B4.1: Understanding of Advance Care Planning by Family Members of Persons Undergoing Hemodialysis

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Presentation Preference: Research Abstract

Abstract Categories:
Research Interest Groups (RIGs): Qualitative
Thematic Areas: End of Life Issues

Abstract:
Introduction: Understanding of family members’ perceptions may enhance communication among patients, their families, and health care providers and promote better end-of-life care for persons undergoing hemodialysis. The purpose of this qualitative descriptive study was to explore hemodialysis patients’ family members’ understanding of end-of-life decision making processes. The project specifically aimed to answer two research questions, based on interviews and observations of family members of hemodialysis patients: 1) What are family members’ constructions of advance care planning, including their roles and responsibilities?; and 2) What are family members’ perceptions of health care providers’ roles and responsibilities in advance care planning?

Method(s): Eighteen family members of persons undergoing hemodialysis for at least three months were recruited primarily from outpatient dialysis facilities and interviewed individually
between October 2008 and June 2009. Confirmed transcript data were analyzed, coded, compared, and categories were established. The coded schema was then applied to the entire data set. Interpretations were validated throughout the interviews and peer debriefing sessions were used at a later stage in the analysis.

**Results:** Family members of hemodialysis patients acknowledge uncertainties that make it difficult to articulate advance care plans. Strategies are developed to normalize life and avoid perceptions of rushing death. From family members' perspectives, the burdens of life on hemodialysis and the means of supporting hemodialysis patients are multifaceted. Family members of hemodialysis patients perceive health care providers’ responsibilities to include the provision of honest and accurate information within a caring and vigilant environment.

**Discussion & Conclusions:** Findings imply that family members want hemodialysis patients to feel cared for by attentive health care providers. Education about dialysis—from beginning treatment to discontinuation or death—would minimize the family member burden of independently seeking out necessary information. Further research is needed to explore advance care planning of persons undergoing hemodialysis who do not have a family support system.

**Abstract History:**
This abstract has not been presented or accepted for presentation in whole or in part at the SNRS or other scientific meeting.

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