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End of Life Decision Making

Palliative care is defined by the World Health Organization as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."[1]

Over the past decade there has been significant growth in palliative care in the United States. In 2000, there were 600 palliative care hospital-based consultation programs; in 2005, the number rose to 1200 programs.[2] Among hospitals with over 250 beds, 70% have an in-patient palliative care consultation service.[2]

One of the key components of palliative care is to assist in improving the quality of communication and end-of-life decision making between healthcare teams and patients and their families. A growing body of research has studied the end-of-life decision making process. One such study was completed here at Jefferson by an inter-professional team of physicians, nurses, and researchers from various departments including Family and Community Medicine, the Center for Applied Research on Aging and Health (CARAH), the School of Nursing and Department of Medical Oncology. This team, with its diverse background and experience, brought a unique perspective to the complex issue of end-of-life decision making.

This two-year study, sponsored by the National Institutes of Health and the National Institute of Nursing Research (NIH/NINR),[3] examined end-of-life decision making using hypothetical illness scenarios among older people and their proxy decision makers. Two hundred two elder-proxy dyads (404 subjects) were recruited from community settings including senior centers, continuing care retirement communities, and primary care practices. Inclusion criteria for the elders were: age over 70, English-speaking, and cognition intact. The proxy criteria were: age 21 and over, English-speaking and cognitively intact. Each subject in the dyad was interviewed separately, with the elder being interviewed first. The elder named the person they would want to make decisions on their behalf if they could not and that person was considered the proxy. There did not need to be any legal designation of the proxy, such as a power of attorney document. Both subjects completed a 40-minute telephone interview including: demographics, history of advance directive completion, depression screening, telephone Mini-Mental State Exam (MMSE), an end-of-life values scale, a religiosity scale, and a modified life support preferences questionnaire.

The study team first completed an analysis of end-of-life decisions regarding only one scenario presented to the elder-proxy dyads.[4] This scenario involved advanced Alzheimer's disease. The study team was interested in this sub-analysis around dementia since it is often wrongly not perceived, either by healthcare teams or patients and their families, as a life-threatening condition. We asked both the older person and their proxy about the use of three treatment options: cardiopulmonary resuscitation (CPR), feeding tubes, and palliative care.

The elders were 74% female with a mean age of 77. The proxies were 72% female and a mean age of 60. This analysis revealed interesting preferences for end-of-life care for the hypothetical illness scenario of advanced Alzheimer's disease. Among the elders, 33.8% selected CPR, 21.3% selected tube feeding, yet 79.1% chose palliative care. Interestingly, among the proxy decision makers, 49.8% selected CPR, 43.1% selected tube feeding and 68.7% chose palliative care. Thus, the highest degree of concordance for this illness scenario was with the preference for palliative care.

These findings have interesting clinical and research implications. If the highest degree of concordance among our dyads was for palliative care within an Alzheimer's disease scenario, how would concordance between older patients and their proxies be for other diseases more traditionally viewed as terminal illnesses? This preliminary analysis points our research team toward exploring interventions that provided palliative care treatment options earlier in the course of illness and assisted families with end-of-life decision making. Additional findings from this larger grant will guide our team towards developing interventions to help enhance the end of life decision making process. ■

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