Understanding Moral Distress When Providing Care at the End-of-Life

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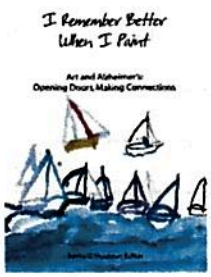
Case Presentation

- 83 yo with Alzheimer's dementia hospitalized for second time with pneumonia
- Attended adult day care 5 days/week; in-home attendant present 24/7
- Son requested 'do everything you can.'
- Patient said "@!#& you!" and refused all care, required restraints.



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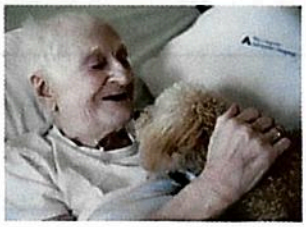
Hospital Course

- Invasive mechanical ventilation for 3 days then extubated
- Transferred back to ICU and again placed on mechanical vent for another 2 days
- Extubated again, but the patient had respiratory distress the following day and was deteriorating quickly
- Physiologic problem: recurring aspiration of oral mucus and saliva resulting in hypoxemia
- Son traveled to China for business and was available only by telephone.


Association of Increasing Use of Mechanical Ventilation Among Nursing Home Residents With Advanced Dementia and Intensive Care Unit Beds

Teno, 2016

- Called son to discuss preferences:
  - Patient would not want prolonged time (month or more) in a healthcare facility
  - Patient was most comfortable when at home with pet dog
  - Would want to die at home
  - Conclusion: arrange home hospice, DNR, do not re-intubate
- Home hospice staff called son to make arrangements.
- Significant change: son requested restart ventilator and change code status to full until his return in 2 days.



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Reflect

- What is the right thing to do?
- Why do you believe it is the right thing to do?
- How much would it bother you if the right thing to do could not be done?

Objectives

- Develop an understanding of the term moral distress and learn how different definitions reflect a spectrum of professional and occupational distress.
- Describe how moral distress has been measured and quantified.
- Understand unique end-of-life circumstances that can lead to moral distress.
- Learn about strategies and skills that may mitigate or prevent the development of moral distress.

Starting point

Moral distress can happen to a person who knows the right thing to do but is prevented from doing it.

- What happens?
- When does it happen?
- How does a medical professional know what is right?

Jameton's Description of Moral Distress

- Moral Distress: 'the painful psychological disequilibrium that results from recognizing the ethically appropriate action, yet not taking it, because of such obstacles as lack of time, supervisory reluctance, an inhibiting medical power structure, institution policy or legal consideration.'
  - Key elements:
    - In 1984 concept was nurse-specific
    - Constraint external to person
    - Originates from nurses external responsibilities: patient, medical orders from physicians, supervisor, hospital policies

Corley, 2001

Effects of Moral Distress on the Individual

- Initial psychological response:
  - Anxiety, depression, frustration, anger
- "Moral Residue" from repeated small episodes or a few major ones
  - Cynicism
  - Depersonalization
  - Disengagement
  - Low job performance
  - Poor job satisfaction
  - BURNOUT– "when you are not in control of how you carry out your job, when you are working toward goals that don't resonate with you and when you lack social support," (Carter, 2013)

Frequently Cited Causes of Moral Distress

- Participating in low quality care
- Poor relationships with patients, colleagues
- Amount of care provided (too little, too much)
- Conflict between staff and patients/family
- Recommendations for patient care ignored
- Lack of support or resources

Are any of these nursing-specific?

Henrich, 2016

Concurrent Factors

- Employment distress: night shifts, holiday work, high volume, difficult co-worker or supervisor
- Compassion fatigue: Frequent witness to suffering
- Failure distress: Working in units with patients who have poor prognosis; cure not a source of professional satisfaction.

'All my training is on what to do to keep the patient alive. When a family member begs me to do something, its really hard to say I am sorry your loved one is going to die.'

Restated Description

- Moral distress arises when one believes one knows the morally right thing to do, but one's ability to do this is constrained by internal and /or external factors.
  - It involves compromising of one's moral integrity or the violation of one's core values.
  - Has both immediate and long-term psychological effects

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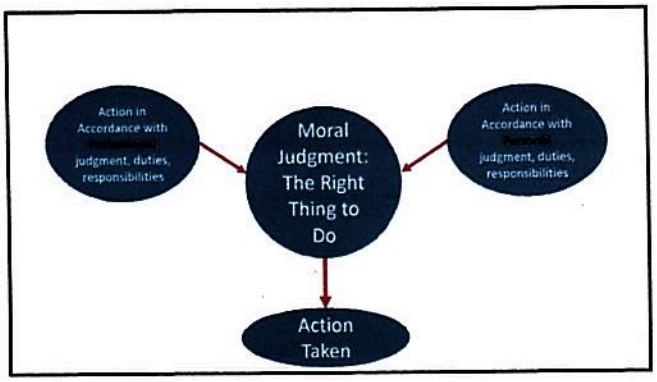
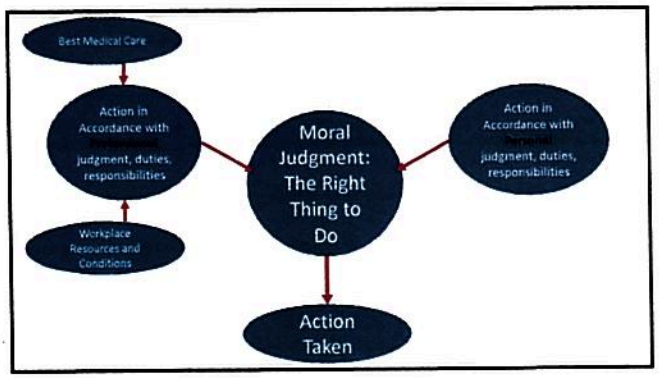
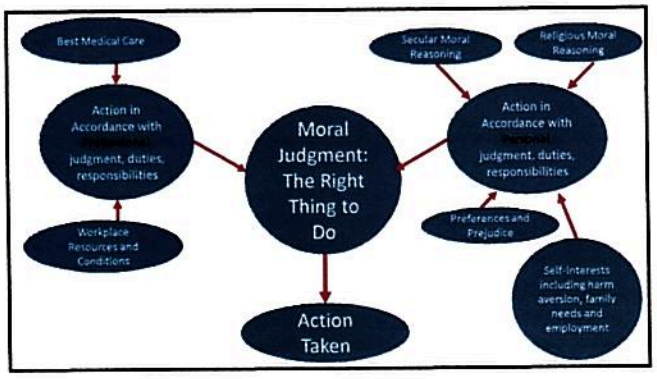
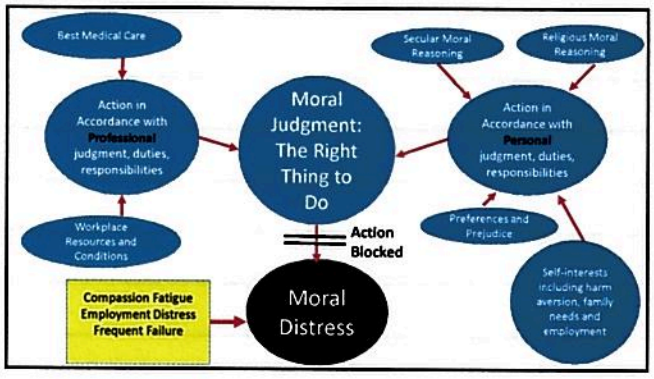

Action in Accordance with judgment, duties, responsibilities
Moral Judgment: The Right Thing to Do
Action in Accordance with judgment, duties, responsibilities
Action Taken

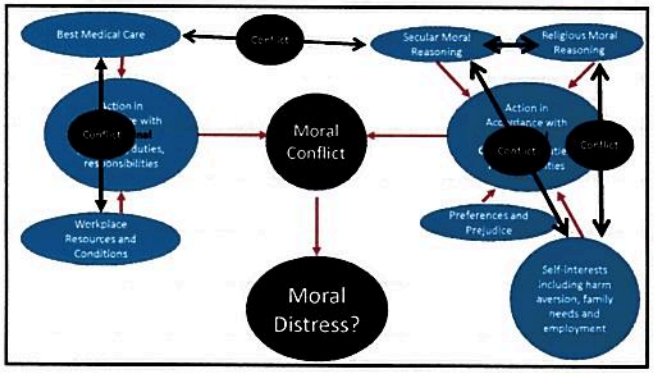

Best Medical Care
Action in Accordance with judgment, duties, responsibilities
Workplace Resources and Conditions
Moral Judgment: The Right Thing to Do
Action in Accordance with judgment, duties, responsibilities
Action Taken


Best Medical Care
Action in Accordance with judgment, duties, responsibilities
Workplace Resources and Conditions
Moral Judgment: The Right Thing to Do
Secular Moral Reasoning
Religious Moral Reasoning
Action in Accordance with judgment, duties, responsibilities
Preferences and Prejudice
Self-Interests including harm aversion, family needs and employment
Action Taken



Are external, institutional or workplace constraints necessary?

- Multiple sources of reasoning create potential conflict points
  - Conflict between and within personal and professional duties or obligations do not necessarily require external constraints to become personally significant



Emerging Concepts Moral Distress

- In addition to external constraints on actions, there may be other morally relevant factors causing personal moral compromise or that leave one feeling morally tainted
  - Moral dilemma – distress related to not being able to resolve equal claims or conflicting priorities
  - Moral challenge arising from uncertainty and not knowing the right thing to do, "moral confusion" or "moral uncertainty"
  - Moral "bad luck" – making and acting upon a decision that in retrospect was incorrect or lead to poor outcome
  - Distress by association – participating in care that is suboptimal or working in an institution where expectations for care are not met

Fourie, 2015.
Campbell, 2016

Example of expanded definition

- One or more negative, self-directed emotions or attitudes that arise in response to one's perceived involvement in a situation that one perceives to be morally undesirable.
  - Critique of self linked to personal moral compromise

Campbell, 2016

Quantitative Research on Moral Distress

MDS-R
Nurse Questionnaire (ADULT)

Moral distress occurs when professionals cannot carry out what they believe to be ethically appropriate actions because of internal or external constraints. The following situations occur in clinical practice. If you have experienced these situations they may or may not have been morally distressing to you. Please indicate how frequently you experience each item described and how disturbing the experience is for you. If you have never experienced a particular situation, select "0" (never) for frequency. Even if you have not experienced a situation, please indicate how disturbed you would be if it occurred in your practice. Note that you will respond to each item by checking the appropriate columns for two dimensions: *Frequency* and *Level of Disturbance*.

	Frequency					Level of Disturbance				
	Never				Very Frequently	None				Great event
	0	1	2	3	4	0	1	2	3	4
1. Provide less than optimal care due to pressures from administrators or unwarranted orders.										
2. Witness healthcare providers giving "false hope" to a patient or family										

Hamric, 2012

Examples of Specific Survey Elements

- Initiate extensive life-saving actions when I think they only prolong death
- Carry out the physician's orders for what I consider to be unnecessary tests and treatment
- Assist a physician who in my opinion, is providing incompetent care
- Witness medical students perform painful procedures on patients solely to increase their skill
- Follow family's wishes for the patient's care when I do not agree with them, but do so because of fears of a lawsuit

Hamrick, 2012

Gaps and Unaddressed Issues in Moral Distress Research

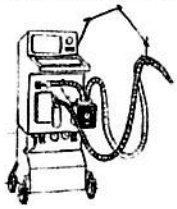
- The degree of personal involvement not specified, eg. active, passive.
- Specific attitudes and emotions not identified, eg. anger or guilt.
- Defining source for "knowing the right thing to do" and point of conflict
  - Conscience, professional guidelines, institutional policies, laws
- Surveys are based on generalized scenarios that are retrospective and difficult to measure against actual events.
- Simultaneous perceptions of other involved healthcare providers not possible.
- Concurrent factors not measured simultaneously.

Is this limited to health professionals?

- Is moral distress experienced by surrogates, family, non-medical caregivers?

Hospital-based end-of-life environment

- Time-pressured
- Multidisciplinary
- High tech
- Higher risk for adverse consequences
- Increased role of surrogates
- Emotionally charged



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End-of-Life Conflict Points

- Legal boundaries
  - eg. NOK, surrogate hierarchy
- Professional guidelines emphasize early, automatic actions and interventions
- Hospital policies reflect both legal and medical priorities
- Conscience
  - Secular and religious moral reasoning – moment of life and death central to foundational beliefs
- Bias and preferences of colleagues

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End-of-life situations may preclude conscientious objection

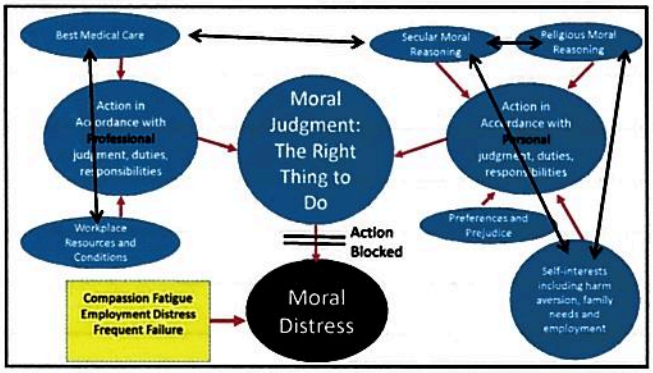
- C.O.: considered when providing health care would seriously damage the health professional's moral integrity by constituting a serious violation of deeply held conviction
  - The objection has a plausible moral or religious rationale
- At end-of-life, the negative consequences and burdens of carrying out conscientious objection may be large
  - Life-threatening conditions usually require treatment without delay
  - Actions immediately impact patient and outcome
  - The burden to colleagues and healthcare institution significant
  - There may be no resources available for transfer of care

Magelssen, 2012, J Med Ethics, 38:18-21

Disagreement about conscientious objection

"When duty is a true duty, conscientious objection is wrong and immoral. When there is a grave duty, it should be illegal... If people are not prepared to offer legally permitted, efficient and beneficial care to a patient because it conflicts with their values, they should not be doctors. Doctors should not offer partial medical services or partially discharge their obligations to care for their patients."

Salvescu, 2006



Best Medical Care

- Consistent with professional ethical norms
- Technical best-practices
  - Focus on effective and well-studied treatments
- If good evidence for treatment benefits and harms lacking:
  - Acknowledge "judgment calls" and recognize that the right thing to do may have a wide latitude
- Clarify goals of care with patient:
  - Cure, comfort, live longer, improve health, achieve life goals, support family
  - Identify and acknowledge gaps between medical effectiveness and goals of care

Communication

- Moral judgment related to a perception of the situation and available options
  - Accurate perceptions hampered by lack of information
  - What can all health professionals do?
    - Identify goals of treatment and discuss progress toward goals in rounds with staff
    - Include representatives of all teams in treatment planning and GOC discussions
    - Communicate effectively with each other at transitions and transfers of care
    - Revisit discussion when circumstances change

Personal Reflection and Education

- Examine conscience
  - Identify when conflicts are likely to occur
- Review institutional policies and legal limits
- Review of professional guidelines and best practices

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American Association of Critical Care Nurses 4As

ASK: *Review the definition and symptoms of moral distress and ask yourself whether what you are feeling is moral distress. Are your colleagues exhibiting signs of moral distress as well?*
AFFIRM: *Affirm your feelings about the issue. What aspect of your moral integrity is being threatened? What role could you (and should you) play?*
ASSESS: *Begin to put some facts together. What is the source of your moral distress? What do you think is the "right" action and why is it so? What is being done currently and why? Who are the players in this situation? Are you ready to act?*
ACT: *Create a plan for action and implement it. Think about potential pitfalls and strategies to get around these pitfalls.*

Epstein, Delgado; Online J Issues Nurs. 2010;15(3)

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