



Trapped Inside a Failing Body
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Case: JD is a 66-year-old African-American female with cardiomyopathy and pulmonary hypertension who has been in and out of the hospital for the past two years. She had biventricular assist devices placed in August, 2007. Since then, she has experienced numerous setbacks and subsequently has been on and off the heart-lung transplant list. Most recently, she went to the OR to have her current LVAD replaced with a smaller unit. The procedure was aborted.

JD is divorced with no children. Prior to hospital admission, she lived alone, independently, in a one-story home. A supportive brother and sister live nearby. She is very sharp, speaks her mind, and has no patience for what she perceives as incompetence or “stupidity.” She expects staff to communicate with her directly and has no tolerance for ambiguity, mixed messages or superficiality. She has alienated several of the staff who don’t meet her expectations.

Over the past couple years, I have visited JD numerous times. In my first visit, she *told* me where to sit and *told* me to read certain passages of Scripture to her. (She has taught adult Bible study and has been very active in her church). I went along with her request (i.e., “order,”) and we actually had a stimulating theological discussion. Our visit ended with prayer. After this first visit, she no longer told me what to do. In subsequent visits, she shared her life story. I found that gently kidding around with her diffused her intensity. We spent many visits with her telling me about her life from childhood on, and we’ve shared much laughter. I enjoyed celebrating with her those memories that gave her joy.

In the last few months, her emotional ups and downs have become more pronounced. She was focused on getting a heart-lung transplant, which turned out not to be an option. She faced a surgery with a questionable predicted outcome, knowing she might die on the operating table. That surgery ended up being aborted. I have seen her at all-time emotional lows as well as in periods of bouncing back. Spiritually, she says she knows that God is with her; she has “no doubts” about that. She also says she must make all decisions, including life and death decisions, on her own – without God’s help.

Interventions: The anchor in all my visits with her is prayer—prayer for guidance for her in decision making, prayer that lifts all her specific concerns and joys to God. We always hold hands in prayer, which she anticipates and appreciates. The healing aspects of this relationship are consistency and love. In the time we spend together, JD has shared precious, sometimes outrageously funny memories of her life. I have lifted up these memories to God in prayer with her, sometimes in a humorous way. My hope is that rather than compartmentalizing her spirituality she will allow God more and more into her decision making, that she will let God carry the weight of her burdens. This seems to be difficult for her, since she is so fiercely independent.

More and more, she seems now to be dealing with the prospect of her earthly life ending. While she remains trapped in a failing body with future prospects dim, she is now looking at her life with a sense of “well done, thou good and faithful servant” (*Matthew 25:21*) which is the ultimate healing.

Discussion: Addressing quality of life is essential for patients with prolonged hospital stays. Patients on LVADS or BIVADS are physically restricted. While the body may be restrained, the mind is free to roam. Well-being must be viewed holistically, with emotional and spiritual needs being addressed. One researcher found that patient coping strategies include family support, religious convictions, and diversional activities, and that best way to support these patients is to establish a trusting relationship, foster independence and incorporate humor into their care. (*Savage*)

References:

1. Savage, Laura, RN, MSN (2003) Quality of Life among Patients with a Left Ventricular Assist Device: What is New? AACN Clinical Issues 2003 Feb. 14 (1) pp.64-72
2. Savage, Laura, RN, MSN (1999) Life With a Left Ventricular Assist Device: The Patient’s Perspective American Journal of Critical Care Vol. 5, No. 5, pp. 340-343

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.