

At the age of twelve, Amy Yamakami was one of the “brightest and best” at Marietta Country Day School. She was in middle school, seventh grade, one year ahead of her peers. She worked diligently and was a shining star in her family, the first generation to attend school in the United States. In the spring of her twelfth year, Amy began to have bouts of acute fatigue, sometimes accompanied by what appeared to be a viral-type sore throat and cough. These respiratory episodes would last ten days or more, making it extremely hard for her to attend school consistently, and once she even missed attending a state math contest. Amy received all her immunizations at the County Health Clinic, and participated in required school physicals. Routinely, Amy’s mother, Mrs. Yamakami (Lei), treated her with remedies that she had learned from her grandfather in China. Lei became increasingly concerned and spoke with Amy’s father, Chang, about her daughter. Chang, in turn, spoke with a neighbor, a local doctor, who referred the family to the University Hospital.

Amy is now fourteen years old. Her father was told shortly after her first visit to the adolescent clinic almost two years ago that she had a disease called acute lymphoblastic leukemia. Chang was told that without specific treatments the disease could be fatal. Chang understood this and told the attending physician that neither his daughter nor his wife should be informed of this diagnosis. He assured them that he would make their decisions. “That is the way it is done in my country,” he told them. “That is the way my father taught me.”

Under Chang’s direction, Amy has received several rounds of chemotherapy and experienced one short period of remission. She exhibits a somewhat complacent attitude, especially when she is very ill. At other times, she is quite inquisitive. All healthcare staff have been advised to give Amy minimal information. Her mother is quite submissive to Chang; however, she has never stopped giving Amy herbal treatments, especially for intermittent infections.

Amy is currently hospitalized for anemia, malnutrition, general weakness, and pneumonia. Staff know that she is very ill. One nurse in particular, Karen, has been taking care of Amy on a regular basis and begins to question others about the information being withheld from Amy and her mother. It is rumored that Amy’s father may consent to an intense effort to “spiff” up the patient and allow her to receive a bone marrow transplant. He has always refused this treatment, but he now thinks it may be her last chance. Karen is worried. She has been uncomfortable off and on in her time with Amy, and now that everyone knows that Amy is nearing the end of her life, Karen believes that she and her mother should be told the truth. When she asks the oncology team to discuss this issue, they assure her they have already thought it through. A young resident from China is on the team, and he, too, tells Karen that Mr. Yamakami is acting according to values that are essential to his culture.

Case Study

What Amy Doesn’t Know —
Respect for Cultural Diversity or Bad Ethics?

Discussion

QUESTIONS

1. Is Amy being treated with respect?
2. Would the caregiver decisions about informing Amy be any different if she were age eighteen or an "emancipated minor"?
3. When Amy asks her caregivers for direct information, how should they respond?
4. How do you imagine the attending physicians justify their withholding information?
5. Does the obligation of truth-telling challenge the obligation to respect cultural values enough to make it our duty to tell the mother and patient?
6. Because Amy has lived all of her life in the United States, of what culture is she a member; Chinese or American? When a person is from two cultures, which one dominates in what circumstances?
7. What if the father chose to withhold or withdraw treatment? Would this bring the issue of truth-telling to a crisis and climax?
8. Is there justifiable reason to consider the father's withholding of information a case of child neglect or abuse?

SELECTED READING

- Fadiman, Anne. 1997. *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures*. New York: Farrar, Straus and Giroux.
- Midwest Bioethics Center Task Force on the Healthcare Rights of Minors. 1999. Revised Ed. *Health Care Treatment Decision-Making Guidelines for Minors*. Kansas City, MO: Midwest Bioethics Center.
- . 1995. "Minors' Rights in Health Care Decision Making." (Entire Issue.) *Bioethics Forum* 11(4):1-37.