

What Matters in The End: Empathy and Ethics in End-of-Life Care



One focus. One purpose. Your child.

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Objectives

- 1. Examine changing concepts of dying across the age spectrum
- 2. Identify unique psychosocial and medical dynamics to the provision of care in severe chronic and life-threatening conditions in the pediatric population.
- 3. Identify challenges in discussing poor outcomes
- 4. Construct practical frameworks of “arc of life” and “scale of life” to discuss outcomes
- 5. Design tools to build trust with parents
- 6. Construct methods to foster hope, even as end-of-life for a pediatric patient approaches, by reframing the dying experience into an opportunity to take control

You do what????

- The Road to Medical Director of a Pediatric Palliative Care Program
 - Western Michigan University, Comparative Religion and Biomedical Science
 - Wayne State University School of Medicine
 - MD
 - Pediatrics Residency/Chief Residency
 - Hospice and Palliative Medicine Fellowship
 - Children's Hospital of Michigan



“A simple child, that lightly
draws its breath,
And feels its life in every limb,
What should it know of
death?”

William Wordsworth, 1798

#1 thing heard: the death of a child is so unnatural...

- Or is it...
 - In 1600 AD: 40% child (under 18) mortality
 - In 1900: 30% child (under 5)
- Only recently have major changes occurred
 - In 2000: 1.4 % child (under 5) mortality
 - In 2000: 2.2% child (under 18) mortality
 - In 2017: 0.9 % child (under 5) mortality
 - In 2017: 1.5% child (under 18) mortality



- We are the only species, and only recently, who have the luxury of saying the death of a child is unnatural...

- We may be the only species where the old aren't dying either...
- Ancient Greece—28 years
- Early 20th century—30-45 years
- 2000, worldwide—67 years
- 2018, USA—79 years

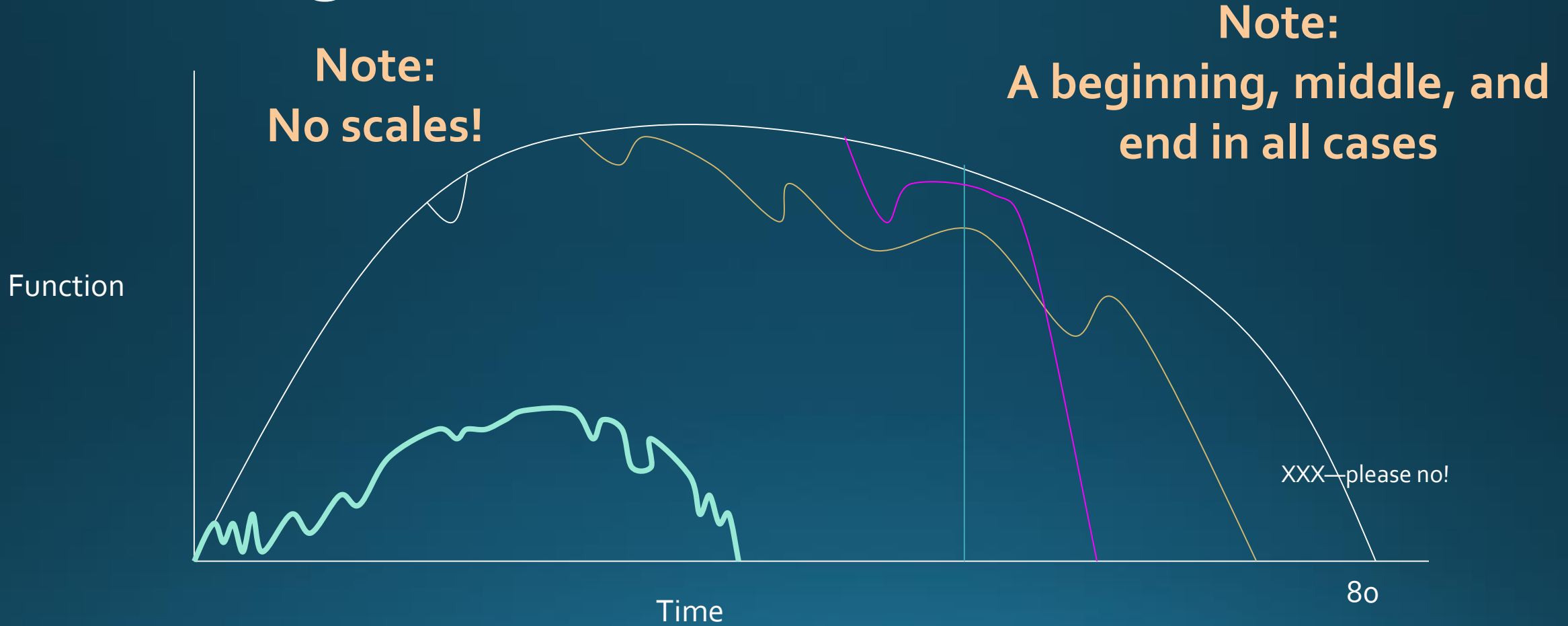


Kane Tanaka 117 years old, born 1/2/1903

Medical Success is Bittersweet

- Good news:
 - Less kids dying
 - More people living longer
 - (77,000 Americans over 100 years old!!!)
- Bad news:
 - Death has become abnormal, the enemy
 - Isolation and lack of support for those still suffering
 - The “Art of Dying” has been lost
 - How do we support those going through this?

Providing a framework for discussion



Defining Quality of Life

- Never Walk, Never Talk, Never Eat
- Joy—Pure “unadulterated” joy
- Survival
- Success as a parent, as a person
- Meaning
- “Beating the odds” and “proving them wrong”

Building Trust to
Start the Conversation

Listen

Relieve

Empower

Listen

- Get the medical record from the medical record....
Get the story from the family.
- Stay silent, don't interrupt
- Be aware of misperceptions and altered timing, but don't correct unless needed
- Make note of what family thought was important

Relieve

- Always look for something simple that you truly can fix
 - A blanket
 - A good night's sleep
 - Pain
 - A billing problem
- Trust is a two way street, and both parties must be invested

Empower

- Identify things family can do
 - Advocate for their children
 - Involve in treatment plan
 - Types of medications
 - Discharge criteria
 - Anticipate problems and provide solutions
 - “Back up” Medications
 - Access to pager/phone

Making dying sound good????

- The palliative care perspective
- Blumenthal-Barby J, Loftis L, Cummings CL, et al. Should Neonatologists Give Opinions Withdrawing Life-sustaining Treatment?. *Pediatrics*. 2016;138(6):e20162585
- Best Interest Standards
 - Life
 - Health and health care
 - Basic needs
 - Protection from neglect and abuse
 - Emotional development
 - Play and pleasure
 - Education and cognitive development
 - Expression and communication
 - Parental relationship
 - Identity
 - Sense of self
 - Autonomy

GOOD
DEATH

Thinking about *The End*

- Has someone very close to you died?
- Have you seen somebody die outside of your professional life?
- Have you ever had to make end-of-life decisions for a family member?
- Approximately how many funerals have you attended in your life?
- Have you seen someone die in an ICU or ED?
- What do you think happens to you when you die?
- Burial or Cremation
- Do you believe in ghosts...

Opportunity to Ensure “A Good Death”

- Common Themes
 - Not to be alone
 - To be free of physical pain
 - To be surrounded by loved ones
 - To be at peace and die naturally

Finding good choices when they all seem bad...

- There is never
 - “nothing more we can do”
 - “withdrawal of support or care”
 - “futile care”
- There is hope for something incredible, that none of us have to offer each other, but we can offer to our terminally ill patients:

A Good Death

Opportunity to Ensure “A Good Death”

- Personal Views
 - Identifying with struggle
 - Fear of ghosts
 - Sudden or anticipated
 - Location of death
 - Would you like your last day to be your best or your worst?

- What would you give to guarantee yourself a good end?





“We are a culture that denies death...
Therefore we are all walking towards death backwards! It is better to turn
around.”

--Michael Meade

- *"A medicine that embodies an acceptance of death would represent a great change in the common conception, and might set the stage for viewing the care of dying people not as an afterthought when all else has failed but as one of the ends of medicine. The goal of a peaceful death should be as much a part of the purpose of medicine as the promotion of good health. That means medicine must abandon the modern cultic myth that in the cure of disease lies the cure of death.... Disease and death will have their day."*
- *--Daniel Callahan, adapted from "The Troubled Dream of Life"*

On a dark and stormy night...



Thank you for your attention!
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