UCLA Health System Ethics
New Grad Program

Katherine Brown-Saltzman, MA, RN
Co-director
UCLA Health System Ethics Center
Assistant Clinical Professor
UCLA School of Nursing
Moral Distress in New Grads

- New material
  Kelly, B. Associate Professor, Preserving moral integrity: a follow-up study with new graduate nurses. Journal of advanced nursing v.28 (5), 1998, 1134-
Ethics Center Team

- Neil Wenger, MD, MPH
  Director

- Katherine Brown-Saltzman, MA, RN
  Co-director

- James Hynds, LL.B., PhD
  Senior Clinical Ethicist

- Joseph Raho, PhD
  Clinical Ethicist

- Janine-Mariz Burog, MSHA
- Administrator

**Clinical Ethics Fellows**
- Valerye Milleson, PhD
  Senior Fellow
- John Frye, PhD
  Fellow
Contact the Ethics Center

Pager: “ETHIC”/38442
Webpage: www.uclahealth.org/ethics
Email: ethicscenter@mednet.ucla.edu
Phone: 310 794-6219
History of the Ethics Center

The Ethics Center began in 2002 Board of Directors identified ethical issues as an area for improvement in providing cutting edge care at UCLA.

2005 Appointment of Director and Co-director

2006 Hiring of Clinical Ethicist

2011 Ethics Fellowship
Some Institutional Benefits of the Ethics Center

- Availability: 24/7 emergent on call
- Facilitate relationship-based care in the midst of conflict
- Provide continuity of care
- Promote discussion of values and ethical awareness
- Address moral distress = reduction of burnout, staff turnover, and a leaving of the profession
- Encourage awareness of resource allocation
The Center’s Activities

- Clinical Consultation
- Professional Consultation
- Education
- Ethics Committees (RR, SMH, NPH)
- Policy Development and Review
- Research/Publication
- Innovative Programs
- Staff Support
- Community Resource
Education

- Bi-monthly Noon Ethics Lecture Series
- Ethics Fellowship
- Nursing Ethics Associate Program
- Ethics Committee Programs
- Monthly Journal Club
- Community/National/International Presentations
- Lectures/Panels
  - Departments (Nursing, Spiritual Care, Medicine, Geriatrics, etc.)
  - Schools (Medicine, Nursing, Law, Public Health)
  - Community
  - Pediatric Palliative Care Comfort Panels
  - Community/National/International Presentations
Ethics Fellowship

• The goal of this two year fellowship is to provide extensive clinical consultation experience, with opportunities in the second year for research, teaching, and mentoring of the junior fellow.

• The Fellowship is for individuals who hold an advanced degree in health care ethics.
Innovative Programs

• Collaborating with Department of Nursing
  • Bi-annual Circle of Caring: A Renewal Retreat for Healthcare
    • This program teaches self-care as an ethical practice.
  • Ethics Institute Fellowship (Prior)
    • The Ethics Institute gives nurses the tools to deal with the ethical questions they face every day and helps them become influential participants in the larger discussion of ethics taking place throughout the healthcare profession.
    • Nine nurse fellows – NICU, MICU, PICU, Medicine, CTU, MOU Neuro ICU
  • Nursing Ethics Associate Program Summer 2017
Innovative Programs

• Moral Distress Writing Retreat

• End-of-Life Education Program for Respiratory Therapists
Community Resource

• Ethics of Caring Conference
  • Collaboration with 16 institutions
  • Over 300 attend
  • Grew to a National Nursing Ethics Conference NNEC (2011, 2013, 2015, 2017)
  • Now an annual National Nursing Ethics Conference NNEC March 8-9, 2018 here on campus, at the UCLA Luskin Conference Center
An invitation to Reflect, Celebrate, Reimagine, and Transform Join your colleagues at the 5th National Nursing Ethics Conference

5th National Nursing Ethics Conference

Reimagining Nursing from the Inside Out

Save the Date
March 7 - 9, 2018

UCLA Luskin Conference Center
Los Angeles, California

Reflections from past participants:
- Very informative and eye-opening
- Really touched my soul
- Highly relevant to my current practice
- Attending was an intentional effort to refresh and renew myself

The NIEC aims to empower nurses to engage in complex, ethical challenges of care to effect needed change and to affirm the mutually enriching qualities of patient-family-clinician encounters.

www.ethicsofcairng.org
Ethics of Caring Conference
Survey of Participants

Those who attended 2 or more of the conferences were significantly

✓ More confident in ability to identify ethical issues
✓ More comfortable approaching colleagues to discuss ethical issues
✓ More satisfied with personal skill to address ethical issues
✓ More aware of available resources to address ethical issues
Clinical Consultation

A snapshot of consultations over the past year:

• UCLA  
  \( n = >275 \)

• National  
  90% of consult services surveyed performed fewer than 25 consults per year  
  \( (n = 519 \text{ hospitals}) \)
What is Clinical Consultation?

Having All the Answers.
Not Quite!
What are the issues?

- Conflicts about goals of treatment
- Conflict between family members
- Un-represented patients (without surrogates homeless, elders etc.)
- Patient suffering/non-beneficial treatment
- Confidentiality – HIV Status, Misattributed paternity, Privacy
- Informed Consent
- Innovative treatment
- Pediatrics – wishes of parents vs. best interest of patient
- Evaluating complex capacity for decision making
- Moral distress
- Resource utilization
Sources of Consults

• SW’s, RN’s, MD’s, Families, Patients, Case Managers, Chaplains, Risk Management

• Units with requesting consults routinely:
  • MICU, MOU, NICU, CCU, Neuro ICU, PICU, Medicine, CTU, Surgery, Transplant
  • SM – ICU & Geriatrics
What’s the problem?

- Generally, teams have not communicated well about ethical issues\(^1-5\)
  - Conflict
  - Not knowing
  - Disagreement
  - It takes time
  - Hierarchical structures
  - Fears
  - Perspectives vary
  - Hope of resolution
  - Avoiding harm
The Consequences of Conflict

- Persistent moral discomfort / stress / distress.\textsuperscript{6,7}
- Crescendo effect of moral distress; moral residue.\textsuperscript{8}
- Can lead to medical errors, harmful decisions and unnecessary patient suffering.\textsuperscript{9-11}
- Affects all HCPs, especially nurses (time / space).\textsuperscript{6,7}
- Influences professional relationships, teamwork.\textsuperscript{12-16}
- Contributes to disengagement, professional burnout.\textsuperscript{2,3,6,7}
- Accounts for substandard health care.\textsuperscript{9-11,17}
Ethical Principles

- Beneficence
- Nonmaleficence
- Autonomy
- Best Interest
- Justice – Distribution of Limited Resources
- Fidelity
Autonomy

• Right to self-determine about how one’s body will be treated

• Capacity
Complexity of Autonomy

• Patients with C4 C3 spinal cord trauma
   90% asked to dc the respirator post-accident

  Autonomous Decision?

• Following rehab –
   95% of the pts were glad to be alive and no longer wished to have their respirators turned off

Futility

“A treatment is medically futile when the magnitude of the benefit, however it contributes to the patient’s treatment goals is disproportionately small in relation to the magnitude of the risks of violating the patient’s integrity worsening the patient’s condition or when compared to the magnitude of the effort needed to achieve the benefit.”

RMEC National Center for Ethics 1993
Prognosticating Differences between nurses and physicians

- n = 603 pediatric ICU patients
- 36 deaths 5.61%

- Mean mortality predictions
  - attendings (6.09%)
  - fellows (7.87%)
  - residents (10.00%)
  - nurses (16.29%)

Prognostication Study for Patients with Advanced Cancer
1,018/1,783 Multicenter

<table>
<thead>
<tr>
<th>Clinician</th>
<th>Error Rate</th>
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<tbody>
<tr>
<td>Physician</td>
<td>43.7 %</td>
</tr>
<tr>
<td>Nurse</td>
<td>44.8 %</td>
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<tr>
<td>Multi Professional Estimate</td>
<td>42.5 %</td>
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Harmful Treatment

Harming a patient violates the principles of:

- Nonmaleficence
- Beneficence
- Best Interest
- Fidelity
- Justice
An Inkling of the Difficulties

- Nurses see the suffering of many
- Physicians see the possibility of cure
- Benefits vs. Burdens
- Best Interest
- Quality of Life
- Who Decides?
64% doubted the accuracy of the physician prognosis
32% elected to continue life support with a < 1% survival estimate
18% elected to continue treatment when the physician believed there was no chance of survival

N = 50

View of the World by Patients

- Despite the fact that 71% participants had metastatic or recurrent disease. The level of hope was relatively high, even in those patients who knew that their disease was in an advanced stage.

- Hope was positively related to coping in patients with cancer, regardless of gender, age, marital status, education, or site of malignancy.
Why do patients or their families want non-beneficial treatments?

- Confusion – i.e. why would I be offered treatment that is non-beneficial?
- Do not believe the prognostication is correct
- Hope that has been inaccurately sustained
- Waiting for a miracle or other faith beliefs
- Inability to make a decision – do not want to carry the responsibility
Policy to Address Non-beneficial Treatment

• **Policy 1319**
  • Withdrawing or Withholding Medically Inappropriate Life Sustaining Treatment

• **Policy 1319.1**
  • No CPR Orders
EXPEDITED UNILATERAL NO CPR ORDER: IMMINENTLY DYING PATIENTS

A. Where the attending physician judges that CPR is not a medically appropriate intervention for the patient because it would serve only to prolong the patient’s irreversible dying process and is reasonably certain that the patient’s death is imminent, and there is a conflict between the patient/Legal Decision Maker and the physician about providing CPR, he may write a No CPR order without the consent of the patient or their Legal Decision Maker and without exhausting the conflict resolution process delineated in Section I. D (above), if, but only if, the procedures in this section are followed.
Definition: Moral Distress

1984

• Occurs “when one knows what to do but institutional constraints make it nearly impossible to pursue right course of action” (Jameton, 1984)

2012

• “Experience of being seriously compromised as a moral agent; relational experience shaped by workplace environment” (Varcoe, Pauley, Webster, & Storch, 2012)
Consequences of Unresolved Ethical Dilemmas / Conflicts

- Persistent moral discomfort / stress / distress
- Crescendo effect of moral distress; moral residue
- Affects all HCPs, especially nurses (time / space)
- Influences professional relationships, teamwork
- Contributes to disengagement, professional burnout
- Can lead to medical errors, harmful decisions and unnecessary patient suffering
- Accounts for substandard health care
  - Epstein & Hamric, 2009; Leonard, Graham, & Bonacum, D. 2004
"The Crescendo Effect" Epstein, Hamric

Moral Distress

Deflation of moral distress

Moral residue

Nursing staff believes that further aggressive treatment is futile

Parents agree to withdraw

Time
Problem: Ethical Conflicts

Critical Incident Study
(70 nurses – risk factors, early indicators)

Ethics Advocacy Tool
(28 ICU/oncology nurses; 2 sites)

Focused Ethnography
(30 oncology nurses; 12 key informants)

Ethics Online Survey
(114 physicians)

Nurse-Physician Focus Groups
(6 nurses and 6 physicians)

Critical Incident Study
(100 CNS, nurse leaders)

Exploratory Study on collaboration with physicians and nurses

Protocol validation:
Case consultation document review N=25

Collaborative Proactive Ethics Protocol
(6 ICU’s/3 sites)

Protocol validation:
Case vignette with 15 clinical ethicists

Concerns about:
Safety, Quality, Moral Distress
Findings: Risk Factors for Ethical Conflicts
Nurses’ Perspectives

**Individual Risk Factors**
- Patient vulnerability (87%)
- Near end of life (73%)
- Patient suffering (71%)
- Failed treatments (64%)

**Family Risk Factors**
- Disagreement with plan (42.9%)
- Adamancy (30%)
- Uncertainty (27.1%)

**Multi-level Risks**
- Poor communication
- Lack of knowledge
- Different cultures

**HCP Risk Factors**
- Lack of team cohesion (34.3%)
- Unethical behavior (28.6%)
- Conflict among team (22.9%)
- False hope offered (21.4%)

**System Risk Factors**
- Lack of limit setting (37.1%)
- Unclear policies (25.7%)
- Limited resources (14.3%)
Risk Factors for Ethical Conflicts: Physicians’ Perspectives

**Increased Risk for Ethical Conflicts**
N=206

**System Circumstances**
N=13 (6.3%)
- Inadequate resources (N=7)
- Inadequate institutional support (N=4)
- Unequal distribution of resources (N=2)

**Interactional Circumstances**
N=111 (53.9%)
- Inadequate processes (N=53)
  - Poor communication (N=34)
  - Lack of cohesive plan of care (N=19)
- Differences (N=58)
  - Differing worldviews (N=25)
  - Moral disagreements (N=33)

**Personal Circumstances**
N=82 (39.8%)

**Families (N=17)**
- Low trust in providers
- Negative past experiences
- Unrealistic expectations
- Lack of education
- Poor decision making skills
- Multiple family members

**Patients (N=51)**
- Complex medical needs
- Lack of capacity
- Mental illness
- Very young or very old
- No family support
- Low SES / homelessness
- Lack of education
- Drug dependence

**Providers (N=14)**
- Overly-aggressive
- Emotionally involved
- Over-worked
- Stressed, burned out

N = number of times risk factor was identified
Findings: Nurses’ Regrets

40% reported regrets (n=28)

- Unnecessary patient suffering (n = 10)
- Not doing enough (n = 9)
- Lack of policies on medical futility (n = 5)
- Being dishonest (n = 3)
- Nurse’s position (n = 1)
  - “My hands were tied”
  - “Being in the middle of situations created by others”
  - “This case has haunted me for years as I feel I could have been a better advocate for her.”

“This case has haunted me for years as I feel I could have been a better advocate for her.”
Physicians’ Quotes on Moral Stress

• “The desire to meet others’ needs makes you think about whether your own moral code is absolute or whether you can act according to someone else’s and still sleep at night.”

• “The ability to take oneself out of the situation when forced to do something such as a procedure.”

• “Not really knowing in one’s heart what the right answer is.”
Contextual and Dynamic Model of Moral Action

Professional Goals
- Prevent suffering, injury
- Be honest and inform patient
- Contribute to patient’s improvement/stated goals

Moral Appraisal of Ethically-Difficult Patient Situation

Challenges for Nurses Working in Ethically-Difficult Situations
- Being the eyes and arms of suffering (often without a voice)
- Experiencing the precariousness of competing obligations
- Navigating intricacies of hope and honesty
- Managing urgency caused by waiting
- Straining to find time
- Weighing risks of speaking up in hierarchal structures

Risk Appraisal (Mediators of action)
- Trust in team relationships, management
- Strength of relationship with patient
- Self-confidence (education/experience)
- Opportunity for communication
- Influence of time: emotions build; limited time

Possible Consequences for Nurses
- Moral comfort, stress, distress
- Broken trust, relationships, confidence
- Learning, self-confidence, satisfaction

Depends on action taken and patient, family, team, management responses to nurse action. Responses affect all who witness and influence future actions for many.

Nurse Actions in Ethical Conflicts
- Speaking up: Directly addressing concerns
- Speaking around: Creating other avenues
- Speaking sideways: “Murmuring” to one another
- Staying silent: Suffering quietly
- Looking away: Focusing on tasks

Situational Outcomes for:
- Patient and family
- Healthcare team
- Healthcare organization

James Rest, 1994

Nurses’ Moral Kaleidoscope

Moral Sensitivity
Moral Motivation
Moral Judgment
Moral Character

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James Rest, 1994
Findings: Risky Environments

Nurses perceived considerable risks when speaking up under conditions of:

- Moral uncertainty
- Significant power differentials
- Inadequate management support
- Fractured care planning
- Relational conflict

Pilot Study of an Ethics Screening and Early Action Tool

- 28 critical care and oncology nurses
  - UCLA and Mayo Clinic
- 4 hour ethics workshop
- 3 months utilization of screening tool
  - Complete brief questionnaire including ethics situation (pt dx, situation), time needed to complete tool, and its usefulness for that particular situation
- Post Tool use after 3 months:
  - Complete a survey
  - Attend a focus group
Ethics Screening and Early Intervention Tool

1. Identify risk factors and early indicators
2. Assess likelihood of conflict occurring
3. Identify appropriate actions
4. Appraise risk of negative consequences occurring
Top Risk Factors & Indicators

<table>
<thead>
<tr>
<th>Individual/Patient</th>
<th>Family</th>
<th>Health care team &amp; System</th>
</tr>
</thead>
<tbody>
<tr>
<td>-Patient vulnerability</td>
<td>-Adamancy about aspects of care</td>
<td>-Need for cohesive plan of care</td>
</tr>
<tr>
<td>-Life-threatening illness</td>
<td>-Unrealistic expectations</td>
<td>-Conflict among team about plan</td>
</tr>
<tr>
<td>-Failed treatments</td>
<td>-Disagreement with plan of care</td>
<td>-Prognostic differences of views</td>
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<tr>
<td>-Unnecessary suffering</td>
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<td></td>
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<tr>
<td>Early Indicators</td>
<td></td>
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<tr>
<td>-Signs of patient suffering</td>
<td>-Signs of unrealistic expectations</td>
<td>-Signs of nurses’ moral distress</td>
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<tr>
<td></td>
<td></td>
<td>-Signs of conflict</td>
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<td></td>
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<td>-Signs of poor communication</td>
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</table>

- Risk factors and early indicators most frequently checked in each category.
Top Three Indicators of High Risk for Ethical Conflicts

Top 3 indicators in both settings pertained to:

- Patient suffering
- Provider distress
- Family’s unrealistic expectations

Three Aspects Equals Shared Suffering

*Image - Mica Endsley, Ph.D., President, SA Technologies
Silence Despite an Evidence-Based Screening Tool$^5$

- Despite nurses’ comments about the empowering benefits of the screening tool, several nurses still remained silent about their concerns.
Perceived Risk in Following Up$^5$

Other options: colleagues, nurse management, social work, chaplain, palliative care, other.
1. **Discuss with physician:**
   - “You bring up your concerns to the doctor and concerns are shooed away, like what you have to say is not necessarily important or I shouldn’t be questioning a doctor.”

2. **Explore with patient/family:**
   - “One thing I see as being the most risky is how much should I tell [the family], how should we talk about [what might happen], or ask what are your goals here? It feels risky.

3. **Initiate ethics consult:**
   - “Ethics is kind of sometimes taboo because… you don’t want anyone to feel like you’re a whistle blower or you always have a problem with something.”
“So I knew that there was something going on and this guy might code and we’re doing all these things to him and I already knew that this was going to end up being some sort of ethics thing, but the tool confirmed it. I think in a less obvious case where the son just wasn’t letting us do anything [for pain], the problems were not quite as clear and so checking off ‘Disagreements’ Yes. ‘Patient suffering.’ Oh my God, yes. ‘Moral distress.’ Of course. ‘Unrealistic’ I mean it was like yes, yes, yes. So it [tool] really puts words to the things that are ambiguous or the things that you can’t hone in on because you’re so busy delivering care, especially to critically ill patients.”
Pilot Study Conclusions

• **Nurses judged the tool to be:**
  - Feasible
  - Easy to use
  - Effective

• **Suggested Improvements:**
  - Standardize use of the tool for all patients.
  - Make the tool multidisciplinary and collaborative.
  - Provide more objective criteria for determining risk level.
  - Give more specific guidelines for follow up actions.
Revisions to the Tool

- Suggestions from Pilot Study
- Expert Review of the revised tool
  - 15 Clinical Ethicists
  - Document Review of Ethics Consultations
- Incorporated Other Voices
  - Physician Survey\textsuperscript{19}
  - Nurse Leaders Survey\textsuperscript{23}
Current Project

GOAL – to study effectiveness of an interdisciplinary, ethics early action intervention

• Multi-site study in 6 ICUs in three settings:
  • UCLA, Mayo Clinic and Massachusetts General Hospital

• Enrolling ICU nurses, physicians, PAs, and NPs

• Outcome Measures:
  ✓ Primary: number/timing of family care conferences, code discussions, and ethics consultations; LOS
  ✓ Clinicians: moral distress, ethical climate, ethics self-efficacy
  ✓ Families: satisfaction with care and decision making

Funding –
Impact Grant from American Association of Critical-Care Nurses
Implementing the Protocol

- Incorporated into existing systems of care
  - Daily rounds/Interdisciplinary Rounds
  - Nurses initiate – succinct discussions on rounds

- Assessment:
  - Every ICU patient
  - Initial assessment, scoring, and plan within the first 48 hours of ICU admission
  - Brief daily reassessment and plan update

- Documentation
## Summary of Preliminary Findings

<table>
<thead>
<tr>
<th>Clinician Outcomes</th>
<th>Hypothesis</th>
<th>Result</th>
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<tbody>
<tr>
<td>• Decrease in clinician moral distress</td>
<td>↓</td>
<td>↓</td>
</tr>
<tr>
<td>• Increased perception of individual effectiveness in dealing with ethical issues</td>
<td>↑</td>
<td>↑</td>
</tr>
<tr>
<td>• Increase in perception of ethical climate of their work environment</td>
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# Summary of Preliminary Findings

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<tr>
<th>Clinical Outcomes</th>
<th>Hypothesis</th>
<th>Result</th>
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</thead>
<tbody>
<tr>
<td>Length of ICU stay</td>
<td>↓</td>
<td>→</td>
</tr>
<tr>
<td>Family Conferences (frequency and timing)</td>
<td>↑</td>
<td>↑</td>
</tr>
<tr>
<td>Code Conversations (frequency)</td>
<td>↑</td>
<td>↑</td>
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<tr>
<td>Ethics Consultations (frequency; small N)</td>
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Collaboration as a Key Component of Moral Communities\textsuperscript{4,24,25}

- Patients as a common interest / responsibility
- Ethics as normal, everyday conversation
- Open space for ethics dialogue
- Open communication with patients
- Shared decision making and cohesive care planning
- Mindful interdependence and mutual empowerment
- Leadership support for collaborative and proactive ethics
The Human Side of Ethics
Integrity

“The whole course of human history may depend upon a change of heart in one solitary and even humble individual.”

M Scott Peck
References


References


