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A Resource Center for Today's Case Manager

Ethics in palliative care:

Patients and families who "want everything"



Robert Macauley, MD

Endowed Chair, Pediatric Palliative Care
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Author: *Ethics in Palliative Care: A Complete Guide*



Michael Demoratz, LCSW, CCM

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Commission for Case Manager Certification

Author: *Dying 101: "A Candid Conversation on Terminal Illness"*



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Agenda

- Welcome and Introductions
- Learning Outcomes
- Presentation:
 - **Michael Demoratz, LCSW, CCM, Commissioner**
Commission for Case Manager Certification
 - **Robert Macauley, MD**
Cambia Health Foundation Endowed Chair in Pediatric Palliative Care
at Oregon Health and Science University
- Question and Answer Session

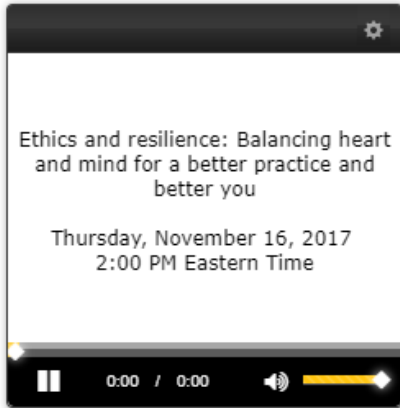




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Audience Notes

- There is no call-in number for today's event. Audio is by streaming only. Please use your computer speakers, or you may prefer to use headphones. There is a troubleshooting guide in the tab to the left of your screen. Please refresh your screen if slides don't appear to advance.



How to submit a question

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Ask Question

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Materials **Ask Question**



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Audience Notes

- A recording of today's session will be posted within one week to the Commission's website, www.ccmcertification.org
- One CCM continuing education ethics credit for board-certified case managers (CCM) and one ANCC nursing contact hour continuing education credit is available for today's webinar only to those who registered in advance and are participating today.

Learning Outcomes Overview

After the webinar, participants will be able to:

1. Develop an approach to discuss goals of care, which may include palliative measures, so patients and their families can plan ahead when facing a serious diagnosis;
2. Describe an ethically appropriate response to an ethical scenario where patients and/or families have expressed interest in palliative care but then request potentially non-beneficial (and conflicting) treatment; and
3. Incorporate advocacy on behalf of clients and their palliative care preferences in interaction with providers and caregivers.

Ethics in palliative care: Patients and families who "want everything"



**Michael Demoratz, Ph.D., LCSW, CCM
*Commissioner***

**Commission for Case Manager Certification
Co-author: *Dying 101: "A Candid Conversation on
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What is palliative care?

Palliative care is specialized health care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a specially-trained team of physicians, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

It is important to note that palliative care is based on *need*, not prognosis.

Source: Center to Advance Palliative Care

Ethics and palliative care



Commission for Case Manager Certification

CODE OF PROFESSIONAL CONDUCT for CASE MANAGERS

Principle 2:

Board-Certified Case Managers will respect the rights and inherent dignity of all of their clients.



Introduction

Robert Macauley, MD

**Endowed Chair, Pediatric Palliative Care
Oregon Health and Science University**

**Author: *Ethics in Palliative Care: A
Complete Guide***





Patients who want “everything”

PRESENTED BY: Robert Macauley, M.D., F.A.A.H.P.M.
Cambia Health Foundation Endowed Chair in Pediatric Palliative Care, OHSU

Case

A seventy-six year old man with multiple medical problems—hypertension, coronary artery disease, chronic obstructive pulmonary disease, and chronic kidney disease—is admitted to the ICU with sepsis. He does not have an advance directive and for years has been reluctant to see his doctors, let alone talk about what he wanted should his health decline.

Case (cont'd)

Recognizing the patient's very poor prognosis, the medical team engages in a thoughtful approach. Through conversation with the family—since the patient lacks decision making capacity—the team identifies the patient's goals and fears, his functional needs and the trade-offs he is willing to make. It seems clear to the team that he would not want the aggressive treatment he's receiving—especially with the low probability of benefit—and they recommend to the family that he be made DNAR and consideration should be given to forgoing intubation, as well.

Case (cont'd)

To the team's surprise, the family is adamant that "everything be done." They remain resolute in this demand, even when the team identifies how this is incompatible with the goals they've just identified.

A couple of preliminary points

- Nobody literally wants everything done
- And “everything” can mean different things to different people

From: Discussing Treatment Preferences With Patients Who Want “Everything”

Ann Intern Med. 2009;151(5):345-349. doi:10.7326/0003-4819-151-5-200909010-00010

Table 1. Different Treatment Philosophies Underlying Requests for “Everything”

Everything that might provide maximum relief of suffering, even if it might unintentionally shorten life.

Everything that has a reasonable chance of prolonging life, but not if it would increase the patient's suffering.

Everything that has a reasonable chance of prolonging life, even if it may cause a modest increase in suffering.

Everything that has a reasonable chance of prolonging life even a small amount, regardless of its effect on the patient's suffering.

Everything that has any possible potential to prolong life even a small amount, regardless of its effect on the patient's suffering.

Table Title:

Different Treatment Philosophies Underlying Requests for “Everything”

Stepwise approach

1. Figure out what this patient means by “everything”

Table 2. Potential Underlying Meanings of “Everything”

Domain	Concept	What “Everything” Might Mean	Questions to Ask
Affective	Abandonment	“Don’t give up on me.”	“What worries you the most?”
	Fear	“Keep trying for me.”	“What are you most afraid of?”
	Anxiety	“I don’t want to leave my family.”	“What does your doctor say about your prospects?”
	Depression	“I’m scared of dying.”	“What is the hardest part for you?”
Cognitive		“I would feel like I’m giving up.”	“What are you hoping for?”
	Incomplete understanding	“I do not really understand how sick I am.”	“What are your most important goals?”
	Wanting reassurance that best medical care has been given	“Do everything you think as a doctor is worthwhile.”	“What is your understanding of your condition/prognosis?”
	Wanting reassurance that all possible life-prolonging treatment is given	“Don’t leave any stone unturned.”	“What have others told you about what is going on with your illness?”
Spiritual		“I really want every possible treatment that has a chance of helping me live longer.”	“What have they said the impact of these treatments would be?”
		“I will go through anything, regardless of how hard it is.”	“Tell me more about what you mean by ‘everything.’”
	Vitalism	“I value every moment of life, regardless of the pain and suffering (which has important meaning for me).”	“Does your religion (faith) provide any guidance in these matters?”
Family	Faith in God’s will	“I will leave my fate in God’s hands; I am hoping for a miracle; only He can decide when it is time to stop.”	“How might we know when God thinks it is your time?”
	Differing perceptions	“I cannot bear the thought of leaving my children (wife/husband).”	“How is your family handling this?”
Family	Family conflict	“My husband will never let me go.”	“What do your children know?”
	Children or dependents	“My family is only after my money.”	“Have you made plans for your children (other dependents)?”
		“I don’t want to bother my children with all this.”	“Have you discussed who will make decisions for you if you cannot?” “Have you completed a will?”

Domain: Affective

Concept	What “Everything” Might Mean	Questions to Ask
Abandonment	“Don’t give up on me.”	“What worries you the most?”
Fear	“Keep trying for me.”	“What are you most afraid of?”
Anxiety	“I don’t want to leave my family.”	“What does your doctor say about your prospects?”
Depression	“I’m scared of dying.”	“What is the hardest part for you?”
	“I would feel like I’m giving up.”	“What are you hoping for?”

Domain: Cognitive

Concept	What “Everything” Might Mean	Questions to Ask
Incomplete understanding	“I do not really understand how sick I am.”	“What are your most important goals?”
Wanting reassurance that best medical care has been given	“Do everything you think as a doctor is worthwhile.”	“What is your understanding of your condition/prognosis?”
Wanting reassurance that all possible life-prolonging treatment is given.	<p>“Don’t leave any stone unturned.”</p> <p>“I really want every possible treatment that has a chance of helping me live longer.”</p> <p>I will go through anything, regardless of how hard it is.””</p>	<p>“What have others told you about what is going on with your illness?”</p> <p>“What have they said the impact of these treatments will be?”</p> <p>“Tell me more about what you mean by “everything.””</p>

Domain: Spiritual

	What “Everything” Might Mean	Questions to Ask
Vitalism	“I value every moment of life, regardless of the pain and suffering (which has important meaning for me).”	“Does your religion (faith) provide any guidance in these matters?”
Faith in God’s will	“I will leave my fate in God’s hands; I am hoping for a miracle; only He can decide when it is time to stop.”	“How might we know when God thinks it’s time?”

Domain: Family

Concept	What “Everything” Might Mean	Questions to Ask
Differing perceptions	“I cannot bear the thought of leaving my children (wife/husband).”	“How is your family handling this?”
Family conflict	“My husband will never let me go.”	“What do your children know?”
Children or dependents	“My family is only after my money.” “I don’t want to bother my children with this.”	“Have you made plans for your children (other dependents)?” “Have you discussed who will make decisions for you if you cannot?” “Have you completed a will?”

Stepwise approach

1. Figure out what this patient means by “everything”
2. Propose a treatment plan based on the patient’s goals/fears/concerns

Proposing a treatment plan

- “Given what we know about your illness and what I have learned about your priorities, it sounds like you would prefer the following balance of burdens and benefits in your treatment.” (Quill et al., 2009)

Two possible responses from the patient

Two possible responses from the patient

- Patient concurs
 - Team then offers recommendation
 - Framed not entirely in the negative

Two possible responses from the patient

- Patient concurs
 - Team then offers recommendation
 - Framed not entirely in the negative
- Patient does not concur, which means either
 - Medical team misunderstood, or
 - Patient does not appreciate why certain treatments (e.g., CPR) will not benefit him, or
 - He may be facing his own mortality

If patient is resolute

- Honor request
 - Largely depends on harmfulness of requested treatment
- Revisit later
 - Risks making the patient feel “badgered”

From: Discussing Treatment Preferences With Patients Who Want “Everything”

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Table 3. Harm-Reduction Strategy When Patients Request Treatments That Do More Harm Than Good

Acknowledge and adhere to the patient’s treatment philosophy so that patient and family feel heard and respected.

Stop regularly discussing limitations on invasive treatments unless this issue is raised by the patient or family.

Address the medical team’s discomfort and disapproval by:

Communicating the reasoning behind the treatment decision.

Finding other patient-centered goals to work toward (symptom management, support, disease treatment).

Use clinical judgment to limit treatment that does not advance patient-defined goals.

Table Title:

Harm-Reduction Strategy When Patients Request Treatments That Do More Harm Than Good

If patient is resolute and treatment is harmful

- Offer time-limited trial
 - No way to “enforce” shift in plan at conclusion of TLT
- Unilaterally withhold treatment

Organization of meeting with patients +/- family, data collection

Single, open-ended question, "What have the doctors told you about what is going on?"

Assess coping

"I believe my cancer has spread."

"You should know, you're the doctor."

Adaptive coping

Maladaptive coping

Proceed with open-ended questions
patient directed-approach

Proceed with focus, clinician-directed
approach

Adaptive coping

Declarative statement, "Unfortunately, your
cancer is worse despite our best treatments."

Assess coping

Maladaptive coping

Proceed with forced choice options, "Where would you prefer
to take your last breath? At home or in the hospital?"

If continued maladaptive coping, proceed with empathic truth
telling. "You are dying. We are calling hospice to help you."

Adapted from "Palliative paternalism" in response to requests that are not consonant with patient goals (Roeland, 2014)

Things to bear in mind

- Easier to act unilaterally when decision is made by surrogate, potentially not reflecting the patient's wishes
- Difficult to justify acting unilaterally when the *patient* is requesting the treatment
 - Better to show humility and preserve relationship
 - Be prepared to address moral distress among the team



Thank You

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Question and Answer Session



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Thank you!

- Please fill out the survey after today's session
- Those who signed up for continuing education will receive an evaluation from the Commission.
- A recording of today's webinar and slides will be available in one week at <http://ccmcertification.org>

Commission for Case Manager Certification

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