The Serious Illness Care Program: Considering health literacy for a scalable intervention to improve serious illness care

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Objectives

• To describe a scalable intervention to improve interpersonal communication between clinicians and their seriously ill patients.

• To explore the relationship between health literacy, communication, and access to palliative care.

• To characterize a process of adaptation to address issues of health literacy in minority and underserved populations.
Definitions

Health Literacy
• Occurs when the expectations, preferences and skills of both patients and clinicians meet;
• Emergent not possessed;
• Sensitive to complexity, dynamic and situation dependent.

Palliative Care
• Focused on serious illness, not just end of life.
The Serious Illness Care Program addresses two fundamental gaps in serious illness care

1. The gap between what we want for care at the EOL and what we get.

1. The gap between what we know about how to provide high quality EOL care and what we do.
The Serious Illness Care Program is a systems-level intervention to address these gaps:

- Pt identification
- Clinician training
- Prepare patient
- Prompt a discussion
- Have conversation
- Document in EMR
- Family Guide

### Serious Illness Conversation Guide

<table>
<thead>
<tr>
<th>CLINICIAN STEPS</th>
<th>CONVERSATION GUIDE</th>
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<tbody>
<tr>
<td>Set up</td>
<td>Understanding</td>
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<td><em>Thinking in advance</em></td>
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<td><em>Is this okay?</em></td>
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<td><em>Comprehensive approach</em></td>
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<td><em>Benefit for patient/family</em></td>
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<td></td>
<td><em>No decisions today</em></td>
</tr>
<tr>
<td>Guide (right column)</td>
<td>Information preferences</td>
</tr>
</tbody>
</table>
| Summarize and confirm | *How much information about what is likely to be ahead with your illness would you like from me?*
| Act             | *For example: Some patients like to know about things, others like to know what to expect, others like to know both.* |
|                 | Inform patient. |
|                 | Make recommendations to patient. |
|                 | Document conversation. |
|                 | Provide patient with family communication guide. |
|                 | Share prognosis, tailored to information preferences. |
|                 | Goals. |
|                 | If your health situation worsens, what are your most important goals? |
|                 | Fears/Worries. |
|                 | What are your biggest fears and worries about the future with your health? |
|                 | Perception. |
|                 | What abilities are so critical to your life that you can’t imagine living without them? |
|                 | Trade-offs. |
|                 | If you become sicker, how much are you willing to go through for the possibility of gaining more time? |
|                 | Family. |
|                 | How much does your family know about your priorities and wishes? (Include bringing family and/or health care team to next visit to discuss together.) |
The conversation guide addresses illness understanding, prognosis, values and priorities

- What is your understanding of where you are now with your illness?
- How much information about what is likely to be ahead would you like from me?

**Share Prognosis**
- If your health situation worsens, what are your most important goals?
- What are your biggest fears and worries about the future with your health?
- What abilities are so critical to your life that you can’t imagine living without them?
- If you become sicker, how much would you be willing to go through for the possibility of gaining more time?
- How much does your family know about your priorities and wishes?
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• To characterize a process of adaptation to address issues of health literacy in minority and underserved populations.
The POLST Paradigm
POLST: the cart before the horse?
What is health literacy?

Provider

Patient

Culture

Expectations

Preferences

Skills

What is said?

How it’s said?

What illness?

What is heard?

What Relationship?
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African-Americans have poor EOL outcomes, including less goal-concordant care.

Advance Care Planning

End-of-Life Outcomes

MISTRUST
RELIGION
FAMILY DECISION-MAKING
HEALTH LITERACY

STRUCTURAL BARRIERS
Health Literacy
RACISM
How will an intervention developed in one place work in a very different place?
Adapting a conversation guide involves incorporating the perspective of stakeholders.

Focus Groups
- Experts
- Church members
- Seriously Ill patients

Pilot
- Intervention

### Serious Illness Conversation Guide

- \[ \text{Currently in use} \]
- \[ \text{Hospitals} \]
- \[ \text{Nurses} \]
- \[ \text{Nurse Practitioners} \]
- \[ \text{Physicians} \]
- \[ \text{Physician Assistants} \]
- \[ \text{Pharmacist} \]
- \[ \text{Family/Primary Care} \]

- \[ \text{Communication skills} \]
- \[ \text{Understanding} \]
- \[ \text{Information} \]
- \[ \text{Perspectives} \]

- \[ \text{Program} \]
- \[ \text{Goals} \]
- \[ \text{Barriers} \]
- \[ \text{Functions} \]
- \[ \text{Needs} \]
- \[ \text{Family} \]

- \[ \text{Suggested language} \]
- \[ \text{Value} \]
- \[ \text{Prioritization} \]
- \[ \text{Quality Improvement} \]
What lessons have we learned so far?

• By and large, the space in which goals of care are discussed with African-Americans with serious illness is in the hospital, in a crisis.

• These interactions are emotionally traumatic for families and add to a collective historical trauma felt acutely by members of the African-American community, heightening senses of stigma and mistrust.

• The relationship between the patient and family and members of the clinical team, the physician chief among them, is paramount to the sense of safety for patients and families in approaching the end of life.

• The questions in the serious illness conversation guide are easily understood, acceptable to African-American participants in our focus groups, and enhanced our participants sense of feeling cared for.

• The addition of a question - What gives you strength and comfort as you think about the future with your illness? – effectively elicits and allows for religious faith to enter a conversation in a way that enhances this sense of caring.
What have our participants said?

I think it will be good, because some doctors don’t know how to really talk to us. ...this is a conversation that I’m going to need to have and then I’m going to have to tell my husband what it is I want, because there are some things I just don’t want. I don’t want long suffering. I don’t want to be on any machines. I don’t want to be without my limbs. I don’t want to be without my kidneys, there are things I don’t want. And so when you ask that question how far are you willing to go. Okay, if you become sicker, how much are you going to go through. I don’t want to live my life with somebody else having to take care of me.

I would like to see this [conversation] come from my primary care doctor. If they knew how to use language that encourage you to participate more in your health, instead of scare you, or run you out the door with their bedside manners - which they don’t use. You would have more people [seeking care], regardless of whether they had health insurance, it wouldn’t matter, it really wouldn’t, as long as you had a doctor who...cares. That means the world.”
Concluding thoughts

• It is more useful to think of health literacy as an emergent phenomena, rather than something that is or is not possessed by one individual.

• In order for health literacy to emerge in a way that supports advance care planning and palliative care, we must focus not on advance directives – even those that are “easy to read” – but on scalable, translatable communication practices that help patients and clinicians enter an inevitable space together, arm-in-arm, without fear of ineptitude (clinicians) or abandonment (patients).

• Conversations that focus on procedures will never be effective on their own with certain populations because they are hard to understand and they prioritize the clinicians goals, not the patients.

• An conversation intervention focused on eliciting goals, priorities and strengths is understandable, acceptable and needed for communities for whom these conversations are poor quality, infrequent and late.
Objectives

• Heard about a scalable intervention to improve interpersonal communication between clinicians and their seriously ill patients.

• Explored the relationship between health literacy, communication, and access to palliative care.

• Characterized a process of adaptation to address issues of health literacy in minority and underserved populations.