Barriers to Accessing Health Care for Hematopoietic Cell Transplantation Recipients Living in Rural Areas: Perspectives From Healthcare Providers

Heather K. Moore, MPH, CHES, Martha E. Burton Santibañez, MPA, Ellen M. Denzen, MS, Diane W. Carr, MPH, and Elizabeth A. Murphy, EdD, RN

Hematopoietic cell transplantation (HCT) is a curative therapy for patients with malignant and nonmalignant bone marrow disorders. Life after transplantation can vary significantly among HCT recipients, who deal with a variety of physical and emotional issues. This presents numerous challenges, particularly for rural recipients who are required to travel long distances to access specialized HCT care. The objective of this study was to better understand barriers to providing care for HCT recipients living in rural areas. This study uses a cross-sectional design to collect primary data via an Internet survey of HCT healthcare providers. The authors analyzed factors restricting post-HCT care and whether having standard post-transplantation care instructions influenced the resources provided to distant-to-care recipients. Respondents reported limited transportation, coordination of care, and distance to facility as major barriers to post-HCT care, regardless of the number of distant-to-care recipients treated annually. HCT centers with standard post-transplantation care instructions were more likely to provide visits from social workers and medical leave resources to distant-to-care recipients. These instructions may improve recipient and local provider ability to make informed decisions regarding post-HCT care. The findings will help guide the development of programs and resources targeted to recipients of HCT who are distant to care.

Hematopoietic cell transplantation (HCT) is a potentially curative but complex and resource-intensive therapy for patients with hematologic malignancies as well as other genetic and immune disorders. In the United States, 20,000 HCTs are performed annually, with an estimated 100,000 HCT survivors living in the United States (Pasquini & Wang, 2011). The number of HCT recipients is expected to grow two-to-three times by 2020 as advances in transplantation techniques and supportive care practices lead to progressive improvements in survival for recipients of HCT (Majhail, Murphy, et al., 2012). HCT is only offered at select centers with appropriate expertise, resources, and experience (Majhail et al., 2011; Majhail, Rizzo, et al., 2012). To access specialized HCT care, recipients living in rural areas have to travel long distances for appointments or temporarily relocate closer to the center. A study by Chan, Hart, and Goodman (2006) found that rural residents had to travel two-to-three times further for healthcare than their urban counterparts. A study demonstrated that distances of 160 minutes or more negatively impacted overall survival for recipients of HCT one year after transplantation, independent of other patient-, disease-, or HCT-related variables (Abou-Nassar et al., 2012).