

Open School

Case Study: The Protective Parent

(<http://www.ihl.org/education/IHIOpenSchool/resources/Pages/Activities/TheProtectiveParent.aspx>)

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Learning Objectives

At the end of this activity, you will be able to:

- Discuss ethical challenges that can arise in the treatment of patients under the age of 18.
- Describe possible adverse consequences of concealing a patient's personal health information from him or her.
- Describe how families and providers usually expect patients to react to bad news compared to how they often do.

Description

During a 50-year career in medicine, Dr. Paul Griner accumulated hundreds of patient stories, most of which are from the 1950s and 1960s, prior to what we now refer to as “modern medicine.” In this case study, he struggles with a serious ethical dilemma when a patient's mother asks him to keep her 17-year-old daughter's diagnosis a secret from her. Read the case and consider what you would do.

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Key Topics

Transparency, pediatrics, engage patients and families in care, patient- and family-centered care, satisfaction: patient and family, communication.

One Friday evening, I was called to the emergency room to see a patient for one of my colleagues who was out of town. The patient was a 17-year-old girl, a senior at a local high school. She had developed acute lymphoblastic leukemia some years before, but treatment had resulted in a complete remission.

Recently, she had relapsed and was again under treatment.

The patient's mother intercepted me before I walked into the examination room to tell me that her daughter did not know of the leukemia diagnosis. She also told me not to tell her. I asked her to explain the situation further. She indicated that when the diagnosis of acute leukemia was initially made, she kept this diagnosis from her daughter. She requested that everyone involved with her care agree to tell the daughter that her problem was an unusual anemia. Up to that point, everyone had complied. And when the leukemia went into remission, the mother considered this chapter of her daughter's life to be closed.

When I asked her why she chose not to tell her daughter, she said, "I had enough problems to deal with. I didn't need any more." The mother then asked where I lived. When I replied, she said, "Oh dear! A number of my daughter's friends live in that area. I'm concerned that they will hear of her diagnosis from you."

I told the mother I was very uncomfortable with the request, but that I would respect her wishes during the weekend. I indicated to her that I would bring my concerns to my colleague when he returned.

I supervised the treatment of the patient for the next two days. Upon my colleague's return, I spoke with him about the confidentiality. He elected to continue to respect the mother's wishes.

Discussion Questions

1. What would you have done in the situation? Would you have told the patient about her leukemia? Why or why not?
2. Can you think of at least two reasons why the mother may not want to share the news of the diagnosis with her daughter?
3. What would you have said to the mother when she told you not to tell her daughter?
4. Would the case be any different if the daughter was 18 years old? Why or why not?
5. What right does the patient have at the age of 17 to know her own diagnosis?
6. Imagine if the daughter accidentally found out about her diagnosis — perhaps she sees a chart or another clinician who wasn't part of the original conversation lets it slip. What impact might that have on the daughter? How much might it affect the trust she has in her mother or in future health care providers?
7. Have you ever witnessed a similar situation? What was the end result?

Case Commentary

I was disappointed that my colleague had been a participant in keeping the patient in the dark about her disease. I elected not to tell the patient about her disease during the two days of my care only because I was a "substitute" physician. Having never seen her before, I had not established a

doctor/patient relationship. As mentioned, and to my disappointment and anger, when my partner returned, he elected to continue this charade.

Study after study shows that patients are better able to handle bad news than either relatives or doctors may think. In fact, some patients may even be concerned about the person who delivers the news. Sometimes, I've heard people say, "It must have been hard for you to tell me this."