Death with Dignity Act; Respecting Choices at the end of Life

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#### Abstract

Under specific circumstances, having a choice as to how and when to die should be a right for everyone. This paper explains the concept of dying with dignity, also commonly referred to as right to die and assisted physician death. Provisions of the Oregon Death with Dignity Act (DDA) will be outlined. Oregon was the first U.S. state to enact a DDA and subsequently Washington and Vermont have enacted similar legislation. In these states, this law is working as intended. The paper will illustrate various reasons people are opposed to physician assisted death and examine the reasons why we need to have a DDA in place in all U.S. states. Two examples of end of life experiences will be examined. These examples will further demonstrate how end of life scenarios are personal and specific for every individual. Although there is opposition, there is also a growing interest and support in allowing each individual the right to determine how and when they will die, if they so desire. No law will be perfect, but the Death with Dignity Act comes very close.

# Death with Dignity Act; Respecting Choices at the End of Life

We make choices about how we will live our lives, we need the option to legally make choices about the manner in which our life will end. With phrases such as death with dignity, right to die, aid in dying and physician assisted death, we should be concerned with the meaning and the importance placed on these values. All of these phrases pertain to having a choice at the end of life. Today, only three U.S. states have enacted state legislation that allows for end of life choices, specifically aid in dying; Oregon, Washington and Vermont. As a society that has difficulty openly and honestly discussing death, we need to do better to meet the patient and family member's needs at the end of life. To continue to ignore the need to grant the right to make choices about death is to perpetuate our "death denying" culture.

Oregon was the first U.S. state to enact legalized physician assisted death (PAD) through Death with Dignity Act (DDA) in 1997. It is important to understand specific provisions in the DDA. The patient must be an Oregon resident, over the age of 18 and determined to be capable and mentally stable by two physicians. A patient must be diagnosed by two physicians to be terminally ill. In Curran's (1998) article regarding the legalization of physician assisted death, he notes that there is confusion and controversy in the medical community as to the exact definition of terminal illness. He raises the question of at what point is a diagnosis terminal, when a cancer returns after remission, or perhaps when chemotherapy has been proven to be ineffective. The DDA defines terminally ill as having a prognosis of less than 6 months to live as determined by two doctors. The DDA also defines terminal disease as one that is incurable and irreversible (Curran 1998). If there is concern about a mental disorder such as depression, the patient must

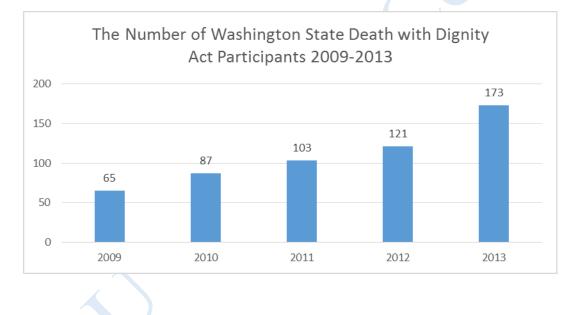
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be referred for a mental health evaluation. The DDA specifies that only capable patients have access to physician assisted death. Furthermore, the patient must make the request for aid with dying on their own behalf, in writing and witnessed by two other individuals with no more than one being a relative. The request must also be made verbally and the patient always has the option to change their mind. The DDA does not mandate that anyone close to the patient, including family, be notified of a person's decision or intent to obtain a lethal prescription for the purpose of ending their life. Also of note, any actions taken under the DDA "shall not for any purpose constitute suicide, assisted suicide, mercy killing or homicide; rather, the individual is obtaining medication to end his or her life in a humane and dignified manner" (Curran, 1998, p. 726). The DDA allows for a physician to prescribe lethal medication, but not to administer the medication. It is important to understand that death with dignity is not euthanasia. (Curran, 1998).

The Washington state DDA has essentially the same provisions as does the Oregon state DDA. According to the Washington State Department of Health 2013 Death with Dignity Act Report Executive Summary, in 2013 medication was dispensed to 173 individuals under the DDA. The report states that of these 173, 159 are known to have died; 119 participants died after ingesting the medication, 26 people died without having ingested the medication and status is unknown for the remaining 14. This report goes on to provide information regarding the end of life concerns these people listed. Loss of autonomy, less able to enjoy life, loss of dignity, becoming a burden to their family and losing control of bodily functions were the top five reasons listed (Ganzini, Goy, & Dobscha, 2007). As Kay Toombs (2004) notes, prominent features and attributes of autonomy imply "a robust independent individual capable of acting without help" (p. 193). Toombs also notes that a person's fear of becoming burdensome on

others is a predominant rationale for requesting physician assisted death. According to Toombs, Oregon statistics show that patients with amyotrophic lateral sclerosis (ALS) are more likely to seek physician assisted death than patients with any other medical illness. ALS is a progressive neurodegenerative disease wherein the patient gradually loses autonomy and of which there is no known cure.

The chart below displays the number of participants in the Washington state DDA from 2009-2013. It is evident that the number of people seeking physician assisted death with dignity is small. Even so, these individuals had the option to pursue the right to die on their own terms.



As mentioned earlier, it is important to understand the distinction between physician assisted dying and euthanasia. The difference is well described by Wesley Sowers (2004) in his article from the Psychiatric Times, "In the case of assisted dying, a person whose death is inevitable within a short period of time chooses the time and circumstances of their death" (p. 37). He goes on to explain that this is considered a thoughtful response to escape prolonged suffering when life has virtually reached the end (Sowers, 2004). Euthanasia, on the other hand, is the deliberate act of ending life, usually occurring when a nurse or physician performs an act such as administering a lethal injection that ends a person's life. Under the DDA, the physician does not administer the medication.

Opponents of death with dignity acts have varied reasons for their opposition. One common theme is the moral and ethical responsibilities of a physician. What about the Hippocratic Oath and the duty to do no harm? Some would argue that the Hippocratic values are alterable and allow for loose interpretation (Snyder, 2001). According to Snyder, (2001) "There has long been agreement that stopping treatment when patients are overmastered by disease is ethical and appropriate" (p. 16). The death with dignity act does not require a physician to participate in prescribing a lethal medication, participation by the physician is a choice. Wesley Sowers (2004) explains that physician participation is humane and that they have a responsibility to respect and support personal autonomy and decision making processes at the time of death (p.38). Sowers goes on to explain that although critics may argue that physician aided dying will undermine the public opinion of the role of the physician, there is no evidence to support this claim.

Another often raised concern is the "slippery slope" objection. If death with dignity is broadly legalized, will that lead to abuse such as applying the law to simply avoid continued health care costs? Will the disabled, disadvantaged or elderly population be at risk or pressured to make these types of decisions? This has not been the situation in Oregon or Washington. In a study conducted between the years 2004-2006, family members of patients who requested assisted death stated that these were individuals that valued independence and control over their lives. They had anticipated the negative aspects of dying and opted not to endure the approaching loss of autonomy, loss of abilities, and a quality of life that would be unendurable for them (Ganzini, Goy, & Dobscha, 2008).

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Another concept that can make it difficult to accept death with dignity and physician assisted death is the general denial of death. In our society, everyone is expected and practically obligated to stay alive and to labor for life to the utmost ability. Often this is due to faith and religious convictions regarding the sanctity of life (Heath, 2012). In earlier times, older adults would decline in health until death occurred. With the advances in medicine and technology over the last several decades, lives can now be extended with procedures and treatments, sometimes without regard as to the quality of life, but rather quantity. North American culture has placed an almost "magical confidence in the curative power of medicine" (Toombs, 2004 p.193). Today, many older people may seek to preserve life for as long as possible, while others might prefer to hasten death rather than extending their lives (Cicirelli, MacLean & Cox, 2000). Death with Dignity Acts will allow for hastening death in certain circumstances within the confines of the law. A terminally ill person receives information, instructions, and other resources necessary to end their life on their own terms.

Perhaps the notion of death with dignity is easier to understand when put in the context of real life (and death) situations. In his article titled Physician-assisted death: Progress or peril? Timothy Quill (1994) relates the story of his patient, Diane. Diane had a diagnosis of Acute Myelomonocytic Leukemia. Many patients with terminal disease, for one reason or another, are not fully educated about their diagnosis and often do not recognize that the most likely outcome will be that they will die while undergoing very trying and difficult treatment. Diane was informed and recognized that this would likely be her outcome. She was aware that hospice care would be an option, but she feared a long and painful death and the possibility of not having control of her body and mind. When she reached the last stages of her illness she wanted to die quickly and without prolonged agony. Diane discussed these wishes with her physician and

family openly, this led to a prescription for a lethal dose of barbiturates. Through the course of her disease she took life extending treatments such as antibiotics and blood products. She ultimately lived for 3 months, free of worry that she would meet an excruciating or humiliating death. At the last meeting with her physician, she was suffering from fevers due to sepsis, tumor pain and total body rash. She did not want to die, yet the circumstances had become unacceptable to her. Two days later she took the lethal prescription while alone to protect her physician and family from potential prosecution. Diane was evaluated by more than 20 medical professionals during the course of her disease, none of whom raised any concern about her mental health. All who knew her recognized her clarity, openness and courage. The decisions that she made at the end of her life were in line with her values and the manner in which she had always lived her life.

Consider the patient with a chronic, terminal lung disease. This type of patient may face suffocation, much like drowning prior to their death (Quill, 1994, p. 324). Physicians are legally allowed to provide morphine to control the symptoms and the discomfort of the disease. They are only allowed to provide the medication to the level that the patient relaxes and the symptoms are relieved. This can create a cycle where the patient is medicated and relaxed, the medication wears off and the patient awakes to the drowning sensation and then more medication is given, thus keeping the patient at the edge of death for hours or days or weeks. Even though the patient may have expressed that death is desirable to this situation, in states without a DDA in place, it is not acceptable for the health care team to help the patient die. When the burden of illness, debilitation, and loss of autonomy, pain and humiliation outweigh the prospect of continued life, should we not be able to legally and rightfully respect the wishes of people in these situations?

Sigmund Freud was a strong proponent of suicide prevention. When his oropharyngeal cancer progressed to the point that his life became torture and no longer made sense, he called on his physician and friend Max Schur, to provide progressive doses of morphine with the specific intent being to end his life. Freud had a contract with his friend and physician that if and when his suffering became intolerable, Schur, with the use of opiates, would help him find a peaceful death (Quill, 1994).

According to Quill (1994), "Hospice care should be the standard of care for the dying" (p. 320). Often, hospice care can contribute to a meaningful and comfortable death. Unfortunately, there are limitations, and when the care is ineffective or unacceptable to the patient or the suffering is intolerable, physician assisted dying should be regarded as an acceptable alternative.

In conclusion, it would be safe to say that most people would desire that their demise would be a sweet slipping away in their sleep. If we have given this much thought at all, we probably have contemplated how we do not want to die as well. Unfortunately, more than likely our deaths could be an exhaustive battle of treatments and procedures which may prolong life, all the while prolonging loss of autonomy and quite possibly misery and suffering. A terminally ill person whose life has deteriorated to the point where death would be preferable is aware when their good days are over (Heath, 2012). A person should have every right to say good by to their family and friends, give up the good fight and die on their own terms. The option of physician assisted death should be viewed as a way to regain control in an essentially uncontrollable situation (Tombs, 2004).

The DDA in place in Oregon, Washington and Vermont provides dignity and choices to people in their final stage of life, the dying process. Society needs to recognize that just as we

make our own decisions about life, we must be allowed to make decisions about how we will die. Yes, there is opposition, but many of the reasons for opposition are antiquated and not responsive to individual values. Autonomy, and the freedom to choose is what is at the heart of the matter. Imposing individual or societal beliefs without consideration to personal wishes and desires at the end of life must not continue. Indeed, it is difficult to construct a law or an act that will take every situation into consideration. Of course no law will be perfect. It is clear that the states of Oregon, Washington and Vermont have proven that the Death with Dignity Act in place in these states has not caused harm but rather, has brought grace and dignity to the dying process for many. The empowerment that the DDA provides should be extended to all of the United States. With open communication and allowing individuals to make end of life decisions, we can learn to die better.

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# References

- Cicirelli, V. G., MacLean, A. P., & Cox, L. S. (2000). Hastening Death: A comparison of two end-of-life decisions. *Death Studies*, 24 (5), 401
- Curran, P. M. (1998). Regulating death: Oregon's death with dignity act and the legalization of physician –assisted suicide. *Georgetown Law Journal*, 86.3, 725-749
- Ganzini, L., Goy, E. R., & Dobscha, S. K. (2007). Why Oregon patients request assisted death:
  Family members' views. *Society of General Internal Medicine* 23 (2), 154-7. doi: 10.1007/s11606-007-0476-x
- Heath, I. (2012). Living, dying and the nature of death. *Journal of Evaluation in Clinical Practice*, 1365-2753. Doi:10.1111/j 1365-2753.2012.01921.x
- Quill, T. E. (1994). Physician-assisted death: Progress or peril? Suicide & Life-Threatening Behavior, 24.4, 315-25
- Sowers, W. (2004). Physician aid in dying and the role of psychiatry. *Psychiatric Times*, 21.1, 37-38
- Snyder, L. (2001). Bioethics, assisted suicide, and the "right to die". Annals of Clinical Psychiatry, 13,1,13
- Toombs, K. (2004). Living and dying with dignity: Reflections on lived experience. *Journal of Palliative Care*, 20, (3), 193-200