

BIOETHICS
Summer 2004
Professor Mayo

Class 1:

Case of: “What he doesn’t know won’t hurt him”

To inform or not inform...

Robert Smith is a 9-year-old boy with HIV infection. He presented, at 2 years of age, with recalcitrant peri-anal abscesses and was subsequently diagnosed with HIV. After Robert’s diagnosis, his mother was tested and found to be HIV positive as well. A child, born after Robert, is not infected. Mrs. Smith acquired HIV when she was transfused shortly after the delivery of their first child, in 1980. Since diagnosis, Mrs. Smith has become progressively ill, with complications of PCP, disseminated Cryptococcus, wasting and recurrent fungal infections.

Robert has been relatively well, although he has required PCP prophylaxis now that his CD4 count has lowered, despite aggressive triple anti-retroviral therapy. He is functioning normally, going to school full-day and makes good grades. He plays soccer and basketball for the 3rd grade team and is very well adjusted socially.

Robert’s parents are married, but their relationship is struggling due to Robert’s father’s grief over what is going on with his family. Mr. Smith rarely comes to the office visits, feels somewhat guilty about his wife’s disease process and the lack of his ability to fix things, and therefore defers most medical decision-making to Robert’s mother.

Robert has been told all along that he has hepatitis since birth. This has worked for the school notification of blood precautions and been an excuse to bring Robert to the doctor for check-ups and medicines. However, over the past year, Robert has begun to ask some questions about his health, including his prognosis and if he is going to get sicker like his mom. He is bright and has noticed that she is on some of the same medicines that he is on.

Mom asks that Robert’s physician not tell her son that he has HIV infection. She is concerned about how he may react, stating that sometimes he doesn’t keep secrets very well. Robert’s mom is also very worried about his reaction and whether it will make him depressed, angry at them for not telling him earlier, or non-compliant. At the very least, Robert’s mom senses that telling him will be the turn in his life that will end the relatively free childhood she cherishes.

What should the physician do?

What duty does the physician have to tell Robert about his disease?

How should the physician balance Robert’s autonomy with his mother’s request to protect him?

What result will the physician’s chosen course of action take on his/her relationship with Robert?

-With his mother?

Should the mom be encouraged to tell the school and if so, how would should such a disclosure of his disease to the school, sports teams, friends be handled?