Person-Centered Decision Making in Advancing Illness: Essential Knowledge and Critical Skills

F. Daniel (Dan) Davis, PhD & James (Jay) Joseph, MD

Geisinger || Danville, PA

jwjoseph@geisinger.edu



We have nothing to disclose



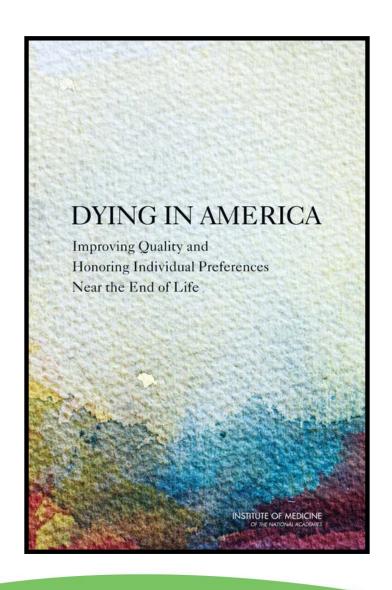
Objectives

- Describe the evidence supporting personcentered decision making and advance care planning in the context of advancing illness
- Understand the decisional and communication challenges in working with patients and families in this context
- Describe and use communication skills and strategies responsive to these challenges









National Academy of Medicine's Dying in America (September 2014):

The bottom line is the health care system is poorly designed to meet the needs of patients near the end of life.

The current system is geared towards doing more, more, more ...

... and that system by definition is not necessarily consistent with what patients want and is also more costly.



I am in a profession that has succeeded because of its ability to fix. If your problem is fixable, we know just what to do.

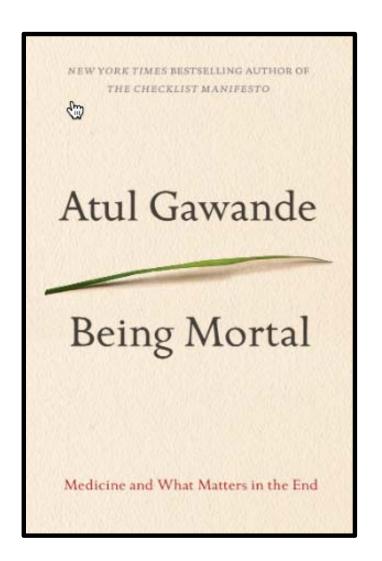
But if it's not? The fact that we have had no adequate answers to this question is troubling and has caused callousness, inhumanity, and extraordinary suffering.

This experiment of making mortality a medical experience is just decades old.

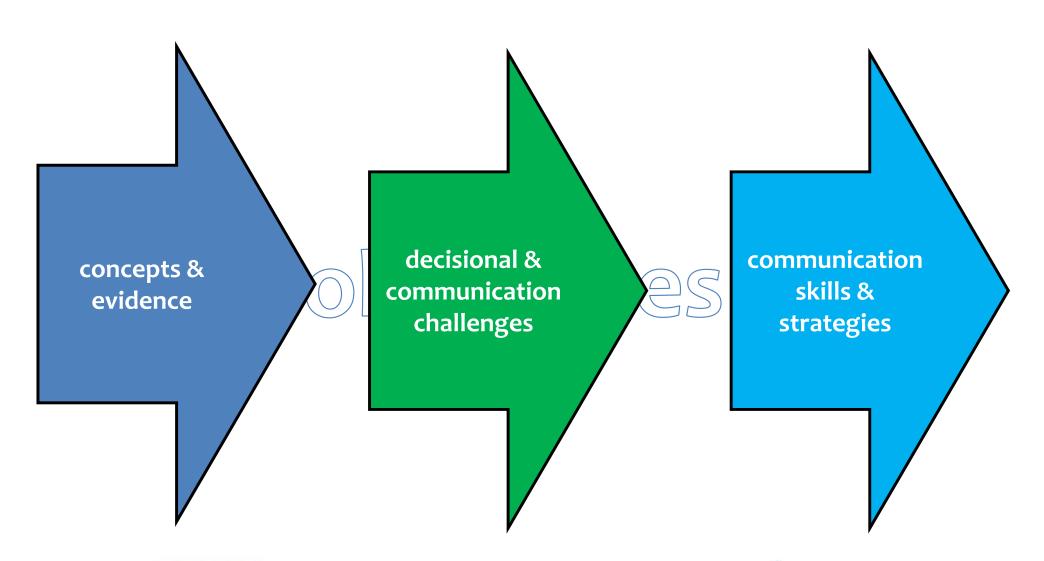
It is young.

And the evidence is it is failing.

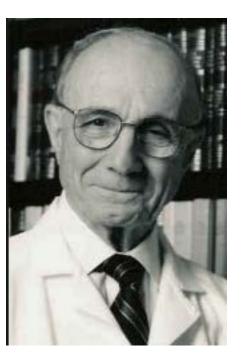
pp 8-9











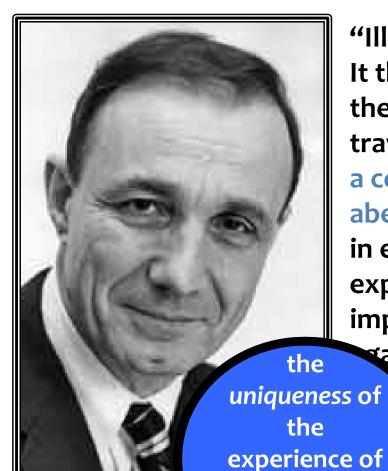




EDMUND D. PELLEGRINO, MD

A Tribute at 100





illness and

the need for

healing

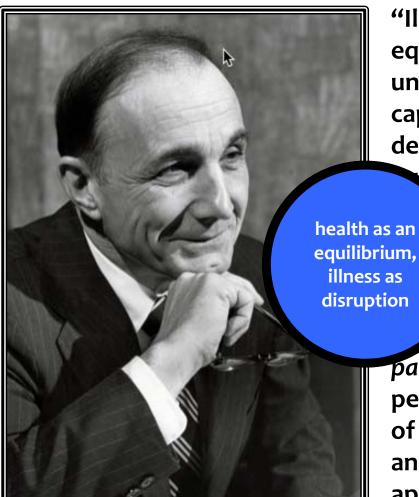
"Illness forces a change in existential states. It thrusts man into contact with the reality of the via dolorosa that all eventually must traverse. It is only in part defined medically as a concrete organic or psychosocial aberration. It is the perception of the change in existential states that forms the central experience of illness—the perception of impairment and the need to be made whole gain—to be cured, healed, or cared for. That

eption is personal and unique because erson has a different meaning for

and illness."



"We feel healthy when we are in a state of equilibrium between our already experienced shortcomings and our aspirations so that we have adjusted our goals to the gap between them. Health is a state of accommodation, defined in different terms by each person."



"Illness rudely upsets that equilibrium. It is an undesired, unsought, capricious irruption demanding a new uilibrium—one that may astically different. It ean the loss of al image, identity, stence itself. The ill son becomes homo

patiens—a patient—a person bearing a burden of distress, pain or anxiety—a person set apart, a person wounded in specific ways."

PENNSYLVANIA ACADEMY OF FAMILY PHYSICIANS FOUNDATION

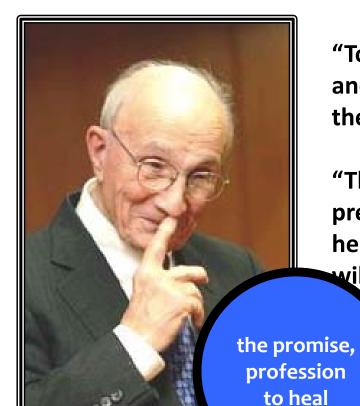
"Homo patiens is therefore man in an altered state: wounded, vulnerable, needing help, and afflicted with a special anguish that must be adequately ameliorated in a bona fide healing relationship with other human beings. It is this fact that defines the healing relationship—between homo patiens and those who profess to make him whole again.

Genuine healing must be based on an authentic perception of the experience of illness in this pers

It must aim at a repair of the particular assaults illness makes on the humanity of the one who

the fact of illness and the healing relationship





"To heal is 'to make whole again' and that entails confronting and ameliorating the ways illness wounds the humanity of the one who is ill."

"This is precisely what is promised when the professed healer presents himself before the ailing person. He promises that he has authentic knowledge and skill, competence; that he will put them at the service of the patient and will act in the ent's best interest. This is the true meaning of the act of seion—a promise made to man as homo patiens. This lary act on the part of the healer signifies willingness to the promise authentic."

PENNSYLVANIA ACADEMY OF FAMILY PHYSICIANS FOUNDATION

Medicine is a special moral enterprise because it is grounded in a special personal relationship—between one who is ill and another who professes to heal.

Pellegrino, Being III & Being Healed, 1979 medicine as a healing relationship

patient- & person-centered care

relationshipcentered care Recognizes that "All illness, care, and healing processes occur in relationship" and that "the nature and the quality of relationships are central." Prioritizes personhood, affect & emotion, reciprocal influence, and relationships are morally valuable.

Beach & Inui, RCC: A Constructive Reframing, 2006

PENNSYLVANIA ACADEMY OF FAMILY PHYSICIANS FOUNDATION

The originators of ... patient centered health care were well aware of the moral implications of their work, which was based on deep respect for patients as unique living beings, and the obligation to care for them on their own terms.

Thus patients are known as persons in the context of their own social worlds, listened to, informed, respected and involved in their care—and their wishes are honored but not mindlessly enacted during their health care journey.

Epstein & Street. The Values and Value of Patient-Centered Care. Annals of Family Medicine, March/April 2011.



patient- & person-centered care

shared, informed decision making advance care planning What matters
most—
patient
priorities in
the context
of advancing
illness

mindful, empathic communication





Illness-orientated medicine

Seeks to identify a fault either in the body or in one of the parts or functions of the body in order thus to diagnose it as an illness and then treat it.

E. Balint, "The Possibilities of Patient-Centered Medicine." Journal of the Royal College of General Practitioners, 1969.

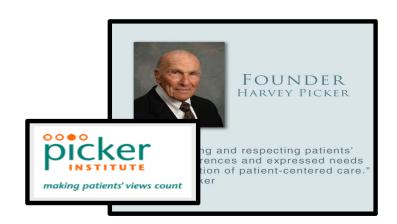
patient-centered medicine

... a patient-centered medicine examines the whole person in order to form an overall diagnosis, including everything that the doctor knows and understands about the patient ...

VS.

... the patient, in fact, must be understood as a unique human being.



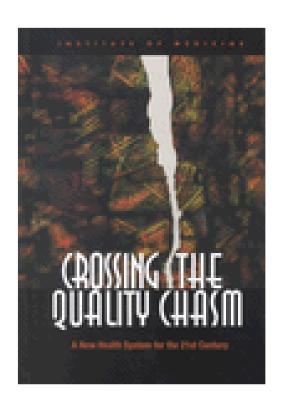


8,000 interviews with patients, their families, physicians, and clinical staff:

What do patients want and value? What helps or hinders their ability to manage their health problems? What aspects of care are most important?



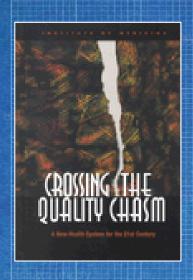




... providing care that is respectful and representative of individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.

high quality health care is patient-centered as well as efficient, safe, equitable, effective, & timely





principles for re-designing the system

- Care is based on continuous healing relationships
- 2. Care is customized according to patient needs and values
- 3. The patient is the source of control
- 4. Knowledge is shared and information flows freely
- 5. Decision making is evidence-based
- 6. Safety is a system property
- 7. Transparency is necessary
- 8. Needs are anticipated
- 9. Waste is continuously decreased
- 10. Cooperation among clinicians is a priority





HOME

ARTICLES & MULTIMEDIA ~

ISSUES *

SPECIALTIES & TOPICS ~

FOR AUTHORS ~

CME »

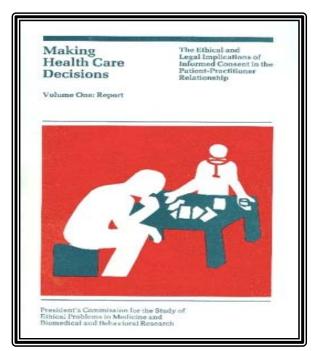


Perspective

Shared Decision Making — The Pinnacle of Patient-Centered Care

Michael J. Barry, M.D., and Susan Edgman-Levitan, P.A. N Engl J Med 2012; 366:780-781 | March 1, 2012 | DOI: 10.1056/NEJMp1109283



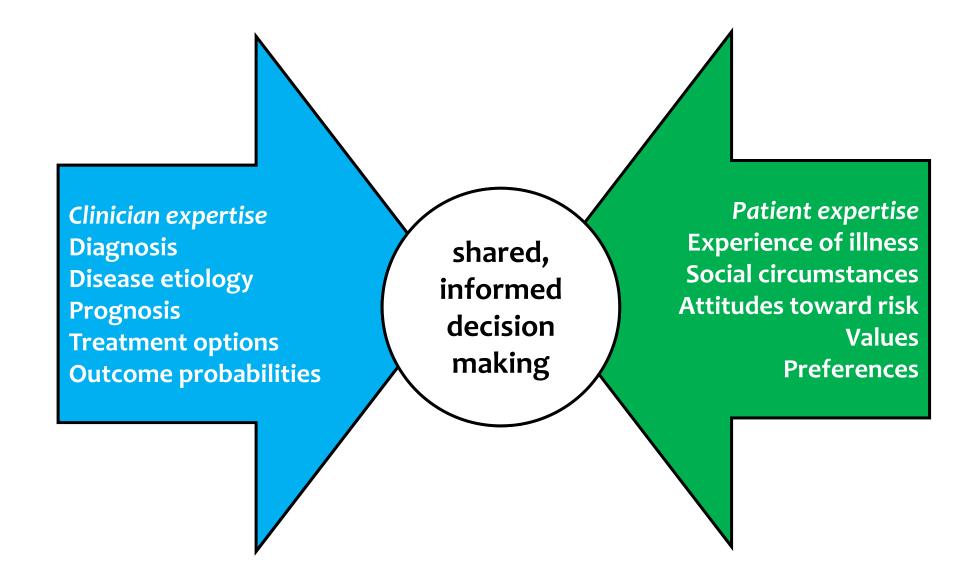


President's Commission 1982

Ethically valid consent is a process of shared decision making based upon mutual respect and participation, not a ritual to be equated with reciting the contents of a form that details the risks of particular treatments.

... a universal desire for information, choice, and respectful communication about decisions ... Informed consent must remain flexible, yet the process ... is ethically required of health care practitioners in their relationships with all patients, not a luxury for a few.









systematic reviews of patient decisionmaking preferences indicate that majorities prefer to be actively involved in decision making ... the trend for a preference for shared decisions has increased over time.

LA Shay & JE Lafata. Where is the evidence? A systematic review of shared decision making and patient outcomes. *Medical Decision Making*. January 2015.



A process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal ... is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness. For many people, this process may include choosing and preparing another trusted person or persons to make medical decisions in the event the person can no longer make his or her own decisions. (Sudore et al, 2017).



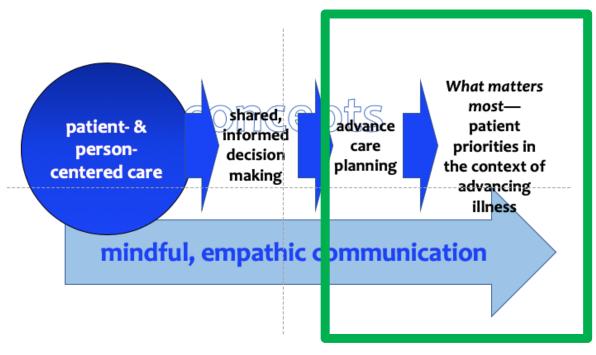
patient goals and priorities

what matters most to patients in the context of advancing illness



- cure
- avoidance of premature death
- maintenance/improvement of function
- prolongation of life
- relief of suffering
- optimized quality of life
- maintenance of control
- a good death
- support for families & loved ones



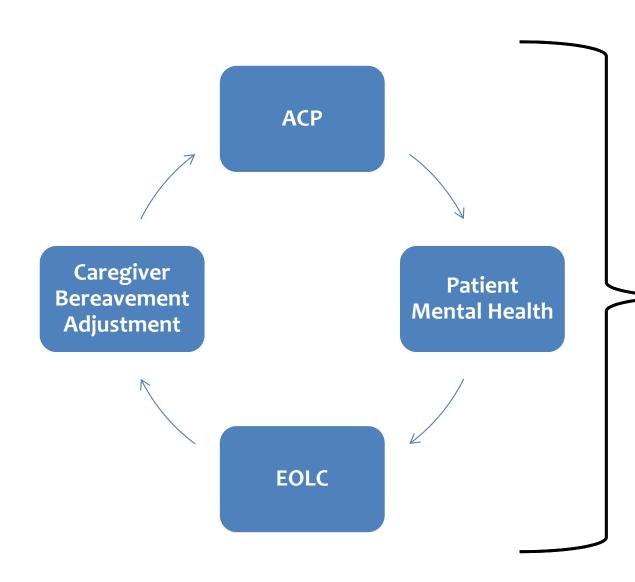


evidence

MORE IS NEEDED!

S.D. Halpern, Toward Evidence-Based End-of-Life Care, NEJM (2015) 373;21: 2001-2003





ACP associated with less aggressive treatment near death & earlier hospice referrals.

Aggressive treatment associated with worse patient QoL and worse bereavement adjustment.

Wright et al. Associations between EOL discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* (2008) 300(14): 1665-1673.



Prospective RCT – 309 patients/154 in intervention (ACP) arm – focus on goals, values & beliefs; future medical preferences; appointment of surrogate; documentation of wishes

Main outcome measure: were patients' wishes known AND respected? Other measures: patient & family satisfaction; stress, anxiety, & depression in surviving relatives

Key findings: ACP improved EOLC and patient & family satisfaction & reduces distress in NoK

Detering et al. The impact of ACP on EOLC in elderly Patients: RCT. *BMJ* 2010;340:c1345.





Respecting Choices & Related Models of ACP

- Increase in incidence and prevalence of advance directives and POLST: low level of evidence
- Increase patient-surrogate congruence: high level of evidence
- Change the consistency of treatment with wishes and overall health care utilization at EOL: mixed & inconclusive

MacKenzie et al. Respecting Choices and Related Models of Advance Care Planning: A Systematic Review of Published Evidence. American Journal of Hospice and Palliative Medicine. (2018) 35(6):897-907.



ACP: Strategic Timing

Fundamental goal of ACP: to assure that care is congruent with a patient's informed wishes

Avoiding the problem of "too early" and "too late": the importance of prognostication in identifying patients who would benefit from ACP

the surprise ?: Would you be surprised if this patient died within the next year? (supporting evidence in cancer and ESRD patients)



Billings and Bernacki.

Strategic Targeting of ACP
Interventions: The
Goldilocks Phenomenon.

JAMA Internal Medicine.
April 2014.



For older adults with multiple chronic conditions is care that is aligned with their priorities associated with improved patient-reported outcomes and reduced unwanted care?

Non-randomized clinical trial of 366 adults 65 years+ with multiple chronic conditions found that participants receiving patient priority-driven care vs usual care reported a greater reduction in treatment burden and their EHRs reflected, e.g., cessation of medications, diagnostic tests, etc.

Aligning care with patients' priorities may improve outcomes for patients with multiple chronic conditions.

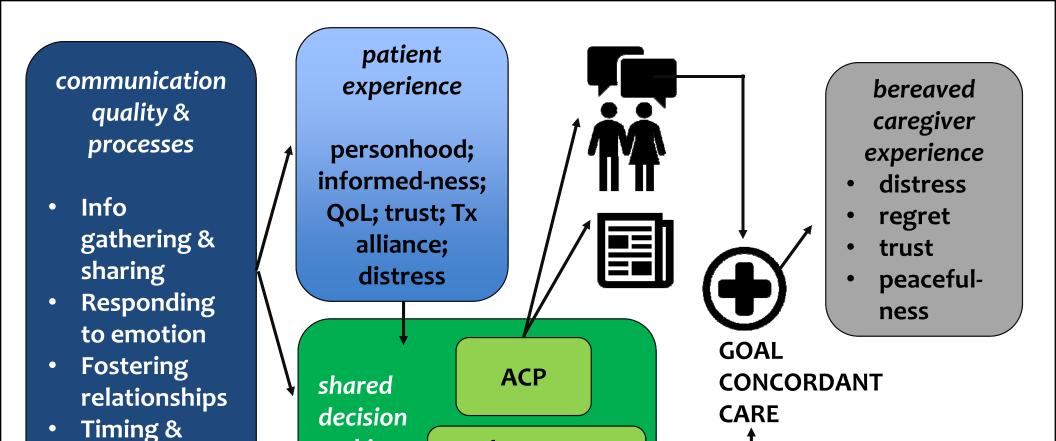
Tinetti et al. Association of Patient Priorities-Aligned Decision Making with Patient Outcomes and Ambulatory Health Care Burden Among Older Adults with MCC: A Nonrandomized Clinical Trial. *JAMA Internal Medicine*, October 7, 2019.





Sanders et al. Achieving Goal-Concordant Care: A Conceptual Model and Approach to Measuring Serious Illness Communication and Its Impact. Journal of Palliative Medicine. 2018; 21(52): S17-S27.





Sanders et al. Achieving Goal-Concordant Care: A Conceptual Model and Approach to Measuring Serious Illness Communication and Its Impact. Journal of Palliative Medicine. 2018; 21(52): S17-S27.

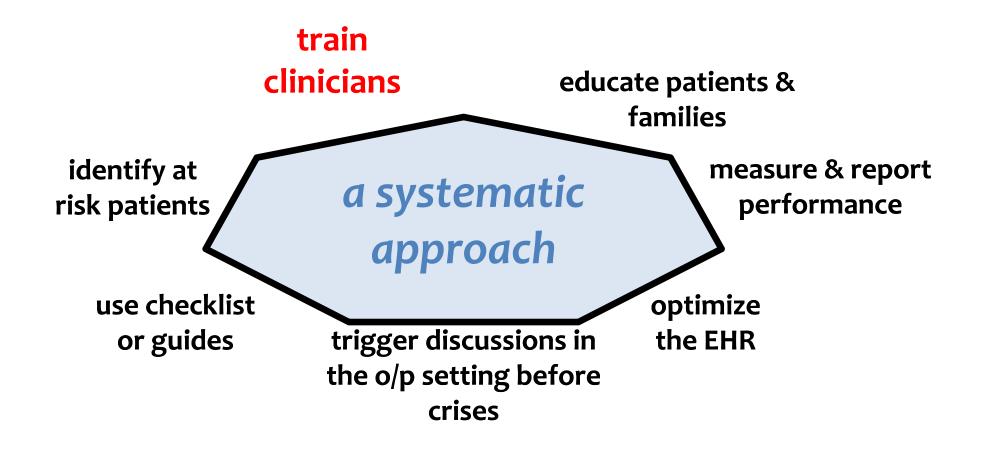
In the moment

decisionmaking

making

setting

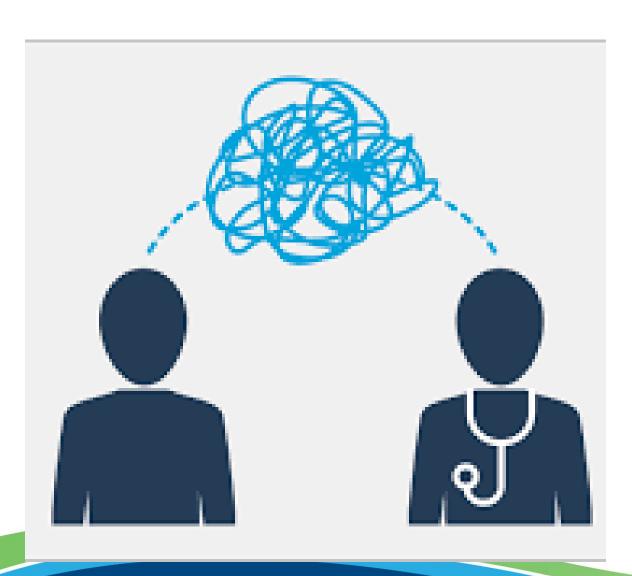




Bernacki and Block/ACP High Value Care Task Force. Communication about Serious Illness Care Goals: A Review and Synthesis of Best Practices. JAMA Internal Medicine. December 2014.



Decisional and communication challenges

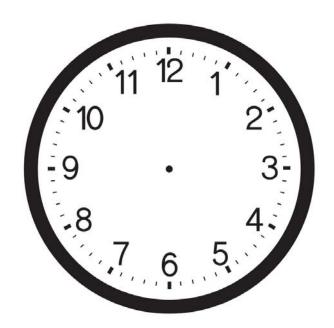


- Time/reimbursement
- Training
- Ideal space
- Getting the "right" people together
- Timing; "too early...until too late"
- Medical complexity
- Family complexity



U.S. physicians spent **17-24 minutes** with their patients, according to a survey conducted in 2018.

https://www.statista.com/statistics/ 250219/us-physicians-opinionabout-their-compensation/ • **Time**/reimbursement



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Training

"It has been observed that **communication skills tend to decline** as medical students progress through their medical education, and over **time doctors in training tend to lose their focus on holistic patient care**. Furthermore, the emotional and physical brutality of medical training, particularly during internship and residency, **suppresses empathy, substitutes techniques and procedures for talk**, and may even result in derision of patients"

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3096184/



Training

"Fewer than one-third (29%) of physicians report having any formal training in communication about goals of care, and nearly half (46%) report that they are unsure about what to say"

https://www.capc.org/strategies/clinical-communication-skills/

- Preserving Autonomy
- Advance directives
- Healthcare Representatives
 - spouse and adult child who is not the child of the spouse
 - adult child
 - •parent
 - adult sibling
 - adult grandchild
 - close friend
- Act 169
 https://www.legis.state.pa.us/cfdocs/Legis/ LI/uconsCheck.cfm?txtType=HTM&yr=2006 &sessInd=0&smthLwInd=0&act=169

Who makes the decisions?



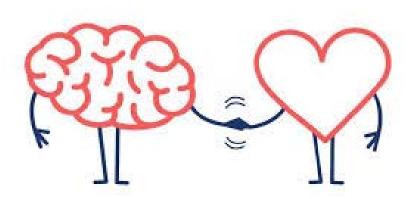


- Who makes the decisions?
- Emotionally laden topics
- Jargon and forms
- Documentation workflows, fidelity and translation into practice
- PENNSYLVANIA ACADEMY OF FAMILY PHYSICIANS FOUNDATION



- Who makes the decisions?
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- Responding to emotions
- Vital Talk
- ADAPT
- Ariadne Labs
- Respecting Choices: Advance Care Planning and Shared Decision-Making in Serious Illness

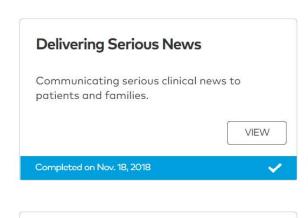


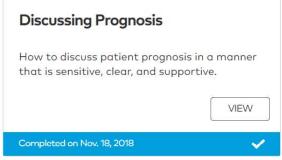


CAPC Communication Courses

https://www.capc.org/

5 Completed













NURSE the Emotions

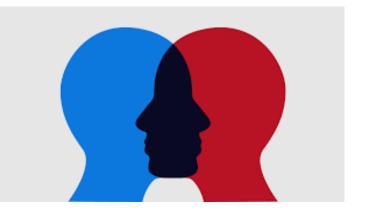
Naming	"It sounds like you are frustrated"	In general, turn down the intensity a notch when you name the emotion	
Understanding	"This helps me understand what you are thinking"	Think of this as another kind of acknowledgment but stop short of suggesting you understand everything (you don't)	
Respecting	"I can see you have really been trying to follow our instructions"	Remember that praise also fits in here eg "I think you have done a great job with this"	
Supporting	"I will do my best to make sure you have what you need"	Making this kind of commitment is a powerful statement	
Exploring	"Could you say more about what you mean when you say that"	Asking a focused question prevents this from seeming too obvious	



Responding to Emotions

Three fundamental skills

	Example	Notes
Tell me more	"Tell me more about"	Use when you are not sure what someone is talking about (rather than jump to an assumption).
Ask-tell-ask	"What do you think about" "Here's what the tests show" "Does that make sense?"	Related to Assess-Knowledge-Respond in SPIKES. Think of this as one unit of information transfer
"I wish" statements	"I wish I could say that the chemo always works"	Enables you to align with the patient while acknowledging the reality of the situation
I		I





Discussing Prognosis: ADAPT

Step	What you say		
1. Ask what the patient knows, what they want to know	What have other doctors told you about what your prognosis, or the future? How much have you been thinking about the future?		
Discover what info about the future would be useful for the pt	For some people prognosis is numbers or statistics about how long they will live. For other people, prognosis is about living to a particular date. What would be more helpful for you?		To provide using statistics: The worst case scenario is [25th percentile], and the best case
3. Anticipate ambivalence	Talking about the future can be a little scary. If you're not sure, maybe you could tell me how you see the pros and cons of discussing this. If clinically deteriorating: From what I know of you, talking about this information might affect decisions you are thinking about.	4. Provide information in the form the patient wants	scenario is [75th percentile]. If I had 100 people with a similar situation, by [median survival], 50 would have died of cancer and 50 would still be alive with cancer. To provide without statistics: From my knowledge of your situation and how you cancer has been changing /responding, I think there is a good/50-50/slim chance that
		5. Track emotion	you will be able to be around [on that date/for that event]. I can see this is not what you were hoping for. I wish I had better news. I can only imagine how this information feels to you. I appreciate that you want to know what to expect.

Serious Illness Conversation Guide

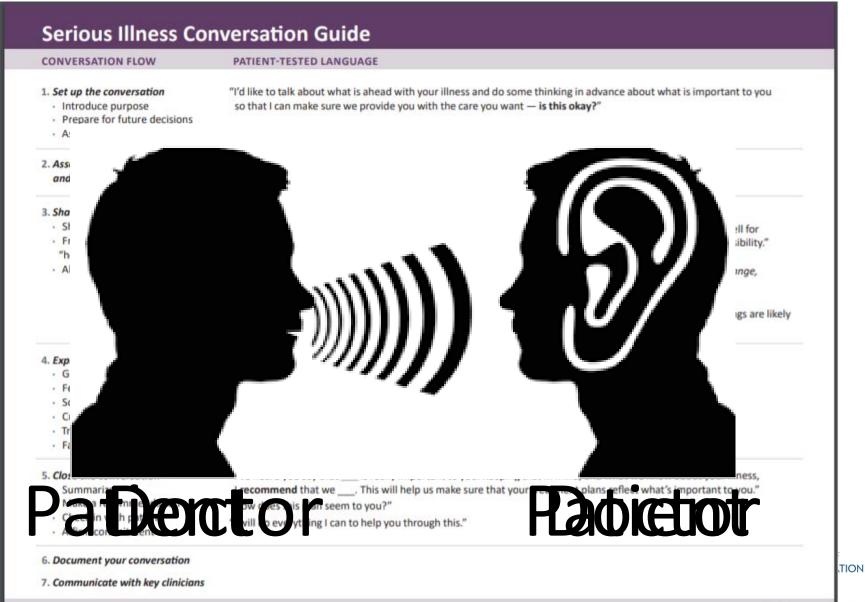
- Ariadne Labs:
 - https://www.ariadnelabs.org/about-us/
- The Guide:
 - https://www.ariadnelabs.org/wpcontent/uploads/sites/2/2017/05/SI-CG-2017-04-21 FINAL.pdf
- Video:
 - https://www.ariadnelabs.org/resources/videos/introducingserious-illness-care-program/



Serious Illness Conversation Guide CONVERSATION FLOW PATIENT-TESTED LANGUAGE "I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you 1. Set up the conversation Introduce purpose so that I can make sure we provide you with the care you want — is this okay?" · Prepare for future decisions Ask permission 2. Assess understanding "What is your understanding now of where you are with your illness?" and preferences "How much information about what is likely to be ahead with your illness would you like from me?" 3. Share prognosis "I want to share with you my understanding of where things are with your illness..." Share prognosis Uncertain: "It can be difficult to predict what will happen with your illness. I hope you will continue to live well for Frame as a "wish...worry", a long time but I'm worried that you could get sick quickly, and I think it is important to prepare for that possibility." "hope...worry" statement Allow silence, explore emotion Time: "I wish we were not in this situation, but I am worried that time may be as short as (express as a range, e.g. days to weeks, weeks to months, months to a year)." Function: "I hope that this is not the case, but I'm worried that this may be as strong as you will feel, and things are likely to get more difficult." 4. Explore key topics "What are your most important goals if your health situation worsens?" Goals "What are your biggest fears and worries about the future with your health?" · Fears and worries "What gives you strength as you think about the future with your illness?" · Sources of strength "What abilities are so critical to your life that you can't imagine living without them?" · Critical abilities "If you become sicker, how much are you willing to go through for the possibility of gaining more time?" Tradeoffs "How much does your family know about your priorities and wishes?" Family 5. Close the conversation "I've heard you say that ____ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we ... This will help us make sure that your treatment plans reflect what's important to you." Summarize · Make a recommendation "How does this plan seem to you?" · Check in with patient "I will do everything I can to help you through this." Affirm commitment 6. Document your conversation 7. Communicate with key clinicians

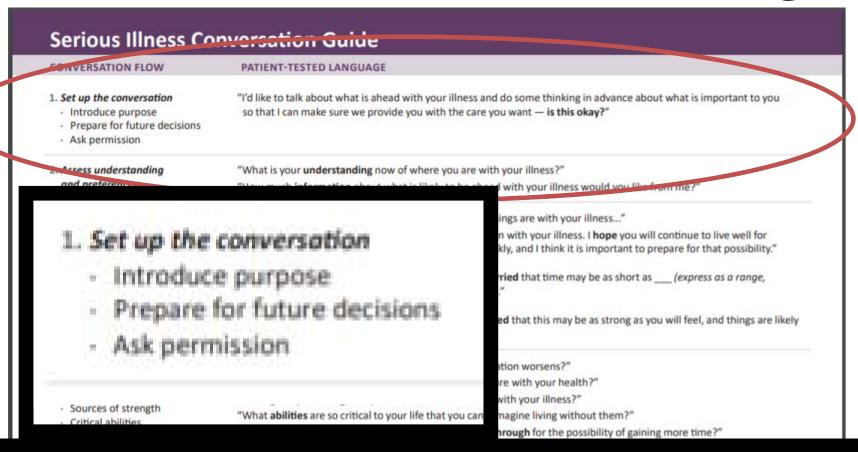












"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — is this okay?"

Serious Illness Conversation Guide CONVERSATION FLOW PATIENT-TESTED LANGUAGE 1. Set up the conversation Introduce purpose Prepare for future decisions Ask permission 1. Assess understanding and preferences "I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — is this okay?" "What is your understanding now of where you are with your illness?" "What is your understanding now of where you are with your illness would you like from me?"

"What is your understanding now of where you are with your illness?"

"How much information about what is likely to be ahead with your illness would you like from me?"



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Serious Illness Conversation Guide

CONVERSATION FLOW

PATIENT-TESTED LANGUAGE

"I want to share with you my understanding of where things are with your illness..."

Uncertain: "It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I'm worried that you could get sick quickly, and I think it is important to prepare for that possibility." OR

Time: "I wish we were not in this situation, but I am worried that time may be as short as ____ (express as a range, e.g. days to weeks, weeks to months, months to a year)."

OR

Function: "I hope that this is not the case, but I'm worried that this may be as strong as you will feel, and things are likely to get more difficult."





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Serious Illness Conversation Guide

CONVERSATION FLOW

PATIENT-TESTED LANGUAGE

"What are your most important goals if your health situation worsens?"

"What are your biggest fears and worries about the future with your health?"

"What gives you strength as you think about the future with your illness?"

"What abilities are so critical to your life that you can't imagine living without them?"

"If you become sicker, how much are you willing to go through for the possibility of gaining more tin

"How much does your family know about your priorities and wishes?"



cneck in with patient

· Affirm commitment



"I will do everything I can to help you through this."



7. Communicate with key clinicians



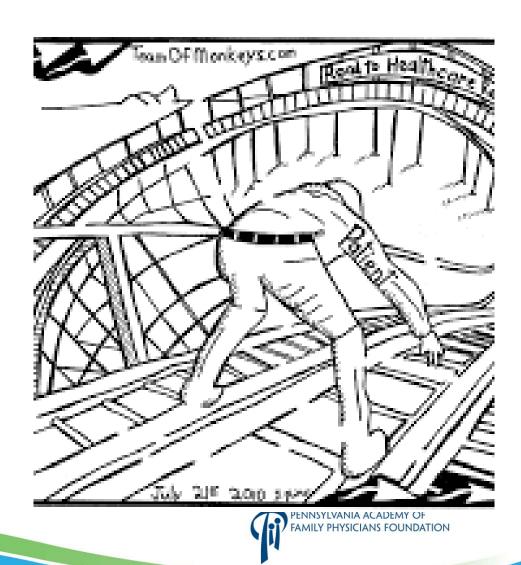






Explore Understanding of Options

- "...how much are you willing to go through to possibly gain more time?"
 - Another hospitalization
 - ICU level of care
 - Another course of chemotherapy
 - LVAD placement
 - Dialysis
 - Intubation and mechanical ventilation
 - CPR



Explore Understanding of Options

What do you understand about the possible *benefits and burdens* of:

- Another hospitalization
- ICU level of care
- Another course of chemotherapy
- LVAD placement
- Dialysis
- Intubation and mechanical ventilation
- CPR



CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
Set up the conversation Introduce purpose Prepare for future decisions Ask permission	"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — is this okay?"
2. Assess understanding	"What is your understanding now of where you are with your illness?"
and preferences	"How much information about what is likely to be ahead with your illness would you like from me?"

"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we ____. This will help us make sure that your treatment plans reflect what's important to you." "How does this plan seem to you?"

"I will do everything I can to help you through this."

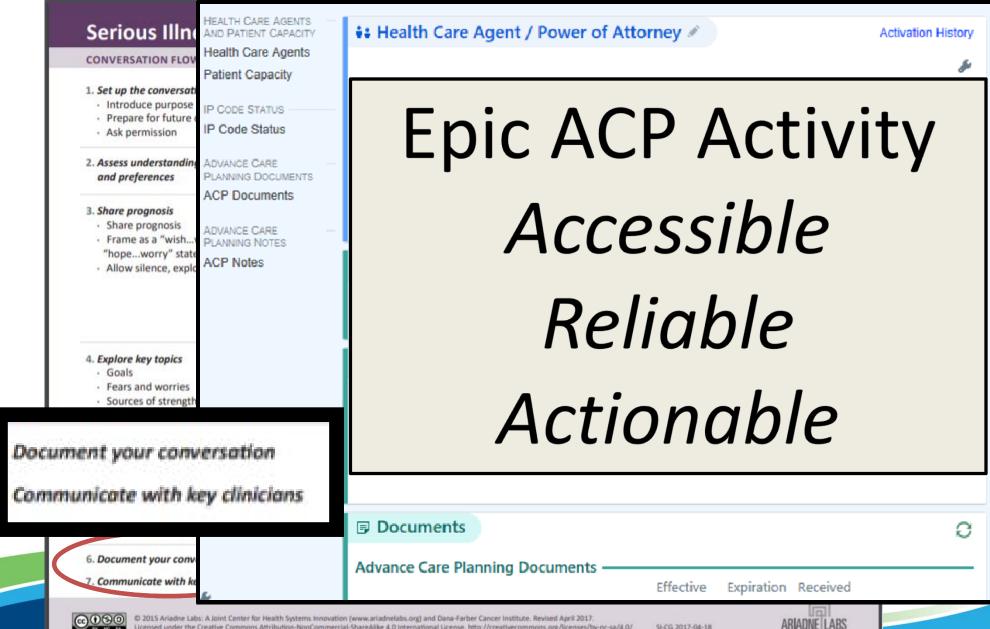
Critical abilities Tradeoffs Family	"What abilities are so critical to your life that you can't imagine living without them?" "If you become sicker, how much are you willing to go through for the possibility of galoing more time?" "How much does your family know about your priorities and wishes?"	
Close the conversation Summarize Make a recommendation Check in with patient Affirm commitment	"I've heard you say that is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we This will help us make sure that your treatment plans reflect what's important to you." "How does this plan seem to you?" "I will do everything I can to help you through this."	

6. Document your conversation

7. Communicate www. 'au clinicians

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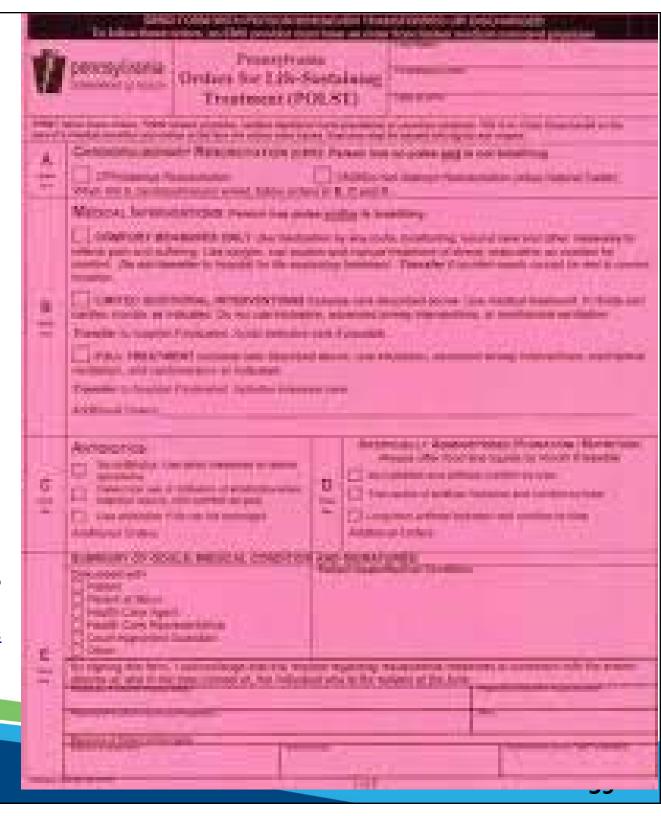


PA POLST

- Medical order
- Signed by patient or HCPOA
- Signed by MD/DO, PA, NP
- Would you be surprised if the patient died in next year? (AUC ~0.80)
- Part A-No pulse/breathing
 - CPR or AND?
- Part B- Compromised state
 - Intubation/MV & hospitalization or comfort care?
- Part C- Antibiotics?
- Part D- tube feeding or not?

https://www.upmc.com/-

/media/upmc/services/aginginstitute/partners hips-and-collaborations/documents/polsteducation.pdf



ACP Billing

- Respecting Choices ACP Billing Guide: https://respectingchoices.org/wp-content/uploads/2018/09/RC 5009 ACP Billing Resource Guide 09.19.18.pdf
- 2016 MC began reimbursement.
- Physicians and non-physician providers can bill. Other staff when under direct supervision of managing physician.
- Any care setting; office, hospital, facility, home. Special rules for telehealth, hospice, FQHC, PACE.
- What should be included?
 - A conversation that is voluntary, with an opportunity to decline.
 - An in-person, face-to-face conversation with a patient who has the capacity to participate OR an in-person conversation with the designated surrogate, if the patient is unable to participate (e.g., a patient on a ventilator or a patient with advanced dementia).
 - A conversation specific to a patient's health status and medical condition.



Role Play Exercise

- Introduce personcentered communication skills
- Practice using Ariadne
 SICG
- Experience from patient and surrogate perspective
- Give and receive feedback
- Acknowledgements:
 - Environmental
 - Personal
 - Time





Role Play Exercise



- Charlie: 78 year-old man.
- PMH: diabetes mellitus type 2 (controlled); HFpEF (NYHA II; hospitalized 9 months ago; ED twice since); severe dementia (limited ability to contribute to decision-making; responses are 'yes/no' with interjected, random, perseverating statements)
- Social: Lives in ranch house with wife (Nancy). Son (John) lives nearby. Has advance directive which is 2 years-old, declaring Nancy as HCPOA and minimalist care choices (DNR/DNI, no transfusion, no mechanical ventilation, no tube feeding)
- Functional: Ambulates with walker; mechanical fall 3 months ago with no major injuries. No driving for 2 years. Dependent for all IADLs.
 Independent for all ADLs but has had a few episodes of urinary incontinence.



Role Play Exercise



Groups of 3 participants, 3 conversations, 10 minutes each, followed by time to debrief.

	Conversation 1	Conversation 2	Conversation 3
Participant 1	Clinician	Nancy	Charlie
Participant 2	Charlie	Clinician	Nancy
Participant 3	Nancy	Charlie	Clinician



Role Play Exercise



- Conversation 1: Communicate about Charlie and Nancy's understanding of Charlie's condition, prognostic awareness, hopes and fears
- Conversation 2: Communicate about critical abilities, what would Charlie be willing to go through to possibly gain more time
- Conversation 3: Shared decision-making regarding CPR (confirming the accuracy of his prior advance directive which could possibly lead to completion of a POLST form)



Role Play Exercise



Debrief:

- Clinician: How did this feel? What went well and not so well? How could you incorporate this into your practice?
- Charlie: How did this feel? Did the clinician and Nancy keep you at the center?
- Nancy: How did this feel? Was the conversation about Charlie's preferences and decisions, or yours?



Wrap-up

- Evidence supports person-centered communication
- Decisional and communication challenges are solvable with evidence-based practice and system design
- Mindful integration of these skills improves patient and family satisfaction, provider and team wellbeing, and reduction in unnecessary costs
- Person-centered, shared-decision making goes beyond 'code status' to include all healthcare decisions
- Commit to a SMART plan of integrating these skills into your practice in the next week



Thank you!



