Talking Death:
Best Ways to Convey the Worst

- Talking Death: Best Ways to Convert the Worst
- No Disclosures
- Who is dying?
- Why we didn't tell him he was going to die
  - Assumed the patient already knows
  - Lack of ownership of responsibility
  - Uncertain trajectory
  - Young
  - We think we have told them (medical gobbley-gook)
  - Didn't want to take hope away
  - Didn't have time
  - We didn't realize he was dying (or uncertain of timing)
    - Bad diagnosis to miss
    - Would it surprise me if patient died in next 12 months? next week? next 24hours?
  - Fantasy that we can be ageless…Talking about death makes the uncomfortable demand to accept they are not
- Why it matters to discuss dying
  - As patients approach end of life
  - Treatments less effective
  - Treatments become more burdensome
  - Patient goals/priorities change
- We need to have the conversation
  - Too few geriatricians, palliative care providers
  - They are under our care
  - Patients and families expect to guide them in this process
- Understand Patterns of Death
  - Help family understand patterns of dying

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- Help you understand and take care of your patients
- Sudden Death
  - This is how everyone dies?
  - This is how EPs think of patients — the spectacular death
  - We don't think of them dying until they do
- But that is not how death happens today
  - Living longer
  - Things fall apart
  - ODTAA (One damn thing after another)
- Terminal Illness (Cancer)
  - Fall of cliff and never come back
  - Lengthy disease with sharp decline
  - Functional status very predictive
    - How much does patient spend in bed
      - >50% 2-3 months
    - Rapid change over last couple months?
- Organ failure (CHF, COPD)
  - This is the hardest one
  - Family has been told before their loved one is dying, but they bounced back
  - Respond well to critical care
  - They fave been through the hospital / critical care system before
  - Prognostician is hard
    - Need more information to know this patient is dying
    - Clues of decline
      - Coming in more often
      - Leaving to higher levels of care
  - Aggressive initially

- Use their past experiences to guide care

- Frailty (Dementia)
  - Slow decline
  - Almost impercebilty to those around patient
  - “Joe is a man of of few words”
  - Profound disability / ADLs
  - What defines the end of their life is complications
    - Infections
    - Eating problems
    - Not setback, but expected complication
  - Can extended but not improve life
  - Months = aD + recurrent infections
  - Not going to leave the hospital better, not going to have improvement like organ failure
  - Difficult question: When should we try to fix and when should we not?

- Seek Trajectories
  - Ask about function
  - Read the chart
  - Ask the family
  - Allows qualitative prognostication
  - Helps you formulate appropriate medical plan and provide guidance

- Change in care of elderly
  - Loss of multigenerational caregiving
  - Elders don’t mind loss of veneration
  - Value of independence

- What Patients Fear
  - It is not generally death that they fear.

- It is what happens short of death
  - Losing their body parts
  - Losing function (vision) and bodily control
  - Losing their memory
  - Losing their family & best friends
    - Being alone and abandoned
  - Losing their independence
  - Losing their way of life
- Dying is a continuous series of losses.

- What do patients want
  - Be clean
  - Mentally aware
  - Caring nurse
  - Control time and place of ones death
  - Be Prepared (resolve unfinished business)
  - Sense of completion
- Not our perspective, but the patients
- Not really what they want
  - Coming to the ED because they want the tube, tests
  - They want the goods
  - They want more time
- Hierarchy of Needs
  - Maslow — Theory of Human Motivation
  - Pyramid
    - Basic needs—the essentials of physiological survival (such as food, water, and air) and of safety (such as law, order, and stability).
    - Need for love and for belonging.

    - Desire for growth—the opportunity to attain personal goals, to master knowledge and skills, and to be recognized and rewarded for our achievements.
    - At the top is the desire for self-fulfillment through pursuit of moral ideals and creativity for their own sake.
  - Simply existing—merely housed and fed and safe and alive—seems empty and meaningless to us.
- How to patients weight decisions
  - In theory, a person should make decisions about life and death matters analytically, on the basis of the facts.
    - But the facts were shot through with holes and uncertainties.
  - Wants are fickle.
  - Everyone has what philosophers call “second-order desires”—desires about our desires.
  - Doctors who listen to only the momentary, first-order desires may not be serving their patients’ real wishes, after all.
  - Brain gives us two ways to evaluate experiences like suffering
    - How we apprehend such experiences in the moment and how we look at them afterward—and the two ways are deeply contradictory.
    - Peak-End Bias
      - Nobel Prize–winning researcher Daniel Kahneman
      - Memory bias for more emotional events (i.e., peak is memorable)
      - Recency bias in memory (i.e., end is memorable)
    - Tradeoff between burden and outcome
  - In the end, people don’t view their life as merely the average of all of its moments—which, after all, is mostly nothing much plus some sleep. For human beings, life is meaningful because it is a story. A story has a sense of a whole, and its arc is determined by the significant moments, the ones where something happens.
  - A seemingly happy life may be empty. A seemingly difficult life may be devoted to a great cause. We have purposes larger than ourselves.
  - And in stories, endings matter.
  - Patients want to seek meaning
    - Worthwhile life is one with a cause beyond ourselves (meaning)

- How we seek to spend our time (ie choices we make) may depend on how much time we perceive ourselves to have.
  - "Socioemotional selectivity theory."
  - The simpler way to say it is that perspective matters
  - Shawshank Redemption
- Allowing people meaning
  - We have room to act, to shape our stories, though as time goes on it is within narrower and narrower confines.
  - How we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life;
  - Technological society has forgotten what scholars call the "dying role" and its importance to people as life approaches its end.
  - People want to share memories, pass on wisdoms and keepsakes, settle relationships, establish their legacies, make peace with God, and ensure that those who are left behind will be okay.
  - They want most to end their stories on their own terms.
  - This role is, observers argue, among life's most important, for both the dying and those left behind.
  - And if it is, the way we deny people this role, out of obtuseness and neglect, is cause for everlasting shame.
  - Over and over, we in medicine inflict deep gouges at the end of people's lives and then stand oblivious to the harm done.
  - In the end most people make decisions
    - Nonmedical >>> medical
    - Quality of life >>> quantity of life
    - Outcomes >>> treatments
- Barriers to holding a Family Meeting
  - Time
    - ICU team is 10 pts, at 30 min for each family meeting that is 5 hours/day

- Multiple caregivers
- Family Dynamics
  - Families of ICU patients are often emotionally distressed— anxious, depressed, traumatized, and grieving
  - Multiple inter-relationships all with their own dysfunction — guilt, anger, resentment, fears
  - Magnified by stressful situation
- Culture and Language
- Stress
  - Hard to overestimate the emotional stresses for clinicians practicing in the critical care setting.
  - Death is a regular event
  - Troubled by personal fears of dying
  - Repeated exposure to death during is psychologically traumatic
  - Long work shifts present dozens of decisions about triage and intensive care therapies, each carrying significant and often permanent consequences.
  - With rapid changes in patient status, there is little “down time” for rest or relief of tension, especially in the face of institutional pressures to maximize bed turnover and minimize length of stay.
  - Physical and emotional fatigue take their toll. The cumulative impact of these stresses contributes to the phenomenon of “burnout,” now recognized as a major problem for both physicians and nurses in the ICU
- Space
- Ill-defined goals
- Lack of skills

- Identify automatic triggers for family meetings
  - Within 24 hours of admission for patients
  - Predicted length of stay >5 days
  - Mortality risk greater than 25%
  - Significant decline in functional status

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- Strategies for a successful Family Meeting
  - Maximize time efficiency
  - Include the family meeting in daily checklists, reminder tools
  - Use printed informational aids
  - Clarify goals of meetings ahead of time
  - Engage and empower nurses in the family meeting process
  - Involve other professionals and staff: social work, pastoral care, case management
- Holding the Family Meeting
  - 28 minutes avg length
  - Our task in the meeting room is enormous
  - We must empathetically break bad news.
  - Sifting through the details of the hospitalization
  - Speak about the transformation that the person is making
  - Emphasize that their loved one is entering a new phase – possibly the last phase of their life, in which meaningful recovery is not possible
  - Help families rework their sense of hope – shifting from a hope for cure to a hope for comfort and peace as death approaches
  - Even though families witness their loved one growing increasingly ill, few physicians feel comfortable confirming the unthinkable: that Mom will not walk again, Dad will not wake-up again, Jimmy will never fish, laugh, or say “I love you” again.
  - In many ways, doctors skirt around the big picture, preferring to emphasize issues that can be controlled. This translates into physicians sharing only small pieces of information, such as: “We have corrected her magnesium level,” or “the tumor has shrunk by 14%.”
- Types of Doctor-Patient Relationship
  - Authoritative (commander)
  - Interpretative (technician)
  - Intepretative (guide)
- Helping Patient / Family Make Choices
  - Start with, “I'm so worried about your family member,” and see the response

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- Then, “Tell me how things have been going with your family member”
- Technique: Ask, Tell, Ask, Tell
- “ask, tell, ask.”
  - “What would you like to know"
  - Tell them what they have asked about
  - Then ask what they understood
- Use open-ended questions
  - What are biggest fears and concerns?
  - What goals were most important to her?
  - What trade-offs was she willing to make, and what ones was she not?
  - As for what trade-offs she was willing to make, what sacrifices she was willing to endure now for the possibility of more time later.
  - What if things don't get better?
- Always caring
- Always loving
- Never do nothing
- We actually want to intensify the treatment, with a focus on peace and dignity