ETHICS ROUNDS

An 8-Year-Old Foster Child With Behavioral Problems Who Needs a Bone Marrow Transplant

Patients who undergo bone marrow transplant (BMT) must adhere to a complex follow-up regimen. Nonadherence may lead to graft failure and death. Serious psychological disorders that interfere with the recovery process may be a contraindication to BMT. This issue’s “Ethics Rounds” raises issues about whether psychosocial issues should ever disqualify a child from receiving a transplant. Respondents are Maureen Kelley, PhD, a philosopher and bioethicist at the University of Washington School of Medicine and Seattle Children’s Hospital; Yoram Unguru, MD, MS, MA, a pediatric hematologist/oncologist and bioethicist at the Herman & Walter Samuelson Children’s Hospital at Sinai and Johns Hopkins Berman Institute of Bioethics; and G. Douglas Myers, MD, a hematopoietic stem cell transplant (HSCT) physician at Children’s Mercy Hospital.

PART I

Case Presentation

B.K. is an 8-year-old boy with relapsed acute myelogenous leukemia (AML) and multiple social and psychiatric problems. B.K. has been a ward of the state since 3 years of age when his single mother lost parental rights due to substance abuse. The father is not known. B.K. has been in and out of 3 foster homes, including a medical group home during his first treatment of AML at age 5 years. He was diagnosed by a psychiatrist as having attachment disorder. He is currently in the inpatient psychiatry unit given behavioral difficulties exhibited when on the oncology ward, including aggression and temper fits. B.K. is very intelligent and often asks direct questions about his illness. He has become very close to 1 of the psychiatry nurses, who has considered offering temporary medical foster care for B.K.

He has no relatives other than his mother. A court-appointed guardian ad litem and a state case worker are charged with making medical decisions on his behalf. They report that there is no immediate prospect for foster placement for B.K. given his medical and behavioral issues. The recommended treatment is a related matched-donor BMT. With his subtype (nucleophosmin 1 mutation), he would have a ≥60% 5-year survival probability. His predicted 5-year survival with an unrelated human leukocyte antigen (HLA)-matched donor is 30% to 50%. Without a transplant, he will die. A donor who is a near match has been identified.

The oncologist wonders whether a BMT for a child with little social support would be “adding insult to injury” and subjecting the child to...
more suffering and uncertain ultimate benefit. He also feels it would be unethical to put B.K. through a second round of induction chemotherapy if there is no hope of him undergoing the transplant. The oncologist calls for an ethics consultation, asking whether it is appropriate to consider the patient's social situation in weighing the risks and benefits of transplant.

Maureen Kelley

Although the medical and social facts of this case are complicated, the answer to the central ethical question posed here seems clear: B.K. deserves the same chance for survival that any child with this prognosis would be offered, regardless of his tragic social situation. I would go even further: because of his particularly vulnerable social position, those involved in his care have a greater obligation to advocate for his interests than they might if B.K. had parents to advocate on his behalf.

B.K.'s clinical prognosis seems sufficiently good that, but for his social situation, it is hard to imagine any physician recommending against a transplant, particularly with a matched donor. Few, I would guess, would even permit his parents to refuse, if he had parents to make decisions. If, sadly, his prognosis were to significantly worsen (eg, if he were to suffer another relapse or the severe adverse effects of graft-versus-host disease [GVHD]), discussing a shift to palliative care would make more sense in light of his suffering and decreased prospect of cure. At this stage of his illness, however, there seems a great deal that can still be done, a reasonable chance of cure, and a nearly definite chance of dying with no treatment. Shifting to palliative care at this stage would not be ethically appropriate for a child with parental support. It should not be considered for B.K.

Of course, this is not to ignore the oncologist's concerns. Children who undergo BMT need parental support. The oncologist raises the concern that the high morbidity treatment may "add insult to injury." Being sick, having to come to a hospital, and go through painful treatments, even with parents and family as support, is a tough road for any child. It is especially heartbreaking for a child such as B.K. who has probably already been through so much. B.K. will certainly have a tougher road ahead than he would have with a parent by his side. That does not mean that he should be allowed to die.

What would add insult to injury would be if B.K. were to lose his fight with cancer by default, without a concerted effort by all involved to create a surrogate family around him. The question is not whether to aggressively treat his AML but how to provide him with the psychosocial support that he will need during treatment.

The way to do that is straightforward. First, talk to him. B.K. is 8 years old and by all accounts a smart child. What does he understand and want? What are his fears? What comforts him? Are there more constructive outlets for his anger, healthy distractions, or strategies for avoiding his trigger points? Many children in our care act out, hide medication, deny symptoms, and have tantrums, and seasoned staff are very good at providing compassionate care in the face of even the most challenging behavior. The case mentions that B.K. is in the inpatient psychiatric ward and that 1 of the nurses there has considered fostering him. The psychiatric nursing staff are likely more comfortable and skilled at caring for children with his behavioral issues. They might consider cross-staffing nurses between psychiatry and oncology. With these types of strategies, B.K.'s behavioral problems might be manageable.

It is also important to appreciate the reasons for acting out in children such as B.K. His behavior is common with children who have suffered transience, neglect, and often abuse associated with a life in and out of foster and group homes. Although concerns about non-compliance sometimes justify denial or delay of solid organ transplants in competent adults, they do not justify similar responses to a child. B.K. exhibits attention-seeking, negative behavior because he is hungry for affection and attention, not because he is irresponsible.

Yoram Unguru

Good ethics starts with good facts and from the facts in this case, it would seem that B.K.'s chances of survival are not very good. Chances of survival are worse after a relapse. Conversely, children with the nucleophosmin 1 mutation have a better prognosis than others.1

The treatment of choice for relapsed AML is an HSCT from an HLA-matched related donor. Although we are told that B.K. has a "near match," we do not know the extent of mismatch. Additionally, we are not told what stem cell source is being pursued (marrow, peripheral blood, or umbilical cord blood). These are important questions because they affect both the potential success of the transplant and its toxicities, as unrelated-transplants are associated with a higher likelihood of graft rejection and a greater degree of GVHD.

The transplant team's requirement for a stable home is not unreasonable. Rigid adherence with the posttransplant medication regimen and regular follow-up are critical to guarantee success. In the immediate posttransplant period, children often require multiple medications and frequent clinic visits. Accordingly, a successful transplant is a joint endeavor simultaneously dependent on health care providers and patients/families. An unstable home environment makes B.K.'s prognosis worse than it would be in

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a stable home. It is appropriate for the team to be concerned that nonadherence with the posttransplant regimen and B.K.’s “issues” will jeopardize the transplant’s success and thus cause B.K. much pain and suffering with no compensatory benefit. However, in light of his poor prognosis without HSCT, it is morally problematic to categorically refuse B.K. a potentially life-saving and nonexperimental therapy merely on the basis of his social situation. “Social situation” is a vague and loaded term. I would like to know what exactly the team means by “social situation.” Do they mean B.K.’s lack of a stable home environment? His psychiatric diagnoses? Is the team’s quasi-refusal to transplant based on a gut feeling or previous experience with children in similar situations in whom transplant was more difficult? How do they weigh these psychosocial risk factors against B.K.’s own wishes and preferences?

As presented, it seems that the transplant team has not met B.K. Perhaps the team would consider meeting this “intelligent” boy who seemingly appreciates what it means to have relapsed AML and in doing so, they might reconsider their alternatives. B.K. is portrayed as inquisitive and interested in knowing about his disease. Has anyone asked him what he understands of his current status in general and transplant specifically? Has he had an opportunity to express his thoughts and wishes with regard to ongoing care? This is imperative before making any decision.

The overriding factor that should drive the decision is B.K.’s well-being (and not others’ interests). B.K. is at no fault for his mother’s behaviors and his predicament. Accordingly, refusing him care because of “social issues” is punishing him for something for which he is not to blame and is a path preferably not embarked on. Before deciding to proceed with the transplant, if they have not already done so, the transplant team should formulate objective criteria that qualify or disqualify a child from proceeding with the procedure.

Perhaps the lengthy hospitalization after HSCT (typically on the order of ≈30 days) might be used to educate B.K. regarding the importance of compliance. It is also important to remember that B.K. has a potential ally in the psychiatric nurse who is considering becoming his temporary guardian. On discharge from a transplant unit, children often need to be in close proximity to the hospital for ongoing care. Instead of returning home, many children temporarily live at a Ronald McDonald House or similar facility. Thus, staying in a Ronald McDonald House can serve dual purposes. First, by virtue of being in a stable and trusted facility, the transplant team can feel better about B.K.’s post-HSCT course. Second, this time can afford B.K. and the nurse an opportunity to strengthen their relationship outside the psychiatry unit, in a safe and neutral environment.

C. Douglas Myers

The oncologist’s question has 2 parts. The first part is relatively easy to answer; the second, not so simple. First, is it appropriate to consider the patient’s highly unstable and uncertain social situation in weighing the risks and benefits of proceeding with the BMT? In my opinion, it is not only appropriate but essential to consider all barriers to proper care, including donor availability and the availability of proper caretakers. It is essential to consider who will be responsible for delivery of essential medications to prevent GVHD and infections. Someone will have to be responsible for getting B.K. to up to 3 outpatient visits each week for an undetermined period of time. Identifying the person or entity responsible for this is essential. It is only fair to commit/expose the child to the upfront conditioning regimen, as well as transplant and posttransplant complications, if careful consideration has been given to this issue.

The job is not easy. It is difficult to prepare even the most emotionally stable family, with parents fully dedicated to and bonded to the child, for the potential complications during and after the transplant. Even in the most ideal situation (ie, matched sibling donor transplant for a nonmalignant condition such as severe aplastic anemia) there is a level of uncertainty about how much care will be required in the years after the transplant even if the child survives treatment. It is difficult to presume that the potential medical foster mother identified in the case could be adequately prepared for the potential difficult outcomes. Long-term (years) commitment to medication delivery, clinic visits, and even multiple admissions to the hospital could be required. Given this possibility, it would be necessary to discuss with this individual the level to which she would commit. Even with this commitment, foster care can be terminated by the foster parents at any time. This possibility should be considered.

Part 2 of the question is more difficult to answer. Should these psychosocial considerations lead to a recommendation that a transplant should not be performed? To me, that turns on the prognosis. I would want to know more about the donor. Clarification of “nearly matched HLA-matched donor” would be necessary for any attempt at calculations of potential complications posttransplant. There may be significant differences in outcomes between donor sources at individual institutions (eg, mismatched adult unrelated...
donor; 5/6, 4/6, or 3/6 cord blood; double cord blood). One could consider the biomedical mother as a haploidentical donor. For context, many institutions do not offer this form of transplant because of the significant complications that can arise after transplant from a donor with only half of the HLAs matched.

We have performed transplants in a number of children with behavioral disorders and absent parents. The outcomes have been positive in regard to their emotional and psychological outcomes. I find it hard to argue that social status can alone be grounds for denial of a standard of care to children.

For me, much more would hinge on the medical variables, particularly the donor source, which would change the likelihood of long-term survival and the potential for chronic, severe/systemic GVHD. If the prognosis for survival was sufficiently low, that would sway me not to offer transplant, especially in a case such as this with significant psychosocial risk factors.

PART II

Case Presentation

The ethics consultants’ opinion was that the patient should not be denied a BMT on the grounds of an unstable social situation. Instead, they recommended that the hospital and state agencies work to find an immediate medical foster placement. The state case worker and guardian ad litem insisted that they were trying but could not identify a suitable medical foster home. They were clearly overburdened, did not know B.K. well, did not feel comfortable making “life and death decisions” for a child they did not know, and preferred to follow “whatever decision the oncologist thinks is best.” The oncologist, in turn, feels this is placing too heavy a burden on him. Who should make decisions for B.K.?

Yoram Unguru

Decisions concerning care are best made independent of social criteria; consequently, the ethics team should be commended for their recommendation to proceed with HSCT. The question of who should make decisions on B.K.’s behalf, the state or B.K.’s pediatric oncologist, demands a basic appreciation of the limits of proxy consent. Parental authority is not absolute and when a parent’s decision is not in a child’s best interest, the doctrine of parens patriae allows the state to intervene and act as a “surrogate parent” for those who cannot care for or protect themselves.

The moral rationale behind this legal practice is that children are simultaneously members of their own family and members of the larger community. The state has authority to intervene when parents fail to protect family members who are also community members. It is troubling, but not unusual, that B.K.’s case worker and guardian ad litem do not know him well, especially as he has been in state custody for 5 years.

This case highlights the distinction between recommending a treatment and actually deciding on and accepting responsibility, something typically reserved for parents. Based on B.K.’s best interest, his oncologist has already indicated his preference to proceed with HSCT, a potentially life-saving therapy. The oncologist must now decide if he is willing to shoulder the burden for this decision. His reticence is understandable.

In addressing the question of who should make decisions for B.K., the ethical virtue of fidelity, and the ethical concept of a fiduciary, are helpful. Physicians serve as fiduciary of their patient. In this role, they are morally obligated to protect the interests and promote the health of their patients. This ethical tenet can be traced back to the Scottish physician/ethicist, John Gregory. This is especially true in B.K.’s case as he lacks a trustee; his mother is unable to decide for him, and his court-appointed guardian is unwilling to make decisions on his behalf. Fidelity, on the other hand, calls for placing the patient’s interests first, ahead of the physician’s personal interests, and is the basis for a meaningful therapeutic relationship.

The American Academy of Pediatrics, in the spirit of Gregory, has stated, “Pediatrician’s duties to their patient are independent of parental wishes or proxy consent.” Following this dictum in this case, the pediatric oncologist must assume and bear responsibility for making decisions on B.K.’s behalf. A less desirable alternative is for the ethics committee to collectively make decisions for him. However, given his oncologist’s long-standing relationship with B.K., I believe that the pediatric oncologist is best-suited to represent B.K.’s interests and to decide for him while the state continues the search for an appropriate foster family for B.K.

C. Douglas Myers

The state has “charged” the guardian ad litem and case worker with making medical decisions; an unfortunate and difficult position, but a position they are obliged to fulfill. A discussion within the state institution may have to take place regarding moving up the chain of command for decision-making on behalf of the child, but a decision must be made. It is not unreasonable for the state workers to decide to move forward or cancel transplant plans based on the recommendation of the medical team.

The oncologist and transplant physicians will have to come together to make a recommendation regarding whether to proceed with the transplant. The recommendation should consider the patient’s pretransplant comorbidities, the donor source and degree of
match, and risk of disease relapse. Anticipated outpatient medication compliance risk and foster care status will likely play a role in the length of hospital stay.

Based on the facts presented, the most likely course for B.K. after a transplant is that of an intense 1 to 3 months of therapy followed by improvement. There will be a slight chance that the course for this child would be 1 of severe posttransplant illness and long-term, debilitating complications. Relapse and palliative care after transplant would likely take a course similar to that which the child would experience without a transplant. If a medical foster home cannot be found, B.K. should stay in the hospital. Patients should not be discharged until they are medically ready and there is a stable environment available. This policy extends not only to transplant patients but to patients hospitalized for months or years in an intensive care nursery, for example, who may have periods during their stay of indeterminate discharge disposition.

Although it seems that a recommendation will make the decision, it is still a recommendation on which the state will have to make the decision. The state will determine if the guardian ad litem/case worker will decide or if their protocol will require upper level or judicial overview and approval of the final decision.

Maureen Kelly

B.K. is adrift within a complex health system and overwhelmed child protection system. He could easily fall through the cracks, not because people want him to but because when too many people share responsibility, nobody has responsibility. For a child living as a ward of the state it is common to have several adults involved in health care decisions and to lack a clear, single decision-maker. The guardian and state social worker are responsible for making treatment decisions in the place of a parent, until B.K. has a permanent home. What the oncologist and medical team need to appreciate are the limitations of that role.

Court-appointed guardians and state social workers are usually responsible for multiple children at a time, and, unlike parents or foster parents, they may be scarce at the bedside. More important, they may not know the child well, making it difficult to speak for his best interests. They need the clinician’s help making difficult choices.

Good parents are fierce advocates for their children because they care only for their children. B.K. needs such an advocate. Instead, he has multiple advocates, none of whom is primarily focused on him. It may be time to bring B.K.’s mother back into the picture. What is the status of her recovery? Is she capable of supervised hospital visits? Even a parent who has lost custody may be involved in medical decisions at the hospital. She may be the advocate that he needs. If she cannot step up, then the clinicians must.

Social support is critical to the clinical success and emotional well-being of all patients, and especially children. In that sense, the team has to consider these facts very carefully in crafting a care plan and thinking creatively about how to address these challenges to give B.K. the best chance for success with his cancer treatment, and the care and emotional support to aid in his recovery. The measure of a good society is how well it treats its most vulnerable members. This case shows what is at stake for one child when the social safety net is in tatters. But that should not be an excuse for the physicians, nurses, and hospital administrators. Instead, it should be a call to action. B.K. has had an unfair start in life and a hard journey. He likely faces an even tougher road ahead. But he deserves the loving support and care that any child deserves. He deserves a fighting chance.

Editor’s Comments

The consensus among the experts in this case likely reflects a consensus of societal opinion about a case such as this. Simply put, children must not be denied access to potentially life-saving treatments because of their parents’ inadequacies or because of their own psychological problems. The treatments for such children can be challenging, expensive, and emotionally draining. We must rise to those challenges and pay the costs. B.K. underwent his transplant, and a foster family was found to care for him during and after the transplant.

—John D. Lantos, Section Editor

REFERENCES


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