A Multidisciplinary Care Team Perspective on Children’s Emotional Experience in Isolation for Stem Cell Transplantation

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Background: Fatigue is a common side effect of chemotherapy, but is poorly studied in pediatric HSCT recipients. Hope, or goal-directedness, may be impacted by fatigue. The incidence and severity of fatigue and its impact on hope warrants investigation.

Patients and Methods: Patients were eligible for enrollment in this prospective study if they were between the ages of 5-18 years. Patients unable to read English or otherwise unable to complete the survey were ineligible. Subjects completed the PedsQL Multidimensional Fatigue Scales (Fatigue QOL) and Children’s Hope Scale. Subjects were enrolled during a regular follow-up clinic visit and completed the survey. The results of the fatigue surveys were then compared to healthy subjects and oncology patients in a validated sample as reported by Varni et al (Cancer, 2002; 94:2090-2106).

Results: A total of 25 subjects who had HSCT were enrolled, at a mean of 12 yrs. (range of 6-19 yrs). 2 had received autologous HSCT, 23 had received allogeneic HSCT, and 1 patient received an auto followed by an allo HSCT. 6 had GVHD at the time of survey completion. HSCT recipients had an average Total Fatigue QOL score of 69.9 (range 38.9-95.8) and 18/25 (72%) had a lower score than the average for healthy subjects. HSCT recipients had a statistically significant lower average Total Fatigue QOL score (69.9 vs. 80.5; p = 0.002) and average General Fatigue QOL score (71.3 vs. 85.3, p = 0.002), and a trend to a lower average Sleep Fatigue QOL score (62.65 vs. 75, p = 0.002), when compared with healthy subjects. There was no statistically significant difference in average Cognitive Fatigue QOL scores (73.98 vs. 81.14, p = 0.63). There was no statistically significant difference in average Fatigue QOL scores in SCT recipients when compared to patients undergoing chemotherapy. Proxy reports of fatigue were higher than comparative populations. An analysis of factors failed to show any significant impact on fatigue including age, days post transplant, sex, TBI received, GVHD, mental illness, ICU admission, and malnutrition-impacted fatigue or hope. The average hope score was 0.76 (range of 0.46-1), which corresponds to feeling hopeful “a lot of the time.” There was a direct correlation between Total Fatigue QOL and hope scores (r = 0.472, p = 0.02).

Conclusions: Fatigue is more prominent in pediatric HSCT recipients than a control population. Fatigue is related to hope. Fatigue experienced by HSCT recipients was similar to that seen in children receiving chemotherapy. Proxy reports of fatigue were much greater than those reported by both the subject and compared to healthy and oncology proxy reports. Larger prospective studies are needed to determine risk factors for fatigue and to develop interventions to alleviate fatigue in pediatric HSCT recipients.

Metabolic Syndrome Occurs within the First Year after Hematopoietic Cell Transplantation

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Background: Improved survival after allogeneic hematopoietic cell transplantation (allo-HCT) enables us to learn more about potential late complications after HCT, including metabolic syndrome (MS). This is the first study investigating the prevalence or development of metabolic syndrome within the first year post-HCT in adult myeloablative transplant recipients.

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Methods: This was a retrospective study that evaluated the prevalence of and risk factors associated with metabolic syndrome early post-HCT in 785 human subjects. As data was collected retrospectively, it required substitution for certain metabolic syndrome parameters. Thus, we evaluated metabolic characteristics using available objective data referred to as modified metabolic syndrome (MMS).

Results: We demonstrated that the incidence of MMS was 34% pre-HCT, 48% at day 80 post-HCT, and 40% at one year post-HCT. MMS at day 80 post-HCT was predictive of having MMS at one year post-HCT. Hypertriglyceridemia was the predominant qualifying criteria for MMS, present in 91-93% of patients. Age (>50) and TBI-based conditioning regimen were significantly associated with developing MMS at day 80 post-HCT (p=0.0006 and p=0.005, respectively). Both TBI and age remain highly significant in multivariate analysis (p=0.0009 for TBI and p=0.0001 for age) at day 80 post-HCT. TBI was also predictive of MMS at 1 year post-HCT (p=0.01).

Conclusion: Although we substitute a number of the metabolic syndrome factors based on data availability, we believe that the substituted factors used in this study are still clinically relevant as risk factors for coronary heart disease. These results support the need for nutrition and lifestyle intervention in order to prevent and treat metabolic abnormalities among patients who survive the acute transplant period.

Lack of Early Oncofertility Education in Hematologic Cancer Patients Potentially Referable for HSCT

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Background: Infertility frequently occurs in long-term survivors of hematopoietic stem cell transplant (HSCT). By the time patients are referred for HSCT, they have often undergone cancer treatments that cause infertility. The burden of early education falls on the hematology oncology team that cares for the patient upon initial cancer diagnosis. Comprehensive oncofertility education should include two areas: the risk of cancer treatment on future fertility and fertility preservation (FP) options. This study sought to characterize the education practice and attitudes of hematology oncology physicians and nurses towards oncofertility education in patients who may be HSCT eligible and to determine patients’ interest in education.

Methods: A multidisciplinary team developed 3 surveys to evaluate patients, nurses, and physicians using published literature and unique questions targeting our population. The University of Virginia’s Institutional Review Board (IRB) authorized the surveys as IRB exempt. Practicing hematology oncology nurses and physicians were eligible. Potential HSCT eligible patients diagnosed with lymphoma, leukemia, or myeloma in the last 2 years and were either women ages 18-45 or men ages 18-60 at time of diagnosis were eligible.

Results: A total of 23 hematologic cancer patients ages 23-49 completed the survey as well as 43 providers (Figure 1). Education on the risk of cancer treatment on future fertility was received by 52% of patients, and only 26% of patients received FP options. 81% of women and 31% of men were interested in discussing their fertility, learning about FP options, or a fertility referral and counseling service. Of those interested, 67% received education on the risk of cancer treatment to fertility and 42% received FP education. Of interested patients who received education, 63% were satisfied with risk of cancer treatment education, and 80% were satisfied with FP education. Of the surveyed providers, 75% of nurses and 33% of physicians did not feel comfortable discussing FP options with patients and 89% of nurses and 86% of physicians felt they needed more information on FP options. Physicians indicated patients’ illness and nurses indicated their own knowledge of FP as the greatest barriers to education (Figure 2).

Conclusions: The majority of hematology oncology patient participants did not receive comprehensive oncofertility education. Unfortunately, many patients interested in education did not receive it. Providers need oncofertility education to improve their ability to address topics. HSCT programs should collaborate with local fertility specialists to educate primary