

Palliative Care Needs in Rural Complex Chronic Illness: “Do I have to die so my daughter can have a life?”

BACKGROUND: The human and societal burdens associated with chronic illness are pronounced in Appalachia where rates of co-morbidity, disability, and premature death are among the highest in the nation. Little is known about the need for or the feasibility of integrated palliative care in rural areas. This paper reports first year findings from an ethnographic study investigating the intersection of rural culture and palliative care in complex chronic illness.

METHODS: Criterion-based sampling was employed to select 25 participants with complex chronic heart and lung conditions from home-health and hospice settings. In-depth, semi-structured interviews with participants, their caregivers, and health professionals were recorded and transcribed verbatim. Data were organized by respondent group using Atlas.TI for data management. The domains of palliative care and the concept of transition were used as a start list for semantic content analysis.

RESULTS: Navigating care structures, processes, and transitions were universally exasperating, albeit from different perspectives. Finances, personal preferences, transportation, and program eligibility were common barriers to care. Rugged individualism, realism, self-reliance, and importance of kin and place served as both barriers and facilitators to optimal care. Emergent themes included fear of progressive dependency, preferences for non-medical self-management tools, and struggle to balance needs of self and kin.

CONCLUSION: Significant disparities in rural complex chronic illness outcomes exist that are often culturally mediated. Formal care structures and processes are poorly articulated with patient and caregiver needs and preferences. These and other barriers to optimal care are complicated by geography, lack of transportation, strained health infrastructures and poor communication between lay and professional caregivers.

IMPLICATIONS: The intersection of policy and human experience emerged as an important area for further study. Such analyses are critical to interventions that aim to reduce rural health disparities and improve the quality of life for persons living with complex chronic illness.

This study is supported by funding from the National Institute for Nursing Research: 1R15NR012298-01, 2010-2013.