

# Social Work Ethics and Values Considered in the Case of a 15-Year- Old Leukemia Patient Facing Peripheral Blood Stem Cell Transplantation

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## Abstract

The application of social work values and ethics, as defined by the NASW Code of Ethics (1999), in work with a 15-year-old acute lymphoblastic leukemia patient facing the possibility of Peripheral Blood Stem Cell Transplantation (PBSCT) is explored. Highlighted are issues common in pediatric medical social work: both the constant reconsideration of who to define as the primary client, the patient or the parents, and the intricacies of working on a medical interdisciplinary team. Also considered are the legally defined medical decision-making rights of a minor. Following the outlining of several possible courses of action, one scenario is presented as the best course to follow.

*Key Words:* social work ethics, social work values, medical social work, peripheral blood stem cell transplantation (PBSCT), Code of Ethics, rights of a minor, interdisciplinary team

## Introduction

Josiah is a 15-year-old male who has spent the majority of his past eleven years in and out of treatment for acute lymphoblastic leukemia (ALL). His last hope of cure is peripheral blood stem cell transplantation (PBSCT), a newer procedure that has a survival rate of only 40% for children with disease histories like Josiah's. Whereas both Josiah's parents and his medical team are interested in pursuing PBSCT, Josiah current desire is to cease any further attempts at cure. Wanting to serve both Josiah and his parents while also considering the desires of Josiah's medical team, how should a social worker proceed in her work with this family?

## Presenting Information

Josiah was diagnosed with ALL when he was 45 months old. His medical history includes three years of initial chemo and radiation therapies, 28 months of remission, and a relapse at age nine. From ages nine to fourteen, Josiah received both highly aggressive and more moderate chemo

and radiation therapies, depending on the lymphoblast cell count in his blood. However, during that time, he was never completely blast free.

For the past seven months, Josiah's health has worsened. His absolute neutrophil count, used to measure the body's ability to withstand infection, is erratic and can drop quickly and unexpectedly. He often develops fevers, twice he has contracted infections around his right atrial catheter, and he is now starting to show signs of kidney and possible liver failure. Of the past 245 days, he has spent 193 of them on the pediatric in-patient floor of one of Boston's leading teaching hospitals, and for almost half that time, he has been in isolation.

### **Identifying Information and Emotional Health History**

Josiah is the third of three boys born to a middle-income couple. Although his two older brothers are both away at college--one a freshman, one a senior--he is well supported by his entire family: his parents are actively involved in all his medical care and decision-making, both his brothers call and write him frequently, and his maternal grandparents visit him in the hospital two to three times per week. Josiah also has peer support in his two or three friends who contact him regularly and, in his classmates, who ran a fund-raiser for him five months ago.

Throughout the time since his relapse, Josiah has had to battle mild to moderate depression. According to his parents, before his initial diagnosis, Josiah was an active child who found great excitement in outdoor activities. He loved to explore the nearby forest with his brothers and to act out imagined stories in his backyard with his friends. Once he became sick and was diagnosed with ALL, Josiah was often isolated from his germ-carrying friends and sheltered from the more rambunctious activities of his older brothers. Further, his debilitating treatments and frequent hospitalizations over the years have kept Josiah from successfully participating in the sports and other extra-curricular activities in which his peers have partaken. His thwarted efforts at participation have left him unwilling to try new activities or even hope for a day when circumstances would permit otherwise.

Frequent treatments and hospitalizations have also hindered Josiah's efforts at schoolwork, forcing him to repeat a grade twice in his academic career. While Josiah's delayed emotional development as a result of his chronic illness has enabled him to relate well to his current classmates, the fact of twice failing to move up to the next grade has negatively affected his self-esteem. Josiah claims that he now feels most at ease when he is at home, either alone or with a

couple of close friends in his room, or when his brothers come home on holiday. Every other situation tends to bring anxiety about what might happen next physiologically or sadness about everything he is unable to do.

### **Introduction of PBSCT for Josiah**

The current dilemma in Josiah's treatment is regarding whether or not he should undergo PBSCT. PBSCT is a procedure found to help restore a cancer patient's bone marrow stem cells (hematopoietic stem cells) that were destroyed either by high-dose chemo and radiation therapies or by the ALL itself. The hope in the procedure is that the transplanted healthy bone marrow stem cells will restore the marrow's ability to create healthy blood cells and platelets rather than cancerous lymphoblast cells, thereby eradicating the cancer (NCI, 2004, pp.1-2).

Talk of using this procedure for Josiah was initiated by the attending physicians who recognized the excitement and potential success of this newer procedure. Josiah's parents joined in the conversation as they saw the procedure as their only hope for chasing Josiah's leukemia into complete remission. Even Josiah entertained the idea, as he regarded it as his ticket back to a normal life, one that might be free from painful procedures and instead be full of typical adolescent activities. The talk went far enough to find an unrelated donor who is a good match for Josiah.

The physicians focused their talks of interventions on PBSCT, because while the benefits of conducting this procedure over a more traditional bone marrow transplant are few, they are significant. First, while the process of harvesting the hematopoietic stem cells is longer in PBSCT, it is less invasive and thereby less painful for the donor. Further, the donor requires no anesthesia for this process, eliminating the risks associated with anesthesia (NCI, 2004, p.4). Finally, the process overall is somewhat less costly, as recovery times for the recipient are generally quicker, reducing hospital stays and thereby hospital fees (NCI, 2004, p.6).

Stem cell transplants are not, however, without their difficulties and risks. The process alone is difficult, as it requires multiple weeks of hospitalization in which the patient's body has to not only recover from the high-dose pre-transplant radiation and chemotherapies given to kill the last of the blast cells, but also accept and adapt to the foreign cells being introduced into it. Further difficulty comes in managing the cost of PBSCT. Lengthy hospital stays coupled with the technologically complex procedures (from harvesting cells from the donor through to the frequent blood tests of the patient) make PBSCT expensive. Costs can range from \$700 for blood testing

the donor to \$25,000 for stem cell procurement (NMDP, 2005, pp.1-2). Typically, insurance companies only partially cover PBSCT procedures.

Moreover, PBSCT poses a number of risks for the patient. First, it is successful only 40% of the time in patients with relapsed ALL that has never again gone into complete remission (NMDP, 2005, p.3). Thus, the patient risks the emotional and psychological devastation that can follow enduring a long and difficult recovery process that does not produce hoped-for results.

Graft-versus-host disease (GVH) is another possible risk. GVH occurs when donated stem cells are perceived by the patient's white blood cells as foreign invaders and are, therefore, attacked. This disease is more likely when the donor is unrelated to the patient, as in Josiah's case, and can cause liver, skin, and intestinal damage (NCI, 2004, p.5).

Finally, the patient faces potential long-term risks that accompany high dose pre-transplant radiation and chemotherapies, such as infertility, cataracts, secondary cancers, and damage to multiple body organs (NCI, 2004, p.5). Because of all of the aforementioned risks, and because Josiah's blast count never went into complete remission, talk of PBSCT has never reached the final decision to proceed.

### **Presenting Problem**

Despite the potential risks, within the past four months, Josiah's medical team has again intensified its pursuit of this procedure. The attending physicians now feel PBSCT is the only possible chance of cure for Josiah. However, in doctor's rounds, these physicians also have confided their desire to increase the number of PBSCTs performed at the hospital. This desire stems from the fact that the hospital's inclusion in the Children's Oncology Group (COG) is currently in question; they feel that an increase in the frequency of use of this procedure will lead to an increase in its chances of remaining a member of COG.

Josiah's parents also are still interested in pursuing PBSCT. They recognize that all other treatment options have been tried and have been, thus far, unsuccessful in leading to cure. They see PBSCT as their last hope for saving Josiah's life. Whereas they are emotionally close to their other sons, they claim a special connection to Josiah, their baby. Once while discussing the possibility of Josiah's death, his mother admitted to the social worker her fear of becoming an empty nester and her willingness to do just about anything to preserve Josiah's life.

The complication comes, however, in that Josiah is no longer interested in pursuing PBSCT. He has stated a lack of desire to endure the risky procedure and difficult recovery when he feels fairly certain that it will not cure him. When asked about this lack of hope he stated, “Nothing else has worked. Why should this?” He fears that more physiological complications will further hinder his already diminished capabilities.

Josiah has also communicated some discomfort around the mandated isolation during PBSCT recovery. He already carries a sense of isolation from the life he observes happening around him. He finds that while he enjoys his family, his friends, and his time at school, it is more the enjoyment of being entertained by what is going on around him than the enjoyment of participating in it. In his words, *life feels like something I get to watch but not be a part of. Whenever I am at school or even with my family, I feel like people like me and everything, but I’m not really one of them. I’m not ever going to be like them and I’m not going to ever do the same stuff they do.* Even Josiah’s involvement in cancer support groups has not provided him with a strong feeling of inclusion. While participating, he finds himself saddened both by the children who have died and by the ones who, unlike himself, have stayed in remission. He has stated, *even if this does work, I’ll still be different. I’ll still be on the outside. What’s the point?*

These thoughts Josiah has voiced only to the social worker and nobody else on his medical decision-making team. With his parents and the physicians, he states that he understands the details of PBSCT, without ever indicating his lack of desire for pursuing it. The social worker has raised the issue of Josiah’s lack of desire with the attending physicians, in the hope of facilitating conversation among the medical staff, Josiah, and Josiah’s parents. However, their response has been more dismissing, believing that Josiah is too young to make that decision and that his depression is keeping him from wanting PBSCT. They believe that they only need the parents to agree to the procedure to be able to go forward. Further, they have suggested the need to act quickly, as Josiah’s blast counts are currently low, and have requested that the social worker immediately begin helping Josiah’s parents both to fill out necessary paperwork and to procure the funds needed to cover procedural costs.

### **Ethical Challenges to Social Work Values**

The social worker must now decide how to go forward. What is the course of action that will best promote the interests of the patient, family members, and intervening medical team?

Several scenarios are possible. However, she will need to consider how each scenario ethically challenges significant social work values.

### **Value 1: Commitment to Clients**

The NASW *Code of Ethics* (the *Code*) stipulates that a social worker's first responsibility is to promote the well-being of clients; the client's interests are primary (NASW, 1999, p.5). However, in the case of Josiah, as is often true in pediatric social work, the social worker serves both the pediatric patient and the patient's family members, primarily the parents. Who, then, is the primary client in this setting, the patient or the parents? Whose well-being needs to be promoted? These questions become most poignant when promoting one party's well-being might mean compromising that of the other. In this situation, Josiah's parents' well-being could be compromised by watching him die when they believe they could have saved his life, or Josiah's well-being could be compromised by enduring yet another treatment and long recovery that might again prove unsuccessful.

One consideration in determining the definition of the client in Josiah's case is the medical decision-making rights of a minor. Could Josiah's desires legally override those of his parents? In December 1991, the regulations of the Patient Self Determination Act, which Congress had passed in 1990, went into effect. These regulations specified that patients have the right to make choices and decisions about the types and extent of medical care they wish for themselves (Hays, 2003, p.1). However, that act does not specify how these regulations pertain to minors and their ability to decide.

The state of Massachusetts, however, provides a bit more guidance, its courts having adopted the mature minor rule. Even though the age of majority in Massachusetts is legally 18, the mature minor rule allows for doctors to follow the desires of a minor if they believe that the child 1) is mature enough and 2) is able to give informed consent to the medical care (Children's, p.6). This latter stipulation, however, brings up the question of competency.

Competency must be considered from three angles: developmental achievement, emotional health, and knowledge capacity. With Josiah, the first two of these angles draw his competency into question. First, the length of his illness has caused some delays in his emotional development. When other children were starting the process of emotionally detaching from their parents and attaching instead to peers and other adults outside the home (teachers, coaches, friends, parents, etc.), Josiah was emotionally dependent upon his parents to help him through the bouts of sickness

and painful medical treatments. Further, because his times of interacting with peers and other adults outside the home were interrupted or limited by sickness and hospitalizations, Josiah has had less experience in forming those attachments than his same-aged peers. He has now reached the emotional developmental level of a 12- or 13-year-old, placing him approximately two years behind his chronological age. The question for Josiah becomes, then, not one of the emotional capacities of a 15-year-old for making a decision between life and death, but one of a 12-year-old.

Second, Josiah's emotional health can be currently defined as depressed. A common manifestation of depression is hopelessness, and without hope, it is difficult if not impossible for a chronically ill person to fight the battle of ongoing treatments and treatment complications. Josiah seemingly is no longer willing to face a life of medical complications, and he has little hope that any treatment is going to bring a life of cure and freedom from the complications. Is this recent state of hopelessness negatively affecting his ability to make a well thought out and rational decision about the procedure?

A third consideration of competency, knowledge capacity, is a strength for Josiah. His capacity for retaining and understanding knowledge about his condition seems to indicate a realistic understanding of his situation. From the earliest days of his treatments, Josiah's medical teams included nurses, child life specialists, and social workers who all worked to educate Josiah about everything that was happening to him, helping him feel more a participant in his treatments and less a victim. That early education created Josiah's tendency to ask questions and expect answers. Josiah's parents, as well, generally made an effort to answer his questions and to include him in the medical process whenever they felt it appropriate. After eleven years of dealing with leukemia, its complications, and the world of medicine surrounding it, Josiah appears to comprehend all of the ramifications of his current circumstances. Although he has not directly stated that he wants to die, he has stated that he knows of the likelihood of imminent death without PBSCT. His affect indicates no immediate concern with this understanding. Is this comprehension enough to warrant his right to decide to die?

Even if it is decided that Josiah is not mature or competent enough to make his own medical decisions, the *Code* does stipulate that social workers should take reasonable steps to safeguard the interests and rights of those clients who lack decision-making capacity (p.10). Thus, the social worker must still commit to bridging any divergent interests of the patient and the patient's family.

## **Value 2: Self-determination**

Also stipulated within the *Code* is the social workers responsibility to promote the client's socially responsible self-determination, assisting him/her in identifying, clarifying, and pursuing his/her personal goals (NASW, 1999, p.5). Again, when multiple clients are involved, the same question arises: who is the primary client, and therein, whose goals should be identified, clarified, and pursued? This question is especially poignant when differing goals appear to conflict, as in the case of Josiah and his family. And even when a primary client can be identified, an important consideration is whether the client's desired acts of self-determination can be considered socially responsible.

Josiah's current determination is to stop medical interventions and allow his life to take its natural course toward death. However, it may be considered socially unacceptable for him to inflict his parents with grief and guilt of whether they did everything possible to save his life. Further, it could be questioned whether it is ethical to allow him to decide to make such a decision at a time of emotional depression.

The current determination of Josiah's parents, on the other hand, is to do everything possible to preserve his life. However, this option poses a number of ethical questions. One question is whether it is socially responsible to use limited medical technology resources on someone with Josiah's poor survival prognosis when they could be used on another patient with a better chance of survival. A second question to consider is whether it is in Josiah's parents' best interest to incur significant financial debt to pay for this procedure, especially if it is not successful. A final question to consider is whether it is socially acceptable for them to force their son through a difficult procedure that he has no desire of enduring.

## **Value 3: Privacy and confidentiality**

The *Code* also requires that social workers protect the confidentiality of all information obtained in the course of professional service, except for compelling reasons (NASW, 1999, p.7). During private counseling times with the social worker, Josiah confided his desire to forego PBSCT. He also stated that he does not want his parents to know of his desire because it will generate a lengthy discussion toward which he has no energy to contribute. Although the social worker knows that communicating Josiah's desires could slow proceedings enough to address her concerns about his emotional state, she believes that Josiah would feel betrayed if she did so

without his consent. She also hears him say that currently he would rather do whatever he is told than to be forced into a lengthy discussion over divergent goals. The dilemma comes in that the social worker believes that without breaking confidentiality and telling his parents, they will continue along with the physicians to push PBSCT to happen quickly. Such a pace will mean little time to get Josiah on board with their decision to go ahead with the treatment, or them on board with Josiah's decision to decline.

#### **Value 4: Respect of medical colleagues and the interdisciplinary team process**

Also stipulated within the *Code* is the need of social workers to respect the qualifications, views, and obligations of their colleagues. Further, it stipulates that social workers who are members of an interdisciplinary team should participate in and contribute to decisions that affect the well-being of the client (NASW, 1999, p.11-12). In the case of Josiah, do these two stipulations conflict with each other? For instance, in respecting her medical colleagues, the social worker needs to consider their obligation to the hospital. Could the hospital be sued by Josiah's parents if they do not perform PBSCT? In addition, she needs to consider that their medical qualifications might merit her simply agreeing with them that PBSCT is a good thing for Josiah's family to try. However, if she remains silent in deference to her colleagues' qualifications and obligations, she could then fail in her responsibility to contribute to the team. Further, if she remains silent and Josiah is forced into PBSCT, she could be jeopardizing Josiah's emotional well-being.

#### **Possible Courses of Action**

The aforementioned values are all pertinent to Josiah's situation. All are important, yet it is impossible for all to be upheld simultaneously. Below are possible courses of action the social worker could take. Outlined within them are the ethical dilemmas created in trying to uphold these values.

##### **Course 1: Say nothing more**

In following this course, the social worker would follow the direction of the attending physicians. She would work with Josiah's parents to begin the process of filling out paperwork and procuring needed funds. She would help educate his parents about resources that may be helpful to them after the procedure, but never tell them of Josiah's desires. Moreover, she would continue to work with Josiah in addressing his depression and finding him sources of social support outside his family.

The social worker could only choose this course if she believes that it is in Josiah's best interest to go through with PBSCT and if she believes that Josiah's level of emotional development and state of health preclude him from having a voice in his medical decisions. This course of action would allow the social worker to uphold the values of respecting the self-determination of the parents and holding confidential the desires Josiah has shared. Further, it would allow her to respect her colleagues' qualifications and obligations to the hospital by not questioning their reasoning for going forward with the PBSCT, and she would be allowing them to do so in a timely manner. Finally, it would allow her to uphold the value of commitment to both Josiah as her client, in working to address his depression and his need of social supports, and Josiah's parents as her client, helping them proceed with the procedure they desire to pursue.

However, this course of action would not allow the social worker to support Josiah's self-determination: his desire to forego PBSCT would be ignored. By so overlooking his desires, catering to his current apathy, and allowing him to be forced into PBSCT, the social worker may be allowing a situation wherein Josiah's depression would worsen to the point of complete withdrawal. Such an emotional state could undermine Josiah's recovery. This course of action, too, would draw into question whether, by being completely silent about Josiah's desires and her concerns about his emotional health, the social worker was truly upholding her responsibility to contribute to the interdisciplinary team.

### **Course 2: Keep Josiah's desires before the medical team**

In this course of action, the social worker would communicate first to Josiah's medical team and then to Josiah's parents the importance of Josiah having more voice in what happens to him; chances of recovery improve if Josiah is more emotionally invested in the process than he currently is. In order to communicate this fully, the social worker would need either to explain or to convince Josiah to explain that he is currently not interested in pursuing this treatment. If more time were then granted, the social worker would spend more time in educating Josiah's parents about the ramifications of both PBSCT complications and possible death than in providing them resource management support. The social worker would also continue to do work with Josiah surrounding his depression while also encouraging him to stay open to the possibility of pursuing PBSCT.

Because asking for more time before proceeding with PBSCT could mean losing the opportunity to perform this procedure if Josiah's condition worsened, the social worker will choose this course of action only if she believes that in Josiah's current emotional state PBSCT either has little chance of success or runs the risk of tipping his precarious emotional well-being toward further decline. She would also need to believe that even at his level of emotional development and state of health, he should have some voice in medical decisions. This course of action would allow the social worker to uphold her commitment to supporting Josiah as her client in making sure his voice was heard, to respect her colleagues in trying to bring them to agreement first before going to Josiah's parents, and to fulfill her responsibilities in contributing to the interdisciplinary team. Further, it would allow her to uphold her commitment to Josiah's parents as her clients in working to prepare them emotionally for the potential risks of PBSCT, while also still supporting their desire to keep the option of PBSCT alive.

However, in choosing this course of action, the social worker might have to break confidentiality by telling Josiah's parents his desires without first getting his consent to do so. This breach could have long-lasting ramifications on her continued work with him, negatively affecting her efforts at getting him past his depression and able to embrace the idea of yet pursuing PBSCT.

### **Course 3: Talk to Josiah's parents about his desires**

In this course of action, the social worker would first communicate Josiah's desires to his parents in order to convince them to give Josiah more time, and to ask them to convince the physicians to do the same. After so doing, she would then approach the physicians with Josiah's parents' new conviction and her concerns. Simultaneously she would begin conversations with Josiah and his parents together, with the intention of getting them to a place of agreement and understanding. These conversations might also include the physicians, depending on their initial responses to her expressed concerns. As in the first two courses of action, she would continue work with Josiah in addressing his depression.

Again, because she would recognize that waiting to start the procedure poses the risk of losing the opportunity to perform PBSCT, the social worker would choose to speak first to Josiah's parents only if she again has serious questions about the viability of PBSCT for Josiah. She would also need to believe that even at Josiah's level of emotional development and state of health he should have some voice in medical decisions. To choose this course of action, she would also have

to believe that the only way to convince the physicians to give Josiah more time is to first convince his parents and then have them work to convince the physicians. This course of action would allow the social worker to uphold her commitment to Josiah as her client in making sure that his desires are heard and that he is able to exercise his right to self-determination. It would also allow her to uphold her commitment to Josiah's parents by helping them work with Josiah to emotionally prepare together for the possibility of giving up on treatments.

With this course of action, however, the social worker would not be upholding many social work values. She would have to breach confidentiality in talking to Josiah's parents, again putting at risk her relationship with Josiah. She would also show a lack of respect for her colleagues by first approaching the parents, thereby potentially undermining the physicians' relationship with them. Further, she would not be upholding her responsibility as a member of the interdisciplinary team by working counter to the team's desires, and not working to find agreement before going ahead with her plans.

### **Best Course of Action**

Keeping Josiah's desires before the medical team appears to be the best course of action in this case. Although it holds the risk of both losing the window of opportunity for PBSCT and causing a serious breach in the social worker's relationship with Josiah, it yet contains the most promise for providing the best support to Josiah and his parents while also upholding social work values and responsibilities.

For Josiah, this course of action gives him the sense of having his voice heard and heeded, while also recognizing that his level of emotional development and state of health preclude him from having complete control over deciding between life and death. Also, should the work around his depression prove at all successful, it gives him the best chance at successful recovery, as he will have more emotional energy to put toward recovery. Further, it allows him the opportunity to work with his parents in preparing for what lies ahead rather than feeling isolated either by being forced to comply with their desires or by forcing them to comply with his. It also allows him to feel like a participant in the procedure rather than a victim. Finally, it gives Josiah one last possible chance at living life for at least a couple of years, a possibility he would not have without PBSCT. The focus of the work with Josiah would be his depression and helping him envision a more positive, yet realistic, life post-PBSCT.

For Josiah's parents, this course of action upholds their determination to go through with PBSCT while also allowing them to work with their son, not simply decide for him. However, it would also help them prepare for the emotional difficulties that may come if the procedure is unsuccessful. Part of the focus of the work with Josiah's parents would be to help his mother address the issues underlying her grief of becoming an empty nester.

For the interdisciplinary team, this course of action allows the social worker to respect her colleagues' position to do the PBSCT, but also gives her space to contribute to the team by asking that the procedure wait until Josiah receives more treatment for his depression.

Although there are many benefits that come with this course of action, the risk of the broken relationship between Josiah and the social worker is worthy of serious consideration. If that breach becomes irreparable, it could undermine efforts to alleviate his depression, rendering him unable to ever fully embrace PBSCT and to find hope in a post-PBSCT life. However, that risk could be diminished if Josiah first talks through his fears and hesitations with his parents, the medical team, and a psychiatrist. It could also be diminished if he felt a sense of self-determination in the process. And, again, giving Josiah time to become emotionally stronger might mean that the window of opportunity to perform PBSCT will close and Josiah will not get that one last chance at longer life. However, even if that happened, stepping through the process more slowly and intentionally, with all players in mind, has the promise of leading to a better ending, an ending wherein all those involved are left a bit less emotionally scathed than might otherwise be true.

## **Conclusion**

As for a social worker in any other setting, the decisions facing a medical social worker are rarely, if ever, of black and white simplicity. Rather, the complexities of most cases bring shades of gray that not only dictate thorough analysis of all possible ramifications but also mean often choosing an option that promises a less than ideal outcome for a client. However, by taking time to carefully consider the legal and ethical issues as well as the social work values pertinent to her client's situation, the medical social worker can more confidently make a decision, believing that though it might not be ideal, it is a significantly positive step toward the psychosocial well-being of all involved.

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