

Humanities: Art, Language, and Spirituality in Health Care

Series Editors: Christina M. Puchalski, MD, MS, and Charles G. Sasser, MD

Spiritual Distress Manifested in a Teenager After a Stem Cell Transplant



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A mother and nurse 20 years after her son's tragic death, after a high-risk stem cell transplant, learns that his major behavioral changes while in strict isolation came under the term of spiritual distress. Through her personal experience, the writer describes how her son's thoughts and feelings were expressed in behaviors, atypical for his usual demeanor.

This article highlights the importance and value of healthcare providers listening to a parent's perceptions of their child's state of mind.

Atypical behavior could be a manifestation of spiritual distress and requires further assessment from the health care team. *J Pain Symptom Manage* 2020;60:176–178. © 2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

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Spiritual distress, pediatric spiritual pain, pediatric oncology, spiritual assessment, pediatric transplantation, pediatric end-of-life

They say that parents know their child best. I agree with this premise, especially when the child is seriously ill. The following story highlights how a parent's intuition should be taken seriously by health care professionals when it comes to a seriously ill child.

Our family was in a complicated situation when our 15-year-old son, David, was in strict isolation, after a high-risk stem cell transplant in 2000, at a prestigious children's cancer center. After being in remission for three and a half years, David's leukemia had returned and was more aggressive than before. We were unable to find a perfect match for a bone marrow transplant, and his only chance for survival was to receive allogeneic donor stem cells from his 10-year-old sister, Sarah, who was a near match. The procedure would be performed using a T-cell depletion, which ideally minimizes complications, especially from graft-versus-host disease. Before receiving the stem cells, our son's immune system had to be medically eradicated by total body irradiation to prepare him for the specialized procedure. Our daughter's donor stem cells were

collected via apheresis, underwent treatment for the T-cell depletion, and were infused into our son. We then waited to see if the stem cells would regenerate and adjust to being in their new host. Sarah's transfused stem cells would become David's new immune system. He would remain in strict isolation until his platelet and other critical blood counts emerged—which took approximately 28 days. Anyone entering his room had to wash their hands meticulously, don a gown and gloves, and wear a cap and booties. Being quarantined like that had a profound effect on David's state of mind.

Around the second week after receiving his sister's stem cells, David's personality began to change. Our once easy-going, good-natured son soon started acting belligerently and was confrontational with the health care team. His change in behavior was unsettling, but the doctors and nurses assured us this was very normal for a child in strict isolation. My heart told me something different. I sensed he had concerns about his mortality and needed someone to talk to

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share his feelings. We called in a psychiatrist, but he could not decipher what was bothering David even after I told him my thoughts on the problem. None of the health care team members wanted to have this challenging conversation. Finally, in total desperation, I pleaded with David's favorite doctor to talk to him. The doctor appeared reluctant to have this dialogue, but we pressed on until he complied. We watch as he apprehensively entered David's room. Three hours later, he re-emerged. He appeared utterly exhausted and admitted to us that David had many philosophical questions about life. He then walked away like a defeated boxer. My husband and I then looked at each other apprehensively and wondered how David would behave after such an intense discussion. We entered his room, ready for whatever came our way. To our astonishment, David was sitting up in bed and displaying one of his magical smiles. It appeared as though a heavy burden had been lifted from his shoulders.

Seven months after having this existential conversation with the pediatric transplant physician, David died from complications from graft-versus-host disease, an *Aspergillus* infection, and multiorgan failure. The trauma of his death was so profound that we decided as a family to relocate to London to start a new life for our daughter, a new job for my husband, and for me to heal privately and on my own terms. There were just too many reminders of what we had been through if we stayed in our hometown.

My husband and I founded the Kanarek Family Foundation in 2006 as a way to pay tribute to David's memory and honor the man he could have become. The mission of the foundation is "to improve the quality of life for those affected by cancer and other serious, life-threatening conditions through the promotion, education, and integration of palliative and supportive care into all aspects of health care."

Our projects to date have included pediatric and young adult palliative care curriculum integration into Fairfield University School of Nursing (Fairfield, CT), financing the reorganization of their masters of nursing program to include stronger leadership components and establishing an advanced communication module for nurse practitioners caring for pediatric patients at Memorial Sloan Kettering Cancer Center in New York City by utilizing live actors for simulation. In 2017, the Kanarek Center for Palliative Care was established at the newly unveiled Egan School of Nursing at Fairfield University; the goal was to introduce all nursing students to the concepts of palliative care throughout their nursing education. There, they learn the fundamental components of palliative care, from birth to death, through didactic classes, clinical experience, simulation, and in-depth classroom discussion.

It was in this center two years later, in the spring of 2019, that I heard Christina Puchalski, MD, explain the role of spirituality in palliative care at a symposium at Fairfield University School of Nursing. Dr. Puchalski was the keynote speaker—and I sat in the back of the room, eager to hear what she would say. She described her work developing an Interprofessional Spiritual Care Education Curriculum (ISPEC) for adult patients at George Washington Institute for Spirituality and Health with Betty Ferrell RN, PhD, from the City of Hope in Los Angeles.

Imagine, to my surprise, Dr. Puchalski began discussing the behavioral manifestations that adult patients demonstrated when experiencing spiritual distress. All the symptoms she described were those that David had displayed 20 years before when he was in strict isolation after his stem cell transplant! As she spoke, I had an epiphany—what I had guessed was David's fear of his mortality came under the term of spiritual distress. Finally, someone described an aspect of care that our son so desperately needed! At the end of Dr. Puchalski's presentation, I stood up and told everyone I had an "aha" moment and shared my story with them. Everyone in the room, including Dr. Puchalski, was aghast; we were sitting in the Center that had been established because of an unsettling memory of having no one willing to listen to a child's turmoil when they are so seriously ill. I had gone in a full circle in my healing, and it hit me like a bucket of ice water.

After that day, I spoke to a friend who also lost a child to a life-threatening illness. She acknowledged that she, too, had a similar experience with her five-year-old son before he died. The child sensed that something was wrong and became angry and inconsolable. My friend thought she had done something wrong. After I told her that her son might have experienced spiritual distress, she looked at me with a blank stare. It took several minutes for her to process the information. Then tears welled up in her eyes. She got it. Yes, her child had also gone through spiritual distress. The adult symptoms Dr. Puchalski described pertained to children as well.

I assumed David had questions about his mortality, but I now believe—a more precise term would have been that he was undergoing "spiritual distress." He had not received any emotional support or guidance from his health care team (and he was already aware of our distress and did not want to add to it) during this crucial time in his care and was suffering from lack of attentiveness to an essential part of who he was as a person. The U.S. National Consensus Project for Quality Palliative Care (4th edition, 2018) identified eight domains of care for those suffering from a serious illness; one of those domains includes

spiritual, religious, and existential issues. Palliative care was not available when David was so ill; had it been, the palliative care team may have been able to elicit what was bothering David and intervene. Although I was most grateful to the physician who did finally have the conversation with him, I am still distraught that David had to suffer and that no one was willing to take the time to decipher what was the core of the problem. The health care team appeared more concerned with his medical progress and less with his emotional distress. It was evident that once David was able to share his feelings with an essential member of his health care team, his demeanor immediately improved.

A patient's mental and emotional state of mind is a crucial indicator of how one copes with a life-threatening illness. Palliative care, as we know it today, treats the whole patient and focuses on how to best address their concerns, how to improve their quality of life and assists in prioritizing what is most important to the patient and their family. As palliative care becomes more integrated into consideration

for those who are seriously ill, it will be a foregone conclusion that rather than isolating the individual both physically and emotionally, we follow the advice of Dame Cicely Saunders, the founder of the first modern Hospice. Saunders introduced the concept of "total pain" in the 1960s, by addressing the physical, psychological, social, and existential/spiritual dimensions of distress. Anticipating that children have difficulty after transplant in strict isolation, the health care team could have initiated a discussion earlier, which would have prevented David from having to suffer needlessly and endure "spiritual distress."

It has been almost 20 years since David's death. The conversation he had with his transplant doctor when he was in strict isolation after his stem cell transplant brings me solace in knowing that David had this vital conversation and felt better after doing so. Although our family continues to grieve his loss, I am forever grateful to the doctor who courageously took the time to help our son come to terms with what he was going through.