215

IN THEIR OWN WORDS: AN EXAMINATION OF THE EXPERIENCE OF SEXUALITY IN INDIVIDUALS WHO HAVE UNDERGONE HEMATOPOIETIC STEM CELL TRANSPLANTATION

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Objective: The primary objective of this study was to identify patients' experience of sexuality following autologous or allogeneic hematopoietic stem cell transplantation (HSCT).
Methods: This study utilized a concurrent, mixed qualitative-quantitative design. Participants completed the Functional Assessment of Chronic Illness Therapy-BMT (FACT-BMT) as well as underwent semi-structured interviews.
Results: Eleven individuals participated in the study. The mean age at time of transplant was 43 years (range: 17-62) and mean number of months from transplant to time of study participation was 29 (range: 2-86). Participants scored relatively high on the FACT-BMT (mean 106 [range: 56-134] out of a possible 148), where higher scores indicate better quality of life. Despite the high FACT-BMT scores, the majority of participants indicated some level of dissatisfaction with his/her sex life. Regarding sexual function, the most common changes experienced by the participants were: decreased libido (67% of female participants; 63% of male participants), difficulties with erectile function (88% of male participants), dyspareunia (67% of female participants), vaginal dryness (100% of female participants) and not feeling desirable (33% of female participants; 38% of male participants). Analysis of the qualitative data obtained from the interviews revealed several themes pertaining to sexuality and HSCT including: changes in sexual function, the impact of the disease/treatment on the participant's relationship, the experience of discussing sexuality with health care providers, and recommendations for potential strategies that may make it easier for patients to discuss sexuality with health care providers. Interview responses provided context for the participants' FACT-BMT scores and perspectives on each individual's experience with sexuality throughout the illness and treatment trajectory.
Conclusion: In this study, 100% of participants experienced changes in sexuality following HSCT. While many participants encountered changes in sexual function, the interview component of this study revealed that sexuality, as a broader concept, went beyond the physical realm. The study findings have led to the development of a proposal to involve more participants as well as to include the participants' partners or spouses, if available.

216

IMPLEMENTATION OF A POPULATION CARE MODEL UTILIZING THE ELECTRONIC MEDICAL RECORD TO SCREEN AND MANAGE LATE EFFECTS OF HEMATOPOIETIC STEM CELL TRANSPLANT IS AN EFFECTIVE WAY TO ENSURE GOOD INTERMEDIATE HEALTH OUTCOMES AND COST EFFICIENT CLINICAL PROCESSES

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Background: Despite best efforts to reduce the toxicity of conditioning regimens, the development of hematopoietic stem cell transplant(HSCT) related late effects remains inevitable. Recent studies report up to 90% incidence of at least one chronic condition with close to 25% being severe. Consistent screening efforts are key to the early diagnosis and appropriate management of these chronic conditions. We share our experience using an electronic medical record (EMR) system to track pediatric HSCT survivors in a healthcare system that spans 12 medical centers over a large geographic area.
Hypothesis: Utilizing a population care approach to screen and manage late effects of HSCT ensures good intermediate health outcomes (eg handling of test results) and efficient clinical processes (eg test frequency).
Methods: The EMR charts of 86 pediatric (0-18yrs) HSCT survivors over the last 4 years were reviewed for compliance with American Society for Blood and Marrow Transplantation and Childrens' Oncology Group survivorship guidelines.
Results: The majority of patients surveyed had timely screening and appropriate management of visual, endocrine, cardiac, and pulmonary HSCT late effects concordant with published guidelines. Concordance was higher within the last two years once a centralized, designated team was formed comprised of a lead physician and nurse case managers who were fluent in the EMR.
Conclusions: An EMR based, population care approach is a good model for small to medium sized HSCT program to consistently track and manage pediatric HSCT survivors. It may be especially suited for healthcare systems that cover small numbers dispersed over large geographic areas where centralized case management can promote concordance with published survivorship guidelines.

217

CONTRIBUTION OF GRAFT-VERSUS-HOST DISEASE TO ANDROGEN DEFICIENCY IN WOMEN AFTER ALLOGENEIC STEM CELL TRANSPLANTATION?

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Background: After allo-HCT, ovarian failure and chronic GvHD contribute to sexual dysfunction and reduced quality of life (QoL) in women. We hypothesized that androgen hormone production, both in ovaries and adrenal cortex, also might be impaired after allografting. We report systemic levels of androgens in adult women after allo-HCT compared to controls.
Patients: Twenty-four women in complete remission, 54 (3-149) months after allo-HCT for hematological malignancies. Conditioning therapy was myeloablative or reduced in 11 and 13 pts, respectively. Glucocorticoid treatment was ongoing in 11 pts, 10 of whom because of chronic GvHD (cGvHD). Nine pts were on systemic hormone replacement therapy (HRT). Controls were 26 healthy age matched women, 3 on HRT. The HCT group and controls were similar with respect to age (mean 49 vs 50 yrs, NS), weight (70 vs 67 kg, NS), S-albumin (mean 40 vs 41 g/L, NS), and in S-SHBG (mean 72 vs 78 nM, NS).
Methods: Total serum testosterone was determined using a modified RIA with a sensitivity of 0.03 nM, and the biologically active free testosterone was calculated using S-albumin and serum S-HBG. Wilcoxon's rank-sum test was used for comparisons.
Results: Compared to findings in the control group, free testosterone and dehydroepiandrosterone sulfate (DHEAS) was significantly lower in HCT pts (5.1 vs 7.9 pM, $p = 0.0008$) and 1.3 vs 2.5 uM ($p = 0.0009$), respectively. In HCT patients with cGvHD, median free testosterone level was 2.1 compared to 4.1 pM in patients without cGvHD, $p = 0.046$). The corresponding levels for DHEAS were 0.25 and 1.45 uM ($p = 0.0009$). There was a tendency to lower estradiol levels in HCT pts (mean 61 vs 206 pM, $p = 0.09$). S-LH and S-FSH were significantly higher in HCT pts (39 vs 19 U/L $p = 0.0001$, and 59 vs 33 U/L, $p = 0.005$, respectively). Within the HCT group, there were no significant differences in free testosterone and DHEAS levels with respect to weight, previous acute GvHD, conditioning intensity or ongoing HRT.
Conclusions: Our findings of low testosterone and DHEAS suggest that not only ovarian dysfunction, but also a reduced adrenal steroid production contributes to low androgen levels. The androgen deficiency observed, possibly related to cGvHD and corticoid steroid treatment, could be an additional cause of impaired vitality and sexual dysfunction reported after allo-HCT.

218

FERTILITY PRESERVATION IN PEDIATRIC PATIENTS UNDERGOING STEM CELL TRANSPLANTATION: SPERM BANKING BEFORE OR AFTER CHEMOTHERAPY

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Purpose: As survival rates among stem cell transplant (SCT) patients continue to improve, the long-term consequences of