Spiritual Warfare: Moral Distress

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Abstract

Honoring 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 outcome as in the case of a 51 year old African-American woman with advanced ovarian cancer. Facing insurmountable odds for survival at the time of diagnosis, this woman pursued aggressive curative care and shunned any mention of defeat, death, and "negative talk" throughout the course of her illness. With "expect a miracle" as a literal and figurative banner during her hospitalization, her faith would not allow for discussion of prognosis, decline, or death. During the last 11 weeks of her life, spent in an ICU, her dedicated family upheld these desires for aggressive care. Nothing illustrated this commitment more than when family, dressed in combat fatigues for a bedside vigil, prepared for "battle with the devil".

Moral Distress is a common occurrence when providers are compelled to offer care that conflicts with their own values and is perceived as increasing the suffering and distress of patients. Nursing staff often referred to this patient's room as "the torture chamber". This case illustrated how the palliative care team supported both the ICU staff and the family, while respecting the family's coping style and spiritual needs.

Objectives

- ❑ Describe ways that palliative care teams can provide optimal spiritual care
- ❑ Describe ways that palliative care teams can support staff experiencing moral distress
- ❑ Describe ways that palliative care teams can facilitate conflict resolution in the setting of perceived futile care

"Hope is not the conviction that something will turn out well, but the certainty that something will make sense, regardless of how it turns out."

Vaclav Havel

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
- Received chemo, TPN, NG suction

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
- Symbols of faith, gospel music always present
- Did not allow "negative talk" about prognosis
- "Expect a miracle" sign above bed, "Jesus blanket" on bed

Hospital Course
- Remained in ICU, ventilated and unable to participate in decision-making for 75 days
- Family steadfast in desire for aggressive care
- Staff referred to patient's room as "the torture chamber"
- Days before death, family wearing combat fatigues and prepared to "battle the devil"

Outcome
- Family agrees to DNR minutes before death
- Family expressed gratitude for care both on the day of death and subsequently

Spirituality

Broadly defined, spirituality is that which gives meaning and purpose in life[1] When confronted with life-limiting illness, spirituality takes on increasing significance for many patients and families. According to Puchalski, religious beliefs are one expression of spirituality that plays an important role at the end of life.[1] Many health care professionals feel unprepared to provide spiritual care and often feel that this is best left to clergy and chaplains.[4] In this case, exploring the spiritual beliefs of the patient and family was critical in establishing trust and helping staff make sense of the situation.

Opportunities to Explore Spirituality

- **Ask** questions: "What has helped you to get through this hard time? or "What beliefs or spiritual practices are important to you?"
- **Listen** for cues that patients & families give: "All I can do now is pray", "I believe in miracles"
- **Look** for clues such as religious objects or books (Bible, Koran, inspirational books, etc)

FICA Spiritual Assessment Tool

F: *Faith* and beliefs
I: *Importance* of spirituality in the patient's life
C: Spiritual *community* support
A: How does the patient want spiritual issues *addressed* in their care

Puchalski 2002[2]

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 & mistrustful of repeated conversations aimed at limiting treatments
- Family expressed that staff did not know or care "who the patient was" (as a person)
- Palliative care team was a familiar presence when ICU nursing and physician staff rotated
- Palliative care team met daily with staff to debrief and share family concerns
- Palliative care team met daily with family and presented staff view point

Discussion

Palliative care teams have a reputation for excellence in facilitating communication and clarifying treatment goals. In our experience, the referring physician often perceives the palliative care team as the "persuader" of 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.

The role of palliative care clinicians when there is conflict and moral distress:

- Mediator: adopting an attitude of neutrality[3]
- Continuity: (when primary clinicians change)
- Debriefing: Allowing each side to be heard

Ruston suggests "pausing" and approaching ethical conflicts with space for self-reflection and careful evaluation [3]:

- Be transparent (acknowledge own biases, ambiguity)
- Evaluate your mindset (judger or a learner?)
- Monitor your own responses (am I angry, sad, defensive?)
- Ask questions (an opportunity for listening and exploring)
- Get clarification (what are the facts, avoid assumptions)
- Be open to new possibilities (what can I learn from this situation?)
- Let go of outcomes (closes off our ability to see other possibilities)
- Become a witness rather than an actor (listening and presence rather than acting out a specific stance from one point of view)

As palliative care clinicians, we must take meticulous care not to project our own emotions onto a situation or simply assign "guilt" on families who request care we deem futile. By moving cautiously and carefully, we can remain open to more than one possibility and help patients, families, and staff make sense of a situation regardless of the outcome.

References

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