First Do Not Abandon: Realistic Treatment Options Avoiding Overtreatment

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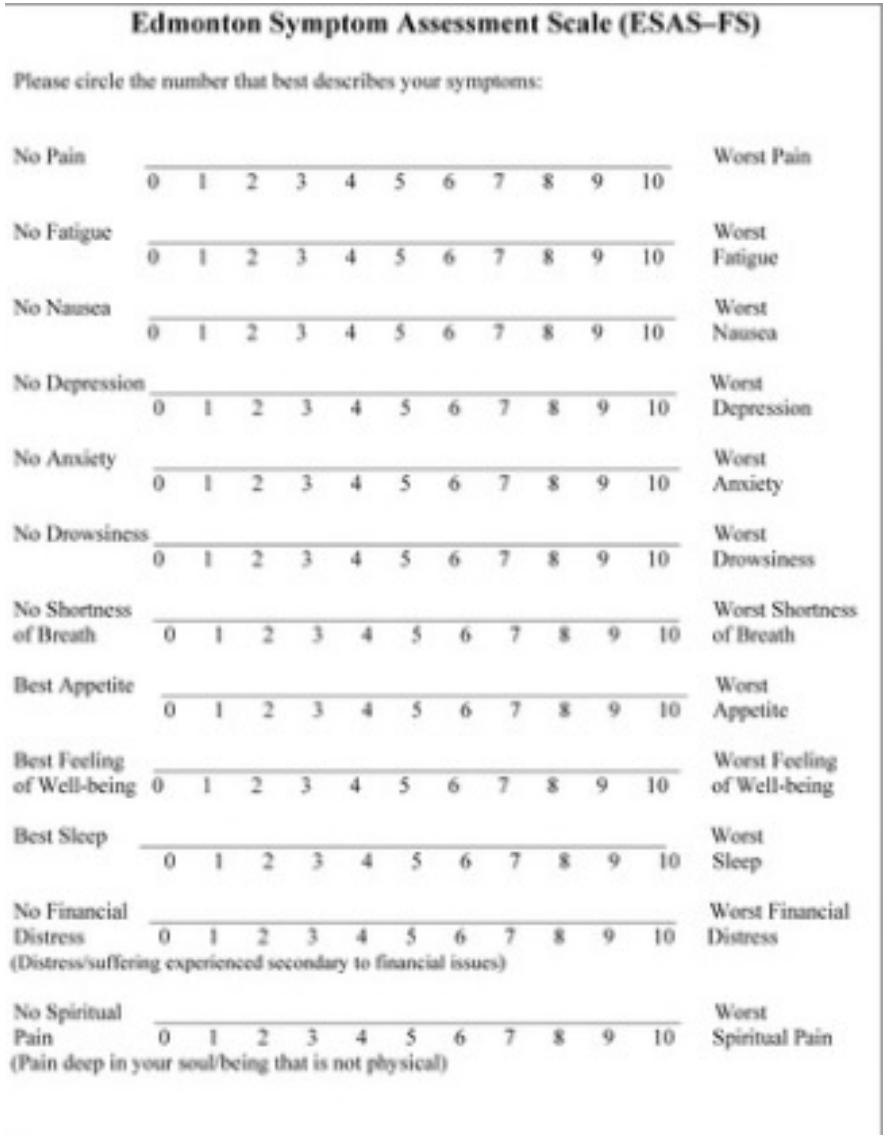
Objectives

1. Define the terms related to nonbeneficial treatment and realistic treatment options
2. Describe the issues identified in the perception of abandonment.
3. Identify words clinicians can use in supportive communication regarding goals of care discussion.

Checking In on their Well Being

Edmonton Symptom Assessment System (ESAS)

- Pain
- Fatigue
- Drowsiness/Tiredness
- Nausea
- Anxiety
- Appetite
- Depression
- Feeling of well-being
- Shortness of Breath
- Spirituality
- Other



Edmonton Symptom Assessment Scale (ESAS–FS)

Please circle the number that best describes your symptoms:

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Pain
No Fatigue	0	1	2	3	4	5	6	7	8	9	10	Worst Fatigue
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Nausea
No Depression	0	1	2	3	4	5	6	7	8	9	10	Worst Depression
No Anxiety	0	1	2	3	4	5	6	7	8	9	10	Worst Anxiety
No Drowsiness	0	1	2	3	4	5	6	7	8	9	10	Worst Drowsiness
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Shortness of Breath
Best Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Appetite
Best Feeling of Well-being	0	1	2	3	4	5	6	7	8	9	10	Worst Feeling of Well-being
Best Sleep	0	1	2	3	4	5	6	7	8	9	10	Worst Sleep
No Financial Distress	0	1	2	3	4	5	6	7	8	9	10	Worst Financial Distress

(Distress/suffering experienced secondary to financial issues)

No Spiritual Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Spiritual Pain

(Pain deep in your soul/being that is not physical)

Value- Ladened Words vs Non-Beneficial Treatment

- ‘too much’,
- ‘futile’,
- ‘inappropriate’
- ‘disproportionate’

Often said,

“There is nothing more I can do…”

Forgetting the three little words… “for the disease.”

The Impact of Unwanted, Uncoordinated Treatment

- 30% of treatment is unwanted, unnecessary
- Sentinel Event- Joint Commissions
  1.. Human factors
  2. Leadership
  3. Communication
  4. Assessment
  5. Information management
  6. Physical environment
  7. Continuum of care
  8. Operative care
  9. Medication use
  10. Care planning
- Patient, Family and Clinician Satisfaction
- Decreased distress
- Improved Trust / Communication

Non-beneficial treatment (NBT)

An objective inverse correlation between intensity of treatment and the expected degree of

- **Treatment** is medically non-beneficial because it offers no reasonable hope of recovery or improvement, or because the patient is permanently unable to experience any benefit.
- **Treatments** that offer no physiological benefits to the patient are **futile**
- **Care and Comfort is ALWAYS Possible**

What about Non- Beneficial Interventions? (NBI)

- Is there a medical intervention that can help obtain that benefit?
- NBI the risks of interventions may outweigh the benefits in this scenario?
- Would/does the patient desire the intervention? Informed refusal?
- Is the clinical team comfortable providing the intervention? Contentious objection (withdraw from or transfer care)?

Five Questions to Ask at Diagnosis

1. Can you tell me that again?
2. Can I say that back to you, so I know that I understand what you are telling me?
3. What do we do next?
4. How serious is this?
5. What else should I be asking at this point?

Five Questions to Ask Your Doctor- GetPalliativeCare.org website.

Four Crucial Questions To Ask Your Doctor- As a Consumer

1. What are the odds this test/medicine will benefit me?
2. What are the downsides or harms of the test/medicine?
3. Are there simpler safer alternatives options?
4. What happens if I do nothing?

JOHN MANDROLA, MD, 2017

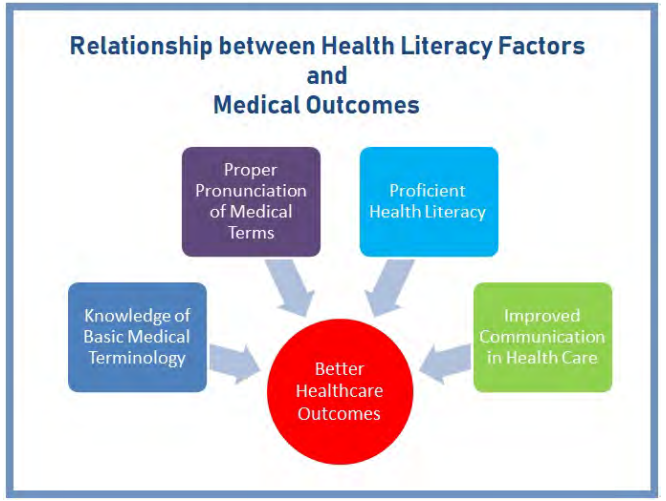
Terminology Matters- Health Literacy

Medical Terminology

- Acute
- Curative/reversible
- Treatable
- Chronic/Progressive
- Seriously Ill
- Life Threatening
- Terminal
- End Stage
- End of Life

What the Layperson May Hear

- Going to get better (return to baseline)
- Improving
- Stable
- Long Term
- Incurable/not reversible
- Not doing as well
- May be a vegetable
- Brain dead
- Very Sick
- Dying



Language Used at the End of Life

- “Discontinuation”
- “DNR”
- “Withdrawing/withholding”

Teach Patient/Family Questions

- Do I have a serious or life-limiting illness?
- Can my illness be cured?
- If my illness can’t be cured, are there treatments that can slow down my illness?
- What kind of care is available to focus on making me comfortable?
- If my illness keeps getting worse, when is it a good time to think about getting supportive and comfort focused care?
- Will you be the one to tell me when to contact hospice?
- Will you stay involved with my care even when I am no longer looking for treatment for my disease?

Centering Treatment on Patient's Needs and Preferences

- Results of Patient Family Questions
- Serious Illness Conversation Guide
- Health Literacy
- As a healthcare consumer
- Documentation/Communication across services / disciplines
- Coordination and transition services

Responding to Emotion

- Suggestions for clear communication: Value statements made by family members
- **Acknowledge emotions**
- **Listen**
- Understand the patient as a person (goals, values, etc)
- Elicit and answer questions from family (options, prognosis, etc)
- Consider using the term Nonbeneficial Intervention (NBI)

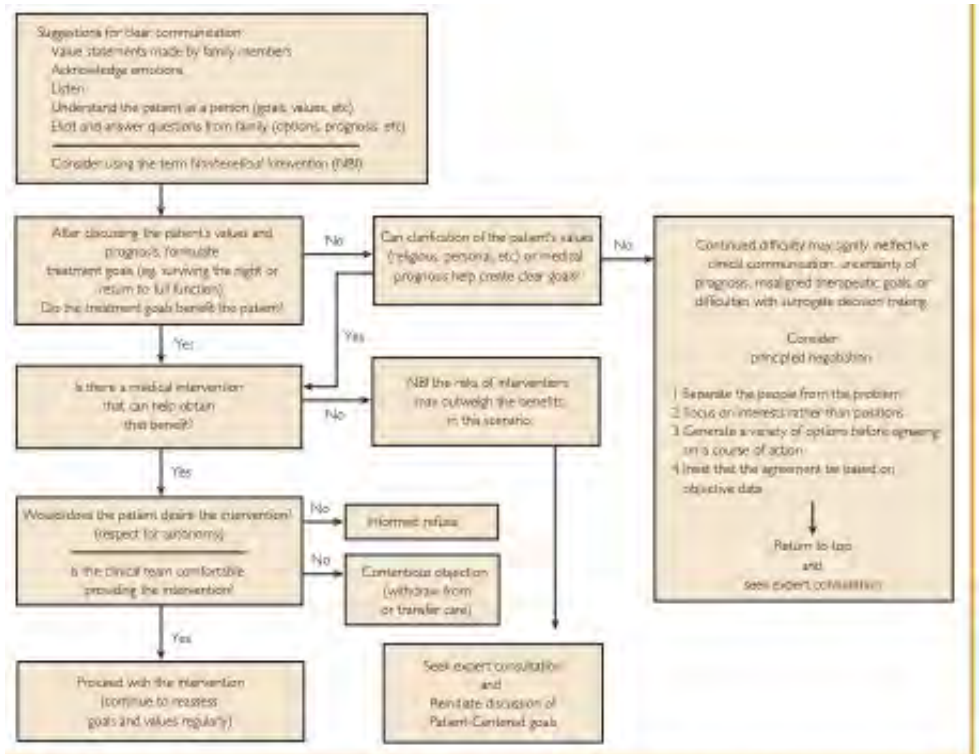


FIGURE. A conceptual framework for discussion of goals, risks and benefits, and common ethical concepts in the clinical setting. Open and clear communication should always be used. When goals are discussed, support from all parties should be sought. Interventions moving toward at least 1 goal should be pursued. Interventions without physiologic or quantitative effect will likely not satisfy criteria for autonomous decisions and should be evaluated critically. Situations without qualitative benefit also fall under the nonbeneficial intervention (NBI) spectrum and should be discussed with care and empathy. Understanding the differences between interventions considered futile (McMath, Baby K, Wangle) and informed refusal cases (Cruzan, Quinlan) as well as contentious objection are illustrated here as well.

Consider Principled Negotiation

A. Separate the people from the problem
B. Focus on interests rather than positions
C. Generate a variety of options before agreeing on a course of action
D. Insist that the agreement be based on objective data

New Strategies

- Need to try a new/different approach
- Empowering the community to bring up the questions
- Providing resources to providers to have the discussions earlier
- Setting the conversations as a priority
- Get the opportunity to have the co
- Groundswell approach

Extremis- Netflix Original

By Dr. Jessica Zitter, Oakland, CA

(Released on Netflix ***September 13, 2016*** – 24 minutes)

(First released in April 2016 at the Tribeca Film Festival)

At the intersection of Quantity & Quality

Patient-Centered Care in the ICU

"Witness the wrenching emotions that accompany end-of-life decisions as doctors, patients, and families in a hospital ICU face harrowing choices."

- Genres: Documentaries, Tearjerkers
- This movie is :Emotional, Dark, Understated
- 2017 Academy Award nominee for Best Documentary Short Subject

Extremis Trailer

Extreme Measures *(February 21, 2017)*


EXTREME
MEASURES
FINDING A BETTER PATH
to the END of LIFE
JESSICA NUTIK ZITTER, MD

Case Study- John

John is a 75-year-old gentleman with chronic obstructive pulmonary disease (COPD) and hip pain related to long-term steroid use for his COPD. Javier has had multiple hospitalizations for shortness of breath, including admissions in which he was put on a ventilator. You are out to visit him in his home after a recent hospitalization.

John says, ““**I'm not sure I can keep going like this.”**

How would you reply?

How to Reply

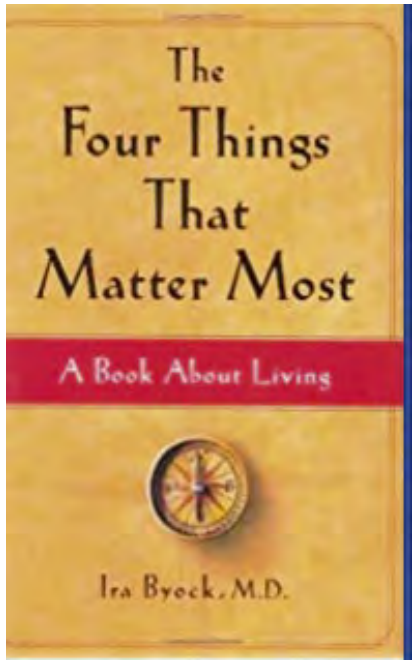
- Acknowledge the emotional subtext of John's statement;
- Invite him to explain more.
- **Understand John's perspective. John might get the impression that the clinician thinks he is giving up if you suggest changing the goals of care now.**
- John responds: "I've had to go to the hospital many times - including twice when they put me on a mechanical breathing machine, which was miserable. Things seem like they're getting worse."
- Respond empathically to patients and caregivers by acknowledging and exploring enables you to understand their values.

Loss/Lack of Continuity

- Approximately a quarter of families feel abandoned
- Prevalence of complicated grief was higher in the families with a sense of abandonment
- Patients reassured that they had received the “best treatment”
- Hospice was recommended as one potential choice rather than as mandatory
- Provider says, “there is nothing more I can do”
- Non-abandonment is one of the central ethical obligations

Providing Closure- Four Things That Matter

- “Please forgive me,”
- “I forgive you,”
- “Thank you,”
- “I love you”



(Ira Byock, 2004,2014)

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