"Challenging Family Conferences at End of Life: A Case-Based **Presentation**" Karen J. Nichols, DO, MA, MACOI Professor, Internal Medicine, retired Past President, AOA, 2010-2011 Past President, ACOI, 2000-2001

Dean, MWU/CCOM, 2002-2018

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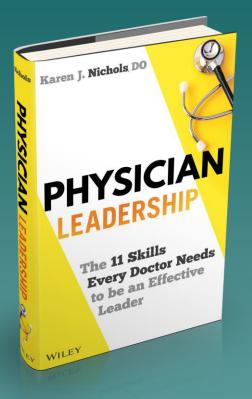
Disclosure

Author, "Physician Leadership: The 11 Skills Every Doctor Needs to be an Effective Leader"

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Karen J. Nichols, DO Leadership Consultant and Speaker on End-of-Life Care Issues



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Objectives

- 1- The participant will list two commonly seen content issues for family conferences.
- 2- The participant will describe two approaches to determining the patient wishes.
- 3- The participant will describe two pitfalls encountered in family conferences.

End of Life

The Osteopathic Profession's Finest Hour

Caring for patients near the end of life why is it so hard? Uncertainty about prognosis Decision to shift goals often irrevocable Insufficient technical training Then Medical culture regards death as failure Suffering is difficult

. . . How Americans died in the past Prior to antibiotics, people died quickly - infectious disease - accidents Medicine focused on caring, comfort Sick cared for at home - with cultural variations

Medicine's shift in focus . . . Potential of medical therapies - "fight aggressively" against illness, death prolong life at all cost Improved sanitation, public health, antibiotics, other new therapies increasing life expectancy Prior to Opioid Crisis Prior to COVID-19

End of life in America today

Modern health care

 only a few cures
 live much longer with chronic illness
 dying process also prolonged

Sudden death, unexpected cause

<10%MI, accident

Health Status

Death

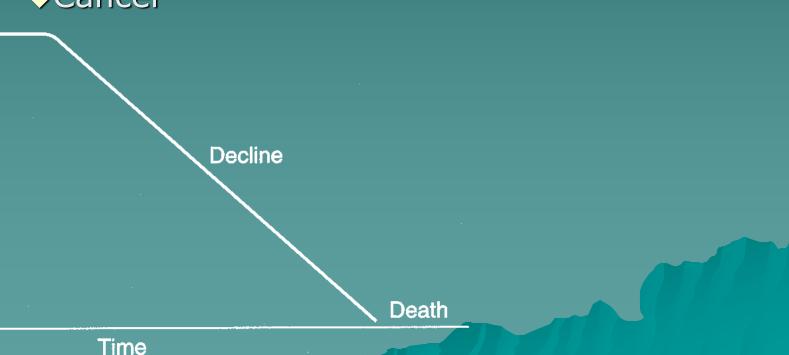
Protracted life-threatening illness

♦ > 90%

 A - predictable steady decline with a relatively short "terminal" phase

♦ Cancer

Health Status



Protracted life-threatening illness

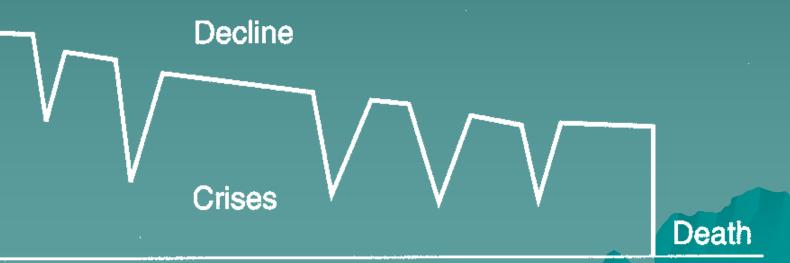


Health Status

 B - slow decline punctuated by periodic crises

Time

 CHF, emphysema, Alzheimer's-type dementia



Issues for Family Conferences CONTENT: Difficult Dilemmas - When we are not sure of the outcome of a specific treatment - When we are pretty sure of the outcome of any treatment PROCESS: Family Conferences - Principles Advance Directives → Goals of Care
 - Pitfalls

<u>Content of the Issues</u> for the Family Conference

Difficult Dilemmas

 When we are not sure of the outcome of a specific treatment

 "Withholding vs. Withdrawing a Treatment"

When we are pretty sure of the outcome of <u>any</u> treatment
 – "Medical Futility"

Case #1

A 35-year-old severely ill patient with lymphoma develops acute shortness of breath and has a positive V/Q scan. He has a living will which states he wishes no heroic measures if terminal. The nurse calls you to put the patient on life support, since he is not terminal.

 The patient can't indicate their interests. You are already meeting with the family and can now discuss this situation.

It feels harder to withdraw than to withhold therapy.

A. AgreeB. Disagree

There is no ethical difference between withholding and withdrawing therapy.

A. AgreeB. Disagree

 Withholding treatment vs. withdrawing treatment

 Time limited trials
 Ethical differences?



An 82-year-old female with breast cancer develops an acute bowel blockage requiring emergency surgery. She suffers a massive stroke in surgery and can't be extubated. Brain CT shows massive brain swelling which has stopped her ability to breathe on her own and can't be reversed.

An EEG is consistent with criteria for brain death. You recommend discontinuing life support. Her family says, "No, she is still breathing and still has a heart beat."

You are required to follow the family's direction.

A. AgreeB. Disagree

Medical Futility

Physicians and futility
 Patients / families may be invested in interventions
 Physicians / other professionals may be invested in interventions

Definitions of medical futility Won't achieve the patient's goal Serves no legitimate goal of medical practice Ineffective more than 99% of the time Does not conform to accepted community standards

Is this really a futility case?

Unequivocal cases of medical futility are rare
 Miscommunication, value differences are more common
 Case resolution more important than definitions

Process for Conducting Family Conferences

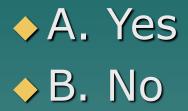
Preparing for Family Conference Principles – Any Known Guidance? ♦Yes - Advance Directive ♦ No - Goals of Care -"BREAKS" Responding to Feelings ♦ Pitfalls – Inappropriate surrogate - Personal factors - Values conflict - Misunderstanding



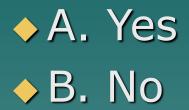
 A 55 year old severely ill patient with lymphoma develops acute shortness of breath and has a positive V/Q scan. He has never wanted to talk about what to do in case to worsening prognosis.

What are ways to express your wishes?

Do you have a Living Will?



Do you have a Durable Medical Power of Attorney?



A Living Will is preferable over a Durable Medical Power of Attorney

A. AgreeB. Disagree

Living Will <u>What</u> the patient wants done Durable Medical Power of Attorney (for Health Affairs) Who knows what the patient would want

 <u>Who</u> knows what the patient would want done in this specific set of circumstances

What if no advance directive has been prepared?

Goals of Care

 The most important starting point for any conversation about end of life!

What are the choices available?

What does your patient want?
What do YOU want?
Does anyone else KNOW what you want?

 Everyone has a personal sense of -who we are
 -what we like to do
 -control we like to have
 -goals for our lives
 -things we hope for

 Hope, goals, expectations change with illness
 Physician's role to clarify goals, treatment plan

Potential goals of care

disease. CLIFE O Avoidance o premature death Maintenance or improvement in function Prolongation of

Relief of suffering Quality of life Staying in control A good dying Support for families and loved ones

Determine specific priorities, with or without an advance directive

- Based on values, preferences, clinical circumstances
- Influenced by information from physician, team members
- Right to refuse any intervention
- All patients have rights even the incapacitated

Principles for Family Conferences

♦ "BREAKS" Background ◆ Rapport ♦ Explore ♦ Announce Kindle (process information/feelings) ♦ Summarize

RESPONDING TO FEELINGS

Affective Response

- Tears
- Anger
- Anxiety

Cognitive Response

- Denial/mistrust
- Blame
- Guilt
- Fear

- Intellectualization

RESPONDING TO FEELINGS

Basic Psychophysiological Responses

 Fight or flight
 "You can't answer a feeling with a fact!"

Pitfalls in Family Conferences

A. Inappropriate surrogate

- B. Personal factors
- C. Values conflict
- D. Misunderstanding

A. Inappropriate Surrogate The "Five Year" Daughter

B. Personal factors

Distrust
Guilt
Grief
Intra-family issues
Secondary gain

C. Difference in values

Religious
Miracles
Value of life

D. Misunderstanding: underlying causes . . .

Doesn't know the diagnosis
Too much jargon
Different or conflicting information
Previous overoptimistic prognosis
Stressful environment

... Misunderstanding: underlying causes

Family is not getting any sleep
 Emotional distress
 Psychologically unprepared
 Unable to understand what is happening

Misunderstanding: how to respond . . . **Choose a primary communicator** Give information in -small pieces Use understandable language Do not hedge to "provide hope" **Involve other health care professionals** Social services Ethics committee

Summary: Challenging family conferences at the end of life

 Clarify the <u>content</u> issues in the current situation

 Determine the process that is triggered by the current situation
 Be aware of pitfalls of any family conference

"...cure sometimes, care always"

End of Life

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The Osteopathic Profession's Finest Hour

www.osteopathic.org/EPEC

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