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

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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.,
Additional factors that may contribute to inadequate HCT care for rural residents include healthcare professional shortages, no insurance or underinsurance, low income, and poor follow-up care (Bennett, Olatosi, & Probst, 2008; Gamm, Hutchinson, Dabney, & Dorsey, 2003). Recipients of HCT, their families, and their caregivers often experience significant quality-of-life issues, including physical and psychosocial challenges that begin immediately after HCT and continue into long-term survivorship (Kisch, Lenhoff, Zdravkovic, & Bolmsjö, 2012; Majhail, Rizzo, et al., 2012; Niederbacher, Them, Pinna, Vittadello, & Mantovan, 2012; Pidala, Anasetti, & Jim, 2009; Rizzo et al., 2009; Socié et al., 1999). Acute physical challenges include debilitating immune system problems, fatigue, memory and concentration problems, infertility, infections, and graft-versus-host disease (GVHD) (Pasquini & Wang, 2011; Socié et al., 1999). Long-term recipients of HCT with chronic GVHD also may face organ-specific effects and secondary cancers (Majhail, 2011; Pidala et al., 2009; Rizzo et al., 2009). Psychosocial issues after HCT include a decrease in functional well-being, diminished ability to perform everyday activities, and deterioration in social and family well-being (Kisch et al., 2012; Niederbacher et al., 2012). The medical issues faced by recipients of HCT can be frequent, intense, and persistent; therefore, specialized care is essential.

The authors inquired specifically about HCT recipients living in rural areas. A standard definition for “rural” does not exist; therefore, for guidance on establishing a definition, the authors looked to the Economic Research Service of the United States Department of Agriculture (ERS/USDA) and the National Rural Health Association (NRHA). The ERS/USDA recommended that the definition for rural be based on the activity’s objective (Cromartie & Bucholtz, 2008). Likewise, the NRHA (2013) also advised that a program’s designation for rural should be based on the reasons the program targets the population. The results of the literature review showed that distance is one of the most common factors that prevents follow-up medical care for rural residents. Therefore, the authors designated rural as “distant to care.”

The National Marrow Donor Program (NMDP) helps people get the life-saving HCT they need, when they need it, and operates the Be The Match Registry®, the world’s largest listing of potential marrow donors and donated cord blood units. NMDP Patient Services provides free services and resources for patients, families, caregivers, and healthcare providers to meet the unique needs of patients undergoing HCT and address access issues. Healthcare providers within the NMDP’s U.S. network were surveyed by the authors to gather their perspectives on barriers to specialized care for distant-to-care recipients of HCT and identify what resources, if any, they provide to facilitate access to follow-up care.
Methods

Defining “Distant to Care”

The authors consulted with eight HCT providers to better understand how their centers defined “distant to care” and determined when a patient needs to relocate to be more proximal to the transplantation center. Through informal interviews, it was learned that a universal distance requirement for relocation does not exist. Most centers consider geographic distance and traffic restrictions when determining whether a patient needs to relocate. “Two hours or more by car” was identified as inclusive of possible geographic and traffic restrictions because that distance poses potentially serious problems in accessing specialized HCT care. For the current study, distant to care refers to patients living two hours or more by car from their transplantation center.

Study Design

The survey was conducted to address recommendations from the survivorship working group of the Marrow Donor Program's Symposium on Patient Advocacy in Cellular Transplantation Therapy: Addressing Barriers to Hematopoietic Cell Transplantation. The working group comprised of HCT experts, patient advocates, research experts, and healthcare providers from across the United States.

The survey contained 13 items, including five open-ended questions. To ensure validity, the survey items were developed based on group interviews with HCT providers, anecdotal feedback from recipients of HCT, a review of the literature, and expert consensus.

This study used a cross-sectional design to collect primary data via an Internet survey from May 28 through June 19, 2009. The survey was administered to 890 HCT healthcare providers in the NMDP network of 170 transplantation centers in the United States, which included nurses, patient educators and advocates, patient insurance staff, social workers, and center coordinators. The participant sample did not include physicians. Nonphysician targets by the authors' survey typically coordinated a large part of care for recipients of HCT and the survey was not designed to query physician perspectives on distant-to-care recipients. Follow-up contacts were not made and an incentive was not offered. The study was conducted under guidance of the NMDP's institutional review board.

The authors analyzed factors that restrict access to specialized care for recipients of HCT and whether existing survivorship resources facilitate access to specialized care. The primary objective to identify factors restricting follow-up HCT care was measured by inquiring about three separate themes: the three most common factors, the three most serious factors, and whether any internal factors restricted provider ability to better care for their distant-to-care recipients. The secondary objective was assessed by inquiring whether healthcare providers consistently offered survivorship resources to recipients living distant to care and provided “standard discharge, or after-care, instructions” for recipients living distant to care. The NMDP facilitates unrelated allogeneic HCTs; therefore, the primary focus of the survey was on recipients of allogeneic HCT.

Limited Funding

“Limited funding—if we could help patients with the cost of gas, parking, and overnight stays, that would be very helpful.”

“[The] lack of ability to acquire prescription drug coverage when [a] patient is outpatient locally.”

“Patients from outside of our county may not get approval for transplant at our center or there is a delay in getting approval.”

Housing

“Funding is a tremendous factor for our transplant patients. They do not have money for the housing they need to come back to do follow-ups at the transplant center or pay the price of gas for multiple trips.”

“We do not have funds to help patients pay for guest housing; they are required to live at the guest housing for 1–2 months post-transplant if they live more than one hour from our center.”

Transportation

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Coordination of Care of Services

“Limited resources available in patient’s community . . . to provide post-transplant care [are] becoming more of a problem with insurance restrictions.”

“[There is] not always good communication or follow-up once they are discharged home, so sometimes problems aren’t addressed until they are at a near-crisis point.”

Limited Time

“Limited time to locate resources [and] weak professional linkages between distant referring physicians, [distant] specialists, and local specialists can make it very difficult to provide a quality continuity of care for patients.”

“[There is] limited time for pre- and post-transplant preparation and limited time for education for staff and patients.”

Limited Staff

“Dealing with the social issues related to one’s inability to follow-up; however, if there is a significant red flag noted during pre-transplant evaluation, such as lack of support or psychosocial instability, we will not transplant the patient.”

“The most difficult issue is the lack of supportive care available to those patients in their home communities.”

FIGURE 3. Participants’ Perceptions of Their Facilities’ Restrictions in Serving Distant-to-Care Recipients of Hematopoietic Cell Transplantation

Data Analysis

Data were recorded in Microsoft® Excel® and exported to SPSS®, version 14.0, for analysis. To ensure data quality, 10% (n = 12) of the completed surveys were randomly audited. Quantitative results were reported using descriptive statistics. Chi-square analyses were conducted for the bivariate relationship between number of distant-to-care recipients served and
resources provided. In the presentation of results, the percentages are used as the reference point rather than the actual number of survey respondents. The percentages in this report have been rounded to the nearest whole number.

The open-ended questions were analyzed separately and coded by common themes. Two experienced coders familiar with the area of study analyzed the data. The qualitative analysis process included inductive coding of the textual data line-by-line (i.e., segmenting the data into meaningful analytical units). Coded textual data were then explored using content analysis for saturation of themes. In the current study, participant quotes are used to support key themes and show the diversity of opinions. Recommendations for improvement also were analyzed qualitatively.

Results

Participants

A total of 121 individuals responded to the questionnaire (14% response rate). Among respondents, 77 (64%) self-identified as transplantation center coordinators, 36 (30%) as nurses, 13 (11%) as social workers, 6 (5%) as patient advocates, and 3 (3%) as patient insurance staff. The majority of respondents indicated that their transplantation center served more than 20 distant-to-care recipients each year (see Figure 1).

Factors Restricting Access to Follow-Up Care

Participants were asked to identify the three most common and most serious external factors restricting recipients of HCT from getting the follow-up care they need (see Figure 2). Regardless of the number of distant-to-care recipients treated annually, the same three factors were perceived by participants as both the most common and most serious factors restricting access to follow-up care. “Limited or no transportation” was rated the most common and serious factor (60% and 52%, respectively). “Post-HCT care not available at local clinic or hospital” was rated the second most common and serious factor (54% and 48%, respectively), and “clinic or hospital too far away” was rated third (47% and 47%, respectively).

Participants also were asked about the internal factors restricting their ability to better provide survivorship care (see Figure 3). Themes were identified that described internal factors restricting healthcare provider ability to serve distant-to-care recipients of HCT. Most commonly, respondents reported limited funding (24%), limited housing (17%), transportation...
Barriers to Accessing Health Care Post-Transplantation

Hematopoietic Cell Transplantation Survivorship Resources

Participants were asked if they provided resources to distant-to-care recipients of HCT and, if so, what resources they provided most frequently (see Figure 4). Eighty-six percent of participants indicated that their center had standard discharge or post-care instructions for distant-to-care recipients of HCT. “Patient education” was identified as the most frequently provided resource to distant-to-care recipients of transplantation (91%), “caregiver education” and “discharge or after-care instructions” (hereafter known as “standard after-transplantation care instructions”) were rated the second most frequently provided resources (86%), and “social work visits” was the third most frequently provided resource (73%). A statistically significant positive association occurred between having standard post-transplantation care instructions and providing visits from social workers (chi-square = 3.986, p < 0.05) and medical leave resources to distant-to-care recipients (chi-square = 8.417, p < 0.01). Medical resources may include assistance with completing and submitting forms for disability pay, legal advocacy referrals, and educational materials on medical leave.

Limitations

Several limitations exist in the current study. The survey only yielded a 14% response rate. However, the findings are consistent with barriers reported in the literature. The authors did not specifically inquire about perceived barriers in accessing follow-up HCT care among autologous (self-donor) versus allogeneic (sibling or unrelated donor) survivors; however, survival disparities and barriers did exist for recipients of both types of HCT. A study that examined outcomes of recipients undergoing autologous HCT according to primary residence found that recipients living in rural areas had a higher relative risk of death than their urban counterparts (Rao et al., 2007). A subsequent study by Loberiza et al. (2010) investigated outcomes of unrelated allogeneic HCT according to place of residence and found no survival disparities between urban and rural recipients. However, unrelated recipients of allogeneic HCT remain under the care of their HCT team for longer than autologous survivors, which could account for the differences in the findings of the two studies. Although the authors provided a definition for distant to care (two hours or more by car) in the survey instructions, the respondents might not have known how far their patients drove to access follow-up HCT care. Respondents were asked to use their best estimate when responding to the survey questions.

Conclusions

The purpose of the survey was to gather HCT provider perspectives on the barriers to accessing specialized care for recipients of HCT and identify what resources, if any, are provided to this population to facilitate access to specialized follow-up care. The respondents indicated that limited or no transportation, lack of post-transplantation care at recipients’ local clinic or hospital, and distance to their transplantation facility as the top factors restricting access to follow-up care. These findings indicate the need for post-HCT care in the recipient’s local community as well as education for local healthcare providers on the recommended screening and preventive practices for recipients (Majhail, Rizzo, et al., 2012). Similarly, a study that inquired about the educational needs of nurses working with physicians who refer patients to HCT found that respondents desired more communication from their HCT recipient centers and basic education on the HCT continuum (Tierney, Schmit-Pokorny, Sorensen, McDermott, & Devine, 2007).

In addition, facilities that had standard post-transplantation care instructions were significantly associated with providing visits from social workers and medical leave resources to distant-to-care recipients of HCT. Standard post-transplantation care instructions, also known as “survivorship care plans” for recipients of HCT are a potential solution to mediate barriers restricting recipient care while transitioning to the survivorship phase. The survivorship care plan is a customized summary document describing a patient’s cancer treatment history and potential late and long-term health effects of treatment. It also provides recommendations of surveillance for recurrence and new cancers, as well as resources about health-promoting behaviors, appropriate medical and psychosocial care, and financial assistance (Salz, Oeffinger, McCabe, Layne, & Bach, 2012). The survivorship care plan offers guidance to patients on maximizing personal health outcomes, clarifies oncologist and primary care physician roles and responsibilities, and helps protect against gaps in services (Miller, 2008). Survivorship care planning for adult recipients of HCT includes a short-term phase for the first six months after HCT and a long-term phase beginning at one year (Majhail, Rizzo, et al., 2012; Rizzo et al., 2006; Syrjala, Martin, Deeg, & Boeckh, 2007).

To address the need for customized survivorship care plans and to support non-HCT providers in successfully transitioning recipients of HCT into the survivorship phase, the NMDP

Implications for Practice

- Psychosocial care and supportive resources for distant-to-care recipients can be improved by survivorship care plans.
- Survivorship care plans help educate distant-to-care recipients on important tests and procedures throughout the transplantation continuum.
- Care plans foster communication between distant-to-care recipients and referring physicians.
developed the Post-Transplant Care Guidelines. The guidelines provide expert recommendations for screenings, tests, and psychosocial assessments for regular post-HCT checkup appointments (Majhail, Rizzo, et al., 2012). This resource can be accessed in print, electronic, and mobile formats at www.BeTheMatch.org/careguide. In addition, the authors provide a free survivorship newsletter, Living Now: A Guide to Life After Transplant, which includes a series of six issues for recipients and one exclusively for caregivers. Audiences receive the issues at specific time points—from three months to two years post-HCT. The newsletter offers tips to staying healthy as well as survivorship stories and experiences. The newsletter is available in print and online. The NMDP also provides comprehensive Web pages for patients, caregivers, and family members on transplantable diseases and treatment options at www.BeTheMatch.org/patient. Incorporating evidence-based resources and published guidelines into nursing practice can improve the care of recipients of HCT (Bevans et al., 2009; Fink, Thompson, & Bonnes, 2005; Krugman, 2010).

Despite the creation and dissemination of HCT survivorship resources, problems endure for recipients living distant to care. Although anecdotal feedback suggests that the guidelines are helpful to recipients, they have not been adapted by all HCT centers and, therefore, many recipients continue to face unmet needs with their follow-up care. The findings from this survey will be used by the NMDP to guide the development of new programs and resources targeting the barriers faced by distant-to-care recipients of HCT. Current nursing practice and future research should consider the HCT-patient transition processes in use among HCT centers in the U.S., patient preferences with the transition from HCT specialty care to local providers, the educational needs of local providers in caring for recipients of HCT, adapting the NMDP’s Post-Transplant Care Guidelines in care protocols, and continuing to evaluate the effectiveness of post-HCT resources in improving patient satisfaction with follow-up care and adherence to recommended care.

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References


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