

## The Role of the Patient's Family - Overview



The primary therapeutic relationship is between the doctor and the patient. Unless the patient is not competent, e.g., the patient has severe dementia, it should not be assumed that decisions regarding the patient's care will be made by, or shared with, the family. The family is not entitled to information about the patient without the patient's knowledge and explicit consent. It is always important to ascertain from the patient what role he or she wishes family members to play in his or her care. It is of equal importance to respect and abide by that decision.

## The Role of the Patient's Family - Scenario Script

*An elderly female patient is sitting on exam table in a gown. Her adult daughter is sitting in a chair. The doctor is sitting, facing them both.*

Doctor: So there are a number of different treatments that we can consider here.

Patient: Like what? [Anxiously]

Doctor: Well, first of all, I was thinking that...

Daughter: [interrupts doctor] Doctor, excuse me. Can I speak to you outside for a minute?

Doctor: [looks a bit confused] Sure, I guess so...

Daughter: Mom, we're gonna go outside, but we'll be right back. I just want to talk to the doctor.

Patient: Okay. [slightly hesitant]

[Doctor and daughter exit the exam room and close the door. They are now facing each other in the hallway.]

Daughter: Doctor, my mother gets very anxious around doctors. So, why don't you just tell me what her diagnosis is and what the possible treatments are and then we can decide what's best for her?

Doctor: Are you sure that that's what she wants?

Daughter: Trust me, I know my mother.

### The Role of the Patient's Family - Discussion Questions

1. What are the likely motivations for the daughter's request that the doctor deal with her, and only with her, with respect to her mother's care?
2. Are there any circumstances in which the daughter's request should be honored? If so, what are they?
3. Should the doctor verify the patient's preferences directly with the patient? If so, how should that be done?
4. If the patient expresses the preference to have her daughter act as her intermediary with respect to information and decision making, how should this be documented?
5. If the patient expresses a desire to continue to receive information and participate in decision making herself, how should the physician proceed with respect to the family?
6. If the patient chooses to assume primary responsibility for her own health care, how much information should the physician provide to her family?
7. Assuming the patient concurs with her daughter's request, how should the doctor proceed if the patient's son becomes involved and disagrees with his sister's decisions?
8. To what degree are these considerations affected by the patient's age?
9. Under what circumstances would it be inappropriate to continue to allow the patient to take primary responsibility for decisions regarding her own care?
10. If the patient is found to be mentally incompetent to make decisions regarding her own care, how should the physician proceed?

## The Role of the Patient's Family - Scenario Analysis

This scenario deals with the role of the patient's family in health care decisions, particularly in situations where the patient is elderly. As the doctor is about to explain treatment options to the patient, her adult daughter, who has accompanied her on the visit, interrupts and asks to speak to the doctor outside of the examination room where her mother cannot hear.

The doctor agrees, and when they are out of the room the daughter proposes that she assume all decision-making responsibility with regard to her mother's medical management. The daughter explains that her mother gets very upset and worried around doctors and implies that her mother would not be comfortable with receiving information or making decisions. The doctor questions whether the patient would actually prefer such an arrangement, and the daughter responds, "Trust me, I know my mother."

In some cultures, such an arrangement would be entirely acceptable, even expected, both by the family and the patient. As a sign of deference or respect for the elderly, families may attempt to spare them the burden and discomfort of dealing with unpleasant medical information or making difficult decisions and may assume those roles for them. So a request like this daughter's might not seem unusual to a physician coming from a culture where such practice is common.

In U.S. medical practice, it is the wishes of the patient that are most important. If the patient does indeed prefer to have her daughter act as her medical decision-maker, that would be acceptable in our medical culture, provided that such a preference be stated clearly and freely by the patient herself without pressure from the family. Obtaining the mother's consent for this arrangement in an ethical and proper manner might require a one-on-one conversation between the doctor and the patient *without* any members of the family being present. If, and only if, the physician is convinced that this is the patient's choice, he then may proceed to manage the patient's care with a family member serving as intermediary. It would also be important to document the patient's expressed wishes in her medical record.

If the patient does express a desire to defer to her family, the situation may become complicated if more than one family member wants to play the role of decision-maker or there is disagreement among family members regarding the best course of action. It may be necessary for the physician to go back to the patient for clarification of which family member she prefers to serve as the primary decision-maker.

### The Role of the Patient's Family - Scenario Analysis (continued)

If, on the other hand, the patient expresses a desire to be informed of her condition and participate in making decisions about her medical care, her wishes must take precedence over the family's preference. This could lead to a difficult confrontation with the family. In such a situation it would be important for the physician to serve as a patient advocate and try to ensure that the patient is not pressured or intimidated by the family.

If the patient continues to take responsibility for her own health care, it is also important for the physician to respect the patient's confidentiality. Unless the patient indicates that it is all right to do so, information about the patient's condition should not be shared with family members.

All of this discussion assumes that the patient is, in fact, competent and capable of receiving information and making decisions. If the patient is not mentally competent, then another individual—possibly family, possibly not—must be legally designated to make such decisions. Ideally, such an arrangement would have been established previously through the use of a living will or a durable Power of Attorney.