compared to participants with lower exercise compliance during pancytopenic phase after transplant.

Conclusions: By undertaking this study we will find out whether there is preliminary support for the effectiveness of the currently used in-hospital exercise program for people who are undergoing HSCT with various levels of pancytopenia. We will also determine whether higher compliance with an exercise program is associated with better functional outcomes.

Clinical Relevance: Since there are few studies supporting patient exercising or performing functional activities with acute pancytopenia, we hope to lay some groundwork in this area for further research into this and other similar patient populations.

207

Supporting Siblings Through the Allogeneic Hematopoietic Cell Transplant Process: The Perspectives of Minor and Young Adult Siblings of Successful Transplant Recipients

Jennifer P. D'Auria [1], Cammie Moore Presler [2], Kimberly A. Kasow [2]. [1] School of Nursing, University of North Carolina, Chapel Hill, NC; [2] Pediatrics, University of North Carolina, Chapel Hill, NC

Allogeneic hematopoietic cell transplantation (AHCT) remains an arduous medical therapy that challenges the physical and psychological reserves of the family unit at all stages of the process. Few studies have focused on the perspectives of healthy siblings regarding the types of support needed as they journey across the AHCT trajectory. This IRB-approved qualitative study explored the minor/young adult siblings' experiences of the AHSCT experience, specifically the types of support they would recommend to other siblings going through this experience. A retrospective interview approach was used to capture the perspectives of 12 siblings of successful pediatric matched sibling donor transplants at our institution between January 1999 and September 2009. All 12 participants had been HLA tested, with 8 serving as matched sibling donors. Median age at the time of the AHCT was 12 years (yrs) (range, 2-23 yrs) and at the time of the interview was 16 yrs (range, 10-30 yrs). The median time between donation and the interview was 6 yrs (range, 2-10 yrs). A grounded theory approach was used to analyze and interpret transcribed interview data. Semi-structured private interviews, demographic data, and field notes were the primary sources of data. Seven themes emerged: (a) being included in the health care "family", (b) being involved with the ill sibling, (c) being prepared for each step of the process, (d) meeting others who have been through the experience, (e) receiving reassurance and hope, (f) drawing on the support of parents/family after the procedure, and (g) talking to others about their experiences. The stories of these participants supported that the ill sibling, the family, and the health care team all play an important role in supporting them across the transplant trajectory. Interventions must be designed to focus on the unique physical, emotional and social needs of siblings to help them make sense of the transplant process. Age-appropriate educational materials will provide youth with accurate information as well as a way to help them ask questions and express emotions. Finally, providing professional support that extends beyond the transplant itself is essential for helping them piece together the meaning of the transplant and related events for their lives.

208

Development of a Pediatric HSCT Multi-Disciplinary Survivor Clinic

Lisa McDonald [1], Julie Luke [1], Taylor Fletcher [2], Robert Sanders [1], Veronica H. Jude [1], Ka Wah Chan [1]. [1] Pediatric Blood and Marrow Stem Cell Transplant, Texas Transplant Institute, San Antonio, TX; [2] Oklahoma State University

Pediatric cancer survivorship is a growing subspecialty however few clinicians focus solely on survivors of hematopoietic stem cell transplant (HSCT). There were 100,000 HSCT survivors in the US in 2009 and an estimated 250,000 survivors by 2020 (CIBMTR data). Approximately 80% of pediatric HSCT patients survive at least two years post transplant and are expected to become long term survivors. Post-transplant complications are the third cause of death in this patient population. The focus of clinical management then shifts toward decreasing the morbidity of long-term treatment effects through early detection and intervention.

We piloted a multi-disciplinary pediatric HSCT survivor clinic. From more than 400 patients transplanted at our center between 2003 and 2011, 32 patients were seen at one of 5 long-term follow-up clinic days in July and August 2012. Eligible patients were at least one year post HSCT and off immune suppression, and were invited based on availability. Fourteen patients were male, 18 female. Average age at time of transplant was 6.7 years (0.1-17 years); average age at time of survivor clinic was 10.7 years (range 2-20 years). Most were greater than 4 years post HSCT (range 17-117 months) and had undergone allogeneic HSCT. The most common late effects detected were musculoskeletal (59%, primarily vitamin D deficiency and bone mineral loss), and endocrine (56%). Cardiac late effects were seen in 2 patients and were not life threatening (1 hypertension and 1 hyperlipidemia). Pulmonary late effects were seen in 9% of patients, dermatologic in 12%, psychological in 18% and 44% were categorized as other, mostly low vaccine titers. No second malignancies were identified. School performance concerns were common (n= 40%).

More than 40 referrals were generated to other pediatric specialists as a result of our evaluation. A comprehensive cancer summary with specific recommendations from the multi-disciplinary team was mailed to each patient and appropriate medical providers.

Late effects in the growing population of HSCT survivors are common and, thus create an obligation to screen, apply early interventions, and refer to appropriate specialists as part of their post-transplant care.

209

Osteoporosis/Osteopenia (OP) and Osteonecrosis (ON) in Survivors of Pediatric Stem Cell Transplantation has a High Assiciation with Graft Versus Host Disease (GVHD)

Joan Morris [1], Christopher Morris [1], Jarrett Riley [1], Brenda Hernandez [1], Rebecca Lee [2], William Brown [2]. [1] Pediatrics, Loma Linda University, Loma Linda, CA; [2] Pharmacology, Loma Linda University Medical Center, Loma Linda, CA

Background: With improved survival following pediatric stem cell transplantation (SCT), long term effects of the therapy including OP and ON need to be addressed. These problems are known to occur in adult solid organ transplantation and adult SCT but little is reported in the pediatric literature. High-risk features associated with diminished bone density include hypothyroidism, hypogonadism,