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Patient-Initiated Discharge Needs of Allogeneic Transplant Patients

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Introduction

The National Marrow Donor Program (NMDP) reports that approximately 25,000 allogeneic hematopoietic cell transplants (bone marrow, Peripheral Blood Stem Cell transplant (PBSC), or cord blood transplants) are performed annually worldwide (National Marrow Donor Program, 1996–2011). It is a fast growing specialty which is now considered standard of care for many hematological cancers. Hematopoietic cell transplant (HCT) patients are perhaps the most complex population among oncology patients due to the number of complications, increased mortality, long trajectory of rehabilitation, immune function complexity, and patient and procedure intensity. The first weeks and months after transplantation may be filled with unexpected readmissions, and setbacks due to factors such as graft-versus-host disease, infection, relapse, and gastro-intestinal complications (Cooke, Gemmill, Kravits, & Grant, 2009).

When allogeneic transplant patients approach the time of discharge, distress may actually increase (McQuellon, et al., 1998). The informational needs for both the patient and the caregiver can be overwhelming as they both struggle to learn about infections, infection precautions, eating again, rehabilitation needs, and signs and symptoms to immediately report to the health care team. Although patients look forward to going out of the hospital, the care remains very complex and informational needs are high at the time of discharge. Readmission rates of 51% have been reported with the allogeneic transplant population, but adequate educational preparation at the time of discharge from the transplant admission may have the potential to affect the number of readmissions and subsequent readmission length of stay (Grant, Cooke, Bhatia, & Forman, 2005). Transplant units are trying various models of care delivery to both save costs and improve outcomes (Schmit-Pokorny, Franco, Frappier, & Vyhldal, 2003). Hospital stays have become shorter, diseases have become more chronic, technology has advanced, and hospital patients are more acutely ill with chronic conditions and complex needs (Foust, 2007). There has been a recent interest in refining discharge teaching for acute patients to decrease unscheduled readmissions and preventable complications. However, this interest to decrease admissions coupled with the shortened length of stay due to economic factors heightens the importance of adequate discharge teaching (Jacobs, 2000). Research has shown that patients knowledge and information at discharge can be minimal and in many informational areas of need the patients felt they were not given essential specifics (Holloway, 1996). Allogeneic transplant patients remain one of the most fragile populations to prepare for discharge and present a challenge for the nurse to be “information ready”. The purpose of this paper is to discuss the qualitative themes that emerged from spontaneous concerns that patients had during a structured teaching intervention study (Please see Figure 1).

This study tested an APN intervention that focused on teaching the allogeneic transplant patient after discharge. Because the intervention was a tailored intervention, the APN addressed all concerns that the patients had whether or not they were scheduled teaching topics. However, all spontaneous concerns were recorded to assess for qualitative data themes. This data on spontaneous concerns were collected at the time of discharge for 141 allogeneic transplant patients. The overall goal of the larger study was to test a 2 group intervention study (control vs. intervention) designed to compare quality of life, functional status, caregiver issues, mortality and treatment complications between the 2 groups of allogeneic transplant patients. The qualitative data arranged and presented in this article is from the spontaneous content initiated by patients at the time of the discharge teaching.

Methods

The data in this study are part of a mixed methods larger study which compared outcomes in 2 groups of allogeneic transplant patients. The intervention patients had six sessions with an APN. The first session, at the time of discharge, is the focus of this article. It was during this session when concerns over discharge were collected from patients in a nurse charting form called a “Debriefing Form”. The APN covered the manualized content in the intervention, and because the intervention was tailored also addressed all additional questions of the patients. Each session was 45–60 minutes in length allowing for covered content and any additional concerns that patient might have.

Sample

The sample of 282 patients who participated in the larger study consisted of adult allogeneic transplant patients at a single site collected over a period of a 5-year study. The qualitative sample consisted of 141 patients who were enrolled in the intervention arm of the study.

Procedures

The intervention study consisted of 6 individual sessions with the patient. Family caregivers were encouraged and welcomed to attend any session. Content for each session was based on an extensive literature review on topics for allogeneic transplant patients and organized according to the quality of life model which consists of physical, psychological, social and spiritual/survivorship domains. (See Figure 2). The first 3 sessions consisted of topics that dealt with the physical domain, the last 3 sessions each covered psychological, social and spiritual/survivorship respectively (Please see Table 1). Session 1 was done during the time of acute inpatient hospitalization before discharge, which was usually between day 25 and 35 after allogeneic transplant, and included topics in the physical domain. The standardized topics in Session 1 taught by the APN included: preparing for discharge, hygiene, skin management, venous access device care, clinic routines, signs and symptoms to report to the MD, dehydration prevention and a review of medications (Please see Table 2). These topics were “high priority” topics because of the shifting of care from hospital staff to patient and family caregiver at home.

Analysis

Content analysis was conducted on the narrative comments provided by the nurse in the “Debriefing form” completed by the APN at the end of the first teaching session. The study team read and examined data to identify units of analysis, which were defined in paragraph, sentence, verb phrase, or single words that conveyed a single meaning or concept (Miles, 1994). The content was organized into 3 structured groups: topics covered during Session 1, topics that were scheduled to be covered in subsequent sessions, and topics that were not scheduled to be covered at all during the teaching sessions. All investigators participated in

content analysis with coding completed by at least two investigators. Discordant coding was reviewed by the team for final consensus.

Results

Table 3 lists the demographics of the intervention group of the study. The average age was 49, with slightly more males than females, $n = 73$ vs. $n = 68$. Our population had a 22.7% Hispanic ethnicity, most patients were Caucasian by race, 82.3%. The top four common diagnoses were acute leukemia (55.3%), Myelodysplastic syndrome (17.7%), Non-Hodgkin's lymphoma (13.5%), and Chronic Leukemia (10.6%). Matched unrelated allogeneic transplant patients were the majority (52.5%), and most patients also underwent reduced intensity transplant (55.3%). Reduced are transplants that have reduced doses of chemotherapy and radiation in hopes to augment the graft versus disease affect. There were very few mismatched transplants (12.3%). Most of the patients were either transplanted in persistent disease (51.1%) or first remission (26.2%).

Table 4 lists the topics initiated by the patients and slated to be covered in subsequent sessions. These topics included: diet details, physical symptoms, emotional and psychosocial issues, family role change, sexual issues, caregiver strain and resources for financial needs. Examples of content are listed alongside each topic heading.

Table 5 lists the topics that were not included in the standardized content. Since the intervention was tailored, all topics were discussed that were included in the content, but the APN-led intervention also addressed the spontaneous topics that were patient-initiated. These topics included: diabetes and blood sugar control, comorbid illnesses, homesickness, worry about pets, caregiver issues specifically "who is the caregiver", childcare and children coping issues, family disruptions, marital conflicts, family relocation, financial concerns, cultural issues, and retelling the story of the diagnosis and journey. Examples are included in each content area (See Table 4). Several of the patients had developed steroid-induced diabetes due to the treatment for Graft-versus host disease, and although followed by the endocrinology service and taught by a diabetes educator before discharge, they continued to ask several questions about their diabetes management and long-term outcomes. Some patients received reduced-intensity transplants. These patients were often older than the ablative transplant patients, and it was not unusual to have other comorbid illnesses and concerns. One patient had developed a hearing loss from the antibiotic treatment of septicemia. She needed hearing aids at discharge. Many of the patients expressed homesickness. Since the transplant was performed at a tertiary National Cancer Institute-Designated Cancer Center, it was not usual for the patients to travel long distances from their homes. They would often have to stay in on-campus outpatient housing or local hotels and expressed the desire to return to their own communities. Many patients expressed concerns over their pets: who would care for them, how the pets would adjust without them, when they could have contact with the pets again, and the level of contact they were allowed to have in the post discharge period. Another issue was caregiver support. Although it was a mandated requirement that patients have caregivers after transplant, some did not have full-time caregivers available to them. Some caregivers had to work to maintain the insurance, or care for children. Some patients also had to arrange rotating caregivers over the weeks after transplant. Also, when caregivers came down with a virus, patients had to problem-solve how to continue caregiver coverage during a vulnerable time. A number of patients had children who were under the age of 12. One mother, in particular had an infant and the APN discussed how bonding with the infant could occur while balancing her infection precautions such as being restricted from diaper changing. The stressor of transplant was challenging for some families, especially for those who exhibited behaviors of coping which were not helpful. One caregiver in particular, began drinking alcohol while taking care of her

daughter, the patient. The intervention nurse enlisted the support of a social worker to set boundaries, and help the caregiver cope with the experience in healthy ways. Some marital conflicts occurred during the time of discharge. One patient in particular was served divorce papers during her transplant admission and had significant challenges with post transplant care. Family relocation was not uncommon. The travel away from social support networks seemed to contribute to isolation and family upheaval. Financial concerns were a common concern at the time of discharge. The patients faced significant co-pays for outpatient medications and often found that the cost was more than they expected. Cultural issues were also a concern for some patients who had language and dietary issues. At the first visit with the APN it was not unusual for the patient to retell the story of the diagnosis and trajectory to transplant. Often these patients felt the need to share the challenges along the journey in an effort to “be known” by the APN.

Discussion

Transplant patients at the time of discharge have many concerns. Content that patients initiated at discharge included all domains of the quality of life: physical, psychological, social, spiritual/survivorship. In regard to physical issues, the topics initiated by the patients tended to be covered at subsequent sessions and dealt with symptoms and diet which was consistent with the literature. In comparison to chemotherapy patients, the capacity for oral intake is less favorable in transplant patients (Mank, et al, 2010). Also, appetite loss, diarrhea and fatigue sleep disturbances have been reported in the literature at the time of discharge and within 100 days (Hacker & Ferrans, 2003). The physical issues that patients initiated focused on two main topics: hyperglycemia, and comorbidity. Patients with hyperglycemia and steroid induced diabetes needed more teaching content which was interesting since they did spend time with a diabetes educator. Perhaps the patients needed either more reinforcement or had additional anxiety regarding their blood sugar at home. The rate of acute graft-versus host disease among transplant patients is approximately 12–36% (Couriel, et al., 2004). Graft-versus host disease is often managed with the use of steroids in the acute phase, and steroids are known to be a risk factor in the development of hyperglycemia and diabetes in transplant patients (Baker, et al., 2007; Faiman, Bilotti, Mangan, & Rogers, 2008). Tight blood sugar control is essential for better outcomes for transplant patients and content on glucose monitoring and insulin injections need to be routinely assessed before discharge (Volarelli, et al., 2007). Patients who are older are also more likely to have comorbid illnesses (Sorrer, et al., 2005; Sorror, et al., 2007). Managing the comorbid illnesses was an unexpected topic for the APN nurse, however the issue of comorbidity with transplant patients is becoming more and more common with older patients (Sorrer, et al., 2007). Transplant nurses will need to incorporate the comorbid illnesses and adequate symptom management in the teaching content to provide more comprehensive instructions.

Psychological issues that were initiated by patients but scheduled later in another session were feelings of depression and anxiety. These psychological responses are supported by Lee and colleagues who found that 44% of the patients post transplant had symptoms of depression, anxiety of post traumatic stress disorder either at the first clinic visit after discharge or at 100days (Lee, et al., 2005). The other topics that patients wanted to discuss were family role changes which were normally discussed during the fourth session. Mosher found that 27% of the patients were concerned about keeping their job including work in the home. Other topics, in the psychological domain, initiated by the patients were homesickness and concern over pets. The fact that many patients were homesick was an unexpected finding and has not been reported in the literature; however, it makes perfect sense. These patients are often away from home for weeks at a time, away from the comfort of familiar people and possessions. What the APNs suggested was that patients bring in

blankets, pillows, pictures, books and other items from home to assist with the transition which did seem to help most patients. Another topic initiated by many transplant patients was their pets. Although the APNs reviewed the Center for Disease Control and Prevention (CDC) guidelines for transplant patients as needed, the patients wanted to discuss the guidelines and how the relationships with their pet would be impacted (Center for Disease Control Prevention, 2000). The patients missed and worried about their pets. Cohen (2002) in an article titled "Can Pets Function as Family Members?" discusses the importance that pets can have in the life of an individual (Cohen, 2002). Pets provide companionship and comfort, and allow people to express deep feelings with nurturing (Cohen, 2002). Transplant nurses need to be aware of the role of pets in patients' lives, especially if the separation from those pets is extremely difficult for the patient.

The topics that the patients initiated that encompassed the social aspects of their lives were the greatest in number. Interestingly, social issues at discharge is the one area of which nurses are both least familiar and least interested (Atwal, 2002). The medical literature also reports social issues challenging at discharge (Kripalani, Jackson, Schnipper, & Coleman, 2007). The issues scheduled for discussion in later sessions centered on patient worry about caregiver strain, sexuality, disability and work adjustment. Concerns about financial issues, work adjustment and sexuality are all reported in the literature (Hacker & Ferrans, 2003; Mosher, Redd, Rini, Burkhalter, & DuHamel, 2009; Siegel, 2008). In addition, caregivers have increased fatigue, cognitive dysfunction, depression, sexual issues and insomnia much more than healthy controls (Pidala, Anasetti, & Jim, 2010). With caregivers having their own strain together with the patients' concerns about returning to work and roles, it is understandable that these concerns may impact patient worry about the caregiver. The additional topic about caregivers centered on the presence and availability of the caregiver. Research has shown that not having a in-hospital lay care partner is a significant independent risk factor for death (Foster, et al., 2005). Although the transplant program makes it very clear that each patient at the time of transplant is to have a committed available caregiver for 24 hours a day for the first 100 days, the reality was that not all patients had this resource. The literature is clear that the time commitment and financial hardship of a 24 hour caregiver on the family of a transplant patient is immense (Meehan, et al., 2006). Since these patients are desperate to live and see transplant as their only hope for survival, it became clear to the APNs that they often gave the impression of a committed caregiver when one was not always present. Therefore, flexible scheduling and clear guidelines after discharge had to be communicated with patients and working caregivers to manage potential emergencies, such as a fever spike if the patient was alone. Another topic was children and childcare concerns. As previously mentioned one patient had a newborn and the APN needed to discuss bonding with the infant and balance the infection precautions and fatigue. Other patients were concerned about how their kids cope with the changes in the family life. The APN made frequent referrals to child life specialists, and also offered to meet with the children to teach age-appropriate content and answer questions to decrease the children's anxiety about their parent. Family disruptions did occur; however challenging coping behaviors occurred among families that seemed to have a history of -problems, such as substance abuse. Perhaps transplant admission assessments need to include past history of stressful events and family coping. Marital conflicts also occurred. Some patients did feel they had the expected support from their spouse, but others did not feel supported enough by their spouses. For the transplant patient, studies have indicated that social support and the presence of the caregiver improves patient mortality, and patient psychological and physical functioning (Foster, et al., 2005; Frick, et al., 2006; Grassi, et al., 1996; Jacobsen, et al., 2002; Jenks Kettmann & Altmaier, 2008; Lloyd-Williams & Friedman, 2001; Rodrigue, Pearman, & Moreb, 1999; Widows, Jacobsen, Booth-Jones, & Fields, 2005). Being aware of the powerful impact the presence of a caregiver makes is key for nurses as we support both the patient and the caregiver.

Family relocation was another issue that came up for discussion. As families had to leave support systems and stay close to the medical center, this isolation was challenging for patients who missed family members, children, their homes, friends and communities. Pidala and colleagues reported that partners of transplant patients reported significantly less social support and spiritual well-being, as well as more loneliness when compared to the transplant survivors or a control group (Pidala, et al., 2010). The financial impact of transplant can be devastating, and the APN nurses uncovered complicated factors involved with insurance coverage and financial responsibilities after transplant. Although the content of the sessions included preparation of disability paperwork and financial resources, insurance issues were not included. Often the patients make a desperate rush judgment to proceed to transplant due to the urgency of the hematologic malignancy. Financial concerns may not be in the forefront of their minds, however, the time of discharge may be the first awakening of co-pays for expensive medications and hotel bills for outpatients stay. The topic of the financial impact after transplant is a topic of high interest and currently the National Marrow Organization is researching this issue (National Marrow Donor Program, 2008). Many recent studies have shown that the financial concerns of patients affect their quality of life (Hacker & Ferrans). Perhaps clear financial review is needed with both patient and family before admission to cover both expected events and possible unexpected events to assure more financial stability. The last topic of social concerns is cultural issues. The site of the study is in a major metropolitan center with many different cultures. Adapting diet precautions, isolation precautions, and activity level were issues that could have cultural influences. Diet teaching needs to take into account the possible foods that the patient normally enjoys.

The last domain includes spiritual, existential, and survivorship issues. Session 6 in the structured content included benefit finding exercises, which is the ability to find benefit in challenging circumstances, and spirituality. However, the patients at discharge also often felt the need to retell their story of their diagnosis and journey before the teaching session began. Leak, Mayer and Smith's (2011) integrative review on survivors found that having cancer may prompt patients to revisit their outlook in life, and finding purpose and meaning (Leak, Mayer, & Smith, 2011). Often these patients need to sift through the experience to make sense. Referral to social work or psychology may be essential to support the patient's search for meaning as they progress through this challenging experience after transplant. After presentation of the study's multiple findings, major changes have been made at our institution. The institution already had an orientation for all patients, now before transplant admission, all transplant patients, both autologous and allogeneic are invited to attend a one hour teaching session. This session is taught by nurse coordinators, and covers information about the transplant admission, immediate follow-up, and long-term follow-up. Required modules were created for transplant staff to read and pass which included patient teaching. Teaching post transplant has improved. The next focus is improvement in post-transplant teaching in the outpatient clinic, and a team has been created to address this change.

Implications

"Hospital discharge is a critical point in the continuum of care that affects patients' outcomes" (Foust, 2007). This paper reviewed topics that patients initiated at discharge that were both scheduled for later topics in later educational sessions or not included in the standardized educational materials. When considering adult learning principles, the motivation to learn is best when patients are convinced for the need for knowing the information (Russell, 2006). Discharge is a prime time for motivation. Transplant patients have incredible informational needs, and literature from other populations indicate that patients feel they have a lack of information (Jacobs, 2000). It is plausible that transplant patients may also need more preparation and information. One suggestion for preparation is

to improve pre-transplant admission education to address post-transplant needs. In regard to teaching information during admission, a recent study compared nursing practice variations among HCT units (M. Bevens, et al., 2009; M. F. Bevens, Mitchell, & Marden, 2008). Most education was done by the bedside nurse, with common topics surrounding infection prevention and precautions, and nutritional restriction (M. Bevens, et al., 2009; M. F. Bevens, et al., 2008). Some potential sources for additional physical information are recommended guidelines (Center for Disease Control Prevention, 2000; Rizzo, et al., 2006). However, beyond the physical needs, nurses need to be aware of all areas of quality of life: physical, social and spiritual as well... It is clear from this study that psychosocial issues were the most prevalent for transplant patients. Besides expansion of content to include psychosocial material, it is also essential that transplant nurses be prepared in the art of teaching. Excellent educational assessment skills assist with what to teach “in the moment”, competence with a sound knowledge base provides the ability to teach complicated content, flexibility is needed to adapt to the complexity of changing content to the needs of the patients, and comfort with challenging content is needed to cope with topics that are tough on a personal level.

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At a glance

1. Research indicates that the time of discharge is a stressful time for allogeneic transplant patients and a significant moment for informational needs.
2. At the time of transplant discharge nurses may focus on education of physical issues and task mastery, however the patient may also be concerned with complicated psychosocial issues.
3. Teaching allogeneic transplant patients at the time of discharge involves sophisticated teaching skills.

TEACHING TOPICS FOR ALLOGENEIC PATIENTS ON STUDY	SPECIFICS
Discharge review	Discussion of teaching topics, and relevant literature
Oral hygiene	Mouth integrity protects against infection Reasons for mouth sores Strategies to help with mouth healing
Skin management	Skin integrity protects against infection Care of skin: soap, water temperature, moisturizer, use of sunscreen, sun protection
Venous access device care (VAD)	Mastery of care for VAD Protection strategies
Outpatient clinic routines	Review schedule for clinic visit Possible orders in clinic to prepare patient's expectations: IV fluids, procedures, etc.
Signs and Symptoms to report	Review of list of symptoms to report Review who, when and how to call to report a symptom
Dehydration prevention	Review the importance of adequate hydrate Review common strategies for hydration Develop a strategy for hydration
Medication review	Discuss each medication's role in the transplant process Populate an excel spreadsheet with the

Figure 1.
Quality of Life/HCT Model

TEACHING TOPICS FOR ALLOGENEIC PATIENTS ON STUDY	SPECIFICS
Discharge review	Discussion of teaching topics, and relevant literature
Oral hygiene	Mouth integrity protects against infection Reasons for mouth sores Strategies to help with mouth healing
Skin management	Skin integrity protects against infection Care of skin: soap, water temperature, moisturizer, use of sunscreen, sun protection
Venous access device care (VAD)	Mastery of care for VAD Protection strategies
Outpatient clinic routines	Review schedule for clinic visit Possible orders in clinic to prepare patient's expectations: IV fluids, procedures, etc.
Signs and Symptoms to report	Review of list of symptoms to report Review who, when and how to call to report a symptom
Dehydration prevention	Review the importance of adequate hydrate Review common strategies for hydration Develop a strategy for hydration
Medication review	Discuss each medication's role in the transplant process Populate an excel spreadsheet with the patient for each of medication administration

Figure 2.
Outline of Scripted Topics for Session 1 (Time of Discharge)

Table 1

Demographics and Characteristics of Allogeneic Transplant Intervention Patients on Study

Characteristics	N = 141	%
Age		
Mean	48.76	
Range	19–71	
SD	12.77	
Gender		
Male	73	51.8%
Female	68	48.2%
Hispanic Ethnicity		
Yes	32	22.7%
No	109	77.3%
Race		
African American	2	1.4%
American Indian/Alaskan Native	0	0%
Asian/Pacific Islander	21	14.9%
Caucasian	116	82.3%
Mixed/Other	2	1.4%
Diagnosis		
Acute Leukemia	78	55.3%
Chronic Leukemia	15	10.6%
Myeloproliferation Disorder	5	3.5%
Myelodysplastic Syndrome	25	17.7%
Myelofibrosis	5	3.5%
Non Hodgkin's Lymphoma	19	13.5%
Hodgkin's	4	2.8%
Other	3	2.1%
Types of BMT= Allogeneic		
Related	67	47.5%
Matched, Unrelated donor	74	52.5%
Types of BMT-Myelosuppression		
Full	63	44.7%
Partial/Reduced Intensity	78	55.3%
HLA Match		
Match	114	82.6%
Mismatched	17	12.3%
Unknown	7	5.1%
Remission Status at Transplant		
First Remission	37	26.2%

Characteristics	N = 141	%
Second remission	18	12.8%
Third remission	2	1.4%
Persistent disease	72	51.1%
Chronic phase	8	5.7%
Accelerated phase	2	1.4%
Blast crisis	2	1.4%