



Online Ethics Center
FOR ENGINEERING AND SCIENCE

Conflicting Obligations

Author(s)

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2000

Description

A scenario that covers ethical issues that arise when seeking informed consent from children.

Body

Part I

You are a first-year fellow caring for Melissa, a fifteen year old diagnosed three months ago with a Ewing sarcoma of the femur and metastatic pulmonary disease. The prognosis is poor, but you are hopeful that therapy in a newly opened national study will benefit Melissa. The study calls for three months of chemotherapy, followed by autologous bone marrow transplant for patients who have a good response. You meet with the patient and her parents to discuss the diagnosis and prognosis. You have the informed consent document and begin to describe the study.

Discussion Questions

- How would you approach this conference?
- To whom would you direct your comments?
- How would you present the study?
- Would you be neutral or more directive, actually recommending enrollment?

Melissa and her parents seem to understand the information you have patiently attempted to convey, and agree to enroll in the study.

- Who should be asked to sign the consent document?
- What are the implications of the signature and of the question of who actually signs?

Part II

You have prescribed a chemotherapy treatment plan according to your current open Childrens Oncology Group study, with a great deal of input from your faculty mentor. You have worked hard to cultivate a therapeutic relationship with Melissa, attempting to demonstrate both your concern for her medical well-being and respect for her emerging autonomy.

During several of your one-to-one meetings with Melissa, she expresses a desire to stop chemotherapy because of side effects of nausea and mouth sores she finds intolerable, but tells you that her parents will be devastated if she actually makes this decision. You always manage to persuade her to continue with treatment. After a difficult three months of induction chemotherapy, Melissa has a CT scan of the chest and MRI of the femur. These studies show an excellent response to therapy, and make her a good candidate to proceed with the study. The next step will be high dose chemotherapy followed by reinfusion of stem cells, a procedure known as autologous bone marrow transplant.

Suppose that you and your mentor meet with Melissa and her parents to discuss the scan results and current plan. Your mentor is relatively silent, and you do the talking.

Discussion Questions

- How would you approach the subject of continuing on with the study?

- Suppose that your mentor is the PI on the study. How might your approach be affected by the fact that your mentor was the national Study Chair and a powerful advocate for the research trial?
- What issues might be different if Melissa was not entered on the study?

Part III

You begin the conversations by acknowledging how difficult this has been for Melissa, but you emphasize her excellent response to therapy. You reinforce the initial prognostic issues but remain cautiously optimistic in the tone of your discussion.

After reviewing the expected complications during the transplant, Melissa's parents seem eager to proceed. You would like to elicit the views of Melissa herself, but your faculty mentor and Melissa's parents all signal their wish to end the meeting and proceed with the planned transplant. After the meeting, your mentor expresses that Melissa will be enrolled in the transplant portion of the study.

Discussion Questions

- How can you find out what Melissa thinks?
- What do you do if everyone is not in agreement about the next step?
- How might you try to achieve consensus?
- Should you try to stop the transplant until you are able to gain her consent?

You speak with Melissa privately and discover that, as you expected, she does not wish to proceed with the transplant. She is obviously frightened, and speaks very openly about her concern that she not "let her parents down."

- What are some ways you can distinguish Melissa's legitimate fears from actual dissent?
- Is her assent to proceed absolutely necessary? Why or why not?
- Should you attempt to allay her fears about transplant or about her parents' expected reaction? If so, how might you do this? If not, why?

Rights

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