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FAST FACTS AND CONCEPTS #219 (PDF)

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Background What do you do when a family member asks you not to tell your patient important medical information such as a diagnosis or prognosis? Requests for non-disclosure can represent a loving family's efforts to protect a patient from emotional harm, an inaccurate assessment by the family about a patient's preferences or emotional resilience, or an accurate reflection of how the patient would prefer to make decisions. This *Fast Fact* will introduce readers to a practical approach to these clinical dilemmas.

The Problem Contemporary medical ethics and professional standards dictate that patients have the right to choose the medical care that best allows them to meet their life goals. To make such choices requires they be fully informed of their condition, prognosis, and reasonable treatment options (see *Fast Facts* #164, 165). One needs to differentiate the right to such information from the duty to hear the information, however. Patients have different preferences for medical decision-making, ranging from individualistic, to paternalistic (doing whatever the physician recommends), to communal (sharing, or deferring, important medical decisions to family members or religious/community leaders). Truly respecting patient autonomy requires clinicians to identify and respect patient wishes to share or defer decision-making, including a patient's preference to not be informed of key medical information.

Prevention Negotiate with the patient *before* the results of testing arrive as to how much information they would like and who they would like to have present for information sharing. *Are you the kind of person who wants to know the results of the test or would you rather I talk to your children?*

Managing Requests for Non-Disclosure (adapted from Hallenbeck and Arnold, 2007):

- *Stay Calm.* These situations can be confusing and emotional for clinicians. The calmer you remain the more information you will gain from the family as to why they do not want their loved one to be informed of the bad news. Demonstrating frustration or implying that the request is inappropriate can break trust and derail your efforts to resolve the situation.
- *Try to understand the family's viewpoint.* They know the patient best and can provide insight into the cause of the request. Politely ask questions to understand the nature of the request. *Can you tell me more about why you feel this way? How does your family typically handle difficult information? How are important decisions made by your family?* Ask about how the patient has responded in the past to bad news and if they have made specific statements to others about what they want to know. Is the family more worried more about *how* the information is given rather than the information itself (e.g. given to the patient when alone, use of 'death' or 'dying,' the disclosure of specific prognostic time-frames)?
- *Clarify what the patient already knows.* Politely ask questions to understand what the family believes the patient already knows. Does the family think the patient already knows or strongly suspects what is going on and would rather not talk further about it, or is the patient completely in the dark? Have other clinicians already told or implied to the patient what is going on? How did the patient respond to that? Is the patient talking with the family about their concerns? A patient's reluctance to talk with family members may represent an attempt to protect them.
- *Respond empathically.* A family's request to not tell their loved ones usually comes from a kind and loving place; they are often frightened for themselves and the patient. Responding empathically (see *Fast Fact* #29) allows

them to recognize that you care about them. It may allow them to see your ability to give information to their loved one in a compassionate way.

- *State your views openly, but as your own views.* Disclose any discomfort you have with the family's request; explain your professional obligation to ensure the patient is able to make informed decisions in the manner they prefer. Disclose this specifically in the context of you wanting what is best for the patient, including respecting how she or he would like to hear information.
- *Be willing to brainstorm possible solutions.* Rigidly informing the family that you must tell the patient breaks trust and is inaccurate. There is no 'one-size-fits-all' solution to these scenarios. Often, there are solutions neither of you have thought about that will meet everyone's goals. In other cases, the family may not have thought about the implications of the request (e.g. giving Mom chemotherapy but not telling her she has cancer).
- *Negotiate a solution.* Recommend to the family that you, in their presence, share with the patient a limited amount of information, and then specifically ask the patient if they would like to hear more. Tell the family what you plan on saying, i.e. – *You came to the hospital because you were not eating well and became dehydrated. We have been trying to figure out what is going on. Some people want to know everything about their medical condition, others prefer the doctors talk with family members about what is happening and the best way to help a patient. What would you prefer?* Contract with the family that they, and you, will respect the patient's decision.

References

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