Parent Outlook Regarding Their Child’s Potential Health Outcomes During the Hematopoietic Stem Cell Transplant (HSCT) Course (TH346-D)

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Objectives
• Describe patterns of parent outlook regarding potential child health outcomes (future health and mortality) at baseline through 12 months post HSCT.
• Delineate factors associated with changes in parent outlook regarding potential child health outcomes during the first 45 days of HSCT.

Original Research Background: Hematopoietic stem cell transplant (HSCT) affords potential cure for some life-threatening conditions, but for families embarking on this intensive, high-risk therapy, their child’s outcome is uncertain. Parent outlook regarding potential child health outcomes during HSCT is unexplored.

Research Objectives: To evaluate parent outlook regarding child health and mortality during HSCT using data from two longitudinal health-related quality of life (HRQL) studies.

Methods: Parents of children undergoing HSCT (n=363) at eight US transplant centers completed the Child Health Ratings Inventories (CHRIs) measuring parent and child general health and HRQL at baseline (BL) through 12 months post HSCT. Main outcomes were responses to two CHRIs items developed to assess parent outlook regarding potential child outcomes, “might die” and “future health worse,” rated on a 5-point Likert scale ranging from worrying about the outcome none to all of the time. Analyses focus on BL to day +45 when improvement in parent outlook was pronounced. Clinical data were abstracted from charts. Personal, clinical, and HSCT course characteristics with p<0.2 on univariate analysis were entered into adjusted multivariable models, then eliminated by backward selection (p<0.1).

Results: Parents were 83% female, 77% white, mean age 38.6 years (SD=7.5). Child mean age was 9.6 years (SD=5.1). Most (72%) had cancer; 78% underwent allogeneic HSCT. By day +45, 33% had systemic infection, 33% acute graft versus host disease, and 20% intermediate/poor Bearman toxicity score. Mean parent “might die” worry decreased from BL (41.9, SD=8.3) to day +45 (26.6, SD=24.6, p<0.001). “Health worse” worry similarly decreased. For both outcomes, identified risk factors for ongoing parent worry at day +45 include younger child age (p=0.03) and malignancy (p<0.001) but not actual clinical outcomes.

Conclusions: Some parents remain at risk for unmitigated worry about their child’s health, largely irrespective of the HSCT course.

Implications for Research, Policy, or Practice: Enhanced clinician awareness of parent outlook and augmented support may benefit parents during HSCT.