

CHALLENGING CASE: ADOLESCENCE

Decision Making About Medical Care in an Adolescent with a Life-Threatening Illness*

CASE

Jorge, a 13-year-old Hispanic male, was admitted and treated for acute lymphocytic leukemia 9 months ago. He promptly experienced remission in the first month of therapy. This was followed by 6 months of intensive consolidation that required numerous hospitalizations. He then was placed on maintenance chemotherapy. Jorge is the oldest son of five children born to working-class parents who were both high-school graduates. While undergoing induction, Jorge and his parents seemed to be aware of his treatment course and prognosis. The family related well to the treatment team, and Jorge developed a close relationship with the oncology social worker. At first, he appeared depressed. At times he would state that he was "cursed" and would never live to graduate college, a long-term goal he shared with his family. However, despite his age, Jorge appeared to be quite mature and was always cooperative with medical procedures.

During his second month in maintenance therapy, Jorge's hair was growing back well, and he had returned to school for partial day attendance. His mood was pleasant, and he seemed to be adjusting to resuming life. During a routine clinic visit, a bone marrow aspiration detected the resurgence of his acute lymphocytic leukemia, and he and his family were told about this by the oncologist who worked closely with them. Jorge appeared devastated, as did his parents and the two siblings who were with them that day. The oncologist explained that Jorge's only real chance at survival would require a bone marrow transplantation, and because they did not have a matched related donor, he would have to be placed on a list for an unrelated donor. Jorge immediately asked what his chances of living were, and he was told that approximately 40% of children would survive and be disease-free for 5 years. Jorge and his family were devastated. After a prolonged consultation during which various options were discussed, his family agreed to visit the transplantation center to get additional information.

At the center, they were informed about the lengthy time he would need to be in seclusion, the amount of pain and invasiveness involved in the procedure, the long-term issues about graft-versus-host disease, and the likelihood of success using a partially matched nonrelated donor. His parents report that Jorge asked very few questions and did not

get along well with the supervising oncologist at the transplant referral center.

On returning home, Jorge announced to his parents that he would refuse the transplantation and did not want to be placed on the list. His parents called the oncologist for help. A meeting was arranged the next day, and Jorge, his parents, doctor, social worker, and primary nurse met to discuss the options. His doctor noted that Jorge appeared to be very firm in his decision that he would refuse to cooperate. Jorge had read about other teenagers who had also chosen to die, rather than accept additional painful treatments. His parents were absolutely firm that every possible treatment should be pursued. They felt that a 40% chance was better than no chance at all. They asked his doctor to place Jorge on the waiting list, despite Jorge's strenuous objections.

Index terms: medical ethics, adolescent autonomy, informed consent.

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Advances in biomedical technology have led to cures that were only imagined a few years ago. These advances have also brought new ethical dilemmas into the medical care of patients, especially those with life-threatening conditions. Decisions for medical treatment must include a thorough understanding of the procedure and major side effects, especially pain and disability and their duration.

Cognitive and psychological competency has always been important in the decision process. For critically ill adults and patients with severe mental illness, guidelines have been developed to assist clinicians and families in the evaluation of competency. For an adolescent with a serious illness, the decision to accept or reject a potentially life-saving medical procedure is also affected by developmental considerations. The variability among teenagers in whom major developmental tasks are negotiated reflect individual patterns of temperament and cognitive processing, past psychosocial achievements, family, and other social systems. Developmental variability is especially important when assessing a youth's progress in the tasks of autonomy, personal identity and separation-individuation.

The case of a 13 year old with acute lymphocytic leukemia who refuses a potentially lifesaving bone marrow transplant highlights these issues. The first commentary is by a pediatric psychologist, **Dr. Robert Wells**, and a pediatric oncologist, **Dr. Steve Stephenson**, who work together on a medical team with responsibilities for child and adolescent cancer patients. They are on the faculty of the University of

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Jorge's treating physician is facing a very difficult quandary. Is a potentially depressed 13 year old mature and capable enough to make a critical decision about his life and/or death? What are the differences in the ways that Jorge and his parents understand the treatment demands, potential costs and benefits, and likelihood and importance of survival? How can his physician understand the disagreement within the family and help them reach consensus? What event or series of events transpired that caused Jorge to lose confidence in medical treatment and can this be reversed? Is it possible to actually force a teenager to accept oncologic treatment against his or her will?

It is neither developmentally appropriate nor practical to force a teenager to accept prolonged and invasive oncologic treatment against his or her will. As a teenager confronts further loss of control of major life decisions, noncompliance and potentially combative behaviors may occur. The anger is often directed at parents and the health care team who feel compelled to "take over" decision making in the best interest of the adolescent patient. Every effort to help a family resolve these internalized conflicts is a valuable part of the treatment plan.

The first step in this case is to suggest that Jorge and his parents agree to hold a series of meetings with the physician and social worker. It is also advisable to request a mental health consultation to determine whether Jorge is clinically depressed. Children and teenagers who are being treated for life-threatening illnesses have high rates of depression that may be amenable to treatment.¹ From the history, it appears that something changed when Jorge and his family went to the transplantation center, and it is important to learn more about this experience. Because the social worker may have the best relationship with this teenager, a series of individual sessions should be held to help support him and to listen to his concerns. If Jorge identifies significant concerns about this particular center and its staff, a referral to a different center should be considered.

If Jorge is clinically depressed, all other medical decisions should be deferred, and he should be treated for depression. A combination of antidepressant medication and individual therapy may be needed.^{2,3} Jorge may have reduced bioavailability of

serotonin, and he is unlikely to experience an optimistic social environment for some time. Individual therapy can help him focus on ways to improve the quality of his life and to enhance his capacity to use nonavoidant coping techniques, such as problem solving, seeking social support, making positive appraisals, and utilizing information. He can also be helped to find ways that have a positive impact on his environment. The findings of one recent study demonstrated that the vast majority of depression in pediatric oncology patients is related to their overuse of avoidance coping, their depressive attributional style, and their lack of social involvement.⁴ It may be helpful to have Jorge and his family meet with other teenagers who have faced the same decision to observe firsthand how they are faring. Discussions about posttreatment quality of life should also be held. As many as 96% of autologous bone marrow recipients report that the quality of their life is good. Forty percent reported no disability, and 33% reported only minimal disability.⁵ Counseling and support for the family and health care team is also critical to help them recognize and cope with issues of control and medical decision making. They need to avoid forming a "new team" that excludes the recalcitrant teenager.

If Jorge is capable of making an informed decision about his health care, and he and his family continue to disagree, an ethics consultation may be helpful. Medical professionals recognize that mature minors have decision-making capacity and need to be involved in making important decisions regarding their life.⁶ Patients, families, and the treatment staff may be helped if they can present their dilemma before a group of concerned, but nonaligned, professionals. The committee can help them focus on the underlying value conflicts and can offer feedback regarding the opinions of others. At times, the process of hearing all sides and respecting all views can be quite helpful, because it guides a family and treatment team to reach consensus.

If there is no resolution and Jorge continues to resist bone marrow transplantation, his parents should be encouraged to accept his wish and allow him to feel supported. His physician can continue to monitor him, and supportive care can be implemented. It is likely that his parents and siblings will benefit from involvement in family group meetings, such as those held by Candlelighters. The treatment team may require significant consultation-liaison services to help them accept the limitations of their own efforts. In many cases, when the resistance is dismantled, the teenage patient may then change his or her mind and consent to treatment.

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This case exemplifies the chaos theory of medical ethics, namely how small nuances in initial conditions have immense final consequences—in this case, either life or death.

Jorge is described as young, yet “quite mature.” What then can we say about his capacity to make rational decisions? Do we emphasize that he is young and therefore subject to short-sighted emotional impulses? Or do we accept that he, like many other 13-year olds with long exposure to illness, is capable of making a decision that other reasonable people might make, namely to forego a burdensome treatment in which the odds of success are less than even? No doubt different observers (with their own agendas and temperaments) would evaluate Jorge differently and draw contrary conclusions. Nor is there any “proof” that either conclusion is right or wrong. Ethical reasoning is not a process that proves answers right or wrong, but rather is one that examines whether they are ethically defensible, as opposed to arbitrary and incoherent.

In my view, it is important that everyone involved in Jorge’s care recognizes that his best interests can be met only by enhancing his autonomy. This is important for ethical reasons, because respect for autonomy is a fundamental principal of ethics in this country. In Jorge’s case, it is important for medical reasons, because it will be almost impossible to involve him in a complex treatment program without his full understanding and participation.

Probably everyone wishes that Jorge would take a chance and undertake the bone marrow transplantation. If he comes out at the other end alive and well, won’t he be grateful that his objections were overcome? Certainly it is ethical to try. What are the small nuances in initial conditions that might be altered?

Jorge apparently “did not get along well” with the supervising oncologist at the transplant referral center. This is certainly an initial condition that needs to be addressed. Does the oncologist know how Jorge feels? Is there any way the oncologist can reach out to mend that relationship? Possibly the oncologist has personal traits that did not mix well with Jorge? Are there other available choices in oncologists or transplant centers? Of course, it is possible that the messenger is being blamed for bearing the news. Jorge is described as having developed a “close re-

lationship” with the oncology social worker. How does this person feel about Jorge’s choice? What about allowing this person time to explore Jorge’s feelings, perhaps clear up misunderstandings (if there are any), and reconsider his fears and hopes? Might this person serve as an intermediary?

The question arises about placing Jorge on the transplant list. I would not risk violating his trust by doing this without Jorge’s agreement. However, I would try to persuade him that listing him does not obligate him; it simply leaves the door open to the possibility that he might change his mind. I would emphasize the freedom it gives him, something he may crave as he sees his disease and the pressure of his parents closing around him.

Whatever efforts are made, in the end, Jorge must accept the treatment willingly. And everyone must accept his decision if he does not. Whatever his choice, it is the obligation of the health providers to help his parents cope with it so that they maintain a relationship that is supportive and loving.

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SUGGESTED READING

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David Elkind has described adolescence as “. . . an age when the imaginary audience and personal fable are most powerful and teenagers are most vulnerable to their influence.”¹ Teenagers are in the process of formulating their own personal identities and simultaneously learning to think hypothetically and symbolically. These powerful developmental events occur in the context of a changing body image beginning with puberty, sexual curiosity and exploration, new roles for social relationships, and experimentation with separation from and loss of identification with parents. This normal developmental process is challenged when a teenager has a chronic illness with significant morbidity and potential mortality.

Both Drs. Wells and Stephenson and Dr. Schneiderman recognize the importance of Jorge’s psychological autonomy as a mechanism to help focus the actions and feelings of the health care team and his parents. Without this perspective, Jorge may not be an active participant in his medical care. With it, he can be encouraged to join his family, doctors, and other members of the health care team. Although his cognitive capacity to understand how a bone marrow transplant works in a patient with leukemia or to comprehend the risks and benefits of treatment is not known from the data in the case summary, the commentators point out that preservation and enhancement of his autonomy is a major objective. They correctly make this point both as a developmental necessity and in recognition that, in the future, it may be a potential wedge for him to view his illness and treatment in alternative ways.

Consent for a medical procedure or treatment is considered as a basic requirement for the provision of health care. It is also an ethical obligation to ensure respect for patients and their autonomy. The legal and ethical history of consent among adolescents undergoing health care has been defined in the past 40 years. The Supreme Court determined that the Constitution protects minors in critical areas of due process, free speech, and privacy.² In particular, privacy decisions that emerged from legal decisions and state legislation have had a significant impact on an adolescent's right to make health care decisions. These policies were generated to encourage adolescents to seek health care, to deter the effect of parental consent requirements in specific situations, and to recognize the capacity of a "mature minor" to make health care decisions.³

The legal definition of a mature minor is one who can comprehend the risks and benefits of the proposed treatment and is therefore able to give informed consent for the care.⁴ The developmental prerequisites for this task would seem to be the acquisition of an ability to think in hypothetical terms ("if I accept this procedure now, it *may* have a good effect on my disease") and to think about the future ("today's decisions will affect subsequent outcomes"). As with many teenage patients, it is difficult to assess Jorge's mastery of these skills. At the least, his anger about his condition has prevented discovery of more adaptive coping strategies, fueled by a sense of loss of control and fears about the perceived level of pain and discomfort associated with a bone marrow transplant. Drs. Wells and Ste-

phenson offer several potentially therapeutic suggestions. Attention to the symptoms of depression, focusing on antecedent events that may have brought about a loss of confidence in medical treatment, arranging a meeting with a teenager who has had a bone marrow transplant, and engaging the assistance of the social worker with whom Jorge has established trust may be helpful in Jorge's process of decision making.

Finally, Dr. Schneiderman provides us with a useful definition of ethical reasoning as ". . .not a process that proves answers right or wrong, but rather one that examines whether they are ethically defensible, as opposed to arbitrary and incoherent." It outlines a tough course for Jorge, his parents, and his health care team. However, with the recognition that autonomy is a major developmental task in adolescence as well as a fundamental ethical principle for medical decision making,⁵ we can begin to assist Jorge and his family.

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