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Caregivers' Quality of Life after Blood and Marrow Transplantation: A Qualitative Study

Heather S.L. Jim¹, Gwendolyn P. Quinn¹, Anna Barata^{1,2}, Mallory Cases¹, Julie Cessna³, Brian Gonzalez¹, Luis Gonzalez¹, Alexis Koskan¹, Francisco Montiel-Ishino¹, and Joseph Pidala⁴

¹Health Outcomes and Behavior Department, Moffitt Cancer Center, Tampa, FL

²Psychiatry and Legal Medicine PhD Program, Universitat Autònoma de Barcelona, Barcelona, Spain

³Department of Psychology, University of South Florida, Tampa, FL

⁴Blood and Marrow Transplant Department, Moffitt Cancer Center, Tampa, FL

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A sizable literature has documented the challenges of providing care to a family member with cancer, although fewer studies have reported on caregivers of allogeneic hematopoietic cell transplantation (HCT) recipients. Existing studies of HCT caregivers suggest that they are at risk for distress. For example, prior to HCT, caregivers report significantly higher levels of anxiety, traumatic stress, and insomnia than population norms (1, 2). Several years after transplant, risk of depression among spouses of HCT recipients is 3.5 times greater than that of similar peers (3). Spouses of HCT recipients also report less social support, greater marital dissatisfaction, greater loneliness, and less spiritual well-being than their peers (3). In qualitative interviews of HCT recipients and spouses, spouses were more likely than patients to report negative life changes as the result of transplant (4).

The goal of the current study was to qualitatively examine post-HCT quality of life from the caregiver's perspective. As part of a larger qualitative study of patient education regarding quality of life after allogeneic HCT, patients and caregivers were recruited from a single institution to participate in separate focus groups. At this institution, caregivers are required to attend a class regarding how to care for an allogeneic HCT recipient. Caregiver support groups are available as well. Results of the patient focus groups have been reported previously (5). Caregivers were asked about their quality of life and their perceptions of the patient's quality of life, with a focus on how the transplant team could better prepare future

Corresponding Author: Heather S. L. Jim Ph.D., Department of Health Outcomes and Behavior, Moffitt Cancer Center, MRC-PSY, 12902 Magnolia Drive, Tampa, FL 33612; heather.jim@moffitt.org.

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caregivers for life after transplant. As the study was exploratory in nature, there were no *a priori* hypotheses.

Caregivers were nominated by eligible patient participants (5). To be eligible, caregivers had to be able to speak and read English and provide informed consent. Caregivers attended one of four caregiver-only focus groups held in November 2011 and March 2012. Groups ranged in size from three to six caregivers. Details of study methodology have been described previously (5). Focus group questions are listed in Table 1.

A total of 16 caregivers participated in the focus groups. Participants had a median age of 55 (range 25-80). The majority was Caucasian (100%), non-Hispanic (88%), married (94%), had not completed college (62%), and reported a current annual household income of US\$ 40,000 a year or more (79%). Representative quotes from caregivers are displayed in Table 2.

Nearly all participants agreed that providing care to a HCT recipient entailed significant physical and emotional demands. Several participants noted that caregiving required permanent life changes and a lifelong commitment to the patient. Social isolation was commonly reported and perceived to be detrimental for both the patient and caregiver. Many described constant vigilance about disinfecting their surroundings to prevent infection, sometimes far longer than required by the transplant team. Some caregivers reported a loss of identity as they no longer engaged in the activities they used to find meaningful. Although some caregivers reported significant emotional support from family and friends, others felt overlooked as loved ones' concerns were typically centered exclusively on the patient.

Caregivers reported feeling unprepared for the severity and duration of emotional and physical changes in the patient. They also expressed difficulty determining how much they should push patients to engage in activities the caregivers perceived to be beneficial (e.g., exercising, resuming previous hobbies). Nearly all caregivers reported that their relationship with the patient was significantly changed due to the transplant process. Some felt that the transplant brought them closer together while others perceived significant strain in the relationship.

Caregivers commonly voiced feelings of gratitude for the patient's survival in addition to insomnia, helplessness, guilt, fatigue, and fear about cancer recurrence. They also described high levels of anxiety at each outpatient follow-up appointment, which were temporarily assuaged by hearing the patient's blood counts. Although caregivers described significant negative emotions, few reported receiving psychosocial services.

In general, caregivers were reluctant to discuss ways in which they took care of themselves. Many reported guilt about focusing on their own needs. Prayer, use of social support, and focusing on one day at a time were the most commonly reported coping strategies. Use of web-based sharing systems such as blogging, email, or other social networking sites to inform family and friends of the patient's progress and receive support was also widely perceived to be helpful.

Caregivers reported being well-informed regarding physical symptoms patients were likely to experience during the acute transplant period, symptom management, and other requirements for daily care of an HCT recipient (e.g., flushing lines, precautions against infection). Caregivers wanted more information regarding how to cope with emotional and cognitive changes in the patient. It was suggested a mentoring program be created, in which names and phone numbers of experienced caregivers were provided to caregivers new to HCT.

In general, caregivers echoed many of the same themes as patients (5), including greater need for information regarding post-transplant morbidities such as graft-versus-host disease (GVHD). Caregivers also provided unique information about the patients' experiences, most notably observed changes in personality, difficulty handling stress, and cognitive impairment. Caregivers participating in the current study frequently expressed significant unmet needs for information and support. We are aware of only one previous study of an intervention for caregivers of allogeneic HCT recipients, which found that caregivers perceived emotional expression to be helpful in dealing with stress (6). Caregivers may also benefit from greater information regarding long-term morbidities, tools to help manage their own and the patient's emotional distress, and awareness of the importance of self-care and outside support (7). Studies among cancer patients suggest that this type of intervention can significantly reduce caregiver burden and improve quality of life (8). Although evidence-based caregiving interventions are currently lacking in HCT, caregivers should be directed towards resources available through cancer- and transplant-specific websites (e.g., National Marrow Donor Program, National Bone Marrow Transplant Link, Leukemia and Lymphoma Society).

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