

Patient and Family Readiness Near the End of Life: Applications to Medical Decision-Making

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Overview

- The context of medical decision making near the end of life.
 - The disconnects that impair decision making
- The poignant question
 - Are you ready to die?
- How to assess readiness
- How to facilitate readiness
- Bioethical questions

*“I want to die the old-
fashioned way.”*

(Elderly patient with cancer.)

The New Way



"You've got six months, but with aggressive treatment we can help make that seem much longer."

Two differences between the “old” and “new” ways of dying in the United States

- The number of apparent “choices”
- The complexity of decision-making for the patient, family and health care team

Clinical Vignette: Fred

- 67 year old man with stage IV adenocarcinoma of the lung with brain metastases, admitted with post-obstructive pneumonia, doing well on IV antibiotics.
- 4 chemotherapy trials did not succeed.
- His daughter is hoping he can live to see the birth of his first grandchild (she is recently married, not yet pregnant.)
- The patient strongly believes God will help cure him.
- They want a second opinion at Sloan Kettering.
- No advance directives in the chart.

Fred (continued)

- Attending asks resident to get the DNR order.
- Resident asks the intern to get the DNR order.
- Intern does not have a medical student this month!!!

The Usual Question

If your heart stops beating or you stop breathing, what do you want us to do?

The Patient's Response

“Get out of my room!”

What didn't work about this approach?

Problems in Medical Decision-Making near the End of Life

- Robust literature (e.g., SUPPORT study)
- We will focus on three disconnects between the patient, family and clinical team regarding the decision-making process

Starting Points

- We are all good, bright people who went into medicine to:
 - Help people
 - This includes the clinician that prescribes an ill-advised, invasive life-extending treatment
- Hardly anyone has formal training in medical decision-making during professional school.
- My discussion of medical decision-making problems is in this context.

Quality of this data

- Anecdotal
- Literature review
- Psychological theory
- I'd like to hear your thoughts at the end of the talk

Disconnect #1

- The clinician commonly perceives that:
 - Medical decisions are primarily guided by medical factors.
 - Perceives his or her job is largely cognitive.
 - *“If I educate the patient or family well, they will make a rational medical decision.”*
- From the patient’s and family’s perspective, social and emotional factors often dominate over the medical factors.

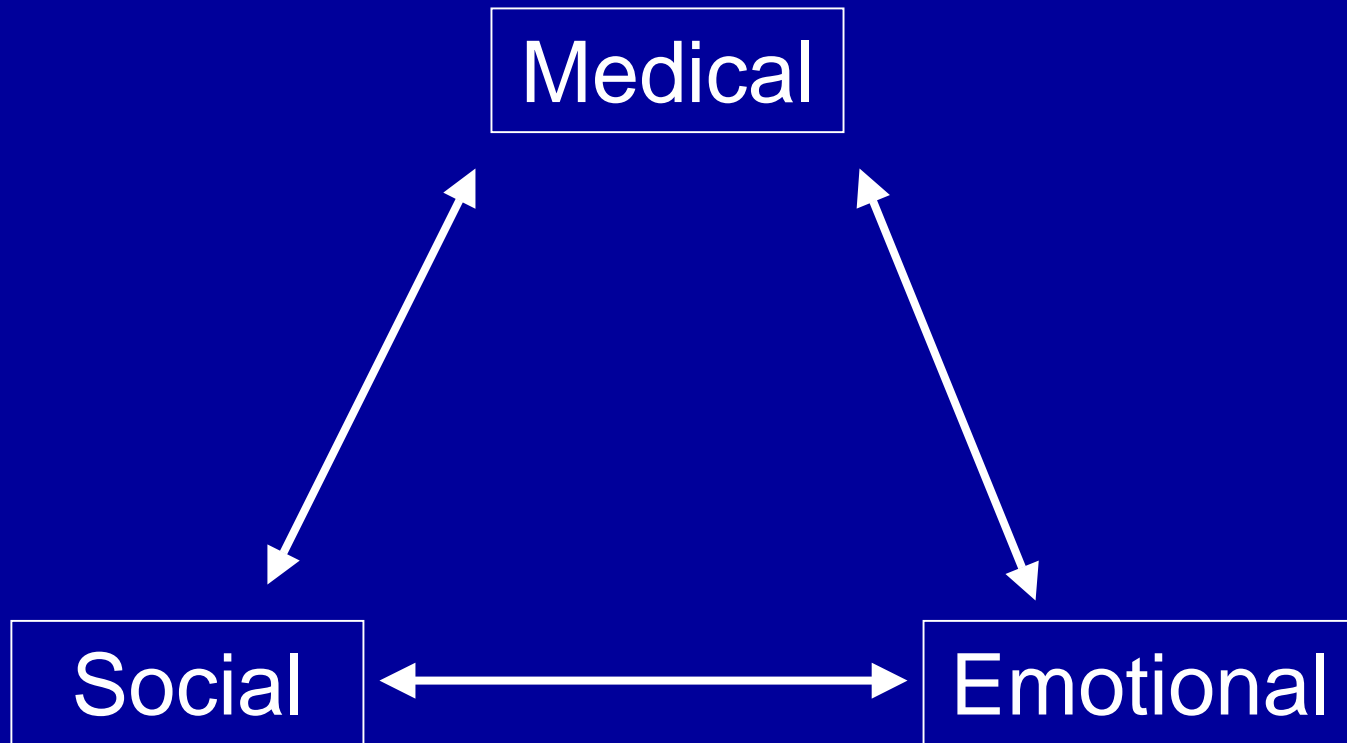
Missing the Patient's Point of View

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“If your heart stops beating, what would you like us to do?”

Medical Decisions are also Social and Emotional Decisions



Disconnect #2

- Common clinical dilemma: the pressure to “get” the patient near the end of life and the family need to accept the fact that the patient will die.
 - Resuscitation is the default mechanism.
 - The staff is pressured to know what to do.
- If the patient and family does not achieve acceptance, they are often misdiagnosed as being in denial.

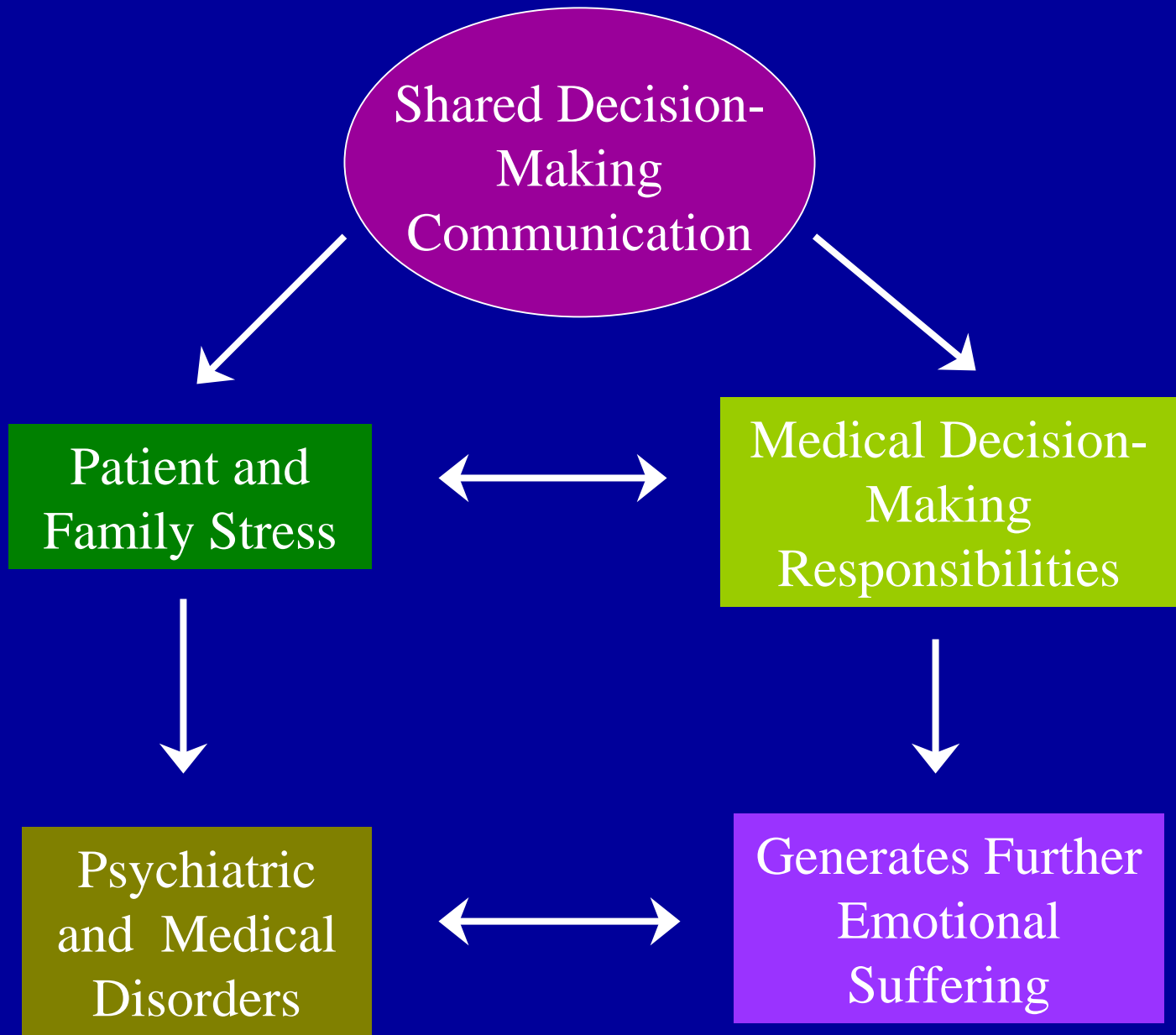
A Narrow Framework of Autonomy

The Medical Choices

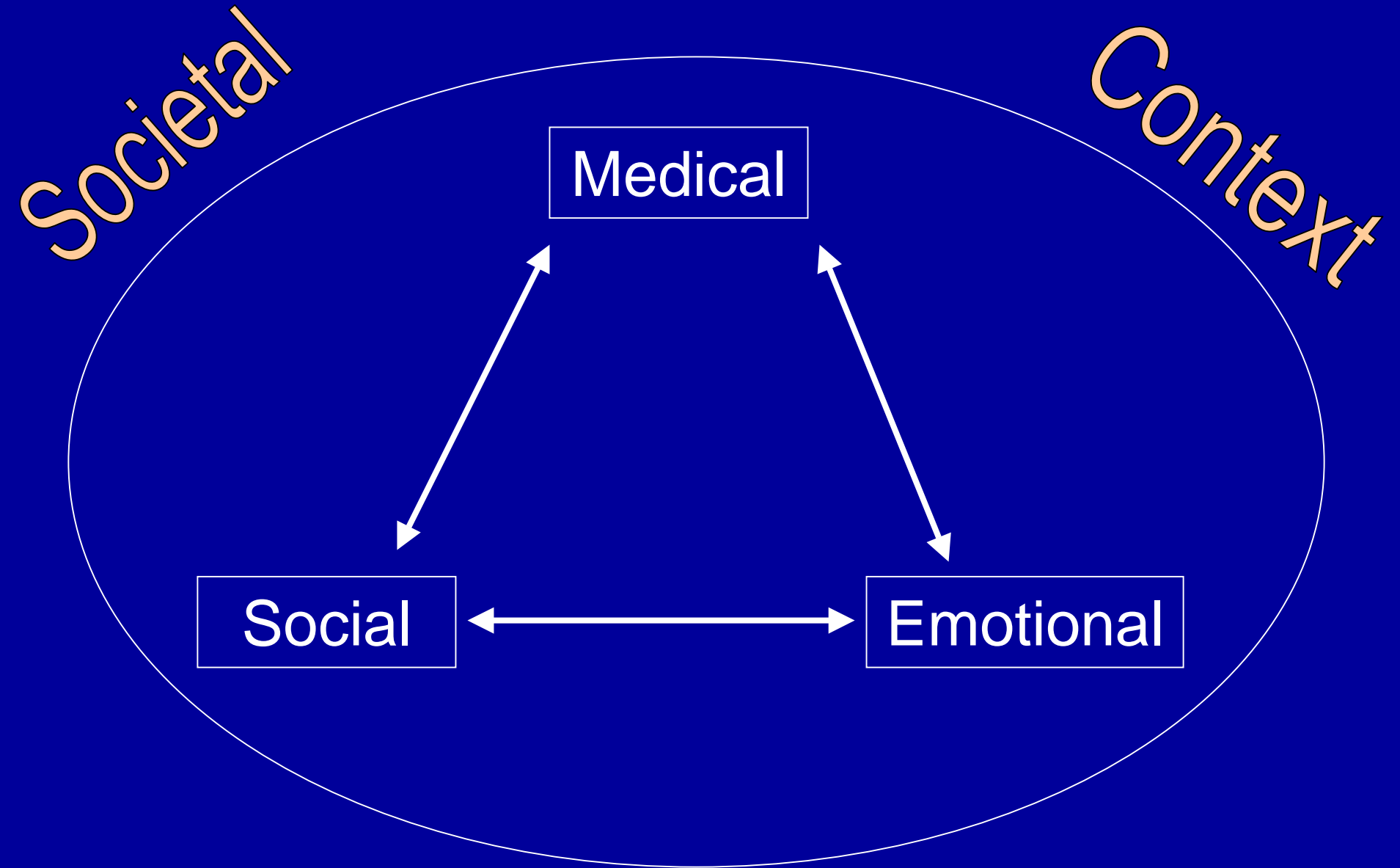


The Medical Decision

Medical Decision-
Making
Responsibilities
(eg, “Autonomy”)



Societal Context Surrounds the Decision



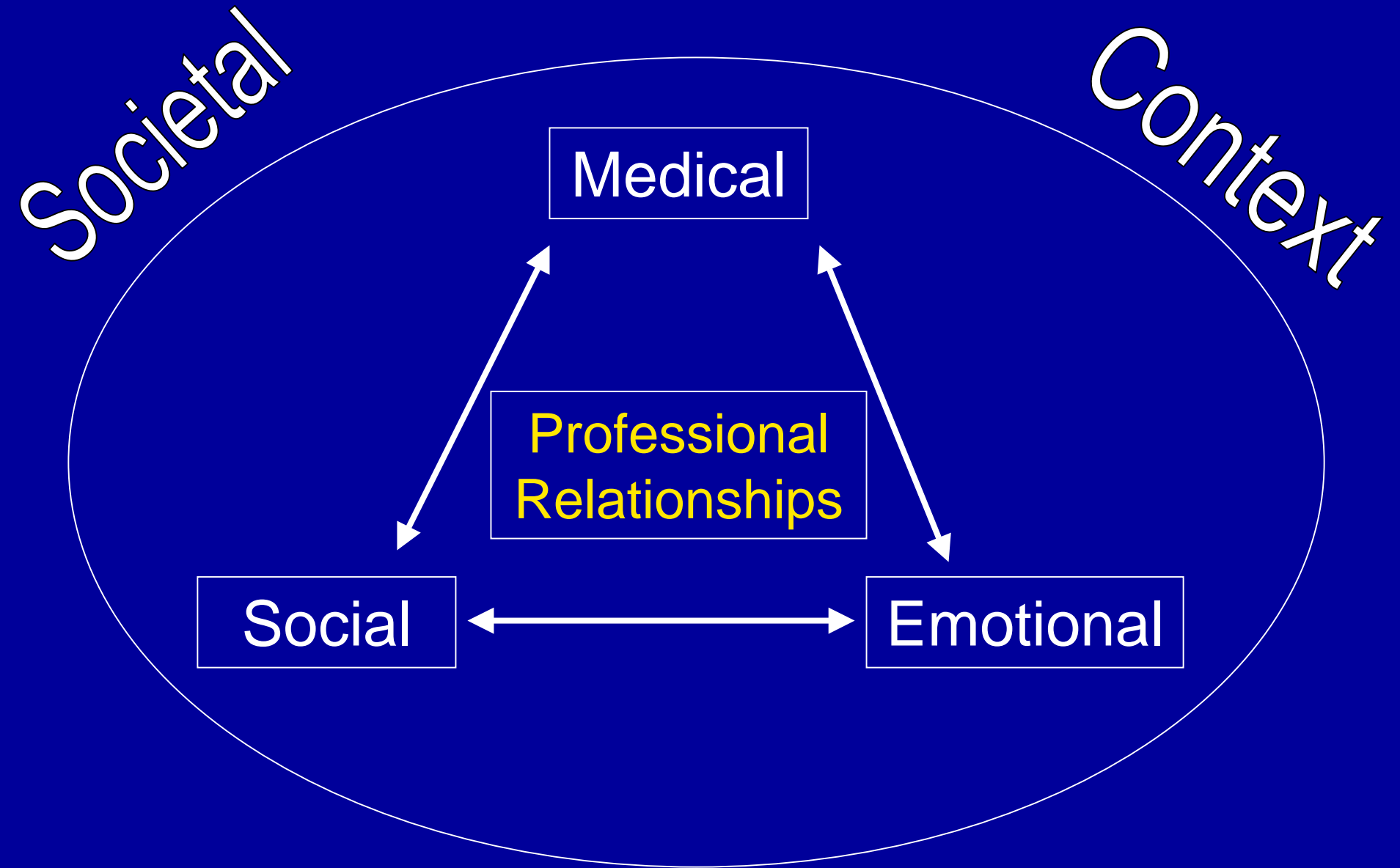


"Look, call it denial if you like, but I think what goes on in my personal life is none of my own damn business."

Disconnect #3

- The patient and family often make complex medical decisions based primarily on their relationship with the clinician, then rationalize their decision in other ways.
- This is often underappreciated by the medical team.
 - Discussions about medical decisions frequently occur without first establishing the professional relationship that supports those decisions.

Relational Model of Decision Making





"Not so fast. I got life plus seventy-five years."

Decisions are impacted by relationships

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“Both of you are rotten and hateful—from a kid’s perspective.”

Clinical Vignette: Fred

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Who is Fred?

- A person with complex medical, social and emotional considerations being asked to make an important decision by someone he doesn't know well.
- A father who's daughter hopes he will live to a milestone
- A man of deep religious conviction who hopes to live fully as long as his God will allow.
- Who Fred is clashes with a medical system that is pressured to seek simple "yes, no" answers to very charged, irreversible decision-making questions.
- Fred's readiness to engage in our agenda is not a subject of consideration.

Why assess readiness?

- Understand who the patient is (medical, social and emotional elements).
- Allow the patient to appreciate your understanding (form a strong relationship).
- Understand the broader forms of suffering that enables more effective treatment.
- Appreciate more fully how complex decisions can occur through a process of growth and adaptation.

Assessing the Readiness of the Patient or Family

Two kinds of readiness

Is the patient or family ready to:

1. Explore and discuss the patient's mortality?
2. Assume the responsibilities of medical decision-making about life and death issues?

How can we assess readiness?

Stages of Change Model

- Developed by Prochaska and DiClemente
- Outgrowth of substance abuse research
- Conceptualizes readiness as a process that moves through stages

Prochaska JO, DiClemente CC (1984): The transtheoretical approach: Crossing the traditional boundaries of therapy. Malabar, FL: Krieger.

“Relational Decision Making” versus Stages of Change

- Stages of Change

- Patient has socially problematic behavior
- Patient comes to you to change behavior
 - Internal or external leverage
- Your job is to motivate and facilitate change

- Relational Decision Making

- Patient dying.
- Behavior problematic in the context of health care culture
- Autonomy versus beneficence
- Your job is to first support patient autonomy.

“Relational Decision Making” versus Stages of Change

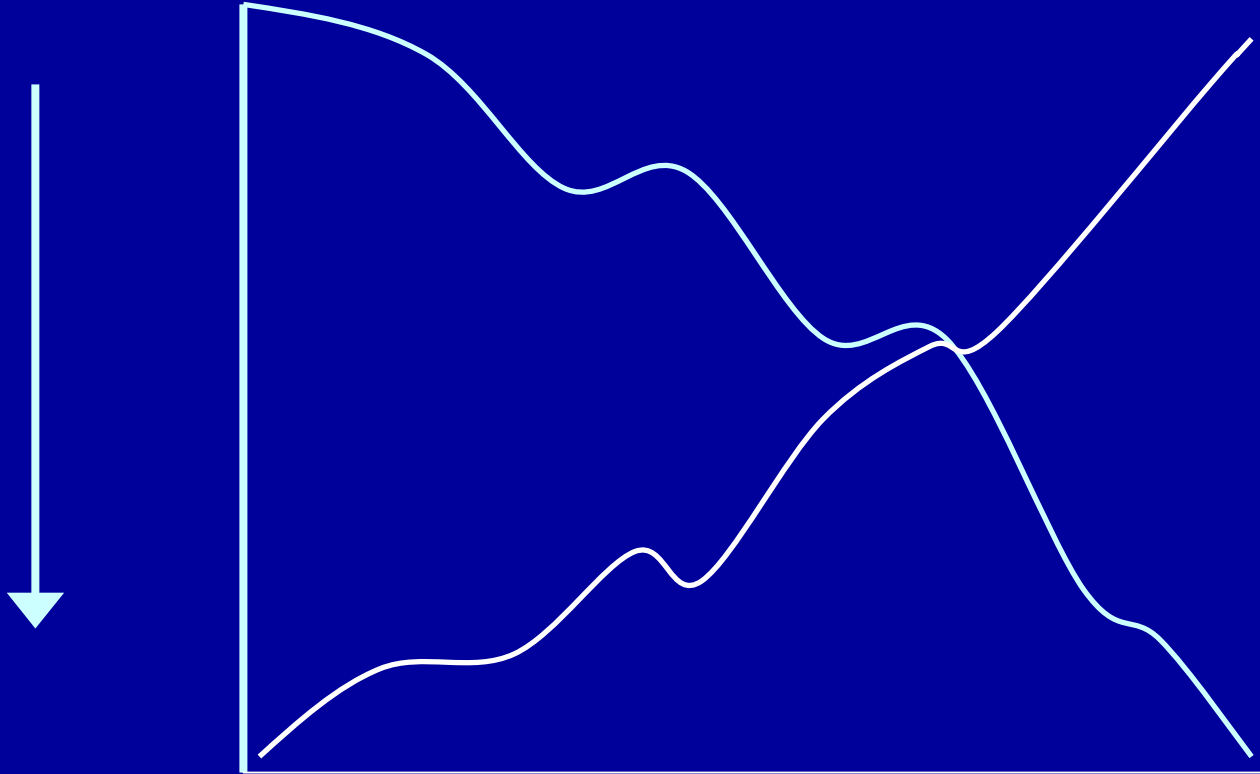
- We must first decide if it is appropriate to move the patient or family through stages of readiness.
 - Respect for the patient’s/family’s values.
 - E.g., The preciousness of human life.
 - Harm versus benefits.
 - Allowing the patient or family to make a “bad decision” when challenging it is counterproductive.

Stages of readiness

- Precontemplative
- Contemplative
- Preparative
- Ready

Death
Trajectory

Readiness



Ready



Preparative



Contemplative



Precontemplative

TIME



Simple working definitions

STAGE	INTERNAL CONFLICT	DISAGREEMENT WITH CLINICIAN	BARRIERS
Precontemplation	None to Low	High	Attitudinal, Emotional, Practical
Contemplation	Moderate to High	Moderate to High	Attitudinal, Emotional, Practical
Preparation	Low to Moderate	Low to Moderate	Practical
Ready	Low to Moderate	None to Low	Practical

Simple working definitions

STAGE	INTERNAL CONFLICT	DISAGREEMENT WITH CLINICIAN	BARRIERS
Precontemplation	None to Low	High	Attitudinal, Emotional, Practical

Precontemplation

- Athlete with metastatic pancreatic cancer.
- “Exercise and diet will cure me.”
- Mother of two young children with end stage ovarian cancer.
- “There has to be a cure. I won’t die.”
- Patient receiving news of advanced testicular cancer from medicine resident.
- “You don’t know what you’re talking about. I’m not coming back here!”

It's common to call these
patients as being in....

Denial

Denial: A Relational Definition

You are in denial if:

- 1) I am right and you are wrong.
- 2) You are sure that you are right.

What is the difference between
Precontemplation and *Denial*?

Precontemplation: A relational conceptualization

- Denial

- The clinician is right and the patient is wrong

- The patient must engage in the clinician's agenda



- Precontemplation

The patient has a different view of the situation than the clinician.

Meet the patient where they are and clearly demonstrate appreciation of their point of view.

Precontemplation: Offer the opportunity to contemplate.

- Athlete with curable Hogkin's disease.
 - Pt: "Exercise and diet will cure me. I don't trust doctors."
 - Clinician: "Let's try that. Let's discuss how we will know if it works."
- Mother of two young children, hospitalized with end stage ovarian cancer and a poor performance status who has undergone several trials of chemotherapy.
 - Pt: "There has to be a cure. I won't die."
 - Clinician: "Death is clearly not acceptable for you. You have two young children at home."
 - Pt: "Yes, I have to be there for them."
 - Clinician: "We can hope for scientists to come up with a cure, but I don't have one to offer you now. I'm so sorry."
 - Pt: "Then I'll find another doctor that can." (Patient fires the doctor.)

Simple working definitions

STAGE	INTERNAL CONFLICT	DISAGREEMENT WITH CLINICIAN	BARRIERS
Contemplation	Moderate to High	Moderate to High	Attitudinal, Emotional, Practical

Contemplation

- Athlete with Hodgkin's disease.
- Mother of two young children with end stage ovarian cancer.
- Patient receiving news of advanced testicular cancer from medicine resident.
- I doubt I'll benefit from chemotherapy. I usually don't trust doctors.
- It's true that most people die with my condition, but I'm not a statistic.
- You may be right that I have cancer, but I want a second opinion.

Contemplation: Sustain hope while encouraging preparedness.

- Athlete with Hogkin's disease.
 - Pt: "I doubt I'll benefit from chemotherapy. I usually don't trust doctors."
 - Clinician: "You're doing great with diet and exercise. It just may not be enough by itself. Could we hope for it to succeed if we supplement it with chemotherapy?"
 - Pt: "I have to think it over."
 - Clinician: "What factors will you consider as you prepare to make that decision?"

Mr. Smith (continued)

- What do you understand about your illness? (*They say there's no cure.*)
- Where do you see things going? (*I pray to God. He will heal me.*)
- Facilitated shift from contemplation to precontemplation. (*We hope God provides a miracle for you. Sometimes God gives us other things besides a miracle....*)

Contemplation: Sustain hope while encouraging preparedness.

- Mother of two young children hospitalized with end stage ovarian cancer and a worsening performance status since two days ago. She asks to see you again.
 - Doctor: “How are you doing?”
 - Pt: “It’s true that most people die in my condition, but I’m not a statistic.”
 - Doctor: “Are you saying that you understand the seriousness of your condition, but you’re still hoping for a cure.”
 - Pt: “Yes. Don’t you believe in miracles?”
 - Doctor: “Anything is possible. We can hope for a miracle together.”
 - Pt: “Thank you.”
 - Doctor: [Spends time assessing and treating symptoms. Patient appreciates this.]
 - Doctor: “While we hope for a miracle, have you thought about what might happen if your condition continues to worsen?”
 - Pt: “I try not to.”
 - Doctor: “What do you think about when you do?”
 - Pt: “I’d rather not discuss it now.”
 - Doctor: “OK. May I see you tomorrow?”
 - Pt: “Yes, please.”

Preparation

- This usually involves practical problems that require practical considerations.
 - E.g., “I would be open to chemotherapy, but who would watch my children while I’m in the hospital?”
 - E.g., “I would speak to my wife about hospice, but I don’t know how.”

Mr. Smith (continued)

- Internist and psychiatrist met with patient and daughter
- Reviewed FMH: cousin died from cancer
- Linkage: patient only wants chemotherapy if it helps more than harms
- Patient still looked towards God for a cure
- Next hospital admission: patient was open to hospice

Summary

- Medical decisions are also social and emotional decisions influenced by relationships within a larger societal context.
- A “relational model” of decision making accounts for, amongst other factors, the patient’s or family’s readiness to confront mortality and make complex decisions.
- While assessing readiness, decide if it is appropriate to encourage change.
- The patient and family do not have to be ready for the death of the patient. To think otherwise risks iatrogenic harm.
- Visualizing medical decisions as occurring through a process of growth and adaptation allows a relationship to flourish that is compassionate, satisfying and effective.

Thank You.

Email me for the slides,
questions, comments.

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