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PALLIATIVE CARE CASE OF THE MONTH

"If That Was My Mother": The Danger of Quick Labeling

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Case: Mrs. O is a 94-year-old woman who was admitted from a nursing home for the fourth time in two months with congestive heart failure. The resident telephones the patient's only child, a daughter, to discuss the case. She tells him she "wants everything done." This statement is met with immediate judgmental responses from the healthcare team. The second order on the chart is for a palliative care consultation to "assist with the establishment of code status." The remainder of Mrs. O's history contains a history of end-stage heart disease with an EF of 20%, end-stage renal failure and end-stage dementia whereby she has lost her ability to swallow. The patient's daughter chose to have her father removed from a ventilator five years ago and was "given hell for it by the family." She doesn't want to face the family if she makes what they might see as the "wrong choice." The family consists of the patient's 96-year-old brother and a cousin, who is the son of this brother and a physician.

The consultant was greeted by the bedside nurse who related her opinion that the daughter "is totally unrealistic and is torturing her mother." The patient's brother told the consultant that he does not require any assistance considering the options for his sister, for his son, the doctor, is guiding this process. Finally, the consultant was able to assist the patient's daughter in arranging a family meeting whereby the uncle and nephew [MD] could ask the treating physicians questions related to the patient's diagnosis, treatment and ultimate prognosis. During this meeting the daughter of the patient deferred decision-making to her uncle and cousin. They became very uncomfortable with the shift of responsibility to them. With this level of responsibility comes a fear of doing the wrong thing, a fear of not knowing enough and the ultimate fear of making a mistake which results in death.

The brother began to cry and admitted that a great deal of his reason for wanting to keep Mrs. O alive was emotionally based, and not logical. He later admitted that he himself didn't see life on a ventilator as life. If it were for him, he would favor removal of all life-sustaining therapy. "If I were thinking logically and not emotionally, I would say, 'take her off of this machine.'" The physician-nephew agreed with his father and stated that he was only pushing for "full-care" out of his desire to make sure his father could emotionally deal with the death of his sister. With time and conversation, all agreed that Mrs. O would never want "heroic" forms of therapy. She had made her wishes clear to her caregiver (who has cared for her for the last ten years and who was present at the bedside every day), and to her primary care physician.

What became obvious was that the emotional of the situation was over clouding the logic required to solve this problem. With time and effort the consultant was able to keep part of the emotion at bay allowing for a more logically considered response to the question of code status. The patient's code status was made comfort measures only and she was removed from the ventilator, which all agreed was reasonable considering her situation. She survived extubation and was discharged to home where she died peacefully under home hospice care.

Discussion: Moral decision making is a matter of emotion and logic. Emotion is important because it is often a key to intuitions about the personal significance and meaning of the decisions that have to be made, in the lives of the people who are most affected by them. Logic is important because reasonable decisions must accommodate empirical reality, and—especially in end-of-life decision making—this requires a clear-eyed assessment of reasonable medical expectations, an ability to weigh risks and benefits, and an ability to take careful account of what is known about the preferences and values of the patient. When emotion overwhelms logic, bad, though well-intended, decisions can result.

According to psychologist and family therapist Murray Bowen, those who have a differentiated self are able to utilize logic over emotion when making complex choices (Bowen, 1985, p. 321). The degree to which our self is differentiated from the group, whether that be our family or the team with which we work, is what dictates the degree to which we can remove emotion from our decision-making, or at least keep it from overwhelming our logical, rational capacities. The truly autonomous person would be the one who is most self-determined and therefore most self-differentiated.

When working with enmeshed families, where individuals have not differentiated themselves very much, one should be prepared for decisions based firmly upon the feelings of the family and less upon the facts of the case. This applies to enmeshed treatment teams as well. Those caretakers who are unable to differentiate their role as it relates to the patient may find that they are more emotional when it comes to discussing such a case and therefore more overwhelmed. We all will be over invested at times when it comes to the patients we care for. The degree of emotion felt might serve as a good indicator of over enmeshment, and the palliative care consultant can play an important role in allowing the emotions to surface so they may be dealt with in a more open and constructive way, rather than letting them overwhelm the decision process. (Bowen, 1985, pp. 321-325; Csikai and Chaitin, 2006, pp. 122-158).

References:

Bowen, Murray 1985. *Family Therapy in Clinical Practice*. Jason Aronson Publishers Northvale, New Jersey.

Csikai, Ellen and Elizabeth Chaitin 2006. *Ethics in the End-of-Life Decisions in Social Work Practice.* Lyceum Books, Chicago.

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