Eliciting Patient Goals, Values and Preferences for Serious Illness Care

COMMUNICATION REFERENCE GUIDE

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Introduction

The Institute of Medicine (IOM) defines **patient-centered care** as: "Providing **care** that is respectful of, and responsive to, individual **patient** preferences, needs and values, and ensuring that **patient** values guide all clinical decisions."

Understanding and Promoting Patient-Centered Care

This reference guide was created for nurses, social workers and other clinicians working with patients with Serious Illness.

The guide was prepared using content from, and with permission from, the Veteran's Program for Life Sustaining Treatment Initiative, the Veteran's Administration of Eastern Colorado Health Care System Structured Communication Guide and the Ariadne Labs Serious Illness Conversation guide. The questions in this guide have been field tested with patients and families to ensure the language is as clear as possible.

We are grateful to those who led the way by demonstrating the courage to engage in critical conversations foundational to patient centered care. Let us begin our journey.

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TRIGGERS FOR SERIOUS ILLNESS CONVERSATIONS

Disease-based/Condition-based criteria

Hospital admission in the last 6 months AND any one of the following conditions:

- Chronic obstructive pulmonary disease or interstitial lung disease, only if using home oxygen or hospitalized for the condition
- End stage renal failure
- Congestive heart failure, only if hospitalized for the condition
- Advanced liver disease or cirrhosis
- Progressive metastatic cancer
- Advancing dementia
- Complex medical conditions resulting in frequent unplanned hospital or ED admissions

Additional criteria

- Two or more unplanned hospital admissions within past 6 months
- Resides in long term care facility
- Significant and rapid decline in ability to complete activities of daily living

Surprise question

- Would you be surprised if this patient died in the next 1-2 years?

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STEP 1: INTRODUCE CONVERSATION

Sample Scripting: Mr./Mrs. XXX. Thank you for taking the time to speak with me today. On our next call/meeting I would like to discuss how we can provide care that lines up with what's most important to you. It would be beneficial to understand what your goals and preferences are for health care if you were to become sicker or at the end of your life and to help make a plan to make those things happen.

Alternative Scripting: Mr./Mrs. XXXX. Thank you for taking the time to speak with me today. On our next call, I would like to discuss how I could make sure you have the best care possible. To do this it would be good to talk about what is happening with your health and what things are important to you. Is that okay?

<u>If any resistance</u>*: *We know these conversations are hard, and you might not know all of the answers today but we at least want to start the conversation. Ideally, by the end of the time we work together we will have talked about and made a plan to help you make those things happen.

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STEP 2: ASSESS UNDERSTANDING OF HEALTH

What have you been told to expect in the future with your (insert their words for their illness)?

Alternative phrasing:
To make sure we are on the same page, can you tell me your understanding of what is happening with your health at the moment?

What changes have you noticed over the past 3 months?

What have your providers said you might expect in the future with your medical condition?"

Probes

- *"What do you think the future holds?"*
- *If applicable, "I am not raising this issue because we are worried you are getting sicker right now, it can be helpful to think about the future."*

IF INADEQUATE UNDERSTANDING OF MEDICAL CONDITION: "It may be helpful to talk with your provider more about your medical condition."

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STEP 3: ELICIT VALUES AND GOALS OF CARE

If you were to get sicker, what would be most important to you?

Alternative phrasing
What matters most to you as you think about the future?
Is there anything that would be helpful for me to know about your religious or spiritual beliefs?

What do you hope for with your medical care?

Concerns and Worries

As you think about the future with your health, what are you most worried about?

Listen for:

- *Being a burden*
- *Being in pain or uncomfortable*
- *Prolongation of dying*
- *Not being in control or not being mentally aware*
- *Leaving loved one's behind*

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STEP 3. ELICIT VALUES AND GOALS OF CARE (cont.)

All of us at some point will reach the end of our lives and different people want different things at that time. Some people are at one end of the scale where they want to focus on comfort and quality of life, and others are willing to have their lives be shortened to be more comfortable.

Other people are on the other end of the scale where they want to live longer no matter what treatments or procedures they would need?

When you think about the scale, where are you?

<u>Alternative phrasing</u>

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

Now we are going to move onto the second part. I know you said (insert patient's answers) is important to you. We would like to make a plan so we can help make sure your wishes are followed.

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STEP 4: MAKE A PLAN

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

- *If family knows a lot, affirm benefits of good communication and ensure HCPOA set up*
- *If family doesn't know a lot, troubleshoot barriers and perhaps role model discussion with family members. Educate about HCPOA.*

How much does your doctor know about your priorities and wishes?

- *If doctor knows a lot, affirm benefits of good communication and ensure HCPOA set up*
- *If doctor doesn't know a lot, ask how much they would like their doctor to know. Educate about the importance of doctor being aware of wishes.*

What documents do you have in place about your priorities and wishes?

- *If they have document in place, ask if they are in their medical chart?*

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STEP 5: SUMMARIZE

We want to make sure we heard you correctly so I'm going to summarize our plan.

- *What is most important to you?*
- *Who do you need to talk to about what is important to you?*
- *What forms do you need to complete?*

STEP 6: CLOSE

What are your thoughts about how this conversation went?

Probes:

- *How did this conversation make you feel?*
- *What were some of your thoughts about what we talked about today?*
- *Did our conversation bring up things for you to think about that were hard to talk about?*

We covered some important topics today and you might start thinking about things later. If you do and would like to talk more, please feel free to contact us/me.

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Key Skills & Sample Statements

Affirmation- Acknowledging patient's strengths and abilities

- *You are such a (strong, committed) person*
- *You (or your dad, mom, child, spouse) is such a strong person and have been through so much.*
- *This is very difficult to think about and yet you are still willing to talk to me about it.*

Simple Reflection- restate or rephrase what patient says.

- *This is really important to you.*
- *You just aren't ready to discuss this yet*
- *Dealing with this illness has been such a big part of your life and taken so much energy.*

Complex Reflection- interpretation such as naming feelings

- *One of the hardest things for you is all the uncertainty. On one hand,….and on the other, xxxx*
- *This sounds frustrating (scary, overwhelming, difficult, challenging, hard).*
- *Other people in your situation have told me this feels very (name emotion)*
- *You can't imagine discussing this with your son, but at the same time you're worried about this could affect him later.*

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Strategies for Common Scenario's

Patient says: "I don't want to talk about it"

- *Help me understand the reasons you would prefer not to talk about this?*
- *I'd like to understand what kind of thinking and planning you would find helpful as we think about what is ahead with your illness.*
- *I hear you saying you know it is important to do some planning and also that you worry this process will be too overwhelming.*

Patient says: "My daughter (family member) takes care of all of this for me."

Ask if patient has a POAHC for family member to make decisions.

- *"These are difficult discussions and should involve your family. Would you like to schedule time to talk together?"*

Patient says they are not ready to make any decisions

- *Reassure patient there is time to think things through. I brought up these issues early so you would have time to think about what's important you.*

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Key Skills & Sample Statements

Exploring- Encourage patient exploration

- *What do you mean when you say I don't want to give up (be a vegetable/a burden/on life support)?*
- *What else?*
- *Tell me more….*
- *Tell me more about what (a miracle, fighting, not giving up, etc.) might look like for you.*

I wish- aligning with the patient's experience

- *I, too, hope that …. happens.*
- *I wish things weren't so stressful for your family.*
- *I wish the situation were different*
- *I hope for a miracle, too*

"Silence isn't empty; it is full of answers." ***Anonymous Proverb***

For more information about Serious Illness Communication Education, contact Mary Beth Billie, DNP, RN-BC, CCM at mbillie@gmail.com