

# Negotiating Goals of Care: Crucial Conversations in the ICU

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# Objectives

- After this presentation participants will be able to:
  - Reflect on their on experience with shared decision making
  - List the steps for assessment of coping skills
  - Identify the indications for an ICU Family Meeting
  - Demonstrate the steps for an effective ICU Family Meeting

# Introduction

- 90% of ICU deaths are associated with decisions to stop life-prolonging treatment and change focus to comfort



# Crucial Conversations: Case 1

- Discussing prognosis and GOC

# Crucial Conversations: Case 2

- Deciding on EOL care

# Crucial Conversations: Case 3

- Addressing Family Concerns and Expectations

# Decision Making

Only 9% of decisions met criteria for fully informed decision making



# Crucial Conversation: Patients

- Advanced cancer
- ESRD
- COPD/ARDS/Pulm Fibrosis
- CHF
- Severe stroke
- ALS, Parkinson's, Dementia
- Traumatic Brain Injury
- Post-cardiac arrest with hypoxic brain injury
- Sepsis
- Severe infections in immunocompromised
- Failure to wean from vent
- Covid-19

# Shared Decision Making

- Ethics
  - Beneficence
  - Respect for autonomy
- Physician Obligation
  - Best clinical advice and judgment
  - Offer patient meaningful role

# Ask Don't Assume

- 70-80% Patients want information
  - “You could be involved in this decision”
  - “I really want to give you a chance to share your thoughts about this too”
  - “What are you thinking right now”

# Shared Decision Making

- Variables
  - Need for information
  - Ability to handle information
  - Medical complexity of information
  - Urgency
  - Importance
  - Meaning

# Shared Decision Making

- Involvement
  - Create atmosphere
  - Explore values
- Partnership
  - Decision which both doctor and patient support

# General Framework

- Invitation
- Assess patient's understanding
- State the facts
- Describe alternative courses of action
- Give the pros/cons of alternatives
- Discuss uncertainties
- Assess understandings
- Get preferences
- Make adjustments
- Continue the relationship

# Invitation

- “This is really a decision we should make together”
  - Preferences may change
  - MD actively follows up (walk with pt)
  - Patient implements agreed plan



# Understanding

- Nature of the Problem
  - Difficult to reach agreement about plan if differ on ideas about the problem
  - Get patient's perspective
    - Cause
    - Severity
    - Expected course





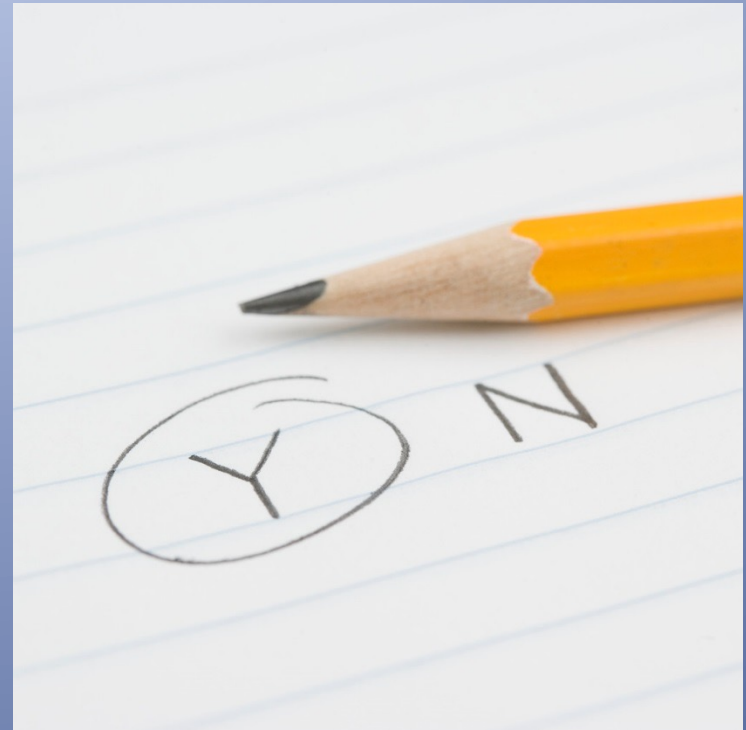
# Understanding: Health Literacy

Health Literacy Level	Description	Size of Vocabulary
Below Basic	Very limited ability to read & Understand health info	500-1000 words
Basic	Can read & understand simple health materials with difficulty	1000-3000 words
Intermediate	Can read and understand most health-related texts and instructions	3000-6000 words
High	Strong ability to understand complex health information and contexts	>6000 words
Physicians	Significantly large and specialized vocabulary	30,000-50,000

National Assessment of Adult Literacy  
The Institute of Medicine

# Delineating Alternatives

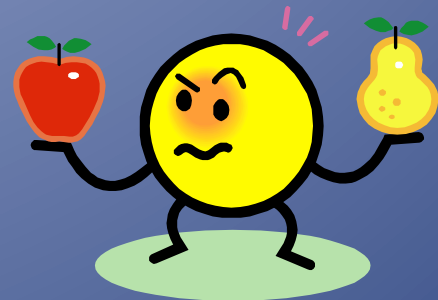
- “We can consider starting this treatment, but it’s important to understand what it involves and what to expect”
- “We can work together to decide whether to try new treatments or focus on your comfort”



# Pros/Cons

“The new medication is more expensive but you only take it once a day”

“We can start the new immunotherapy but you may have diarrhea and sometimes it is severe enough to require hospitalization”



# Uncertainties

- “There is a good chance that this will help you”
- “There is a 1 in 20 chance of infection from this procedure”
- “I am not certain if your cancer will respond to the trial medication”



# Mutual Understanding

- “Do you follow where I am going with this”
- “Does what I say make sense to you?”



# Communication Elements

- Provision of clear information
- Questions from the patient
- Willingness to discuss and share decisions
- Agreement about plans or problems



Stewart MA. Effective physician-patient communication and health outcomes:  
A review. Can Med Assoc J. 1995;152:1423-1433

# Mistakes

- Making assumptions
- Failure to discuss/define nature of problem
- Failure to discuss goals of treatment
- Blanket recommendations/plans
- Not re-evaluating decisions/goals
- Labeling “non-compliance”
- Not recognizing cognitive dysfunction

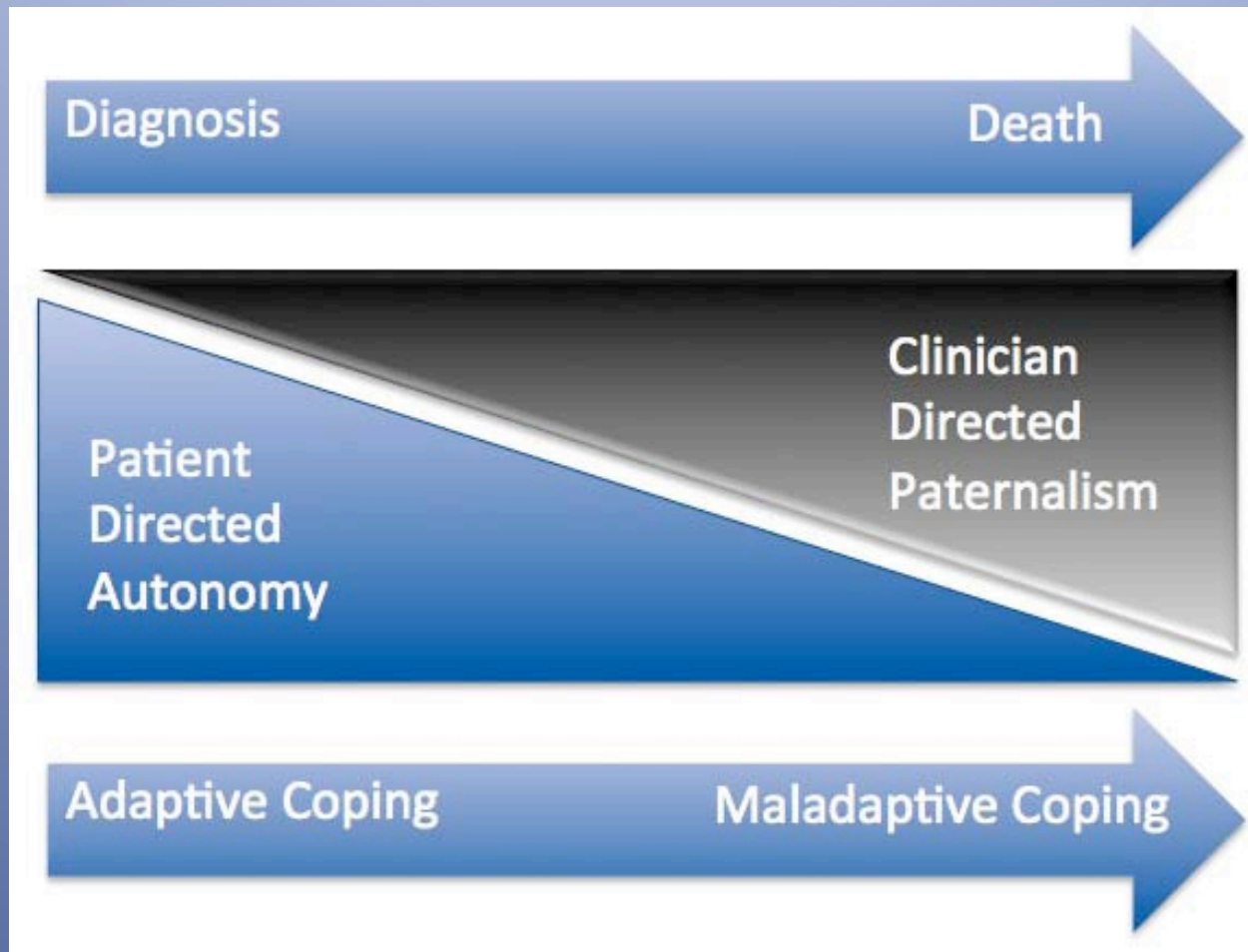


# Delayed Decisions

- Suffering
  - May occur if patients delay decisions
  - Giving too much information
  - Persuade patients to do “right thing”
    - Patient’s can’t absorb all the information
    - Emotional
    - Can be met with resistance
  - Key is to LISTEN



# The Illness Communication Continuum



# Cognitive Coping Skills

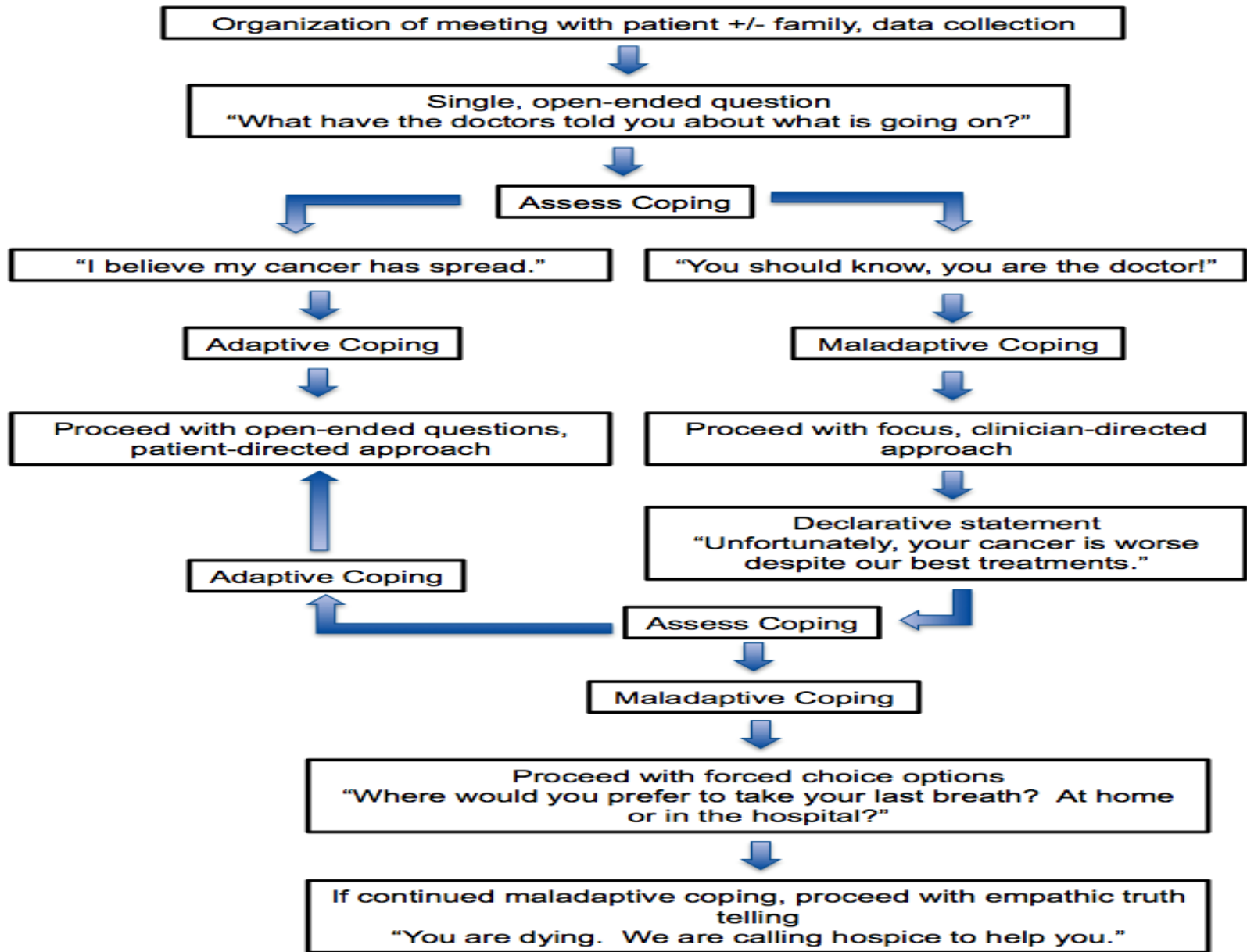
Adaptive	Maladaptive
Bright- ability to compare/contrast 2 complex ideas	Cognitively delayed- unable to conceptualize possible outcomes
Articulate	Medically naïve- view body as parts (car)
Problem solvers	Extremes of age (young, old, dementia)

# Emotional/Psychological Coping Skills

Adaptive	Maladaptive
Capacity for self-awareness	Emotionally arrested
Have a history of utilizing strategies to maintain emotional equilibrium	Shame is a predominant emotion May believe illness is their fault
	PTSD
	Emotionally reactive
	Serious Mental Illness
	Need to assert own authority in spite of possible harm to self
	Substance abuse

# Social/Cultural Coping Skills

Adaptive	Maladaptive
Value Autonomy	Cultures who are traditionally mistrustful of medical community
Have good support system	Believe only option is a miracle
Utilize direct and open communication	Cultures focused on the collective rather than individual
	Cultures which value deference to authority



# ICU Family Meeting

- Goals
  - Assess family understanding, concerns, coping
  - Share information
  - Provide emotional support
  - Elicit patient's goals and values
    - Substituted judgment
  - Sustain trust

# ICU Family Meeting

- Proactive Indications
  - First 48-72 hours
  - “chronic critical illness”
  - Specific illness
  - Poor prognosis
  - No DPOAH
- Reactive Indications
  - Response to crisis
  - Prospect of withholding care
  - Major care decisions
  - Conflict over goals
    - b/t staff and family
    - Within family
  - Discharge planning

# Preparation

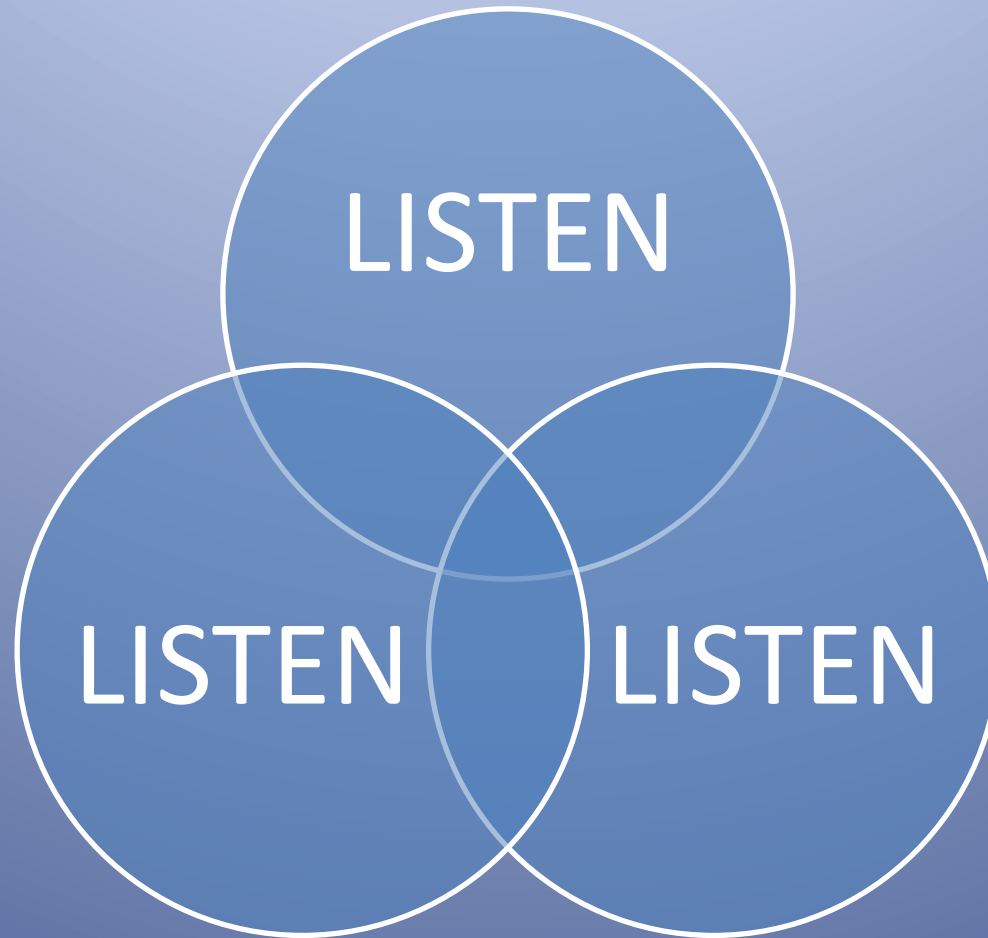
- Agenda
- Key players
  - Family decision makers
  - Spiritual support
- Staff participation
  - Attending, resident
  - Primary nurse
  - Social worker
  - Chaplain
- Pre-meeting conference
  - Agree on facts
  - Leadership
- Setting
- Deep breath and center yourself....
  - Prepare your emotional response



# Introductions

- Names
  - Family members should identify their relationship
- Ground rules
- Purpose statement for meeting
  - “We routinely like to invite you... in the first few days ...so we make sure to get to know you , make sure you are up to date, and questions are answered”

# Assess Family Understanding



# Preferences

- Many different values among families
  - Personal
  - Cultural
  - Religious beliefs
- “When there is important news, how do you prefer to hear about it? How, especially, are you feeling about getting bad news”

# Summarize Facts

- **Briefly** describe patient's medical condition
  - Big picture
  - Address issues that family is not understanding
  - Avoid jargon
  - Open to questions from the family
  - “Even with all the medication we are giving him, his heart is so weak that his other vital organs are failing”

# Explore patient's current condition



## Brief Survival or Suffering

- Ventilator
- Feeding tube
- Chest tube
- Privacy/dignity

# Explore Patient's Values

- “You know your father the best. The information we need from you is about what your father would really want if he could speak for himself now. How do you think he would want us to take care of him?”
- Use stories to help guide families
  - “Was your father ever involved in decisions like this with family or friends?”
  - “What was most important to your father in his daily life?”

# Frame Recommendations

- “We want to do the right thing for your father, and it seems that he would not want us trying to prolong his life by feeding him artificially, knowing he is not going to be able to recover and enjoy himself or have meaningful interaction with the people he loves. I know you wish he could get better, but stopping these intensive treatments is a respectful, brave, and loving decision. I will write orders now about adjusting his medication to make sure he is comfortable and honored. How does this plan sound to you?”

# Facilitate Grieving

- Anticipatory grief
  - Recognize
  - Reflect
  - Empathize
- An inability to grieve associated with resistance to dealing with futile care
- Aids decision making
- “Have you ever thought of what life might be like without him?”



# Follow-up

- Assure family that you are accessible
  - Instruct on how they can communicate with you
  - Referral for support services
  - “For any questions I may be reached by asking the nurse to page me.”

# ICU Family Meeting

- Discuss
  - Staff feedback
- Debrief
  - Facilitates learning
  - “What went well”
  - “What would you do differently”
- Document
  - Focus on key decisions
  - Clear concise

# Patients who want “Everything”

- Potential Meanings
  - Affective
    - Fear, abandonment, anxiety, depression
  - Cognitive
    - Incomplete understanding
    - Reassurance
  - Spiritual
    - Vitalism
  - Family
    - Differing perceptions
    - Family conflict
    - children or dependents

# Conclusion

- Patients and families want to participate in their medical decisions
- Patients and families need information to make decisions

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- Patients and families need information to make decisions
- Defining goals of care can improve satisfaction

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