

Virtual Mentor

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CLINICAL CASE

Withholding Information from an Adolescent

Commentary by Libby Brockman and Megan A. Moreno, MD, MEd, MPH

“I get that my cancer’s back,” said Blake, obviously frustrated and eager to leave Dr. Conrad’s office. “So what’s the plan? How tough is it going to be?”

Dr. Conrad answered, “Well, it is a fairly aggressive treatment. I can’t deny that. But you’re 16 now and pretty strong. The side effects are different for everyone; they can range anywhere from mild to harsh. This therapy has worked for a lot of patients and I believe it can work for you. What do you think?”

Just then Blake’s cell phone rang. “I’m stepping out for a second,” he said to Dr. Conrad. “It’s one of my best friends.”

“Sure, go ahead.” Dr. Conrad said and turned to Blake’s parents for some corroboration. They had been over this ground before when Blake’s initial chemo treatments had put his acute lymphoblastic leukemia into remission, giving him several years of normal life.

“I’ve been talking to him about the importance of starting treatment again,” said Blake’s father. “Maybe I didn’t do a good enough job explaining the urgency of it. He says he wants to know what to expect before deciding.”

Blake’s mother also weighed in, “I think he should be the one to make this decision. He asked directly, what does this treatment entail? He doesn’t like it when we hold out on him. He wants to know the truth—and he deserves to be given all of the information straight.”

“This time treatment will consist of not only high doses of chemo but radiation, too. But I don’t want to lay all that on him right now,” said Dr. Conrad. “All I want is for him just to agree to begin the new round of treatments.”

Commentary

During adolescence, teens like Blake typically engage in important developmental tasks such as defining their identities and asserting their independence. This experience has been complicated for Blake by the diagnosis, remission, and return of his cancer. When he is told how aggressive his new treatment will be, Blake appears apprehensive and unsure of whether he wants to proceed with Dr. Conrad’s recommended treatment plan. We immediately wonder whether Blake’s hesitancy is

part of normal adolescence in which he seeks autonomy, or the result of rational thinking that has led him to seriously consider death over painful cancer therapy.

In the case scenario, we learn that Dr. Conrad hasn't been completely forthright with Blake regarding the extent of the treatment plan because he fears Blake will refuse his recommendation. Dr. Conrad appeals to Blake's parents, who are aware that he has withheld information, and admits that his priority is obtaining Blake's assent and beginning therapy; only after Blake begins treatment does Dr. Conrad plan to reveal the full extent of the care plan. Dr. Conrad's approach raises questions about how much disclosure is required when informing a patient and obtaining his or her consent for medical treatment, and whether it is ethical to keep Blake uninformed of the details of his treatment.

We will first address the question of whether Blake has the right to make this medical decision for himself—in other words, is his consent needed to proceed with treatment? While Dr. Conrad strives to involve Blake in the decision-making process, is he required by law to do so? In 1990, the Supreme Court granted adults the right to refuse medical treatment, assuming they are competent to make their own decisions [1]. This right was not extended to children, and today parental consent is still needed for the medical treatment of individuals under the age of 18.

Though most would agree there are cognitive differences between a 7-year-old and a 15-year-old, such distinctions are less discernable between older adolescents. Is an 18-year-old significantly more mature than a 17-year-old? What about a 16-year-old like Blake? The “mature minor” distinction was created to address this issue and allows “a minor to consent to medical treatment if he is found competent enough to make the decision on his own” [2, 3]. Judging the competence of a minor has proven to be quite complicated, and medical literature has questioned the validity of the concept [4]. While Jean Piaget's four-stage model of development proposes that individuals begin to employ mature thinking processes between the ages of 11 and 15, critics are quick to point out that Piaget's developmental stages fail to take into account the social and environmental pressures that can affect an adolescent's decision-making capability [2, 5]. Some studies have shown that 14-year-olds possess the same competency and decision-making skills as adults [6]. Other research claims that adolescents and adults have very different perspectives on the world: adolescents are generally more susceptible to peer pressure, make riskier choices, and tend to focus on immediate rather than long-term consequences [7, 8]. Finally—and importantly—the intense stress of disease can drastically impair one's decision-making abilities, regardless of age.

Moving, then, to Dr. Conrad's strategy for disclosing the details of Blake's treatment plan, both the American Medical Association (AMA) and the American Academy of Pediatrics (AAP) state that physicians have a duty to provide decision makers with all information pertinent to their treatment options, including details about risks, discomforts, side effects, and alternative therapies [9, 10]. There is reason to believe “patients, family members, or other decision makers want to hear the reality of their

situation,” and consequently the AAP declares, “[i]nformation may not be withheld on the grounds that it might cause the patient...to decline a recommended treatment” [9]. Research involving cancer patients has shown that they much prefer their physicians to offer realistic, individualized prognoses [11]. Such open communication fosters a trusting patient-physician relationship, which is imperative for the provision of good health care.

It is clear that these two ethical concerns are inextricably linked. From a legal standpoint, whether or not a physician is required to provide the patient with complete details of a given treatment directly depends upon whether the patient is able to consent to his or her own care. The doctor’s legal obligations are to the decision maker. In this specific case it is unclear whether Blake can be considered a mature minor; there isn’t enough evidence to determine his level of competency. For the sake of argument let us consider the teen before us who has recently learned his cancer has returned. Instead of participating in a discussion of treatment options, he answers his cell phone and leaves the room. Though details of the past discussions between father and son are not provided, Blake’s father may not be at fault for unsuccessfully convincing Blake to begin treatment again—it is quite possible that Blake just isn’t getting it. Based on this limited amount of information, Blake does not seem to fit the profile of a mature minor, in which case Dr. Conrad would not be legally required to obtain Blake’s consent to begin treatment. It is reasonable to conclude, therefore, that Dr. Conrad is not acting *unlawfully* when he withholds details of the treatment plan from Blake and provides them only to the minor’s parents.

Dr. Conrad’s legal obligation can provide a framework for this case, but it is only part of the story. Professional ethical obligations often transcend legal obligations. Ethically, Dr. Conrad must consider what is in his patient’s best interest, not just what is in the decision maker’s best interest. Although Dr. Conrad doesn’t legally *need* Blake’s consent to begin treatment, he should *want* it. There are two main reasons why fully disclosing the treatment plan and obtaining assent for treatment would be in Blake’s best interest. Firstly, doing so will improve Blake’s investment in and compliance with the cancer therapy. Research has shown that patients who understand and assent to their treatment plan are more likely to adhere to it [12]. Given that compliance is a particular problem among adolescent patients, Dr. Conrad should make every effort to obtain Blake’s buy-in to the plan [13].

The second reason why Dr. Conrad should disclose the details to Blake is that failure to do so might threaten the heretofore positive patient-physician relationship. When Blake eventually learns that he wasn’t given the whole story, he may feel betrayed by Dr. Conrad and his parents, which could easily result in a weakening of those important bonds. This deception is unnecessary and may impact Blake’s further investment in his treatment. Therefore, if Dr. Conrad is truly acting in Blake’s best interest, he should *want* and actively seek Blake’s assent; such agreement could improve Blake’s chances of success.

In this case, we recommend that Dr. Conrad be up front with Blake and allow him reasonable time to ponder his options. If Blake persists in his hesitancy, Dr. Conrad can negotiate by offering Blake the option of stopping treatment at any point after its commencement. This plan would highlight for Blake that he and his doctor are actually partners. Allowing this type of negotiation to continue throughout the course of chemotherapy and radiation treatments would provide Blake, despite his illness, some control and autonomy while simultaneously letting Dr. Conrad accomplish his goal of getting the treatment started.

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