

Original Article

Symptoms and Quality of Life in Diverse Patients Undergoing Hematopoietic Stem Cell Transplantation

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Abstract

Context. Symptoms and quality of life (QOL) are critically important in hematopoietic stem cell transplantation (HSCT). However, few studies have examined these factors by transplant type among diverse cultures.

Objectives. To identify and compare QOL and symptom severity and prevalence by transplant type in a diverse population having HSCT.

Methods. The M. D. Anderson Symptom Inventory Blood and Marrow Transplantation (MDASI-BMT) module measured symptom severity and its impact. The Functional Assessment of Cancer Therapy-Bone Marrow Transplant (FACT-BMT) measured QOL.

Results. Symptom data were collected from 164 patients at eight points (pretransplant to 100 days post-transplant) and QOL data at four times. Over time, symptom severity was significantly correlated with QOL and patients who had allogeneic transplants with myeloablative regimens showed more severe sleep disturbance and poorer QOL than patients having autologous transplants. Male patients reported less fatigue than female patients. However, ethnicity was not significant. Patients whose functional status was good had fewer of the five worst symptoms and higher QOL than patients with a poor functional status. Patients with acute graft-versus-host disease had more severe symptoms than those who did not.

Conclusion. Type of transplant and preparative regimen are the most important aspects to consider when managing symptoms and QOL. This information is important for providing anticipatory guidance and support needed during the transplantation experience, to explore in future research the mechanisms

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involved in symptoms after HSCT, and to develop additional effective interventions. *J Pain Symptom Manage* 2012;44:168–180. © 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Hematopoietic stem cell transplantation, symptoms, quality of life, ethnic diversity, transplant type

Introduction

Comprehensive reviews have examined studies of quality of life (QOL)^{1,2} and symptoms³ after hematopoietic stem cell transplantation (HSCT). Numerous studies have found both significant short- and long-term sequelae. Although patients report good overall QOL, they also report compromised aspects of QOL. Physical functioning rapidly declines after HSCT and improves after 100 days, with plateaus reported to occur between one year^{4,5} and four years.⁶ Emotional functioning is most compromised immediately before and after HSCT,⁵ with improvements over time.^{5,7} Data are conflicting about whether social functioning improves,⁸ deteriorates,⁷ or has no change.⁹ Role functioning gradually improves after an immediate decline after transplantation.⁷

Recent studies have examined symptoms in persons having autologous stem cell transplantation.^{10,11} Campagnaro et al.¹¹ used the M. D. Anderson Symptom Inventory (MDASI), and Anderson et al.¹⁰ used the MDASI Blood and Marrow Transplantation (MDASI-BMT) module. Both studies found that symptoms intensified throughout transplantation and decreased by Day 30.

Although symptoms have been examined, many of these studies are limited by small sample sizes and considerable attrition. Because transplantation protocols have changed, the earlier studies must be viewed with some caution. In addition, although health disparities in ethnic minorities have been examined, few studies have examined African American or Hispanic experiences or symptoms with HSCT. Studies have included primarily Caucasian and upper middle class patients. Serna et al.¹² reported that between 1995 and 1999, Hispanics compared with whites had lower survival one and three years after HSCT. No significant differences were found between whites and blacks

or with Asians. Survival did improve for the entire cohort over time. Loberiza et al.¹³ described the difficulties in conducting research with sufficient numbers of ethnically diverse patients to understand differences among persons having HSCT that may be based on biologic or psychosocial determinants such as the role of socioeconomic status. Whereas Bevans et al.^{5,14} had a diverse sample (35 Caucasian, 23 Hispanic, five black, seven Asian, and six “other” participants), only survivorship was reported in relation to ethnicity. Potential differences in diverse cultures underscore the importance of examining a diverse sample. In addition, most studies have included only persons who had either allogeneic or autologous transplants, and few compared these types of HSCT.

When the source of stem cells is allogeneic donors, 25%–80% of patients will experience graft-versus-host disease (GVHD). GVHD can occur in the early, acute or later stages or as chronic GVHD. Chronic GVHD usually appears 100 days after HSCT, but the timing can vary.¹⁵ Clinical manifestations of GVHD are more important criteria than time, according to the National Institutes of Health consensus criteria.¹⁶ GVHD has features of autoimmune and immunologic disorders, although the pathogenesis is not well understood.¹⁶ Treatment options are less than satisfactory but usually include additional immunosuppressants to control GVHD, which further increase the risk of infection and may cause hypertension, hyperglycemia, and muscle atrophy. In the most severe cases, GVHD is life threatening for patients as a result of infection, acute liver dysfunction, or gastrointestinal bleeding. Symptom patterns may be different for patients with GVHD compared with those without GVHD. Pidala et al.¹⁷ found that the severity of chronic GVHD was significantly associated with QOL reports, independent of other factors. The effect was found over several

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