

A Culture of Comfort Palliative Care at Thomas Jefferson University Hospital

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To say that Yolanda never had much of a childhood is too easy. She was diagnosed with sickle cell disease at birth. Her mother died when she was a girl and her father never took an active role in her life. She moved into adulthood with pain requiring intravenous narcotics. And then things got worse. Her kidneys failed four months ago. Her life was constrained by her three-day-a-week dialysis appointments. Recently, she was admitted to intensive care for seizures. Today she spends more time in the hospital than home. She knows she faces an early death. And she is terrified.

Yolanda, not her real name, is a 38 year-old patient on the Palliative Care Service at Thomas Jefferson University Hospital. Palliation is synonymous with comforting; therefore palliative care optimizes quality of life by addressing physical, emotional and spiritual needs. The skill set of palliative care professionals includes pain and symptom management, communication, and finesse at planning health care post-hospitalization. Doctors and nurses on the Palliative Care Service come from family and internal medicine, geriatrics, and oncology. Jefferson physicians have consulted the team for nearly 400 hospitalized patients since the inauguration of the service in March, 2006.

The Palliative Care Service visits Yolanda to offer support and monitor her pain regimen. The team has earned her trust by being there on good days and bad. Visits from a massage therapist are arranged; scented oils and a gentle touch provide some relief. A social worker provides supportive counseling. An art therapist helps to reduce stress by providing an outlet for creative expression. Conversations with Yolanda reveal fears and wishes about the end of her life.

Many physicians avoid frank talks with patients about their prognosis so as to “keep hope alive.” Without a forecast of the chances for long-term recovery, seriously ill patients and their families often choose aggressive and futile medical treatments. Surveys report that surviving family members regret their lack of preparation for death and the memory of a “medicalized”^{1,2} death rather than a more peaceful passage for their loved one. Palliative Care Service members navigate these touchy conversations

during family meetings. They help primary physicians relay the bad news with compassion, and support goals that are both realistic and consistent with the patient's wishes.

Palliative Medicine, recently deemed a medical subspecialty, grew out of the hospice movement.³ The common thread linking palliative care and hospice is the focus on relieving symptoms of chronic illness and supporting patients and families.⁴ Palliative care supports individuals during medical treatment while hospice care targets patients in the final months of life. Outreach to grieving families closes the care loop.

Though new to Jefferson, palliative care is growing nationwide. According to the Center to Advance Palliative Care, 1,240 hospitals now have interdisciplinary palliative care teams, most often in academic medical centers.⁵ Training for health care professionals, from continuing education programs to palliative care fellowships and certification, is available at centers such as the Harvard Medical School Center for Palliative Care.

Palliative medicine administers a dose of humanity to a health care system criticized for not caring. And it cuts hospital costs, perhaps as much as \$3,000 per patient, by facilitating transitions out of acute or intensive care to more appropriate and less costly settings.³ However, hospitals will have to find a way to support this important work until a time when reimbursement for palliative care is better established.

For now, Yolanda wants to continue aggressive care. However, at the point at which medicine offers her longer life without quality, she has asked her doctors to change gears in accordance with her wishes. She relies on the Palliative Care Service to prevent pain and suffering at the end. She deserves that final dignity.

References

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