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PALLIATIVE CARE CASE OF THE MONTH

The Family Says Not to Tell

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Case: Mrs. X is a 75-year old woman who was admitted to the hospital with abdominal pain and severe depression. During the course of the work-up she had a CAT scan of the abdomen that revealed metastatic pancreatic cancer. Given her functional and nutritional status, her prognosis is less than three months. The patient has two daughters who are adamant that no one should tell their mom she has cancer. They understand that treatment is unlikely to prolong her life and want to take her home with hospice.

Discussion: The current ethical and legal consensus emphasizes that patients have a right to information about their illness. Knowing her prognosis, Mrs. X may choose to live her last few months differently. Moreover, rather than going home with hospice, she may want to try chemotherapy. In these situations, health care providers feel that it is their duty to tell the patient her diagnosis and prognosis so she can make decisions based on her values. The result is a battle where the health care providers tell the family that they have to tell the patient what is going on and the family refuses to allow such a conversation, arguing that it is their relative and they know her best. These discussions are a zero sum argument: if doctors tell the patient about the diagnosis, the family feels violated; if doctors do not tell the patient, they feel that they have not performed their ethical duty.

There is another, hopefully more successful, way to deal with these difficult conversations. Based on the conflict resolution literature, it involves three steps. First, rather than trying to convince the family that the patient should be told her diagnosis, the health care providers try to understand the family's point of view. Just listening may help change the encounter from a battle to a learning conversation. Families often have a variety of reasonable explanations for not wanting to tell their loved one: she would not want to know her prognosis based on her culture or previous conversations. Or she may be too cognitively or emotionally impaired to process the information; or it will lead to a worsening depression; or giving this information will make her too sad to enjoy her last days. Learning the family's story accomplishes multiple purposes. First, it helps convince the family that you do care about their mom and understand that they are trying to make a good decision for her. Second, the information you gather will help you successfully negotiate a decision that satisfies your, the family's and the patient's values. Third, in letting the daughters tell their story, they may be forced to think through issues that they initially neglected. For example, many families have not thought about what the patient will think as she gets sicker, how they will explain the grandchildren's flying in from across the country or how they will explain the hospice nurses.

Second, attend to your and the family's feelings. You are feeling frustrated and angry because the family is asking you to do something that you think is morally wrong. Attend to your emotions or they may "leak" into the

conversation either in tone, body language or words. (*I told you that I cannot do that.*) The family also may be overwhelmed by their feelings of sadness, guilt or grief. Moreover, they may be frustrated that people that they do not know are telling them how to deal with their mom. Showing empathy is critical. This will decrease their emotional overload and allow them to be more rational in their discussions. By dealing sensitively with their emotions, you show the daughters that you also can be sensitive with their mom.

Third, do not reach premature closure. In the family's emotional state they may view their only alternatives as either telling their mom nothing or telling her everything about her cancer and its prognosis. Brainstorm about all the solutions that might result in a win:win situation. They may not know, for example, you can negotiate with their mom regarding the information that she wants. It is important that you obtain consultation from experienced clinicians who have dealt with this issue before. Ethics and palliative care consultations are often helpful as these clinicians have experience with these types of issues. Take your time, the information does not need to be communicated urgently. With time, emotions often die down and you will be able to reach a solution.

Conclusion: The above method tries to change a conflictual situation to one where you and the family are trying to develop a plan that respects everyone's autonomy and wellbeing. It should not be interpreted to mean that the patient does not have the right to the information (if she wants it). But that is the end game, not the initial move in the conversation. You may not be able to completely please the family. It is important that, after negotiation, you are as clear as you can be with the family about what you can and cannot do. These techniques, however, often can keep a contentious issue from destroying your relationship with the family at the same time you are respecting the patient's values.

References:

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