Abstract

Sharing patient values and caring for the human spirit is central to the work of palliative care teams. When deeply held spiritual beliefs, patient values, and the health care system collide, conflict is a common occurrence as in the case of a 51 year old African-American woman with advanced ovarian cancer. Faced with an incurable illness, the woman pursued curative care despite the odds of survival, and the role of spiritual care. Her beliefs and values were rooted in the Judeo-Christian tradition and she wanted to control her own care. In the face of such a difficult case, the health care team, nurses, oncologists, and palliative care clinicians, worked with the patient and her family to provide care that was congruent with her values.

Her Story: 51 year old woman with stage IV ovarian cancer

Medical History

- Extensive disease at time of diagnosis
- Disease not amenable to surgical debulking or venting gastrostomy tube
- Refused chemo. 1PP, 3 Sarcometers in 2002

Spiritual and Social History

- Sister was the primary caregiver and a minister
- One adult child, supportive local community
- Vocal about strong faith in God and belief in miracles
- Days before death, family wearing combat fatigues and prepared to “battle the devil”

Hospital Course

- Family agreed to DNR minutes before death
- Staff referred to patient’s room as “the torture chamber”
- Family expressed gratitude for care both on the day of death and subsequently

FICA Spiritual Assessment Tool

F: Faith and beliefs
- Importance of spirituality in the patient’s life

I: Importance of spirituality in the patient’s life
- Let go of outcomes (closes off our ability to see other possibilities)

C: Spiritual community support
- Do you have a spiritual community that supports you? (Church, synagogue, temple, mosque, or other)
- A: How does the patient want spiritual issues addressed in their care?
- Trapped by opposing demands
- When conflict is perceived as insurmountable, it is best to talk about end-of-life care early and often.

Trapped by Opposing Demands

- Nurses and Residents suffered distress over administering care they deemed futile
- Staff could not make sense of family demands; felt frustrated and angry
- Family grew tired and mistrustful of repeated attempts to limit treatments
- Family expressed that staff did not know or care “who the patient was” (as a person)
- Palliative care team met daily with staff to debrief and share family concerns
- Palliative care team met daily with family and presented staff viewpoint

Discussion

Palliative care teams have a reputation for excellence in facilitating communication and clarifying treatment goals. In our experience, referring physicians often perceive the palliative care team as the “pawns” or the patient or family to their point of view. As this case illustrates, the ability to remain neutral, curious, willing to listen, and empathetic was of great value to staff and family alike. Though the family and the ICU staff never reached consensus, in no way did this diminish the perception of the team’s effectiveness.

Opportunities to Explore Spirituality

- What has helped you to get through this hard time? or “What beliefs or spiritual practices are important to you?”
- Look for clues such as religious objects or books (Bible, Koran, inspirational books, etc)

References

3. Vaclav Havel