

Palliative Care: Between Patient's Rights Autonomy and Clinicians' Moral Responsibility

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Personal Disclosure applicable to the two presenters

“Neither I nor my spouse/partner have, or have had in the past 12 months, any financial relationships with commercial interests with this topic.”

Objectives

Objective 1:

Clinicians will be able to articulate and distinguish different conceptions and misconceptions of key ethical principles relevant to the context of Palliative Care;

Objective 2:

Clinicians will be able to apply to their own practice a shared decision-making model that truly honors “patient autonomy”;

Objective 3:

Clinicians will be able to develop a renewed perception of their own sense of moral agency as well as promote the moral agency of their patients.

Four Most Common Ethics Principles in Health Care

- **Autonomy**
 - Informed consent/ refusal of treatment
 - Decision-making capacity
- **Beneficence**
 - Patient's best interests
- **Non-Maleficence**
 - Disproportionate harm
- **Justice**
 - Fair and equal quality treatment, respect of personal values/religious beliefs

Consent / Informed Consent

- Informed Consent is the full disclosure sharing of information: Diagnosis, risks and benefits of proposed treatment, risks and benefits of alternative treatments, risks and benefits of no treatment.
- Consent is a record of informed consent in writing.
- Physician's progress note

What is capacity?

“Capacity means a person’s ability to understand the nature and consequences of **a decision**, and to make and communicate a decision, and includes in the case of proposed health care, the ability to understand its significant benefits, risks, and alternatives.”

California Probate Code, Section 4609

Decision-Making Capacity:

- is always presumed [PROB 4657];
- is determined by a minimum of ONE physician, the primary or attending;
- the primary or attending can ask for a second opinion;
- second opinion can come from a psychiatrist or licensed psychologist, but does not have to be;
- **is contextual** (it does not need to be an “either or” situation!);
- once it has been determined that a patient does not have decision-making capacity, the primary or attending has to document (in addition to the second opinion if any)[PROB 4658];
- a patient does not need to have advance dementia to be considered without decision-making capacity.

Patient or Legally Recognized Healthcare Decision Maker

- Court appointed Conservator of the Person or Guardian
- Agent as designated in an Advance Directive
- Surrogate as orally designated by patient or self-appointed
- Family members: spouse, domestic partner, parent or a minor, available relative, or person who the patient's physician believes best knows the patient's wishes or has the patient's best interest in mind. NO LEGAL ORDER OF PRIORITY WITHIN THIS CATEGORY
- Friend, neighbor, etc...
- If none, call ethics. Depending on local policy!

Patient Autonomy... when in a vulnerable state

EX: Palliative Care physician with years of experience commenting about her practice to a resident:

“Depending how I present Palliative Care, I can pretty much make the patient say what I want him/her to say!”

Outcry: manipulation! When in a vulnerable and critical position, most patients/LRHCDM are open to anything.

Patient Autonomy... “assumption of an equal relationship”

- Paternalistic

“I know best for you”

- Patient centered care (Patient dictating care)

“You know best for yourself”

- Shared decision making model

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QUESTION: Where is true patient autonomy?

Shared Decision-Making

The Spectrum about Patient Autonomy

Positive Right:
“I request”

Negative Right:
“I refuse”



Patient Dictating Care



Patient Centered Care

(Manifestation of feeling powerless)

Did we really honor patient autonomy?!? Case #1

Ethics Consult in what turned out to be hours before death. 89yo female dying from advanced dementia. Also in the room, husband (early dementia), son with some cognitive limitations, pt's brother with limited education. Family has refused palliative care multiple times before.

After there was agreement for comfort measures, social worker goes through the POLST form with one question after the other, waiting for a reply for each question, and wondering who will sign POLST.

Did we really honor patient autonomy?!? Case #2

93yo female with moderate dementia on dialysis for 12 years, was found to have Stg IV breast cancer. Mostly bedbound for one month. Should dialysis be continued?

Niece (DPOAHC) says: “We should ask my aunt.” And the niece takes upon herself to ask without any reference to risks and benefits, no context, just the direct question: “do you want to continue dialysis?” Pt said “Yes.”

Did we really honor patient autonomy?!? Case #3

62yo male walks into ER for intractable abdominal pain. Mr. J. was found to have a large renal mass with extensive thrombus and went into fulminant liver failure including persistent hypoglycemia. Dextrose IVF was started overnight until goals of care were clarified. Family insisted that IVF be continued despite concerns for fluid overload.

What should the medical team have said?

- a) “No problem, as you would like.”
- b) “We do not recommend continuing the IV fluid.”
- c) “IV fluid is not an option at this point as it is already causing significant discomfort and difficulty breathing.”

Did we really honor patient autonomy?!? Case #4

32yo male with stage IV colon cancer in setting of Crohn's disease on methadone drip for pain management. Pain control has finally been achieved on a high dose, however, with the secondary effects of sedation. Mom is struggling with making end-of-life decisions as she never had this conversation with her son. There is no Advance Directive. Hospitalist suggests holding the opioid drip to get the patient more alert to ask patient about his wishes.

Patient Autonomy... menu approach of all the possibilities

Is it really respecting patient autonomy when the clinician lays out a menu of all the possibilities?

“I offered them the trach but I would never do this to my mother!”: says one physician after a family consult.

To put the burden of the decision entirely on the family may very well leave potential lawsuits at bay, but it does not mean that this is an example of respecting patient autonomy. The fact that the patient/family is in agreement with a treatment does not make it medically, ethically indicated! Consent does not absolve the physician from the morality of the proposed treatment. No clinician can ever leave at the door his/her moral agency.

Discourse of “Patient Rights”

- Consumer approach with the “**right to know**”:
“I present to my patients all the facts.” “I stay objective, and let them decide.”
- Consumer approach with the “**right to choose**”:
“Freedom to choose.”

Try to promote Palliative Care to patients of an organization with an advertising campaign such as “We never give up the fight for you.”

Try to promote shared decision making with family members with a copy of an Advance Directive with the subtitle: “My values, my choices, my care.”

IPC: the new Goals of Care Talk

Hospitalist's referral for IPC because the physician knows that goals of care should change but would not bring this up with the patient.

In the context of Palliative Care

Patient Autonomy

Vs.

Physician's Moral Responsibility:

Beneficence + Non-Maleficence

From a Culture of Autonomy to a Renewed sense of Beneficence

Renewed beneficence that leads to a consensus, a process that varies from patient/family to patient/family.

Could it be possible that some patients are better served, beneficence, with some guidance especially seriously ill patients requiring palliative care?

Renewed Beneficence Model

- Both physician and patient must be free to make informed decisions and to act fully as moral agents;
- Physicians have the greater responsibility in the relationship because of the inherent inequality of information and power between themselves and their patients;
- Physicians must be persons of personal moral integrity;
- Physicians must respect and comprehend moral ambiguity yet not abandon the search for what is right and good in each decision.

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- Beneficence is not authoritarianism
 - Beneficence is not a more subtle form of paternalism
 - Beneficence, not only autonomy, really respects patients' rights, really honor the patient in his/her most vulnerable condition... could even restore autonomy.

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“You know best for yourself”

- Shared decision making model

“I have a pretty good idea... and let me hear how you feel, where you stand.”

Questions?

Thank you!

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