Shared Decision Making

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Objectives

- Understand the complex processes involved during informed consent discussions
- Learn how to apply Shared Decision Making techniques as treatment options are explored
- Choose appropriate language during Shared Decision Making

The Approach

The traditional objective of ACP (Advance Care Planning) has been to have patients make treatment decisions in advance of serious illness so that clinicians can attempt to provide care consistent with their goals.

The Approach

- Treatment preferences and values change when health changes: ADAPTABILITY
- Treatment preferences and values change when health changes: BURDENS OF TX
- Difficult to predict when a patient is terminal or condition is irreversible
- Dignity and Comfort are difficult to define within treatment options

The Approach

- AD (Advance Directives) often refer to technologically intensive therapies; SDMs (Surrogate Decision Makers) often struggle to decide whether to continue antibiotics in a patient with recurrent aspiration pneumonia or whether even to continue to hospitalize the patient
- Antibiotics, blood transfusions, and dialysis may decrease suffering and provide comfort and quality of life for some patients.

The Approach

- Reversal of Code Status and Intubation may be appropriate when a new illness presents on top of one or more chronic illnesses:

Pneumonia in a patient with advanced cancer who has become less symptomatic with palliative treatments, who now has hopes to celebrate her spouse's birthday.

The Approach

- The Basically Healthy
- Those with Advanced or Chronic Illness(es)
- Imminently Dying

The Approach

- Life Prolonging Goal
- Restorative or Rehabilitative Goals/Maintenance of Function
- Comfort

Timing the Discussion

- Any non-elective admission to hospital
- Any elective admission for a high-risk surgical procedure.
- The diagnosis of a serious, incurable or end-stage illness.
- Any clinical deterioration that signals a change in prognosis.

Timing the Discussion

- Any admission to a critical care unit.
- A patient who considers stopping therapy for a chronic or end-stage condition.
- A patient feels that his/her quality of life is unacceptable.
- The physician feels that further non-palliative treatment would be futile.

Timing the Discussion

- Any time a patient or family member brings up discussions about appropriate treatments or code status.

Assessing Readiness

Not Ready to Engage

"I do not plan to get sick."
"I don't want to burden my family."

Explore concerns, appeal to the benefits of the process (reducing SDM burden, maintaining control, achieving peace of mind).

Assessing Readiness

- Assessing Readiness

"If you were to get very sick, have you thought about how you want to be cared for during this time?"

"Is there anyone you trust to make medical decisions for you, and have you talked with this person about what is important to you?"

"Can we talk about this today?"

Educating and Motivating

"Because of an illness or an accident, most patients will be unable to make their own decisions at some time in their life."

(Up to 76% of patients at end of life are not decisional.)

Educating and Motivating

"Because making decisions for someone is very stressful, you could help to take the burden off of your family/friends by starting to think about what would be important to you if you became very sick."

Educating and Motivating

"When patients talk with me and their loved ones about what would be important to them if they were to become very sick, it helps them to keep a sense of control about their medical care and to have peace of mind."

Framing the Discussion

- Goals of care should be discussed rather than "code status"
- Explore patient/family's values, current perception of their illness, hopes for the future.
- Understand goals of care AND

Prioritize with the patient and family:

Prolongation of Life,

Maintenance of Current Status,

Comfort

Framing the Discussion

Focus on the patient's goals and values, not the disease:

"How can we help you live well as this point in your life?"

NOT

"How can we treat your disease?"

Framing the Discussion

- "What treatments will best help you live well at this point in your life?"
- "I know you really want the best care for your (mom, dad, spouse, etc.)."

Framing the Discussion

We are in Health CARE,

NOT

Health TREATMENT.

Framing the Discussion

"How can we help you live well?"

"What fears or concerns do you have?"

"What or who helps or supports you when you are in distress?"

In the Moment Decision Making

- Barriers
  - Patients and surrogates often don't consider the logistics, financial issues, and caregiver burdens when making decisions
  - Patient and surrogates sometimes don't want to discuss issues with illness, death and dying, and refuse to participate in the process
  - Clinicians are time constrained to have these discussions

In the Moment Decision Making

- Keys to Success
  - Choosing an appropriate SDM
  - Clarifying and articulating patient's values over time
    - Are patients adapting to illness over time or are they at a point where the treatment options are burdensome
  - Establishing leeway to surrogate decision making

Choosing An Appropriate Surrogate Decision Maker

- "As your clinician, it would be helpful to know who to contact if you were to become really sick."
- "If you were to become really sick, is there anyone you trust to make medical decisions for you?"
- "Does this person know that you have chosen him/her for this role? It is important to ask him/her if he/she is willing to do it."

Clarifying and Articulating a Patient's Values Over Time

- "Patients are often deeply affected by their past medical experiences."
- "Have you seen someone on television/has someone close to you/had your own experience with serious illness or death?"
- "If you were in this situation (again), what would you hope for? What would you be most worried about?"

Clarifying and Articulating a Patient's Values Over Time

- "Did this situation make you think of ways of being that would be so unacceptable that you would consider it worse than death?"
- "Some patients say that if they became so sick that they could not recognize or talk to their loved ones (for example if they had dementia or were in a coma), they would want all possible treatments to prolong their life. Other patients say they would rather have care focused on comfort. Which kind of person are you?"

Use of Neutral Language

"**SOME** patients say that if they became so sick that they could not recognize or talk to their loved ones (for example if they had dementia or were in a coma), they would want all possible treatments to prolong their life. **OTHER** patients say they would rather have care focused on comfort. Which kind of person are you?"

MOST, MANY, A FEW are not neutral, but may be important to give weight to appropriate treatments.

Have Values Changed?

"Your health has changed/will change over time. Sometimes patients can get used to these changes and sometimes they cannot. In the past, you told me that (e.g., staying out of the hospital) was important to you."

Have Values Changed?

"When (e.g., you were in the hospital with your heart failure, when your brother died), did this situation change your opinion about the ways of being that would be unacceptable or a state worse than death?"

"If you went through this situation again, would it be worth it to you?"

Establishing Leeway for Surrogate Decision Makers

"If your loved ones have to make medical decisions for you, they have to think about what you said in the past, but also about what the doctors are telling them about your medical condition and what they are able to do for you. If these differ from one another, this can be very stressful for your loved one."

Establishing Leeway for Surrogate Decision Makers

"Having told me what is important to you, what if your surrogate finds it difficult to provide this for you?"

"What if it is too hard for loved ones to provide care for you/help you die at home?"

Establishing Leeway for Surrogate Decision Makers

"What if, based on changes in your health, the doctors recommend something different from what you have told your loved one?"

"Will you give your loved one(s) permission to work with your doctors to make the best decision they can for you even if it may differ from what you said you wanted in the past?"

Establishing Leeway for Surrogate Decision Makers

"Are there certain decisions about your health that you would never want your loved one to change under any circumstances?"

Modifying discussions based on the patient's condition or beliefs

- Remain sensitive, but essence of discussion should remain the same
- Ask what the patient/family **knows and wants to know** about the medical situation
- If the patient is very ill or does not wish to be involved in the discussion/decision, substituted decision-making can be used.

Modifying discussions based on the patient's condition or beliefs

- Keep discussions simple unless detailed medical discussions are requested.
- If the patient is moribund or actively dying, or goals of care clearly emphasize comfort measures, it may not be appropriate to discuss CPR or LST as a treatment option.

Making a Recommendation

- **Always** offer a recommendation to the patient/family based on the clinical situation as well as goals of care.
- A recommendation helps to shoulder some of the burden of decision-making.

  Based on your desire to focus on comfort and independence, as well as the fact that your cancer has spread, I would recommend …….

Making a Recommendation

- When prognosis is uncertain or clinician is unsure what to recommend, consult a colleague.
- In some cases of uncertainty, a **time trial** of LST can help indicate the likely future clinical course.

Shared Decision Making

- Patient/SDM driven decision making
- Physician recommendation decision making
- Equal partners decision making
- Physician bearing major burden of decision making (Informed nondissent decision making)
- Physician driven decision making

Shared Decision Making

In Patient/SDM driven decision making, the physician presents all options and the patient makes his/her own choice. The physician provides expert knowledge only and makes no recommendations.

Shared Decision Making

In physician recommendation decision making, the physician explains all options and also makes a recommendation. Because many decisions in health care are value laden, physicians must base their recommendation on the patient's values rather than on their own. Ascertaining the patient's values, however, often requires time and advanced communication skills.

Shared Decision Making

Physician recommendation decision making continued:

Furthermore, when a patient asks the physician what he/she would do, the physician must consider the patient's perspective and ensure that he/she is neither intentionally nor unintentionally coercive.

Shared Decision Making

In equal partners decision making, the patient and physician work together to reach a mutual decision. This process often requires a longstanding relationship, and both parties must understand the values and biases of the other. Mutual respect and understanding are essential. Because the patient and physician necessarily have different perspectives, the physician must ensure that it is the patient's values, not his/her own, that guide decision making.

Shared Decision Making

With physician bearing major burden of decision making—**Informed nondissent decision making**, the physician, guided by the patient's values, determines the best course of action and fully informs the patient. The patient may either remain silent, thereby allowing the physician decision to stand, or veto the decision. In this approach, the patient must understand all pertinent information (as he/she would in any method of decision making).

Shared Decision Making

Informed nondissent decision making continued:

Furthermore, the patient must appreciate that silence will be construed as tacit agreement. Patients must understand that they are welcome to veto the decision and if so, their wishes will be honored and they will receive excellent care.

Shared Decision Making Imminently Dying

"Unfortunately, because we cannot treat your underlying disease, it will soon cause your death. When that happens, your heart will stop beating. Therefore, I would recommend that, when your heart stops, we focus on assuring that you die peacefully and comfortably, rather than using shocks and machines to try to restart your heart. Does that make sense to you?"

Shared Decision Making Imminently Dying

If the patient or SDMs disagree with recommendation, clarify why they disagree.

Do they not believe the patient is dying?

Are they too emotionally overwhelmed to make a decision?

Do they want every possible effort made to stave off death, based on their personal, religious, or cultural values?

Shared Decision Making Imminently Dying

Resuscitation serves as a powerful and complex symbol: the most familiar "death ritual" in our secular, medicalized society.

Even if the treating physician is confident that resuscitation will be futile, it may provide the patient or family with the symbolic assurance that the physician did not "give up" on the patient and that he or she died despite every effort being made to save him or her.

Shared Decision Making Imminently Dying

If this symbolic meaning or the emotional distress is explored and addressed compassionately, patients and families often recognize that transition to comfort care can provide the most powerful evidence of commitment and care.

Shared Decision Making

With physician driven decision making, physicians should independently make only those decisions that are value neutral (e.g., deciding what size endotracheal tube to use). Physician must be extremely careful because patients may have strong feelings about seemingly value-neutral issues.

Shared Decision Making

Are decisions value neutral?

A child may wish to have an intravenous line placed in the right hand because the intensive care unit allows parents to sit only on the left side of the bed due to equipment placement and the patient wishes to have her left hand free to hold her mother's hand.

Shared Decision Making

Are decisions value neutral?

A patient may prefer a conventional ventilation mode even when high-frequency ventilation could provide greater lung protection because conventional ventilation require less sedation, and being able to interact with family members is paramount.

Shared Decision Making

- Patient preferences must guide the approach used.
- Physicians must appreciate that each patient is different and may have different preferences at different times and for different types of decisions.

Shared Decision Making

- Some physicians tend to use the patient/SDM directed approach for end-of-life discussions; however, even in EOL decisions when decisions require value judgments, many patient simply want the physician to decide.
- It is the patient and not the decision under consideration that guides the process.

Shared Decision Making

- Determine where on the shared decision-making continuum the patient feels most comfortable.
- Active listening skills are essential so that the physician does not inappropriately take too much control nor force patients to bear more of the burden than they wish.

Shared Decision Making

Aim for Trust and Rapport

- Good communication is time-consuming
- Check frequently that the patient/family understand the conversation
- Primary goal is to establish trust and dialogue rather than to get an outcome (DNR order)
- Some patients/families require time or multiple family conferences

Decisions, Decisions

75 y/o male, S/P CVA with residual global aphasia. He has inadequate oral intake and is losing weight. He **has a living will** stating that he does **not want** tube feeding. He does not have decision making capacity. His **family wants tube feeding.**

Would you be likely to start tube feeding?

Decisions, Decisions

75 y/o male, S/P CVA with residual global aphasia. He has inadequate oral intake and is losing weight. He **has a living will** stating that he does **not want** tube feeing. He does not have decision making capacity. His **family wants tube feeding.**

Same patient has feeding tube for 3 months.. His oral intake remains inadequate.

Would you be likely to continue tube feedings?

Decisions, Decisions

80 year old female with metastatic lung cancer has a DNR order in place. She comes in with an initial episode of HF and is in respiratory failure.

Would you be likely to offer a trial of ventilatory support while you aggressively treat the heart failure?

Decisions, Decisions

82 year old female with Parkinson's disease with a portable DNR who presents to the emergency room in acute respiratory distress secondary to choking on a piece of meat.

Would you be likely to offer attempts to relieve her choking with Heimlich maneuver and intubation if needed?

Decisions, Decisions

93 year old nursing home resident with advanced dementia, who does not recognize family members and no longer gets out of bed presents with sepsis from aspiration pneumonia.

Would you be likely to offer antibiotics?

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