BIOETHICAL CHALLENGES AT THE BEGINNING OF LIFE

How Who We Are and What We Believe Influence Reproductive Options and Counseling

Carol Taylor, PhD, RN

New technologies and fundamental changes in the way we perceive basic human realities, fertility, conception and birth, 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 beginning 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.

Objectives

Upon completion of this session participants will be able to:

1. Relate personal and societal beliefs and values concerning human life and reproduction to clinical decision-making
2. Describe the ethical issues related to: avoiding reproduction, assisted reproductive techniques to relieve infertility, technologies to control the quality of offspring, and non-reproductive use of reproductive capacity
3. Reconcile conflicts between faith beliefs and clinical responsibilities.

Reflection questions:

1. What does it mean to be finite--to be creature? Are there ways in which our efforts to control and master nature work against our innate dignity as humans? How are new technologies influencing our sense of what it means to be family, parent, child, spouse?
2. Do persons have a right to produce a child that meets certain specifications (designer baby) at the time and in the manner of their choosing?
   a. If you grant this right, are health care professionals and institutions obligated to meet all the requests patients make, so long as they are requests for legal interventions.
   b. Does the public (taxpayers) have an obligation to fund the services you desire?

3. Since science and technology are increasingly able to produce a perfect child, are parents obligated to use all the means at their disposal to insure a "perfect outcome?" Are those parents who elect not to avail themselves of prenatal screening morally irresponsible?

4. Should access to reproductive technologies be limited? On what basis: marital status? sexual orientation? age? ability to pay? Who should control the use of these technologies? Are reproductive technologies appropriately regulated?

5. In what concrete ways do our faith commitments influence our response to the above questions? How should we respond when our religious beliefs and commitment to personal integrity conflict with our clinical responsibilities?

Reflection

The term "reproductive revolution" is not mere hyperbole. Most human reproduction will, of course, continue to occur as the result of sexual intercourse with only the technology of modern obstetrics involved. The major issues of human reproduction will remain access to prenatal and postnatal care, reduction of infant mortality, provision of adequate childcare, and access to contraception and abortion.

What is revolutionary, however, is the unprecedented technical control that medical science now brings to the entire reproductive enterprise, thereby creating a fertile source of options for individuals facing reproductive decisions. Consider the reproductive topics that have been the focus of media attention since the 1978 birth of Louise Brown: frozen embryos, surrogate motherhood, genetic screening, manipulation of embryos, forced cesarean section, criminal punishment of pregnant drug users, Norplant and RU486, in utero fetal surgery, and fetal tissue transplants. In years to come, other technologies will cascade out of medical laboratories and into social practice, as micromanipulation of embryos, nuclear transplantation, egg fusion, cloning, interspecies gestation, ectogenesis, and gene therapy are developed.

...**The decision to have or not have children is, at some important level, no longer a matter of God or nature, but has become a matter of choice whether persons reproduce now or later, whether they overcome infertility, whether their children have certain genetic characteristics, or whether they use their reproductive capacity to produce tissue for transplant or embryos and fetuses for research** (John Robertson, *Children of Choice*, Princeton, NJ: Princeton University Press, 1994, p. 5)

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Styles of Reasoning: A Comparison (Jean DeBlois)

Donum Vitae	***Secular***
✸ Teleological reasoning	✸ Consequentialist reasoning

✸ Ends/means	✸ ends
Objective	
■ Good of person(s). There is a *givenness* to the good of human persons.	■ Good of person(s) is relative to what I want/ desire and to what is possible ... the technological imperative
Fundamental Values	
■ Life is called into existence	■ Procreative liberty
■ Specific nature of transmission of life in marriage	■ Right to a child of one's own
■ Stewardship is a foundational concept	■ Autonomy is a foundational concept

Assumptions underlying the values expressed in *Donum Vitae*:

1. Human life is present from conception onward and is to be respected in an absolute way.
2. Human life is inviolable.
3. The transmission of human life is to be achieved through a conscious and loving act (marriage).
4. Fertilization must take place within the bodies of the couple.
5. Some actions are wrong regardless of consequences.

For a concise summary of Catholic teaching on Beginning of Life issues read Part Four of the Ethical and Religious Directives for Catholic Health Care Services. 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

Scenarios:

1. A report of one case of sexual transmission of the Zika Virus in Texas has health officials reminding the public that next to abstinence, condoms are the best prevention method against sexually transmitted infections. You are practicing in a clinic in a city with one of the highest rates of HIV infection. Is contraceptive counseling compatible with your religious beliefs? What priority does it have in your professional practice? Is using condoms with the intent to prevent acquiring a sexually transmitted infection ethically different than using them to prevent pregnancy?

2. The State of Virginia is pushing for a program to reduce unwanted pregnancy by making free, long-lasting birth control eligible to women with little or no health insurance. Virginia's Lt. Governor, Ralph Northam, pointed to a similar program in Colorado that led to a 40 percent decline in the birthrate among teens between 2009 and 2013. The Colorado governor's office said the state saved $42.5 million in health-care expenditures associated with teen births. And the abortion rate for 15- to 19-year-olds in participating counties fell 35 percent.

The intrauterine devices and skin implants would be distributed through Department of Health centers across the state. There is no requirement in Virginia for minors to have parental consent before having a contraceptive device implanted. Do you support such a program and the politicians who are promoting it?

3. During your mental health rotation you routinely counsel women with mental health disorders who are ambivalent about continuing an unplanned pregnancy. You are taught that "nondirective counseling" is the standard but are concerned about being morally complicit in decisions to terminate a pregnancy.

4. A couple contemplating in vitro fertilization explain that they "feel better" about the problem of unnecessary embryos because they've been told that they can donate any unused embryos for stem cell research. They ask your opinion about this. Is it ethically relevant if the sperm comes from a donor because the husband is infertile?

5. A colleague tells you that he can't understand "the big to do" about embryonic stem cell research. "What's the issue? We're talking about great benefits for huge numbers of people. To name but a few: 1) a better understanding of human biology at the earliest stages of development, 2) a potentially limitless source of transplantable tissue from people suffering from diabetes, Parkinson's Disease, multiple sclerosis, etc., 3) a way to test new drugs without putting people at risk."

6. A woman with a strong family history of early Alzheimer's disease wants to use preimplantation genetic diagnosis (PGD) to ensure the birth of a child without the gene for early Alzheimer's disease. She asks you if there is any downside to doing this?

7. Britain became the first country to legalize three-parent babies. The treatment, called mitochondrial transfer, creates a genetically modified embryo, with DNA from a mother, a father, and from a female donor. Mitochondrial transfer involves intervening in the fertilization process to remove faulty mitochondrial DNA that can cause inherited conditions such as heart problems, liver failure, brain disorders, blindness and muscular dystrophy. Apart from safety concerns, are there any ethical issues with introducing a third party into the process of fertilization?

Recommended Readings

Cahill, Lisa Sowle. "The Embryo and the Fetus: New Moral Contexts." Theological Studies 54 (1993): 124-142. Analyzes current uncertainty, arising from recent scientific and technological developments, about the "personhood" of life in the earliest stages of embryonic development, as well as to how human life should be treated in any possible prepersonal stages.

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http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19870222_respect-for-human-life_en.html

Congregation for the Doctrine of the Faith [CDF]. Dignitas personae (Instruction on Certain Bioethical Questions). 8 September 2008. Found on the Vatican web-site at the following URL:
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Paul VI. (1968). Humanae Vitae. Libreria Editrice Vaticana. 12: AAS 60 (1968) 488-489.
Available at: http://w2.vatican.va/content/paul-vi/en/encyclicals/documents/hf_p-vi_enc_25071968_humanae-vitae.html

Shannon, Thomas A. and Wolter, Allan B., O.F.M. "Reflections on the Moral Status of the PreEmbryo." Theological Studies 51 (1990): 603-626. Reviews the scientific literature to help determine when the early human embryo becomes an individual, a single entity, and analyzes the claim to personhood in the light of these findings.

BIOETHICAL CHALLENGES AT THE END OF LIFE

How Who We Are and What We Believe Influence Options and Counseling for the Seriously Ill and Dying

Carol Taylor, PhD, RN

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 clinical ethicists play in informing conversations and decisions about treatment and care for those experiencing aging, illness, suffering, dying and death?

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?

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_doc_19800505_euthanasia_en.html

For Roman Catholic teachings see also:
Libreria Editrice Vaticana. (1997). Catechism of the Catholic Church, 2nd ed. Vatican: Author. Available at: http://www.usccb.org/beliefs-and-teachings/what-we-believe/catechism/catechism-of-the-catholic-church/epub/index.cfm

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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/
- Kalanithi, P. (2016). *When breath becomes air*. New York: Random House.

- Maynard, B. (2014). A new video for my friends. Available at: https://www.youtube.com/watch?v=1lHXH0Zb2QI&feature=youtu.be

- 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."

- 24 & ready to die. Economist Films. YouTube: https://www.youtube.com/watch?v=SWWkUzkfJ4M

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.

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