

Christian Perspective on End of Life Issues

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Introduction

- My background
- Disclaimers

1. Background – geriatrician for about 10 years. Took care of nursing home patients for 10 years, to the end of life. Dementia center. Hospital consults, trauma, end of life, goals of care – have had to help many families wade through these issues
2. Disclaimer – have not had to do this directly with family members (recognize that there has been much loss in the church recently)
 - a) Mostly pertains to elderly
 - b) Mostly pertains to Christians
3. Family story – Grandpa and Grandma Woltjer

Agenda

- Overview of Key Ethical Principles
- Advance Directives
- End of Life Decisions

- Time for questions at the end

1. Mention how Jim Ressler gave me several questions on which to discuss – these topics seem a good way to touch on most
2. This is a very complicated field - the information I am giving will be fairly generalized – each case is unique and there can be very complex cases that do not have simple answers

Ethical Principles

- **Morality**
 - What is right and wrong?
 - Beliefs
- **Ethics: the study of morality...**
 - Why is something right or wrong?
 - Rational arguments to justify beliefs

1. Morality and ethics are often used interchangeably. We come to difficult decisions it can be helpful to break down why we think something is right or wrong to help use see our way through the decisions
 - a) a personal or social set of standards for good or bad behavior and character
2. The field of medicine also attempts to do this to introduce some “objectivity” into decision making
3. In general, ethical principles of medicine are parallel to Christianity, but there are some differences, and there are slippery slopes. There have been arguments to transform the teaching and practice of medicine to more closely align with the principles of evolution - this can change some of the fundamental ethics of medicine, and this is why we need to remain anchored on God’s word.

Autonomy

- self rule, free from interference and control by others
- Related to the Sovereignty of God
- Accountability

1. Autonomy – the word is not in the Bible
2. Seems to be based on the attribute of God – Sovereignty
Psalm 115:3 - Our God is in the heavens; he does all that he pleases.
3. The opposite of autonomy: malice, oppression, hate, murder

Problems with Autonomy

- Loss of decision making capacity
 - (un)informed consent
- When autonomy...
 - interferes with others' autonomy
 - produces undue burden on societal resources

1. Capacity defined: choice, understanding, appreciation, reasoning
2. Informed consent
3. Examples of lack of capacity – temporary or permanent
4. Interfering with other's autonomy – pregnant women, exposing others to health risks (driving, smoking), "blasting your radio" – autonomy may be restricted
5. Undue burden on society – excessive use of life support at the end of life. We may restrict autonomy in these situations

Acting in Patients' Best Interests

- **Beneficence** – an obligation to act for the benefit to others
 - Promote benefit
 - Prevent harm
 - Remove harm
- **Non-maleficence** – “*do no harm*”
 - Commission or omission
 - Avoid ineffective treatments
- **Benefit vs. Risk**

1. **Non-maleficence** – Biblical doctrines related to do not kill, avoid malice and oppression
 - a) Doing harmful things to patients
 - b) Doing ineffective things
 - c) Not doing things that would be beneficial
2. **Beneficence** – based on the attributes of God: Goodness, Grace, Mercy, Love; this is respecting the sacredness of life
 - a) Patients are typically seeking help from their physician – expect them to do good, it is our profession
 - b) Physicians should try to convince patients who are refusing clearly beneficial care – we need to try, to provide caring, negotiate a compromise – requires education, communication
 - c) Can involve preventing and removing harm, promoting benefit
3. These terms work together, and often difficult cases involve balancing the 2 sides of this – not always clear cut
4. Examples – removing someone from their home due to risk of stairs, removing treatments that are causing suffering and no clear benefit

Ethics

- Difficult medical decisions often having underlying competing ethical issues
 - Benefit vs. risk vs. autonomy...
- Considering the ethical issues can help guide decision making
- Some of these things can be considered in advance...

Advance Directives

- Regarding Surrogate Decision Maker
- Regarding Medical Interventions
- Practical issues and pitfalls...

“Many patients fear that they will lose control over care if they become mentally incapacitated and that medical interventions will be imposed on them against their wishes.” Advance directives address these concerns.

“Following advance directives respects the individuality and self-determination of patients, even when they can no longer make decisions”

Ideal Advance Directives

- Preferences are informed
- Specific clinical situations and treatments are addressed
- An intention to direct future care is expressed
- Directive is consistent over time

1. Informed – patient needs to be given and understand information about what they are signing. This can be a problem when people are making decisions for future scenarios as they can't fully know all that will be happening at the time. Also can be a problem if a patient lacks capacity
2. Specific situations addressed – terminal vs non-terminal, “no heroics” vs specific medical interventions
3. **Interpretation** – the less specific a directive is, the more room for interpretation - they can be over or under interpreted
4. Intention to direct future care – be careful of verbal comments “if anything like that ever happens to me, just let me go” when discussing someone else in casual conversation
5. **Other problems:** AD's may conflict with patient's best interests when it comes time to use them. **Patients may change their minds**

Types of Advance Directives

- Oral
- Written
 - Living Will
 - Power of Attorney
 - POLST

Oral are not ideal – if they are given to a physician they should be documented, but they can be fraught with problems

Living Wills

- Directives that allow for withholding or withdrawing life-sustaining treatment *only if...*
 - No decision making capacity
 - “terminal condition”
- Problems
 - Very specific situations
 - Made out of context

1. Limited scenarios – **no capacity**, fairly narrow definition of **terminal condition** – they don’t apply in many/most situations
2. Patients often falsely believe this “covers them”
3. They are made “out of context” which can limit their usefulness

Power of Attorney (POA)

- Designation of legal surrogate decision maker
 - Immediately or future
- More comprehensive and flexible than Living Will
- Agent must “act on behalf of the patient”

A person simply needs to assign a trusted individual to be the POA, but does not necessarily need to understand and think about all possible future scenarios.

It can be good to discuss some values/preference with the POA, especially if there is no document stating such

Key Point – the POA must act in the best interests of the patient according to what the patient would have chosen, not simply on the POA’s personal preferences

Without a POA – PA state law has provisions for “health care representative”

Medical POA - Essentials

- Appointment of surrogates (and alternates)
- Clarification of surrogate's role
- Duration of POA
- Statement of Immunity for POA
- Witnessed or notarized

- Can a POA be changed?

Alternates – consider an aging spouse, or death of a spouse – things may need to change

Surrogates should be aware they are being named and agree to it, and patient should discuss values/preference with them

Other close family members should be aware of who the surrogate is and how this role works

Role – doing what the patient would have chosen if they could participate
- POA is not the decision maker unless POA is incapacitated

Immunity as long as POA acts in patient's best interests

POLST

- Pennsylvania Orders for Life Sustaining Treatment
- Differences from Living Will
 - Active when signed
 - Can be signed by surrogate
 - Honored by EMT, nursing home, hospital

Orders are valid wherever patient is, as long as form can be found
POLST does not rely on incapacity or terminal condition
Can be done patient or their representative/surrogate

End of Life

- Ethical Principles
- Advance Directives
- **Medical Decisions at End of Life**

- Communication is crucial
 - Patient, family, medical team, God

We've given some background, now we are going to talk about medical decisions in later life and at the end of life.

Ideally we would have excellent communication with relevant parties at this stage. God included. Making good decisions requires patients/families to be informed and this can only come through communication.

Christian View of Aging and Death

- Phil. 1:21 “To live is Christ, to die is gain.”
- Hope
 - Rev. 21:4
 - 2 Corinth. 4:16-18
- Finishing Well

1. We as Christians have a unique perspective related to death. Death is not the end. Earthly life is a temporary stop on our way to eternity
2. Philippians 1:18-21: Yes, and I will rejoice, ¹⁹ for I know that through your prayers and the help of the Spirit of Jesus Christ this will turn out for my deliverance, ²⁰ as it is my eager expectation and hope that I will not be at all ashamed, but that **with full courage now as always Christ will be honored in my body, whether by life or by death.** ²¹ For to me to live is Christ, and to die is gain.
3. Hope
 - a. **Hope for a cure and continued life on earth:** not bad to hope and pray for. Hope for a long life will be doomed to failure. I Corinthians 15:19 - If in Christ we have hope^a in this life only, we are of all people most to be pitied
 - b. **Hope in heaven;** eternal life with God, hope in his grace given through Christ – but you can rest on this hope too early – God may want us on earth longer
 - c. **Hope in God** – the most appropriate hope. Trust him... **The fundamental question is, do we believe that he is good and that he is in control of the situation, allowing us to have hope in him?**
 - d. Rev. 21:4 - He will wipe away every tear from their eyes, and death shall be no more, neither shall there be mourning, nor crying, nor pain anymore, for the former things have passed away.
 - e. 2 Corinthians 4:16-18: So we do not lose heart. Though our outer self is wasting away, our inner self is being renewed day by day. ¹⁷ For this light momentary affliction is preparing for us an eternal weight of glory beyond all comparison, ¹⁸ as we look not to the things that are seen but to the things that are unseen. For the things that are seen are transient, but the things that are unseen are eternal.
4. **Finishing well “God is glorified in our lives until the moment of our deaths and then by the legacy we leave behind.** (Dunlop book)

- “Spiritual life begins while we are living on this earth, but we will not experience its fullness till we are free from sin in the presence of God; then we will enjoy it through all eternity. We err when we overemphasize the value of physical life at the expense of our life with God.”
– Dunlop

Easier said than done...

- Sin leads to aging and death
- Acts 14:22
- Death is an enemy... but a defeated enemy

- Role of pastors, chaplains...

Acts 14:22: through many tribulations we must enter the kingdom of God.

Death is an enemy – we fear it due to pain and suffering we will experience in the process, separation from loved ones. But **God is in control**

Role of pastors/chaplains – can help us see God through this difficult process when we are caught up in the emotion and pain of the dying process

Changing Gears

- From “cure” to “comfort”
- From quantity of life to quality of life

- Benefits
- When?
- How?

There comes a time as people grow older and are suffering from one or more serious medical conditions when the focus and goals must shift from “cure” to “comfort”
-From quantity to quality of life

-The challenge is knowing when and how this can be done

-- as Christians, we also have the tension between “letting go” and honoring the sanctity of life

Benefits of Changing Gears

- Psalm 90:12
- How should we spend our final days?
 - “Being Mortal” by Atul Gawande
- Surrendering control to God
- Honoring the Gospel

1. Psalm 90:12: So teach us to number our days that we may get a heart of wisdom. By recognizing the little time that is left in life, focus can be put on the things that really matter
2. We stop fighting to try to control our medical condition and prolong earthly life, and recognize that God is ultimately in control

When to Change Gears

- Communication
- Diagnosis is clear
- Death is a strong probability
- If treatment will likely:
 - prolong pain and suffering
 - prolong life with a severe and progressive condition with little chance of benefit
 - lead to death “on machines” when this not what individual would want

1. Communication – need to talk to medical team, family, pastors, God
2. Diagnosis – sometimes you need to do more treatments or testing to arrive at a more clear diagnosis – the diagnosis will help you then change gears when you understand option
3. Death is likely no matter what you do

Important Considerations

- Emotional
- Spiritual
- Social

1. Emotional – DAGBA, you and/or family may have to work through some of the grieving process to be ready for letting go
2. Spiritual – people may need to feel “right with God” to be ready to let go – they may need help with this
3. Social - How does letting go affect others close to the patient? This may impact when/how we change gears

Objection – Do Not Kill

- The 6th Commandment
- Westminster Confession Question 136:
 - Forbidden: “neglecting or withdrawing the lawful and necessary means of preservation of life”
 - Matthew 25:42-43
 - James 2:15-16

Matthew 25:40-45: ⁴⁰ And the King will answer them, ‘Truly, I say to you, as you did it to one of the least of these my brothers, ^[a] you did it to me.’

⁴¹ ‘Then he will say to those on his left, ‘Depart from me, you cursed, into the eternal fire prepared for the devil and his angels. ⁴² For I was hungry and you gave me no food, I was thirsty and you gave me no drink, ⁴³ I was a stranger and you did not welcome me, naked and you did not clothe me, sick and in prison and you did not visit me.’ ⁴⁴ Then they also will answer, saying, ‘Lord, when did we see you hungry or thirsty or a stranger or naked or sick or in prison, and did not minister to you?’ ⁴⁵ Then he will answer them, saying, ‘Truly, I say to you, as you did not do it to one of the least of these, you did not do it to me.’

-This speaks to withholding something that is needed and beneficial to a person’s wellbeing, something that is ordinary and common: I do not think this pertains to extraordinary measures

James 2:14-18: ¹⁴ What good is it, my brothers, if someone says he has faith but does not have works? Can that faith save him? ¹⁵ If a brother or sister is poorly clothed and lacking in daily food, ¹⁶ and one of you says to them, “Go in peace, be warmed and filled,” without giving them the things needed for the body, what good ^[a] is that? ¹⁷ So also faith by itself, if it does not have works, is dead.

¹⁸ But someone will say, “You have faith and I have works.” Show me your faith apart from your works, and I will show you my faith by my works.

-This passage relates to how faith and works must intersect. This is similar to the first passage in that it is speaking about necessary and ordinary necessities of life. I do not think this requires us to keep people alive at all costs.

-Miracles:

- God can do miracles with and without God
- Trust God and pray
- Read the signs...

How to Change Gears

- Communication (family, God, MDs)
- Advance Directives?
- Focus medicines/treatments on comfort
- Role of Hospice (Barbara Heisey)

The Very End

- Use of technology
- Withholding care
- Withdrawing care

Technology

- Opportunities
- Challenges

1. Types – dialysis, ventilators, surgical procedures, ICU, feeding tubes – **we have more than ever before, creating new dilemmas**

2. Opportunities:

- a) God gave us the knowledge and resources to use it
- b) God often wants us to be healed – Jesus healed many

3. Challenges

- a) Doctors and technology can become idols
- b) Just because we can do something doesn't mean it is wise – what is the financial cost, suffering that results – “it is not essential to do everything medically possible to affirm the sacredness of human life. There comes a time when death by natural causes must be accepted.” Hollman
- c) Technology can get in the way of necessary reflecting and relating at the end of life
- d) Are we honoring loved one's wishes
- e) Nothing is without risks

Technology – Guiding Principles

- Ordinary vs. Extraordinary
- Proportionate vs. Disproportionate
 - context
 - burden vs. benefit
 - futility
- Be aggressive early
- Clarify purpose and goals, review often
- Pray – recognize God’s Sovereignty

1. Ordinary vs extraordinary, proportionate vs. disproportionate

- a) We need to look at the overall clinical context to determine how aggressive to be with technology
- b) Weighing the likely or potential benefit vs the expected burden of the treatment can help
 - i. Example: ventilator for younger person with rib fractures/pneumonia vs ventilator for very frail older person with multiple organ failure and dementia
 - ii. **It could be wrong to forgo aggressive care in someone in whom it would be beneficial...**
- c) **Futility**
 - i. Very low likelihood of significant clinical improvement despite the addition of treatment
 - ii. Harm is much more likely than benefit
 - iii. Are we defying God’s will that the patient should die? **Are we delaying natural death?**
 - iv. “Medicalizing technology to prolong life indefinitely is as futile as it is obscene.” Hollman

2. Be aggressive early

- a. People will respond to treatments better early in the disease process (MI, trauma, cancer, etc)
- b. As the body weakens, organs fail, side effects develop – there will be less and less benefit to aggressive treatment

3. Clarify purpose and goals, review often

- a) Is technology achieving a specific purpose in line with patient’s values/wishes (e.g. keeping them alive until family arrive, special event, etc)
- b) Need to include key medical professionals, **palliative care**

Practical Points

- Nutrition
 - Hunger at end of life
 - Comfort or pleasure feeding
 - Tube feeding
 - IV nutrition
- Breathing
 - Ventilator – “breathing machine”
 - Non-invasive support
 - Oxygen
 - Morphine
- CPR

Nutrition

- People are not hungry when they are dying – we are not starving them
- Tube feeding – does not prevent aspiration – especially in dementia
- IV nutrition – only in hospital, not long term
- Comfort feeding – at end of life, giving bits of food or drink can provide comfort

Breathing

- Ventilators: only a few facilities can take them, can be hard to get off
- Non-invasive: BiPAP
- Oxygen – can provide comfort
- Morphine – can take away “air hunger” and if used properly does not hasten death

Withholding vs. Withdrawing Care

- No moral or ethical difference
 - Goals
 - Values
 - Futility/value of treatment
- There is a psychological difference...

It is often questioned if withholding care and withdrawing care are the same?

-Is withdrawing are killing?

-If you have considered the goals, values, and futility of the treatment, then they are ethically and morally similar

Psychologically – it can feel like you are causing death if you remove treatment

-This should be considered before you start something

-Remember that the person is being artificially kept alive when the natural course would be death – you are allowing natural death to occur

Quality of Life

- Sanctity of Life
- Considerations – what is the context?
 - trajectory
 - potential
 - values
 - suffering
- Palliative care honors the sanctity of life

1. Sanctity – extreme situations can occur

- a. “Life begins at conception” – a helpless being that has the potential to become a fully functioning human
- b. End of life in very elderly – they lived a natural life, natural death is expected and welcomed
- c. Challenges are in the middle - babies with birth defects, younger people with severe illness/injury

2. Trajectory – where are things heading – continued loss of function and progression to natural death? Recovery? Stabilization?

3. Potential – what can we expect? Will a person be able to relate to others? To God? Will they require machines/artificial support to live?

- a. Requiring a certain level of “productiveness” or “function” can be against Christian principles
- b. Can create dilemmas in people with dementia, stroke, MR, etc.
- c. “A health care system that only cares for me when I can be expected to return to productive life denies the sacredness of human life. When humans care and love without expectation of return, they mimic God’s caring and loving; they enhance the value and beauty of life; and they will reap eternal rewards. These benefits are not in the secularist’s equation.”
Hollman

4. What would the person value?

5. Suffering – someone may be alive, but what level of suffering will they have?

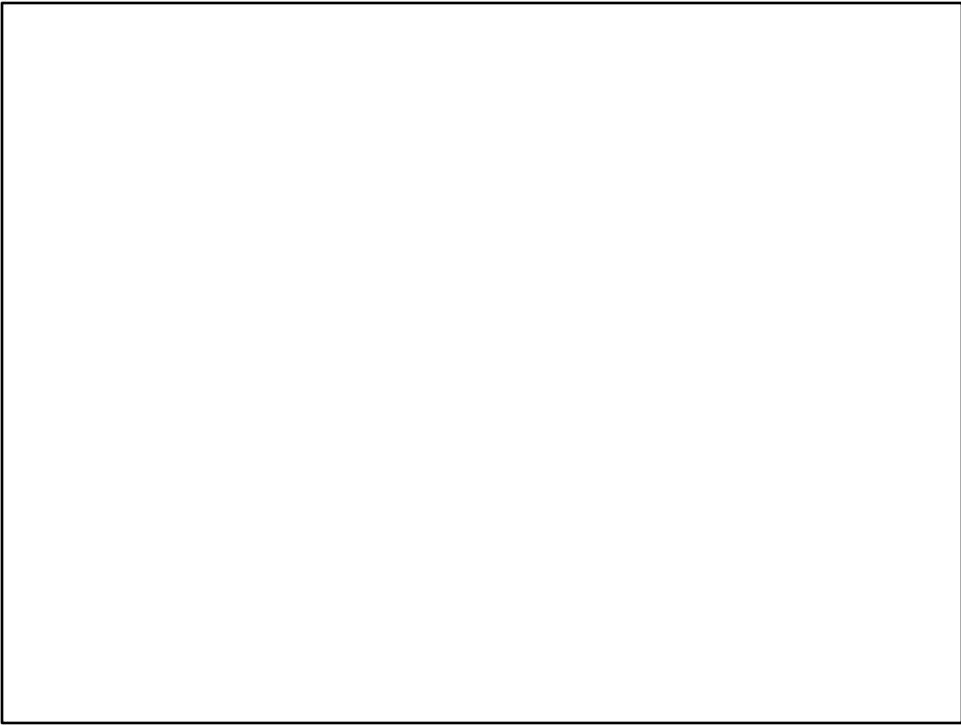
6. Palliative Care – relief of suffering when death is imminent still honors the value of the person and their life

Closing Thoughts

- Genesis 3:22, John 3:16 – the Gospel
- Accepting aging and death as part of spiritual maturity
 - Quote
- Questions?

Quote:

“Realizing and accepting the limitations imposed by the summation of disease and the aging process are important steps in spiritual maturity. Once consensus is reached by the patient, family, and health care professionals, and it is decided that the patient will live out the natural history of the disease, it is important to affirm the decision, accept the inevitable, and make the remaining time as pleasant as possible. To continue to second-guess the decision for conservative therapy or to deny the scientific evidence that death is highly imminent and probable, will make the last days of life unnecessarily anxious. God is still sovereign.” Hollman page 175.



Later Life Decisions

- Weigh Benefit VS Harm
 - Time to Harm
 - Time to Benefit
 - Magnitude of *clinical* benefit
- Consider life expectancy

1. For many things in medicine – as you age the potential harms increase and the benefits decrease
2. Time to harm – usually fast
3. Time to benefit – longer (cancer screening: colon 10 years, breast 5 years. Lipids: 5-10 years, DM control 8-10 years, HTN 6m-1 year, OP 1-2 years.)
4. Magnitude of clinical benefit – a new heart valve may make the heart pump better but will it make the person feel or function significantly better??
5. Life expectancy - ? Life table in handout.

Justice / Fairness

- God is just
 - Jeremiah 17:10
 - Ecclesiastes 12:14
- Giving to the Needy / Avoidance of Greed
- Stewardship / Societal Resources

1. Bible – God is Just Jeremiah 17:10: “I the LORD search the heart and test the mind, to give every man according to his ways, according to the fruit of his deeds.”
2. Bible - *Ecclesiastes 12:14*: For God will bring every deed into judgment, with every secret thing, whether good or evil.
3. This principle is not as much about giving people what they deserve based on their actions, but treating people with similar ethical situations in similar ways - giving people of all races/SES an opportunity for similar treatment.
4. On a population level we need to consider stewardship, allocation of resources
5. This can be hard for individuals to incorporate into personal decision making

Other Ethical Principles

- Confidentiality
 - Giving vs. receiving information about a patient
- Truthfulness
 - Important for informed consent

Biblical principles – do not bear false witness

Confidentiality – may need to be broken to protect individuals from harm – only certain people can be given information about a patient

Truthfulness – we need to avoid misrepresentation or withholding key info to optimize individual autonomy