Based on Joint Commission for Accreditation of Hospitals Organization (JCAHO) requirements, patients are asked if they have advance directives at the time of admission and given information if they do not have the proper documents. Despite these measures, however, the percentage of inpatients nationally with AD remains low (approximately 30%). As part of a quality improvement process, AD information was collected on 100 BMT inpatients. Survey results indicated that 39% of patients said they had AD, 29% supplied a copy before admission, and only 20% had a copy available in their inpatient chart. Some patients (19%) had both a living will and medical power of attorney.

In an effort to increase advanced care planning discussion and advanced directive completion, the Bioethics in BMT task force initiated several activities, including participating in an admission class for BMT patients, providing for viewing of a video on advanced directives, preparing a document titled “Hope for the Best,” and providing BMT attendings with information about patients’ living will choices pretransplant. Follow-up survey results and information about these activities will be presented and discussed.

Late Effects of Stem Cell Transplantation Compared to Chemotherapy/Radiation Reported by Survivors in a Web-Based Survey

Barnes, Y.J.1, Hauff, M.2, Shenoy, S.21 St. Louis Children’s Hospital, St. Louis, MO.2 Washington University School of Medicine, St. Louis, MO.

Background. The intensity and duration of chemotherapy and/or radiation delivered for the treatment of cancer dictates therapies. Age at diagnosis, tumor location, and surgical intervention are additional factors that influence complications. Further intervention, such as stem cell transplantation (SCT), can compound residual toxicities. The aim of this study was to analyze toxicities perceived by survivors after SCT compared with survivors (without SCT) using a web-based electronic survey as a tool. Methods. A project undertaken by the Late Effects and School/Societal Reintegration Program at our institution included a summary of the main side effects encountered post therapy on our website: http://webbugs.wustl.edu. The goal was to disseminate basic information, raise medical awareness, list resources, and encourage follow-up. An anonymous survey invited visitors to report their treatment and describe residual late effects, if any. Data were compiled from surveys of survivors with and without SCT. Survey questions included diagnosis, age, treatment, duration posttherapy, medical and psychosocial complications, and adequacy of medical care, as perceived by the respondent. Results. Twenty-two SCT survivors responded. Responders were parents (19), patients (1), and friends (2). Median age at diagnosis was 2–5 years (range, 0–17 years). Sixteen had completed therapy < 5 years earlier, 3 were 5–10 years posttherapy, and 3 were unknown. There were 7 males and 9 females (and 6 unknown). Diagnoses included leukemia in 7 patients, solid tumors in 12, lymphoma in 2, and other in 2. Conditioning for SCT included radiation in 13 (59%) and no radiation in 4 (18%). Overall, 63.6% (14 of 22) reported adequate medical support. Table 1 compares the percentage of side effects in survivors from the 2 groups. Conclusions. SCT recipients were 1.2 times more likely to experience late effects than non-SCT patients. Growth failure, delayed puberty, infertility, and cosmetic, dental, and endocrine problems were more frequent after SCT. Radiation and chemotherapy survivors described learning disabilities with increased frequency. Interestingly, both groups had rare patients (2 in each group) who perceived no side effects. The high incidence of late effects in survivors range from medical issues to psychosocial problems and underscores the need for dedicated “late effects” multidisciplinary clinics to recognize these problems. Successful cancer therapy should be combined with formal programs that address these issues.

Parents Rooming-In during Their Child’s Hematopoietic Stem Cell Transplantation


Background. HSCT in children is a stressful experience for their parents. At the inception of our program in 1993, we decided to not permit parental rooming-in. We thought that parents could thus benefit from a rest period, maintain their family system, and conserve energy for the long hospitalization expected for their child. Some parents questioned our policy, because throughout our hospital, with the exception of the ICU and HSCT units, children can benefit from the presence of their parents. In contrast to our position, most transplantation centers in North America allow parental rooming-in during a child’s HSCT. A literature review was inconclusive. We therefore surveyed 120 families whose child received HSCT at our center, to evaluate the effect of our policy on the parental level of stress, the child’s anxiety, and/or the impact on the nursing team. Methods. Families who had a child recipient of an HSCT between 1993 and 2002 were surveyed by mail. One of the parents answered the questionnaire, which evaluated the degree of information on the rationale for the policy, parent and child reaction, current perception on the policy, current choice that parents would make, and suggestions on possible rooming-in. Results. A total of 42 questionnaires (35%) were returned. Responses were provided mainly by the mothers (54%). At the time of HSCT, 14 families (34%) returned home daily (median distance, 32.5 km), whereas 28 (67%) stayed at the hospital suite in the immediate vicinity of the hospital. Before the HSCT, 20 (48%) stayed overnight with their child during hospitalization; for 7 (17%), this was a first hospitalization. Thirteen (32%) initially agreed with the program policy. Twenty-six (62%) of the surveyed families stated they would have stayed the night with their child at the time of HSCT if permitted; however, after HSCT, 16 (53%) of the families who would have or may have stayed overnight now indicated that they would not stay. The main reason given was to benefit from a greater period of rest. None of the families that did not consider staying at night reconsidered their choice in retrospect. Six families (14%) noted that their child never grew accustomed to their absence at night. Conclusion. Rooming-in during HSCT may be an option for some families. We are currently studying the benefits and disadvantages of rooming-in for the child, the parents, and the nursing team during this period of intensive care.