Our Ethic of Care Endures

Learnings from the International Perspective

Carol Taylor, PhD, RN
Georgetown University School of Nursing and Health Studies
taylorcr@georgetown.edu

www.cha.org.au
Objectives

• Upon completion of this session participants will be able to:

• Affirm or challenge the claim that our ethics of care endures

• Critique the role of the Church and our social and healing ministries in responding to challenges created by Victoria’s Voluntary Assisted Dying Act.
Reclaiming the Healing Ministry of Jesus—for Today

• We are each charged with writing today’s Gospel

• Some illustrious models: Mother Teresa of India, Jean Vanier, Sr. Marguerite Therese Maguire, CSFN, ____________
Gospel Healing Narratives—little resonance

Does our “Ethic of Care Endure”? 

- We continue the healing ministry of Jesus...
Our Ethic of Care Endures...

• So what is our ethic of care? Does it get me up in the morning and incentivize my practice?
• Does it give me meaning and purpose—especially when the everyday challenges are huge?
• Does it create a compelling alternative to the terminate life at will thinking that sees no value in suffering or responding to human suffering?
Gospel Care in 2019
see handout...
Caring defines (and blesses) Christians

• Come you who are blessed by my Father. Inherit the kingdom prepared for you from the foundation of the world. ...Amen I say to you, whatever you did to one of these least brothers of mine, you did for me.
Caring is Prophetic in Today's World

- God chose human caring in the person of Jesus as the means of salvation
- The mission of Jesus was a prophetic mission--one of conversion of hearts and cultures
- Our prophetic challenge is to relate the Gospel to today's culture, nurturing, nourishing, and evoking a consciousness and perception which is an alternative to the dominant culture around us [what does it mean to care in today's world]
- The prophetic dimension expresses itself in wisdom, word, and witness (E. Johnson)
So what kind of prophets are we?

• Your photo here...
• How does the prophetic dimension express itself in your wisdom, word, and witness?
• Have we capitulated to secular wisdom?
Pathways to Convergence

- Examined diverse perspectives of Catholics on Advance Care Planning, Palliative Care, and End-of-Life Care in the U.S.
Pathways to Convergence
Charge

• Given the Church’s long-standing commitment to and practice of caring for the sick and dying, grounded in the healing ministry of Jesus, and its social teaching, what is the role of the Church in the public square regarding Advance Care Planning, Palliative Care, and End of Life care.
Outline of Group 1 Report

• When Catholics speak in the public square who is speaking?

• How should we be in the public square?

• What direction do we derive from recent papacies and their themes/priorities around end of life care?

• What messaging does/should the Church give in cases like Brittany Maynard? What does it mean to “companion” those who make choices we cannot support?

• What is the Church’s role to educate about advance care planning, palliative care, and end of life care in general?
When Catholics speak in the public square who is speaking?

- We speak and act as Christians
- We speak and act as the Church
- We speak and act as citizens
- We speak and act as caregivers—family and professional
We speak and act as Christians

- We have a distinctive vision of the dignity of the human person and of the sacredness of human life. We acknowledge God as the Lord of life and the imperative of caring for the injured, sick, and dying (Matthew 25).
We speak and act as Christians

• Consideration: Western society continues to secularize in breadth and intensity. This will continue to negatively impact care of the poor and vulnerable. In this context, we offer a clear and compelling witness to the fullness of life to which our faith calls us.
Dr. Bob Barnet’s Human Drivers: 5 P’s

- Power
- Position
- Prestige
- Profit
- Politics

Strikingly Absent:
- Patients, People, the Public, the Poor
HOW SHOULD WE BE IN THE PUBLIC SQUARE?
Considerations

• One of the places where there is divergence: How prophetic do we think we need to be inwardly to the Church? Is there an appropriate forum for *sensus fidelium* as one of the sources of truth? Can people in the pews, clinicians and Catholic bioethicists bring their experience to theologians and the bishops to inform Church teaching?
Considerations

• I don’t think the public square gives one hoot about our differences with one another. I think that causes people’s eyes to glaze over. I think the question is: whether or not one has the right to decide when to end one’s life. The fact of the matter is how can we help people deal with these questions and what contribution can we make in the public square to pragmatically help people.
Considerations

– Is it possible to acknowledge the fears that lead to physician assisted suicide and redirect the conversation to better explain palliative care?

– Are there particular models of Church that are helpful for engaging the public square?

– Do we need to address the question of competency? i.e. how do we demonstrate the competency of those who speak on this issue on behalf of the Church? Put another way, who is the Church and who speaks for the Church?

– How do we evangelize so that the faithful can join in the public discourse around this issue?
“Last Resort” Palliative Interventions

Ranked From Least to Most Controversial Ethically

• Standard pain management
• Forgoing life-sustaining therapy
• Voluntarily stopping eating and drinking
• Terminal sedation: heavy sedation to escape pain, shortness of breath, other severe symptoms (newer terminology, proportionate palliative sedation [PPS] and palliative sedation to unconsciousness [PSU])
• Assisted suicide
• Euthanasia
As people of faith, avoiding two extremes

Whole person care includes meeting universal spiritual needs:

1. Meaning and purpose
2. Love and relatedness
3. Forgiveness
New Cigna Study Reveals Loneliness at Epidemic Levels in America

- [https://www.multivu.com/players/English/8294451-cigna-us-loneliness-survey/](https://www.multivu.com/players/English/8294451-cigna-us-loneliness-survey/)

The survey of more than 20,000 U.S. adults ages 18 years and older revealed some alarming findings:

- **Nearly half** of Americans report sometimes or always feeling alone (46 percent) or left out (47 percent).
- **One in four** Americans (27 percent) rarely or never feel as though there are people who really understand them.
- **Two in five** Americans sometimes or always feel that their relationships are not meaningful (43 percent) and that they are isolated from others (43 percent).
- **Generation Z (adults ages 18-22) is the loneliest generation** and claims to be in worse health than older generations.
Suicides Have Increased. Is This an Existential Crisis?
Clay Routledge, The New York Times, June 23, 2018

• Suicide deaths are up 25% in the U.S. since 1999 across most ethnic and age groups.

• I am convinced that our nation’s suicide crisis is in part a crisis of meaninglessness. ...greater detachment and a weaker sense of belonging are increasing the risk of existential despair.
WHAT MESSAGING DOES/SHOULD THE CHURCH GIVE IN CASES LIKE BRITTANY MAYNARD?
How to be “present” to the suffering
• We are fighting strong cultural currents, the focus on autonomy, messaging promoted by compassionate choices... It will be increasingly necessary for us to be able to articulate the Catholic teaching and vision on end of life care in a compelling and clear way... part of the goal of this project... bring something to broader Church that would be articulated

• With regard to Brittany Maynard. People throughout the country really connected with her. She had an enormous effect on our society. Unfortunately some within the Church judged her and condemned her and as soon as they did that, what they had to say became irrelevant.
• So how should we be in the public square? Pope Francis provides a powerful witness. He is non judgmental and acutely aware of people’s experience. We do not need to agree with Maynard but acknowledging her experience and the difficulties she faced and not judging her but saying, we do think there is another way to proceed and here it is. Acknowledges and connects with the experience, nonjudgmentally, and offers another way.

• How do we redirect in a positive sense the conversations about legalizing assisted dying to what can we do to address the suffering that creates the demand for assisted dying. Some Catholic groups are adopting the notion “whole person care” which while not unique to Catholic health care is certainly compatible with the best of our teaching.
Distinction between *being a companion* and *becoming an accomplice*

- Then it raises the question, how do we place our selves in companionship with people who make the choice for PAS? How do we walk with people when we’ve laid out options and they make the choice we cannot agree with? How do we walk with them in a nonjudgmental way. Is there a role for us. I think some in the Church would say no. Where is it we continue to place ourselves—not just in the front end as people make decisions but as they continue on their paths.
- If we go back to the Gospel, Jesus walked with all these people, he didn’t just turn his back on them.
- In that sense you are witnessing and modeling the prophetic to be there even in the hard times when you might disagree. It is the prophetic and the pastoral together.
• We can companion people with compassion and a non-judgmental stance while ultimately objecting to the choice. I believe faith based organizations and health care providers need to think carefully about their responses at these multiple levels.
• Many Catholic health care systems and facilities are now in states where assisted dying is legal and they have developed policies. While these provide guidance they don’t address all the human complexities particularly as clinicians deal with patients who are struggling with this decision. While professional associations provide some guidance for clinicians about the boundaries of ethical practice in these circumstance there has been a shift in that positioning with organizations like NHPCO & AAHPM to one of neutrality and the AMA is considering the same shift.
• There are very real practical concerns for clinicians who accompany people choosing assisted dying. For example, what if the attempt to cause one’s death via a lethal prescription is unsuccessful? Our role?

• Are we saying, as we did often with abortion, that we’re not just against abortion but 100% with women who find themselves pregnant and worried about bringing this child to life? The teaching isn’t ambiguous about whether or not we have the right to decide when and how we want to die. But how can we be pastorally present to those suffering?
Two documents from Canada are interesting on the question of appropriate accompaniment in cases of assisted suicide. They take different approaches and clearly illustrate convergence on the moral teaching but great divergence on the pastoral approach. Here they are in order of their publication.

• Addresses death by assisted suicide and euthanasia as “grievous affronts to the dignity of human life from beginning to natural end” and states they are never morally justified. Offers guidance to pastors who are approached for the Sacraments of Healing (Penance and the Anointing of the Sick) and requests for the celebration of ecclesiastical funerals.


- Canada’s legalization of medical assistance in dying “challenges us as a Church and as individual Catholics to grow in our understanding of the Church’s moral teaching on this issue, and it calls us to discern how best to accompany those who find themselves struggling with illness, pain and difficulty medical circumstances.

- In our efforts as Christians to understand and respond pastorally to this issue, the example of Jesus’ own ministry is an important starting point. He ministered to those who were disillusioned as he walked with the disciples on the road to Emmaus (Luke 24:13-35). He listened attentively to the stories of these disciples, and his profound attention allowed them to share the things that troubled them deeply. He eventually led them, through a reflection on the scriptures, to a new awareness and encounter of his presence as they recognized him in the breaking of the bread. The example of Jesus shows us that pastoral care takes place in the midst of difficult situations, and that it involves listening closely to those who are suffering and accompanying them on the journey of their life situation.

US Responses to Dying

• Growing interest in the topic of death
  – Death cafes
  – Death doulas
  – “Death Positive” movement
  – Hospice work
  – End of Life University
  – Special decks of cards that allow families to work through EOL decisions

• But even people trained in comforting others feel a sense of helplessness when a friend or family member is dying
The Comfort of Quiet Companionship
The Washington Post, Dec. 25, 2018

• Sister Rose Marie Dougherty, 79, a member of the religious order School Sisters of Notre Dame, decided to dedicate her attention to what she calls companioning and began teaching it to others

• She created a 9 month Companionsing the Dying Program

• “Its sitting with loving alertness.”
Divergence: Understanding of prophetic voice

- Prophetic (to the world, as well as inwardly to our Church and healing ministries)
- Condemnatory versus “Aspirational”
  - “Prophetic” can be used by those on both the “right and left” of the theological and political spectrum
- Is being Prophetic saying “no” to things or being prophetic in terms of calling people to the good?
Palliative Care and Spirituality for Life Conference

• Partnership: Pontifical Academy for Life, MD Andersen Cancer Center, and Houston Methodist (September 16-18, 2018)

• The conference brought together palliative care and spiritual leaders to explore how to integrate spirituality into palliative clinical practice, develop ecumenical approaches to palliative care that support the spiritual life of patients and caregivers, and advocate for best practices in palliative care around the world [https://www.pcslife.org].
Moral Reflection and Discourse

• Brittany Maynard approaches you one week after learning about her glioblastoma diagnosis and being told that this will more than likely be a horrible way to die. She tells you that she knows she has options and she wants to die when she decides she is ready—certainly before her life becomes a living hell. She asks you if you can help her make this happen.

• How do you respond? What do you want to convey and what words will you use?
What types of medical assistance in dying (MAID) are permitted in Canada?

In Canada, two types of MAID are allowed:

- A physician or nurse practitioner can directly administer a substance that causes the death of the person who has requested it (euthanasia), and
- A physician or nurse practitioner can give or prescribe to a patient a substance that they can self-administer to cause their own death (assisted suicide).
Who is eligible for MAID under Canadian law?

- Be eligible for government-funded health insurance in Canada;
- Be 18 years of age or older;
- Have a *grievous and irremediable condition*, as defined by Section 241.2, para. 2 of the *Criminal Code*;
- Have made a voluntary request for MAID that was not made as a result of external pressure;
- Give informed consent to receive MAID after having been informed of the means that are available to relieve their suffering, including palliative care.
Slippery Slope

- US: Terminally ill (incurable, irreversible disease expected to cause death within six months, as determined by the attending physician and a consulting physician)
- Canada: Have a *grievous and irremediable condition*, as defined by Section 241.2, para. 2 of the *Criminal Code*
- Some European Countries: Severe and incurable distress including *psychological suffering*
In order to have a “grievous and irremediable medical condition,” as defined by Bill C-14, a person must satisfy all of the following requirements:

• Have a serious and incurable illness, disease, or disability;
• Be in an advanced state of irreversible decline in capability;
• Endure physical and psychological suffering that is intolerable to them; and
• Their natural death has become reasonably foreseeable.

Patients must also be capable of providing informed consent at the time that MAID is provided.

https://www.dyingwithdignity.ca/get_the Facts_assisted_dying_law_in_canada
Belgium and the Netherlands

After Assisted Suicide and Euthanasia became legal

• Expansion of inclusion criteria to include psychological suffering
  – 24 and Ready to Die
    [https://video.search.yahoo.com/yhs/search?fr=yhs-SGMedia-sgmedia_emailmoji&hsimp=yhs-sgmedia_emailmoji&hspart=SGMedia&p=24+and+ready+to+die+documentary#id=2&vid=a7e5ff435c6fc446971f35c0a8c20b73&action=view]

• Expansion of inclusion criteria to include children, see e.g., the Groningen Protocol
Million Dollar Question

• The natural lottery has some of us healthy until we die in our sleep or die suddenly in a motor vehicle accident, while many others live long hard lives of suffering. What does the ethics of caring for vulnerable persons dictate as our responsibilities when we cannot cure or even ameliorate the suffering of individuals and their loving families? In what tangible ways can we be “present” to the vulnerable?
What does it mean to continue “the healing ministry of Jesus” in a culture that does not accept the sacredness of human life and that believes there should be no limits to our exercising our autonomy at both the beginning and end of life for any and all legal options?
Legal and Ethical Responsibilities

Navigating Conflicts of Commitment

• How should professional caregivers licensed to practice by a government that now allows VAD respond to requests for VAD?

• Have we successfully resolved the question about whether or not VAD is compatible with the government’s duty to preserve human life and the ethics of our respective professions?

• See the hospice handout and the Oregon Nurses Association assisted suicide guidelines

Slippery Slope

• US: Able to voluntarily express his or her wish to die

• Some European countries: Unfair to those who lack capacity like infants, children, adults with dementia

• Dr. Stanley Terman: “Natural Dying Living Will Cards” and “My Way Cards for Natural Dying” [http://caringadvocate.org/]
Slippery Slope

• A New York Times article recently recounted the story of a U.S. widow with long-term care insurance and a $900,000 nest egg. She developed Alzheimer’s disease and outlived the 5 years of nursing home care her insurance covered and spent down her entire life savings. She had to be moved to a nursing home accepting residents on Medicaid, a prospect friends said would have horrified her. Reflecting on this account, a writer suggested that euthanasia might be an acceptable solution if the U.S. cannot find a way to better meet the needs of vulnerable older persons whose needs exceed our ability/willingness to care.
• 1 in 3 seniors die with Alzheimer’s or another dementia. It kills more than breast cancer and prostate cancer combined.

• 2018 Alzheimer’s disease (AD) Facts and Figures

• More spouses and adult children of individuals with advanced dementia are asking nurses not to feed their loved one. “Mother would never want to live like this.”
Today’s Outcasts

- 16.1 million Americans provide care for people with Alzheimer’s or other dementias.
- These caregivers provided an estimated 18.4 billion hours of care valued at over $232 billion.
- In 2018, Alzheimer’s and other dementias will cost the nation $277 billion.
- By 2050, these costs could rise as high as $1.1 trillion.
In short, we worry about whether we can afford to care, whether we will be willing and able to care, and what we must sacrifice in order to care for the elderly.

How we care for the dependent elderly will test whether modern life has not only made things better for us, but also made us better human beings, more willing to accept the obligations to care and more able to cope with the burdens of caregiving. The President’s Council on Bioethics. (2005). *Taking Care: Ethical Caregiving in our Aging Society.*
Moral Reflection and Discourse

• See the “What to do with Mom” handout.
Does the fact that most would never want to live in late (or even early) stage Alzheimer’s disease, make it ethically justified to cause the death of a person with advanced Alzheimer’s disease by not providing food and fluids? Note, persons with advanced Alzheimer’s disease do not meet the criteria for physician-assisted suicide since they lack decision-making capacity at this point.

• Is withholding food and fluids to cause death compatible with the ethics of nursing?
• Does it make a difference if the person has an advance directive stating that this is what they want?
• Does it make a difference if the attending physician writes an order to honor the daughters’ request?
• What sense do you make of the daughters’ saying that they could not bring their mother home and not feed her because of the guilt they would feel but they believe that health care professionals should be able to do this?
• If you knew that a family planned to do this, would you need to report them to Adult Protective Services?
Moral Reflection and Discourse

• How would you respond to daughters who tell you that they absolutely LOVE their pets but had to euthanize “put down” a Black Lab that was getting increasingly frail. “His death was so peaceful... why can’t mother have a death like this?”
Humane care for animals
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?

2. What does good care at the end-of-life “look like?”
   - pain and symptom management,
   - clear decision making,
   - preparation for death,
   - completion,
   - contributing to others, and
   - affirmation of the whole person

3. How can family and professional care givers respond to the holistic needs of dying persons? What does it mean to be a healing presence for the dying and their families?
4. Do persons have the right to choose the time and manner of their dying? 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. Does the public (taxpayers) have an obligation to fund the services you desire?

5. Is reasonable to assume that once we grant the right to die this may evolve into a duty for some to die so that the resources they are consuming may be better allocated? Should government or some other body be granted the authority to determine who lives and who dies?

6. In what concrete ways should/do individual beliefs, values and faith commitments influence our response to the above questions?
References


