PALLIATIVE CARE
CASE OF THE MONTH

Pain vs. Suffering

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Case: During a weekly Palliative Care Consult meeting, it was discussed that if D, a 53-year-old woman with congestive heart failure, did not receive a heart transplant within several weeks to a few months at the most, she would probably die. I felt led to visit her, even though she was not on my normal unit rounds. On the initial visit, D was welcoming when I stopped by her room. After introducing myself as a Protestant staff chaplain, I inquired about her pain. D told me how uncomfortable she was and how she felt so limited by her physical condition. When I asked how she was coping with any other areas of suffering in her life, her lips quivered and her eyes filled with tears as she told of the burdens in her soul…deep, personal stresses in her life that continued to that very day. She had tearfully vented for about an hour, as I reflectively listened and reassured her that every word was confidential and I was there for her to listen, if nothing else.

After hearing her life’s trials, it was important to let her know, as a chaplain and pastor representing Christ’s church, that God could help not only with the treatment of the pain in her heart but also with the trauma of her suffering soul. I prayed for her and the medical team that would work with her and those behind the scenes to care for her, to harvest the new heart and skillfully transplant it into her body; as well as for the opportunity to deal with some of the issues of suffering that were plaguing her. Thankfully, the issues that she was suffering from began to be addressed within her family as the real possibility of D’s death triggered the process of reconciliation. As those issues began to be resolved and forgiveness and harmony blessed her life, hope and new meaning for her life made the anticipated pain of transplant more tolerable. D was sent home with a VAD long enough to appreciate how some of the stress that existed in the home before had dissipated. Within 48 hours D was back in for her heart transplant.

Surgery went very well, and D was out of the ICU with few complications. Yet, once D was on a step-down unit and dealing with post-operative pain in her body and the anxiety and depression that ensue after transplantation, she was troubled by her years of living as a sufferer. It was reassuring when she made her suffering known. Thankfully, the issues were addressed by those that contributed to her suffering within her family, and positive changes brought meaning back into her life. D did embrace her new life with meaning and purpose, and as she healed from the pain of the transplant, it was made bearable by the liberation from suffering.

This was a process that was not resolved as in our modern media. It was assisted in by others in the Palliative Care Team, the Transplant Team, Unit Staff, Pastoral Care, Providence, and, of vital importance, D’s family members who realized D’s mortality and took ownership of her suffering and their contribution to the dysfunction in their household.

In many of the rooms of the hospital are laminated Comparative Pain Scales with 1 being expressed as ☺ demonstrating No Pain to 10 being Unbearable/Excruciating Pain. Modern technology addresses this pain well. Suffering of the soul, mind, psyche, what ever terminology you are comfortable with, also needs to be addressed with awareness and compassion. Everyone should participate. According to Thomas R. Egnew, “Suffering arises from perceptions of a threat to the integrity of personhood, relates to the meaning patients ascribe to their illness experience, and is conveyed as an intensely personal narrative.”

While the medical community has established procedures, protocols, and treatment plans that factor in typical emotional responses, suffering is personal, individual and commonly expressed as a narrative that needs the freedom and respect to be presented and the dignity to be acted on to reestablish meaning and significance. Pastoral Care is one piece of the solution, but by far, not the only piece in total patient care.

References:

For palliative care consultations please contact the Palliative Care Program at PUH/MUH, 647-7243, beeper 8511, Shadyside Dept. of Medical Ethics and Palliative Care, 623-3008, beeper 263-9041, Perioperative/ Trauma Pain 647-7243, beeper 7246, UPCI Cancer Pain Service, beeper 644 –1724, Interventional Pain 784-4000, Magee Women’s Hospital, 641-2108, beeper 917-9276, VA Palliative Care Program, 688-6178, beeper 296. For ethics consultations at UPMC Presbyterian-Montefiore, and Children’s page 958-3844. With comments about “Case of the Month” call David Barnard at 647-5701.