PALLIATIVE CARE
CASE OF THE MONTH

"Emotion vs. Fact"

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Case: It had been a tough day rounding. We had four family meetings one after another. In one, the daughter walked out in the middle because she just could not hear any more. In another, the daughter made it clear that she just was not ready to think about the therapy not working. As we walked to our next meeting, the resident said to me, "Sometimes, I feel that you are too easy on them. Why do you not just tell them that it will not work? They need to understand that the therapy will not work."

Discussion: There is a common misperception that conversations about goals of care are always factual conversations. The doctor has to tell the family about the medical condition, the fact that current treatments are not working, and what, if any, options there are. The object of the conversation is to tell the information in a way so that family members "get it" and make "appropriate decisions." Doctors often think that families who do not understand this information are in "denial" or worse, have a financial motive for not understanding what is happening.

In my experience, this is rarely the case. Families often understand the information that the healthcare providers give—they just do not agree with it. (Given that we are giving prognostic information about what is likely to happen in the future, we cannot claim to hold the truth. We are probabilistically more likely to be more accurate, but what the future will bring is, until it occurs, unknown.)

Instead these conversations are about loss, sadness and anxiety. Loss about the current treatment not working. Sadness that the patient will not be able to achieve the goals they were hoping for. Anxiety about what the future might bring. Until these emotions are heard, acknowledged and processed, it may be hard for family members to move onto the next step—thinking about what their loved one would say given the new medical situation.

What data do I have for this belief? The family says things like "I know, but we cannot stop hoping," or they just keep wondering if there is not something else that might work, or they hope for a miracle (which by definition means they know that what we are doing is not working). In these cases, the family does understand what clinicians are saying—they just do not agree with it, do not want it to be true or cannot imagine the consequences if our view of the future proves true. Trying to convince the family that our view of the future is the correct one often leads to conflicts where we are repeatedly giving bad news, the family keeps wondering or demanding something else, and we all leave unsatisfied. The family feels like we are giving up, and we feel like they "do not get it."

There is another way to think about how to have these conversations. Think about them occurring on two planes—a factual plane and an affective (or emotional) plane. Typically we operate on the factual plane where we try to convince the family that our view of the future is the correct one. The problem is that what is happening on the emotional level precludes family members from cognitively processing and using this information. Psychologists know that we do not process cognitive information when we are emotionally flooded. In addition, when the information is too painful, one may actively resist acknowledging it because it is too painful ("denial").

In addition, family members' emotional reactions tell us about what is most important for them at this time. It gives the clinician a window into the things that the family is most concerned about, cares about and is worried about.

Finally, these emotions are normal when someone is being asked to confront or see something that they do not like. The fact that the family is having these emotions is, in fact, pretty good evidence that they do understand what you are saying, and they do not like it. Rather than trying to convince them on the factual plane that you are right, it will lead to a healthier relationship and better conversations if you meet them on the affective plane.

(Discussion Continued)

What does this mean for the clinician? It means, rather than giving information, attending to family members' emotions. It means acknowledging that "this is scary," or that things are not going the way that they want. It means not fighting with them about the facts about what might happen and joining them on the emotional plane: This is not what we wanted to have happen, and, in fact, there is a part of us who, like them, wishes the better story would come true.

When people feel heard and appreciated, their emotions often decrease making them more able to think through the facts. They are able to think about situations that otherwise would be too frightening, scary or sad. They can begin to consider what their loved one would say about this new situation.

Conclusion: I know this is a long answer to my resident's question, probably more information than he or you wanted. So I will end with a suggestion: If it feels like the conversation you are having with the family is a battle, if it feels like they are not listening to you or do not want to attend to what you are telling them, or they keep asking the same questions, think about what the affective plane of the conversation is. Try to identify the emotions that the family is expressing and see if you can acknowledge or name the situation for them. Stop trying to convince them and try to join them on that plane to see if you can help move the conversation from a fight over who is "right" to jointly confronting the situation they are facing.

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