

Q&A: Communications with the Seriously Ill: A Guide for the Health Care Team

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- 1) Are there some instances where you find it is best not to inform patients of their prognosis, and, if so, how do you make that decision?
 - The question immediately prior to the prognostic disclosure, "How much information do you want from me about what is likely to be ahead with your illness?" is meant to help you titrate how much information to provide to the patient. If the patient says they want to know everything they can, I usually ask a follow-up question or provide a warning prior to giving a prognosis. Some patients like to know how long they might live, while others like to know what to expect. I may ask, "What kind of person are you?" That gives the patient an opening to direct you on how much information to give, and in what form (a time-based prognosis or more a functional prognosis).
- 2) How do you address cultures that prefer not to tell the patient about the news of a terminal illness?
 - I try to talk to the patient alone and say, "I have information about what is likely to be ahead for you. Is it best that I discuss this information with you or your family?" Then, "How do you like to make decisions regarding your health?" Some will defer everything to their family, and, in that case, I believe it is our job to respect that wish.
- 3) Is there a role for medications to reduce anxiety or depression in palliative care or to assist a patient's ability to participate in palliative care?
 - Yes, medications are part of treatment of anxiety and depression in palliative care, but not all patients that have limited prognoses need medication. Talking to your patients about their fears and worries may be just as effective for some patients, especially if it is mild to moderate anxiety or depression.
- 4) How do you determine which care team member has the conversation with the patient?
 - I think this varies by practice site and individual; however, someone in each team should be accountable for ensuring the conversations occur. Each practice site should set up norms and expectations for conducting these conversations and have a way to monitor and evaluate if they are occurring.
- 5) In your experience, is there ever a time that is "too early" to have these discussions?
 - In our Dana-Farber Cancer Institute (DFCI) trial, we required that each patient have at least 4 visits with his/her clinician prior to beginning this discussion. I think it is best conducted after a relationship is established between the patient and clinician.
- 6) How do you handle patients who change their minds about their expectations or decisions about decreased abilities after the initial conversations?
 - That is very common. Patients adjust to their situations and may find their quality of life acceptable. If that is the case, then I believe it is best to advocate for them and what they want.
- 7) What do you do in instances where you are dealing with health care professionals who do not believe in hospice when the patient needs it?

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- This is a tough one, but I think exploring why the colleague does not believe in hospice is a start (especially if you are going to be working with them a lot). This is a process that may take some time to sort out. When I have asked further probing questions about some colleagues' beliefs, I have found that they had legitimate poor experiences with a particular hospice agency or are so attached to their patient that they are not ready to accept that the patient is dying. For these colleagues, establishing an attitude of compassion and curiosity is the best way to start the process. If that does not work, try to find another health care professional who shares your view and team up to determine next best steps. Never worry alone!
- 8) How do you approach the conversation when the patient is ready but the family is not? In these instances, patients may avoid the topic because they feel guilty.
- In this case, I might try to talk to the patient alone, ask the patient what he or she wants and then ask how best to address the issue with the family. Most family members will respect your request to speak with a patient alone.
- 9) Has this program been implemented with pediatric patients or with any other serious illnesses?
- Daniela Lamas, a member of our team, piloted the guide in patients with chronic critical illness. Ernest Mandel piloted it with nephrology patients. Please see the Community of Practice (COP) website for webcasts and articles about these efforts. We have not done any work with pediatric patients, but there are health care professionals who have posted on the COP website who are interested in looking at this population.
 - To join the COP:
 - Go to: <https://portal.ariadnelabs.org>
 - Click "Create an Account" on the right side of the page
 - Complete the account information page. You will receive an email to authenticate your account
 - Return to <https://portal.ariadnelabs.org> and click on Serious Illness Community of Practice on the bottom left of the page
 - Click "Request Membership." Complete the additional profile information
 - You will receive an email once the Administrator has accepted your request
- 10) For those of us who are telecommuters, is it appropriate to address this over the phone? Would it be appropriate to refer a patient to a primary care provider (PCP) or treating physician and possibly contact that office for them?
- If you have an established relationship with the patient, sometimes it may be appropriate to discuss over the phone. It is definitely appropriate to refer a patient to his/her PCP, but I would give the PCP a heads up about what you are hoping will occur at that visit.
- 11) Are more PCPs buying into palliative care/hospice?
- In my setting, I have found that PCPs are pretty open to hospice/palliative care (more so than some specialists). Here is a link to an article we wrote about communication in serious illness in primary care: <http://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2532792>
- 12) How do you openly dialogue with patients who are in denial about their prognosis when they are in a transitional stage or starting to have symptoms to help them accept palliative treatment?
- I think this article, <https://www.ncbi.nlm.nih.gov/pubmed/23786425>, is helpful for how to think about these patients. Acceptance of prognosis is a process and will vary over time. Patients who have persistent denial are appropriate for palliative care referral.