Literacy, Language & Culture & Preserving the Patient’s Story

Rebecca L. Sudore, MD
Associate Professor of Medicine
University of California, San Francisco
San Francisco VA Medical Center
We Need Better Documentation

- 70% documentation of EOL wishes are missing from medical chart or wrong!!

What Have We Learned?

• Literacy, language, and cultural needs to be addressed

• We need to confirm understanding of choices

• We need to document patients’ stories along with POLST and code status
Optimal POLST Flow

- Doctor initiates conversation
- Patient asks questions
- Patient identifies wishes
- Patient discusses wishes with surrogate
- Patient discusses wishes with doctor
- Patient has full understanding of choices
- Doctor documents code status, levels of care
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Patient tasks affected by:
- literacy
- language
- culture
Definition: What is Health Literacy?

• “The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”

IOM. Health literacy: a prescription to end confusion. 2004
Prevalence: Limited Literacy

- 22% (40-44 million) Level 1 < grade 4
  - can’t read signs, medication bottles, poison warnings, or city bus schedule

- Additional 25% (50 million) Level 2 = grade 4-8
  - Difficulties with executive functions such as simple forms

- Average reading level = 8th grade
  - Medicaid and the elderly = 5th grade

National Adult Literacy Survey: http://nces.ed.gov/naal/
Written Information

- Forms
  - 100% with inadequate literacy
  - 94% with marginal literacy
  - 17% with adequate literacy

Did not understand the rights and responsibilities section of the Medicaid application

Gazmararian JA, et. al., Health literacy among Medicare enrollees in a managed care organization. JAMA 1999
Written Information

• Forms
  - 100% with inadequate literacy
  - 94% with marginal literacy
  - 17% with adequate literacy

  Did not understand the rights and responsibilities section of the Medicaid application

• Advance Directive Forms and POLST
  - written beyond 12th grade level

Gazmararian JA, et. al., Health literacy among Medicare enrollees in a managed care organization. JAMA 1999
Issues Related to Language

• 55 million people in U.S. (~20%) speak language other than English at home

2007, US Census Bureau
Issues Related to Language

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• Lack of linguistically-appropriate materials

2007, US Census Bureau
Issues Related to Language

- Often experience poor communication
  - Do not achieve rapport, or receive empathy, information, or encouragement to participate in decision-making.

- Worse if literacy + language barriers

- Often lack of appropriate interpreters

- Pérez-Stable, EJ & Karliner, LS, What Do We Know About Patient–Clinician Interactions. J Gen Intern Med 2012
Issues Related to Culture

- Non-Western views on autonomy & decision making
  - ~25% do not want to make own medical decisions

- Family decision making model

- Mistrust and perceived racism
  - Minorities given less information by clinicians and less time for discussion → often do not want to fill out forms

- Crawley L, et al., Palliative and end-of-life care in the African American community. JAMA. 2000
- KwakJ, et al., Current research findings on EOL decision making among racially or ethnically diverse groups. Gerontologist. 2005
- Smith AK, et al. Palliative care for Latino patients and their families: whenever we prayed, she wept. JAMA. 2009
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Need to Confirm Understanding: Informed Consent

1. Consent form written at 6th grade reading level in English & Spanish

2. Read verbatim in English or Spanish

3. Knowledge assessment:
   – 7 basic questions about consent content

4. “Teach-to-goal”: repeated, targeted education until comprehension was achieved

Number of Passes Required to Complete Consent Process

- Number of Passes Required
  - N=205
  - 28% required 1 pass
  - 52% required 2 passes
  - 20% required 3 or more passes

Worse if LIMITED:
- Literacy
- English-proficiency
Lessons Learned

- Interactive teach to goal process may be necessary for informed decision making
- Literacy and language need to be addressed
Uncertainty @ Hypothetical Scenarios
Summary:

50% of diverse older adults who reported a treatment preference based on a hypothetical scenario were uncertain about their decision.

Uncertainty associated with:
- Limited literacy, lower education
- Latino, Asian/Pacific Islander, African Am.
- Poor health status

References:
- Sudore RL & Schillinger D, et. al., J Health Comm. 2010 in press
Lessons Learned

• Just because someone makes a choice does not mean they fully understand the meaning and ramifications

• Need to confirm understanding
Why Need to Confirm Understanding

<table>
<thead>
<tr>
<th>MEDICAL INTERVENTIONS:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Comfort Measures Only Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Antibiotics only to promote comfort. Transfer if comfort needs cannot be met in current location.</td>
</tr>
<tr>
<td>□ Limited Additional Interventions Includes care described above. Use medical treatment, antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.</td>
</tr>
<tr>
<td>□ Do Not Transfer to hospital for medical interventions. Transfer if comfort needs cannot be met in current location.</td>
</tr>
<tr>
<td>□ Full Treatment Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and defibrillation/cardioversion as indicated. Transfer to hospital if indicated. Includes intensive care.</td>
</tr>
</tbody>
</table>

Additional Orders: ___________________________
Why Need to Confirm Understanding

- What does this mean to you?

“This means that I only want to be on machines for a few days. My family knows this.”
Difficult for Clinicians to Interpret Checkboxes
85-year-old NH resident w/ dementia, broke hip.

Pinning, may provide pain relief and maintenance of mobility.

Dr. and daughter agree on comfort, not sure what plan will maximize comfort and quality of life.

Smith AK, Lo B, Sudore R. When previously expressed wishes conflict with best interests. JAMA Intern Med. 2013
Forms and checkboxes

• No form or checkbox will ever eliminate the uncertainty and the complexity of the human condition.

• Nor does any one checkbox tell the patient’s full story or ensure informed decision making.
Preserving the Patient’s Story

• How can we use documentation of patients’ stories for clinical care?
Example of a Patient’s Story

• 93 yr old frail Filipino man with end stage CHF. He is unresponsive, going into respiratory failure.

• POLST says “Attempt Resuscitation” & “Full Treatment”

• EMS called. Transferred to hospital and ICU. Bipap is failing. Family has arrived. Now what?
Mr. D had been DNR/DNI for years until learned his petition to bring children from Philippines would “die when he dies.”

He had 1 successful cardioversion for afib and has been on bipap. He is willing to try CPR & ventilation because of the petition, but only for a few days. He does not want to “live on machines.” If he cannot wake up, talk to or recognize his family, or get out of bed, life would not be worth living.

He wants his family to know it is OK to stop the machines if he is suffering.
Documenting the Patient’s Story

• Ensures we have captured the very information (patient’s voice) that would help to inform complex ongoing decisions about care.
  – Provides an anchor for ongoing discussions about goals, especially over multiple care transitions.

• The story describes the meaning behind patients’ choices & ensures choices are informed
  – Regardless of literacy, language or culture

Schenker Y, Smith AK, Sudore RL. Thinking Outside the Checkbox: Preserving the Patient’s Story in Code Status Documentation. Submitted to Annals
How do we document patients’ stories in addition to POLST?

• Need interventions that take into account diverse populations with differing literacy, language, and cultural needs.
Welcome to PREPARE!

**PREPARE** is a program that can help you:

- make medical decisions for yourself and others
- talk with your doctors
- get the medical care that is right for you

You can view this website with your friends and family.

Click the NEXT button to move on.
My Action Plan

Ask John Doe to be your decision maker.
You will do this by July 21.

Summary of All Steps

Step 1: Choose a Medical Decision maker
- You have chosen John Doe (your spouse/partner) to be your decision maker, but you have not asked John Doe yet.
- You want John Doe to make medical decisions for you only if you cannot make your own decisions.

Step 2: Decide What Matters Most in Life
- What is most important to you are: family and friends, living on your own and caring for yourself, not being a burden on your family.
- You feel that there may be some health situations that would make your life not worth living, such as never being able to wake up from a coma.
- You want to try treatments for a period of time, but stop if you are suffering.

Step 3: Choose Flexibility for Your Decision Maker
- You chose TOTAL flexibility in medical decision making for your decision maker.

Step 4: Tell Others About Your Wishes
- You have close family and friends who may have strong opinions about your medical care.
- You told your decision maker about your wishes. But you have not yet told your doctor and family and friends.
Goals of Care Information: This document reflects preferences your patient chose on the advance care planning website called PREPare (www.prepareforyourcare.org). This is not a legal document.

SURROGATE DECISION MAKER

Who is the surrogate:

John Doe (your spouse/partner)

When surrogate is to make decisions:

- [ ] I ONLY want someone to make medical decisions for me if I become too sick to make my own decisions.
- [x] I want someone else to make medical decisions for me now, EVEN when I can make my own decisions.
- [ ] I am not sure.

Flexibility or leeway for the surrogate: Meaning permission to change prior medical decisions.

- [ ] TOTAL FLEXIBILITY: It is OK for your decision maker to change any of your prior medical decisions if the doctors think it is best for you at that time.
- [ ] SOME FLEXIBILITY: It is OK for your decision maker to change some of your medical decisions. But, some decisions you NEVER want changed, even if the doctors recommend it.
- [ ] NO FLEXIBILITY: Your decision maker must follow all of your medical wishes exactly, no matter what. It is NOT OK to change your decisions, even if the doctors recommend it.
- [ ] I am not sure
GOALS FOR MEDICAL CARE

What is most important in this patient's life:

- Family or friends
- Religion
- Living on your own and caring for yourself
- Not being a burden on your family
- Hobbies
- Pets
- Something else

Future health situations (states worse than death):

When you think about your health and health situations you may experience in the future, how do you feel?

- Life is always worth living no matter what type of serious illness, disability, or pain I may be experiencing.
- There may be some health situations that would make my life not worth living.
- I am not sure

In the event of serious illness:

How do you balance quality of life with medical care? If you had serious illness, what would be important to you?

- I want medical treatments to try to live as long as possible. I would not want to stop treatment even if I were in pain, could not feed or care for myself, or needed machines to live.
- I want to try treatments for a period of time, but I don’t want to suffer. If after a period of time the treatments do not help or I am suffering, I want to stop.
- I am not sure
Teaching Communication Skills

• California Coalition for Compassionate Care & California HealthCare Foundation

  – Teach Respecting Choices Model with POLST
### CONVERSATION GUIDE

**Understanding**

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

**Information preferences**

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

*For example:* Some patients like to know about time, others like to know what to expect, others like to know both.

**Prognosis**

*Share prognosis, tailored to information preferences*

**Goals**

If your health situation worsens, what are your most important goals?

*For example:* Being at home, being mentally aware, being in control of decisions, not being a burden, achieving life goal, supporting my children.

**Fears / Worries**

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

**Function**

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

*For example:* Ability to eat, recognize or interact with others, be aware, or care for yourself.

**Trade-offs**

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

*For example:* Being on a machine temporarily versus permanently, being in the hospital or ICU, having a feeding tube.
Using the EMR: NYU & EPIC
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