Moral Distress – There IS something we can do about it!

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Objectives

- Define moral distress as a separate phenomenon from emotional distress and understand major root causes of moral distress.
- Examine the potential impact of moral distress on healthcare workers, teams (including palliative care teams), and health systems.
- Discuss social work-led strategies for addressing moral distress on both clinical and systemic levels.
Social Work Leadership

- Social Work Leadership Fellowship in Palliative and End-of-Life Care at NYU Silver School of Social Work
  - 18 month fellowship
  - Aim to develop and strengthen social work leaders in end-of-life care to influence the delivery and environment of care
  - Participants develop a capstone project and leadership goals and receive individual mentorship over the course of the fellowship
What is moral distress?

The internal conflict that occurs when you know the ethically appropriate action to take but are unable to act on it

- Not the same as emotional distress
- Ethical component must be present
Ethical Issues

Autonomy
- Every individual has the right to choose and follow his or her own plan of life and actions
- Obtain informed consent
- Honor patient preferences

Beneficence
- Action that is done for the benefit of others

Non-Maleficence
- “Do no harm” - refrain from providing ineffective treatments or acting with malice
- Weighed with beneficence

Justice
- Fairness - persons who are equals should qualify for equal treatment
Case Study: Jaclyn

- 61-year-old Female
- ESRD, endocarditis, septic shock
- PEA codes x3
- Vent-dependent, maximum doses of 5 pressors
- All medical teams agree life-sustaining measures now non-beneficial
Case Study: Jaclyn

• No living will or named healthcare power of attorney

• Sister wants comfort measures, children disagree - no agreement can be reached after multiple family meetings

• Jaclyn dies on the ICU while undergoing full resuscitative efforts
QUESTION:

What issues raised in this case might cause a social worker, palliative care team, or other healthcare provider to experience moral distress?
Why are we morally distressed?

Internal sources, external sources, and clinical situations

Internal Sources

- PERCEIVED POWERLESSNESS
- Lack of assertiveness
- Self-doubt

- Lack of knowledge of alternative treatment plans
- Inability to identify the ethical issues
- Increased moral sensitivity
- Lack of understanding the full situation
- Socialization to follow others
External sources

- Inadequate communication among team members
- Inadequate staffing and increased turnover
- Differing inter- or intra-professional perspectives
- Compromising care due to pressures to reduce costs
- Tolerance of disruptive and abusive behavior
- Hierarchies within healthcare system
- Lack of administrative support
- Lack of collegial relationships
- Policies and priorities that conflict with care needs
- Nurses not involved in decision-making
- Following family wishes of patient care for fear of litigation
Clinical situations

- Providing unnecessary/non-beneficial treatment
- Prolonging the dying process through aggressive treatment
- Providing inadequate pain relief
- Working with caregivers who are not as competent as care requires
- Providing false hope to patients and families
- Inadequate informed consent
- Hastening the dying process
- Lack of truth-telling
- Disregard for patient wishes
- Lack of continuity of care
- Conflicting duties
- Lack of consensus re: treatment plan
Demographic and Acuity Challenges

- Number of Medicare recipients with cancer, dementia, or COPD who spent at least a week in an ICU during the last month of life increased significantly from 2000 to 2009, from 24.3% to 29.2%

- ICU utilization in the U.S. rose at 3x the rate of general hospital stays between 2002 and 2009

- Individual population characteristics such as poverty, trauma, family estrangement, and limited resources

(Barrett, Smith, Elixhauser, Honigman, & Pines, 2014; Teno, et al., 2013)
Implications

Moral distress causes personal, emotional, and physical problems
What does moral distress look & feel like?

**Symptoms can be:**

- Physical
- Emotional
- Spiritual
- Behavioral
Physical symptoms

- Fatigue
- Appetite changes
- Headaches
- GI disturbances
- Impaired sleep
- Forgetfulness
Emotional Symptoms

- Anger/Resentment
- Fear
- Guilt
- Depression/Anxiety
- Overwhelming grief or sorrow
- Cynicism
- Apathy/Indifference
Spiritual Symptoms

- Loss of meaning
- Crisis of faith
- Loss of self-worth
- Disrupted religious practices
- Disconnection with family, friends, or other community supports
Behavioral Symptoms

- Boundary violations (over or under-involvement with patients/families)
- Depersonalizing patients or families
- Becoming overly aggressive or controlling
- Emotional outbursts or emotional shutdown
- Addictive behaviors
Implications

Burnout
- Emotional suffering of workers over time can cause burnout
- Burnout may harm our ability to compassionately care for patients and families

Risk of leaving the workforce
- Nurses who report high levels of moral distress are more likely to leave their jobs
What does the research say?

Moral distress widely studied among ICU nurses
Limitations of moral distress literature

- Very little about social workers
- Very little about palliative care

- Also very little FROM either of these groups
Most distressing for social workers

• Provide less than optimum care due to pressure from administration or insurers to reduce costs
• Watch patient care suffer because of a lack of provider continuity
• Follow the family’s wishes to continue life support even though I believe it is not in the patient’s best interest

(Allen, et al., 2013)
The Role of Powerlessness

• Nurses’ positive perceptions of institutional ethical climate have been associated with lower levels of moral distress (Pauly, Varcoe, Storch, & Newton, 2009)

• Nurses’ moral distress often associated with following either a physician’s or a family’s wishes to carry out tests or treatments the nurse does not believe are in the patient’s best interest
Moral Distress Scales

- **Moral Distress Scale (2001)**
  - 38-item scale
  - Used only with ICU nurses
  - Now out of use

- **Moral Distress Scale-Revised (2012)**
  - 21-item scale
  - Versions for adult and pediatric nurses, physicians, and other healthcare professionals
  - Shows promise of reliability and construct validity in early studies

- **Moral Distress Thermometer (MDT) (2013)**
  - “Snapshot” view of current intensity of moral distress
Interventions

- ICU Based Moral Distress Workshops
  - Share personal experiences
  - Discuss signs and symptoms
  - Develop individual and unit actions plans

- Ethics Consultation Service Workshops
  - Symptom management
  - Ethical/legal issues
  - Communication/culture
  - Spiritual/anxiety issues at EOL
  - Compassion fatigue

- Moral Distress Consultation Service
  - Hospital-based service
  - Not an Ethics Consult Team
  - Provides moral distress education and debriefing for staff members on request

(Beumer, 2008; Rogers, Bagbi, and Gomez, 2008; Epstein and Hamric, 2009)
Leadership In Action

Reflective Debriefing – Emily Browning
Mission in Action, Organizational Change – Lori Eckel
Reflective Debriefing

Emily Browning
Reflective Debriefing Methodology

- Problem: no formal places or methods for hospital staff to discuss moral distress or to debrief
- Goal: utilize a regular, formal protocol to address concerns contributing to moral distress among MRICU nurses
- Hypothesis: participating in the experimental intervention will lower nurses’ moral distress scores
- Design: pre/post-test experimental design with a control group
What is Reflective Debriefing?

- Utilizes current cases on unit identified by nurses as distressing
- Series of 10 questions

- Based on 3D Model of Debriefing (Zigmont, Kappus, & Sudikoff, 2011)
  - Pre-briefing
  - Defusing
  - Discovering
  - Deepening
Goals of Reflective Debriefing

- Dialogue about distressing clinical situations and process emotions
- Reflect on individual feelings and actions, communication, and systemic issues
- Engage in ethics education with the goal of increasing moral (ethics) voice
- Discuss areas for improvement and steps for further action
- Evidence organizational recognition and support for coping with ethical issues
Theoretical Basis

- Ethics education
- Reflective practice
- Didactic debriefing
- Narrative medicine
- Therapeutic group work
Results

- 42 RN participants over 6 months/7 sessions

- Findings: low-moderate levels of moral distress
  - Nurses most frequently distressed about non-beneficial treatments delivered at EOL
  - Nurses most intensely distressed about “false hope” and unsafe staffing levels

- Outcome: overall reduction in moral distress scores
  - 100% of respondents reported that they wanted to continue Reflective Debriefings

- Caution: small sample size prevents claims of statistical significance
## MRICU Moral Distress Frequency

<table>
<thead>
<tr>
<th>Situation</th>
<th>Control</th>
<th>Experimental Time 1</th>
<th>Experimental Time 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Rank</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Following family’s wishes to continue life support against patient’s best interest</td>
<td>3.13 (0.82)</td>
<td>1</td>
<td>3.63 (.52)</td>
</tr>
<tr>
<td>Initiate extensive life-saving actions when I think they only prolong death</td>
<td>3.10 (.76)</td>
<td>2</td>
<td>3.38 (.52)</td>
</tr>
<tr>
<td>Continue to participate in care for hopelessly ill person who is being sustained on a ventilator, when no one will make a decision to withdraw support</td>
<td>2.57 (1.01)</td>
<td>3</td>
<td>3.13 (.83)</td>
</tr>
<tr>
<td>Situation</td>
<td>Control</td>
<td>Experimental Time 1</td>
<td>Experimental Time 2</td>
</tr>
<tr>
<td>-----------------------------------------------------------</td>
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<td>---------------------</td>
</tr>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Rank</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Witness healthcare providers giving “false hope” to a</td>
<td>2.87 (1.17)</td>
<td>1</td>
<td>2.75 (1.16)</td>
</tr>
<tr>
<td>patient or family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Following family’s wishes to continue life support against</td>
<td>2.80 (1.13)</td>
<td>2</td>
<td>--</td>
</tr>
<tr>
<td>patient’s best interest</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Witness diminished patient care quality due to poor team</td>
<td>2.77 (1.10)</td>
<td>3</td>
<td>2.88 (0.64)</td>
</tr>
<tr>
<td>communication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work with nurses or other healthcare providers who are</td>
<td>2.77 (1.14)</td>
<td>4</td>
<td>--</td>
</tr>
<tr>
<td>not as competent as the patient care requires</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Work with levels of nurse or other care provider staffing</td>
<td>--</td>
<td>--</td>
<td>3.38 (0.52)</td>
</tr>
<tr>
<td>that I consider unsafe</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Provide care that does not relieve the patient’s suffering</td>
<td>--</td>
<td>--</td>
<td>2.75 (1.49)</td>
</tr>
<tr>
<td>because the physician fears that increasing the dose of</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>pain medication will cause death</td>
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</tbody>
</table>
Overall mean change in moral distress scores after intervention

Overall mean change (-7.83)
# Themes Noted in Majority of Debriefing Sessions

<table>
<thead>
<tr>
<th>Case Discussion Theme</th>
<th>Number of Sessions Theme Noted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-beneficial treatment (medical futility)</td>
<td>6</td>
</tr>
<tr>
<td>Feelings of powerlessness</td>
<td>6</td>
</tr>
<tr>
<td>Conflict in physician versus nursing values</td>
<td>6</td>
</tr>
<tr>
<td>Death, suffering, and end of life decision-making</td>
<td>5</td>
</tr>
<tr>
<td>Poor nurse/physician communication</td>
<td>5</td>
</tr>
<tr>
<td>Family desire to continue non-beneficial treatment</td>
<td>4</td>
</tr>
<tr>
<td>Dealing with families</td>
<td>4</td>
</tr>
</tbody>
</table>
Regression analysis: what factors contributed to changes? (n=19)

- Numbers of sessions attended
- Constructive confrontation (improvement in confronting other staff members about truth-telling in prognosis)

(To account for the small sample sizes, Independent t-test, Mann Whitney U test, and regression analyses were undertaken with the control and experimental groups divided differently)
Number of debriefing sessions attended related to moral distress score (n=19)
Improvement in constructive confrontation related to moral distress score (n=19)

(0= not at all improved, 1=slightly improved, 2=somewhat improved, 3=moderately improved, 4=greatly improved)
Strategies for coping with moral distress

Engage in reflection and dialogue
Engage in reflection

- Assess how your own values and assumptions contribute to your preferences for patient/family care
- Speak up when organizational processes are contributing to situations that cause moral distress
- Take care of your body, mind, and spirit
Dialogue with colleagues and organizational supports

- Debrief difficult clinical situations
- Seek counseling if needed
- Discuss ethical concerns and instances of moral distress in team meetings and with managers
- Focus on overcoming feelings of powerlessness, including utilizing opportunities for inter-professional dialogue
- Utilize formal supports such as an Ethics Committee
Creating a norm of constructive confrontation

- Group norm of diverse opinions on team
- Encourages open expression of individual opinions without a negative response to disagreement
- Dependent on mutual respect among team members
- Requires intentional change of hierarchical structure
- Must be led by example and discussed on interdisciplinary team

(Kellermanns, Floyd, Pearson, and Spencer, 2008)
Norm of constructive confrontation may help to resolve some root causes of moral distress

- Perceived powerlessness
- Inadequate communication among team members
- Differing inter- or intra-professional perspectives
- Witnessing patient treatment perceived as non-beneficial
Mission in Action - Organizational Response to Moral Distress

Lori Eckel
I'd like this book on chutzpah and I want you to pay for it.
Not all bad news

- Addressing moral distress suggests principles are taken seriously

- Opportunities for
  - Reflection
  - Reorientation
  - Reprioritization
Organizational Change

- Requires organizational readiness
- Gain commitment of stakeholders
- Surface dissatisfaction
- Communicate a vision
- Promote participation
- Utilize clear and consistent communication

Organizational Readiness

- Annual employee survey – 31% report compromise of integrity
- Organizational costs
  - Burnout, leaving the profession
  - Disengagement
  - Absenteeism
  - Patient safety and quality of care
  - Morale
- Individual approaches and interventions are NOT enough

Whitehead (2015), Bell (2008)
Organizational/Ethical Climate

- Are organizational values congruent with
  - Structures?
  - Strategies?
  - Processes?
- How are dilemmas addressed?
- What influence, latitude or support do workers have?
- Is there explicit time or space to reflect on or contribute to an ethical climate?
- Health care workers are the moral agents – is the workplace morally habitable?

Schluter (2008), Rushton (2016)
Ethical Climate

- Climate alone won’t erase moral distress but may help decrease the intensity or frequency

- Promote more sustainability in the work force
Structural, Organizational and Cultural Change Activities

- Build on or create infrastructure and align with institutional priorities and values
- Oriented towards employee well being, ethical climate and delivery of end-of-life care
  - Education Session
  - Distress Map
  - Policy
    - NBT
    - DWD
  - EOL Care Champions Committee
  - Schwartz Rounds
Education Session

- Raise awareness
- “Ask, assess, affirm and act”
- Differentiate normative emotional distress, moral dilemmas and moral distress
- Examine moral distress in clinical practice and establish framework to discuss it within the ethical context
- Consider methods of self-regulation and self-care
- Attended by 75 employees, recorded and accessible for employees at any time

Distress Map

- Conceptual framework to consider organizational processes, resources, structures and opportunities to address moral distress
- Prompts reflection
- Supports organizational cohesion and collaboration re: distress
Distress Map

Employee Resources for Distress

**WORK ISSUE**
- THE "QUICK FIX" CHARGE RN/ MANAGER:
  - Matters of Unit based or shift related function; Employment related matters; Staffing, safety, protocol; Availability/contact as per unit.
- M UDDLES
  - Unit Huddle: Team forum to address issues on the “local” level & identify themes that require collaboration with hospital wide partners.
  - Safety Huddle: Daily briefing for hospital leadership on issues from a 24-hr period, anticipates issues that require shared problem solving both now and future.
- THE BIG PICTURE
  - IPC: INTERDISCIPLINARY PRACTICE COUNCIL
    - Forum that promotes shared decision making across disciplines to provide remedy, suggestion, and solutions around initiatives, issues, and problems to enhance the Good Sam Community.
- SCHWARTZ ROUNDS:
  - Gathering of hospital community to discuss cases that highlight the emotional impact of our work and how to handle difficult cases.

**PERSONAL ISSUE**
- SPIRITUAL CARE
  - The Spiritual Care staff can provide immediate assistance. Chaplains are trained to listen without judgment and help make sense of life events and create narratives within your larger frameworks of meaning and make appropriate referrals to other resources.
- EAP: EMPLOYEE ASSISTANCE PROGRAM
  - This CONFIDENTIAL benefit through Legacy provides assistance in coping with life matters: emotional, legal, financial, relationships, etc. A 24/7 line is available for support or referrals. Contact 800-433-2320.

**CASE SPECIFIC**
- P A R T: PRO-ACTIVE RESPONSE TEAM
  - Provides immediate response to proactively plan for potential behavior or safety issues and development of a person-centered care plan. Available 24:7 via Chaplain on call.
- ETIQUET: third party consultation addresses uncertainty or conflict in rates; a deliberative process to evaluate laws, policy and ethical principles and make non-biased recommendations. Available M-F, 8 AM—4:30 PM via hospital operator.
- C I S M: CRITICAL INCIDENT STRESS MANAGEMENT
  - Group crisis intervention team provides "Psychological first aid" for units/teams to debrief a singular traumatic event facilitated by trained and certified team. Available 24:7 via hospital operator.
- LENGTH OF STAY/RE-ADMISSIONS REVIEW COMMITTEE:
  - Multi-disciplinary group that meets twice a month to review length of stay and readmissions. The goal is to identify barriers for successful discharge from our care, as well as strategies to break down those barriers. Contact Care Management department for details.

**COMMUNITY RESOURCES**
- The following resources are available to address personal, safety, crisis, addiction, financial or other concerns:
  - Mental Health Crisis Line: 503-988-4888
  - Alcohol/Drug Helpline: 800-923-4357
  - Call to Safety: 503-235-5333
- Dial 211 to speak with a person or use their website: 211.org for information & referral to community resources.

Created by Legacy Good Samaritan Ethics Program
Policy

• Non-Beneficial Treatment Policy
  • Proposed, drafted and implemented new policy
  • Inter-professional collaborative project
  • Established a process to address non-beneficial treatments
  • Goal is to reduce incidence or intensity of moral distress

• Death with Dignity Policy
  • Proposed revision of existing policy
  • Brings alignment to organizational values and priorities

End of Life Care Champions Committee

- Addresses the environment and delivery of EOL care
  - Revised standing orders for comfort care to reflect best practices
  - Promotes communication and continuity across care environments
  - Addresses environment of care, promoting the “sacred” event of death in the hospital with messaging and cues
  - Supports competence and confidence with development of resource book for unit nurses

(Whitehead, 2015)
Schwartz Rounds

- Provides moral space to consider the ethical dimensions in caring and the emotional impact of moral distress
- Prepared grant to secure funding to implement Schwartz Rounds
- Social Worker as co-facilitator of rounds sessions offered every other month
- Recruited buy-in from leadership includes compensation for staff to attend and funds to provide lunch
Challenges beyond EOL care

- Staffing
- Competence
- Communication and Continuity
- Disruptive and abusive behavior
- Decision-making and hierarchies
- Environment of care
- Fiscal and regulatory priorities or conflicts
Looking ahead

- Structures
- Decision-making process
- Employee roles, responsibilities
- Job design
- Information systems
- Management processes
There IS something we can do!

Summary
"I do this for the money" said no social worker ever.
Social Work Strengths and Opportunities

- Focus on social and organizational issues
- Expertise in justice and ethical concerns in healthcare
- Interpersonal skills and emphasis on inter-professional collaboration
- Ability to facilitate difficult conversations
- Training in advocacy work and focus on empowerment
- Build on relationships already present in the system to assist teams to educate about and process distress
Social Work Leadership

- Defined beyond job title, job description, position or role
- A practice
  - Relationship
  - Communication
  - Action
- Can be done by anyone, anytime!
References


Questions?

Comments?