DNP Final Project

The Frequency of Interval Surveillance in the Adult Hematopoietic Stem Cell Transplant Survivor

By

Jill R. Beavers, MS, CCRN, ACNP-BC

Graduate Program in Nursing

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DNP Project Committee:

Jodi McDaniel, PhD, RN, CNP, Committee Chair

Elizabeth Barker, PhD, RN, CNP, FAANP, FACHE

Joanne Lester, PhD, RN, CRNP, ANP-BC, AOCN

Barbara Warren, PhD, RN, CNS-BC, PMH

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Abstract

Cancer treatments for hematologic malignancies can include radiation, chemotherapy, immunosuppression, stem cell transplant, and targeted biological therapies. These therapies can cause long-term side effects that may negatively affect quality of life. Many of these late effects are modifiable when a proactive systematic plan of prevention and surveillance is implemented. This plan is most effective when factors such as past treatments, chromosomal prognostic factors, comorbid health conditions, and lifestyle behaviors are considered.

A survivorship care plan specific for cancer survivors who have undergone a hematopoietic stem cell transplant (HSCT) would enhance the ability of clinicians to monitor for these late effects. The Center for International Blood and Marrow Transplant Research, the European Group for Blood and Marrow Transplantation, and the American Society for Blood and Marrow Transplant have recommended that a HSCT-specific survivorship care plan include 6-month, 12-month, and annual assessments of physical and psychosocial well-being including preventive screenings unique to the HSCT survivor.

This quality improvement study described the frequency of documentation of the recommended cancer survivorship guidelines by oncology clinicians in the medical records of adult HSCT survivors at 12 and 24 months post-transplant in one comprehensive cancer center. This retrospective chart review found that only three of the 29 recommended guidelines were documented as being completed in more than 50% of the charts at 12 and 24 months. Furthermore, the data indicated that the remaining indicators were documented in less than 50% of the charts at both 12 and 24 months. These findings were used to inform the oncology clinicians of the need for adherence to recommended guidelines and in the planning of a hematology and transplant survivorship clinic for individuals who have completed the acute phase of their cancer treatment.

Chapter One

Nature of the Project

The National Cancer Institute (NCI) and Centers for Disease Control (CDC) estimated in 2006 that approximately 11.4 million people in the United States were living with a history of cancer (National Cancer Institute, 2009). This estimate was 3.5 times higher than in 1971 (National Cancer Institute, 2009). Of these 11.4 million, approximately 900,000 were adult survivors of lymphoma, leukemia, and myeloma. While cancer survivors are experiencing extended periods of disease-free or disease-controlled states, they are at increased risk for co-morbidities such as liver disease, diabetes, cardiovascular disease, osteoporosis, secondary cancers and psychological issues with functional decline (Stull, Snyder, and Demark-Wahnefried, 2007). Cancer survivorship should be celebrated; however, the effects of cancer and related treatments on long-term health can be devastating.

Cancer treatments for leukemia and lymphoma include radiation, chemotherapy, stem cell transplant, and targeted biologic therapies. Furthermore, high dose and/or prolonged corticosteroids are often added to chemotherapy regimens. While potentially lifesaving, these standard cancer therapies are associated with long-term negative health consequences such as liver disease (Rizzo et al., 2006), graft versus host disease (Syrjala, Martin, Deeg, & Boeckh, 2007), viral and bacterial infections (Syrjala et al., 2007), pulmonary disorders (Ravel & Wingard, 2006), secondary malignancies (Ezzone & Beavers, 2008), cardiovascular disease (Ravel & Wingard, 2006; Majhail et al. 2007), and endocrine disorders (Antin, 2002). Additionally, individuals who have had hematopoietic stem cell transplants (HSCT) are at an increased risk for developing cataracts, cognitive changes, neuropathies, osteoporosis, and hypertension (Haylock, Mitchell, Cox, Temple, & Curtiss, 2007). As the length of cancer survivorship increases, the long-term side effects of cancer therapies become more evident in the adult HSCT survivor. However, studies have demonstrated that many of the late effects of cancer treatments are modifiable when a proactive systematic plan of prevention and surveillance is implemented (Haylock et al., 2007).

The plan is most effective when factors such as past treatments, chromosomal prognostic factors, comorbid health conditions, and lifestyle behaviors are considered (Oeffinger & McCabe, 2006).

The American Society of Clinical Oncology (2006) provides cancer survivorship care plans for common cancers such as breast, lung and colorectal, but care plans for the HSCT survivor are not available. A survivorship care plan is a record of a patient's cancer history and recommendations for follow-up care. It is recommended that HSCT-specific survivorship care plans would include 6-month, 12-month, and annual assessments of physical and psychosocial well-being with a special emphasis on preventative screenings that address the unique needs of the HSCT patient (Stull et al., 2007). Examples of these screenings would include bone densitometry scans for patients who were prescribed steroids for more than three months, and pulmonary function tests and mammograms for patients who received radiation (Center for International Blood and Marrow Transplant Research, 2007).

An effective cancer survivorship plan for the HSCT patient would also monitor for recurrent and secondary cancers and provide for coordination of care between primary care and specialty care providers. Early recognition of the potential long-term adverse effects of cancer treatments may improve outcomes and quality of life for the HSCT survivor. The HSCT survivorship care plan would be premised on collaboration among multiple disciplines and care settings in the support of the HSCT survivor who must navigate from acute inpatient care to subacute outpatient care and finally, to long-term chronic care (Beavers & Lester, 2010). However, because studies have not characterized how oncology clinicians use current cancer survivorship guidelines in the HSCT setting, it is necessary to collect additional data to identify the potential gaps in survivorship care planning in this unique population.

Purpose

The purpose of this quality improvement doctorate of nursing (DNP) final project was to describe existing documentation of cancer survivorship care in the electronic medical records of adult HSCT survivors at 12- and 24 months post-transplant in one cancer hospital. The current recommended guidelines from the Center for International Blood and Marrow Transplant (CIBMTR), the European

Group for Blood and Marrow Transplantation (EBMT) and the American Society for Blood and Marrow Transplant (ASBMT) for survivorship care of this population were the standards used to guide the chart review process. The documentation of type and frequency of follow-up care was evaluated to determine whether the recommended interventions contained within the guidelines were completed.

Significance of DNP final project to the healthcare of HSCT cancer survivors

Most healthcare providers will likely encounter a HSCT cancer survivor in their practice. It is important for providers to be aware of the potential long-term sequelae of cancer treatments and how to effectively manage the health of the HSCT survivors in the post-treatment period. Studies investigating the health and welfare of HSCT patients after cancer treatment have identified numerous physical and psychosocial consequences. For example, Rizzo et al. (2006) noted that HSCT survivors were very susceptible to infections, especially if they had experienced chronic graft-versus-host disease. Therefore, the long term goal of this DNP final project was to facilitate survivorship care planning for the HSCT survivor by the oncology healthcare team and share the plan with the primary care provider (PCP). Active communication among the healthcare team members would potentially improve health outcomes for the HSCT survivor. The survivorship period provides multiple opportunities for healthcare providers to improve the health outcomes and quality of life in cancer survivors (Hewitt, Greenfield, & Stovall, 2006).

This DNP final project was significant because the findings revealed that oncology practitioners could improve on the frequency and type of their documentation patterns of recommended survivorship guidelines containing the 29 surveillance indicators as recommended by the CIBMTR, EBMT, and ASBMT. The 29 indicators address the unique medical and psychosocial needs of HSCT survivors who have completed their acute treatment regimen. These unit-specific adherence data were necessary to the planning of a HSCT- specific survivorship care plan.

Project Objectives

Specific aims

Primary Aim #1: To describe the frequency of documentation of existing cancer survivorship guidelines at 12 to 24 months post-transplant in the charts of adult HSCT survivors by oncologists and nurse practitioners.

Primary Aim #2: To describe the prescribing patterns of oncologist and nurse practitioners in the provision of survivorship care in the adult HSCT survivor.

Hypotheses

Hypothesis #1: Survivorship care in accordance with the 29 evidenced-based indicators included in the cancer survivorship guidelines will be documented in less than 50% of the charts of adult HSCT survivors.

Hypothesis #2: Prescribing patterns for tests within the 29 indicators for surveillance and symptom management in the adult HSCT survivor will be implemented in less than 50% of the charts.

Chapter 2

Review of Literature

Theoretical Framework: Shared Care Model

The shared care model is a theoretical framework that supports the long-term care of cancer survivors and the implementation of survivorship care plans. Shared care refers to the care of a patient that is shared by two or more providers of different specialties with the provision of comprehensive care (Orton, 1995). The underlying concepts of shared care include personal communication and periodic transfer of knowledge between the specialist and the PCP (Oeffinger & McCabe, 2006). Typically, cancer patients are guided into the cancer trajectory by their PCP. Once diagnosed with cancer, the care swiftly transfers from the PCP to the oncology team. In the case of a patient undergoing HSCT, the care may remain with the oncology team for several months. Following the acute phase of stem cell transplantation, the HSCT patient is typically referred back to their PCP. As a result, the PCP may be more likely to identify and treat chronic conditions such as graft-versus-host disease. HSCT survivors can also develop secondary health issues that may or may not be related to their cancer treatment, yet require ongoing management by the PCP.

The shared care model can guide survivorship care planning for long-term follow-up of HSCT survivors. The model (Figure 1) developed by Oeffinger and McCabe (2006) illustrates ongoing communication between the oncologist and the PCP. Communication point ‘a’ in the model refers to the oncologist and the PCP. This communication should include information about the cancer diagnosis, staging, grading, past treatment regimens and future treatment plans. In the majority of cases, the PCP would continue to treat the patient’s comorbid conditions and provide routine health maintenance.

When considering the HSCT survivor, the PCP would begin seeing the patient in routine follow-up after the HSCT survivor has completed the early survivorship phase of their care. The responsibility of the PCP would be to ensure that the emotional and physical needs of the patient are met. The PCP could consult with the oncology team whenever necessary and refer the patient back to the oncology team for

specific problems and periodic evaluations. A copy of the patient's survivorship care plan and treatment summary would be given to the PCP to assist in monitoring the long-term care of the HSCT survivor. Periodic communication between the oncologist and PCP would be an expectation to ensure that there was consistency of care.

A three-year follow-up study by Blaauwbroek, Tuinier, Meyboom-de Jong, Kamps, and Postma (2008) assessed the feasibility of shared care between pediatric oncologists and family physicians in the long-term follow-up of survivors of childhood cancers. Opinions about the shared care model by survivors and family physicians were also evaluated. The study noted that 89 of the 101 (88%) survivors were satisfied with the shared care model; 94 of 115 (82%) of the family physicians were satisfied. The shared care model has demonstrated improved patient outcomes in the management of patients with various chronic diseases including diabetes, chronic kidney disease and those patients who receive oral anticoagulant therapy (Oeffinger & McCabe, 2006).

Over time, the incidence of long-term treatment effects experienced by survivors of HSCT may increase as their anticipated length of life increases. With scheduled long-term follow-up, certain late effects may be identified at an earlier, more treatable state. Earle and Neville (2004) reported that five-year survivors of colorectal cancer who were followed by an oncologist and PCP were more likely to receive the recommended follow-up care in comparison with survivors who were seen by just one physician type. To date, there have been no published data from a U.S. study evaluating the shared care model for cancer survivors.

Related research

The related research studies that were reviewed prior to implementing the current project were selected through PubMed and MEDLINE searches using the specific search term "cancer survivor" as well as cross-referenced medical subject heading terms such as "survivors," "care plan," "long-term follow-up," "cancer guidelines," "bone marrow transplant," "stem cell transplant," "quality of life, "and

"complications." Although all articles from 1995 to 2010 were considered, the search was limited to articles in the English language; over 75 articles and books were reviewed.

Previous studies document that the HSCT survivor has an increased risk of premature mortality, morbidity, and adverse health events that vary according to the treatment regimen (Syrjala et al., 2007). For example, patients who have undergone a HSCT are at risk for developing liver disease (Strasser et al. 1999), graft versus host disease (Syrjala et al., 2007), viral and bacterial infections (Rizzo et al., 2006), pulmonary disorders (Ravel & Wingard, 2006), secondary malignancy (Ezzone & Beavers, 2008), cardiovascular disease (Majhail et al. 2007), and endocrine disorders (Antin, 2002).

Liver disease

Liver disease is commonly found in HSCT survivors. Strasser et al. (1999) discussed the multiple potential liver conditions that can occur after HSCT, including liver cirrhosis, veno-occlusive disease, and chronic graft versus host disease of the liver. Liver cirrhosis is prevalent in long-term stem cell transplant survivors. Of the 3,721 patients who survived one or more years after HSCT, 31 patients had clinical or histological evidence of cirrhosis. Of the 1,850 patients who had survived five or more years, 23 patients had evidence of cirrhosis; of the 860 patients who survived 10 or more years from transplantation, 19 were diagnosed with cirrhosis. Of interest, 48% of the patients who developed cirrhosis died at a median of five years after HSCT. The most common factor related to the development of cirrhosis was the presence of chronic viral hepatitis.

Hepatic veno-occlusive disease, also known as sinusoidal obstructive syndrome (SOS), is another serious potential complication of HSCT. The clinical features of SOS include hyperbilirubinemia, fluid retention, and painful hepatomegaly. While liver dysfunction with accompanying jaundice is common after HSCT, patients with SOS exhibit symptoms of circulatory interference that precedes abnormal liver tests. Patients who receive a myeloablative conditioning regimen prior to HSCT are at increased risk for SOS. Patients who undergo a myeloablative conditioning regimen that includes high dose chemotherapy with cyclophosphamide (120mg/kg) plus total-body irradiation have a higher risk of developing SOS

(DeLeve, 2003). Treatment for SOS consists of supportive care including management of volume status, monitoring of multisystem organ failure, and possible hemodialysis and mechanical ventilation.

Graft versus host disease

Graft versus host disease (GVHD) is another potential long-term side effect in patients who undergo HSCT. GVHD occurs when donor T cells recognize major or minor histocompatibility antigens and the T cells become activated and subsequently attack the organs. Symptoms of GVHD are variable but frequently involve the collagen portions of the skin, liver, eyes, mouth, sinuses, and esophagus. The skin, gastrointestinal system, and eyes are the most common body systems that are affected by GVHD. GVHD is considered acute if it occurs within the first 100 days after transplant, or chronic if it occurs 100 days after transplant. Left uncontrolled, GVHD interferes with immune reconstitution and is strongly associated with increased risk of opportunistic infections (Syrjala et al., 2007).

Studies have identified risk factors for the development of chronic GVHD (Vogelsang, 2001). Five-year survival rates for patients with high-risk chronic GVHD are approximately 40% to 50%. Only 50% of patients with chronic GVHD are able to discontinue immunosuppression within five years of diagnosis. The remaining 40% die or develop recurrent malignancy before the GVHD resolves. Ongoing treatment with high-dose glucocorticoids causes significant morbidity, which often leads to additional medical therapies to decrease the dependence on steroids for controlling the disease (Lee, Vogelsang, & Flowers, 2003).

Viral and bacterial infections

Rizzo, et al., (2006) reported that all HSCT survivors are susceptible to infections, but that infections may be more prevalent in survivors who develop GVHD. Immunization with pneumococcal vaccines does not provide complete protection against these bacterial infections; therefore, antibacterial prophylaxis is also recommended, especially in patients with GVHD (Rizzo, et al., Syrjala, et al., 2007). Viral-induced infections occur commonly in the HSCT patient, especially infections from varicella-zoster virus (VZV) or cytomegalovirus (CMV) and may cause considerable complications (Syrjala, et al., 2007).

Fungal infections with late invasive aspergillosis can also occur with devastating outcomes that include lifelong pulmonary dysfunction, chronic obstructive pulmonary disease and possibly death. Drug-induced immunosuppression complicated by high-dose steroid use can increase the frequency, morbidity, and mortality from these infections (Syrjala, et al., 2007).

Pulmonary complications

Diffuse alveolar hemorrhage is a potential complication of HSCT that may occur up to four weeks after transplant (Ravel & Wingard, 2006). Symptoms and complications of this condition include dyspnea, hemoptysis, hypoxemia, decreased hematocrit, diffuse chest infiltrates, an increased alveolar-arterial gradient, and restrictive ventilatory defects. Diffuse alveolar hemorrhage is treated with high dose corticosteroids which can suppress the patient's immune system and cause the patient to be at risk for opportunistic infection (Ravel & Wingard, 2006).

Patients who have had HSCT are also at increased risk of developing bronchiolitis obliterans organizing pneumonia (BOOP) (Ravel &Wingard, 2006). Advanced disease and the presence of GVHD are associated with a higher risk of developing this complication. The collective incidence of BOOP two years after an unrelated donor HSCT was lower in patients who received a reduced-intensity conditioning regimen (fludarabine, busulphan and/or cladribine) compared with patients who received a myeloablative conditioning regimen (busulphan, total-body irradiation, and/or cyclophosphamide), with rates of 17% compared to 2.3% (Ravel & Wingard, 2006).

Secondary malignancy

Secondary malignancies are also common in HSCT survivors. One example of a common secondary malignancy is post- transplant lymphoproliferative disorder (PTLD). PTLD is a potential complication that involves an abnormal growth of lymphocytes. This lymphocyte growth may be inflammatory or neoplastic (Ezzone & Beavers, 2008). Most PTLDs arise from B-cell proliferation induced by infection with the Epstein-Barr virus (EBV) in the chronically immunosuppressed patient. Since 1968, EBV has been known to cause infectious mononucleosis and has been associated with non-

Hodgkin's lymphoma and oral hairy cell leukoplakia. The EBV genome is found in more than 90% of B-cell PTLD occurring in the first year after HSCT. In a patient who has had HSCT, the EBV may activate proliferation of B lymphocytes leading to an overgrowth of hyperplastic, polyclonal lesions occurring early after transplant (Knowles, Cesarman, & Chadburn, 1995).

Cardiovascular disease

Cardiac abnormalities are commonly related to the preparation regimen before HSCT. Anthracycline therapy at doses greater than 300 mg/m^2, ablative dose cyclophosphamide greater than 150 mg/kg, chest radiation therapy, total body irradiation, and high-dose corticosteroids increase a patient's risk of developing congestive heart failure (Ravel & Wingard, 2006; Majhail et al. 2007). Many HSCT patients have cardiac dysfunction during and immediately after transplant and as many as 50% of HSCT survivors have persistent abnormalities manifesting as congestive heart failure, exercise-induced shortness of breath, and blood clots in the extremities (Majhail et al. 2007).

Endocrine dysfunction

Endocrine dysfunction is also common after HSCT and can occur in up to 25% of adults (Ravel & Wingard, 2006). Total body irradiation places the adult HSCT survivor at risk for gonadal dysfunction (Antin 2002) and a multitude of thyroid disorders.

Gonadal failure can result from high-dose alkylating agents or total body irradiation. The severity of failure depends on the dose of radiation. Post pubertal female patients can experience ovarian failure which increases the risk of early osteoporosis, bone fractures, lipid metabolism disorders, and atherosclerotic heart disease (Ravel & Wingard, 2006).

Compensated hypothyroidism and euthyroid sick syndrome, which is low free triiodothyronine, free thyroxine, or both, along with normal or low thyroid-stimulating hormone are the most frequent thyroid abnormalities after HSCT (Toubert et al., 1997). The threat of hypothyroidism is increased in patients who receive irradiation of the head and/or neck (Boulad et al., 1995). HSCT survivors who have been diagnosed with hypothyroidism will require lifelong thyroid replacement therapy. A study of 72

HSCT survivors revealed that 6% of male patients and 5% of female patients had overt hypothyroidism (Ravel & Wingard, 2006). All HSCT survivors who have received irradiation should have their thyroid function studies evaluated annually.

Chapter 3

Methods

Research Design

This DNP final project used a descriptive design involving retrospective chart reviews. The electronic medical records of adult HSCT patients from one Midwest cancer center were reviewed for 29 indicators in 10 categories of long-term cancer survivorship follow-up at 12 to 24 months. A convenience sample of autologous and allogeneic stem cell survivors was identified from the Bone Marrow Transplant Unit database which provides data about primary disease, type and date of transplant. All eligible HSCT survivors at least 24 months from date of transplant were considered for inclusion in the DNP final project. Furthermore, adult HSCT survivors from all seven oncology clinicians' practices were eligible for the study. An exemption for informed consent was obtained as this was a retrospective chart review of existing data from electronic medical records.

Sample

Inclusion criteria

- Autologous or allogeneic hematopoietic stem cell transplant (HSCT) survivor
- ≥ 18 years of age
- At least 730 days status post HSCT
- Primary diagnosis of acute leukemia, lymphomas, myelomas, myelodysplastic syndrome and/or myelofibrosis.

Exclusion criteria

- Those patients less than 730 days post HSCT
- Patients with a primary diagnosis of aplastic anemia and/or multiple sclerosis
- Survivors not receiving at least 24 months of follow-up care in the HSCT clinic

Methods

The medical records of all eligible autologous and allogeneic HSCT survivors were reviewed at 12- and 24-months status post HSCT. Documentation of the ten categories, as based on the Joint Recommendations of the EBMT, ASBMT, and the CIBMTR (CIBMTR, 2006) were observed at 12 and 24 months post transplant. The 29 indicators contained within the ten categories that were tracked in this retrospective chart review included:

- Liver function, including serum liver panel and ferritin
- Blood pressure monitoring, heart rate, echocardiogram, chest x-ray, smoking habits/cessation, and pulmonary function studies
- Kidney function, including serum levels of BUN, creatinine, and protein
- Musculoskeletal symptoms such as muscular strength/weakness, muscular atrophy, bone density
- Endocrine and fertility issues, including menstruation, serum (male/female) hormone levels, libido, expressed desire for parenthood, erectile dysfunction
- Infectious disease prophylaxis, including vaccinations such as influenza, pneumococcal, hepatitis, tetanus, cytomegalovirus, pneumocystis carinii pneumonia prophylaxis.
- Healthy lifestyle, including dietary habits/restrictions, exercise regimen, and routine screening for secondary cancers
- Emotional health, including psychosocial symptoms, coping mechanisms, counseling referrals, sexual function assessment
- Dental health, including annual dental exams
- Vision screening, including annual vision exam, pain and dryness

Documentation of prescribing patterns at 0 to 24 months was reviewed to determine if appropriate screening and survivorship follow-up interventions were performed. These included documentation of appropriate serum and radiographic studies, healthy lifestyle measures, cancer screenings, psychological

assessments, and vaccinations. Additionally, potential negative outcomes of these interventions as related to omission of recommended long-term survivorship care were reviewed.

Sample size estimation

The Bone Marrow Transplant Unit at this Midwestern cancer hospital provides care for approximately 200 autologous and allogeneic HSCT patients per year. It was recommended that 385 charts be reviewed in order to obtain a 95% confidence interval with a margin of error less than 5% surrounding the fraction of charts completed (Stommel & Wills, 2004).

Instruments

Data were collected from electronic medical records (EMR) using two separate EMR systems. The first system, TransChart, contained medical information documented by the outpatient hematological transplant clinic from September 2006 through July 2009. The second and current system, Integrated Health Information System (IHIS), provided data from July 2009 to present. These retrospective chart reviews provided data relevant to oncology clinician documentation of the 29 indicators at 12- and 24-months; clinicians included advanced practice nurses (APNs), and physicians.

Patients were assigned an identification number, i.e. HSCT 01, HSCT 02, etc., in order to maintain confidentiality. Data were collected by members of the research team and documented on a Microsoft Excel (2007) spreadsheet. Available data were recorded and when information was not available, the data field was marked not applicable. Abstracted data were stored in a locked cabinet in a locked office to protect confidentiality.

Data collection was confined to the listed investigators to provide for inter-rater reliability. The lead NP reviewed the first 30 charts completed by every member of the research team so that inter-rater reliability could be assessed. When the inter-rater reliability co-efficient between the NP and the research team member was found to be unacceptable ($r < 0.90$), the NP provided appropriate education and clarification for the reviewer, after which inter-rater reliability was reassessed.

Data Analysis

Data were imported into Statistical Package for the Social Sciences (SPSS), Version 19.0.

Primary Aim #1: To describe the frequency of documentation of cancer survivorship guidelines at 12 to 24 months post-transplant in the adult HSCT survivor by oncology clinicians.

Data were analyzed for the practitioner adherence to the 29 indicators at 12- and 24-months. One sample tests of proportions were used to test whether adherence was less than 50%. A Chi-square test was used to compare the frequency of long-term follow-up recommendations that were documented across the recommended 29 indicators. Appropriate post-hoc Chi-square tests were used to test for differences between pairs of indicators.

Primary Aim #2: To describe the prescribing patterns of oncology clinicians in the provision of survivorship care in the adult HSCT survivor. Data analysis has not been completed.

Compliance to the DNP essentials

The third DNP essential describes clinical scholarship and analytical methods for evidence-based practice. This project was a retrospective descriptive analysis of specific outcomes related to HSCT survivorship care. The hypothesis that survivorship care for adult HSCT survivors would be documented in < 50% of the charts reviewed represents the paradigm of scholars giving meaning to isolated phenomena. To my knowledge this is the first DNP final project at a comprehensive cancer center to explore the frequency of adherence to recommended evidenced-based guidelines that have been developed to guide the care of HSCT survivors in the post-hematopoietic transplant period.

Chapter 4

Findings

Data retrieval

The data were collected via a chart review process that was an interdisciplinary endeavor by three registered nurses (RN) and a clinical researcher/NP; all four nurses had been employed in the hematology and transplant clinic for at least one year. Data collection began in September 2010 and was completed within four months. The 385 charts identified for review were accessed from two different electronic medical records, TransChart and IHIS, which provided data over the intended time period.

The first 30 charts that each RN reviewed were also reviewed by the lead NP to assess inter-rater reliability. It was determined that Cronbach's alpha was < 0.90. Therefore each RN received additional instruction from the lead NP regarding the existing cancer survivorship guidelines for autologous and allogeneic stem cell transplant survivors. The lead NP clarified the meaning of each categorical item with each RN prior to additional extraction of data. For example, unlike allogeneic stem cell transplant survivors who are required to have cytomegalovirus (CMV) testing done at 12 months and annually, autologous stem cell transplant survivors are not required to have CMV testing and therefore should not be marked 'deficient' in their long-term follow-up. For this type of patient, "not applicable" was placed on the data collection sheet. Following the brief instructions, inter-rater reliability was again calculated for each RN/NP after the review of 30 additional charts using Cronbach's alpha and deemed satisfactory ($r > 0.90$).

During the process of inter-rater reliability testing it was discovered that the indicator 'risk for cardiovascular disease' was essentially documented twice because 'smoking cessation' and/or 'aggressive management of blood pressure' provided proxy measures for 'risk for cardiovascular disease'. This finding indicated a potential duplication of data among the combined indicators as provided by ASMT, EBMT, and CIBMTR guidelines. Therefore, the indicator of 'risk for cardiovascular disease' was deleted; 'smoking cessation' and 'aggressive management of blood pressure' were retained.

Results

A total of 385 charts of HSCT survivors were reviewed to determine if evidence-based indicators were implemented at 12 and 24 months post-transplant in at least 50% of the charts in the adult HSCT survivor sample. The sample included the following diagnoses: 102 (26%) leukemia, 154 (40%) multiple myeloma, 83 (22%) non-Hodgkin's lymphoma, and 41 (11%) Hodgkin's lymphoma and 5 (1%) myelodysplastic syndrome (Table 1). A total of 84 (22%) patients were evaluated only at 12 months, and not at 24 months due to loss to follow-up or death. Therefore, a total of 301 charts were subsequently reviewed for documentation of the evidenced-based indicators of long-term follow-up at 12 and 24 months post HSCT by oncology clinicians.

The Clopper-Pearson interval test was used to calculate binomial confidence intervals. A binomial confidence interval relies on the assumption of a binomial distribution (Stommel & Wills, 2004). A binomial distribution applies in this data analysis because each trial of the variable had two possible outcomes: either the recommended guideline was followed, or the recommended guideline was not followed. The confidence interval chosen for this project was 95% with a margin of error less than 5% surrounding the fraction of the charts completed

Data analyses

The review consisted of the RNs documenting adherence to 10 health categories containing a total of 29 evidenced-based indicators (Figure 2). The hypothesis was that these evidenced-based indicators would be documented as completed in less than 50% of the charts for each of the 29 indicators at 12 and 24 months. Of the 29 indicators, only three were documented as being completed in greater than 50% of the charts (Table 2). These three indicators included aggressive management of blood pressure, serum blood urea nitrogen (BUN) and creatinine and serum liver function testing (LFT). Blood pressure was managed aggressively in 60.2% of the charts at 12 months and in 57.7% of the charts at 24 months. Serum BUN and creatinine were obtained in73.2% of the charts at 12 months and in 71.2% of

the charts at 24 months. Serum LFTs were obtained in 71.4% of the charts at 12 months and in 69.6% of the charts at 24 months (Table 2).

There were two additional indicators which were documented as completed in more than 50% of the charts at 12 months, but in less than 50% of the charts at 24 months. These were 'consideration of herpes simplex virus and antifungal prophylaxis' and 'pneumocystis carinii pneumonia (PCP) prophylaxis'. At 12 months, these were provided in 60.2% and 60.5% of the charts, respectively and in 43.4% and in 46.1% of the charts, respectively, at 24 months (Table 3).

The remaining 24 indicators were documented as completed in less than 50% of the charts. Cytomegalovirus (CMV) testing was documented as completed in 47.7% of the charts at 12 months and in 43.0% of the charts at 24 months. Female sex hormone levels were documented as completed in 3.8% of the charts at 12 months and in 4.0% of the charts at 24 months. Serum levels of male sex hormones were documented as completed in 25.4% of the charts at 12 months and in 17.7% of the charts at 24 months. Serum ferritin levels were documented as completed in 7.0% of the charts at 12 months and in 9.2% of the charts at 24 months. Finally, thyroid function assessment was documented as completed in 24.5% of the charts at 12 months and in 24.9% of the charts at 24 months (Table 4).

Imaging studies were also documented as completed in less than 50% of the charts. Bone densitometry testing was documented as completed in 10. 8% of the charts at 12 months and in 9.8% of the charts at 24 months. Chest radiography was documented as completed in 26.3% of the charts at 12 months and in 20.1% of the charts at 24 months. Mammograms were documented as completed in 5.8% of the charts at 12 months and 5.9% of the charts at 24 months. Pulmonary function tests (PFT) were documented as completed in 23.4% of the charts at 12 months and in 19.2% of the charts at 24 months (Table 5).

Preventive exams and screenings were documented as completed in less than 50% of the charts as were education concerning breast, skin, and/or testes self exam. These interventions were documented as completed in 0.5% of the charts at 12 months and in 1.6% of the charts at 24 months. Endocarditis

prophylaxis was documented as completed in 2.0% of the charts at 12 months and in 1.1% at 24 months. Osteopenia prophylaxis with bisphosphonates was documented as completed in 23.0% of the charts at 12 months and in 23.8% at 24 months. Papanicolaou (PAP) tests were documented as completed in 2.7% of the charts at 12 months and in 2.1% at 24 months.

Regular dental exams were documented as completed in 1.8% of the charts at 12 months and in 1.9% at 24 months. Routine vision exams were documented as completed in 5.7% of the charts at 12 months and in 5.2% at 24 months. Schirmer testing was documented as completed in 29.2% of the charts at 12 months and in 31.8% at 24 months. Screening for steroid myopathy was documented as completed in16.8% of the charts at 12 months and in 12.6% at 24 months. Secondary cancer screenings were documented as completed in 3.9% of the charts at 12 months and in 4.1% at 24 months. Smoking cessation was documented as completed in 32.3% of the charts at 12 months and in 34.2% at 24 months. Vaccinations were documented as completed in 7.6% of the charts at 12 months and in 6.8% at 24 months (Table 6). Psychosocial support recommendations were documented as completed in less than less than 50% of the charts. These recommendations included emotional health counseling, (10.6% at 12 months and 8.7% at 24 months), sexual function assessment (1.0% at 12 months and 0.5% at 24 months), and use or the offer of support groups (1.3% at 12 months and 1.1% at 24 months) (Table 7).

Compliance to the DNP essentials

The second DNP essential describes organizational and systems leadership for quality improvement and systems thinking. This quality improvement project will improve patient and healthcare outcomes because it described the frequency of documentation of cancer survivorship guidelines at 12- and 24- months post-transplant in the adult HSCT survivor by oncologists and advanced practice nurses. These results were then analyzed and changes implemented based on study findings.

One quality improvement initiative that was a direct result of the study findings was the assessment of HSCT survivors' vaccination status. The omission of this important indicator was

identified early in the chart review process. The issue was quickly resolved with collaborative efforts among the oncology clinicians in the outpatient hematology clinic.

The sixth DNP essential describes interprofessional collaboration for improving patient and population health outcomes. This essential was integrated into the project by having three registered nurses and a clinical researcher/NP perform data collection.

Discussion

Interpretation of data

The DNP final project data demonstrated that several components of the cancer survivorship guidelines as proposed by ASBMT, EBMT, and CIBMTR were not documented at 12 to 24 months post-hematopoietic stem cell transplant in the charts of adult HSCT survivors by oncologists and NPs in a Midwest cancer hospital. These findings suggest that the various health-related and preventive care interventions were not performed, or if completed were not documented in a manner that supports interdisciplinary communication. This apparent lack of long-term follow-up care may contribute to poorer health outcomes and unmet psychosocial needs of HSCT survivors.

A significant finding that emerged early in the chart review process was the frequent absence of documentation regarding revaccination of hemophilus influenza b, tetanus-diphtheria toxoid, inactivated polio, Hepatitis B, and if indicated, measles, mumps, and rubella (Johnston & Conly, 2002). Revaccination of the HSCT survivor is an indicator in the survivorship guidelines and an essential component of preventive health care as chemotherapy and radiation treatments ablate the HSCT survivor's immune system. Therefore, prevention of infection is vital to the long-term health of the HSCT survivor (Syrjala et al., 2007). This information was immediately shared with the RNs, NPs, and physicians in the hematology clinic and a system was developed to ensure appropriate and timely vaccinations.

Additional data generated from the chart review process revealed that only three of the 29 indicators in the cancer survivorship guidelines were documented as completed in more than 50% of the charts at 12 and 24 months post-HSCT, consistent with the DNP final project hypothesis #1: survivorship care in accordance with evidenced-based indicators would be documented in less than 50% of the charts for each of the 29 indicators for the adult HSCT survivor. These three indicators included aggressive management of blood pressure, serum liver function tests, and serum blood urea nitrogen and creatinine (Table 3). Two additional indicators, prophylaxis of herpes simplex and fungal infection and prophylaxis against pneumocystis carinii pneumonia (Table 4) were documented in more than 50% of the charts at 12 months, but in less than 50% at 24 months. Importantly, the remaining 25 indicators were documented in less than 50% of the charts at both 12 and 24 months. These indicators included cytomegalovirus, male and female sex hormone levels, serum ferritin, thyroid function tests, urine protein (Table 5), bone density testing, chest radiograph, mammograms, pulmonary function tests (Table 6), breast, skin, and/or testes self-exam, endocarditis prophylaxis, osteopenia prophylaxis, PAP smear, regular dental and vision exams, and Schirmer testing, screening for steroid myopathy, secondary cancer screenings, smoking cessation, and vaccinations (Table 7), emotional health counseling, sexual function assessment, and support groups (Table 8).

To my knowledge this is the first DNP final project at a comprehensive cancer center to explore the frequency of documentation of the recommended evidenced-based guidelines by oncology clinicians that have been developed to guide the care of HSCT survivors in the post-hematopoietic transplant period. It remains unknown if certain measures were completed but not documented by this institution's blood and marrow transplant (BMT) team at 12 and 24 months. Likewise, it is unknown if 12- and 24-month indicators were fulfilled by the survivors' PCP which could narrow perceived gaps in care. These issues are important to consider as clinicians prepare for the provision of formal survivorship care, specifically in regard to the shared care model.

Integration of findings

The DNP final project findings confirmed the hypothesis that long-term survivorship care planning was sub-optimal (<50%) in this institution's HSCT population. Prior to initiating a formal survivorship care clinic for HSCT survivors, a professional educational plan was developed by the lead NP. She attended the George Washington University's Executive Training Conference on Navigation and Survivorship in Washington, D.C. This intensive, two-day executive training program provided program leaders with the tools and resources needed to launch and sustain navigation and survivorship programs. Attendees were taught elements of business planning as well as internal and external environmental analyses.

A preliminary step in the initiation of the survivorship clinic involved the organization of a HSCT-specific survivorship task force. This committee convened in September 2010 and was charged with decision-making aspects of an institutionally based HSCT survivorship care program. Membership was open; an interdisciplinary team was formed consisting of housekeepers, lab technicians, massage therapists, RNs, NPs, discharge planners, physicians, and the chief nursing officer. The team met at six week intervals. The agenda for the first meeting included a review of short-term and long-term goals, a review of treatment summary templates that were available online and at other cancer centers, and a group discussion. Tasks were assigned and timelines generated. Over the course of several months the task force achieved many of their primary goals. The most significant goal was to create a computerized template to remind BMT providers which surveillance screening tests were required at specific time points. This was accomplished by creating a "best practice" list (Figure 3) based on the recommended guidelines from the ASBMT, EBMT, and CIBMTR (2006). When using the best practice list, the interdisciplinary team learned that survivorship care of the HSCT survivor was more than just an evaluation of the patient's hematologic disease status. The need for a designated outpatient HCST survivorship visit was quickly recognized.

The Hematology and Transplant Survivorship Clinic (also known as the survivorship clinic) that is now in operation is conducted by the NP one day per week. HSCT survivors can expect to spend 60-90 minutes with the NP to review their treatment summary for completeness and accuracy (Figure 4) and to discuss the recommended follow-up care regarding surveillance indicators (Figure 5), cancer screenings (Figures 6 and 7), and any psychosocial needs. Referrals, if needed, are then arranged. A print copy of the completed treatment summary and recommended follow-up care plan is given to the HSCT survivor and an electronic copy is sent to their referring hematologist, PCP, and local hematologist, if applicable.

To date, 12 allogeneic HSCT survivors have been evaluated in the survivorship clinic. The majority of patients have requested additional psychosocial services, such as counseling to help them understand their 'new normal'. Many patients have complained of sexual dysfunction issues and decreased libido. The survivorship clinic is currently examining options to assist survivors with these concerns.

Compliance to the DNP essentials

The fourth DNP essential describes information systems/technology and patient care technology for the improvement and transformation of health care. As a result of this DNP final project, computerized templates for treatment summaries and survivorship care plans have been developed. These computerized templates were developed as a Microsoft Word® document and then imported into the IHIS system as a user-friendly smart phrase. These smart phrases are available to anyone and are easily modifiable.

The seventh DNP essential describes clinical prevention and population health for improving the nation's health. This essential was incorporated into the DNP final project in several ways : (1) development of computerized templates for the HSCT survivor, (2)improvement in administration and documentation of vaccination status in the HSCT survivor. Both of these outcomes focus on health promotion and disease prevention.

Conclusion

The data from this DNP final project revealed the absence of several important recommended indicators of long-term survivorship care planning in the charts of HSCT survivors. One of these indicators, revaccination of the HSCT survivor, was swiftly implemented by the BMT team, while the remaining indicators will be implemented over time. The findings from this DNP final project will guide the further development of survivorship care for the HSCT in this Midwest cancer hospital.

Chapter 5

Summary

Standard cancer treatment for leukemia and lymphoma patients includes radiation, chemotherapy, and steroids. These interventions are often associated with long-term negative health consequences such as cataracts, cognitive changes, neuropathies, osteoporosis, and hypertension (Haylock, Mitchell, Cox, Temple, and Curtiss, 2007). As the length of cancer survivorship increases, the long-term effects of standard cancer therapies become more evident.

Bone marrow transplant is an effective therapy for the treatment of hematologic malignancies such as leukemia and lymphoma. However, the negative health consequences associated with these intense interventions create new challenges for the provider and the survivor. HSCT survivors are at increased risk for developing secondary cancers, other physical side-effects and psychosocial issues. Therefore, it is vital that the clinicians who care for the HSCT survivor understand the unique needs of this population, their families, and groups affected by these diseases. A proposed survivorship care plan including standard screening schedules and a long-term follow-up survivorship clinic could improve the quality of life for HSCT survivors.

Limitations

One limitation to this DNP final project involves the possibility that despite the lack of documentation in the sample of charts reviewed, an intervention may have been completed. For example, HSCT survivorship patients may have received their immunizations or other routine follow-up tests without documentation, or at other facilities; therefore the event may or may not have been appropriately documented in the TransChart or IHIS systems. Improved communication within and between medical systems is necessary to narrow these gaps in care. The survivorship care plan is intended to provide a mechanism to enhance shared care between providers and provide documentation of received care and ongoing long-term care needs.

Implications for practice

The data generated from this DNP final project were used to develop a computer-based survivorship care plan for the HSCT patient and establish a survivorship clinic in a Midwest comprehensive cancer center. The data also provided the basis for ongoing discussions among healthcare providers about the beneficial effects of survivorship care planning and the promotion of healthy outcomes for HSCT survivors. As a result, healthcare providers have begun to contribute ideas for refining aspects of the HSCT survivorship care plan.

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Table 1

Percentage of Distribution of Cancer Types in Charts Reviewed

Cancer	% of the types of cancer n = 301
Myelodysplastic Syndrome	40%
Hodgkin's Lymphoma	26%
Non Hodgkin's Lymphoma	22%
Leukemia	11%
Multiple Myeloma	1%

Table 2

Indicators documented in more than 50% of the charts at 12 and 24 months

		Aggressive Management of Blood Pressure		Total
		No	Yes	
Time: 12 mos.	# HSCT Survivors	152	230	382
	% HSCT Survivors	39.8%	60.2%	100.0%
Time: 24 mos.	# HSCT Survivors	155	211	366
	% HSCT Survivors	42.3%	57.7%	100.0%

$x^2 = 0.51$ $p = 0.48$

		Serum Blood Urea Nitrogen and Creatinine		Total
		No	Yes	
Time: 12 mos.	# HSCT Survivors	103	282	385
	% HSCT Survivors	26.8%	73.2%	100.0%
Time: 24 mos.	# HSCT Survivors	106	262	368
	% HSCT Survivors	28.8%	71.2%	100.0%

$x^2 = 0.40$ $p = 0.53$

		Liver Function Tests		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	110	275	385
	% HSCT Survivors	28.6%	71.4%	100.0%
Time: 24 mos.	# HSCT Survivors	112	256	368
	% HSCT Survivors	30.4%	69.6%	100.0%

$x^2 = 0.31$ $p = 0.58$

Table 3:

Indicators documented in more that 50% of charts at 12 months, but in less than 50% at 24 months

		Consider Herpes Simplex Virus & Antifungal Prophylaxis		Total
		No	Yes	
Time: 12 mos.	# HSCT Survivors	49	74	123
	% HSCT Survivors	39.8%	60.2%	100.0%
Time: 24 mos.	# HSCT Survivors	60	46	106
	% HSCT Survivors	56.6%	43.4%	100.0%

$x^2 = 6.42$ $p = 0.01$

		Pneumocystis Carinii Pneumonia Prophylaxis		Total
		No	Yes	
Time: 12 mos.	# HSCT Survivors	47	72	119
	% HSCT Survivors	39.5%	60.5%	100.0%
Time: 24 mos.	# HSCT Survivors	55	47	102
	% HSCT Survivors	53.9%	46.1%	100.0%

$x^2 = 4.60$ $p = 0.03$

Table 4

Blood and Urine Tests

		Cytomegalovirus		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	67	61	128
	% HSCT Survivors	52.3%	47.7%	100.0%
Time: 24 mos.	# HSCT Survivors	65	49	114
	% HSCT Survivors	57.0%	43.0%	100.0%

$x^2 = 0.53$ $p = 0.47$

		Female Sex Hormone Levels		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	151	6	157
	% HSCT Survivors	96.2%	3.8%	100.0%
Time: 24 mos.	# HSCT Survivors	145	6	151
	% HSCT Survivors	96.0%	4.0%	100.0%

$x^2 = 0.05$ $p = 0.95$

		Male Sex Hormone Levels		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	106	36	142
	% HSCT Survivors	74.6%	25.4%	100.0%
Time: 24 mos.	# HSCT Survivors	107	23	130
	% HSCT Survivors	82.3%	17.7%	100.0%

$x^2 = 2.34$ $p = 0.13$

		Serum Ferritin		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	358	27	385
	% HSCT Survivors	93.0%	7.0%	100.0%
Time: 24 mos.	# HSCT Survivors	334	34	368
	% HSCT Survivors	90.8%	9.2%	100.0%

$x^2 = 1.25$ $p = 0.26$

		Thyroid Function		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	290	94	384
	% HSCT Survivors	75.5%	24.5%	100.0%
Time: 24 mos.	# HSCT Survivors	275	91	366
	% HSCT Survivors	75.1%	24.9%	100.0%

$x^2 = 0.02$ $p = 0.90$

		Urine Protein		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	284	100	384
	% HSCT Survivors	74.0%	26.0%	100.0%
Time: 24 mos.	# HSCT Survivors	283	85	368
	% HSCT Survivors	76.9%	23.1%	100.0%

$x^2 = 0.88$ $p = 0.35$

Table 5

Imaging Tests

		Bone Density		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	107	13	120
	% HSCT Survivors	89.2%	10.8%	100.0%
Time: 24 mos.	# HSCT Survivors	101	11	112
	% HSCT Survivors	90.2%	9.8%	100.0%

$x^2 = 0.06$ $p = 0.80$

		Chest Radiograph		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	283	101	384
	% HSCT Survivors	73.7%	26.3%	100.0%
Time: 24 mos.	# HSCT Survivors	295	74	369
	% HSCT Survivors	79.9%	20.1%	100.0%

$x^2 = 4.12$ $p = 0.04$

		Mammogram		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	131	8	139
	% HSCT Survivors	94.2%	5.8%	100.0%
Time: 24 mos.	# HSCT Survivors	127	8	135
	% HSCT Survivors	94.1%	5.9%	100.0%

$x^2 = 0.004$ $p = 0.95$

		Pulmonary Function Test		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	157	48	205
	% HSCT Survivors	76.6%	23.4%	100.0%
Time: 24 mos.	# HSCT Survivors	156	37	193
	% HSCT Survivors	80.8%	19.2%	100.0%

$x^2 = 1.07$ $p = 0.30$

Table 6

Preventative Exams

		Breast/Skin/Testes Self Exam		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	383	2	385
	% HSCT Survivors	99.5%	0.5%	100.0%
Time: 24 mos.	# HSCT Survivors	362	6	368
	% HSCT Survivors	98.4%	1.6%	100.0%

$x^2 = 2.21$ $p = 0.14$

		Endocarditis Prophylaxis		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	100	2	102
	% HSCT Survivors	98.0%	2.0%	100.0%
Time: 24 mos.	# HSCT Survivors	89	1	90
	% HSCT Survivors	98.9%	1.1%	100.0%

$x^2 = 0.22$ $p = 0.64$

		Osteopenia Prophylaxis		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	107	32	139
	% HSCT Survivors	77.0%	23.0%	100.0%
Time: 24 mos.	# HSCT Survivors	99	31	130
	% HSCT Survivors	76.2%	23.8%	100.0%

$x^2 = 0.03$ $p = 0.87$

		PAP Smear		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	146	4	150
	% HSCT Survivors	97.3%	2.7%	100.0%
Time: 24 mos.	# HSCT Survivors	142	3	145
	% HSCT Survivors	97.9%	2.1%	100.0%

$x^2 = 0.15$ $p = 0.74$

		Regular Dental Exam		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	378	7	385
	% HSCT Survivors	98.2%	1.8%	100.0%
Time: 24 mos.	# HSCT Survivors	361	7	368
	% HSCT Survivors	98.1%	1.9%	100.0%

$x^2 = 0.01$ $p = 0.93$

		Routine Vision Exam		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	363	22	385
	% HSCT Survivors	94.3%	5.7%	100.0%
Time: 24 mos.	# HSCT Survivors	349	19	368
	% HSCT Survivors	94.8%	5.2%	100.0%

$x^2 = 0.11$ $p = 0.74$

		Schirmer Testing		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	17	7	24
	% HSCT Survivors	70.8%	29.2%	100.0%
Time: 24 mos.	# HSCT Survivors	15	7	22
	% HSCT Survivors	68.2%	31.8%	100.0%

$x^2 = 0.04$ $p = 0.85$

		Screen for Steroid Myopathy		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	99	20	119
	% HSCT Survivors	83.2%	16.8%	100.0%
Time: 24 mos.	# HSCT Survivors	97	14	111
	% HSCT Survivors	87.4%	12.6%	100.0%

$x^2 = 0.80$ $p = 0.37$

		Secondary Cancer Screenings		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	369	15	384
	% HSCT Survivors	96.1%	3.9%	100.0%
Time: 24 mos.	# HSCT Survivors	352	15	367
	% HSCT Survivors	95.9%	4.1%	100.0%

$x^2 = 0.02$ $p = 0.90$

		Smoking Cessation		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	86	41	127
	% HSCT Survivors	67.7%	32.3%	100.0%
Time: 24 mos.	# HSCT Survivors	79	41	120
	% HSCT Survivors	65.8%	34.2%	100.0%

$x^2 = 0.10$ $p = 0.75$

		Vaccines		
		No	Yes	Total
Time: 12 mos.	# HSCT Survivors	355	29	384
	% HSCT Survivors	92.4%	7.6%	100.0%
Time: 24 mos.	# HSCT Survivors	342	25	367
	% HSCT Survivors	93.2%	6.8%	00.0%

$x^2 = 0.15$ $p = 0.70$

Table 7

Psychosocial Follow-up

		Emotional Health Counseling		
		N	Y	Total
Time: 12 mos.	# HSCT Survivors	344	41	385
	% HSCT Survivors	89.4%	10.6%	100.0%
Time: 24 mos.	# HSCT Survivors	336	32	368
	% HSCT Survivors	91.3%	8.7%	100.0%

$x^2 = 0.82$ $p = 0.37$

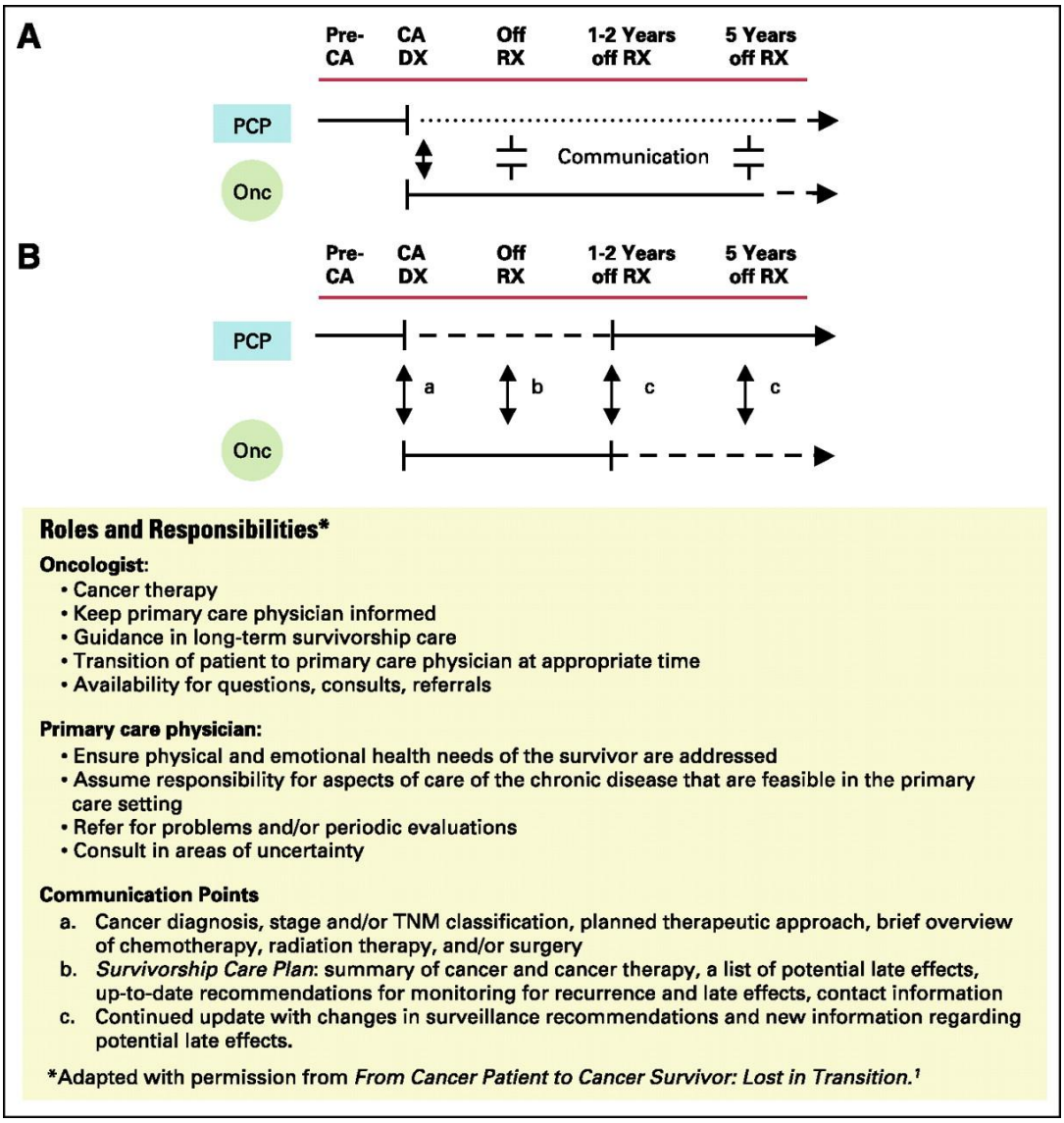
		Sexual Function Assessment		
		N	Y	Total
Time: 12 mos.	# HSCT Survivors	380	4	384
	% HSCT Survivors	99.0%	1.0%	100.0%
Time: 24 mos.	# HSCT Survivors	364	2	366
	% HSCT Survivors	99.5%	0.5%	100.0%

$x^2 = 0.60$ $p = 0.45$

		Support Groups		
		N	Y	Total
Time: 12 mos.	# HSCT Survivors	380	5	385
	% HSCT Survivors	98.7%	1.3%	100.0%
Time: 24 mos.	# HSCT Survivors	364	4	368
	% HSCT Survivors	98.9%	1.1%	100.0%

$x^2 = 0.07$ $p = 0.79$

Figure 1: Shared Care Model



This is the shared care model which is the proposed theoretical model for following patients long-term after cancer treatment (Oeffinger and McCabe, 2006).

Figure 2: Indicator Tracking Sheet

	LIVER		LUNG			RENAL		MUSCULOSKELETAL				GROWTH & FERTILITY			INFECTIOUS DISEASE					HEALTH PROMOTION				PSYCHOSOCIAL			ORAL	EYES	
	LFTs	Serum Ferritin	Chest X-ray	Smoking Cessation	Pulmonary Function Tests	Aggressive Mgmt of BP	BUN/Creatinine	Urine Protein	Bone density if on steroids > 3 months	Screen for steroid myopathy	Osteopenia prophylaxis with bisphosphonates	Thyroid function	Female sex hormone levels	Males (If lack of libido and/or erectile dysfunction	Vaccines	CMV testing	PCP prophylaxis	Consider HSV & antifungal prophylaxis	Endocarditis prophylaxis	Breast/skin/testes self exam	PAP smears	Mammogram for women > 40 y.o. or if they received radiation	Secondary cancer screenings	Emotional health counseling	Support groups	Sexual function assessment	Regular dental exams	Routine vision exam	Schirmer testing
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Figure 3: Best Practice List

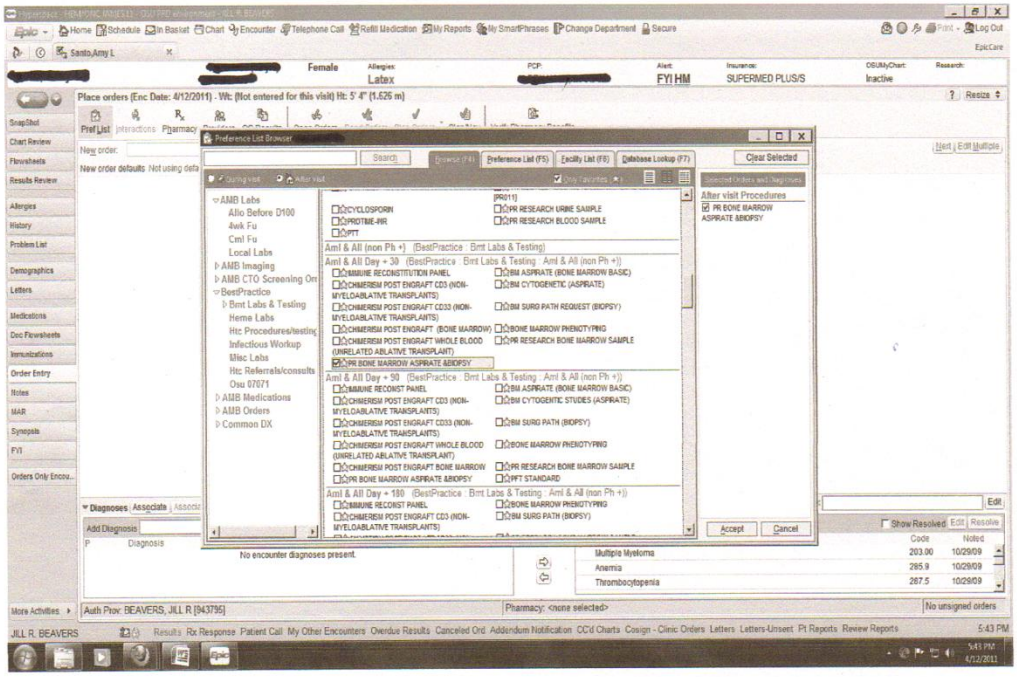

Figure 4: Treatment Summary

Diagnosis:				
Date of diagnosis:	Age at diagnosis:	Date therapy complete:		
Prognostic features:	Cytogenetics:			
Summary of treatment:				
Treatment Center(s)				
Past Medical History				
Problem	Ongoing Therapy			
Relapse(s) Yes No				
Date:	Site	Therapy		
Secondary Malignancy Yes No				
Date	Site	Therapy		
Protocol(s)				
Acronym/Number	Therapy and dates			
Chemotherapy Yes No				
Date(s)	Drug Name	Route	Total dose (mg/kg or mg/m^2)	
Radiation Yes No				
Type	Site	Date	Dose per fraction (Gy)	Total Dose
Surgery Yes No				
Date	Procedure	Surgeon/Institute		
Transfusion History				
Transfusion Reaction	Pre Medication			
Adverse Drug Reactions/Allergies Yes No				
Drug	Reaction			
Hematopoietic Stem Cell Transplant Yes No				
Date of transplant:	Donor source (periph/marrow/UCB):			
Type (auto or allo):	HLA Match:			
Conditioning Regimen:	ABO:			
Cell dose:	Sex:			
Institution:	BMT Physician:			
Graft versus Host Disease Yes (chronic or acute) No				
Organs Involved:				
Grade: None Limited (localized to skin and/or liver) Extensive				
Severity: Mild (signs and symptoms do not interfere with function)				
Moderate (signs and symptoms interfere somewhat with function)				
Extensive (limits function substantially despite appropriate therapy)				
GVHD Treatment Summary				
Drug	Start Date	Stop Date		
HSCT Complications/Late Effects Yes No				
Problem	Dates	Ongoing Therapy		

Figure 5: Recommended Follow-Up for HSCT Survivors

Recommended Screening/Prevention	Six Months	One Year	Annually	Date done
Annual dental exam	NA	X	X	
Annual eye exam		X	X	
Blood pressure screening	X	X	X	
Bone density testing (patients with > 3 months steroid use or calcineurin inhibitor use.) Consider osteopenia prophylaxis	NA	X	If previously abnormal	
BUN/Creatinine	X	X	X	
Cardiovascular risk assessment	NA	X	X	
Chest X-ray	If previously abnormal	If previously abnormal	If previously abnormal	
CMV testing	If chronic graft vs. host disease	If chronic graft vs. host disease	If chronic graft vs. host disease	
Encapsulated organism prophylaxis. Consider antifungal, HSV, PCP prophylaxis	If chronic graft vs. host disease	If chronic graft vs. host disease	If chronic graft vs. host disease	
Endocarditis prophylaxis for dental procedures per AHA guidelines	NA	X	X	
Gonadal function assessment	NA	X	X	
Immunizations	NA	X	X	
Liver function test	X	X	If previously abnormal	
Psychosocial and quality of life assessment; sexual function assessment	X	X	X	
Pulmonary function testing	NA	X	If previously abnormal	
Secondary cancer screenings: Breast/skin/testes self-exam; Pap smear, mammogram for women > 40	X	X	X	
Serum ferritin testing	NA	X	If previously abnormal	
Smoking cessation	X	X	X	
Thyroid function test	NA	X	If previously abnormal	

Figure 6: Cancer Screening for Men (source)

Cancer Screening for Men

Cancer is a health problem that can often be cured or managed when it is found early. Here are guidelines to check for some common cancers that affect men. **Screening** is checking for a disease when there are no signs. All adults should have a cancer related checkup every 3 years between the ages of 20 to 39 and every year starting at 40.

These guidelines are from the American Cancer Society. They are for people who are at normal risk. Some men have a higher risk for a certain kind of cancer. Higher risk may be due to family history, lifestyle or other factors. Each man should talk with her doctor about her risk factors.

You can change some of your risk factors. For example, if you quit smoking you can change your risk for cancers of the lung, mouth, larynx (voice box), bladder and kidney. You cannot change other factors like your genes. In some cases you may be referred to see a Genetic Counselor for an evaluation.

Here are some common types of cancers that affect women and some reasons that may cause a person to have a higher risk. Use this as a guide to talk to your doctor about your own health and screening needs. Note, we use the term doctor, but you may be seen by another type of health care professional for your screening.

Prostate

Risk Factors	Screening for normal risk
• Family history of prostate cancer • Being African American • Age (being older) • Eating a diet high in animal fat or high fat dairy products	• Beginning at age 50 talk with your doctor about getting screened for prostate cancer. • If you have any risk factors you may need to begin screening between ages 40 to 45. Discuss this with your doctor. • The **American Cancer Society** recommends that at age 50, you have a **yearly** digital rectal exam and Prostate Specific Antigen (PSA) blood test • A PSA blood test should be done each year for men who have at least a 10 year life expectancy and for younger men who have higher risk.

Testicular

Risk Factors	Screening for normal risk
• Usually found between the ages of 20 to 54, but can affect men at any age • Risk is 4 times greater for white men than African American men • History of having undescended testicle(s) • History of cancer in one testicle • Family history of testicular cancer	• The American Cancer Society recommends that men talk with their doctor about whether they should practice monthly testicular exam • You should examine your testicles monthly, especially if you are in a high risk group. Tell your doctor right away if you find a mass or a lump.

Colon or Rectal

Risk Factor	Screening for normal risk
• Being over 50 years old • Being inactive and/or overweight • Diet high in red/processed meat • Diet low in fruits and vegetables • Smoking • Heavy alcohol use • Family history of colorectal cancer syndrome or adenomatus polyps • Type 2 diabetes • History of colon or rectal cancer, colorectal polyps, or chronic inflammatory bowel disease (Crohn's Disease)	**Starting at age 50, the following tests may be ordered by your doctor. Talk to your doctor about which test is best for you.** • Yearly fecal occult blood test (FOBT) or fecal immunochemical test (FIT) using the multiple sample method • Flexible sigmoidoscopy • Colonoscopy every 10 years • Double contrast barium enema exam every 5 years • CT colonography (virtual colonoscopy) every 5 years

Lung

Risk Factors	Prevention
• Smoking • Exposure to second hand smoke • Family or personal history of lung cancer • Exposure to cancer causing agents in the workplace or the environment (asbestos, fibers, radon, some chemicals, uranium, arsenic, vinyl chloride, diesel exhaust)	• The best way to prevent lung cancer is to stop smoking or never start. At this time there is no good way to check for lung cancer. The American Cancer Society does not recommend routine screening. Clinical trials are searching for ways to check for lung cancer. • Smoking causes over 85% of lung cancers.

Skin

Risk Factors	Screening for normal risk
• Ultraviolet light exposure (sunlight) • Fair skin (light colored skin) • Family history of melanoma • Severe sunburns before age 18 • Use of tanning beds • Smoking • Some workplace (coal tar, pitch, creosote, arsenic, or radium)	• Look for changes every month with your skin, freckles or moles • Skin exam during a regular health checkup

The American Cancer Society, American Heart Association and the American Diabetes Association have joined together on this advice (source?). To lower your risks for cancer, heart (cardiovascular) disease and diabetes aim at these goals:

- Get to a healthy weight and maintain it.
- Be active – exercise at least 30 minutes 5 or more days a week
- Eat at least 5 servings of vegetables and fruits every day
- Don't smoke or use tobacco. Ask for help to quit
- Limit your alcoholic beverages to 1 drink per day for women and 2 per day for men

Here are some places you may check for more information:

- JamesLine at 1-800-293-5066 or on the web at cancer.osu.edu
- American Cancer Society at 1-800-ACS-2345 or on the web at http://www.cancer.org
- The National Comprehensive Cancer Network at http://www.nccn.org
- National Cancer Institute 1-800-4 CANCER (800-422-6237) or on the web at http://cancer.gov

Other helpful Patient Education handouts: (source, James Nursing)

- The ABCD's of Melanoma and Skin Self-Exam
- Cancer Genetics Consultation
- Colorectal Cancer Screening
- Irritable Bowel Syndrome
- How to Quit Smoking
- Sun Safety Tips
- Testicular Self Exam

Talk to your doctor or others on your health care team if you have questions. You may request more written information from the Library for Health Information at (614) 293-3707 or email: health-info@osu.edu.

Figure 7: Cancer Screening for Women (source)

Cancer Screening for Women

Cancer is a health problem that can often be cured or managed when it is found early. Here are guidelines to check for some common cancers that affect women. **Screening** is checking for a disease when there are no signs. All adults should have a cancer related checkup every 3 years between the ages of 20 to 39 and every year starting at 40.

These guidelines are from the American Cancer Society. They are for people who are at normal risk. Some women have a higher risk for a certain kind of cancer. Higher risk may be due to family history, lifestyle or other factors. Each woman should talk with her doctor about her risk factors.

You can change some of your risk factors. For example, if you quit smoking you can change your risk for cancers of the lung, mouth, larynx (voice box), bladder and kidney. You cannot change other factors like your genes. In some cases you may be referred to see a Genetic Counselor for an evaluation.

Here are some common types of cancers that affect women and some reasons that may cause a person to have a higher risk. Use this as a guide to talk to your doctor about your own health and screening needs. Note, we use the term doctor, but you may be seen by another type of health care professional for your screening.

Breast

Risk Factors	Screening for normal risk
• Being female • Age (being older) • Family or a personal history of breast or ovarian cancer • Having no children, or first child after age 30 • Period (menstruation) started before age 12 or stopped after age 55 • History of abnormal breast changes or dense breast tissue • Being inactive and/or overweight after menopause • Drinking 1 or more alcoholic beverages a day • Estrogen therapy – long-term oral contraceptives (birth control pills) or hormone therapy after menopause	**Between the ages of 20 to 40 a woman should:** • Be familiar with how breasts normally feel and report any changes right away. Talk to your doctor about how to do a monthly breast self exam (BSE) • Women in their 20s and 30s should have a breast exam by their doctor at least every 3 years. After age 40, women should have a breast exam done by a doctor every year. **Age 40 and over a woman should:** • Report any changes you notice in your breasts • Have your doctor examine your breasts every year • Have a mammogram every year

Cervical

Risk Factors	Screening for normal risk
• A human papillomavirus (HPV) infection is the most common risk factor. HPV is passed from person to person by sexual contact. You are at risk if you have: ➢ Sexual contact, especially at a young age (before 17) ➢ A high number of sexual partners; or partners who had sex with many others • Eating a diet low in fruits and vegetables • Mother took DES (diethylstilbestrol) while pregnant • Family history of cervical cancer • Smoking • Being overweight • Estrogen therapy –long-term oral contraceptives (birth control pills) • Chlamydia infection • Multiple pregnancies	• You should begin having Pap tests after becoming sexually active (vaginal intercourse). All women should have a Pap test by age 21. There are 2 kinds of Pap tests – one is done yearly, the other is done every two years. • At age 30, if you have 3 normal Pap tests in a row, your doctor may suggest that you be screened every 2 to 3 years. You may need a Pap test more often due to your health history (if you had abnormal Pap tests, STD's, genital warts or a weakened immune system. • A woman over age 70 may choose to stop having cervical cancer screening after at least 3 normal Pap tests in a row and no abnormal tests in 10 years. • Screening after a total hysterectomy if cervix is removed is usually not needed except if the surgery was done due to cancer or pre-cancer. • Talk to your doctor before you stop getting Pap tests

Colon or Rectal

Risk Factor	Screening for normal risk
• Over 50 years old • Being inactive and/or overweight • Diet high in red/processed meat • Diet low in fruits and vegetables • Smoking • Heavy alcohol use • Family history of colorectal cancer syndrome or adenomatus polyps • Type 2 diabetes • History of colon or rectal cancer, colorectal polyps, or chronic inflammatory bowel disease (Crohn's Disease)	**Starting at age 50, the following tests may be ordered by your doctor. Talk to your doctor about which test is best for you.** • Yearly fecal occult blood test (FOBT) or fecal immunochemical test (FIT) using the multiple sample method • Flexible sigmoidoscopy • Colonoscopy every 10 years • Double contrast barium enema exam every 5 years • CT colonography (virtual colonoscopy) every 5 years

Endometrial (Lining of the Uterus or Womb)

Risk Factors	Screening for normal risk
• Being overweight • Eating foods high in animal fats • Family history or endometrial cancer • Personal history of breast or ovarian cancer • Having infertility or never had a baby • Period (menstruation) began before age 12 and stopped after age 50 • Having taken Tamoxifen or long-term estrogen replacement therapy without progesterone (if you still have a uterus) • Personal or family history of a genetic colon cancer syndrome	• At present there are not screening tests that are reliable to detect most endometrial cancers in a woman who has no symptoms • Report abnormal spotting, bleeding or pelvic pain to your doctor or gynecology professional • For women at high risk of Hereditary Non-Polyposis Colon Cancer annual screening with endometrial biopsy may be offered beginning at age 35.

Lung

Risk Factors	Prevention
• Smoking • Exposure to second hand smoke • Family or personal history of lung cancer • Exposure to cancer causing agents in the workplace or the environment (asbestos, fibers, radon, some chemicals, uranium, arsenic, vinyl chloride, diesel exhaust)	• The best way to prevent lung cancer is to stop smoking or never start. At this time there is no good way to check for lung cancer. The American Cancer Society does not recommend routine screening. Clinical trials are searching for ways to check for lung cancer. • Smoking causes over 85% of lung cancers.

Skin

Risk Factors	Screening for normal risk
• Ultraviolet light exposure (sunlight) • Fair skin (light colored skin) • Family history of melanoma • Severe sunburns before age 18 • Use of tanning beds • Smoking • Some workplace (coal tar, pitch, creosote, arsenic, or radium)	• Look for changes every month with your skin, freckles or moles • Skin exam during a regular health checkup

The American Cancer Society, American Heart Association and the American Diabetes Association have joined together on this advice. To lower your risks for cancer, heart (cardiovascular) disease and diabetes aim at these goals:

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- Be active – exercise at least 30 minutes 5 or more days a week
- Eat at least 5 servings of vegetables and fruits every day
- Don't smoke or use tobacco. Ask for help to quit
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- Cancer Genetics Consultation
- Colorectal Cancer Screening
- Endometrial Biopsy
- Having a Female Pelvic Exam
- Your Pap Smear Test
- Irritable Bowel Syndrome
- Laser Treatment for Gynecology
- Questions and Answers About Having a Mammogram
- How to Quit Smoking
- Sun Safety Tips

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