

challenges to be found for Pre-TED and Post-TED Forms were included in the new work flow. A list of disease-specific staging was developed to guide disease status at annual evaluations. A visual approach was created in the spreadsheet to track forms completion with all patients due dates as follows: green - form may be completed, red - time to complete form has not yet been reached, blue - form is ready to be reported, yellow - form must be reviewed, purple - patient underwent another HSCT and black - death.

Conclusion: In October 2012 our goal was achieved and we were able to update and report all 193 patients. Team work and new efficient tools allowed control of due dates and optimization of time spent with data capturing, CRA/physician meetings and forms review. All items from all patients will now be timely reported.

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A Comprehensive Review of DFCI's Adult HSCT Data

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Background: The DFCI/BWCC HSCT program is estimated to perform 525 transplants in 2012, and has performed 6000 transplants since inception in 1972. The quality of this data had previously not been reviewed on a large scale, only by smaller projects examining selected data fields for limited patient sets. The accuracy of this data is paramount since it is used for analysis of patient outcomes, policy compliance and operational considerations.

The goal of this project was to develop a comprehensive and efficient method of data validation for DFCI's internal HSCT repository and DFCI's SCTOD data.

Methods: Fifty-nine transplant essential data fields were selected for analysis including Day 0, Disease Status at Transplant, Best Response, aGVHD, and cGVHD. A program for comparing DFCI's internal repository data and DFCI's CIBMTR data (retrieved with the Data Back to Center tool) was designed in Microsoft Access, accounting for slight differences in coding rules and logic. In 2011 over 200,000 individual data points were compared. The analysis was performed in 2012 with more recent data.

Results: In 2011 the pre-HSCT and post-HSCT data sets had overall error rates of 0.51% and 0.77%, respectively. The pre-HSCT fields with error rates above 2% were Diagnosis Date (2.16%), KPS (2.23%), and Reason RIC (2.22%). The post-HSCT fields with high error rates above 2% were Cause of Death (3.27%) and Date of Death (3.94%). All errors were corrected and areas for staff education and codebook improvements were determined and implemented.

In 2012 the error rates for the previous year's fields with high error rates were Diagnosis Date (3.71%), KPS (0.80%), Reason RIC (2.14%), Cause of Death (2.34%), and Date of Death (1.37%) for data reported before the educational updates. The coding accuracy improved for data reported after the educational updates. For example, the error rates for the data that was reported after the educational updates for the previous year's fields with high error rates were Diagnosis Date (0.70%), KPS (1.69%), and Reason RIC (1.67%). Very limited post-HSCT data was available for data reported after the educational updates.

Conclusion: The pre-HSCT and post-HSCT data sets for DFCI's internally and externally reported data had overall percent error rates well below the HSCT Program's target error rate of 2% or lower. When the analysis was performed after staff education and codebook revisions, data accuracy improved. Comparing similar data entered into different databases is a valuable tool to correct data errors, as well as to improve data accuracy in the future.

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Cancer Registrars Evolving in Bone Marrow Transplant Data Management

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Cancer Registrars Evolving in Bone Marrow Transplant Data Management Christine Gibson, CTR, CCRP Cancer Registrars are well versed in the language of Cancer. CTR credentials are given once education, training and testing is satisfied. Training includes, anatomy and physiology, AJCC staging, NAACCR (The North American Association of Central Cancer Registries) guidelines for data capture, CDC, NCI SEER guidelines for Hematopoietic Database, Collaborative Staging, NCCN treatment guidelines and Commission on Cancer guidelines. Many resources and many regulatory bodies over see the data as we over see the data in our own institutions. Standards of Care and comparisons are made to assure the best possible patient experience. Diagnosis information, pathology, molecular testing, IHC, FISH; cytogenetic, tumor markers and prognostic indicators are the foundation of cancer reporting. Radiology tests and surgical interventions with histological diagnosis, dictate the stage of cancer. Once a stage of cancer is derived; a treatment plan can be made. Cancer treatment is captured in the cancer registry. Chemotherapy regimens, radiation, immunotherapy, vaccines and bone marrow transplant information is abstracted into the cancer registry. Cancer Programs that are American College of Surgeons, Commission on Cancer approved are required to have Cancer Registries. Annual follow up compliance is mandatory for all cancer patients in the cancer registry. It would seem that if resources were shared between the registries and regulators it could be more cost effective, and provide better data capture for the hematopoietic diseases. While many similarities exist between the two entities there are many differences. Continuous education is mandatory in a research environment. I have expanded my knowledge base. I have since learned about consents, regulatory agencies, engraftment, chimerism, acute and chronic GVHD, toxicities, infections and the many different time lines to report. Cancer registry background helped tremendously and working in a world class facility with world class physicians made the transition much easier.

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Development of a Flexible, Functional Hematopoietic Cell Transplant (HCT) Database, BRAIN

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Multiple data elements are necessary to provide up-to-date information for quality review and outcomes analyses as HCT evolves. Databases must have specificity yet flexibility in customizing data elements. Purchased proprietary applications are used by many HCT programs, but are limited by lack of cost-efficient configurability for center-specific needs. We sought to develop an HCT research application allowing evolution for program and scientific growth without major developmental costs. We identified 5 features essential for a functional HCT database including: 1) Uniform data capture; 2) Center-specific adaptability; 3) Rapid report generation; 4) Accurate, current data; and 5) Productivity tracking.

Between August 2010 and March 2012, our team of IT developers, programmer analysts, data managers, and a HCT physician planned, developed, tested, and launched a new database “BRAIN” (Blood and Marrow Transplant Research Analysis and Information Network). This required assessment of essential data, mapping and migration of data from a legacy database, and interface creation to available center systems. Legacy data was reviewed, standardized, and imported to BRAIN. Electronic interfaces connect institutional systems including lab results and medications via the Moffitt data warehouse to BRAIN. Additionally, discrete data such as staging and disease prognostic factors entered by clinicians into the electronic medical record interface with BRAIN reducing potential reporting errors or missing data elements. These interfaces, along with manual abstraction, enhance data for center specific analyses and electronic submission to CIBMTR via AGNIS. A dashboard identifying data manager specific CIBMTR forms due creates a proficient process of tracking forms. Thus, with the advancement of interfaces within the application and the mapping of this discrete data to the CIBMTR, productivity and accuracy are enriched. To date, two forms are submitted to the CIBMTR via AGNIS. Continuing efforts to map AGNIS-ready forms and development of a simple query tool will allow further growth and functionality within the application.

BRAIN fulfills a program need for cost efficiently, managing evolving data, enhancing data consistency, minimizing labor for data entry, making data easily assessable within the institution, and ensures current and accurate data submission to outside regulatory reporting agencies.

Methods: We obtained data regarding pregnancies and child births in consecutive female transplant recipients from our center. The patients were treated with SCT in the period from 1976 to 2012. Data was obtained through the national centralized access to the patients’ medical records including specialist treatment. Patients less than 17 years of age at the time of analysis were excluded. In total, 161 women were included in the analysis. The median age at SCT was 17.2 years, and 31.4 years at analysis. Of the 161 women, 24 (15%) died in the observation period, the surviving 138 women were observed median 12.3 years (0.5-36).

Results: Of the 161 women, 20 (12.3%) had at least one documented pregnancy (i.e. fertile). One of the 20 women which experienced pregnancy is dead and never gave birth. Thirteen (8%) woman obtained motherhood: 8 had one child, 5 had two children. All children born were healthy. Among the women with a pregnancy, 9/20 (45%) had non-malignant hematological disease, and 11/20 (55%) had malignant disease, among the non-fertile women the numbers were 36/141 (25%) and 106/141 (75%), respectively ($P = .66$). Of the woman with motherhood, 7/13 (54%) had non-malignant disease, whereas 38/148 (26%) of the remaining women had non-malignant disease ($P = 0,029$).

Total body irradiation (TBI) was given to 7 (54%) of the women with completed delivery, at a dosage of 200 cGy in 2 and 850-1200 cGy in 5 patients.

The median age at HSCT was not different among fertile and non-fertile women, 18.6 (2.3-33) years and 16.7 (0.2-34.6) years respectively ($P = .91$).

Among evaluable patients, chronic graft versus host disease (GvHD) was documented in 4/18 (22%) of the fertile women, and 43/116 (37%) of the non-fertile women, $P = 0,22$.

Conclusion: Not all women are infertile following allogeneic SCT, despite treatment with TBI chemotherapy and chronic GvHD. However, only 8% obtained motherhood, emphasizing the need for fertility conservation procedures. The current study benefits from centralized access to patient information ensuring a high quality of accurate and complete data.

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Female Fertility After Allogeneic Stem Cell Transplantation in Denmark. A National Cohort Study

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Background: It is well known that female fertility is impaired after allogeneic stem cell transplantation (SCT), however, more female patients become long term survivors, and wish to have children of their own. Data regarding pregnancies and child births are scarce. The aim of this study was to determine the proportion of female patients obtaining documented pregnancy and motherhood following SCT.

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Retrospective Data Review of Blood and Marrow Transplant (BMT) Medicare Coding to Analyze Coverage and Reimbursement Claims

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The number of hematopoietic cell transplants (HCT) for Medicare beneficiaries has dramatically increased, heightening the need to address Medicare coverage and reimbursement. Previous analysis of CMS claims data by ASBMT and NMDP suggested variability by HCT programs (HCTP) in coding and billing. Addressing these issues may be critical to ensure financial solvency for HCTP and continued HCT access for Medicare beneficiaries.