

Death With Dignity: A Nursing Perspective

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Abstract

Death with dignity has become a hot-button issue over the past several decades, but there is more to it than meets the eye. This paper will explore the legislation, eligibility requirements, and ethical dilemmas in nursing surrounding the issue. Written from the perspective of support for the act, it aims to provide consideration for both sides of the debate.

“The freedom is in the choice. If the option of DWD is unappealing to anyone for any reason, they can simply choose not to avail themselves of it. Those very real protections are already in place” (as cited in Brittany Maynard obituary, 2014). Imagine being 29 years old, newly married, with your whole life in front of you. Now imagine being told you only have six months to live. This was the reality for Brittany Maynard when she was diagnosed with terminal brain cancer. Knowing that her young, healthy body could hold on long after the cancer robbed her brain of life, she looked for options besides hospice. That is when she discovered death with dignity and decided that would be her fate. “Brittany chose to make a well thought out and informed choice to Die With Dignity in the face of such a terrible, painful, and incurable illness” (as cited in Brittany Maynard obituary, 2014).

On October 27, 1997 Oregon became the first state to approve legislation allowing physician assisted deaths, known as death with dignity. The Death with Dignity (DWD) Act allows terminally ill, mentally competent adults to end their lives voluntarily by self-administering lethal medications prescribed to them by a physician strictly for that purpose (Oregon Health Authority Frequently Asked Questions section, n.d.). Currently, there are only five other states with Death with Dignity statutes: Vermont, Colorado, Washington, California, and the District of Columbia. Montana is the only state that has made Death with Dignity legal due to a court decision (Death with Dignity How to Access and use Death With Dignity Laws section, 2017).

In 2007 Robert Baxter, a Marine Corps veteran suffering with lymphocytic leukemia, along with four physicians and the organization Compassion & Choices filed a case that it was against Montana’s Constitutional guarantee of privacy, dignity, and equal protection to prohibit aid in dying. District Court Judge Dorothy McCarter ruled in favor of death with dignity, just

hours before Robert Baxter succumbed to his illness. The Attorney General of Montana appealed Judge McCarter's decision. On December 31, 2009 the Montana Supreme Court ruled that physicians can aid in the death of a terminally ill patient (Compassion & Choices Baxter et al v. Montana section, 2017). The ruling cited the 1991 Rights of the Terminally Ill Act, "because there is so little difference as a matter of public policy between taking a patient off life support and prescribing lethal medication that a patient can take" (Death with Dignity Montana section, 2017).

The decision to receive physician assistance in death may seem to some to be the most difficult part of the process. However, there are strict criteria and an arduous process the patient must go through. The patient must, first and foremost, be a resident of a state with a death with dignity statute. They must also be at least 18 years old, of sound mind, and have a diagnosis of a terminal illness that will, without a reasonable doubt, result in death within six months. The patient is required to self-administer and ingest the prescribed medications (Death with Dignity How to Access and use Death With Dignity section, 2017). Only participating physicians are able to prescribe the medications and the provider must be an MD or DO. Once a patient has found a provider, they must make two oral requests, at least 15 days apart. Following the oral requests, the patient must submit a request in writing, signed by two witnesses. In the District of Columbia, Vermont, Oregon, and Washington the physician must wait 48 hours after receiving the written request to write the prescription. The provider must confirm that the patient is mentally competent to make healthcare decisions and inform the patient of alternatives, such as hospice. The attending physician, as well as a consulting physician, must confirm the patient's diagnosis and prognosis. The physician is responsible for reporting all prescriptions for lethal

medications to the proper state authority and to inform the pharmacist of the medication's definitive use (Oregon Health Authority Frequently Asked Questions section, n.d.).

The medication can be dispensed by the physician or the physician will give the prescription to the pharmacy. The patient is not allowed to have the written prescription. Patients are typically prescribed a heavy dose of sleeping medication in a powder form that must be mixed with four ounces of liquid. The entire cocktail must be consumed within two minutes. Sleep typically follows about 10 minutes after the patient ingests the medication and death typically occurs one to three hours later, but can take as long as six hours with the patient sleeping peacefully until the last heartbeat (Death with Dignity How to Access and use Death With Dignity section, 2017).

As more states have passed legislation to legalize DWD, the pharmaceutical companies have responded with a major price increase in the most commonly used medication – more than double the initial cost. Patients, many of whom had already endured other costly treatment modalities, would be facing a \$3,000 bill for the lethal medication. Coverage by health insurance companies varies and the medications are not covered at all by Medicare. Medicaid will pay depending on the state you live in – Montana is not one of those states. To combat pharmaceutical greed, physicians in Washington experimented with an alternative, mixing phenobarbital, chloral hydrate, and morphine sulfate. While the cocktail was much more affordable at \$500, it was found to be too caustic for many patients causing a profound burning sensation. The most recent cocktail, dubbed DDMP, consists of digoxin, diazepam, morphine sulfate, and propranolol and costs around \$600 (Aleccia, 2016).

Opponents of the law fear that patients who cannot afford to pay for recommended treatment may choose physician assisted death because it is the cheapest route, putting “cost over

compassion” (Wenstrup & Roe, 2017). Additionally, they raised concerns about the effect this would have on minorities and low-income people. In 2013 *The New England Journal of Medicine* released a study on the use of death with dignity at a cancer center in Washington. The study followed 114 patients who inquired about the option of DWD. Of the 40 patients who were given prescriptions for the lethal medications, only 24 utilized them in their deaths. The majority of participants were Caucasian, college educated men, with a mean age of 72 – which is consistent with statewide data in both Washington and Oregon (Loggers et al, 2013). Further studies have shown that vulnerable groups are less-likely to participate in the life-ending option. Only a small number of participants have cited financial concerns as the primary reason for their decision. Rather, patients express “loss of autonomy, inability to engage in enjoyable activities, and loss of dignity” (McBride, 2013) as their primary concerns.

There have been incredible advancements in the medical treatment available for terminally ill patients. Unfortunately, these treatments often come at a cost to the individual’s quality of life. In most treatment options, the benefits outweigh the burden resulting in only temporary side effects and significantly increase life expectancy. Often times, aggressive treatment modalities are not beneficial and prolong the dying process without any improvement in quality of life – increasing a patient’s suffering and destroying the possibility of enjoyment in their final days. The patient has the right to refuse medical treatment – this can be a relief to many patients, but can also result in physical discomfort. This is where palliative care can be valuable.

Palliative sedation is used when patients are in extreme distress. In proportionate palliative sedation, medications are administered at a systematic dose until a patient achieves symptom relief. Alternately, palliative sedation until unconsciousness, a more controversial

practice, renders the patient unconscious when lesser levels of sedation did not achieve adequate symptom relief (Quill, 2012). All additional supportive measures, including nutrition and hydration, are ceased and the patient typically dies within a few days. The use of palliative sedation is up to the healthcare provider or hospice and is not a patient's right (Death With Dignity How to Access and use Death With Dignity Laws section, 2017). Along with the problem that the decision of palliative sedation rests with the provider, palliative care is not as readily available in rural areas and there is an insufficient number of trained providers (Friend, 2011).

Many opponents of death with dignity believe it is the healthcare provider's, "ethical obligation to prolong life and to end needless suffering" (Friend, 2011, p. 115). In doing so, they need to provide more education about end-of-life decisions and referrals to the appropriate services to patients and their families – unfortunately these referrals are often not made in a timely fashion (Quill, 2012). According to the National Hospice and Palliative Care Organization website (<https://www.nhpco.org/about-hospice-and-palliative-care/hospice-faqs>), before an individual can be eligible for palliative care through hospice, their healthcare provider must determine that they have a terminal illness with a prognosis of six months or less to live. Because the healthcare provider is the one that makes the referral, they must be able and willing to initiate end-of-life discussions with their patients, a skill that is lacking in many providers. "A 2003 study on education in American Medical Association-accredited universities found that only 18 percent of students completed a course on end-of-life care" (Stabile & Grant, 2016, p. 71) and 47 percent of the students did not feel they were equipped to deal with their own emotions surrounding a patient's death. In a 2013 survey, 25 percent of students that participated, "reported not being taught to assess prognosis, when to refer a patient to hospice, or

how to conduct a family meeting to discuss treatment options” (as cited in Thomas et al., 2015). Oregon’s Death With Dignity Act has been credited with improving conversations between patients and their providers, as well as a better physician understanding of pain management and comfort (Lee & Grube, 2017). In Oregon 93 percent of patients who consider DWD are enrolled in hospice and “as an unexpected consequence, hospice and palliative care in Oregon are unsurpassed in quality” (Lee & Grube, 2017).

The ethical debate surrounding physician assisted death usually cites the ethical principles of beneficence, nonmaleficence, and autonomy. According to Burkhardt & Nathaniel (2014) “the principle of beneficence means to do good” (p. 69). In respect to nursing this means providing care that benefits the patient. “The nurse takes appropriate action to safeguard individuals, families, and communities when their care is endangered by a co-worker or any other person” (as cited in the International Council of Nurses [ICN] *Code of Ethics for Nurses*, 2006). Opponents of death with dignity believe patients are at risk of coercion and abuse – the patient is not safeguarded from family members or healthcare providers pressuring them to choose lethal medication due to their fragile state. They argue that depression is often a reason people seek death with dignity and a mental health screening is not part of the mandatory requirements for eligibility (Wenstrup & Roe, 2017). However, mental competence is one of the qualifications to participate in physician assistance death and eligibility is reviewed by two physicians. If there is any question about the patient’s mental state, they are referred for an additional evaluation (Death With Dignity How to Access and use Death With Dignity Laws section, 2017). This offers a safeguard, not only against the impact of mental health issues, but also against coercion. The patient must express their desire to participate and must be able to administer the medications themselves.

Closely related to beneficence, the ethical principle of nonmaleficence prohibits any act that will actually cause harm. The principle of nonmaleficence is often a gray area, “because the harm caused may appear to be equal to the benefit gained, because the outcome of a particular therapy cannot be assured, or as a result of conflicting beliefs and values” (Burkhardt & Nathaniel, 2014). Opponents clearly view the lethal medication prescribed by the physician to the terminally ill patient as harmful. Can’t the argument then be made that many of the aggressive medical therapies used in terminally ill patients cause harm? The physicians are well-aware of the potentially harmful side effects, but recommended the treatment anyway. “Included in this principle are deliberate harm, risk of harm, and harm that occurs during the performance of beneficial acts” (Burkhardt & Nathaniel, 2014, p. 71).

Burkhardt & Nathaniel (2014) describe autonomy as, “the freedom to make choices about issues that affect one’s life, free from lies, restraint, or coercion” (p. 60). Respect for a patient’s autonomy is at the core of death with dignity. In a system where patient-centered care is the priority, giving patients the choice in how they die, the final decision many will make, seems paramount. Opponents contend that autonomy is a value and needs to be protected and that death coincides with a loss of autonomy. These beliefs are in line with Immanuel Kant, a classic deontologist, whose categorical imperative is to, “act according to that maxim which you can at the same time will to become a universal law” (Friend, 2011, p. 113). “According to Kant, autonomy is the key to human dignity, and one possesses dignity as long as he or she possesses the ability to engage in voluntary, rational behavior. Autonomy, in Kant’s view, does not mean the freedom to do whatever one wants, but instead to identify and adhere to dutiful rules in spite of one’s desires” (Friend, 2011, p. 113). Kant’s views are in direct contrast to the description of autonomy from Burkhardt & Nathaniel (2014). “True autonomy can be best realized when

people have all the information they need to navigate an increasingly complex health care system not only during illness but also in preparation for their deaths” (Friend, 2011, p. 115).

The U.S. Supreme Court has affirmed the right of patients of sound mind to refuse medical treatment, including food and fluids, a right that is widely accepted by the medical community. These decisions need to be written into the patient’s advance directives to be honored by the medical community. While voluntarily stopping eating and drinking is not a painful route of death, it can be a prolonged one, taking 10 days on average (Death With Dignity How to Access and use Death With Dignity Laws section, 2017). Advance directives were created as a sort of safeguard for patient autonomy. The directives “help to ensure that patients have the kind of end-of-life care that they want” (Burkhardt & Nathaniel, 2014, p. 304). The right for an advance directive is protected by the Patient Self-Determination Act, a federal law that was enacted in 1991 (Burkhardt & Nathaniel, 2014). Through an advance directive a patient can choose not to have CPR and other life-sustaining interventions, often resulting in the death of the patient. What, then, is the difference between withholding medical interventions, or offering palliative sedation, and allowing the patient physician assistance in death? Opponents argue, “that with physician aid in dying, the drug directly causes death, while with sedation, the disease causes death. They also argue that the intent of aid in dying is to hasten death, while with sedation, the intent is to relieve symptoms” (Rosseau, 2016). When it comes to the self-determination of patients, “they’re fundamentally the same: both relieve suffering and symptoms, both use sedative medications, and both end in death—it’s just that one takes a little longer” (Rosseau, 2016).

According to the Hippocratic oath, “physicians will give no deadly medicine to anyone if asked nor suggest any counsel” (Friend, 2011, p. 113). But what does this mean for nurses?

According to the American Nurses Association's 2013 position statement nurses are prohibited from the, "participation in assisted suicide and euthanasia because these acts are in direct violation of Code of Ethics for Nurses with Interpretive Statements, the ethical traditions and goals of the profession, and its covenant with society. Nurses have an obligation to provide humane, comprehensive, and compassionate care that respects the rights of patients but upholds the standards of the profession in the presence of chronic, debilitating illness and at end-of-life" (American Nurse's Association [ANA], 2013).

Although nurses are prohibited, by The Code, from directly participating in physician assisted death, they can still play an essential role in end-of-life care for their patients. The nurse should ensure that patients are given the opportunity to complete advance directives and should be an advocate for the patient in following through with their wishes (Burkhardt & Nathaniel, 2014). The nurse is responsible for assessing the effectiveness of pain management and symptom control. "Nurses should collaborate with other members of the health care team to ensure optimal symptom management and to provide support for the patient and family" (ANA, 2016). Using culturally competent care the nurse can assist in ethical decision-making. "Nurses and other health care providers have a responsibility to establish decision-making processes that reflect physiologic realities, patient preferences, and the recognition of what, clinically, may or may not be accomplished" (ANA, 2016). The nurse can also walk the patient and their loved ones through the dying process – "this includes recognizing when death is near and conveying that information to families" (ANA, 2016). The nurse often collaborates with other professionals, such as palliative care and ethics committees to provide the best care possible and promote patient autonomy.

I have had the unfortunate pleasure of being involved with hospice during the final days of life with my grandma and brother. My grandma died 11 years ago after a 10-year battle with lung disease. A devout Catholic, she had made her peace with God and was ready to be called home. Hospice had been involved for quite some time and had prepared us for her impending death. Once we knew she was in her final days, we began palliative treatment to ease her effort to breathe. For the first time since her illness began, she was confined to a hospital bed in her home and was dependent on her loved ones for all of her care, something she would have hated. Fortunately, the dying process went quickly and although we were filled with grief, there was also a sense of relief not having to watch her struggle for each breath. I don't know that we all could have watched her suffer for days on end as many families are forced to do.

My brother, Nathan, was born with cerebral palsy. He was nonverbal, used a wheelchair, and needed 24/7 care for all of his daily needs. He was also tube fed due to ineffective swallowing. In addition to his CP, he also had a seizure disorder that, up until the last few years of his life, had been a secondary disorder that was fairly well-controlled with medications. His seizure activity began increasing and got to the point that they were intractable. His already damaged brain, was suffering a tremendous amount of further insult, essentially rendering him unconscious. He was placed in hospice care at home on December 31, 2015. After several days of watching him groan and grimace in pain we opted to begin giving him morphine. He had a natural inability to clear secretions related to his disability and this significantly worsened in his final days. Scopolamine was administered to aid in drying the secretions, but he continued to try and cough and labored for every breath. After a discussion with the amazing hospice nurse, we made the decision to stop his enteral feedings as they can cause unnecessary discomfort as the body's natural processes begin to slow. My brother passed away on January 6, 2016, just seven

days after beginning hospice care. As difficult as it was to let him go, it would have been inconceivable to continue trying interventions that would have only delayed the inevitable.

I am well-aware that our decision to stop the enteral feedings was not the cause of my brother's death; however, it was an extremely, ethically challenging decision. We unselfishly chose to give him the best quality of life in those final days. And though he was not mentally competent, nor did the situation arise for him to request aid in dying, I know I would have supported his choice. Just as I would if it were one of my patients.

Renowned surgeon Atul Gawande writes in his book, *Being Mortal*, "modern scientific capability has profoundly altered the course of human life. People live longer and better than at any other time in history. But scientific advances have turned the processes of aging and dying into medical experiences, matters to be managed by healthcare professionals. And we in the medical world have proved alarmingly unprepared for it" (as cited in Gawande, 2014). Brittany Maynard is just one example of this. Her recommended treatment would have caused significant side effects, without curing her disease, and would have bought her only a few months at best. She knew how her story would conclude due to her diagnosis, but because of the Death With Dignity Act, she was able to choose her ending. "Life is meaningful because it is a story...and in stories, endings matter" (as cited in Gawande, 2014).

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