



Inspired by Pope Francis – Identity and integrity in a changing world

Thursday, 15 February 2018

Aid in Dying: Personal, Professional and Agency Responsibilities Carol Taylor, PhD, RN

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For many years, professional caregivers knew exactly how to respond when a patient expressed suicidal ideation. We "knew that healthy minds didn't choose to end life and our responsibility was to prevent suicide, so we placed these individuals on suicide precautions." Today, many accept the concept of rational suicide as an autonomous choice, opening the question of what our roles should be if someone chooses to end life sooner rather than later. This question is vitally important for professional caregivers given the hospice philosophy to do nothing to hasten or postpone dying.

Questions for Reflection and Discussion

- 1. If a patient appropriately expresses the wish to commit suicide, what are our personal, professional, and agency obligations? Select all that apply.
 - a. Compassionately counsel them about choosing to live and initiate suicide precautions.
 - b. Share this information with the team—even if the patient requests that this be kept confidential.
 - c. Ask them to talk more about why they are feeling this way... Use nondirective counseling to help them clarify what they want to do.
 - d. Counsel them about safe, effective, legal ways to achieve their goal. Become the patient's advocate.
 - e. Develop and implement a plan of care that honors the patient's wishes.
- 2. Many consider suicide to be a private decision. Is suicide ever private? What is the impact of a patient's successful suicide on family and staff?
- 3. How confident are we that we can distinguish a rational suicide from a mental health crisis?
- 4. How confident are we that we are meeting the physical, psychological, social and spiritual needs of patients? If unmet patient needs are prompting the request to die sooner rather than later what are our responsibilities?
- 5. How can professional caregivers better respond to attempted and successful suicide attempts? What strategies will best meet the needs of families and staff?
- 6. A New York Times article on April 22, 2016, reported that the U.S. suicide rate surged to a 30-year high, , with increases in every age group except older adults. The rise was particularly steep for women. It was also substantial among middle-aged Americans, sending a signal of deep anguish from a group whose suicide rates had been stable or falling since the 1950s. Causative factors linked to the increase in suicides include: economic recession, more drug addiction,

- "gray divorce," increased social isolation, and the rise of the Internet and social media. What are our obligations to prevent suicide?
- 7. How should one respond if one's personal beliefs about suicide differ from that of a patient or from an agency's philosophy/policies?
- 8. What about voluntarily stopping to eat and drink? Is this suicide? Am I obligated to mention this as an option to patients wanting to die? If I recommend this, or even tacitly allow it, am I participating in a suicide?
- 9. Is there an ethical difference between attempting suicide with a gun, an overdose of liquid morphine, or stopping eating and drinking?
- 10. Should agencies be more careful about limiting a patient's access (or a family member's access) to liquid morphine or other medications if we suspect they are stock-piling medications to cause the patient's death?
- 11. What about palliative sedation to unconsciousness? If someone wants to go to sleep and never wake up, is this an option? Are policies which require that the patient be imminently dying and which exclude emotional angst or existential suffering as criteria, appropriate? Since individuals choosing this will die if we do not feed them, is this the back door to euthanasia?

Bauchner, H. & Fontanarosa, P.B. (2016). Death, dying and end of life. Special supplement. *JAMA*, *315*(3), 215-318.

Lehto, R.H., Olsen, D.P. & Chan, R.r. (2016). When a patient discusses assisted dying: Nursing practice implications. *Journal of Hospice and Palliative Care Nursing*, 18(3), 184-191.

Orentlicher, D., Pope, T. M., & Rich, B. A. (2016). Clinical Criteria for Physician Aid in Dying. *Journal of Palliative Medicine*, *19*(3), 259–262. http://doi.org/10.1089/jpm.2015.0092 http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4779271/

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BIOETHICAL CHALLENGES AT THE END OF LIFE How Who We Are and What We Believe Influence Treatment Options and Counseling for the Seriously Ill and Dying

Carol Taylor, PhD, RN

New technologies and fundamental changes in the way we perceive basic human realities, fertility, conception and birth, aging, death and dying, are dramatically altering the way we are born, live and die. In this exercise, participants will explore some of the ethical issues surrounding these changes at the end of life. Participants will critique new scientific advances, the changing culture of health care, and public policy proposals in light of their potential to influence human wellbeing. The primary objective of this exercise is to clarify personal beliefs, what informs these beliefs, and how these beliefs will affect clinical conversations and actions.

And now, weak, short of breath, my once-firm muscles melted away by cancer, I find my thoughts, increasingly, not on the supernatural or spiritual, but on what is meant by living a good and worthwhile life — achieving a sense of peace within oneself. I find my thoughts drifting to the Sabbath, the day of rest, the seventh day of the week, and perhaps the seventh day of one's life as well, when one can feel that one's work is done, and one may, in good conscience, rest. [Sacks, O. (August 14, 2015). Oliver Sacks: Sabbath. Sunday Review, New York Times.]

The Clinician's Role and Integrity when Counseling Persons Struggling with Life Limiting Diagnoses

The 1983 President's Commission Report on Health Care Decision Making recommended the model of shared decision making over the Hippocratic/ paternalistic model and the patient sovereignty model. In recent years major forces in the U.S., including the current HCAHPS patient satisfaction scores, have resulted in many clinicians abdicating their role in treatment decisions and capitulating to patient preferences/demands. Too often these choices result from deficient knowledge, unrealistic expectations, fears, etc.

Recently several very public figures have engaged media attention by sharing their preferences about how to confront aging, serious illness, and anticipated death. Given the moral heterogeneity in the U.S. and the lack of consensus about the role aging, suffering, illness, dying and death play for humans: evils to be avoided at all costs, necessary evils to be suffered stoically, or paths to our transformation and flourishing, what guidance can/should any clinician, ethicist or sage offer?

We share the following questions for your reflection and discourse.

1. In his new book, *The Road to Character* (2015), David Brooks focuses on the deeper values that should inform our lives. Responding to what he calls the culture of the Big Me, which emphasized external success, Brooks challenges us,

and himself, to rebalance the scales between our "resume virtues"—achieving wealth, fame, and status—and our "eulogy virtues," those that exist at the core of our being: kindness, bravery, honesty, or faithfulness, focusing on what kind of relationships we have formed. What role can the challenges of aging, suffering, illness, dying and death play in our lives? Are they necessarily evils to be avoided at all costs? Might they be invitations/ opportunities to focus on what really matters and to cultivate the virtues that give meaning and purpose to our lives? If Brittany Maynard was your patient and she confided to you that she planned to move to Oregon so that she could die on her terms, how would you respond?

- 2. Have we each clarified our beliefs about what is ethically permissible when aging, suffering, illness, dying and death make lives unbearable? Do religious beliefs inform our judgments and if yes, how? Is assisting with suicide or euthanasia compatible with the roles of medicine and nursing? Should our faith beliefs conflict with our understanding of our clinical responsibilities, what trumps? Our religious or professional obligations? How should we negotiate conflicts of commitment?
- 3. Do health care professionals working with individuals experiencing aging, suffering, illness, dying and death have an obligation to "journey" with them as experienced and wise guides? Is it ever appropriate to make a recommendation or to challenge an expressed preference? Is it obligatory to do so? Do any of us believe we are qualified to be "wise guides?" Should we be?
- 4. What role do/should we play in informing conversations and decisions about treatment and care for those experiencing aging, illness, suffering, dying and death? Is "value neutrality" possible? Do you believe nondirective counseling is always the right choice?
- 5. Given the coming silver tsunami (mass geriatric society) these questions assume a special urgency. Is there a better way to think about aging and death than enemies to be conquered? [Think war on aging and death...] When we think about human flourishing... what do we do with the assaults related to aging, illness and death? Recently someone suggested that we give cyanide capsules to everyone newly diagnosed with dementia to be used when life is not longer deemed worthy of living. "No one wants to live that way." We live in a society that hardly reveres its elders. Should we/must we be part of challenging what we message to older and seriously ill brothers and sisters?

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Sources on Roman Catholic Teaching

Declaration on Euthanasia I. THE VALUE OF HUMAN LIFE

Human life is the basis of all goods, and is the necessary source and condition of every human activity and of all society. Most people regard life as something sacred and hold that no one may dispose of it at will, but believers see in life some thing greater, namely, a gift of God's love, which they are called upon to preserve and make fruitful. And it is this latter consideration that gives rise to the following consequences:

- 1. No one can make an attempt on the life of an innocent person without opposing God's love for that person, without violating a fundamental right, and therefore without committing a crime of the utmost gravity.[4]
- 2. Everyone has the duty to lead his or her life in accordance with God's plan. That life is entrusted to the individual as a good that must bear fruit already here on earth, but that finds its full perfection only in eternal life.
- 3. Intentionally causing one's own death, or suicide, is therefore equally as wrong as murder; such an action on the part of a person is to be considered as a rejection of God's sovereignty and loving plan. Furthermore, suicide is also often a refusal of love for self, the denial of the natural instinct to live, a flight from the duties of justice and charity owed to one's neighbor, to various communities or to the whole of society--although, as is generally recognized, at times there are psychological factors present that can diminish responsibility or even completely remove it.

However, one must clearly distinguish suicide from that sacrifice of one's life whereby for a higher cause, such as God's glory, the salvation of souls or the service of one's brethren, a person offers his or her own life or puts it in danger (cf. Jn. 15:14).

II. EUTHANASIA

In order that the question of euthanasia can be properly dealt with, it is first necessary to define the words used.

Etymologically speaking, in ancient times euthanasia meant an easy death without severe suffering. Today one no longer thinks of this original meaning of the word, but rather of some intervention of medicine whereby the suffering of sickness or of the final agony are reduced, sometimes also with the danger of suppressing life prematurely. Ultimately, the word euthanasia is used in a more particular sense to mean "mercy killing," for the purpose of putting an end to extreme suffering, or saving abnormal babies, the mentally ill or the incurably sick from the prolongation, perhaps for many years, of a miserable life, which could impose too heavy a burden on their families or on society.

It is, therefore, necessary to state clearly in what sense the word is used in the present document.

By euthanasia is understood an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated. Euthanasia's terms of reference, therefore, are to be found in the intention of the will and in the methods used.

It is necessary to state firmly once more that nothing and no one can in any way permit the killing of an innocent human being, whether a fetus or an embryo, an infant or an adult, an old person, or one suffering from an incurable disease, or a person who is dying. Furthermore, no one is permitted to ask for this act of killing, either for himself or herself or for another person entrusted to his or her care, nor can he or she consent to it, either explicitly or implicitly. Nor can any authority legitimately recommend or permit such an action. For it is a question of the violation of the divine law, an offense against the dignity of the human person, a crime against life, and an attack on humanity.

It may happen that, by reason of prolonged and barely tolerable pain, for deeply personal or other reasons, people may be led to believe that they can legitimately ask for death or obtain it for others. Although in these cases the guilt of the individual may be reduced or completely absent, nevertheless the error of judgment into which the conscience falls, perhaps in good faith, does not change the nature of this act of killing, which will always be in itself something to be rejected. The pleas of gravely ill people who sometimes ask for death are not to be understood as implying a true desire for euthanasia; in fact, it is almost always a case of an anguished plea for help and love. What a sick person needs, besides medical care, is love, the human and supernatural warmth with which the sick person can and ought to be surrounded by all those close to him or her, parents and children, doctors and nurses.

Sacred Congregation for the Doctrine of the Faith. (May 5, 1980). Declaration on Euthanasia. Available at:

http://www.vatican.va/roman curia/congregations/cfaith/documents/rc con cfaith d oc 19800505 euthanasia en.html

For Roman Catholic teachings see also:

Libreria Editrice Vaticana. (1997). Catechism of the Catholic Church, 2^{nd} ed. Vatican: Author. Available at:

http://www.usccb.org/beliefs-and-teachings/what-we-believe/catechism/catechism-of-the-catholic-church/epub/index.cfm

Catholic Health Australia. (2001). Catholic Health Australia Code of Ethical Standards for Catholic Health and Aged Care Services in Australia. Australian Capital Territory: Author. Available at:

https://www.cha.org.au/images/resources/Code%20of%20ethics-full%20copy.pdf

Unites States Conference of Catholic Bishops (2009). Ethical and Religious Directives for Catholic Health Care, 5th ed. Washington, DC: Author. Available at: http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf

Sources for Professionals

In a U.S. state where physician assisted suicide is legal, details what nurses who support PAS and those who are opposed for religious or other reasons

Oregon Nurses Association. (1997). Assisted Suicide: The Debate Continues. ONA Assisted Suicide Guidelines. Available at:

http://c.ymcdn.com/sites/www.oregonrn.org/resource/resmgr/imported/Assisted%2 0Suicide%20Adjusted.pdf?forcedownload=1

Recommended Readings/Viewings

- Brooks, D. (2015). *The road to character*. New York: Random House.
- Emanuel, E. J. (October 2014). Why I hope to die at 75. *The Atlantic*. Available at: http://www.theatlantic.com/magazine/archive/2014/10/why-i-hope-to-die-at-75/379329/

That's how long I want to live: 75 years.

I am sure of my position. Doubtless, death is a loss. It deprives us of experiences and milestones, of time spent with our spouse and children. In short, it deprives us of all the things we value.

But here is a simple truth that many of us seem to resist: living too long is also a loss. It renders many of us, if not disabled, then faltering and declining, a state that may not be worse than death but is nonetheless deprived. It robs us of our creativity and ability to contribute to work, society, the world. It transforms how people experience us, relate to us, and, most important, remember us. We are no longer remembered as vibrant and engaged but as feeble, ineffectual, even pathetic. [Emanuel, E.J. October 2014. *The Atlantic Monthly*. Why I hope to die at 75].

- Kalanithi, P. (2016). When breath becomes air. New York: Random House. Kalanithi's diagnosis is both a death sentence and an opportunity—albeit an unwanted one—for the kind of introspection that many of us claim to want but that never seems possible unless forced by tragedy.

 His decision to go to medical school, he writes, was an effort "to forge relationships with the suffering, and to keep following the question of what makes human life meaningful, even in the face of death and decay." Krug, N. January 9, 2016. An affirmation of life in the face of death. Book World. The Washington Post, C1, 4.
- Maynard, B. (2014). A new video for my friends. Available at: https://www.youtube.com/watch?v=1lHXH0Zb2QI&feature=youtu.be
 In April, I learned that not only had my tumor come back, but it was more aggressive. Doctors gave me a prognosis of six months to live.

 After months of research, my family and I reached a heartbreaking conclusion: There is no treatment that would save my life, and the recommended treatments would have destroyed the time I had left.

 I considered passing away in hospice care at my San Francisco Bay-area home. But even with palliative medication, I could develop potentially morphine-resistant pain and suffer personality changes and verbal, cognitive and motor loss of virtually any kind.

Because the rest of my body is young and healthy, I am likely to physically hang on for a long time even though cancer is eating my mind. I probably would have

suffered in hospice care for weeks or even months. And my family would have had to watch that.

I did not want this nightmare scenario for my family, so I started researching death with dignity. It is an end-of-life option for mentally competent, terminally ill patients with a prognosis of six months or less to live. It would enable me to use the medical practice of aid in dying: I could request and receive a prescription from a physician for medication that I could self-ingest to end my dying process if it becomes unbearable.

I quickly decided that death with dignity was the best option for me and my family. [Maynard, B. November 2, 2014. My right to death with dignity. http://www.cnn.com/2014/10/07/opinion/maynard-assisted-suicide-cancerdignity/index.html]

- Rehm, D. (2016). *On My Own*. New York: Knopf.
- Sacks, O. (2015). *Gratitude.* New York: Alfred A. Knopf. "I am now face to face with dying but I am not finished with living."

It is up to me now to choose how to live out the months that remain to me. I have to live in the richest, deepest, most productive way I can. I feel intensely alive, and I want and hope in the time that remains to deepen my friendships, to say farewell to those I love, to write more, to travel if I have the strength, to achieve new levels of understanding and insight. I cannot pretend I am without fear. But my predominant feeling is one of gratitude. I have loved and been loved; I have been given much and I have given something in return; I have read and traveled and thought and written. I have had an intercourse with the world, the special intercourse of writers and readers. Above all, I have been a sentient being, a thinking animal, on this beautiful planet, and that in itself has been an enormous privilege and adventure. [Sacks, O. February 19, 2015. My Own Life. *The New York Times*.]

And now, weak, short of breath, my once-firm muscles melted away by cancer, I find my thoughts, increasingly, not on the supernatural or spiritual, but on what is meant by living a good and worthwhile life — achieving a sense of peace within oneself. I find my thoughts drifting to the Sabbath, the day of rest, the seventh day of the week, and perhaps the seventh day of one's life as well, when one can feel that one's work is done, and one may, in good conscience, rest. [Sacks, O. (August 14, 2015). Oliver Sacks: Sabbath. Sunday Review, *New York Times.*]

- Sulmasy, D. (November December 2017). Holding life and death in dynamic tension. Health Progress, 30-34.
- 24 & ready to die. Economist Films. YouTube: https://www.youtube.com/watch?v=SWWkUzkfJ4M

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24 & Ready to Die: Using Emily's Narrative to Reflect about the Ethics of Allowing Euthanasia for Patients Who Suffer from Severe and Incurable Distress, including Psychological Disorders

In November 2015, the Economist invited subscribers to visit their film site to watch "24 & Ready to Die," a narrative about Emily, a young woman who found life unbearable and requested assisted dying under Belgium's euthanasia law. See: https://www.youtube.com/watch?v=SWWkUzkf]4M

The release of this narrative followed an influential article in The New Yorker entitled "The Death Treatment" by Rachel Aviv (June 22, 2015) critiquing euthanasia as a "treatment" for incurable psychological suffering. See: http://www.newyorker.com/magazine/2015/06/22/the-death-treatment

While many are adamantly against any physician involvement in suicide or euthanasia and others adamant proponents of the same, some of us are unsure of what we ought to think and believe about these as options in a moral society, about what role physicians and other clinicians should play in counseling and assisting, and about what the criteria should be, including whether or not incurable psychological suffering is sufficient ground for a request to end one's life. This session explores how ethicists might best use a film like "24 & Ready to Die" to invite moral reflection and discourse about these topics.

Discussion Questions

- Should Assisted Suicide and Euthanasia be allowed for patients who suffer from severe and incurable distress, including psychological disorders?
- In what way, if any, should clinicians' beliefs about assisted dying inform what they say or don't say when counseling patients who want to control how and when they die?
- What value does a film like "24 & Ready to Die" have in educating the public about assisted suicide and euthanasia?

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