

Decision Making at the End of Life

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Overview

- Participate in a reflective exercise to get us thinking about how we make decisions at the end of life (EoL)
- Discuss the complexity of EoL care today & the "fragile" consensus that has emerged regarding forgoing treatment
- Explore the roots of this consensus & outline moral norms for treatment decisions at the EoL
- Discuss the issue of artificial nutrition & hydration (ANH)

If It Were Me... A Reflective Exercise

Consider This...

- Nearly two years ago you were diagnosed with congestive heart failure (CHF). In addition to this, you have been dealing with diabetes for over five years, which you have been able to control fairly well. Your overall quality of life has been pretty good since you were diagnosed with CHF, especially since you made some lifestyle changes. Throughout you have been able to do most things as you always have. However, in recent months you have been more & more limited because you often become short of breath with moderate exertion. More recently, you have been feeling lightheaded, weak, & fatigued & as such you go see your physician with whom you have a long-standing relationship. After conducting numerous tests, she informs you that your heart failure has worsened & what's causing the lightheadedness & other symptoms is very rapid, irregular heartbeats. She suggests that you have an implantable cardioverter defibrillator (ICD) inserted because she is concerned that in time you could go into sudden cardiac arrest.
- Would you agree to have the ICD implanted? Why or why not? What factors did you consider in reaching this decision?

Consider This... (cont.)

- You have been living with the ICD now for over a year but your overall condition has progressively worsened. Now you become short of breath with minimal activity & you also have experienced significant swelling in your ankles, feet, legs, & abdomen, all due to the buildup of fluid in your body. You have frequent visits with your physician & are mostly confined to your home with your spouse who remains relatively healthy & active. The fluid buildup has caused considerable weight gain & you also have developed a cough that is worse at night when you are lying down. Just last night the coughing was so bad you felt as though you could not breathe & your spouse called 911 & an ambulance took you to the emergency department (ED) of the local hospital where you received treatment for acute pulmonary edema. In the ED you receive oxygen via a nasal cannula, which helps relieve your symptoms somewhat. Because your breathing is still labored, the ED physician suggests you go to the ICU & be placed on a mechanical ventilator for "a short time" until they can decrease the fluid in your lungs & get you breathing normally again on your own.
- Would you agree to be placed on mechanical ventilation? Why or why not? What factors did you consider in reaching this decision?

Consider This... (cont.)

- You were released from the hospital after over a three week stay, with most of those days in the ICU. Since then, you have been mostly inactive & have not ventured out of your home. You are unable to do virtually everything that requires even minimal exertion. In fact, going to the bathroom or getting something out of the refrigerator has become quite a chore. During your most recent visit with your physician, she makes it clear to you that your condition is very grave & that if you have any chance of living more than a year you will need a major surgery to implant a heart pump, or left ventricular assist device, which is inserted into the abdomen & attached to the heart to help it pump. She also suggests putting you on the transplant list to receive a healthy heart from a donor because she is not sure how long the heart pump will reduce the severity of your symptoms.
- Would you have the surgery & agree to being placed on the transplant wait list? Why or why not? What factors did you consider in reaching this decision?

The Complexity of EoL Decisions & the Fragile Consensus

Time Past, Time Present

- Decision making at the EoL was not always as complex as it is today
- Today, however, confusion & doubt often encompass decisions at the EoL
- What accounts for this?

Time Past, Time Present (cont.)

Pre-Modern Medicine

- Trajectory short with little capacity to intervene—simply did what we could
- Death viewed thru faith as a natural evil that could not be thwarted & something for which we are not resp.
- Personal acceptance & social recognition of the limits of medicine & of life itself
- "Tame" death

Post-Modern Medicine

- Trajectory lengthy with great capacity to intervene—rise of technological imperative
- Death viewed thru technical capacity as a moral evil to fight against & something for which we are resp.
- Personal anxiety & social unease coupled w/rise of patient autonomy & judicial involvement
- "Wild" death

"Wild" Death

- Today death is "marked by undue fear & uncertainty, by the presence of medical powers not quite within our mastery, by a course of decline that may leave us isolated & degraded. It is wild because it is alien from, & outside of, the cycle of life, because modern technology makes its course highly uncertain, & because it seems removed from a full fitting presence in the life of the community" (Daniel Callahan, *Troubled Dream of Life*, 26)

The "Fragile" Consensus

- Despite all this, a fragile medical, moral, & legal consensus has emerged over the last 30 years
- Three main elements of the consensus
 - Forgoing treatment is morally & legally acceptable
 - A moral difference exists between killing & allowing to die
 - Patients' values drive treatment decisions (autonomy)

Adapted from David F. Kelly, *Medical Care at the End of Life: A Catholic Perspective* (Georgetown University Press, 2006).

The "Fragile" Consensus (cont.)

- **1. Forgoing (withhold/draw) treatment is morally & legally acceptable**

- Widely accepted today, but not always the case—advent of modern medical technology challenged us to rethink what causes death
 - Debate emerged in literature following landmark articles (e.g., Raymond S. Duff & A. G. M. Campbell, "Moral & Ethical Dilemmas in the Special Care Nursery" *NEJM* 289 (25 October 1973): 890-94)
 - Numerous court cases arose (e.g., Quinlan in 1975, Brother Fox 1979, Claire Conroy 1979)



The "Fragile" Consensus (cont.)

- With this, there is also wide agreement that withholding & withdrawing are on an equal plane morally—no *a priori* difference
 - Same criteria (benefits/burdens) apply
- Recognizing the real differences
 - Physical & emotional
 - As most clinicians struggled with these decisions 30 years ago but are now comfortable, today's families struggle because it feels wrong: like giving up, abandoning, even killing
 - Don't underestimate the emotional impact & religious significance of these decisions on families
- Fragile because being challenged by those who would make some treatments (e.g., ANH) always obligatory

The "Fragile" Consensus (cont.)

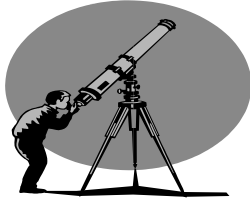


- **2. A moral difference between killing & allowing to die**
 - Some challenge this on basis that result is the same but morally, legally, medically an important line to draw
 - Reduces fear of killing & allows moral freedom to use technology appropriately
 - Goal in allowing to die is not to kill but to forgo a medical means not beneficial &/or burdensome ("hasten" but not "cause")
 - Distinction seems to underlie U.S. Supreme Court decision against constitutionality of PAS—right to forgo but not to receive assistance
- Fragile because of views about PAS

The "Fragile" Consensus (cont.)

- **3. Patients' values drive treatment decisions**
 - Case law, legislation, & moral principles support the right of patients to make treatment decisions in light of their personal values/preferences
 - Assumption is that patients in best position to assess the overall benefits/burdens of treatment
 - Legally much subjective leeway (except for minors & incapacitated w/out ADs) but practical limits
 - Advance directives an extension of legal & moral right
 - Not a panacea, must be part of larger discussion
 - When no AD beware of paralysis & defensive medicine leading to inappropriate & unreasonable treatment
- Fragile because of "medical futility" movement

Exploring the Roots of the Consensus



The Catholic Tradition

- The substance behind the fragile consensus lies in the Catholic tradition on the duty to preserve life
- This tradition has evolved over the course of 500+ years & has largely shaped personal & professional thinking, case law, & legislation
- Three critical features
 - Duty to preserve life
 - Ordinary-extraordinary means: relative norm
 - Meaning of benefit & burden

The Duty to Preserve Life

- Bedrock—Christian understanding of life & death
 - Human life is a great good
 - Strong moral obligation to preserve life
 - Duty not absolutely binding under all circumstances; there are higher, more important values than merely existing physically
 - Philosophically: life foundational but not absolute
 - Theologically: ultimate end lies in eternal life with God

The Duty to Preserve Life (cont.)

- This view is supported in, among others, two relatively recent papal documents
 - "Life, health, all temporal activities are in fact subordinated to spiritual ends" (Pope Pius XII, "The Prolongation of Life," November 24, 1957).
 - "It is precisely this supernatural calling which highlights the *relative character* of each individual's earthly life. After all, life on earth is not an 'ultimate' but a 'penultimate' reality..." (Pope John Paul II, *The Gospel of Life*, 1995, Introduction, Section 2).
- This provides the basis for consensus about the morality of forgoing treatment & the distinction between killing & allowing to die
 - Can't kill ourselves but can refuse non-beneficial &/or burdensome treatment

Ordinary-Extraordinary Means *A Relative Norm*

- Catholic view of life & death stakes middle ground between vitalism & radical self-determinism
- Since the late 15th century, Catholic moralists declared one need only employ "**ordinary**" means of preserving life, but not means that are deemed "**extraordinary**"
 - Extraordinary (or disproportionate) means are those that in the patient's judgment fail to offer a *reasonable hope of benefit* or entail an *excessive burden*, or impose an *excessive expense* on the family or the community

Ordinary-Extraordinary Means *A Relative Norm*

- The substance of this teaching has remained constant throughout the centuries though terms confusing now
- Distinction is **moral not physical**
 - Not treatment but effect on person's overall well-being
 - Simple treatments can be extraordinary (e.g., turning)
- In the tradition, **no means** could be considered ordinary apart from assessment by person of benefits & burdens **relative to** her/his overall condition in life
 - Provides basis for moral right of patients to make decisions according to their personal values

Ordinary-Extraordinary Means

A Relative Norm

- We see this in a comprehensive study of subject, 1958 doctoral dissertation of Daniel A. Cronin (1927-), presently Archbishop Emeritus of Hartford, Connecticut
 - "Another point to understand clearly is the fact that in determining whether a means offers proportionate hope of success & benefit, **one must consider some relative factors**. It is **hardly possible to establish categorically** that a particular means will always offer proportionate benefit under all circumstances & to all people. In other words, it is **difficult to establish an absolute norm** when determining the required hope of success & benefit in **any procedure** designed to conserve life" (emphasis added).

Ordinary-Extraordinary Means

A Relative Norm

- Cronin states further:
 - "In summary, therefore, we may say that the notion of proportionate hope of success & benefit is an essential part of the nature of ordinary means. Without this hope of benefit, a means is hardly an ordinary means & therefore is not obligatory. In determining the presence of this hope of success & benefit, one must consider **not only the nature of the particular remedy or means involved, but also the relative condition of the person** who is to use this means. **Then, & then only**, can the moral obligation of using such a means be properly determined" (emphasis added).

Ordinary-Extraordinary Means

A Relative Norm

- It is against this backdrop that we read in the 1980 *Vatican Declaration on Euthanasia*:
 - "It will be possible to make a correct judgment as to the means by studying the type of treatment to be used, its degree of complexity or risk, its cost & the possibilities of using it, & comparing these elements with the result that can be expected, taking into account the state of the sick person & his or her physical & moral resources."

Ordinary-Extraordinary Means

A Relative Norm

- As well as this in *The Gospel of Life*:
 - "Certainly there is a moral obligation to care for oneself & to allow oneself to be cared for, but this duty must take account of concrete circumstances. It needs to be determined whether this means of treatment available are objectively proportionate to the prospects for improvement."

Benefit/Burden

Its Meaning in Medicine

- Important question:
 - What is the meaning of benefit & burden?
 - How would you define them? What did you consider in our exercise?

Benefit/Burden

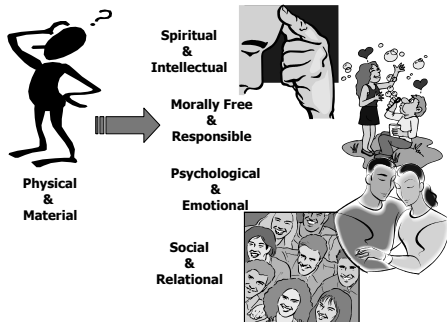
Its Meaning in Medicine

- Danger in medicine is to reduce treatment decisions to technological/physical questions
 - E.g., Can we prolong life? Can we circumvent biological problems?
- Important considerations but fail to understand that what is truly beneficial is a broad human judgment that encompasses more than just the physical
 - Effect vs. benefit

Benefit/Burden *Its Meaning in Medicine*

- This is why the great theologian Francisco De Vitoria (1486-1546) stated:
 - "In the second place, I say that one is not held to lengthen his life because he is not held to use always the most delicate foods, that is, hens & chickens, even though he has the ability & the doctors say that if he eats in such a manner, he will live **twenty years more**, & even if he knew this for certain, he would not be obliged . . ." (emphasis added).

Benefit/Burden *Holistic Understanding*



Benefit/Burden *Holistic Understanding*

- From a moral perspective the question in EoL treatment decisions is:
 - Can the treatment in question improve the person's overall medical condition so that he/she can pursue life's goals, at least at a minimum level, without major burdens?
 - Theologically (McCormick)
 - Experientially (mom)
 - Like the law, much subjective leeway for competent patients but perhaps more limits

Moral Norms

- Physical life is a basic good & as such we have a duty to preserve it; however, this duty is not absolutely binding under all circumstances
- The duty to preserve physical life with medical means is evaluated in light of one's overall medical condition & one's ability to pursue the goals of life (*basic*=relationships; *personal*=values)
- One should be able to make medical-moral decisions for oneself; if one is unable to do this, then a designated proxy should make decisions in light of the stated or implied values of the one in question

Moral Norms (cont.)

- One is morally obliged to prolong physical life with medical means if one's overall medical condition can be improved to the point that one can pursue the goals of life without major burdens
- One is not morally obliged to prolong physical life with medical means if:
 - Medical treatment offers no reasonable hope of benefit in terms of helping one pursue the goals of life *or*
 - Medical treatment imposes an excessive burden & profoundly frustrates one's pursuit of the goals of life, or imposes an excessive expense on one's family or society

Moral Norms (cont.)

- When serious doubt exists as to the overall benefits & burdens of treatment, such doubt should generally be resolved by deciding in favor of life
- Those approaching death should receive compassionate, holistic care & should have their pain relieved to the extent ethically possible so they can enhance relationships at the EoL
 - Support of palliative care

ANH... What's Going on in Catholic Teaching?

A Shift?

Cronin	John Paul II	Burke	Morlino
<p>"In determining the presence of this hope of success & benefit, one must consider not only the nature of the particular remedy or means involved, but also the relative condition of the person who is to use this means. Then, & then only, can the moral obligation of using such a means be properly determined."</p>	<p>■"the administration of water & food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act. Its use, furthermore, should be considered in principle, ordinary & proportionate, & as such morally obligatory, insofar as . . . consists in providing nourishment to the patient & alleviation of his suffering."</p>	<p>"Pope John Paul II made it clear that provision of nutrition & hydration by artificial means constitutes an ordinary & proportionate means. . . For a Catholic, such a document [DPA] will respect fully the dignity of human life. Certainly, it will not exclude the administration of food & water, even by artificial means."</p>	<p>"if someone is terminally ill & close to death & his or her body is still able to process nourishment, then a feeding tube inserted through the nose (nasogastric) would generally be appropriate. A feeding tube inserted into the stomach (gastrostomy tube) more directly involves invasive surgery so that this kind of medical treatment might well be disproportionately burdensome . . ."</p>

ERDs 56-58

- 58: There should be a presumption in favor of providing nutrition & hydration to all patients, . . . , as long as this is of sufficient **benefit** to outweigh the **burdens** involved to the patient.
- 56: A person has a moral obligation to use ordinary or proportionate means of preserving his or her life. Proportionate means are those that in the judgment of the patient offer a reasonable hope of benefit & do not entail an excessive burden or impose excessive expense on the family or the community.
- 57: A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose an excessive expense on the family or the community.

*Note no mention of futility, terminally ill, close to or imminent death

Conclusion

- Summarize main points
- Questions or comments
