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2026 SYMPOSIUM

Shared Decision Making- How?

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Disclosures

- None

Shared Decision Making — The Pinnacle of Patient-Centered Care

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Nothing about me without me.

— Valerie Billingham,
Through the Patient's Eyes,
Salzburg Seminar
Session 356, 1998

Caring and compassion were once often the only "treatment" available to clinicians. Over time, advances in medical science have provided new options that, although often improving outcomes, have inadvertently distanced physicians from their patients. The result is a health care environment in which patients and their families are often excluded from important discussions and left feeling in the dark about how their problems are being managed and how to navigate the overwhelming array of diagnostic and treatment options available to them.

An audio interview with Dr. Barry is available at NEJM.org

In 1988, the Picker/Commonwealth Program for Patient-Centered Care (now the Picker Institute) coined the term "patient-centered care" to call attention to the need for clinicians, staff, and health care systems to shift their focus away from diseases and back to the patient and family.[1] The term was meant to stress the importance of better understanding the experience of illness and of addressing patients' needs within an increasingly complex and fragmented health care delivery system.

The Picker Institute, in partnership with patients and families, conducted a multiyear research project and ultimately identified eight characteristics of care as the most important indicators of quality and safety, from the perspective of patients: respect for the patient's values, preferences, and expressed needs; coordinated and integrated care; clear, high-quality information and education for the patient and family; physical comfort, including pain management; emotional support and alleviation of fear and anxiety; involvement of family members and friends, as appropriate; continuity, including through care-site transitions; and access to care.[1] Successfully addressing these dimensions requires enlisting patients and families as allies in designing, implementing, and evaluating care systems.

This concept was introduced in the landmark Institute of Medicine (IOM) report *Crossing the Quality Chasm*[2] as one of the fundamental approaches to improving the quality of U.S. health care. The IOM defined patient-centered care as "care that is respectful of and responsive to individual patient preferences, needs, and values" and that ensures "that patient values guide all clinical decisions." This definition highlights the importance of clinicians and patients working together to produce the best outcomes possible.

As the definition implies, the most important attribute of patient-centered care is the active engagement of patients when fateful health care decisions must be made — when an individual patient arrives at a crossroads of medical options, where the diverging paths have different and important consequences with lasting implications. Examples include decisions about major surgery, medications that must be taken for the rest of one's life, and screening and diagnostic tests that can trigger cascades of serious and stressful interventions.

For some decisions, there is one clearly superior path, and patient preferences play little or no role — a fractured hip needs repair, acute appendicitis necessitates surgery, and bacterial meningitis requires antibiotics. For most medical decisions, however, more than one reasonable path forward exists (including the option of doing nothing, when appropriate), and different paths entail different combinations of possible therapeutic effects and side effects. Decisions about therapy for early-stage breast cancer or prostate cancer, lipid-lowering medication for the primary prevention of coronary heart disease, and genetic and cancer screening tests are good examples. In such cases, patient involvement in decision making adds substantial value.

In an influential article on clinical practice guidelines, David Eddy argued that an intervention should be considered a "standard" only if there is "virtual unanimity among patients about the overall desirability . . . of the outcomes."[3] For the vast majority of decisions in which there is no intervention that meets this high bar, patients need to be involved in determining the management strategy most consistent with their preferences and values.

The process by which the optimal decision may be reached for a patient at a fateful health crossroads is called shared decision making and involves, at minimum, a clinician and the patient, although other members of the

Patient-Centered Care

The most important attribute:

"**Active engagement of patients** when fateful health care decisions must be made"

Barry MJ. NEJM. 2012, 36



1980-1982

74 Internal Medicine visits

Audio recorded and transcribed

Solicitation of chief complaint

23% Patients completed their statements

41% Completed statements stated no concerns

Completed turn to talk after mean of **4.8** seconds

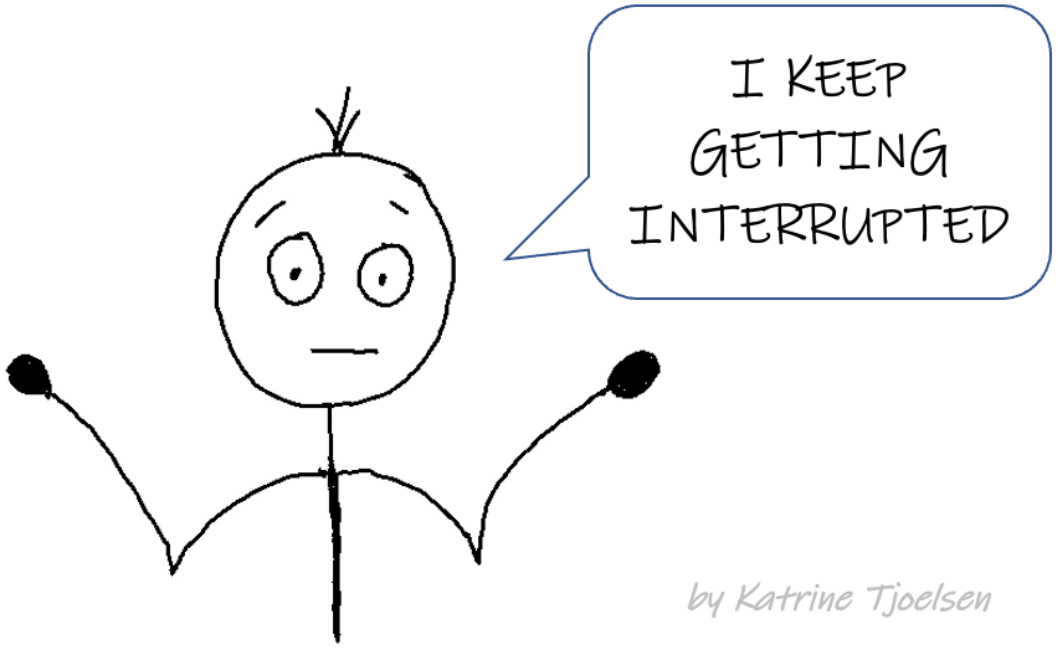
Beckman et al. Annals Int Med 1984;692-6



Interruptions

18 seconds:
Average time to interruption after patient began to speak

150 seconds:
Longest completed statement of concern



Interruptions

1/52 interrupted statements completed

Remaining 51: interruption was transition to **physician-centered**, directed questioning

Do

Give the patient your full attention: sit down, engage with the patient

Ask open ended questions: “how”, “what”, “tell me”

Listen

Don’t

Stand up

Look at the computer

Use “any”

“I don’t know what I don’t know”

“I actually had to do my own research… ”

“I believe there's no education for patients and they're starving for it”



Step-by-Step Guide for Creating your ESKD Life Plan

Supported by
UCLA Vascular Surgery and
The National Institutes of Health

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Kidney Failure

What is kidney failure?

- Kidney failure is when both kidneys are not doing their job
- With kidney failure, the body fills up with extra fluid and wastes

What are my options if I have kidney failure?

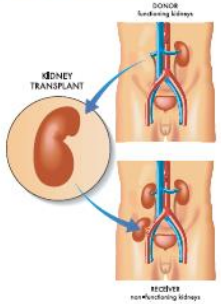
- Hemodialysis (HD)
  - Cleans the blood by using a machine
  - See page 18 for more information



- Peritoneal dialysis (PD)
  - Uses the natural lining inside the abdomen to filter out wastes and extra fluid
  - See page 14 for more information



- Kidney transplant
  - Takes a kidney from another person (donor) and puts it into the body of the person with kidney failure
  - See page 12 for more information



Arteriovenous Fistula (also called AV Fistula, Fistula or AVF)

What is an artery?

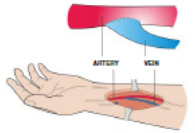
- Arteries are the blood vessels that carry blood and nutrients away from your heart to the rest of your body

What is a vein?

- Veins are the blood vessels that carry blood from your body back to your heart to get loaded up with nutrients again

What is a fistula?

- A fistula is a connection between an artery and a vein



- The fistula is entirely under the skin
- The connection allows the vein to get bigger and have more blood flow. This allows it to be used for HD.



How does the fistula work for dialysis?

- Two needles are inserted into the fistula to carry blood between the patient and the dialysis machine



- The needles are inserted by a nurse or a technician. The patient can also learn how to insert the needles themselves (self-cannulation).

Can everyone get a fistula?

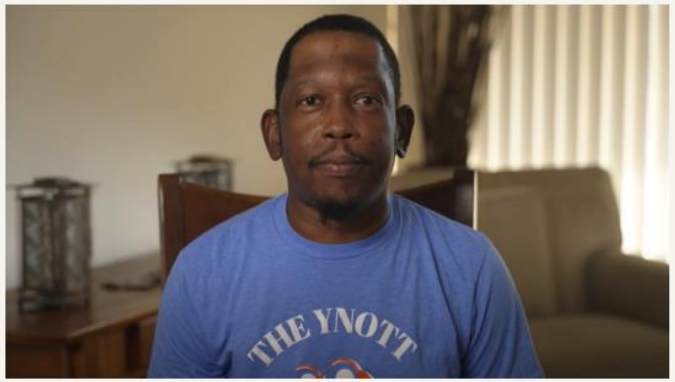
- To make a fistula, the patient must have a vein that is large enough
- An ultrasound (called vein mapping) is done to measure the size of all the veins in the arms

Available at: https://www.uclahealth.org/departments/surgery/divisions/vascular-and-endovascular-surgery/eskd-life-plan-toolkit

Patient Experiences with ESKD



Jonathan and Melissa's Story →



Philip's Story →



Nichole's Story →



Duke and Susan's Story →

Available at: https://www.uclahealth.org/departments/surgery/divisions/vascular-and-endovascular-surgery/eskd-life-plan-toolkit

Patient Role

Rationale:
Many patients are not aware that they can and should participate in decision making.

Examples:
“I’d like us to make this decision together.”
“It helps me to know how you feel about this.”

Discussion of the role of the patient in decision making

Nature of the Issue

Discussion of the clinical issue or nature of the decision

Rationale:
A clear statement of what is at issue helps clarify what is being decided on and allows the physician to share some of their thinking about it.

Examples:
“When you have hemodialysis, you need a place on your body where two needles can be placed…”

Alternatives

Discussion of the alternatives

Rationale:
A decision is always a choice among certain options, including doing nothing at all. This is not always clear to the patient without an explicit discussion.

Examples:
“You could have surgery to make a fistula or graft or stick with the catheter you have now”

Rationale:

We frequently discuss the pros of one option and the cons of another without fully exploring the pros and cons of each. A more balanced presentation allows the patient's decision to be more informed.

Examples:

"The fistula has a higher chance of not working than the graft and the graft has a higher chance of infection than the fistula."

Pros and Cons

Discussion of the pros (potential benefits) and cons (risks) of the alternatives

Rationale:
While difficult, a discussion of uncertainties is crucial for a patient's comprehensive understanding of the options. Thoughtful discussion can promote trust and encourage adherence.

Examples:
"We are not very good at predicting which patients the fistula will work for."

Uncertainties

Discussion of uncertainties associated with the decision

Understanding

Assessment of the patient's understanding

Rationale:
Check in with the patient to see if what has been said so far makes sense. Fostering understanding is the central goal of informed decision making

Examples:
"Does that make sense to you?"

Patient Preference

Exploration of patient preference

Rationale:
Physicians often assume patients will speak up if they disagree with a decision, but patients often need to be asked for their opinion. It should be clear to the patient that they can disagree or ask for more time.

Examples:
“What do you think?”

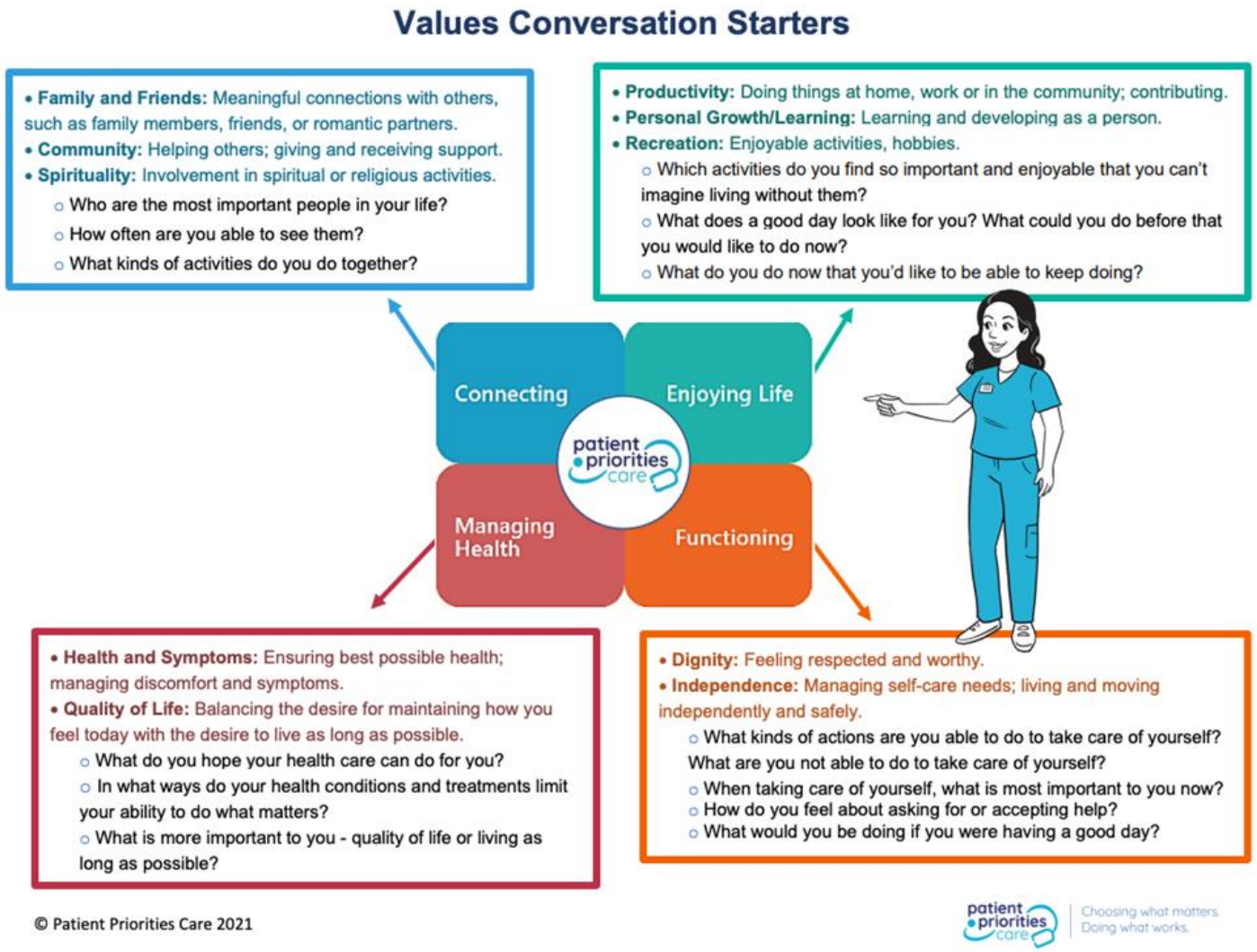
Shared Decision Making



CHALLENGE
Match Treatment with Patient Preference

GOAL
Match Treatment with Patient Preference





Patient Priorities Care

patientprioritiescare.org
Mary Tinetti, MD
Values:
Important people
Quality of life
Dignity
Independence
Productivity

Naik AD, et al. *JAGS*, 2018;66:1872-9.

Best Case/Worst Case

"I have bad news. You have a serious problem that will change your life."

"We have a choice between 2 options"

"In the best case …"

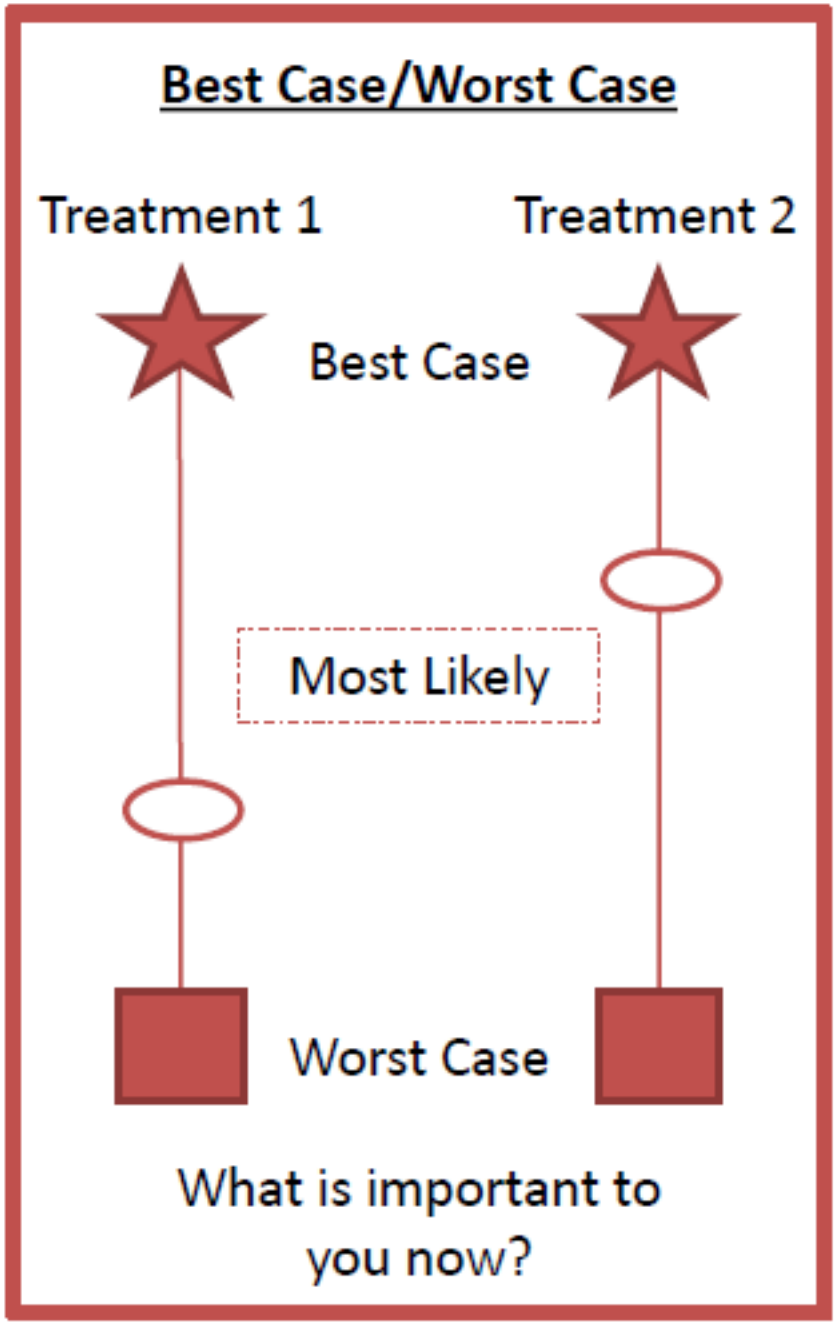
1. Realistic best long-term treatment outcome: *"I think your mom will eventually get home, but weaker and needing more assistance."*
2. Short-term implications: tell a story about what treatment & recovery entail, e.g. hospital course, SNF: *"To get her there, we will need to do a big surgery, she will be in the ICU for 2-4 days, then in the hospital for another week, then rehab for 1-2 months."*
3. Orient into context of patient's overall health & prognosis *"…still needs oxygen for her COPD."*

"In the worst case …"

Describe points 1-3. When death is possible, avoid euphemisms, e.g. "die" is preferred to "pass on".

"Based on what I know about you, what I think is most likely…"

- *"How are you thinking about this?"*
- *"Based on what I'm hearing from you, would it be alright if I make a recommendation?"*



Kopecky KE, et al. *JAMA Surgery*, 2019;154:3-4.



"No doctor has ever listened to me the way you just listened to me"