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**Freedom beyond the “Right to Die”: Ethical and Policy Implications**

**Description:**

This presentation provides a detailed introduction to the ethics of U.S. end-of-life care. It begins with a discussion of the central controversy in end-of-life ethics: medical aid in dying or the “right to die.” It then argues that this debate is taking place amidst a crisis caused by the dependence of the U.S. hospice system on familial caregiving. In response to this crisis, it argues that we should move “beyond” the right to die to consider how to better reform U.S. hospice care. By moving beyond the right to die, we can have a fuller understanding of end-of-life ethics, and a richer toolkit to promote freedom for dying people.

**Structure**:

1. Health care professionals and the “right to die” debate
2. The crisis of US hospice care
3. Freedom beyond the “right to die”

**Learning Objectives**

1. Understand contemporary debates about the “right to die” in the United States
2. Explain how the US hospice system’s dependence on familial caregiving has created a crisis of hospice care
3. Understand how the systemic reform of hospice provides a novel and useful way of promoting freedom at the end-of-life

**Resources**

***Books***

Ball, Howard. *At liberty to die: The battle for death with dignity in America*. NYU Press, 2012.

Dowbiggin, Ian. *A concise history of euthanasia: life, death, God, and medicine*. Rowman & Littlefield, 2007.

Gorsuch, Neil M. *The future of assisted suicide and euthanasia*. Princeton University Press, 2009.

***Articles***

Braswell, Harold. "Putting the Right to Die in its Place: Disability Rights and Physician-Assisted Suicide in the Context of US End-of-Life Care.” Studies in Law, Politics, and Society*,* special issue “Accommodation, Recognition, Justice: Legal Treatment of Persons with Disabilities.” (forthcoming, summer 2018)

Braswell, Harold. “From Disability Rights to the Rights of the Dying (and back again)” Laws, special issue “Health Care Law and the Rights of Individuals with Disabilities,” 6(4) (2017). Available at: <http://www.mdpi.com/2075-471X/6/4/31>

Longmore, Paul K. "Policy, prejudice, and reality: Two case studies of physician-assisted suicide." *Journal of Disability Policy Studies* 16, no. 1 (2005): 38-45.

Singer, Peter. "Voluntary euthanasia: a utilitarian perspective." *Bioethics* 17, no. 5‐6 (2003): 526-541.

***Advocacy Organizations***

Compassion and Choices: <https://www.compassionandchoices.org/>

Not Dead Yet: <http://notdeadyet.org/>

**Some Quotations from Professional Codes of Ethics**

**American Medical Association**

“Physician-assisted suicide occurs when a physician facilitates a patient’s death by providing the necessary means and/or information to enable the patient to perform the life-ending act (e.g., the physician provides sleeping pills and information about the lethal dose, while aware that the patient may commit suicide).

It is understandable, though tragic, that some patients in extreme duress—such as those suffering from a terminal, painful, debilitating illness—may come to decide that death is preferable to life. However, permitting physicians to engage in assisted suicide would ultimately cause more harm than good.

Physician-assisted suicide is fundamentally incompatible with the physician’s role as healer, would be difficult or impossible to control, and would pose serious societal risks.

Instead of engaging in assisted suicide, physicians must aggressively respond to the needs of patients at the end of life. Physicians:

(a) Should not abandon a patient once it is determined that cure is impossible.

(b) Must respect patient autonomy.

(c) Must provide good communication and emotional support.

(d) Must provide appropriate comfort care and adequate pain control.”

*AMA Principles of Medical Ethics: I, IV*

**American Nurses Association**

“The American Nurses Association (ANA) prohibits nurses’ participation in assisted suicide and euthanasia because these acts are in direct violation of Code of Ethics for Nurses with Interpretive Statements (ANA, 2001; herein referred to as The Code), the ethical traditions and goals of the profession, and its covenant with society….

“Nurses have an opportunity to create environments where patients feel comfortable to express thoughts, feelings, conflict, and despair. The issues that surround a request for assisted suicide should be explored with the patient, and as appropriate with family and team members. It is crucial to listen to and acknowledge the patient’s expressions of suffering, hopelessness, and sadness. Factors that contribute to such a request should be further assessed and a plan of care initiated to address the patient’s physical and emotional needs. Discussion of suicidal thoughts does not increase the risk of suicide and may actually be therapeutic in decreasing the likelihood. The relationship and communication between the nurse and patient can diminish feelings of isolation and provide needed support.”

<https://www.nursingworld.org/~4af287/globalassets/docs/ana/ethics/euthanasia-assisted-suicideaid-in-dying_ps042513.pdf>

**National Association of Social Workers (NASW)**

“In addition, the social workers working in palliative and end of life care are expected to be familiar with the common and complex bioethical considerations and legal issues such as the right to refuse treatment; proxy decisionmaking; withdrawal or withholding of treatment, including termination of ventilator support and withdrawal of fluids and nutrition; and physician aid in dying. End of life issues are recognized as controversial, because they reflect the varied value systems of different groups. Consequently, NASW does not take a position concerning the morality of end of life decisions, but affirms the right of the individual to determine the level of his or her care. Particular consideration should be given to special populations, such as people with mental illness, with developmental disability, individuals whose capacity or competence is questioned, children, and other groups who are vulnerable to coercion or who lack decisional capacity.”

--NASW Standards for Palliative and End of Life Care

**American Public Health Association (APHA)**

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* Supports allowing a mentally competent, terminally ill adult to obtain a prescription for medication that the person could self-administer to control the time, place, and manner of his or her impending death, where safeguards equivalent to those in the Oregon DDA are in place. A “terminal condition” is defined in state statutes. Some states specify a life expectancy of 1 year or 6 months; other states refer to expectation of death within a “reasonable period of time.”
* Rejects 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.
* Encourages that where such option is available to vulnerable populations, including persons who have a disability which existed before the terminal illness, data be collected on the incidence when vulnerable populations and persons with disabilities that are independent of their terminal illness decide to hasten their death.
* Supports measures to ensure that patients eligible to receive information about death with dignity and are able to choose alternatives such as aggressive pain and symptom management, palliative care, hospice care, and care to maximize quality of life and independence.
* Supports the provision of information about the full range of end-of-life care options to terminally ill patients permitted by law in the state in which the patient is receiving care, including, for example, voluntarily stopping eating and drinking and palliative sedation. Palliative sedation is the use of medication to induce sedation to relieve a dying patient’s severe distress that cannot be controlled despite other aggressive measures53,54
* Supports a moratorium on DDA should evidence emerge that vulnerable populations are disproportionately impacted by such policies.”

**Notes:**

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