Addressing Moral Distress in Caregiving at the End of Life

Health Ethics Week
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Laying the Groundwork

- What is Moral Distress?
- Why do we Care?
- Common scenarios of internal conflict
- What might we do to manage moral distress?
- Reflections

What is Moral Distress

- Many definitions used:
- The experience of feeling incapable of doing what one believes one ought to do because of some barrier… (Jim Read)

What is Moral Distress

- Recognizing that various options for action are available, where the values, beliefs or sense of rightness and wrongness underlying the choices are competing and not easily reconciled.

What is Moral Distress

- Moral Distress occurs when:
  - Know the ethically appropriate action, but cannot act upon it
  - Act contrary to personal and professional values, undermining integrity and authenticity

  (American Assoc. of Critical Care Nurses, from A. Jameton)

What is Moral Distress

- Do these definitions encompass the scope of moral distress for you…

What is Moral Distress

- In some circumstances, our own competing values make us uncertain about what the right choice is.
- In some circumstances, competing values between persons make us uncertain about what the right choice is.

What is Moral Distress

- After moral deliberation, on balance the chosen action may seem right. But other treasured values may necessarily be subjugated in order to carry out the action.

Scenarios of Internal Conflict

- A woman asks you to approve a travel authorization for treatment in a clinic in Mexico, motivated by a belief that a miracle may happen. You worry that she will die while there, away from her young family and support systems.

Scenarios of Internal Conflict

- A person asks you to not provide food and liquids so that she can die more quickly when you know you can likely provide reasonable quality for many months if given the opportunity.

Scenarios of Internal Conflict

- A dying person's family won't allow you to discuss with him what is happening because of cultural belief, religious imperative, or personal fear.
- Yet you believe firmly in the importance of including him fully.

Scenarios of Internal Conflict

- A person's family demands life prolonging interventions on behalf of their mother who cannot speak for herself, in a situation in which you know you cannot likely prevent substantial pain.

Scenarios of Internal Conflict

- A person's family asks you to carry on with life prolonging interventions for their dying, comatose brother despite what you believe is irreversible major deterioration.

Scenarios of Internal Conflict

- The resources needed to provide reasonably safe, secure care for an elderly, dying widow in her home are not able to be secured, necessitating a placement in LTC, against her wishes.

Scenarios of Internal Conflict

- You are a Resident. The Attending does not want to speak openly with a person about her terminal oncologic condition for fear of taking away hope. Yet you are aware this person has a need to prepare her family for her inevitable death.

Scenarios of Internal Conflict

- You care for a homeless person with terminal esophageal cancer, who is gruffly appreciative of what your team has been providing in hospital, but who desperately seeks return to the street where he is unconfined and back with his people.

Scenarios of Internal Conflict

- You care for a person at home who requires the use of opioids for pain control. But you learn some of her supply is being diverted by a nephew who lives with her.

Scenarios of Internal Conflict

- You believe the direction of care and interventions for a person you are caring for are wrong, maybe even dehumanizing. But you are compelled to follow the orders written into the care plan and feel you have no power to change them or question them.

Scenarios of Internal Conflict

- You care for a person whose daughter insists on avoidance of opioids for her mother, since she believes they make her confused. Yet the patient is obviously in considerable pain. Her daughter is the agent.

Scenarios of Internal Conflict

- The family of a terminally ill man you are caring for is accusing you of withdrawing life sustaining fluids and PEG feeding just so that he will die sooner and you can free up a bed.

Scenarios of Internal Conflict

- A dying person on your unit whose family never visits desperately needs someone to just be present with her. But you are run off your feet with meds to draw up and deliver, and the family in room 6 is very demanding of your time.

Scenarios of Internal Conflict

- A person you are caring for seems to be pleading with his eyes for you to relieve his distress. But due to the complexity of his pathology you don't feel able to sort out his pain diagnosis or know how best to assist him, and there is no one else to help.

Scenarios of Internal Conflict

- Your colleague has just experienced the death of her own brother, and is back at work. Today she is caring for a similarly aged person dying of the same disease as her brother, and you don't know how best to support her.

Commonalities

- What are some common threads that run through all these examples?

Scenarios of Internal Conflict

- You are asked/compelled to provide or avoid certain acts, and the compulsion runs counter to what you believe is right
- You wish to minister to those who depend on you, but you cannot due to limitations outside of your control
- Competing principles and values result in decisional conflict for you

Limited view

- Some authors categorize the range of circumstances producing moral distress as:
  - Arising from a distressing situation
  - Arising from a unit practice or behavior
  - Arising from power imbalances

That is too constrained…

- There are individual circumstances leading to episodic moral distress
  - this can resolve or linger

or

- There can be
  - an accumulation of single distressing events
  - recognition that single events will re-occur
  - a sense that all we do will simply not be enough, outside of major events

Stress versus Dis-stress

- Moral stress can be seen as *positive tension*, creating space for moral reflection individually or as a team, in order to determine ideal care decisions while maintaining moral balance

Stress versus Dis-stress

- Moral distress, on the other hand, is *disempowering tension*, that does not keep us integral, and that leads to internal conflict that is not resolved, despite what may be seen by others as correct or acceptable actions.

Balancing

- Most of our actions require a balance between competing imperatives. When the scales on competing sides are nearly balanced, we have increased the risk of doing the wrong thing.
- That worries us.

Continuum

- Many difficult decisions lay on points of the continuum between being beneficent and not causing harm.
- There are no universal ways to determine if it is better to seek maximum benefit for those we serve, or to avoid major harm.

Human nature

- Yet it is likely human nature that we tend to impart more weight to what we feel we cannot ideally provide – where we feel we have failed – than to what we do right.
- This is especially true in a conflicted situation where we have to choose.

The nature of end of life care

- Reduce suffering
- Optimize function
- So that people can accomplish aims, live until they die, and prepare themselves and their loved ones.

The nature of end of life care

- *Pall* = to cloak
- We feel a driving need to envelope with loving care, to shield from suffering.
- But how do we know this is what patients want universally?
- Does suffering mean the same thing to each of us as it does to each of our patients?

Tension generators

- Where do tensions arise:
  - Personal drive for excellence
  - Genuine caring
  - Professional duty
  - Fear of recrimination (professional sanction, reputational, lawsuit, self-berating, lack of appreciation, negative response from patients and families)
  - Desire for moral wholeness (integrity)

Who we are

- Expert intervenors preventing a potentially bad death and providing a likely good death, or…

Who we are

- A resource to fellow humans who seek our knowledge, experience and wisdom to assist them in this important aspect of their lived existence

Profession

- We profess to do our utmost to provide for those in our care.
- It is not a promise about the unattainable

Limitations

- Even though we are sometimes able to manipulate physiology in order to increase the chances of dying in various versions of what we would refer to as a more desirable manner, much of the deep personhood experience of living and dying is well beyond our control as caregivers…thankfully.

We overburden ourselves

- I believe we take on too much, from a felt need to be caring, but also from a position of benign arrogance.

So what is right

- The right course of action is almost always the course that is chosen if we have:
  - considered morally, with others
  - attended to our collectively determined laws
  - addressed personhood over pure healthcare considerations
  - recognized our human and professional limitations
  - are well intentioned towards beneficence

Back to practicality

- Moral distress will arise, so…
- Separate the systemic, ongoing moral distress from acute situational moral distress and from creative moral stress
- Create space to speak about it fearlessly
- Use a framework to address it

One framework

- AACCN – the 4As to Rise above moral distress:
  - Ask
  - Affirm
  - Assess
  - Act

Ask

- Become aware that moral distress is present in you or in your team

(AACCN)

Affirm

- Affirm distress, validate the feelings and perceptions with others, affirm an obligation (professional and personal) to act.

(AACCN)

Assess

- ID sources of distress, severity, and risks and benefits, then commit to an action plan.

(AACCN)

Act

- Prepare, act and then maintain the desired change so that you preserve your integrity and authenticity.

(AACCN)

Our task

- Recognizing that we do face moral distress…
- How will we build resiliency in order to
  - effectively use moral stress and
  - buttress ourselves against inevitable moral distress

Moral agents

- Useful to remember that we are all moral agents
- We like to say that we best meet people where they are on their journey and respecting how they experience meaning in their lives
- It is important to validate that those we serve must also meet us where we are, and in respect of how we experience meaning as fellow humans and as professional providers of care

Professional or Personal Task

- We bring our minds, experience and professional codes of conduct in order to provide care.
- We accept that we cannot avoid death, but we still work hard to control the manner, time and place of death (Somerville)

Professional or Personal Task

- But the nature of health care and service demands of us much more, and so we bring our own personhood to the task.
- As moral agents we need our actions to be in congruence with our values and beliefs and with our sense of who we are at our cores.

Care Providers & Care Givers

- In end of life care, due to the intensity of felt emotion, the stakes at play, and the recognition everyday of our own humanness and frailty, our personhood is necessarily at the fore.
- We give of ourselves, not simply a personally disengaged and a professionally competent offering.

Addressing Moral Distress

- We have at our disposal:
  - Teams
  - Standards
  - Precedent
  - Understanding of good intentions
  - Opportunities for guidance

Addressing Moral Distress

- Most importantly we have:
  - Each other
  - Huge accumulated capital of goodness and provided service
  - Humility regarding our real place and acknowledgement that we are merely instruments
  - Forgiveness

Vanier – *Becoming Human*

- Compassion and maturity (p 114)
- Fear of rejection, of judgement

My own moral distress

- What is our responsibility regarding those individuals we serve vis-à-vis the millions who do "without" at the end of their lives.
- A justice and collective humanity (communion) issue

Meaning in death

- Dying is a part of our human experience
- The meaning of living and of dying transcends each of us.
- We are mere contributors to the experience

Final thoughts

- Find ways to ramp up creative moral stress
- Be gentle on yourselves in letting go of created moral dis-stress

Final thoughts

- Do not let fear of being judged, or fear of doing harm, overwhelm your awareness of the good you provide

Some further reading

- Ethics in Practice for Registered Nurses (CNA) October 2003, *Ethical Distress in Health Care Environments*
- Webster,G. & Baylis, F (2000) *Moral Residue.* In S.B. Rubin & L. Zoloth (Eds.), *Margin of error: The ethics of mistakes in the practice of medicine* (pp. 217-232)
- American Association of Critical Care Nurses publication: *The 4As to Rise Above Moral Distress*
- Sibbald. R. et al; *Perceptions of "futile care" among caregivers in intensive care units;* CMAJ, November 6, 2007; 177 (10)
- Vanier, Jean; *Becoming Human,* House of Anansi Press Limited, 1998