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Parent Outlook: How Parents View the Road Ahead as They Embark on Hematopoietic Stem Cell Transplantation for Their Child



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ABSTRACT

Pediatric hematopoietic stem cell transplantation (HSCT) offers cure for high-risk malignancies and other conditions, but carries a risk of complications. Parental outlook regarding their child's transplantation course and future health has been largely unexplored. This report presents the Parent Outlook Scale, describes its properties, and examines the outlook of parents embarking on their child's transplantation course and the associated variables. Parents of children scheduled to undergo HSCT ($n = 363$) at 8 US transplantation centers completed the Parent Outlook Scale, comprising 4 items assessing frequency of the parent's thoughts about the potential difficulty of the child's transplantation (Transplant Difficult subscale) and worsened health (Health Worse subscale). Item responses were rated on a 5-point Likert scale (ranging from "none" to "all of the time") and, along with scale/subscale scores, transformed to 100-point scales, with higher scores connoting greater thought frequency. Psychometrics were explored. Multivariable models identified personal and clinical characteristics associated with scale and subscale scores. The Parent Outlook Scale ($\alpha = 0.75$) and subscales were found to have sound psychometric properties. Factor loading supported the single scale with 2 subscales representing distinct aspects of overall outlook. Mean scores (Parent Outlook, 52.5 ± 21.7 ; Transplant Difficult, 64.4 ± 25.6 ; Health Worse, 40.7 ± 25.7) revealed variability within and across scale/subscales. Significantly different mean subscale scores ($P < .001$) indicated more frequent Transplant Difficult thoughts than Health Worse thoughts. Clinical factors (solid tumor diagnosis and unrelated donor transplant) and a parent factor (worse emotional functioning) were associated with higher scale and subscale scores. Our findings show that the outlook of parents embarking on their child's HSCT course is varied and not solely a product of clinical factors readily apparent to clinicians.

These data were presented in part in poster form at the International Society for Quality of Life Research Conference, Miami, Florida, October 2013 and the American Society of Clinical Oncology Palliative Care in Oncology Symposium, Boston, MA, October 2014, and also as an oral presentation at the Annual Assembly of the American Academy of Hospice and Palliative Medicine, Philadelphia, PA, February 2015.

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Referring and transplantation clinicians should create opportunities to explore with parents their perspectives and concerns before and during the course of HSCT.

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INTRODUCTION

Hematopoietic stem cell transplantation (HSCT) affords potential cure, often the sole possibility of cure, for children with high-risk malignancies and other life-threatening conditions [1–7]. However, it is intensive therapy posing a risk for serious complications and lasting health sequelae that impair functioning and well-being [8–13]. Parents therefore embark on their child's transplantation experience holding both hope for their child's recovery and fear of what the future may bring [14].

Given the risks of HSCT and the serious underlying diagnosis, health outcomes (eg, future health, survival) are difficult to accurately predict for a given child. Parents' uncertainty and fears are heightened by the unfamiliar and complex nature of HSCT [15]. In this context of high apprehension and unknown outcomes, how parents regard the transplantation course and their child's potential health outcomes (ie, parent outlook) once they have committed to HSCT is largely unknown.

An understanding of parent outlook provides an important window into a parent's preparation, perspectives, and concerns regarding HSCT. Knowledge of parent outlook positions clinicians to effectively support and communicate with parents and, in turn, maximize the physical and psychological health of children and parents. On the other hand, assumptions or misperceptions about parent perspectives can impede optimal communication, decision making, and preparation, and in fact contribute to patient/parent distress [16,17].

Despite its importance, parent outlook has been largely unexplored. In 2 qualitative studies of parents of children undergoing HSCT, parents expressed their fear of the perils of HSCT and described being either incapable or unwilling to think about the situation or their child's potential outcome [14,18]. Some actively pushed the possibility that their child might die out of their minds, whereas others simply denied this possibility [14]. Additional research building on these 2 relatively small studies is needed to deepen our understanding of parent outlook. It is possible that HSCT parents alternatively have persistent, continuous thoughts (ie, rumination) about the danger that might lie ahead [19], or they may, like other parents of children with cancer, contemplate the future but either not dwell on it or actively focus on positive outcomes or aspects of the situation [15,20–24]. Clearly, parents might think about the upcoming transplantation and their child's future health in a variety of ways.

The factors shaping the outlook of parents as they embark on their child's HSCT course are also poorly understood. Studies suggest that parents' contemplation of HSCT risks and adverse outcomes may be influenced by their sense of culpability for a potentially poor outcome, their lack of control over the situation, and the absence of an alternative treatment offering cure [18,25]. The highly cure-oriented setting of HSCT and the social desirability of positive thinking [26,27] also may promote thoughts focused on positive outcomes.

The need to improve our understanding of HSCT patient/parent perspectives and their preparation for potential outcomes throughout the course of HSCT is increasingly evident [14,16,28–30]. The Parent Outlook Scale was developed to assess parent outlook. In the present study, we evaluated the properties of this instrument, as well as the association of variables with parent outlook as measured by this scale using data from 2 of the largest health-related quality of life (HRQL) studies conducted in this population to date.

MATERIALS AND METHODS

Participants

Participants ($n = 363$) were drawn from 2 prospective, multicenter studies evaluating child and parent HRQL over the first year after the child's HSCT (Figure 1). This analysis focuses on parent-reported outcomes collected just before their child embarked on the course of HSCT. The 2 studies, Journeys to Recovery (JTR) and Hematopoietic Stem Cell Transplant–Comprehensive Health Enhancement Support System (HSCT-CHESS), are described in detail elsewhere [31–36] and briefly summarized here. The 2 studies enrolled child–parent dyads from 8 US transplantation centers and together spanned 2003–2011. Eligible children were aged 5 to 18 years (JTR) or 2 months to 18 years (HSCT-CHESS), were scheduled to undergo HSCT, provided age-appropriate assent, and had an eligible parent who provided consent to participate and informed permission for the child to participate. Parent eligibility criteria included a working knowledge of English (validated study measures were available in English only) and minimum age of 18 years. If more than 1 parent was involved in the child's care, they were asked to select 1 for participation. The Institutional Review Boards of Tufts Medical Center and all participating transplantation centers approved the studies.

Measures

The General Health Module of the Child Health Rating Inventories (CHRIs-General) assesses general health and HRQL (physical, emotional, and role functioning, as well as global HRQL) in chronically ill children in the preceding week via child and/or parent-proxy versions that have been validated in the pediatric HSCT population [33,37–39]. The parent version of the CHRIs-General contains a summary item regarding the child's general health (rated on a 5-point Likert scale ranging from "poor" to "excellent," converted to a 100-point scale) and items assessing parents' own HRQL (physical, emotional, and role functioning and global HRQL).

The version administered before HSCT also contains parent outlook items reflecting frequency of the parent's thoughts about the difficulty of the impending transplantation for the child ("Transplant will be difficult for my child") and parent ("Transplant will be difficult for me"), worsening of their child's health ("My child's future health will be worse than it is now"), and child mortality ("My child might die"). Together the 4 items compose the Parent Outlook Scale, with the 2 transplant difficult and 2 worsened health items forming the Transplant Difficult and Health Worse subscales, respectively.

The primary focus of the present analysis was on parents' response to the 4 outlook items and resultant Parent Outlook Scale and 2 subscale scores. For each item, parents rated the frequency of their thoughts on a 5-point Likert scale, with response options of "1, none of the time"; "2, a little of the time"; "3, some of the time"; "4, most of the time"; and "5, all of the time." Both item responses and computed mean scale and subscale scores (range, 1–5) were converted to a 100-point scale (with higher values representing greater frequency of thoughts) to facilitate interpretation of univariate and multivariable analyses, described below.

Data Collection

Parents provided demographic information and completed the CHRIs-General by paper and pencil either before or during the HSCT preparative regimen. Detailed medical information, including the child's diagnosis, pretransplantation course, transplantation characteristics, and subsequent vital status, was abstracted from the medical record by trained study staff at each site and reviewed by the principal investigator (S.K.P.).

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