The Patient "Failed" or Did She? How a Transplantation Patient and a Donor's Unmet Psychosocial Needs Became the Catalyst for Change

In 1995, my beloved sister, a social worker, died from complications after two bone marrow transplants. This narrative addresses the absence of needed psychosocial services before, during, and after transplantation for my sister and for me, her donor. While these unmet needs were disempowering at the time, subsequently I have become a policy advocate for psychosocial services for bone marrow transplant patients and their families. The narrative describes the events as they occurred my sister, the patient, and to me, her donor before, during, and after the process of transplantation.

by Joan Berzoff

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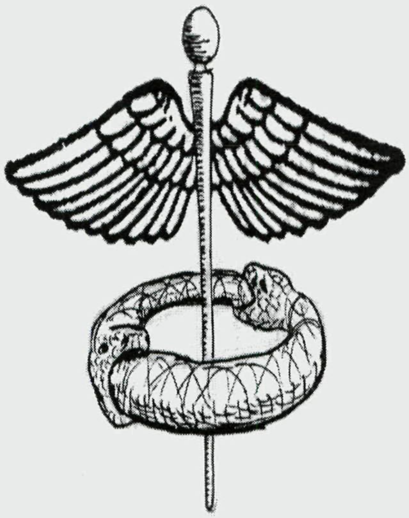


Two years ago, I donated my bone marrow for my sister with myelodysplastic syndrome. She was among the one percent of patients whose leukemia had been caused by the chemotherapy she had received a number of years before for breast cancer. The breast cancer was cured, but the treatment was going to kill her.

My sister, like me, was a social worker. A mother of three children, she was beautiful, bright, vibrant. Forty-seven years old, she walked five miles a day, had wild frizzy hair, wore purple scarves around her shoulders, big earrings, long skirts, big coats. She lived vigorously and generously. In one hand, she held the hands of her three children; the other hand balanced bundles of groceries and a briefcase, metaphors for the multiple demands in her life. This was a woman who loved the outdoors. She planted a garden every spring which blossomed pink, fuchsia, and red, defying the concrete and rock pavement which dominated the uninviting urban landscape where she lived. Her family, like that garden, grew similarly. Despite their many difficulties, her children leaned toward her as if she were their bright and sustaining sunshine. She had a spirit, a vibrancy, and an empathy which was magnetic. Unlike me, she radiated a contentment and peace with her life and its fortunes.

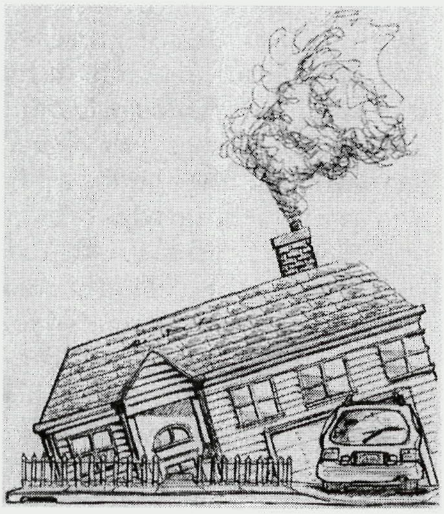
The oncologist who had been following her for her breast cancer was unable to convey to my sister that her deadly diagnosis had resulted from the chemotherapy which she had administered. Rather, for two years, her doctor used euphemisms. Shaking her head, she would lament that my sister's "bloods were bad," with vague reference to some indefinite future time in which a bone marrow transplantation might be necessary. Perhaps because the doctor and patient were so close in age, in life stage, and in social roles, coupled with my sister's fears of knowing, her physician did not reveal the obvious and very painful truth between them: that my sister had a fatal illness and the only hope of survival would be through a bone marrow transplant. When my sister finally developed a cough which persisted, she consulted my physician who bluntly gave her his diagnosis and prognosis.

When she was given her deadly diagnosis, her reaction was absolute and fatalistic. She was sure that she would die and equally sure that the recommended bone marrow transplant would kill her sooner were she to undertake it immediately. She understood that she probably had no more than two years to live, but wanted to see her daughter bat mitzvahed, to be able to choose an appropriate school for her son, and to be alive to see her other daughter graduate from high school. She was clear that she wanted to seek every and all alternative treatments first. She was absolutely clear that she did not want to become a cog in the wheel of a major teaching and research hospital where she, as a person, would not be treated well.

With her fatal diagnosis now manifestly clear, my sister and I drove directly to the city where her oncologist practiced. In our three-hour car ride, we faced the ending of her life and the almost infinite losses which lay before us. Between the folk songs of freedom we sang on that journey, we tried to name the losses: of her children, for her children, for me my dearest friend, for both of us our shared history. Singing love songs and lullabies, belting out songs of freedom, we drove on.

Her oncologist made time to see us but conveyed that there was only one treatment now and it must be done immediately. Since I had earlier been tested and found to be a perfect match, she instructed my sister to check into the cancer center in her city and begin the process leading to transplantation. When my sister made it clear that she was not ready, her oncologist suggested that her own capacity to be helpful was over.

My sister embarked on a combination of experimental chemotherapy and Eastern medicine, and her own resolve did keep her alive long enough to choose a school for her son, see her daughter bat mitzvahed, and see her other daughter graduate. But over the next two years, her friends, family, and physicians, knowing that there was no other hope for her long-term survival, mounted increasing pressure for her to undergo the bone marrow transplantation. Despite her clarity that this was both a procedure and a process which would rob her of any choice about the way she would die, she became increasingly isolated in not wanting to die a high tech death. At the end of two years, feeling trapped, hopeless, and even suicidal, she reluctantly agreed to the procedure, knowing that the legacy of having not tried to save her own life would have been equally damaging to her family.



The Pre-Transplantation Experience

My sister entered a highly prestigious, world-renowned cancer center in the spring of 1995. There was as thorough and rigorous an examination of her disease process as was possible. But noticeable by its absence was any evaluation of the patient's dread and fear. When she signed an informed consent cataloguing almost every catastrophic event which might befall her, both her doctors and the bone marrow coordinator seemed oblivious to the terror which accompanied hearing about potential outcomes of the transplantation itself: graft vs. host disease, the destruction of her organs—liver, heart, reproductive, or brain. In fact, when she met with the bone marrow transplantation surgeon and expressed some of her negative feelings, he became furious with her, clearly unappreciative of the profound ambivalence which had brought her to this place.

Why was she so ambivalent? Had one inquired, this was a woman on whom many depended. Her marriage to an attorney was in disarray. A self-preoccupied man, her husband had been chronically unable to care for himself or for others outside of the office setting. He did not know how to warm his food in the microwave, take out the garbage, open the mail, or pay a bill, and depended upon his wife to execute every one of life's details. Now feeling abandoned, he railed increasingly at my ill sister for her insufficient care of him. He put ads in magazines seeking a new romantic partner to replace her. Sometimes he would not come home at night. Her 14-year-old daughter, sensing that the control and organization which had bound their family was now imperiled, began to over control her eating, becoming anorexic, frail, and weak, like her mother. Her eldest daughter, 17 years old, acted out and smoked cigarettes in places where she was sure to be caught, unconsciously perhaps hoping to rally her mother as she had so many times before. My sister, who had previously met the needs and demands of her family so thoroughly, simply could not meet them now, nor could she envision becoming a dependent herself.

Why else was my sister so fatalistic and seemingly unable to maintain hope? In fact, she was about to turn 49, the very age that our grandfather had died of tuberculosis and the same age that our father had died of sarcolymphoma. Ironically, my sister's children were exactly the ages that we, as children, had been at the time of our father's death. What was the meaning of having a fatal illness, when, at the same age as her eldest daughter, she too had lost a parent in the family where the center could not hold? Was some of her pessimism still bound up with the helplessness and hopelessness from so many years back when her own sense of security and well being had been shattered by loss? Sadly, these questions were not asked nor their answers solicited as she entered into the cancer care center's system.

A deadly diagnosis is traumatic to any individual. Being offered a treatment which in itself may be deadly is especially so. But transplantation does not just deplete the emotions. It also threatens to deplete other resources—both economic and social. For example, bone marrow transplantation is financially costly. By the time my sister died, we calculated that her hospital bill came to over one million, two hundred thousand dollars. She was lucky. Her insurance paid the bill, and she was allowed to die with needed inpatient medical services. Yet, at no time prior to her transplantation was the trauma of the procedure nor the depletion of her resources addressed or acknowledged.

The Process of Transplantation

I had been, not surprisingly, a perfect bone marrow match for my sister: our sensibilities and bodies uncannily twin-like. She chose to undergo the procedure in the summer, coinciding with the opening of the Clinical Doctoral Program which I co-direct: a rigorous academic experience of ten weeks for which students gather from all over the country to study residentially. As both a co-director of the Program and a teacher of three courses, it is normally a very stressful time.

My sister elected to have her transplant in the city in which she lived, a three-hour drive from my home. When I met with the head of her transplant team (for whom I waited over three hours), I asked him, as I had the bone marrow coordinator, about the reality of managing the demands of my career, my two children, and the commute to donate for my sister. He ignored my questions and answered me in a language replete with medical jargon with which I was unfamiliar. There was no literature to translate what he had said, nor to help me to anticipate the process. No one prepared me for the physical pain. No one talked with me about the side effects: anemia, exhaustion, difficulty with my own bones. The donors whom I located myself to talk with were a pessimistic lot. In my small sample of five, each had had a sibling die during the process of transplantation. None had felt that, were they to make the choice again, they would recommend a bone marrow transplant for their sibling. This message was disheartening.

My donation to my sister was done on an outpatient basis because her insurer did not cover a stay overnight. It might have been reasonable for the hospital to have offered overnight care to an out-of-town donor. Despite my having asked for an antiemetic, the request was forgotten, and I spent a sleepless night in a hotel, vomiting and in pain. But my school was beginning, and by the next day, I was driven three hours to my home. Within that day, however, my sister had her first crisis, and I was called to return to her city to give platelets. Since

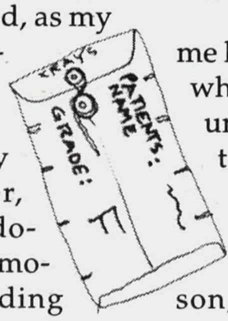
I could not drive, I needed to identify someone to do so, another hotel to stay in, and a way to try to recover so that I could return to teach. Of course, had I known that this might be a scene which was to be reenacted 16 times in the ensuing weeks and months, I might have made very different choices regarding my own life and career that summer. Sixteen hotels, two thousand dollars: what happens to those donors whose financial resources are such that they cannot manage such accommodations?

My sister's first trip to ICU, only a day after the donation, came after her having bled into her lungs. She remained on a ventilator for ten days. Her second trip to the ICU, somewhere in the middle of the summer, was the result of a pneumonia; her third and last trip to the ICU was the result of a stroke.

Halfway into the summer, I was called to do a second bone marrow donation. The first had not taken. I was tired, worn, anxious, and desperate to do anything that might reverse what had now become a nightmare course. My own body ached, as did hers, but neither she nor I experienced an acknowledgment of our difficulties—emotional, financial, or physical—and the ways in which they intersected. This was a time when the emotional aspects of transplantation needed to be addressed for both my sister and her family, and me, her donor, and my family.

After the second donation, I was to stay in a hotel across the street from her hospital. Physically unable to get across the street, I sat on the curb, wondering how, and why, as a donor, a simple wheelchair or nurse were not available. As my own psychological needs to plan and anticipate had been ignored, so too were the simple meeting of physical needs. Like the patient, I had become an organ, but not a person with an organ.

By now, my own two children, then five and nine, were angry at my many absences. I was, myself, quite overwhelmed. Indeed, as my sister began to decline, so too did her family's functioning. Still there was no way to address—for her, her family, or her donor—the very real emotional events unfolding before us.



The inpatient nurses during my sister's five months were both present and caring. But her isolation was profound. Family and friends were masked, gloved, and gowned, stripping them of their identities in order to keep her room germ free. The result of wearing a mask is that it covers up the subtleties of a smile, a frown, a grimace. It masks the feelings. My sister had no access to other patients, no closed circuit TV in which to share this experience with patients also enduring it. How shortsighted and ultimately costly it seemed not to provide forms of human relatedness during transplantation which might have offered some hope, lessened her loneliness, and decreased her helplessness!

By the end of almost five months, this vibrant, beautiful woman, had had a stroke. The hematologist thought the high doses of cyclosporin were to blame. The transplant surgeon thought the patient's first lung bleed had been the original cause of her "failure." Now she was paralyzed and cognitively impaired, her worst fears realized, her worst nightmare actualized. She had become the very mass of non-responsive flesh she had most dreaded becoming.

She had, early on, named me her health care proxy, and so when the next medical disaster unfolded, I made the decision to make no further interventions. She went into a coma and died along with the summer, her favorite season, and the frost of the fall upon us.

Following her death, as prior to her transplantation, there was no follow up for her family or her donor. In the lexicon of medicine, "The patient had failed."

Post Transplantation: From Victim to Advocate

After my sister's death, I re ceived a condolence card from the hematologist and one from the bone marrow coordinator. No one called her family. As there had been no intervention in the crisis facing her husband and three children, there was no follow up help to deal with the aftermath. To my knowledge, the psychosocial aspects of the case were never reviewed.

There was no opportunity to ask what could have been done, how it might it have been better. The case was closed.

For many months after my sister's death, I struggled with the need to express the ways in which her physical needs had been attended to brilliantly but her psychological and social needs had been largely ignored. Should I write an editorial, a letter to her cancer care center, meet with her physicians or with the social work service?

Returning from a conference on the West Coast, I was randomly seated next to a traveler reading *The National Bone Marrow Register*. Since this is unlikely reading for any passenger, and given that we were in for a long flight, I asked whether she or a loved one was about to undergo a bone marrow transplant. In fact, as it turned out, she was the coordinator for the Department of Health and Human Services Division on Transplantation returning from a meeting in which the unmet psychological and social needs of transplantation patients had been the topic.

Six hours later, and many miles traveled, my story and my sister's had become a coherent one in which the absolute need for psychosocial services for donor and patient became clear. I found myself advocating for psychosocial assessment of every patient, family, and donor the need for training of physicians and other personnel regarding the range of feeling encountered and the provision of services—physical, emotional, and economic—for patients and their families.

One week later, my fellow passenger invited me to participate in the first two-day National Policy Forum on Bone Marrow Transplantation in Washington, DC. Without hesitation, and despite another academic summer just beginning, I was glad to participate.

About 150 invited attendees were assembled, many of whom were surgeons, oncologists, ethicists, lawyers, historians, anthropologists, sociologists, and survivors. I was the only bone marrow donor represented. By the end of two intense days working on the psychosocial needs for bone marrow donors and recipients, our small working group made policy recommendations for the psychosocial assessment and intervention for every patient and donor in all three stages of the transplantation process. The formerly unmetabolized experiences of my sister's illness and death were becoming crystallized into national protocol.

Following that meeting, I was invited to give the keynote address to the first collaborative meeting between the Directors of Managed Care and the Directors of Transplantation in the nation's capitol. Again, my story was now taking new meaning and form again. Our seemingly private struggle to deal with overwhelming psychic pain had now become public: a powerful tool to effect change. Soon thereafter, I shared the podium at the tenth anniversary of The National Marrow Donor Network in Minneapolis, Minnesota, where I lectured along with an articulate bone marrow survivor who, like me, told a story of the absolute need for psychosocial assessment and interventions before, during, and after transplantation. While our stories were different in outcome, our processes were hauntingly similar. Every possible physical pathology had been fully attended to, but in each of our cases the patient and donor were left out of the process.

I continue to speak out as an advocate for changing national protocol in marrow transplantation, at professional meetings and on boards, and each time that I invoke my sister's and my own isolation, ambivalence, fear, hopelessness, and dread, I recognize again that I am the living member of the family who can tell her story. It is not, as her doctor suggested, that the patient "failed," but that her experiences succeeded in beginning to secure for others what she could not have for herself. □