

Nursing Ethics: When Reality Collides with What's Right

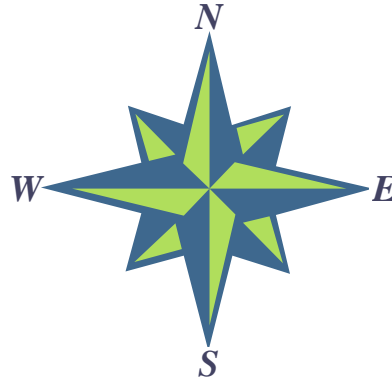
2010 TNA & TASN
Joint Convention Pre Conference
Franklin, Tennessee

Objectives

- At the end of this presentation participants should be able to:
 - To define ethics and ethical dilemmas in the context of health care, in so doing increase your knowledge.
 - List common types of ethical dilemmas in healthcare, and tools for dealing with them
 - Demonstrate the ability to determine best ethical practices.

Why ethics?

- Need a moral compass to guide difficult decisions that have to be made in the health care context.



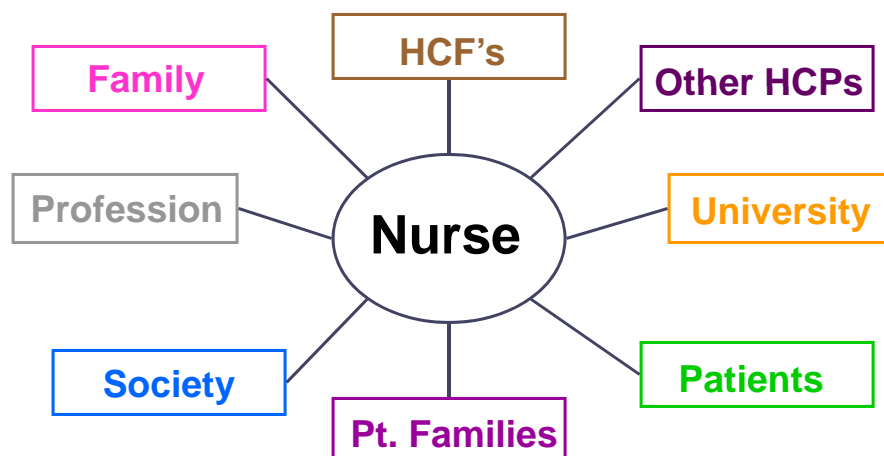
Ethics, morals, manners

- Ethics
 - Ethos: Greek meaning custom, usage, character
 - Science of the ideal human character
- Moral
 - Mos, moris: Latin meaning manner, custom, habit, way of life, conduct
 - What is good
- Manners
 - Canons of good taste
 - Social behavior
 - Rude people can be ethical
 - Unethical people can be really nice

What is ethics?

- It can be about resolving dilemmas,
 - but not only this.
- It can be about individual actions,
 - but not only this.
- It is also about what kind of persons we are becoming – our character and how our choices shape us.
- Ethics is ultimately about human flourishing, about living well, about achieving good through means that are consistent with real human values and needs.

Stake holders



What is organizational ethics?

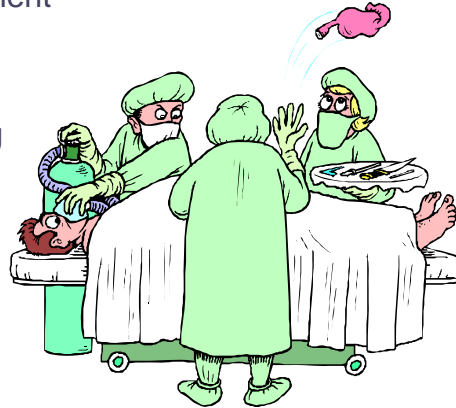
- It can be about compliance,
 - but not only this.
- It can be about due diligence,
 - but not only this.
- It can be about resolving value conflicts,
 - but not only this.
- Organizational ethics is primarily about integrity, about making decisions that are consistent with the moral identity and values of the organization, so that the organization, its employees, and the communities it serves can truly flourish.

Health care models

<i>Model</i>	<i>Nature of Health Care</i>	<i>Nature of Relationship</i>	<i>Professional's Obligation</i>
<i>Business</i>	Commodity	Buyer/Seller	Commitment, Skill
<i>Contractual</i>	Service	Contracting equals	Supply specific service
<i>Covenant</i>	Obligation	Sacred trust	Commitment to life
<i>Beneficent</i>	Negotiated good	Trust (fiduciary bond)	Act for good of patient
<i>Preventive</i>	Life-style	Unilateral option	N/A

Law and ethics

- Protect Ethics/Reduce Liability
 - Identify and clarify the dilemma
 - Demonstrate good judgment
 - Communicate effectively
 - Facilitate negotiation
 - Improve decision-making
- Ethics is the ceiling,
law is the floor



Moral compass



Vision

- Defining and achieving a desired future
- Best hindsight and foresight for action
- Possibilities
- The best healthcare system
- Your best life
- Fat free chocolate



Mission

- Human beings are valuable
 - Ends unto themselves
 - Because they are created by God
 - “Sentient beings are numberless I vow to save them all”
- Mission is purpose
 - It makes us who we are
- Mission finds form and expression in excellent practice.



Values

- Priority
- Worth
- Value set
 - Personal values
 - Professional values
 - Organizational values



Virtues

- Cardinal virtues
 - Prudence, courage, temperance and justice
- Modern virtues
 - Unconditional positive regard, charity, compassion, trustworthiness, vigilance and agility
- Other
 - Dedication, loyalty, honesty, creativity, faith, family, care of the poor



Universal values

- Love
- Truth
- Fairness
- Freedom
- Unity
- Tolerance
- Responsibility
- Respect for life



Ethics

- Act in accordance with values based on universal principles.
- External reflection of an internal moral code.
- Actions that enhance the well being of others.

ANA Code of Ethics

1. Compassion and respect for human dignity.
2. Primacy of the patient.
3. Advocacy for the patient.
4. Accountability for nursing practice.
5. Duty to self and others.
6. Improving care environments and employment.
7. Advancing the profession.
8. Collaboration with other professionals and the public.
9. Obligations to the profession, social reform.



Role of ethics mechanisms

- Improve and enhance the quality of care
 - Care of employees
- Education
 - Committee, staff, community
- Administrative
 - Policy development and review
 - Oversight and comment on operations with ethical impact
- Consultation and case review
 - Conflict resolution
- Inform other institutional efforts
 - Regulatory compliance
 - Reduction of costs (without increasing mortality)

Common issues

• Clinical: Patient and family issues

- Patient rights
- Advance directives
- Surrogate decision making
- Goals of care
- Code status
- End of life
- Culture and Religion
- Mediation

• Organizational: Hospital & system's health

- Resource allocation
- Conflict resolution
- Conflicts of interest
- Confidentiality
- Research
- Public actions
- Mediation

Specific supports for ethics...

• Mission, Vision, Values

• Ethics Committee

• Ethics Consultation

- Clinical and organization issues, policy, education, case review, and consultation

• Institutional Review Board (IRB)

- Ethical conduct of research

• Compliance

- Ethical conduct of business, HIPAA

...supports continued

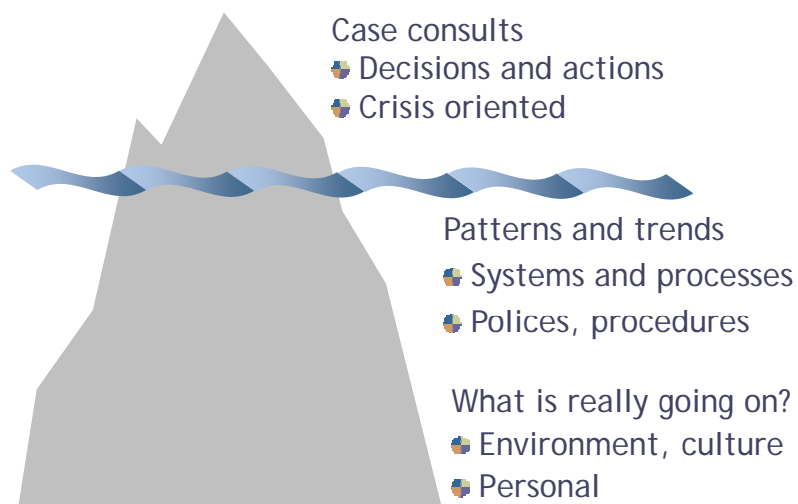
- Pastoral Care
- Palliative Care
- Employee Assistance Program
- Quality
- Outcomes/Utilization Management
- Risk Management
 - Legal liability focus
 - Complaint management, patient rights issues
- Patient safety



Ethical dilemmas

- Conflict between two 'rights'
- Principles, decision making frameworks, or tools help clarify what is important.
- Ethics process
 - ID areas of conflict
 - ID resources
 - Provide support, understanding
 - Help move toward resolution
- Goal/hope: a 3rd way forward
 - Something besides two extremes

The ethics iceberg



Ethics lessons learned

- Elemental work is to protect (the most vulnerable) from harm(s).
- Functions may serve as a social safeguard for complex areas with potential harm(s).
- Issues relate to difference.
- Conflicts also present emotional, psychological, communication challenges.
- Need awareness of values in play, conflicts of interest.
- Ethical theories help clarify, strengthen understanding.
- Ethics is a group activity, levels the playing field.
- Highly individualized decisions worked out in the context of relationships vs. board rooms.

A classic case...

- Mrs. B is 88 with a long history of cardiac disease including a recent MI in the last 3 months.
- Rehabilitation complicated by a massive left-sided stroke
 - Paralyzed on the right
 - Profound expressive aphasia.
 - Can't swallow – nasogastric tube in place.
- No improvement over 10 days with aggressive therapy, including surgical intervention and ventricular drain placement
- Neurological decline, MRI revealed that the stroke has expanded
- Aspiration pneumonia – on mechanical ventilation.

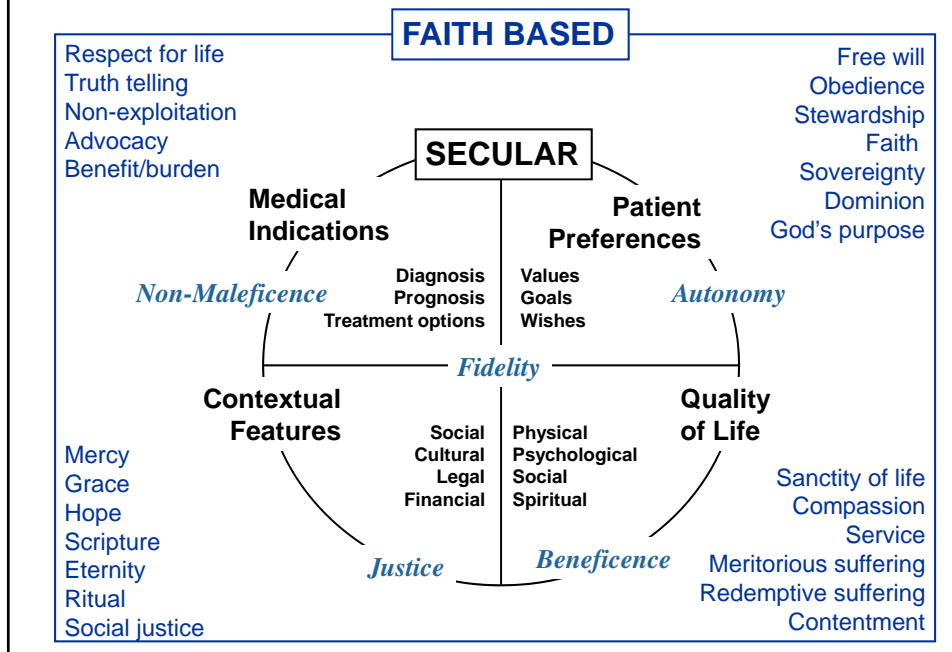
...case continued

- Glasgow coma scale of 5-6
- Neurologist and neurosurgeon believe no chance for improvement.
- Primary care physician reports that this is exactly the kind of situation she wanted to avoid
 - Completed Living Will (LW)
 - Many conversations about her wishes
 - No artificial supports if she was not going to recover to independence.
- Health care power of attorney (POA): her sister. Alternate POA: cousin.

...case continued

- Sister refuses to carry out Mrs. B's wishes,
 - LW can't be right, obviously the patient was coerced
 - The sister feels the POA trumps the living will
 - The documents appear valid
- Cousin not surprised by the sister's response. Willing to carry out the patient's wishes
- Family and friends report the LW is exactly what the patient always said to do in a situation like this.
 - All feel sister is crazy
- ICU attending is spooked by the sister's threats of lawsuit and asks for an ethics consult.

Principled decision making adapted from Robert Orr, MD



Strategies and obligations

- Understand the patient
- Understand the disease
- Understand the system
- Understand yourself

Understand the patient

● How do they make sense of life?

- Role in the family
- Employment
- Social factors
- Cultural factors
- Spiritual factors



Special populations

- Elderly
- Children
- Cognitively impaired
- Substance use/abuse history
- Cultural, spiritual, or religious considerations

Who speaks for the patient?

- Best Interests
 - No clear idea
 - Reasonable person in similar circumstances
 - Implied consent
- Substituted Judgment
 - Specific statements
 - Goals, values, wishes
 - Step into the patients shoes
- State Law
 - Community standard
 - Healthcare surrogate rules



Decision making capacity

- Incompetence is a legal determination
 - General or specific incapacity
- Decision making capacity
 - Is the information understood?
 - Can the person reason, appreciate the consequences?
 - Dialog with you?
 - Can the person make a decision?
- Reassess for each decision
- Caution with neurological conditions, intubated patients, medications, psychological conditions

Determining the surrogate

- Is there paperwork?
 - Power of attorney
 - Healthcare
 - General---may also have healthcare language
 - Durable
 - Court appointed decision maker
 - Guardianship, conservatorship
- Determine validity of any documents
 - Reasonable person determination
 - Reconcile conflicts
- Examine the relationships

Living Will

- Can't make decisions
- Terminal/irreversible
 - Desire natural death
 - Artificial nutrition
 - Organ donation
 - Pain treatment even if death may be hastened
 - Need two witnesses or a notary
 - Healthcare employees CAN witness
 - New form: Advance Care Plan
 - Has POA and Living Will parts

ADVANCE CARE PLAN

Instructions: Competent adults and emancipated minors may give advance instructions using this form or any form of their own choosing. To be legally binding, the Advance Care Plan must be signed and dated, witnessed or notarized.

I, _____, hereby give these advance instructions on how I want to be treated by my doctors and other health care providers when I can no longer make those treatment decisions myself:

Agent: I want the following person to make health care decisions for me:

Name: _____ Phone #: _____ Relation: _____
Address: _____

Alternate Agent: If the person named above is unable or unwilling to make health care decisions for me, I appoint as alternate:

Name: _____ Phone #: _____ Relation: _____
Address: _____

Quality of Life:

I want my doctors to help me maintain an acceptable quality of life including adequate pain management. A quality of life that is unacceptable to me means when I have any of the following conditions (you can check as many of these items as you want):

- Permanent Unconscious Condition:** I become totally unaware of people or surroundings with little chance of ever waking up from the coma.
- Permanent Coma/vegetative:** I become unable to remember, understand or make decisions. I do not recognize loved ones or cannot have a clear conversation with them.
- Dependent in all Activities of Daily Living:** I am no longer able to talk clearly or move by myself. I depend on others for feeding, bathing, dressing and walking. Rehabilitation or any other restorative treatment will not help.
- End-Stage Illness:** I have an illness that has reached its final stages in spite of full treatment. Examples:
 - Widespread cancer that does not respond anymore to treatment, chronic and/or damaged heart and lungs, where oxygen needed most of the time and activities are limited due to the feeling of suffocation.**

Treatment:

If my quality of life becomes unacceptable to me and my condition is irreversible (that is, it will not improve), I direct that medically appropriate treatment be provided as follows. Checking "yes" means I WANT the treatment. Checking "no" means I DO NOT want the treatment.

<input type="checkbox"/> Yes <input type="checkbox"/> No	CPR (Cardiopulmonary Resuscitation): To make the heart beat again and restore breathing after it has stopped. Usually this involves electric shock, chest compressions, and breathing assistance.
<input type="checkbox"/> Yes <input type="checkbox"/> No	Life Support / Other Artificial Support: Continuous use of breathing machines, IV fluids, medications, and other equipment that helps the lungs, heart, kidneys and other organs to continue to work.
<input type="checkbox"/> Yes <input type="checkbox"/> No	Treatment of New Conditions: Use of surgery, blood transfusions, or antibiotics that will deal with a new condition but will not help the main illness.
<input type="checkbox"/> Yes <input type="checkbox"/> No	Tube feeding/IV fluids: Use of tubes to deliver food and water to patient's stomach or use of IV fluids into a vein which would include artificially delivered nutrition and hydration.

PLEASE SIGN ON PAGE 2

Page 1 of 2

Other instructions, such as burial arrangements, hospice care, etc.: _____

(Attach additional pages if necessary)

Organ donation (optional): Upon my death, I wish to make the following anatomical gift (please mark one):

- Any organ/tissue My entire body Only the following organs/tissues: _____

SIGNATURE

Your signature should either be witnessed by two competent adults or notarized. If witnessed, neither witness should be the person you appointed as your agent, and at least one of the witnesses should be someone who is not related to you or entitled to any part of your estate.

Signature: _____ DATE: _____
(Patient)

Witnesses:

- I am a competent adult who is not named as the agent. I witnessed the patient's signature on this form. _____
Signature of witness number 1
- I am a competent adult who is not named as the agent. I am not related to the patient by blood, marriage, or adoption and I would not be entitled to any portion of the patient's estate upon his or her death under any existing will or codicil or by operation of law. I witnessed the patient's signature on this form. _____
Signature of witness number 2

This document may be notarized instead of witnessed:

STATE OF TENNESSEE
COUNTY OF _____

I am a Notary Public in and for the State and County named above. The person who signed this instrument is personally known to me (or proved to me on the basis of satisfactory evidence) to be the person who signed as the "patient". The patient personally appeared before me and signed above or acknowledged the signature above as his or her own. I declare under penalty of perjury that the patient appears to be of sound mind and under no duress, fraud, or undue influence.

My commission expires: _____ Signature of Notary Public: _____

WHAT TO DO WITH THIS ADVANCE DIRECTIVE

- Provide a copy to your physician(s)
- Keep a copy in your personal files where it is accessible to others
- Tell your closest relatives and friends what is in the document
- Provide a copy to the person(s) you named as your health care agent

*Approved by Tennessee Department of Health, Board for Licensing Health Care Facilities, February 3, 2003
Acknowledgement to Project GRACE for inspiring the development of this form.*

Page 2 of 2

Proxy directives

● Durable Power of Attorney for Health Care (DPAHC)

- Any time a person can't make decisions
- Appoint a decision maker
- Need two witnesses or a notary
- Healthcare employees CAN witness
- New Form: Appointment of Health Care Agent

APPOINTMENT OF HEALTH CARE AGENT
(Tennessee)

I, _____, give my agent named below permission to make health care decisions for me if I cannot make decisions for myself, including any health care decision that I could have made for myself if able. If my agent is unavailable or is unable or unwilling to serve, the alternate named below will take the agent's place.

Agent:	Alternate:
Name _____	Name _____
Address _____	Address _____
City _____ State _____ Zip Code _____	City _____ State _____ Zip Code _____
(_____) _____ Area Code Home Phone Number	(_____) _____ Area Code Home Phone Number
(_____) _____ Area Code Work Phone Number	(_____) _____ Area Code Work Phone Number
(_____) _____ Area Code Mobile Phone Number	(_____) _____ Area Code Mobile Phone Number

Patient's name (please print or type) _____ Date _____ Signature of patient (must be at least 18 or emancipated minor) _____

To be legally valid, either block A or block B must be properly completed and signed.

Block A Witnesses (2 witnesses required)

1. I am a competent adult who is not named above. I witnessed the patient's signature on this form. _____
Signature of witness number 1

2. I am a competent adult who is not named above. I am not related to the patient by blood, marriage, or adoption and I would not be entitled to any portion of the patient's estate upon his or her death under any existing will or codicil or by operation of law. I witnessed the patient's signature on this form. _____
Signature of witness number 2

Block B Notarization

STATE OF TENNESSEE
COUNTY OF _____

I am a Notary Public in and for the State and County named above. The person who signed this instrument is personally known to me (or proved to me on the basis of satisfactory evidence) to be the person whose name is shown above as the "patient." The patient personally appeared before me and signed above or acknowledged the signature above as his or her own. I declare under penalty of perjury that the patient appears to be of sound mind and under no duress, fraud, or undue influence.

My commission expires: _____ Signature of Notary Public _____

Approved by Tennessee Department of Health, Board for Licensing Health Care Facilities, February 1, 2005

DNR orders

Hospital

- DOES NOT mean “do not treat”
- NOT automatic with living will
- Requires more nursing hours

Out of Hospital

- Applies between facilities
- Applies at home
- Discharge planning
- Universal DNR
- New form: POST
 - Mandatory for out of hospital DNR
 - Companion to ACP
 - Meant for end of life



COPY OF FORM SHALL ACCOMPANY PATIENT WHEN TRANSFERRED OR DISCHARGED		
Physician Orders for Scope of Treatment (POST) This is a Physician Order Sheet based on the medical conditions and wishes of the person identified as right ("patient"). Any section not completed indicates full treatment for that section. When used occurs, <u>only</u> follow these orders. Then, contact physician.		Patient's Last Name First Name/Middle Initial Date of Birth
Section A Check One Box Only	CARDIOPULMONARY RESUSCITATION (CPR): Patient has no pulse and/or is not breathing. <input type="checkbox"/> Resuscitate (CPR) <input type="checkbox"/> Do Not Attempt Resuscitate (DNR/no CPR)	
Section B Check One Box Only	MEDICAL INTERVENTIONS: Patient has pulse and/or is breathing. <input type="checkbox"/> Comfort Measures: Treat with dignity and respect. Keep clean, warm, and dry. Use medications by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and normal treatment of airway obstruction as needed for comfort. Do not transfer to hospital for life-sustaining treatment. Transfer <u>only</u> if comfort needs cannot be met in current location. <input type="checkbox"/> Limited Additional Interventions: Includes care described above. Use medical treatment, IV fluids and cardiac monitoring as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. Transfer to hospital if indicated. Avoid intensive care. <input type="checkbox"/> Full Treatment: Includes care above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. Transfer to hospital if indicated. Include intensive care. Other Instructions: _____	
Section C Check One Box Only	ANTIBIOTICS – Treatment for new medical conditions: <input type="checkbox"/> No Antibiotics <input type="checkbox"/> Antibiotics Other Instructions: _____	
Section D Check One Box Only in Each Column	MEDICALLY ADMINISTERED FLUIDS AND NUTRITION: Oral fluids and nutrition must be offered if medically feasible. <input type="checkbox"/> No IV fluids (provide other measures to assure comfort) <input type="checkbox"/> No feeding tube <input type="checkbox"/> IV fluids for a defined trial period <input type="checkbox"/> Feeding tube for a defined trial period <input type="checkbox"/> IV fluids long-term if indicated <input type="checkbox"/> Feeding tube long-term Other Instructions: _____	
Section E Must be Completed	Discussed with: <input type="checkbox"/> Patient/Resident <input type="checkbox"/> Health care agent <input type="checkbox"/> Court-appointed guardian <input type="checkbox"/> Health care surrogate <input type="checkbox"/> Power of attorney <input type="checkbox"/> Other: _____ (Specify)	The Basis for These Orders Is: (Must be completed) <input type="checkbox"/> Patient's preferences <input type="checkbox"/> Patient's best interest (patient lacks capacity or preferences unknown) <input type="checkbox"/> Medical indications <input type="checkbox"/> Other: _____
Physician Name (Print) _____ Physician Phone Number _____ Office Use Only		
Physician Signature (Handwritten) _____ Date _____		
COPY OF FORM SHALL ACCOMPANY PATIENT WHEN TRANSFERRED OR DISCHARGED		

HIPAA PERMITS DISCLOSURE OF POST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY			
Signature of Patient, Parent of Minor, or Guardian/Health Care Representative			
Significant thought has been given to life-sustaining treatment. Preferences have been expressed to a physician and/or health care professional(s). This document reflects those treatment preferences.			
(If signed by surrogate, preferences expressed must reflect patient's wishes as best understood by surrogate.)			
Signature	Name (print)	Relationship (write "self" if patient)	
Contact Information			
Surrogate	Relationship	Phone Number	
Health Care Professional Preparing Form	Preparer Title	Phone Number	Date Prepared
Directions for Health Care Professionals			
Completing POST			
Must be completed by a health care professional based on patient preferences, patient best interest, and medical indications.			
POST must be signed by a physician to be valid. Verbal orders are acceptable with follow-up signature by physician in accordance with facility/community policy.			
Photocopies/faxes of signed POST forms are legal and valid.			
Using POST			
Any incomplete section of POST implies full treatment for that section.			
No defibrillator (including AEDs) should be used on a person who has chosen "Do Not Attempt Resuscitation".			
Oral fluids and nutrition <u>must</u> always be offered if medically feasible.			
When comfort cannot be achieved in the current setting, the person, including someone with "Comfort Measures Only", should be transferred to a setting able to provide comfort (e.g., treatment of a hip fracture).			
IV medication to enhance comfort may be appropriate for a person who has chosen "Comfort Measures Only".			
Treatment of dehydration is a measure which prolongs life. A person who desires IV fluids should indicate "Limited Interventions" or "Full Treatment".			
A person with capacity, or the surrogate of a person without capacity, can request alternative treatment.			
Reviewing POST			
This POST should be reviewed if:			
(1) The patient is transferred from one care setting or care level to another, or			
(2) There is a substantial change in the patient's health status, or			
(3) The patient's treatment preferences change.			
Draw line through sections A through E and write "VOID" in large letters if POST is replaced or becomes invalid.			
Approved by Tennessee Department of Health, Board for Licensing Health Care Facilities, February 3, 2005			
COPY OF FORM SHALL ACCOMPANY PATIENT WHEN TRANSFERRED OR DISCHARGED			
DO NOT ALTER THIS FORM!			

Healthcare surrogate selection

1. An adult who has shown special care and concern, who is familiar with the patient's values and who is reasonably available.
2. Preference for
 - a. Spouse
 - b. Adult child
 - c. Parent
 - d. Sibling
 - e. Any other relative
 - f. Adult who satisfies #1

Not mandatory, should rule out persons higher on list first, document

No people/No paperwork

● Attending/treating physician must get:

- Ethics recommendation OR Second attending level physician
 - Not directly involved in the patient's care
 - Not in a capacity of decision making or influence over/under the attending MD
 - Concurs in the decision, documented in the record
 - Any treatment decision including research

● Recommended form: Appointment of Surrogate

APPOINTMENT OF SURROGATE
(TENNESSEE)

I, _____, Designated Physician, made the decision to appoint _____, Name of Surrogate, as surrogate for _____, Name of Patient.

Surrogate Contact Information: Home: _____
Work: _____
Cell Phone: _____

Reasons for Appointment (check all that apply):

<input type="checkbox"/> Knows patient's wishes	<input type="checkbox"/> Demonstrates care and concern
<input type="checkbox"/> Knows patient's best interest	<input type="checkbox"/> Visits patient regularly during illness
<input type="checkbox"/> Had regular contact with patient	<input type="checkbox"/> Engages in face-to-face contact with caregiver
<input type="checkbox"/> Available and willing to serve	<input type="checkbox"/> Participates in decision making process

Physician Signature Date/Time

If designated physician is to act as surrogate, one of the following signatures must be obtained:

Ethics Committee Representative Date or Concurring Second Physician Date

Any individuals in disagreement? Yes ___ No ___
If yes, please explain: _____

ACCEPTANCE OF SURROGATE SELECTION

I accept the appointment as surrogate for _____ Patient
and understand I have the authority to make all medical decisions.

Signature of Surrogate Date/Time

Approved by Tennessee Department of Health, Board for Licensure Health Care Facilities, May 3, 2005

...case continued

- Ongoing conversations, negotiations
- Eventually the sister agrees to hospice care
 - Patient expires 4 days later.
 - Hospice people attend the funeral, paid special attention to helping the sister through the death
- From stroke to death, it was about 21 days.

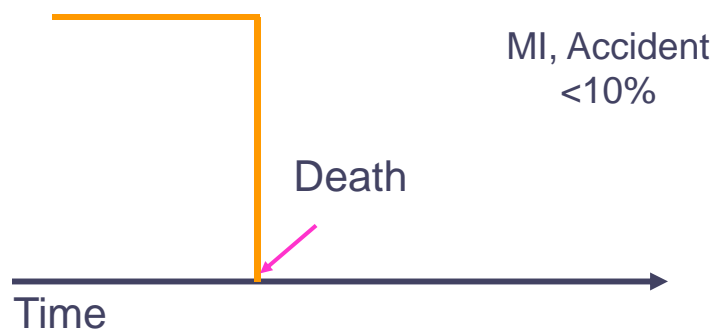
Understand the disease

- Natural course of the disease
 - Symptoms
 - Chronic
 - Acute
- Spiritual dis-ease
 - Fear
 - Isolation
 - Guilt
 - Grief
 - Trust

Expanded notion of pain and suffering

- Physical: “pain” in all its forms
 - Delirium, dyspnea, agitation, constipation, etc.
 - Any physical symptom
- Psychological/emotional
 - Fear, anxiety, grief, guilt, confusion
- Social
 - Isolation, abandonment
- Spiritual
 - Questions of meaning, relationship to God, challenges to personhood

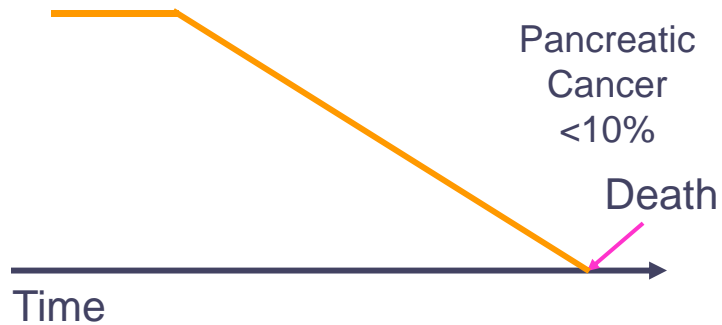
Sudden death



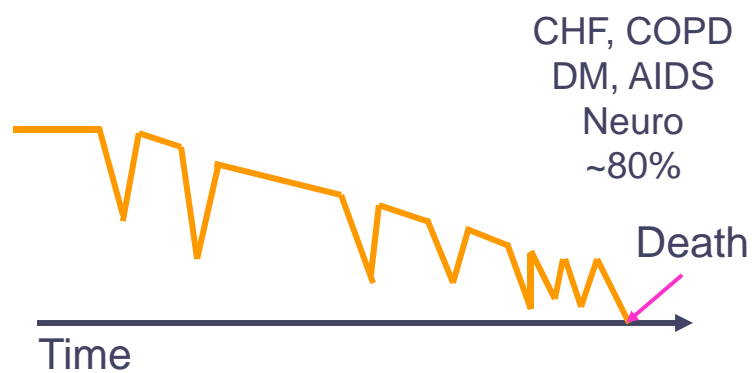
FURTHER READING:

Fields, M., Cassell, C. (Eds) *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academy Press 1997.

Progressive disease with a terminal phase



Chronic, eventually fatal illness, "sudden" death

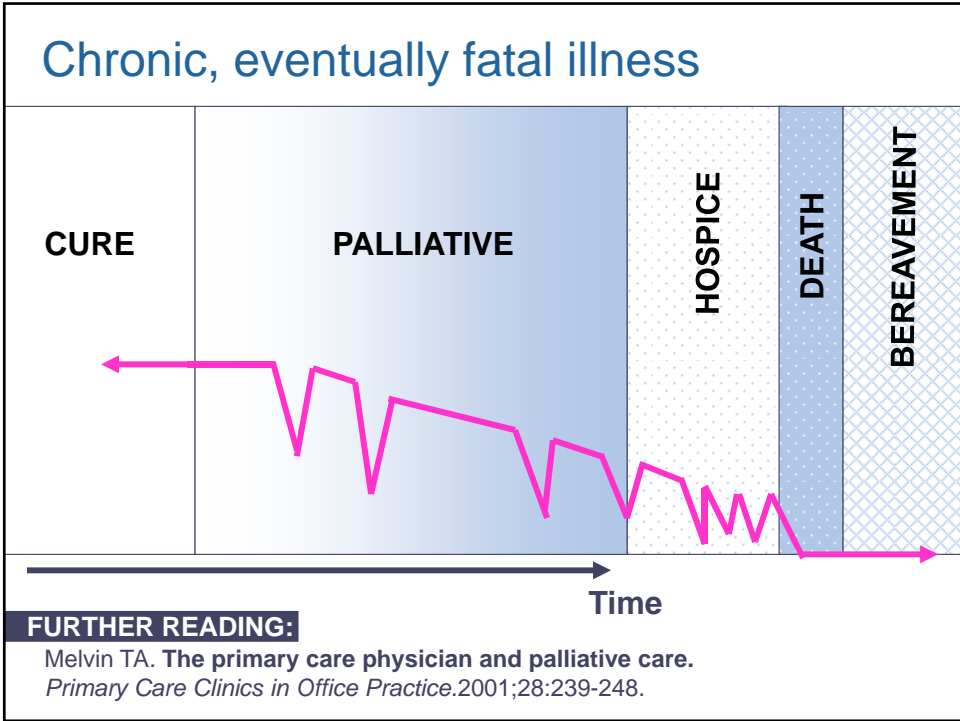


Brain death

- Clinical death and legal death are the same thing. Brain dead is dead.
- UDDA- All states by statute or case law
 - Any individual who has sustained either (a) irreversible cessation of circulatory and respiratory functions or (b) irreversible cessation of all function of the entire brain, including the brain stem, is dead.
- Issues
 - What if the family wants to keep going?
 - What if the don't believe you?
 - Solid organ donation

Understand the system

- Cure orientation
 - High tech
 - Uncertainty
 - Fragmented
 - Organ based
- Lack capacity
 - Surrogates probably don't know
- Economics
- Illness and death are bad, not normal

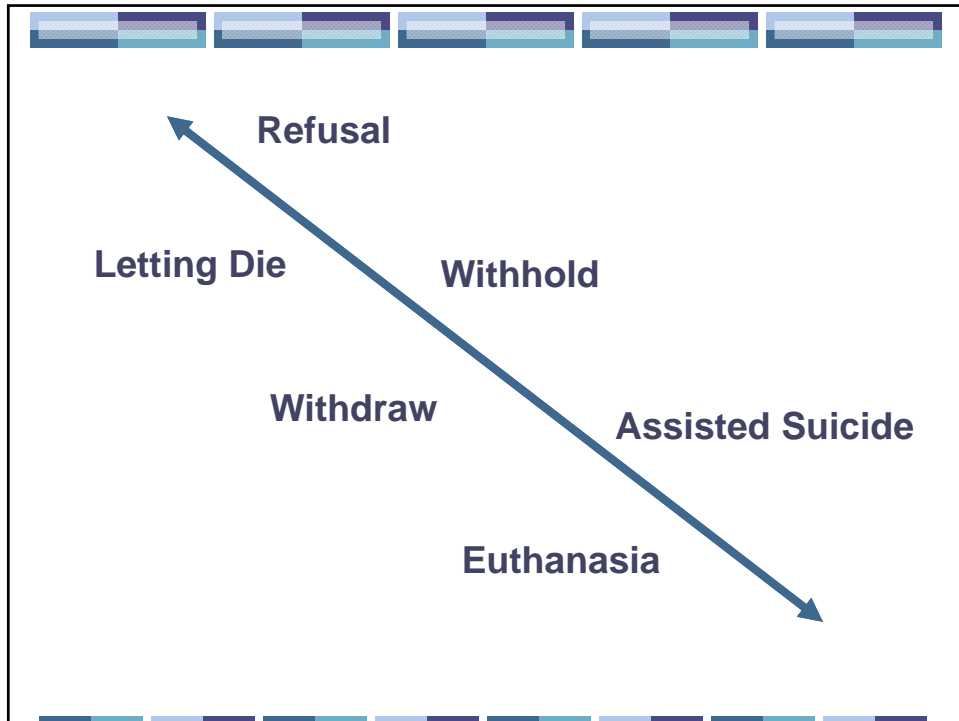


Integrated palliative care

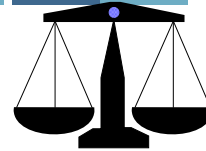
- Symptom management
 - Pain in all its forms, in all realms
 - Comfortable enough to be functional
- Communication management
 - Information flow
 - Anticipatory planning
- Environmental management
 - Adaptive and therapeutic
- Resource management and referral
 - Social services, pastoral care, financial counseling, meals on wheels

Issues in care of the dying

- Tension between two extremes
 - Use of (possibly) burdensome technology
 - Withdrawal of technology (possibly) intending death
 - Killing vs. letting die
- Care even when cure is impossible
- Effective management of pain in all its forms
 - Management of suffering



Double effect



- Inextricably linked actions and effects
 - Pain medication / respiratory depression
- Action itself is a good or at least neutral
 - Giving medications, narcotics
- Intend good, foresee evil effects
 - Pain relief, foresee respiratory depression
- Evil can't be the way to achieve the good.
 - Respiratory depression, death, is not the way to pain relief

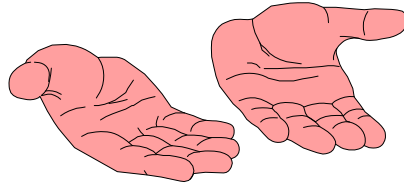
Consensus in the courts

- Major points there is agreement
 - Competent patients have the right to refuse
 - Don't have to be terminal
 - No meaningful difference between WH or WD
 - ADN&H decisions should be viewed like any other treatment (ventilator, CPR, etc.)
 - Best evidence is a written directive
- Diversity on secondary questions
 - Surrogates can assert rights
 - Level of proof with surrogates
 - Decision making without clear wishes

...courts continued

- Litigation from foregoing life support:
 - 0.2%-0.5% have been litigated at all
 - 37-55 in 10,000,000 reached appellate court
 - Alan Meisel, The Right to Die, Eur J Health Law. 1996
 - 1990 AHA (amicus brief in Cruzan) 70% or 1.3 million deaths occur only after a decision made to forego LST
 - SUPPORT study of over 11,000 in hospital deaths, none of them had after death legal claims against providers.
 - SUPPORT Principle Investigators JAMA. 1995;274:1591-98.
 - Personal communication to Meisel By Dr. Teno, 1998

Understand yourself



• Seek first to understand, then to be understood.

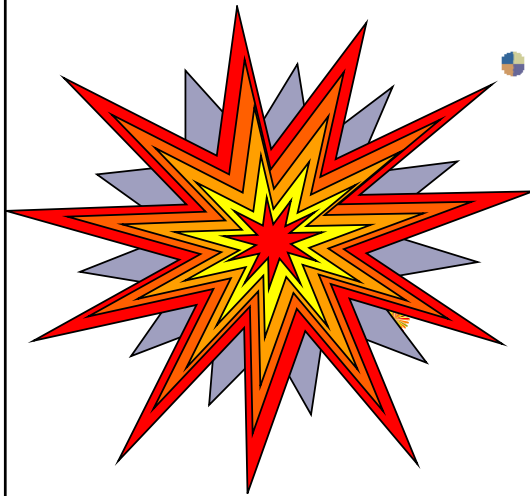
• Covey

Moral distress defined...

• “Painful feelings and/or the psychological disequilibrium that occurs when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action.”

- Jameton A. Nursing Practice: The Ethical Issues. NJ:Prentiss-Hall. 1984

Constraints



- Inability to advocate
 - Societal
 - Organizational
 - Professional
 - Personal

...defined

- 1993 Jameton distinguished:
 - Initial: frustration, anger and anxiety due to
 - Institutional obstacles
 - Interpersonal conflict about values
 - Reactive: due to failure to address initial distress
- 2000 Webster and Baylis included:
 - Failure to pursue “right” course of action due to
 - Error in judgment
 - Personal failing
 - Circumstances beyond control
 - May feel cherished beliefs violated
 - Compromised integrity

...defined

- “...the pain or anguish affecting the mind, body or relationships in response to a situation in which the person is aware of a moral problem, acknowledges moral responsibility, and makes a moral judgment about the correct action; yet as a result of real or perceived constraints, participates in perceived moral wrongdoing.”
 - Alvita Nathaniel MSN, RNCS
 - In Nursing World, July 28, 2002

Other/related distress...

- Jading
 - A process leading to exhaustion from being overdriven to perform long, continued labor and/or severe or tedious tasks.
- Burn out
 - Individual or group stress related to one's relationship with the work environment
- Grief out
 - Repeated, sustained and often unresolved grief and loss

...other distress

- Compassion fatigue (CF)
 - Gradual lessening, over time of ability to be compassionate.
 - The price one pays for caring.
 - Emotional stress experienced from exposure to the suffering of others.
- Secondary Traumatic Stress (STS)
 - Presence of Post-Traumatic Stress Disorder (PTSD) in the caregiver.
- Both STS and CF are caused by exposure to persons who have been traumatized or are suffering, not to the traumatic event itself.
 - Vicarious traumatization

Caregiving: A moral endeavor

- Roots of the caring professions
 - Hotel Dieu: "House of God"
 - Holy work
- Practice
 - Fundamentally ethical
- Promotion of ideal patient care
 - Respect for persons
 - Role as advocate
 - Safe and best care
- Caregiver-patient relationship is complex
 - Patient focused caring
 - Some distress is unavoidable

Ethical components of moral distress

- Obligations of self
- Obligations of others
- Boundaries
- Risks and benefits of action
- Critical thinking/response
 - Knowledge, skills, resources needed
 - Anticipation
 - Management
 - Action

Role morality

- That which nurses do to meet the goals of nursing – Hanna
 - What is done to meet goals as well as a response to an inability to meet goals.
 - Unrelieved distress
 - Self worth
 - Physical and psychological
 - Personal and professional relationships and values
 - How nurses define goals, responses.



Contributing factors...

- Team function
- Role/Relevance questions
- Closeness/Identification
- Isolation
- Lack of, staff, skill, time, resources
- Acuity
- Cure orientation/Death as failure
- Belief “doing everything” a sign of faithfulness
- Assertive/aggressive patients and families



Causes of moral distress...

- Feelings of failure or guilt
- Futility
- Compromise of one’s standards of care
 - Inadequate staffing
 - Inability to meet perceived needs of patient
 - Lack of resources, services
- Feelings of powerlessness or helplessness
- Inability to talk about feelings



...causes

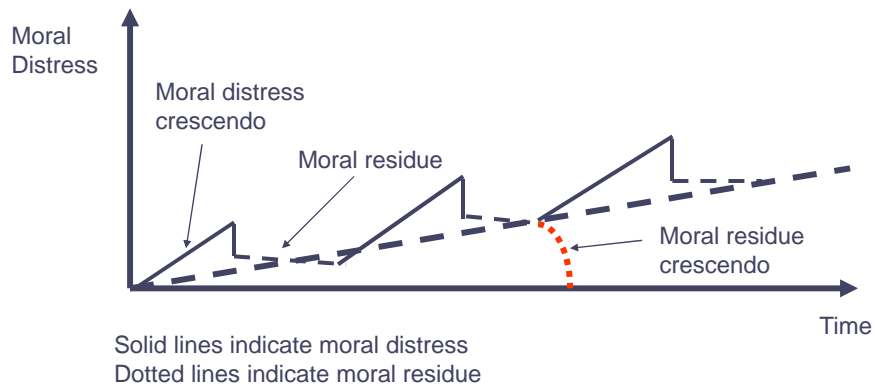
- Limited role in decision-making
- Decisions contradict patient's "best interest"
- Conflict
 - Inter-disciplinary or intra-disciplinary
 - Patient or family
- Sustained proximity contributes to sense of responsibility
 - Others walk away



...causes

- Lack of/or confusion about plan
 - Too many partners or consultants
- Communication failures
 - Within team
 - With patient/family
- Grief and loss
 - Repeated
 - No time to process
 - Lack of closure
 - Isolation

Crescendo effect



Symptoms of moral distress...

- Fatigue
 - Emotional, physical
- Somatic concerns
 - Diet, sleep, physical illness
- Absenteeism
- Poor or inappropriate care
 - Recipients of care
 - Self
- Feelings of inadequacy
 - Personal, professional
 - Feeling victimized
 - Feeling traumatized



...symptoms

- Irritability, anger, insults, resentment, conflicts
- Anxiety
- Frustration
- Depression
- Blaming others




...symptoms

- See self as having lost
 - Integrity
 - Authenticity
- Distancing oneself
 - Isolation
 - Friends, family
 - Colleagues
- Loss of meaning
 - Crisis of faith



Frequency and intensity - Elpren

- 1) Continue to participate in care for a *hopelessly* ill person who is being sustained on a ventilator, when no one will make a decision to 'pull the plug'.
- 2) Follow a family's wishes to continue life support even though it is not in the *best interests* of the patient.
- 3) Initiate *extensive* life-saving actions when *I think* it only prolongs death.

- 
- 4) Follow the family's wishes for the patient's care when *I do not agree* with them but do so because the hospital administration fears a lawsuit.
 - 5) Carry out the physician's orders for *unnecessary* tests and treatments for terminally ill patients.
 - 6) Provide care that does not relieve the patient's *suffering* because the physician fears increasing doses of pain medication will cause death.

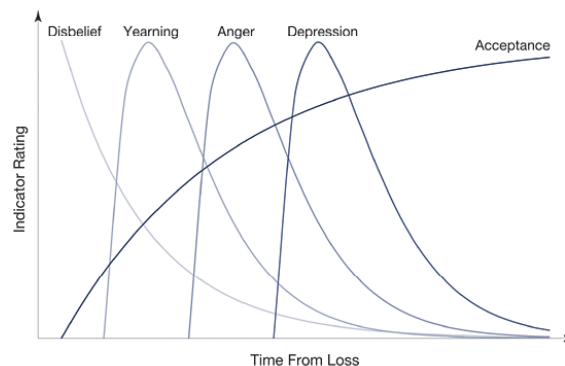
Impact of unexamined feelings

- Patient care
 - Poor quality care
 - Increased complications
 - Unclear goals
 - Inappropriate use of LST
- Caregiver
 - Cynical
 - Loss of meaning
 - Burnout
 - Depression
 - Substance abuse
 - Mental health
 - Fear of death
- Risks
 - Personal relationship
 - Anger either way
 - Too many caregivers
 - Unclear Plan
 - Substance abuse
 - Mental health
- Behavior
 - Relationship problems
 - Mistrust
 - Avoidance
 - Power struggles
 - Signs of stress
 - Guilt, grief, shame, anger, ambivalence, victimization

FURTHER READING:

Meier DE, Back AL, Morrison RS. **The inner life of physicians and care of the seriously ill.** *JAMA*.2001;286:3007-3014.

Hypothesized Stage Theory of Grief

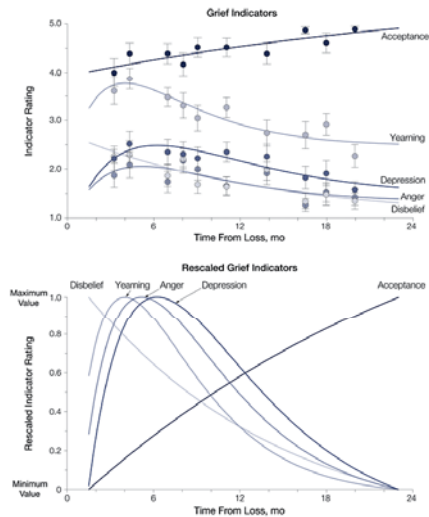


Maciejewski, P. K. et al. *JAMA* 2007;297:716-723.

Copyright restrictions may apply.

JAMA

Empirical and Rescaled Models for Grief Indicators as Functions of Time



Copyright restrictions may apply.

JAMA

Other costs

- Operational
- Legal
- Marketing and public relations
- Competition
 - Wages
 - Price
 - Efficiency
 - Cost of capital

The common good

- Actions or outcomes that have some definable benefit beyond individual gain
 - Generally societal good
 - Determination as to what good is
 - Good for all
 - In all human dimensions

**Cost control,
safety, infection control,
facility, others**

**Organizational awareness,
performance improvement,
information management**

**Customer service, patient rights,
communication, and teamwork**

**Professionalism/self-development/respect and
rational decision making**

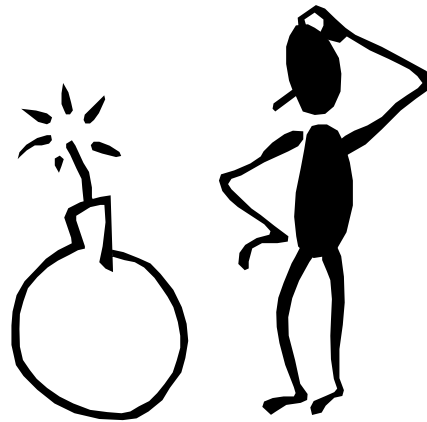
Accountability, self-control, and resilience

Self esteem/self confidence

Decker, Hospital Topics, 1999

Hidden competencies

- Accountability
- Professionalism
- Emotional self-control
- Self-esteem

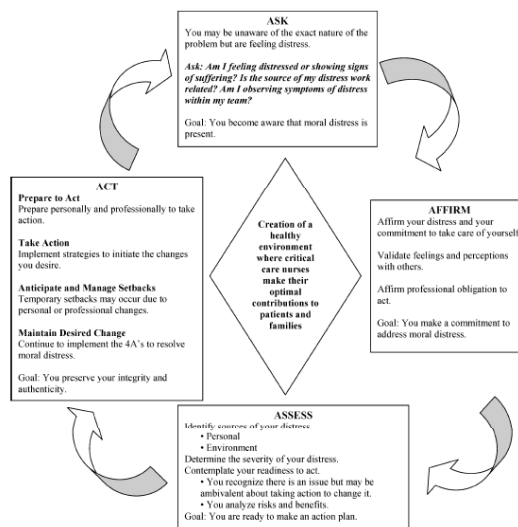


Practice based ethics

- Relationship between professionals and patients.
 - Understanding
 - Agreement
 - Nature
 - Context
 - Focus is on human value

When to get help

- Apparent absence of grief
- Hyperactivity and prolonged restlessness
- Assuming the symptoms of the one who died
- Psychosomatic illnesses
- Emotional numbness
- Abrupt or severe changes in lifestyle
- Self-destructive behavior
- Long-lasting or very deep depression
- Hostility
- Rage
- Continued inappropriate emotional outbursts
- Thoughts or talk of suicide



Rushton CH. Defining and addressing moral distress. Tools for critical care nursing leaders. *AACN Adv Crit Care*. 2006;17(2):161-168.



Interventions

- Ethics mechanisms
- Round table
- Grand rounds
- Facilitated ethics conversations
- Follow up education after consultation
- Curbside conflict management
- Mediation
- Informal, curbside education
- Monthly brown bags



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