

Quality of Life One Year Following Bone Marrow Transplantation: Psychometric Evaluation of the Quality of Life in Bone Marrow Transplant Survivors Tool

Usama S. Saleh, RN, PhD(c), and Dorothy Y. Brockopp, RN, PhD

Purpose/Objectives: To examine a comprehensive view of quality of life (QOL) post-bone marrow transplant (post-BMT) and to evaluate the psychometric properties of an instrument designed to measure QOL in this population.

Design: Cross-sectional, descriptive, mailed survey.

Setting: A large, major BMT referral center for central, eastern, and southern Kentucky.

Sample: 41 BMT survivors with an age range of 18–71 years who were an average of 30 months post-BMT.

Methods: Seven mailed questionnaires, including an investigator-developed demographic questionnaire and the Quality of Life in Bone Marrow Transplant Survivors Tool (QOL-BMT-ST).

Main Research Variables: QOL, BMT treatment, sexual activities, employment, and uncertainty.

Findings: Global QOL was good ($\bar{x} = 6.4$ on a 0–10 scale). Subjects experienced several long-term areas of concern: physical strength, sexual activities, fear of cancer recurrence, fear of developing a secondary cancer, unemployment, family distress, and uncertainty toward the future. Psychometric testing of the QOL-BMT-ST revealed adequate to excellent reliability and validity.

Conclusions: Most BMT survivors reported few long-term disruptions and above average QOL. The QOL-BMT-ST has a promising utility in clinical trials.

Implications for Nursing Practice: Individually structured pre- and post-BMT assessment of physical, psychosocial, and spiritual functioning is significant in identifying vulnerable patients and treating them accordingly.

Key Points . . .

- ▶ More than 45,000 bone marrow transplants were performed worldwide last year.
- ▶ Fear of recurrence of the original disease was the most prominent concern among a sample of cancer survivors for years following transplant.
- ▶ The Quality of Life in Bone Marrow Transplant Survivors Tool is an adequate instrument for measuring quality of life of patients post-transplant.

Literature Review

Quality of Life Post-Bone Marrow Transplant

Several investigations have concluded that BMT treatment negatively affects the quality of patients' lives. A comparison of QOL between women treated with autologous BMT for breast cancer and a "healthy" group of women of a similar age with no history of cancer showed that the post-BMT group had significantly impaired physical functioning, physical role functioning, general health, vitality, and social and emotional role functioning (Hann, Jacobsen, Kronish, Azzarello, & Fields, 1997). Hengeveld, Houtman, and Zwaan (1988) concluded that the emotional states of the 17 patients they studied were severely compromised post-BMT. Using a semi-structured phone interview, Fromm, Andrykowski, and Hunt (1996) found that 40% of survivors reported negative psychosocial outcomes post-BMT, 59% reported anxiety about the future, and 53% reported depressive symptoms.

Research on post-BMT QOL has grown in quantity and quality in recent years. Despite diversity in the outcome variables examined, several QOL outcome domains have served the

Usama S. Saleh, RN, PhD(c), is a doctoral student and a research assistant and Dorothy Y. Brockopp, RN, PhD, is a professor and an assistant dean for undergraduate studies, both in the College of Nursing at the University of Kentucky in Lexington. This study was funded by the Sigma Theta Tau International Honor Society of Nursing. (Submitted September 2000. Accepted for publication February 1, 2001.)

Significant numbers of successful syngeneic, autologous, and allogeneic bone marrow transplants (BMTs) have been reported worldwide for malignant and nonmalignant diseases since the first reported BMT cases in 1968 and 1969 (Bortin, Horowitz, & Rimm, 1992). According to the data available through the International Blood and Marrow Registry, more than 45,000 BMT procedures were performed worldwide in 1998. As a result, patients and healthcare providers have expanded their interests and concerns beyond the length of survival to the quality of life (QOL) after survival. Increasing our knowledge about BMT survivors is a significant step toward achieving a complete outcome evaluation of this important treatment for an increasing number of malignancies (Winer & Sutton, 1994). Thus, an urgent need exists for psychometric development of a tool to measure QOL in a multidimensional manner.