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The Informational Needs of Mothers about Physical Care at Home for Children who Underwent Stem Cell Transplants

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Abstract

Background After children were discharged from the hospital, their mothers generally undertook all of their care responsibilities
Aim To assess the informational needs of mothers related to the physical care of children who underwent HSCT during the early recovery period (within 3 months after transplantation).
Methods: This descriptive and longitudinal study was conducted to assess the informational needs of mothers related to physical care at home of children who underwent HSCT. The sample included the mothers of 74 children who had undergone a transplant within the past three months according to the eligibility criteria. The data collection tools were the (1) Child Information Form and (2) Informational Needs Form.Data collection tools were: (1) Child Information Form, and (2) Informational Needs Form.
Results: The total mean number of informational needs of mothers was very high at 11.3±3.1 (3-15). Both the "moderate" and "high need" rates of mothers were the highest in the areas of "medications and side effects, anticipated complications and their symptoms, skin care, pain, fatigue, nausea, vomiting, diarrhea and sleep management".
Conclusions: The results revealed that the information needs of mothers for physical care at home of children underwent HSCT was very high. The results can assist in planning nursing strategies and collaborations to improve the discharge process for HSCT nurses, prevent and detect complications early and for decrease readmission rates of patients by public/home health care nurses.

Keywords: home care, informational needs, stem cell transplantation

Introduction

Pediatric Hematopoietic Stem Cell Transplantation (HSCT) is an invasive treatment for seriously ill children who have hematological, oncological, or metabolical diseases. However, HSCT is a perilous treatment, associated with significant mortality and morbidity (Bevans, Mitchell, & Marden, 2008; Liu & Hockenberry, 2011). It involves a lengthy hospitalization in an isolated environment to prevent infections and treatment with high doses of chemotherapy and/or radiation, followed by infusions of donor/self-harvested stem cells. Many complications can occur at any time during recovery and persist for days to months following transplants. Early complications may include mucositis, fatigue, nausea and vomiting, diarrhea, pancytopenia, pain, infection, and immune suppression (Barker, Anderson, Sauve, & Butzner, 2005; Fife, Monahan, Abonour, Wood, & Stump, 2009). Acute graft-versus-host disease

(GVHD) occurred in 46% of the population, with liver involvement in 39% and intestinal involvement in 60% of those with acute GVHD. Veno-occlusive disease (VOD) occurred in 18% of the population. Common post-transplant gastrointestinal complications included mucositis in 90%, vomiting in 85% and abdominal pain in 71% (Barker et al., 2005; Liu & Hockenberry, 2011).

Background

The complications occurring along with HSCT treatment influence very profoundly the life of the child and family, both in the acute phase and in the subsequent period. Even 3 months post-HSCT, many children still suffer from the after effects of the HSCT. In the first 6 months post-HSCT, children are still susceptible to infections and need to live with restrictions. After treatment, parents and children are faced with the risk of recurrence, acute or chronic graft-versus-host disease, and numerous possible late effects, such as pulmonary disease. Parents are faced with the need to provide both physical and emotional care for their ill child during the pre- and post-HSCT process, a long and stressful period (Vrijmoet-Wiersma et al., 2009). After the patient is discharged from the hospital, the responsibility of caring for the daily physical and psychosocial needs of children after transplant is placed mostly on mothers (Williams, 2007). The mother has to assume many responsibilities, including basic medical procedures (Rini et al., 2004; Vrijmoet-Wiersma et al., 2009). These are knowing the process and prognosis of the disease, the regular use of medicines, and monitoring of the side-effects and complications, and preventing or managing gastrointestinal system (GIS) symptoms, such as diarrhea, nausea and vomiting, continuing catheter care and preventing infections if discharged from the hospital with a catheter, implementing a neutropenic or immunosuppressive diet and arranging the home environment for the special needs of the child. Providing the information needs of the mother and family members and rendering awareness and consciousness in response to symptoms and complications are important points on these subjects. These efforts of the family caregivers will provide for both the child and the family to have a high quality post-transplantation period and will contribute significantly to an increase in life quality and to an easier return to normal life. The mothers of children who underwent HSCT have an extensive responsibility for their children's well-being and safety (Rini et al., 2004).

In related areas, both qualitative and quantitative studies made have identified adjustment and coping of parents of children with HSCT (Forinder 2004; Oppenheim, Valteau-Couanet, Vasselon, & Hartmann, 2002; Packman, Weber, Wallace, & Bugescu, 2010; Phipps, Dunavant, Lensing, & Rai, 2005; Rini et al., 2004; Vrijmoet-Wiersma et al., 2009); on the quality of life and/or emotional adjustment of children after HSCT; on the psychological adjustment of families of adult HSCT patients (Cooke, Grant, Eldredge, Maziarz, & Nail, 2011; Fife et al., 2009), and on the psychosocial strain and coping of caregivers/mothers (Cooke et al., 2011; Packman, et al., 2010; Wilson, Eilers, Heermann, & Million, 2009; Stetz, McDonald, & Compton,1996). Some descriptive studies have focused on the needs, burdens and experiences of family caregivers of HSCT patients (Aslan et al., 2006; Forinder, 2004; Foxall & Gaston-Johansson, 1996; Wilson et al., 2009). No review articles have been published in this specific area so far. The needs and resource utilization of family caregivers during pediatric HSCT were identified in only one study (Mayer et al., 2009). There are also studies in the literature aimed at the personal needs of pediatric HSCT caregivers (Rini et al., 2004). However, there are no studies, which research the informational needs of the caregivers about the physical care of children with pediatric stem cell transplants. The aim of this study was to assess the informational needs of mothers related to the physical care of children who underwent HSCT during the early recovery period (within 3 months after transplantation).

Method

Design and Sample

This study was conducted from September 2009 to July 2011 as a descriptive and longitudinal study. Pediatric Bone Marrow Transplantation Center of Ege University Medical Hospital was the largest pediatric stem cell transplantation unit in Izmir. A total of 30-35 undergo transplantation annually. A total of 78 patients have undergone HSCT at this center in the past two years. Four patients died after the transplantation period. Thus, they were excluded from the study. The sample consisted of the mothers of 74 children who had undergone a transplant within the past three months according to the eligibility criteria. The eligibility criteria were being between 0-18 years of age and receiving HSCT treatment. Inclusion criteria were as follows: for children, no development of complications and no admission to a hospital due to a transplant-related problem; for mothers, not having psychiatric diseases.

Data Collection and Instruments

Data collection tools were (1) Child Information Form, (2) Informational Needs Form.

1- Child Information Form: It includes descriptive and clinical characteristics of the children's age, gender, diagnoses and transplant-related characteristics (19 questions). Questions about home care needs, such as the use and care of a catheter at home, the need for enteral nutrition and the need for daily life activities are also included.

2-Informational Needs Form: This form was prepared from the literature by the researcher and had two parts. Part one ascertained the mothers' descriptive variables (age, gender, marital status, socioeconomic status, etc.). Part two consisted of 14 informative questions that were identified through a literature review of the informational needs of mothers related to the physical care needs at home of children after undergoing HSCT. The 14 informative questions were, "disease and prognosis; medications and side effects; anticipated complications and their symptoms; in which situations they should come to the hospital; management of gastrointestinal complications, such as nausea, vomiting, diarrhea, oral care, skin care, fatigue, sleep and pain management; catheter care management; neutropenic/ immunosuppressive diet; isolation; and how to organize the home environment according to the needs of the children". The questionnaire asked the mothers to rate the 14 informative questions on a Likert scale to measure how much information felt they wanted about each of these questions. The response options were "No need", "Satisfied", "Low need," "Moderate need," or "High need".

Data Collection Procedure

Each mother was verbally informed about the study after arriving at the outpatient clinic waiting room. After establishing the mother's eligibility to participate, a face-to-face verbal interview was performed. The interviews lasted for approximately ten minutes.

Table 1: The Baseline Characteristics of Children

Categorical variables	n	%
Age (mean)	**8.62±4.2**	**(1-17)**
Gender		
Female	28	37.8
Male	46	62.2
Diagnosis		
Hematological malignancies	34	47.3
Non-Hematological diseases	39	52.7
Transplantation Type		
Allogeneic	65	87.8
Autologous	9	12.2
Transplant Complications[a]		
No	35	47.3
GVHD I-II	10	13.5
GVHD- III-IV	4	5.4
VOD	2	2.7
Hemorragic Cystitis	2	2.7
Discharge Education		
Yes	31	41.9
No	43	58.1
Primary Caregiver		
Mother	56	75.7
Mother and father	9	12.2
Mother and sister	9	12.2
Mothers' Education Level		
Literate	14	18.9
Primary school	43	58.1
High school and university degree	17	23.0
Mothers' Marital Status		
Married	71	95.1
Not married	3	4.9
Mothers' job		
Housewife	67	90.5
Employed	7	9.5

[a] Responses may indicate more than one complication

Data Analysis

Data were analyzed using the Statistical Package for the Social Sciences. Frequencies were analyzed for categorical data, and means and standard deviations were calculated for continuous data. p<0.05 was accepted to be statistically significant. In order to analyze the relationships, the analysis was made by coding the combined responses of "no need" and "satisfied" as "no need" and the combined responses of "low", "moderate" and "high need" as "needed".

Ethical Considerations

Children and mothers were informed about the study and asked if they were willing to participate in the study and their consents were obtained. A written consent was obtained from the institution where the study was conducted.

Results

Children and Transplantation Characteristics

The sample consisted of 28 female (37.8%) and 46 male (62.2%) children. The mean age of the children was 8.6 years (SD 4.2), with a range between 1 and 17 years. The baseline characteristics and underlying diseases of our study population are listed in table 1. Hematological malignancies accounted for 35 (47.3%) of the children and non-hematological diseases were diagnosed in the remaining 39 (52.7%) (table 1).

The types of transplants consisted of 65 allogeneic (87.8%) and 9 autologous (12.2%) (self-harvest) transplants. Forty-one (63.1%) of the allogeneic patients received transplants from matched sibling donors, 7 (10.8%) from matched related donors and 17 (26.1%) from matched unrelated donors. Only 5 of the 10 (13.5%) patients received total body irradiation (TBI). Hospitalization period in the HSCT unit was a mean of 37.2±6.7 days (25-62 days) (table 2). Forty-three (53.1%) mothers received non-formal discharge planning education in the HSCT unit before their children were discharged. As for transplant complications, Grade I-II GVHD developed in 25 (33.8%) children and Grade III-IV GVHD developed in 10 (13.5%) children. VOD developed in 4 (5.4%) children and hemorrhagic cystitis developed in 2 (2.7%) children during the transplantation process.

Of the children, 63 (85.1%) were discharged from the hospital with the double lumen Hickman and Broviac catheters, 6 (6.8%) with the port catheter and 5 (6.8%) with both the port and the Hickman catheters.

Of the caregivers, 44 (59.5%) stated that they experienced problems and fear in providing the catheter care at home (table 2).

Table 2: Characteristics of Home Care

	n	%
Catheter at home		
Double Lumen Hickman Broviac	63	85.1
Implantable port	6	8.1
HB + Implantable port	5	6.8
Catheter problem		
No	30	40.5
Yes	44	59.5
Diet		
No	71	95.9
Yes	3	4.1
Enteral Nutrition Support		
No	64	86.5
Yes	10	13.5
Help for daily living activities		
No	58	78.4
Yes	16	21.6
Function Deficit		
No	69	93.2
Yes (Walking)	5	6.8

Ten (13.5%) of the children were discharged from the hospital with enteral nutrition support.

The nutrition support at home was given by the nurses of a private medical company related to nutrition.

Three (4.1%) children using cortisone, implemented a salt-free diet at home. It was determined that there was a functional loss for walking in 5 (6.8%) of the children and that 16 (21.6%) of the children had a need for support in their daily life activities.

Mothers were the primary caregivers for 56 (75.7%) of the children.

It was determined that for 9 (12.2%) of the children, the father helped the mother in home care and in another 9 (12.2%) children, the elder sister helped the mother in home care. The mean age of mothers was 35.7±5.6 (25-55). The educational level of mothers was mostly primary school (n:43). A large majority of the mothers (n: 67, 90.5%) were housewives and only 7 (9.5%) worked outside the home.

Table 3: Percentage Frequencies of Mothers Response to Informational Needs of Children Undergoing SCT

Area of Information Needs	Satisfied/ No need		Need	
	n	%	n	%
Disease and prognosis	33	44.6	41	55.4
Medications and side effects	7	9.5	67	90.5
Compli-cations	3	4.1	72	97.3
Admission to hospital	18	24.3	56	75.7
Home environment	40	54.1	34	45.9
Neutropenic diet	12	16.2	62	83.8
Isolation	28	37.8	46	62.2
Catheter care	18	24.3	56	75.7
Oral care	34	45.9	40	54.1
Skin care	9	12.2	65	87.8
Fatique management	5	6.8	69	93.2
Pain management	6	8.1	68	91.9
Diarrhoea management	27	28.4	53	71.6
Nausea-vomiting	19	25.7	55	74.3
Sleep management	19	25.7	55	74.3

Prevalence of Informational Needs at Home

The total mean number of informational needs of the mothers was very high at 11.3±3.1 (3-15). It was observed that both the "moderate" and "high need" rates for the needs of mothers were the highest in the areas of "medications and side effects, anticipated complications and their symptoms, skin care, pain, fatigue, nausea, vomiting, diarrhea and sleep management" (table 3).

Nevertheless, it was observed that most of the mothers' information needs were "at a moderate level" in the areas of a "neutropenic/ immunosuppressive diet, in which situations they should come to the hospital and on the implementation of protective isolation". Whereas, it was determined that the mothers "Low need" levels were the most on the subjects of "catheter care and oral care management". It was observed that the highest "satisfied" rate of the mothers was related to "on how to organize the home environment according to the needs of the children".

Determinants of the Informational Needs at Home

The informational needs of the mothers and the age and gender of the child, the transplant complications as well as the age of the mother were not correlated (p>0.05). When the mothers' educational level and presence of informational needs were analyzed, it was determined that the mothers whose educational level was primary school or lower had higher informational needs on the subjects of the disease and prognosis (x^2: 9.85, p=0.007) and skin care (x^2: 11.5, p=0.003) compared to those whose educational level was high school or above. It was determined that there was no relationship between the mothers receiving discharge training and the existence of informational needs. Due to the fact that the children who had allogeneic transplants comprised a very large portion of the study group, the relationship between transplant type and the existence of informational needs could not be analyzed.

When the children's diagnoses and the mothers' informational needs were examined, it was determined that the informational needs of the mothers whose children had non-hematological diseases was statistically higher compared to the mothers whose children had hematological diagnoses for the "disease and prognosis (x^2:4.23, p=0.004, OR:2.6, CI: 1.03-6.85), on how to organize the home environment according to the needs of the children (x^2:8.1, p=0.004, OR:4.0, CI: 1.5-10.6), on oral care management (x^2:10.4, p=0.001, OR:2.6, CI: 1.03-6.85) and on neutropenic diet applications (x^2:4.41, p=0.03, OR:4.15, CI: 1.02-16.85).

Discussion

After the patients were discharged from the hospital, all of the care responsibilities for the children were usually undertaken by the families and generally solely by mothers (Williams, 2007). Families of children who underwent HSCT take on more and more responsibility for medical complex care activities in the home.

However, little is known about the informational needs of mothers . The results of this study showed that the informational needs of the mothers for physical care at home of children undergoing HSCT was very high.

The study results revealed that the mothers had high informational needs for home care of their children, mostly for medicines and side-effects, for anticipated complications and their symptoms, for the management of diarrhea, nausea, vomiting, fatigue and pain and for skin care. In the qualitative studies made, the mothers stated that they wanted to know how they would care for their children when necessary (Mercer & Ritchie, 1997; Pyke-Grimm, Degner, Yiu, & Twinn, 2001).

In studies made on mothers of children who had cancer and who were receiving chemotherapy, the parents stated that they mainly wanted to receive information on the medical condition of their children (Fukui, 2002; Yiu & Twinn, 2001), and desired detailed and well-defined information about the child's treatment (Fukui, 2002; Mayer et al., 2009), just as with the HSCT treatment. Mayer et al. (2009) identified needs and resources of family caregivers of pediatric HSCT patients. According to the results of their study, parents reported that practical care giving strategies (69.9%) was one the two important topics identified as "must have".

Similar to our study, parents of children with cancer also wanted to understand their child's treatment and the risks and side effects involved (Pyke-Grimm, Degner, Small, & Mueller, 1999).

Also, in a qualitative study made on adult HSCT patients, the needs of adult HSCT caregivers, within the first 90 days post-transplant, described feeling responsible for "managing care", which involved providing objective care and protecting the patient (Stetz, McDonald, & Compton, 1996). In the current study, just as the mothers in this study group expressed during the discussions, in the study by Martinson, Liu Chiang, and Yi-Hua (1997) the mothers also stated that they wanted sources/written material from which they could benefit when nurses were not available.

This put forth the importance of home care booklets aimed at the physical care needs, including written and visual materials prepared by nurses. In addition, further research is needed in order to find additional ways for helping mothers to cope with these problems at home. Thus, as a result of this study, the author has started preparing a home care manual booklet for mothers.

No statistically significant difference was found between the mothers who received training before discharged of their children from the hospital and their levels of informational needs. At the clinic where the study was carried out, mothers received only verbal and non-formal training before the discharged of their children from the hospital. Not any other sufficiently written materials/videos except of the neutropenic diet booklet, were included in this training. Consequently, since the training implemented before the discharge from the hospital is considered to be insufficient and ineffective, it is evaluated as a natural result that it would not influence their levels of information needs.

At the clinic where the study was carried out, training on catheter dressings and care is given to the mothers during the HSCT process, starting from the pre-transplantation period until the children are discharged. During this period when it is observed that the mothers implement suitable catheter care in accordance with aseptic conditions, then the responsibility for catheter care is left to them. Thus, the mothers are able to continue the catheter care at home after the children are discharged from the hospital. This application made on the subject of catheter management at home is thought to reflect the appearance of the mothers' information levels at a "low need" level. Nevertheless, in this study, another result that was revealed is that over one half of the mothers experienced problems and fear when continuing the catheter care at home. The mothers were asked their views on this problem during the interviews and responded, "When my child was in the hospital, I felt more secure and brave due to the fact that the nurses were there and when I was left alone at home with this procedure, I experienced anxiety and fear". This suggests a need for better discharge planning by the HSCT unit nurses and more emphasis regarding the teaching role of the nurse. Nevertheless, this reveals the necessity of home health care nurses taking the initiative for the needs of these patients and families. However, in Turkey, home health care services to increase the comfort and quality of life of children and families are not widely available.

It was found that the educational status of mothers was influential on the informational needs related to some subjects about their children. In fact, it was found that the mothers who had a low educational level had high information needs on the subjects of the prognosis of the disease and skin care. The mothers of children in the acute HSCT process have partially seen and tried other care applications (neutropenic feeding, oral care, catheter care, etc.). The delayed side-effects of a high dosage of chemotherapy, along with the skin problems brought by acute-chronic GVHD were complex for these families. Prevention of and treatment for GVHD requires profound immune suppression for months to years, which exposes patients to steroid dependency and continued high risk of infection (Barker et al., 2005; Liu & Hockenberry, 2011). Consequently, detailed training should be planned for families whose educational level is low on the HSCT process, the chronic complications that can be encountered and how to care for them. HSCT nurses and public/home health nurses should be in collaboration with each other to educate mothers.

There is a relationship between the diagnosis of the child and the existence of informational needs of the mothers. It was determined that the mothers of children with non-hematological diseases have higher levels of information needs for some subjects, such as the disease and prognosis, how they would organize the home environment according to the needs of the children, in the management of oral care and neutropenic diet applications.

The mothers of children with hematological diagnoses have learned better and acquired experience compared to the mothers of children diagnosed with non-hematological diseases on how they would care for their children in the complex, long and difficult leukemia treatment up until the HSCT process.

In order to decrease the negative results of the child and mother remaining in an isolated and closed environment for a long period of time, to decrease the costs of long hospital stays and to provide hospital beds for other patients that need transplants, patients whose health status is stable (those who are slightly neutropenic despite the realization of engraftment and those who have a need for nutritional support, etc.) can be discharged early from the hospital (Svahn et al., 2002).

One study (Svahn, Ringdén, & Remberger, 2005) claimed that home care was feasible and safe for allogeneic HSCT patients, and that it was advantageous compared to hospital care.

According to the study by Svahn et al., (2002) home care had several advantages, such as faster discharge, lower rates of both grades II-IV acute graft-versus-host disease (GVHD) and transplantation-related mortality and fewer days on total parenteral nutrition. Miano et al. (2003) reported in their study that home care is feasible for children following HSCT and that it reduces the discomfort of children and parents.

They stated that home care reduces costs. Similar to this study, the developments in technology and medical applications in the future, will bring a shift towards home care and early discharge of patients from the hospital in the HSCT processes.

As a result of these developments, the complex nursing care and highly technical procedures will be realized even more by caregivers at home.

This situation sets forth the importance of knowing what will be the needs of families in a home environment and the preparation for home care by the family along with discharge from the hospital. In these applications, that will gradually become more widespread, important roles and duties will be the responsibility of community/ home health care nurses. Therefore, other community-based nurses, such as health visitors and district nurses, continue to play a significant role in the care of children who underwent HSCT and their families.

Conclusion

This study of the informational needs of mothers will aid institutional nurses in discharge planning and home health nurses in planning individualized care for the children and families. Mothers expressed needs for information related to physical care of their children who underwent HSCT. The results of this study can assist in planning nursing strategies to improve the discharge process for HSCT nurses, prevention and early detection of complications and decrease readmission rates by home health care nurses. The home health nurse is able to provide more and better information following discharge from the hospital and to teach the mother how to give care at home. Thus, the training that will be given to the mother in a home environment will be more beneficial, effective and easy to remember. Training mothers at home will provide for the participation of the family in the care process, will develop adaptation to treatment and will teach how to cope with symptoms that could be encountered at home and thus, it will contribute to an increase in the life quality of the child in the post-transplantation period.

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