family involvement. Losing a family member impacted social workers’ as they expressed value in the dying process and would not have wanted loved ones to choose DwD.

The participants were asked how family disapproval would affect advocating for a client. The majority of the participants would advise their client’s family to participate in a meeting that educated the family on their client's decision to use DwD. One participant said “giving the family a safe place to ask a question about DwD, and explaining why their family member is choosing Death with Dignity for end-of-life care” (Participant D, personal communication, June 6, 2019). The results ranged from the participants referring their clients to a different social worker because that participant refuses to work with any client requesting DwD, or working with any client wanting to participate or want knowledge on the act and offering post-death-care with the family.

The role and impact of family in end-of-life care caused social workers to focus on issues outside of patient choice and autonomy. Their own experiences also informed their opinion and influenced the support or discouragement of DwD.

**Ethical Considerations**

Participants were asked what parameters should be in place if DwD was to become legal in the United States. The participants focused on the waiting period to safeguard for participants wanting to use the act. They felt that having the fifteen-day period between when someone's first request for DwD, and the signature before given the prescription is an important criterion. Participants thought that education should be the main focus and a true priority with people who
want to utilize DwD. Social workers reported ethical concerns about patients provided accurate information, religious influence, and feeling pressured from outside influences. Participants felt facilitating meetings with the clients and family on alternative options instead of doing Death with Dignity was necessary.

When participants were asked how the NASW Code of Ethics applies to DwD, all of the participants had similar answers; they focused on self-determination and patients needing the ability to guide their own lives and make their own choices. Participants mentioned that it is a social worker's duty to educate clients on all end-of-life care options and the best ethical practice regardless of personal values. A participant that does not believe DwD should be legal said “No matter what my opinion and value may be, it is not in my best practice to put those values on my clients. My job is to advocate for all, support choices, and keep separate my own values because my own values should not interfere with my work” (Participant B, personal communication, May 7, 2019). Three of the four participants felt they could work with an individual choosing DwD even if it went against their personal values. One participant reported that she would refer the patient to another social worker because of her strong value against DwD (Participant C, personal communication, May 30, 2019). Social workers reflected values of dignity, worth of the person, and the importance of relationships as considerations when working with those at the end of life.

**Conclusion**

Social workers play an essential role at the end of life decision-making and care provision. Social workers’ values and opinions have the potential to interfere with or impede values of self-determination and autonomy. The research showed the risk factors that personal bias can have when it comes to the NASW code of ethics and patient care. Social workers stated
their ability to provide care despite these considerations but additional research shows conflict with the stated opinions. There is a missing gap between hospice education and end of life care options. All the participants addressed that if DwD were legal, there would need to be more education on hospice services before receiving education on DwD. End-of-life care is complex and challenging as social workers play an integral part in this delicate process. Research can act as an essential role in delineating bias and assuring patients have the best options and the values of the profession are upheld.

For continuing research on DwD, it would be beneficial to study states that legalized Death with Dignity and evaluate the education given to social workers and patients. It would also be important to research for states that do not have legalization what kind of hospice education is being given to clients. It is mentioned by multiple participants in this research that if DwD was legal that there should be more emphasis on hospice and palliative care options. Future research could also demonstrate how end-of-life care options are presented to patients and families. This may identify how bias and values impact the delivery of education regarding care options for those with a terminal illness.
References


Compassion and Choices. (n.d). *Medical Aid In Dying is Not Assisted Suicide, Suicide or Euthanasia.* Retrieved from https://compassionandchoices.org/resource/assisted-suicide/


https://www.oregon.gov/oha/P...EVALUATION
RESEARCH/DEATHWITHDIGNITYACT/Pages/faqs.aspx


Appendix A

1. What do you know about Death with Dignity?
2. What are your opinions about Death with Dignity?
3. Do you feel Death with Dignity should be legal in every state?
4. Do you think you would provide services differently if working with a client that is interested in Death with Dignity?
5. What kind of parameter do you think should be in place if Death with Dignity was legal in all the states?
6. Do you think your personal opinions about Death with Dignity would interfere with clients?
7. How does The National Association of Social Work values apply with Death with Dignity with clients?
8. What role do you think the family should be when involved with Death with Dignity?
9. How would family disapproval and lack of support, affect advocating for a client that is considering death with dignity?
10. Is there anything else you would like to share on your thoughts of Death with Dignity?