CLIMBING UP THE MOUNTAIN: END OF LIFE NEEDS OF PERSONS LIVING WITH HIV/AIDS IN APPALACHIAN TENNESSEE

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Purposes/Aims: The purpose of this study was to explore perceptions of end of life (EOL) needs from the viewpoints of persons living with HIV/AIDS (PLWHA), including diverse subgroups living in Appalachian TN. Specifically, we aimed to assess the EOL care and service needs across physical, psychological, social, spiritual/religious and ethical/legal domains while also accounting for the rich cultural context.

Rationale/Conceptual Basis/Background: Over the past three decades, HIV/AIDS has evolved from a terminal diagnosis to a chronic condition managed by effective pharmaceutical therapies. Despite this evolution, HIV/AIDS remains one of the leading causes of death in American adults. The disease trajectory is also complicated by other comorbid chronic conditions. As such, the emphasis on end-of-life (EOL) planning and care remains essential among PLWHA. This is critical in areas of the United States (US) where the HIV/AIDS infection rates continue to climb, such as the Appalachian region in the southeastern US. The stigma surrounding HIV is a key reason that the South is the epicenter of new HIV infections in this country. Understanding EOL needs of PLWHA in this region is complex, involving multiple sociodemographic factors as well as general lack of health services/infrastructures, and limited access due to the rural and mountainous geographic terrain. Very little is known about the needs of Appalachian PLWHA regarding their anticipation of EOL.

Methods: We employed a qualitative, descriptive design to address the study aim. Nine PLWHA (6 men; 3 women) between 34-67 years at all stages of disease participated in a single, individual semi-structured interview. Interviews were audio-taped and transcribed verbatim. NVivo 10.0 software facilitated data management and qualitative content analysis.

Results: A formative narrative about “coming back up the mountain” emerged from the data. This is a contradictory, repeated metaphor which introduces qualities of the Appalachian value system but also ambivalence, isolation, and stigma. Within this narrative, we found that PLWHA: have strong spiritual beliefs about living and dying; do not desire ‘heroic measures’ at EOL; fear pain at EOL; describe challenges to accessing services both logistically and culturally; identify a lack of and ambivalence toward hospice services; and face specific legal challenges concerning advanced care planning.

Implications for research, rural health and/or rural practice: This is the first study to examine EOL care needs of PLWHA in Appalachia; our findings begin to address a significant gap in the empirical literature pertaining to the provision of rural EOL care. Our findings reveal that Appalachian PLWHA contemplate EOL at all stages of disease; while they are aware of the need to plan for EOL, they indicate that their healthcare providers do not engage them in conversation about EOL planning or provide resources to services that will assist in their planning process. Important considerations regarding the cultural and geographic context of these findings will increase provider awareness of the specific EOL needs of PLWHA and will form the foundation for a subsequent comprehensive investigation of EOL care and service needs among PLWHA in rural, Appalachian Tennessee and Alabama that will incorporate additional epidemiologic strategies to demonstrate disparities in availability and access to care.