

The Dance of End-of-Life Living: Creating an Inter-professional Dialogue with Family Members

Workshop: P9
Saturday, January 31, 2009
8:00 AM - Noon

Presenters:

Doctor, Renee Prince, M.D., Saint. Vincent's Hospital, Ottawa: Assistant Professor, Faculty of Medicine, University of Ottawa

Chaplain, Rebekah Hackbusch, M.A., Saint. Vincent's Hospital, Ottawa

Family Counsellor, Martin Rovers, PhD, Saint Paul University, Ottawa

Pastoral Educator (Inter-professional Coordinator): Doug Longstaffe, STM, The Ottawa Hospitals, Ottawa

The Story:

Mrs. S is a 55 year old woman diagnosed with a form of muscular dystrophy. She has lived at home with her husband, Joe, and she has one daughter, Mary, who lives independently. In 2001, Mrs. S went on ventilator support. Her illness continued to progress. With on-going home care and constant involvement of her spouse, Mrs. S remained very engaged in life. Despite an inability to move any of her limbs and an increasing inability to speak, Mrs. S continued to engage. She was hospitalized in 2007 and, as she began to consider the implications of not being able to communicate her needs, she reflected frequently on the meaning of life and death, and whether or not to continue ventilator assistance. She was informed that ceasing this treatment was her choice and that it would end her life. The patient expressed her wish to discontinue life support when she was unable to communicate verbally. Mrs. S shared these wishes with her husband and daughter and select members of her family as she was aware that not all members would support her decision. Although still able to communicate with much effort, she and her husband discussed her wishes with her attending physician. In the early spring of 2008, Mrs. S set a date for terminating treatment. Within the next month, on the date requested by Mrs. S, ventilatory support was stopped and with the help of sedation and with family at her side, the patient died quietly.

Mrs. S's husband, Joe, has always supported his wife, at first with the help of home care, and then with regular visits to the complex continuing care hospital. He was part of the family discussion about terminating treatment, and even though he grieved to think of life without his wife, he voiced that he would be supportive of his wife's wishes. He was present when ventilatory support was stopped. Mrs. S's daughter is also diagnosed with the same illness, though it has progressed much more slowly. She lives independently and was planning to marry soon: therefore wanted mom to wait until after her wedding. She expressed her opinion that she doesn't want her mother to terminate treatment, though she understands her reasons for doing so.

The Inter-Professional Team:

Doctor, Renee Prince, M.D.

Physicians are often depended upon to offer treatments to cure disease, sustain life and/or alleviate suffering. When the treatment required for sustaining life limits the desired quality of life, the door is opened to discussions about prognosis and treatment options including ethics consultations regarding the case. The hastening of death from removal of treatment is one of the realities of medicine.

Chaplain, Rebekah Hackbusch, M.A.

By nature of their role, chaplains are often looked upon as the team member most likely to invite dialogue about death. A spiritual assessment which includes an in-depth review of the life story of the patient can assist the patient, family and inter-professional team with clarifying the meaning of and attitude toward both life and death. This exploration can help to facilitate the often-times difficult dialogue that is necessary for the end-of-life decisions that are presented.

Family Counsellor, Martin Rovers, PhD

The care of aging parent(s), whether sick or dying, can cause new distress in a family system. Family members are “recruited” to do much of the caregiving and end-of-life decision making. A careful review of family of origin dynamics might better enable a family system, adult children and aging parent(s) to work through the strengths and stresses of this dance of this end-of-life living. Bowen Theory outlines relevant principles and family dynamics that may educate and prepare families for these roles.

Pastoral Educator (Inter-professional Coordinator): Doug Longstaffe, STM

The process for making a decision to initiate or discontinue artificial means of life support involves complex, often emotionally charged interactions between the actual team members themselves, as well as between the team and the patient and or family members. The successful facilitation of crucial conversations at such times is central to achieving effective outcomes. Such conversations need to be dialogical and cannot occur if team members are seeking to force agreement. Nor can dialogue occur if members are abnegating their responsibility to speak to the issue. An algorithm designed by an interdisciplinary committee for guiding a respectful decision making process will be examined, accompanied by a rationale for its use. An exploration of how degrees of self-awareness and interpersonal communication skills interface with this process to affect outcomes will be demonstrated.

Other team Members: Social Worker, Nurses,

Workshop Discussion Areas:

- 1) What is the ethics of termination of treatment?
- 2) Who has power in these cases?
- 3) What is the role of the inter-professional staff: doctor, social worker, chaplain, nursing staff, counsellor, ethicist, other allied health members?
- 4) What is the role of family, and how are they involved?
- 5) What is the best interest of the patient?
- 6) What is the process of inter-professional decision making, and what does each profession bring to the conversation?
- 7) What is the bias of each profession in regard to end of life decision making?
- 8) What is the measure of success in such a story?