ABSTRACT

We must focus on the poliomyelitis experience and the essential role of the patient to understand the history of Long Term Mechanical Ventilation (LTMV). During that time, many solutions were found by patients and their families working in partnership with physicians, other healthcare professionals and engineers. The poliomyelitis era was also the foundation of critical care and rehabilitation medicine and the source of solutions for LTMV.

But "What Ever Happened to the Polio Patient"? To gain insight about LTMV, we must revisit the polio patients and learn how they solved their long-term problems. Persons suffering from "post polio syndrome" required years of LTMV at home; they helped us to "rediscover" home mechanical ventilation. Such ventilator users and their experiences can best help us to understand the patient perspective. By reviewing the insights of the long-term ventilator user at home, we understand needs of all patients with chronic respiratory insufficiency. We understand that home care should not be considered an extension of the medical model into the home. Home care represents another "culture" with different attitudes, beliefs, values, and norms of behavior. Home care demonstrates a person-centered social concept typified by the independent living of persons with disabilities. With sensitivity to cultural differences, we can begin to understand ethical conflicts which provide an ethical foundation for all health care issues. To begin to resolve value-based conflicts, we must prioritize differing values based on ethical principles of:

1. Beneficience: professional concern for overall welfare of the patient
2. Autonomy: patient desire for appropriate freedom for self-determination

Ethical principles are the foundations for health care models (medical vs. home care) and the basis for cultural understanding among health care professionals, patients and families, and health care providers of services and resources. All participants involved must be sensitive to these cultural differences and take these differing culturally-based perceptions into account when they are communicating and working together.

Prolonged LTMV: When informed of the options, realities, and responsibilities, LTMV may be in the best interest of the patient and also the patient's choice. However, LTMV may have enormous impact on friends, families, and communities and their needs must be considered as well. LTMV has never been inexpensive, although creative models exist around the world that provide care at reduced costs. Without specific public policies to encourage designated programs and services, costs can become catastrophic to the family and society.

End-of-life Issues: If a person desires to live, and living on a ventilator provides a life they judge is worth living, there will always be a cost to society. LTMV generates costs for health care professional care, home care provider services, equipment, supplies, and technical support. Whether or not home care is an option depends whether or not and/or how funding is made available/denied to cover these costs. For people who come from different ethical perspectives to work together, they must be aware of, respect, and understand their cultural differences which, depending upon their perspective, can lead to misunderstandings. The challenge is to have cultural sensitivity and respect and work together to find ways to manage them.

Returning to Humanitarianism in Medicine: Lessons Learned from Margaret Pfrommer

Healing relationships with our patients and their families represent a sacred responsibility for physicians. Society give physician privileged roles that can make a difference in their lives and in the global health of our communities. Our potential for doing good for our patients and society must consider our tradition. That requires we respect the values of our patients, the beliefs of their families, and the ways others play a role in our healing community.
Margaret Pfrommer taught me
1. The meaning of co-partnership
2. The importance of mutual respect, trust, honor that fosters cooperation and collaboration and demands communication.
3. The need for compassion in utilizing the advances of science and applications of technology within the spirit of caring
4. The essential efforts we need as physicians to understand the patient's perspective.

TRIBUTE TO MARGARET PFROMMER (1937 - 1998): My mentor and Friend
"The Woman Who Understood No Part of the Word 'No'"
Advocate, Author, Consultant, Counselor, Rehabilitation Engineering Expert, Teacher ... giving insights to the White House, U.S. Congress, National Institutes of Health and international experts about technology needs of persons with disabilities immensely advancing their opportunities for living independently with dignity.