You want us to do everything?!

RETHINKING COMMUNICATION AROUND GOALS OF CARE

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1. Gauge patient/family understanding of disease condition or prognosis.
2. Articulate clearly when things have changed.
3. Acknowledge emotional reaction before moving conversation forward.
4. Elicit (and accept) patient/family values.
5. Recommend a treatment plan to match those values.
GOALS of CARE

Prognosis → Goals of Care → Medical Decisions
<table>
<thead>
<tr>
<th>S</th>
<th>Setting</th>
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<tbody>
<tr>
<td>P</td>
<td>Perception</td>
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<tr>
<td>I</td>
<td>Invitation</td>
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<td>K</td>
<td>Knowledge</td>
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<tr>
<td>E</td>
<td>Empathy/Emotion</td>
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<tr>
<td>S</td>
<td>Summary/Strategy</td>
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“What have the doctors told you so far about your cancer?”

“What is your understanding of how the treatments are working?”

“Have they told you what to expect next with your condition?”
<table>
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<tr>
<th>R</th>
<th>Reframe</th>
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<tr>
<td>E</td>
<td>Expect emotion</td>
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<tr>
<td>M</td>
<td>Map out what’s important</td>
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<td>A</td>
<td>Align with patient/family values</td>
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<td>P</td>
<td>Plan treatment to match values</td>
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 Serious news must be processed BEFORE medical decision-making.

 We must be clear when the situation has changed.
Prospective cohort of 468 terminally ill patients & 343 doctors:

- 63% of estimates were overly optimistic
- Tend to overestimate by up to five times
- Tend to overestimate more with stronger doctor-patient relationship

Christakis NA & Lamont EB. BMJ. 2000; 320:469-72.
“Given where you are in your illness, it seems like a good time to talk about where to go from here.”

“We’re in a different place than we were...months ago.”

“I wish the treatments were working.”
<table>
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<th>Clinician</th>
<th>Patient</th>
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**Clinician**

“Tell me what you understand about your illness...”

“I wish we had a more effective treatment...”

**Patient**

“I’m not getting better with this treatment, but there’s got to be something else out there.”
“I know I’ve got COPD, and my breathing has gotten worse over the last several weeks. But I’ve had this for quite a while, and it will probably get better...”

“What is your sense of where things are?

“You have been living with this disease a long time. I think we’re in a different place now.”
Most patients will have an emotional response to the reframe.

Emotion may sound like a question:

“Is there something else you can do?”

“Are you sure we’ve looked into everything?”
RESPONDING to EMOTION
"The ability to understand and share the feelings of another."

~Oxford English Dictionary
“...an ability to understand patient’s inner experiences and perspective and a capability to communicate this understanding.”

<table>
<thead>
<tr>
<th>N</th>
<th>Name</th>
<th>“I can see that you are frustrated...”</th>
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<tbody>
<tr>
<td>U</td>
<td>Understand</td>
<td>“I can’t imagine how disappointing this must be...”</td>
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<tr>
<td>R</td>
<td>Respect</td>
<td>“I see how well you have been caring for her...”</td>
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<td>S</td>
<td>Support</td>
<td>“I want you to know that I am here for you...”</td>
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<tr>
<td>E</td>
<td>Explore</td>
<td>“Tell me more about what you’re thinking...”</td>
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“I’ve just been going to all these doctors appointments and getting all these tests, and I don’t know...”

“It sounds like you’re feeling overwhelmed.”
Patient

“No one’s really telling me what’s going on. Is this treatment working or not?”

Clinician

“I can’t even imagine what it’s like for you to be going through this.”
Emotion is NOT failure.
You must know patient/family goals & values BEFORE creating a plan.

The only way to know is by asking.

If asked correctly, the question makes sense and isn’t scary.
“Given the situation, what’s most important to you?”

“Knowing that time may be limited, are there things you want to do?”

“As you think about the future, what are you worried about?”
MAP OUT WHAT’S IMPORTANT (demo)
“Given this situation, what’s most important?”

“I admire your fight, and I can see how important it is for you to know that you’re not giving up.”

“MAP OUT WHAT’S IMPORTANT (practice)”

**Clinician**

- Given this situation, what’s most important?

- I admire your fight, and I can see how important it is for you to know that you’re not giving up.

**Patient**

- It’s important to me that I don’t give up – I don’t want to look back and regret that I didn’t give it everything I had.”
“Given this situation, what’s most important?”

“What if you start with what you’re enjoying in your life right now?”

“I’m not sure what to tell you...”
- Repeating what patient has just told you is most important.
- Makes sure you’ve got it right, and the patient feels understood.
<table>
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<th>Patient</th>
<th>Clinician</th>
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<tr>
<td>“This has all been so hard and I’m tired. I’m really worried that the pain might get worse. And I haven’t been able to really be with my wife and my kids. I’d like to get back to that – take a vacation together, if possible.”</td>
<td>“As I listen, it sounds like what’s most important to you is that you stay out of pain and spend more time with your family, including possibly going on a vacation.”</td>
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“I’m really sick of coming into the hospital all the time, and I know this isn’t going to get any better, but I get really scared when I can’t breathe well.”

“I’m sure that’s scary. So, what I hear you saying is that you’re tired of coming to the hospital, but you need a way to deal with your shortness of breath at home.”
“I’m scared. I want to live and I’m worried that the heart medicines aren’t working. But, I don’t want to prolong anything if it just means being stuck on machines. And, I don’t want my kids to have to deal with any of these decisions.”
It may not be possible to immediately formulate a plan

In these situations, map out goals and make an “align” statement

Inform team of the patient’s goal

Return later with recommendation
Ask permission.

Make a recommendation that helps to meet patient’s goals:

1. Focus on what CAN be achieved
2. Consider what MIGHT be possible
3. State what you will NOT do because it will not meet their goal

Ask whether it feels right to them.
“Would it be alright if I offered a recommendation?”

“Given what you’ve told me is most important, there’s a lot we can do to help. We’ll focus on keeping you out of pain. We can also get some services into your home to help you stay there and spend more quality time with your family. We’ll work toward that vacation, and have a better idea of how possible that is after we see how you feel on the new medication.”

“In addition to all the things I’ve mentioned we will do, I also recommend that we don’t consider further scans or blood draws, because at this point it won’t help you reach your goals.”

“What do you think?”
“Would it be alright if I offered a recommendation?”

“Given what you’ve told me is most important, it sounds like you would want to pursue any treatment that would give you a chance of living longer, even if that means your life might be supported by machines for awhile.”

“Does that sound right?”

“If you didn’t get better, and there was no chance you could come off the machines, would you want to live indefinitely on life support?”
Goals of Care Conversations training materials were developed and made available for public use through a U. S. Department of Veterans Affairs contract with VITALtalk.

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Materials are available for download from the VA National Center for Ethics in Health Care at vaww.ethics.va.gov/goalsofcaretraining.asp.