MORAL DISTRESS: FINDING OUR VOICE
A THERAPEUTIC APPROACH
WITH PALLIATIVE CARE DECISION MAKING

SWHPN General Assembly
March 11-13, 2018

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The Palliative Care Service was developed in 1997
PALLIATIVE CARE

“...an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”

(World Health Organization, 2015)
Acute Hospital: An inpatient medical facility providing therapy for severe illness and injury.

The phase of illness includes pre-diagnosis/diagnosis with symptoms.

Palliative care consults are on the increase in acute settings.

NYUMC there were 1,932.00 consults in 2017.
LEARNING OBJECTIVES

• Define moral distress and moral anguish (MDA)

• Distinguish common moral challenges and responses to healthcare providers in palliative care

• Identify therapeutic interventions for coping and building resilience with individual challenges and working within interdisciplinary service teams
MORAL DISTRESS

Jameton (1984) offered the first definition of moral distress in the nursing literature. He stated that moral distress is the stress that occurs “when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action.”

Corley (2002) institutional / ethical decision in which one feels “a power disparity that results in obstacles to an individual ability to act ethically.”
Unlike Moral Distress, which may refer more narrowly to an individual’s emotions in contrast to institutional constraints.

Moral anguish touches more closely on the personal, value laden emotional and existential fact of our own standards of behavior or beliefs concerning what is and is not acceptable to do.

A psychological and spiritual phenomenon; memories and subjective experiences of right and wrong.

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Key words
Moral distress, interprofessional, comparative study, ethical climate

Abstract
Purpose: Moral distress is a phenomenon affecting many professionals across healthcare settings. Few studies have used a standard measure of moral distress to assess and compare differences among professions and settings.

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PREVALENCE OF MORAL DISTRESS IN HEALTHCARE WORKERS

- Study by Whitehead, et al., (2015) explored MD amongst a multitude of professions and settings at an 825 bed medical center in Virginia. A small selection of participant demographics are shown (top right).
- The study utilized the 21 item Revised Moral Distress Scale to gauge MD.
- Findings from the study showed that nurses had the highest levels of moral distress. Those who provided care for adults faced higher degrees of moral distress than those who worked with pediatrics.
- There was a wide variety in distress scores, with some professionals experiencing little MD, and some experiencing very high MD.
Whitehead, et al., found that “Watching patient care suffer due to lack of provider continuity” was a top cause of MD across professions.

“Pressure from insurers or administrators to reduce costs” was more highly reported as a root cause by non-ICU workers than by ICU workers.

“Continuing to care for a hopelessly ill patient when no one will make a decision to withdraw support” was a common root cause for ICU workers, but not for non-ICU workers.

The variance in MD by profession and setting is shown in the study’s table, shown on the right.
EMOTIONAL

- Feelings of powerlessness
- Emotional exhaustion
- Anger, Frustration, Resentment
- Affect and behavioral distress: anger irritability
- Depression, anxiety
- Cynicism and depersonalization
- Pessimism, Isolation, Detachment
- Guilt – I couldn’t fix
- Risks of low self-esteem, feeling weak, stigmatized
- Loss of integrity / sense of accomplishment, numbness

PHYSICAL

- Physical exhaustion
- Chronic fatigue
- Inconsistent thinking such as forgetfulness
- Cardiovascular issues
- Gastrointestinal issues
- Shivering, sweating, headaches
- Weight loss – gain
- Insomnia

(MORAL DISTRESS AND MORAL ANGUISH (MDA) RESPONSES)

(Rushton, Caldwell, & Kurtz, 2016)
MDA RESPONSES, CONT.,

**BEHAVIORAL**

- Hypervigilance
- Lashing out at others
- Addictive behaviors
- Avoidance
- Agitation
- Shaming others
- Horizontal or vertical violence

**SPIRITUAL**

- Crisis of faith
- Disruption in religious belief
- Disconnection from work and/or community
- Existential aloneness

(Rushton, et al., 2016)
IMPLICATIONS OF MDA

- Shares emotional responses with other syndromes: burnout, compassion fatigue, or posttraumatic stress disorder. (Hamric, 2014)

- Physical and emotional distress may lead to difficulties hiring and/or high rates of turnover which may result in repercussions of performance at work - possible issues related to the care and safety of patients and workers. (Corley, 2002 cited in Dalmolin, Lundardi, Barlem, & Silveira, 2012)

- It can also result in a loss of job satisfaction, poorer patient relationships, and even abandoning the job and the profession. (Nathaniel, 2005 cited in Dalmolin, et al., 2012)
IMPLICATIONS OF MORAL DISTRESS AND MORAL ANGUISH

Impact on Patient

- Lack of Advocacy for Patient / Patient Avoidance
- Increased Patient discomfort/suffering

Impact on Healthcare Worker

- Suffering
- Resignation
- Burnout
- Leave Profession

Organization

- High Turnover of Staff
- Decreased Quality of Care
- Low patient satisfaction
- Difficulty Staffing
- Reputation/Accreditation

Adapted from Model for a theory of moral distress (Corley, 2002)
Patient and Family Narrative: Ms. M

- The patient was a 64 y/o female with past medical history of NASH cirrhosis, S/P simultaneous liver and kidney transplant. While the new organs were functioning well, patient’s postop course was complicated by pneumonia, cardiac arrhythmia, persistent fevers, and prolonged ventilator dependency. She did not regain her prior mental status.

- Prior to admission, the patient had completed a Living Will document stating she would not desire life sustaining treatments if it was determined by two physicians that she would not return to what she deemed an acceptable quality of life. Patient named her husband as her Health Care Agent who understood her definition of “quality” included not to live on machines.

- Patient’s family was supportive and by her bedside every day, and attempted to stimulate her senses. Multiple brain scans did not reveal a prominent reason for her condition. Occasionally, the patient would open her eyes when the family called her name. However, she did not track any of their movements or follow commands.

- A palliative care consult request was initiated approximately four months into her admission to discuss treatment options, goals of care and symptom management, and to provide psychosocial support for family’s anticipatory loss/grief. Palliative requested an ethics consult to provide overview.
Ms. M, Cont.

- After weeks of family meetings and counselling it was determined that the patient’s prognosis for recovery was grave and that she was unlikely to return to a standard of living consistent with the patient’s wishes. With great sadness, the family decided to transition the patient to hospice, and to liberate the patient from the respirator, with the understanding she specifically recorded in her Living Will and discussed with her spouse she would not accept a quality of life sustained by machines.

- The day prior to the scheduled extubation, in the first seemingly meaningful activity the patient had displayed in months, the patient seemed to recognize her spouse and when he kissed her hello she kissed him back. On this day for a brief time she seemed to minimally process her family members presence when they were talking to her. She did not verbally respond. Hopeful, the family rescinded the transfer to hospice care.

- Unfortunately the next day the patient returned to her prior level of conscious activity. Twenty days later, two physicians concurred that the patient presented with a poor prognosis for improvement to her prior baseline. The family agreed the goals of care would transition to comfort, with hospice services, included palliative liberation from the respirator and intravenous feeding. The patient died twelve days after the transition.
MORAL CHALLENGES

• **Physicians:** the transplant service who had been caring for her for multiple years aimed at working for her recovery accepting a poor prognosis transitioning to a comfort care goal of care.

• **Surgeons:** who by the outcome of the surgery expected optimal recover declaring her prognosis was poor.

• **Consulting Physicians:** who felt her wishes expressed in her Living Will will not be honored by the prolonged duration of intubation and ng feeding.

• **NPs and RNs:** who had concerns of not honoring her living will and the futility of sustained treatments in which the burdens vs benefits seemed questionable i.e., painful tests, prolonged intubation, ng tube feeding, IV hydration.

• **Social Work:** who had distress with the loss of her autonomy to care for her physical presence. Family distress with continued family meetings to discuss the futility of the goals of care and treatment options. Insurance utilization regarding limitations in planning discharge care.

• **Chaplain:** who experienced intra personal religious belief conflicting with palliative respirator liberation.

• **Ethics:** who negotiated honoring her wishes and finding a consensus among multiple disciplines guiding the process.
COMPLEX AND CHALLENGING

Palliative Care requires critical thought and moral courage related to engagement into difficult biopsychosocial circumstances.

• From Fixing to Being
• Maintaining Perspective: time/tempo
• Negotiating and Maintaining Boundaries
• Paradoxes - detachment / commitment desensitization / compassion

(Breaden, Hegarty, Swetenham, & Grbich 2012)
How Do We Address MDA – Intervene?

How Do We Find Our Voice?

- Acknowledge the existence - not if but when - and set aside the belief we are weak if not able to do it all - the “Miss Fine” philosophy (Cerone, A., 2000)

- Acknowledge our strengths: assess our coping & resiliency mechanisms

- Interventions: Institutional and Personal Assessment & Growth

- Process: Education, Communication, and Collaboration
What is the transforming Idea/Action - Change Agent?

To Prevent MDA
Elevate/Build Moral Courage, and Resilience.
INSTITUTIONAL ACTIONS

- Ethics Forum – i.e., Schwartz Center Rounds
- Education: literature updates, education projects, and interactive competency workshops
- Communication between administration and practitioners
- Organizational - interdisciplinary dialogue, systematic rapid/ongoing response team
- Grass roots organizational events to identify issues and search for solutions

PERSONAL GROWTH

- Remove barriers
- Empower clinicians as moral agents
- Build psychological resilience
- Invigorate one for the work and professional growth
Coping: refers to the strategies employed following the appraisal of a stressful encounter. (Fletcher & Sarkar 2013)

Resilience: influences how an event is appraised. (Fletcher, et al., 2013)

Resilience is “not just an attribute or capacity” it seems a “process to harness resources to sustain well-being.” (Panter-Brick & Leckman, 2013 cited in Southwick, Bonanno, Masten, Pantner-Brick, & Yehuda 2014)
• Mezirow’ Transformative Learning
• Graham Gibbs’ Model of Reflection
• Cognitive Behavioral Theory (CBT)
Mezirow’ Transformative Learning Theory (1990)
A perspective transformation: psychological (subjective responses), beliefs/values (conventional wisdom), and behavioral (knee jerk).
A planned course of action including acquiring of knowledge and skills providing for the purpose of understanding and validating clinical practice. Focus how we know vs what we know.
Example: MDA conflict of treatments benefits vs burdens. Education and critical thinking regarding futility of treatments may enlighten understanding for decision making going forward.
**Graeme Gibbs Reflective Learning Cycle** (1988)
The cycle enables us to effectively reflect/critically think about incidents and occurrences and learn from them.

*Example:* RN “Patient saying I think I am going to die today”.

Response: Fixing vs Being
Cognitive Behavioral Theory (Beck, Emery, & Greenberg 1985)
Experience over time impacts / reinforces the patterns we develop.
Examine the interactions between thoughts, emotions, and behaviors.
Example: Feeling the need to attend the memorials of patients.
Response: Alternative behaviors to find closure/pay your respects.
Focus Points For Building Resilience Skills

• Leveraging personal strengths
• Setting healthy boundaries
• Self-Regulating Emotions
• Recognizing cognitive distortions
• Tracking activation during the day
• Developing realistic expectations for one’s own performance
• Finding meaning in daily work
• Committing to long-term development  (Back, Steinhauser, Kamal, & Jackson, 2016)
CONSIDERATIONS:

- Author’s scope is focused in the area of palliative care in an acute care setting.
- Recognition of ethnic / cultural influences in regard to MDA.
- Neurobiology role in MDA work on the development of research and current knowledge.
- Therapeutic modalities of integrative, self-care, and sensorimotor strategies to address MDA i.e., EMDR, mindfulness, deep breathing exercises, massage, guided imagery, hypnosis, and journaling.
The insights of this presentation explore circumstances, determinates, and therapeutic modalities related to understanding and addressing moral distress and anguish.

They warrant consideration as a guide for Finding Our Voice to understand and facilitate a strengthening of the self and development of external resources.
CONCLUSION:

It is a privilege to be with and care for patients and their caregivers during the most challenging of times. It is a time of sadness, bitter sweet expression, and outstandingly courageous events.

We make moral sense of our work guided by professional ethics and personal values. At times seeming a moth to the flame, managing feelings of intimacy and the fear of falling apart.

Let us not forget we, as healthcare workers, are foremost humans sharing in the experience.

It is by acknowledging and understanding our challenges we soothe our distress, build resilience, and bolster our courage to carry on the work we love and do endlessly, selfless, and brilliant.
Thank You
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