

**The Twelfth Annual University of Maine  
Clinical Geriatrics Colloquium**

**EMERGING PERSPECTIVES  
ON DEATH, DYING, &  
BEREAVEMENT**

**Friday, October 20, 2017**

**8:00 am - 4:00 pm**

**Wells Conference Center**

**University of Maine**

**Orono, ME**

# Ethical Challenges in Caring for Dying Patients

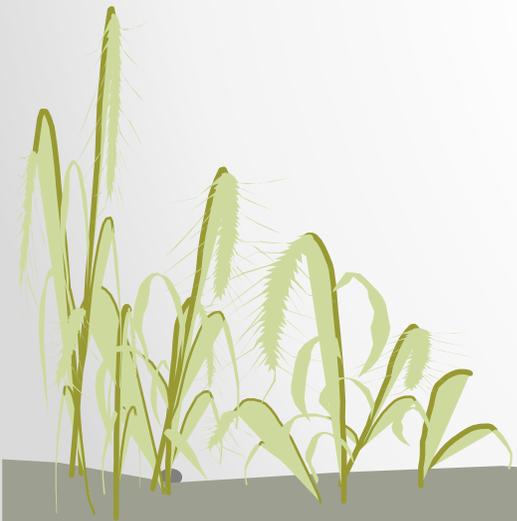
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# Acknowledgements

- Many thanks to Dr. Cara Wallace & Dr. Stephanie Wladowski whose work in this area helped make this presentation possible.



# Presentation Outline

- Introduction and Background
  - Ranking Principles
  - What is an Ethical Dilemma?
- Ethical Challenges at the End of Life
  - Professional Boundaries
  - The Business of End-of-Life Care
  - Decision Making and Other Patient-Related Dilemma
- Ethical Decision Making
  - ETHIC model
  - Practice!



**RANKING PRINCIPLES  
WHAT IS AN ETHICAL DILEMMA?**

**ETHICAL CHALLENGES AT THE END OF LIFE**



# BASIC ETHICAL PRINCIPLES

- **Autonomy:**
  - To promote self-determination
- **Beneficence:**
  - To do good for others and promote the well-being of clients
- **Nonmaleficence:**
  - To avoid doing harm
- **Justice:**
  - To be fair by giving equally to others & to treat others justly
- **Fidelity:**
  - To make realistic commitments & keep these promises
- **Veracity:**
  - To be truthful & honest in dealings with clients.

# CASE EXAMPLE

You are a palliative care social worker in a suburban hospital working with patients & their families. One day you receive a referral from oncology with a note to call and talk with the adult son prior to your visit with the patient. The patient has signed a consent form authorizing hospital personnel to confer with her son. The son tells you that his mother's doctor had just informed him that his mother has a very serious case of uterine cancer. He pleads with you to not share with his mother the physician's dire prognosis, even if his mother asks for details. According to the son, the patient struggles with serious clinical depression and cognitive impairment and would have a very difficult time processing this troubling information. The referring physician also reports concerns about the patient's ability to cope with discouraging details about her health.

The next day when you meet the patient, she tells you, "I don't really know what is going on here. I feel like my body is breaking down, but no one is explaining to me what's happening. Have you heard anything about what is wrong with me and what the doctor plans to do?"

# WHAT IS AN ETHICAL DILEMMA IN END OF LIFE CARE?

1. A decision must be made about which course of action is best
2. Must be able to choose from different courses of action.
3. No matter what course of action is taken, some ethical principle is compromised.



# CONSIDERATIONS FOR DETERMINING WHAT CONSTITUTES AN ETHICAL DILEMMA:

- ETHICS

- Logical & rational criteria to reach a decision
- A cognitive process

- VALUES

- Ideas we prize or value
- Has worth to us; we hold it dear
- Often has feeling or emotion tied to it

- LAWS

- Medical, health, & behavioral practitioners are sometimes required to follow (mandated reporting), but may protect confidentiality “to the extent permitted by law”

- AGENCY POLICIES

- Ethical practice should override agency policies in some professions (i.e. Social Work).

# **AN ETHICAL DILEMMA IS...**

**...when two or more ethical standards  
apply to a situation,  
but are in conflict with each other!**



# IT IS NOT NECESSARILY AN ETHICAL DILEMMA IF...

- You are simply uncomfortable with the situation
  - EX: You have two clients who both need financial assistance and you only have enough funding to help one of them.
- The issue is in conflict with your personal values
  - EX: Client wants to come off a ventilator and you are opposed to this
- The issue is governed by law (“approximate” dilemma)
  - EX: Client discloses abuse, but your reporting to authorities will mean she loses custody of children

**PROFESSIONAL BOUNDARIES**  
THE BUSINESS OF END-OF-LIFE CARE  
DECISION-MAKING (AND OTHER PATIENT-RELATED  
DILEMMAS)

**ETHICAL CHALLENGES AT THE END OF LIFE**



# PROFESSIONAL BOUNDARIES

- Defining boundaries
- Vulnerabilities to Crossing boundaries
- Risks of Poor boundaries
- Who is responsible?
- Situations where poor boundaries can lead to unethical behavior

\*this section is modified from Schunk, 2014  
<http://www.pcaaz.org/wp-content/uploads/2014/07/D56-Managing-Common-Boundary-Dilemmas.pdf>

# DEFINING BOUNDARIES

- “something that indicates or fixes a limit or extent” (Merriam-Webster’s Online Dictionary)
- “mutually understood, unspoken physical and emotional limits of the professional relationship” (Texas Medical Association, [www.texmed.org](http://www.texmed.org))
- “framework within which the ... relationship occurs. Boundaries make the relationship professional, and safe for the client... The primary concern in establishing and managing boundaries with each individual client must be the best interests of that client.” (“Professional Boundaries in Healthcare Relationships.” *The Bulletin*, The College of Psychologists of Ontario, VOLUME 25, NO 1, JULY 1998. [www.cpo.on.ca/WorkArea/DownloadAsset.aspx?id=782](http://www.cpo.on.ca/WorkArea/DownloadAsset.aspx?id=782) )

• *What is your definition?*

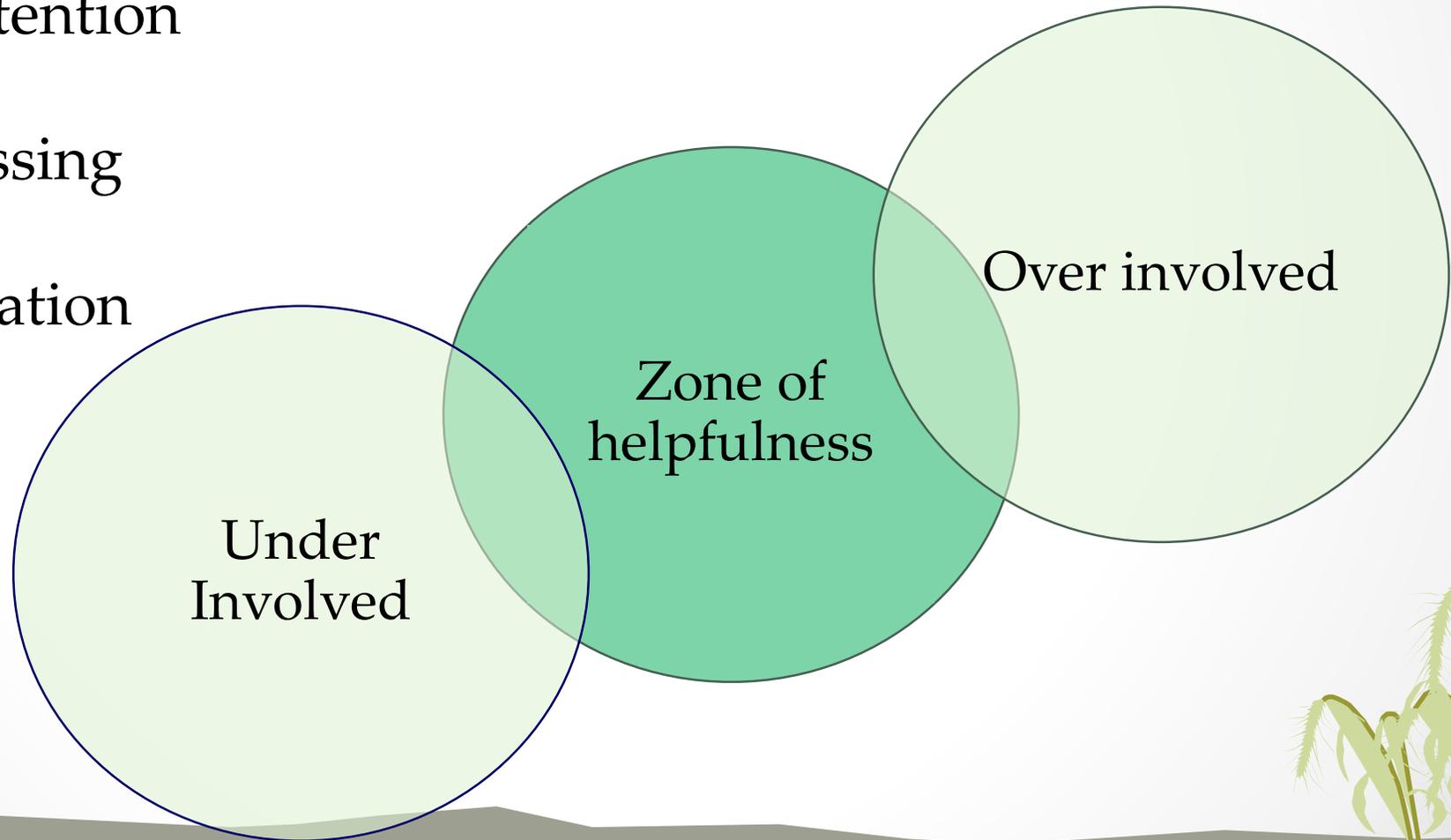
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# DEFINING BOUNDARIES

Boundary Inattention

Boundary Crossing

Boundary Violation



# VULNERABILITIES TO CROSSING BOUNDARIES:

- Patient/family in time of great need
- We genuinely care about the well-being of our patients
- Experience intimate moments with families/patients as they share their experiences
- Visits take place in home environment
- Long-term relationships (at times)
- We are the 'experts,' families desire our assistance/services

# RISKS OF POOR BOUNDARIES

- Unethical service
- Burnout/Compassion Fatigue
- Inconsistent Standard of Practice
- Greater potential for blame of misconduct
- Reputation of agency, profession, and/or provider may be compromised
- Poor client outcomes

# WHO IS RESPONSIBLE?

- Sole responsibility of establishing/ maintaining boundaries is OURS , not patients/families
- Once a boundary is crossed, that often becomes the expectation



# SELF-DISCLOSURE



Remember:

- Appropriate self-disclosure helps build rapport
- Why are you disclosing?
- When patients ask direct personal questions, there is usually a reason behind the questions. Attempt to discover and address that reason.

# DUAL RELATIONSHIPS



Remember:

- We need to be honest and self-searching in determining the impact of our behavior on clients and families
- Constantly ask yourself—“Whose needs are being met?”

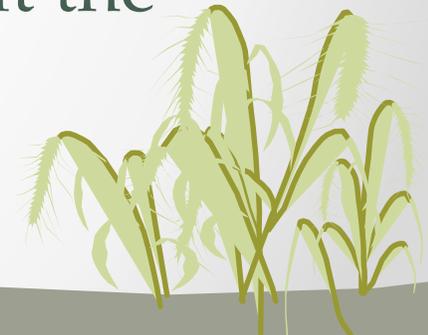


# BECOMING FRIENDS



Remember:

- Explain your role in your first meeting with the patient/family and reiterate it often throughout the professional relationship



# SELF-DETERMINATION



NOT RESPECTING  
DIFFERENCES/DENYING  
SELF-DETERMINATION

Remember:

- Client's have the right to make poor decisions
- Client's have the right to be informed
- Bracket your personal values/beliefs as separate from the professional work you do with clients

# GIFTS



GIFTS

Remember:

- Be aware of agency policy
- Remind client you are paid by agency and cannot accept money for your services
- Attempt to steer towards giving to the agency as a whole
- If no/low monetary value consider meaning to client, impact on relationship (accepting/refusing)



# TIPS:

- Define your role with patients early and often
- Let patients/families know what to expect of your time together at the beginning of each visit
- Utilize other team members
- Recognize your own strengths and vulnerabilities in regards to setting and maintaining boundaries
- **CONTINUE THE CONVERSATION**

# ASK THE QUESTIONS:

- What is the purpose of this action? Is it serving the patient's best interest? What impact will this have on the service?
- Whose need am I meeting with this action? Mine or the patients?
- Am I treating this client differently?
- What does the Profession's Code of Ethics say about this?
- Am I comfortable documenting this information? Do I need to consult my supervisor? How would others view this?

PROFESSIONAL BOUNDARIES  
**THE BUSINESS OF END-OF-LIFE CARE**  
DECISION-MAKING (AND OTHER PATIENT-RELATED  
DILEMMAS)

**ETHICAL CHALLENGES AT THE END OF LIFE**



# THE BUSINESS OF EOL CARE

- Industry Issues
  - Day-to-day Challenges
  - Referrals
  - Fundraising
  - Case loads
- Emerging Ethical Issues



# INDUSTRY ISSUES: DAY-TO-DAY CHALLENGES

- Working on an Interdisciplinary team
- Goals of Care
- Decision Making
- Advance Directives and funeral planning
- Patient and family goals conflicts
- Physician and patient goals conflicts
- Transitioning focus of care
- Pain and symptom management
- Inadequate or Insufficient communication
- Available resources
- Lack of self care... (ahem!)

# INDUSTRY ISSUES (CONTINUED):

- CASE LOADS

- Census fluctuation; budget cuts; service area allocation or inequities

- REFERRALS

- To whom; from whom; service area resources

- FUNDRAISING



# EMERGING ETHICAL ISSUES:

- **Resource Allocation:**

- Staff allocation
- Lack of bedside time
- Lack of time for quality communication
- Level of care, WH/WD treatments

- **Competencies in EOL Skills:**

- Communication skills
- Understanding of euthanasia, terminal sedation
- Cultural and religious issues related to dying persons
- Power issues
- Pain and symptom management
- Balance of patient choices and family needs and choices

PROFESSIONAL BOUNDARIES  
THE BUSINESS OF END-OF-LIFE CARE  
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# PATIENT RELATED DILEMMAS

- Determining Capacity
- Patient Preferences
- Quality of Life
- Live Discharge
- Care Transitions



# CAPACITY: ETHICAL DEFINITION

- Self-determination:
  - The decision to accept or decline treatment rests with the patient
  - Patient's right to refuse treatment is stronger than to demand treatment
- If the patient lacks the capacity to make decisions, then we:
  - Follow advance directives
  - Find out patient's choices and follow them
  - Act in patient's best interests

# CHALLENGE: CAPACITY TO MAKE DECISION

- Patient appreciates that there are choices
- Patient is able to make choices
- Patient understands the relevant medical information (dx, prognosis, risk/benefit, alternatives)
- Patient appreciates the significance of the medical information in light of her own situation and how that influences the current treatment options
- Patient appreciates the consequences of the decision
- Patient's choice is stable over time and is consistent with the patient's own values and goals

# CHALLENGE: PATIENT PREFERENCES

- Ongoing, dynamic process of assessment that decreases chances of conflict
- Contradict clinical indications
- Cultural, ethnic and age related differences
- Common ethical dilemmas
  - Religious and cultural diversity conflicts
  - Truthful communication, disclosure
  - Refusal of treatments
  - Advanced care planning
  - Funeral arrangements

# CHALLENGE: QUALITY OF LIFE

- Knowledge of individual and family's definition of QOL
- Understanding patient's prior QOL
- Sharing expected QOL with or without a certain treatment
- Common ethical dilemmas
  - Artificial nutrition/hydration
  - Withhold/withdrawal of non-beneficial care, including vent, dialysis, etc
  - Assisted suicide
  - Medication side effects

# CHALLENGE: LIVE DISCHARGE

- An estimated 1.6 million people received hospice services in 2014 (NHPCO, 2015)
- 63.4% with non-cancer primary diagnosis:
  - Dementia (14.8%), Heart Disease (14.7%), Lung Disease (9.3%), Stroke or Coma (6.4%)
- In 2011, approximately 278,000 patients were discharged due to achieving an extended prognosis



# CHALLENGE: CARE TRANSITIONS



- Individual:

- Changes in care relationships
- Termination of care providers
- Uncertainty in grief process

# CHALLENGE: CARE TRANSITIONS



- Caregivers:

- Not feeling prepared for the transition, for caregiving tasks and equipment (Byrne, et al., 2011; Levine, et al., 2010)
- Limited access to supportive resources (Byrne, et al., 2011)
- Grief process for those providing care to adults with dementia is complex and transitions impact grief process (Wladkowski, 2016)

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# CRITICISMS OF PRINCIPLISM?

- Core principles have no priority ranking. Beauchamp (2007): “Principles and rules can ... be justifiably overridden by other ... norms with which they conflict.”
- Ethical principles can be vague in their definition and application.

(Gert, 1997, 2006)

\*\*Adapted from Bryan, Sanders, & Kaplan CSWE 2016

# CRITICISMS OF PRINCIPLISM?

- The definitions of the principles and the ways in which they may be valued are not universal, they change across cultures. For example, autonomy – not all cultures view self-determination as a principle; equality and fairness are also not universally defined.
- They tell us what we “ought to do” rather than what we “ought not to do” which confuses what we might consider to be required vs. encouraged.

(Gert, 1997, 2006; Gordon, 2011, Takala 2001, Westra et al, 2009)

# ETHIC MODEL OF DECISION MAKING

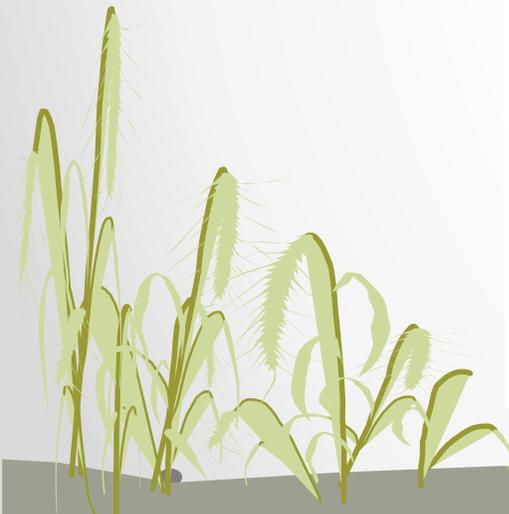
- Congress (2000) proposed this decision-making model for social workers based on the premise that the ethical standards are imperfect and cannot be followed exactly at all times.
- For example: Limits to confidentiality.
  - Social workers should protect the confidentiality of all information obtained in the course of professional service, except for compelling ... reasons. The ... expectation that social workers will keep information confidential does not apply when disclosure is necessary to prevent serious, foreseeable, and imminent harm to a client or others (NASW, 2008)

# ETHIC MODEL OF DECISION MAKING

**TABLE 1. ETHIC Model of Decision Making**

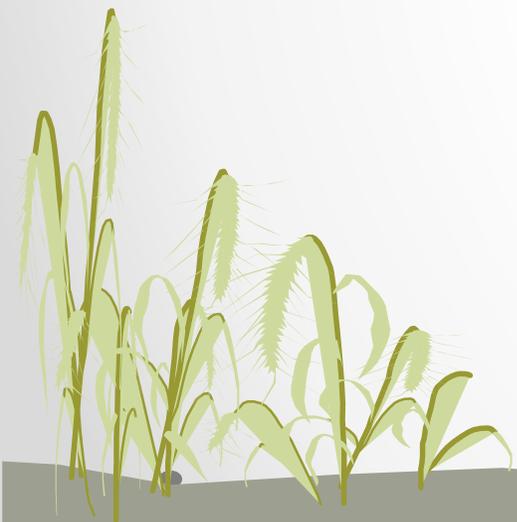
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- E**      **Examine relevant personal, societal, agency, client and professional values.**
- T**      **Think about what ethical standard of the NASW code of ethics applies, as well as relevant laws and case decisions.**
- H**      **Hypothesize about possible consequences of different decisions.**
- I**      **Identify who will benefit and who will be harmed in view of social work's commitment to the most vulnerable**
- C**      **Consult with supervisor and colleagues about the most ethical choice.**
- 



# ETHIC MODEL OF DECISION MAKING

- Let's evaluate the case study using the ETHIC model.



# ASK THE QUESTIONS:

- What is the purpose of this action? Is it serving the patient's best interest? What impact will this have on the service?
- Whose need am I meeting with this action? Mine or the patients?
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- Am I comfortable documenting this information? Do I need to consult my supervisor? How would others view this?

# WRAP-UP & CONCLUSIONS:

- Feelings/thoughts about the model presented? Could this be utilized within interdisciplinary teams where you work?

## Benefits of the model:

- Provides a unified approach across disciplines
- Starts from a framework all participants already agree upon (what is common morality)
- A first step for decision-making
- If no moral rule is violated, then common decision-making models are still useful in assisting with a decision

# QUESTIONS?

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