



PALLIATIVE CARE CASE OF THE MONTH

Talking about Prognosis Robert Arnold, MD

Volume 14, No. 32

January 2014

Case: Doctors find it hard to talk about prognosis for a variety of reasons. Sometimes we do not like to talk about it because we are afraid that if we talk about it, it will happen—a self-fulfilling prophecy. I think this is often a reason that some doctors do not like to make patients DNR—they worry that if we make the patient DNR that we will not try as hard to correct problems and thus they be more likely to have a cardiac arrest (the data is controversial and this may be true). Other times, we do not like to talk about it because it means predicting the future, and when you predict the future you are often wrong (what I call “the weatherman phenomenon”). Patients or families may get mad when our predictions are incorrect which may lead to difficult conversations in which we feel bad. Doctors, not wanting to be wrong or feel inadequate, find it easier to be vague (“He is very sick and may not do well”) is similar to the weatherman saying, “It is going to get brighter as the day goes along before darkness sets in”).

Discussion: The problem is that prognostic information, like the weatherman's predictions, is vital to people's lives. It is hard to make decisions about medical interventions, about when families should come to visit their sick loved one, about when to have serious conversations without some idea of what the future might bring. For that reason, patients and families are often frustrated when doctors refuse to make any predictions about what might happen in the future. Families understand that the future is unpredictable, and the doctors are not all knowing and cannot know the future. Yet, they still want to have some ideas about what we are thinking because like weathermen, while we are not always right or wrong, we do have some expertise in prognostication.

For that reason, I have assembled four general hints to improve your ability to help the family think about prognostic information. (These recommendations assume that the patient/family wants to know prognostic data—about 75% do according to studies.) The purpose of these rules of thumb is to help the family begin to think about what their loved one would say about these possible futures.

Now for the four things that you might want to do:

- 1) Place your information in context. It is ok to admit our limitations in prognostication (“I do not have a crystal ball”). Doing this places your prognostication in context and is honest. However, it needs to be followed by an offer to provide information based on our expertise and the available data (“I can however give you our best prediction, based on our experience and expertise, about what we think the future will look like”).
- 2) Offer outcomes as best, worst and most-likely. Toby Campbell at the University of Wisconsin has talked about the helpfulness of talking to patients and/or families about the best, the worst and the most likely outcomes. What I like about this formulation is that I do not have to be right. I can be hopeful about what may happen if everything goes well and yet it also allows me to be realistic about the most likely outcomes. It also allows space to be pessimistic about what the alternatives are. This formulation is helpful to families because it gives them a range of outcomes to get their head around. They can think about what it would mean if the “best” outcome is one which the patient would find undesirable. If the most likely outcome is the patient is going to be in a nursing home, they have an incentive to start talking to the social worker about disposition. Finally, talking about “worst” outcomes is a chance to think about what outcomes would be “worse than death” for their loved one.
- 3) Include short and long term prognoses. Remember when we prognosticate to think not only about this hospitalization but also about the next 30 days, 90 days and year. It is often the case, particularly when patients are in the hospital, that we prognosticate for the duration of the stay that we are responsible for and forget to talk about the bigger picture. For patients and families the question often is not only what are we going to think is going to happen in the short term, but also to give a sense of what we think the longer term will be like. (Please see e-prognosis.com for what I think is the best website on this data.)
- 4) Include functional prediction in addition to mortality predictions. Finally, when you talk about prognosis, remember to talk both about mortality and about function. Most people in America are not vitalists—that is surviving with no cognitive, physical or social function—is often not a good outcome. Given that they are not vitalists, it is important to get again your sense of what three months from now the best, worst and most likely outcomes are so that they can begin to think about what their loved one might think about those possible realities. Talk both about functional status expectations and what that means for setting of care (home independently, home with 24hr care, SNF)

Personal details in the case published have been altered to protect patient privacy.

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Resolution of the case: You do not have to be quantitative in your description of what you think the future is going to be – in fact, the data suggests that patients' and families' understanding is just as good when we use qualitative terms as when we try to give percentages.

It is also important to remember that when you give this information it is often heard as disturbing news to the patient or family because by you naming it, you make it more real even if they were not worrying or thinking about it. Strong emotions are likely to follow your predictions, and it will take some time to acknowledge these and ask what questions they have about your thoughts of the future.

Someone said that 90% of life is just showing up. This saying might be true of prognostication – you have to show up and give your most informed views (you do not have to be right). Beginning to offer your best judgments about the future will go a long way in helping patients and families understand what they are facing and hopefully do a better job of preparing for and making decisions about the future.

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