

**Q&A: Shared Decision-Making:**

***The Role of the Health Care Team in Empowering Health Care Consumers***

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***Would the CARES framework be beneficial in discharge planning?***

Components of the CARES model can stand independently. The 2 steps most important to discharge planning (assuming there is not a major decision to be made as part of the plan) include:

C: Understand Your Condition: this ensures the patient knows why the discharge plan is important and why it is important to follow through.

S: Start Taking Action: this ensures the patient is aware of and prepared to follow instructions regarding medications, follow-up appointments, self-care activities, etc.

***What is your recommended approach for those patients whose behavioral health and/or substance use disorder diagnoses are adversely affecting their ability to make good choices?***

If a patient has a behavioral health or substance abuse issue, I would not tip toe around those diagnoses but, rather, lay out the facts and data without being judgmental. Use visuals to make sure you are communicating effectively and the patient understands how their life will be impacted by their decisions. For example, if a gastroenterologist is treating patients with alcoholic cirrhosis who continue to drink, explaining the statistics around liver failure, bleeding risks, and showing them pictures of individuals who are jaundiced and have ascites is likely to resonate more than telling them that their liver function tests and prothrombin time are elevated.

***What are options when a patient pursues alternative pseudomedical treatment that is not supported by evidence?***

A few steps:

- First, do not roll your eyes.
- Make sure you know the facts. Is it really “pseudo” or do you have your own bias or lack of information about treatments?
- If the patient is going down a path of using non–evidence-based approaches, encourage the patient to educate you. Ask them to give you the evidence that supports using that treatment (which may not exist) and help them understand the validity (or lack of validity) of the approach.
- The National Center for Complementary and Integrative Health (NCCIH) has a great website on alternative medicine and makes that information available to clinicians and to the public. The “A to Z” health information on the NCCIH ([nccih.nih.gov](http://nccih.nih.gov)) site gives a balanced overview of a wide range of herbs used as alternative therapies.

***Are you familiar with the work of Dr. Atul Gawande and Ariadne Labs around the "serious illness conversation" and the framework to teach providers to have conversations? If so, can you comment on its usefulness in supporting shared decision-making (SDM)?***

The "Serious Illness Conversation Guide" is a wonderful resource for providers. But, it is only half of the solution since doctors can only help anticipate clinical issues and explain medical treatment options. Patients should also have tools to guide their conversations with family, friends, and caregivers about their end-of-life care. Yes, this is hard to initiate, but psychologists have found that sharing a meal makes it easier to talk about stressful or uncomfortable topics. My favorite resources that can help individuals organize these personal (not medical) conversations include:

- Death Over Dinner ([deathoverdinner.org](http://deathoverdinner.org)) and
- The Conversation Project ([theconversationproject.org](http://theconversationproject.org)).

***Do you know of any studies that show whether people neglect their health due to a financial burden?***

A 2015 study published in the *Journal of General Internal Medicine* analyzed the reasons why people avoid medical care. Thirty-eight percent (38%) had financial barriers to medical care including high cost (24%), no health insurance (11%), and high copays (3%). [Taber JM, Leyva B, Persoskie A. *J Gen Intern Med.* 2015;30:290–297].

***Is there a way you suggest offering the "so what" in a way that is meaningful for the patient?***

Besides using plain English, I employ a few techniques:

- Get their attention by saying: "Let me tell you how your condition will affect your life in the short term and long term."
- Use visuals. Draw them a picture or a graph. Do not worry...you do not have to be an artist.
- Use a metaphor. For example, to explain high blood pressure, I have people squeeze a tennis ball 10 times. (FYI: this is not easy.) Then, explain that they are making their heart do this 70 times a minute...60 minutes an hour...24 hours a day. "Every heart beat is a mini-workout and your heart will eventually get tired."

***Please comment about results of the use of "participatory methodologies" that enable people to have more power in front of the powerful care providers and have more equitable health negotiation.***

I will assume that "participatory methodologies" refers to condition-specific decision-aids designed to guide the discussion between patients and providers. These are extremely valuable and help ensure that the conversation is structured, personal preferences are elicited and that patients feel empowered to make decisions. The challenge is that there will never be a decision-aid to address each and every medical decision faced by an individual. The CARES model is a generic framework that can be used independently or in partnership with a provider.

***Can these same concepts be used by non-RN/non-clinician care managers in supporting consumers to take a role in SDM?***

The CARES model and other decision-making frameworks can and should be used by the entire ecosystem of individuals involved in supporting consumers, from care managers to clergy. The model is also one that the individuals can use as a roadmap for themselves.

***How can the patient/caregiver widen the discussion when providers are reluctant to mention anything not aligned with the managed care system employing them? When assisting someone through options for their health care, sometimes the restrictions of prior authorizations and coverage available through their insurance policy can be cumbersome. Should we still be providing all options?***

“Should we still be providing all the options?” An emphatic YES! A patient should have knowledge about all their evidence-based clinical options, not just those that are covered or financed by the managed care organization. A “con” of non-covered alternatives is the out of pocket cost associated with that approach and when “respecting their preferences,” the patient can decide how financial issues factor into their decision. A patient/caregiver can easily widen the discussion by saying, “I would like to know ALL the alternative treatments regardless of whether or not they are covered by insurance, because cost may not be a factor.”

***In regard to breast cancer and lumpectomy vs mastectomy — in the event the provider has recommended a "wait and see" approach and/or a lumpectomy, but the patient/member would prefer a mastectomy — how do we provide the tools to the patient to empower them to have the discussion with their provider? How can we help locate a provider who will listen to the patient, especially with a 71% MD preference for lumpectomy?***

Arm the patient with data and studies regarding lumpectomy/radiation and mastectomy outcomes. I like printing off materials from UpToDate.com, especially since this resource is such a respected one among physicians. Role play with the patient BEFORE their visit to increase their confidence when having the conversation.

***If the patient wants our personal opinion, how do you avoid giving your personal opinion?***

If you have laid out all the objective data and evidence-based pros and cons, and they still want your opinion, then make sure you are transparent about all the factors (professional and personal) guiding you to choose one option over another. Staying with the breast cancer example, are you selecting a lumpectomy/radiation because your sexuality is important to you? Or are you choosing a mastectomy because you need the visual reassurance that the cancer is gone? If you would choose to have a non-covered contralateral prophylactic mastectomy...is it because you can afford it and it would give you peace of mind? Only share your opinion if you are willing to share (and make yourself vulnerable to) the preferences and priorities that influence your choices.

***How can we help the elderly population, who may not be computer savvy, find resources to understand their conditions? Many are reliant on their providers to make the decisions for them.***

First, do not assume that older patients are not computer savvy. But, if there is an individual who does not use a computer, here are some ideas:

- Ask a family member, friend or caregiver to spend some time with them in front of a computer to help them understand their condition and know their alternatives.
- Print off easy-to-read information and mail it to them.
- Many seniors socialize at a local Senior Center. These locations are frequently staffed with personnel who can help them navigate to a website.
- The local library has computers and resources they can use.

***How are health literacy and cultural differences affected by SDM?***

Health literacy and education level must be considered when communicating with an individual about a condition and alternatives. For example, while a sophisticated, health literate individual may benefit from the detail included in MedicineNet.com (another great resource), MayoClinic.org may be easier to understand. Tailor your recommendations to match the needs of the individual patient OR recommend a few different options that span the range of literacy/education levels.

Cultural and religious differences affect individuals' preferences, priorities and the tradeoffs they are willing to make. While these must be respected and acknowledged, try to make sure that an individual understands the science/evidence before applying personal beliefs to the decision-making.

***How does this research pertain to behavioral health (BH)? I would say BH is further along on this curve, but am interested in how you see the relationship with the material you are covering here.***

In the mental health interventions and services literature, consumers are increasingly acknowledged as partners in SDM with their health care providers. However, research outcomes of SDM in mental health are still somewhat limited. SAMHSA (a division of Health and Human Services) offers some excellent resources for implementing SDM approaches in behavioral health. Here is a link:

<http://www.integration.samhsa.gov/clinical-practice/shared-decision-making>.

***How do we influence a terminally ill patient who has given up on himself?***

I am not sure what you mean by "influence," but a clinician's responsibility is to help ensure that a terminally ill patient accurately understands the status of his/her condition and available options while supporting the patient in designing a plan that offers the desired quality of life.

***How do you handle a patient who is "too" empowered? Such as a patient who does not want to listen to your medical advice because he/she feels they know exactly what they need.***

A well-informed patient who does not listen to your medical advice is not "too" empowered. He or she may simply have preferences that are not aligned with your recommendation. That is okay as long as the patient knows the consequences. However, there are times when perceptions and bias can hijack the facts the patient is using to make a decision. Some common (mis)perceptions during health care decisions are:

- "My personal risk is lower than average." Individuals' perception of their personal risk influences their decisions and subsequently their behavior.
- "I've heard of that." Familiarity trumps facts.
- "That treatment worked for my friend, my neighbor, etc." People tend to choose treatments that have worked in the past (for others or for themselves) even if the details of their personal medical situation are different.

Biases are not usually intended to be defiant, but, rather, a quick exit ramp from the discomfort of decision-making. Here is my suggestion: keep these common heuristics in mind and lay out the facts regarding risk factors and the reasons why the patient's condition is uniquely different than the neighbor's, etc.

***As a consumer, how can we address providers when we feel are not being heard about our desires?***

Take a 3-pronged approach:

- 1) Establish an equal playing field with the provider. Readers have shared that one of the most effective recommendations from the book is to address the doctor by their first name. I know it feels uncomfortable, but titles create barriers to communication.
- 2) Be prepared. Prior to your visit, think through the three issues that you want to discuss and write them down. In fact, I recommend that patients type them out and make two copies...one for themselves and one for the provider.
- 3) Verbalize the need/expectation to be heard. Providers cannot read the patient's mind and are probably too busy to be accurately reading their body language. So speak up: "I have three questions I'd like to discuss." And rather than saying, "I have 'a few' questions," be specific about the number of questions on your list so that the provider is not continuously wondering if there is one more question.

If you have questions regarding this document or the content herein, please contact:  
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