

Research Article

Children's lived experiences of hematopoietic stem cell transplantation

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Abstract

Although hematopoietic stem cell transplantation is a valuable treatment in many life-threatening pediatric disorders, a large number of children who receive hematopoietic stem cell transplantation are faced with a variety of physical and psychological problems throughout this process. In this study, we explored the lived experiences of these children during their treatment to provide a better understanding of their main concerns, emotions, and expectations. The participants were six children, aged between 6 and 17 years, who underwent hematopoietic stem cell transplantation. Data were collected through individual, in-depth, and semistructured interviews. Using interpretive phenomenological analysis, the findings revealed that the children experienced “transplantation rejoicing” in this “difficult passage”, which was associated with “deepening of family ties”. Awareness of these experiences, feelings, and concerns can help in the development of more professional interventions to provide children with holistic care during their hospitalization.

Key words

children, hematopoietic stem cell transplantation, Iranian, nursing, phenomenology, qualitative study.

INTRODUCTION

Hematopoietic stem cell transplantation (HSCT) has provided a wealth of opportunities to treat a growing range of childhood diseases since 1970. Although it is an invaluable therapy in life-threatening diseases that has improved the life expectancy and quality of life of children, a large number of children who receive HSCT are confronted by a variety of complications before, during, and after transplantation (Sherman *et al.*, 2004a; Wu *et al.*, 2005; Akkus *et al.*, 2010; Packman *et al.*, 2010; Ullrich *et al.*, 2010).

Most of these children experience somatic complications after treatment, including pain, nausea, fatigue, mucositis, and diarrhea (Sherman *et al.*, 2004a; Bennett-Rees & Hopkins, 2008; Hoodin *et al.*, 2010). As well as physical challenges, they have to deal with psychological issues, such as high levels of anxiety, depression, post-traumatic stress symptoms, poor adherence, low self-esteem, and poor social competence, which are due to lengthy hospitalizations, isolation, and an uncertain future (Streisand *et al.*, 2000; Phipps *et al.*, 2002; Packman *et al.*, 2010).

Indeed, hospitalization is stressful for all children because they have limited understanding of the situation; however, a lack of control over the situation, lifestyle changes, extra

restrictions, and separation from family members further add to the stressful nature of hospitalization for children (Ångström-Brännström *et al.*, 2008). In order to deal with the changes in quality of life brought about by the physical and psychological distress created by HSCT, these children require a high degree of emotional and psychosocial support. According to the literature, HSCT and its immediate and late consequences have substantial negative effects on the child's physical, emotional, cognitive, and social wellbeing, and consequently the child's quality of life (Barrera *et al.*, 2000; Sherman *et al.*, 2004b; Feichtl *et al.*, 2010; Packman *et al.*, 2010). Although it is obvious that children who undergo HSCT experience physical and emotional distress, and require unique supportive care, there is little information about how these needs are addressed (Sherman *et al.*, 2004b). Packman *et al.* (2010) highlighted the negative psychological complications in these children, and the lack of research pertaining to this, because most studies have focused on pediatric cancer patients, rather than pediatric HSCT patients. Therefore, with the improved survival rates of children who undergo HSCT (Epstein *et al.*, 2004; Fletcher, 2010), further studies are required to discover these children's feelings, thoughts, expectations, and main concerns to address their emotional and psychosocial needs. Because the researchers sought to develop a deep understanding and holistic explanation regarding the children's feelings, main concerns, and expectations based on their lived experiences, an interpretive phenomenological approach was used in this study (Streubert & Carpenter, 2011).

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Study purpose

The purpose of this study was to discover the lived experiences of children throughout the course of the HSCT process.

METHODS

Design

The interpretive phenomenology approach was identified as the most appropriate method to gain a deep understanding of the children's lived experiences throughout the HSCT process. The aim of interpretive phenomenology is to understand the participant's practical world in the framework of phenomena and their contexts (Holloway, 2005). Interpretive approaches are mainly used in nursing and healthcare research, as they provide a great opportunity to explore people's lived experiences through in-depth learning and sound critique, and offer rich data to influence nursing practice (Streubert & Carpenter, 2011). As interpretive phenomenology brings new light to current understanding and broadens knowledge, this qualitative study was conducted using this approach to develop a deeper and more comprehensive understanding of children's experiences during the HSCT process.

To better clarify the findings of this study, it is important to briefly discuss the Iranian context. In Iran children are the focal point of the family, and there is a strong relationship between parents and children. As the mother has a tremendous influence on child care, her positive/negative attitude or emotions can affect the child's feelings and interpretation of the HSCT process. It is also important to note that religion has a prominent impact on all aspects of Iranian people's lives, thus religious belief is considered a dominant, influential factor in the child's and family's interpretation of a life-threatening disease and its cure.

Participants and setting

The participants of this study were six children who underwent HSCT (3 males and 3 females), and were hospitalized in the HSCT pediatric ward of the Hematology-Oncology and Stem Cell Transplantation Research Center of Tehran University of Medical Sciences (Tehran, Iran), which is a main national hematology-oncology center. Typically, phenomenological studies involve fewer than 10 participants in order to explore the experience of each participant in sufficient depth (Loiselle *et al.*, 2011). In this study, the participants were chosen through purposeful sampling, with maximum variation in age (6–17 years), primary disease, and to share their experiences. The inclusion criteria were: (i) age \leq 18 years; (ii) receiving HSCT; (iii) ability to speak Persian; (iv) and willingness to share their stories and experiences. The characteristics of the participants are displayed in Table 1.

Data collection

For the data collection, the first and third authors visited each child, together with his/her mother in three sessions; at the

Table 1. Characteristics of participants

Participant	Sex	Age	Diagnosis
1	M	10	Thalassemia
2	M	17	Hodgkin's disease
3	M	14	Acute Lymphoblastic Leukemia
4	F	13	Acute Lymphoblastic Leukemia
5	F	6	Thalassemia
6	F	8	Chronic Myelogenous Leukemia

first meeting, we created conditions to familiarize ourselves with the child, and informed him/her about the aim of the study and the interview process; the second session was planned according to the mother's and child's preferences. If the child was tired during the interview, the researchers suggested continuing the interview at another time. Data were collected through individual, in-depth, and semistructured interviews. The duration of the interviews ranged from 20 min to 60 min, with an average of 40 min, and were conducted in the second or third week of the HSCT process. Mothers were asked to allow the children to voice their thoughts without interruption or correction. Effective communication with the children enabled trustful relationships, which allowed them to express their feelings, experiences, and concerns; the questions were open-ended and concerned children's experiences of HSCT. At the beginning of each interview, the children were asked to tell their stories from the beginning of their disease, with a focus on the transplantation process. We started the interview with a general question, such as: "Please tell me about the events that occurred during this period", and then guided interviews with some questions, such as: "What does HSCT mean to you?". If required, we used explanatory questions to gather in-depth information, such as: "What do you mean?" and "Can you tell me more about that?". Individual interviews were recorded with a high-quality voice recorder, which was followed by simultaneous data collection and analysis. All recorded interviews were immediately transcribed verbatim and analyzed in preparation for the next interview. Discovered meanings of prior transcribed recordings helped us to conduct further interviews, and clarified points we could focus on.

Data analysis

Data analysis was performed by the first and third authors, who are well acquainted with qualitative analysis methods. The researchers read the transcribed interviews carefully to acquire a general understanding of the issues that emerged. Subsequently, related interpretative summaries of interviews were written by each research team member, and important headings were identified and categorized. The data analysis was based on that of Diekelmann, Allen, and Tanner (1989), who developed a well-known process of analysis. The analysis is typically conducted by an interpretive team and involves seven steps: (i) reading the interviews to obtain an overall understanding; (ii) writing interpretive summaries and

coding for emerging themes; (iii) analyzing selected transcripts as a group to identify themes; (iv) returning to the text or to the participants to clarify disagreements in interpretation, and writing a composite analysis for each text; (v) comparing and contrasting texts to identify and describe shared practices and common meanings; (vi) identifying patterns that link the themes; and (vii) eliciting responses and suggestions on a final draft from the interpretive team and from others who are familiar with the content or the methods of the study (Diekelmann, 2003; Wojnar & Swanson, 2007). In this study, data collection and analysis continued simultaneously until the analysis of the sixth transcribed interview, when the researchers had collected enough adequate information. In some cases, further interviews were conducted in order to clarify any ambiguities about the team members' interpretations and to ensure the accuracy of the data; this step was obviously done according to the child's developmental age. Prolonged engagement and immersion in data also supported the trustworthiness of the study. The credibility of the findings was established through independent analyses conducted by each team member separately, followed by comparing the process of themes and interpretations. Initial codes and the categories were also audited by the second author, who is a faculty professor expert in phenomenological studies. The major themes that emerged were "transplantation rejoicing", "deepening of family ties", and "difficult passage".

It is worth mentioning that all the researchers and participants were Iranian, and accordingly, all of the interviews were in Persian. After accomplishment of the analysis process, English translation was done by the first author and checked by an English-language editing center to ensure its accuracy and to preserve meanings.

Ethical considerations

This study was the result of an approved project conducted in the Hematology–Oncology and Bone Marrow Transplantation Research Center of Tehran University of Medical Sciences. Considering the fact that the participants of the study were underage children, informed consent was received from both the child and his/her mother. Furthermore, both were informed about the voluntary conditions of participation in the study and the anonymous reporting of recorded interview.

RESULTS

Three major themes emerged through the data analysis: "transplantation rejoicing", "deepening of family ties", and "difficult passage", with two subthemes: "loneliness" and "sense of fear".

Transplantation rejoicing

All of the children spoke about their happiness, and cited different reasons for it. As they were on long waiting lists before their transplantation, some of them, particularly the older children, stated that the opportunity to undergo HSCT

was the main reason for this. They were hopeful about their recovery and a positive response from the treatment, and overcoming complications. Transplantation was considered a window of hope to a healthy future and long-lasting happiness for the children; they stated that hope and their faith in God helped them to move forward and overcome difficulties:

It is difficult to explain that happiness . . . I felt that I was reborn and I was granted a new life by God . . . I was eagerly waiting for this moment, and I knew this moment would arrive . . . I believed that this kind of treatment would help me to regain my health. (17-year-old boy)

I have a good feeling, I think everything will be ok and there will be no need for repeated blood transfusions . . . it is the most pleasant feeling I have ever had . . . you know, last year was hard for me, as I was feeling sick, sleepy, and tired most of the time . . . I was not even able to go to school for a long time (14-year-old boy)

The children expressed their happiness in having a relaxed and enjoyable life for themselves and their families after the transplantation:

I am very happy for my parents more than others, because they endured a lot of problems. I think transplantation will help the whole family to get rid of this burden. (17-year-old boy)

In the beginning, I was happy, because I was supposed to be transplanted, and I told myself everything would finish . . . and those happy days would come back again and we would live happily and travel all together. (13-year-old girl)

One 6-year-old girl compared HSCT to a lollipop to express her happiness: "It is like a lollipop for me". This simple description encompassed all of her feelings, without need of further explanation.

Deepening of family ties

An important point mentioned by most children was the closeness of family relationships as a result of a life-threatening illness and transplantation. If the stem cells were donated by one of the siblings, the ill child experienced more appreciative and positive feelings about him/her. A 10-year-old boy with thalassemia expressed his love for his sister:

I have good feelings about my sister. When she was donating her bone marrow cells, I was so worried. Only after talking to her and making sure that she was fine, I was relaxed.

Furthermore, all of the children mentioned the importance of their mother's or other family members' constant presence in their stress reduction. In addition, the staff's explanations regarding the transplantation process helped them to better understand their conditions, and consequently, reduced their anxiety. An eight-year-old girl with CML spoke of her sister's emotional support:

My older sister comes here every two days and always tells me that I should be brave and not cry like a little girl . . . yesterday, she brought me a funny cartoon and we watched some parts of it together like we used to at home.

As mothers were often the primary caregivers, the children emphasized the importance of being close to their mother; all of the children mentioned the significant role of their mothers to comfort them, and also referred to her as the most important emotional supporter in the transplantation process. Despite the warmth and love that the children received and expressed, they sometimes experienced deep sorrow when they witnessed their families' sadness:

Yesterday, I saw my mother crying behind the window; it was so difficult for me to see the scene . . . when I am sad, she always comes to me and comforts me . . . now it is terrible, as I understand that she is so worried about me and I am not able to do anything to comfort her. (14-year-old boy)

Difficult passage

Almost all of the children reported some difficulties during the transplantation process. "Loneliness" and "sense of fear" were the subthemes derived from the theme "difficult passage". According to the children's narratives, their main concerns were recognized as being away from their family members, or even from their toys or possessions. This passage was made even more difficult because of their fear and uncertainty of HSCT.

Loneliness

The common experience of all children was the feeling of loneliness. All longed for home and their families. They felt alone because of the altered family life:

I want to be with my sister and play with her . . . it is so boring here . . . there is no one to play with . . . my sister always comes to visit me, but I want to play with her . . . yesterday, I cried because the nurses didn't let her stay with me . . . they always tell me she should go back home and they don't let her stay with me for a longer time. (8-year-old girl)

I want to go back home and be with my sister, father, grandmother, and also all my dolls . . . I miss them a lot . . . I used to talk with my dolls, change their clothes, wash their hair . . . but now they don't let me bring all my toys to this room. (6-year-old girl)

Sense of fear

Most of the children experienced a sense of fear during their HSCT process. This feeling was mostly related to a lack of information regarding the conditioning and the transplantation process. Any uncertainty caused adverse psychological effects to the children, such as experiencing a sense of fear, which could be alleviated by correcting and misunderstanding

and by giving clear and understandable answers to the children's questions about the illness, treatment, and prognosis:

I was so scared when they told me that they were going to start my transplantation process. . . . I started to cry and felt terrified. My mother took my hand and said that there was nothing to be scared of, but I was so frightened when they inserted the syringe needle into my body . . . it was a terrible feeling. (10-year-old boy)

No one said anything about the process; at first, I thought it was like a surgery, and I was very afraid because I didn't know what was going on, and sometimes I thought it would be a very painful procedure. They should have given me more explanation about the treatment. (14-year-old boy)

Considering the children's main concerns regarding the HSCT process, nurses have a pivotal role in providing emotional support and information; because of their sensitivity toward children's educational needs, nurses can help children to understand the situation and to overcome negative emotions. The need for delicate care was explicitly mentioned in the children's stories; most of them described healthcare professionals as kind, caring, and affectionate individuals:

The good memories of nurses will stay in my mind; they are so kind . . . they always remind me that I am not alone, and they are my friends . . . sometimes, they play with me or tell stories . . . when I am sad, they make funny faces (6-year-old girl)

DISCUSSION

According to the literature, children experience different feelings, and often suffer emotional distress during hospitalization (Ångström-Brännström *et al.*, 2008; Roberts, 2010); moreover, these experiences are aggravated if they are associated with a life-threatening illness (Felder-Puig *et al.*, 1999; McCaffrey, 2006). Learning and understanding the experiences of ill children is fundamental in pediatric nursing (Watson, 2008). However, qualitative studies regarding children's lived experiences (Woodgate, 2000), especially with respect to pediatric HSCT, are insufficient (Sherman *et al.*, 2004a; Bennett-Rees & Hopkins, 2008). This study was performed based on a phenomenological approach to discover the lived experiences of children who received HSCT. The study results revealed that children experienced various and sometimes contradictory feelings, from happiness to fear. A range of facilitating and threatening factors can influence children's experiences and feelings. Moreover, based on our findings, the process of transplant can enhance family relationships.

According to the literature, HSCT is the most effective treatment for the management of life-threatening pediatric disorders, which has led to improved life expectancy and quality of life in children (Wu *et al.*, 2005; Packman *et al.*, 2010; Ullrich *et al.*, 2010). As this treatment provides great hope for recovery and a better future, it is likely that there will be more optimistic and hopeful feelings from those who are on waiting lists. Children's happiness, hope, and

excitement after completion of treatment have been reported in other studies on pediatric cancer (Haase & Rostad, 1994; Björk, 2008; Lee *et al.*, 2012). Epstein *et al.* (2004) stated that being hopeful for the future and positive thinking are strategies that help pediatric cancer patients endure their suffering. In addition, considering that emotional support and sustained hope are necessities for dealing with life-threatening diseases (Felder-Puig *et al.*, 1999; Anderzén-Carlsson *et al.*, 2007a; Kiernan *et al.*, 2010; Nasrabadi *et al.*, 2011), parents and healthcare providers should help children with effective psychological adjustment and give them with hope (Ångström-Brännström *et al.*, 2008; Bracken, 2010).

In line with other studies (Wu *et al.*, 2005; Packman *et al.*, 2010), the children also talked about closeness of family members, which helped them move forward and overcome difficulties. Some children emphasized the significant role of their siblings in helping them tolerate difficult conditions, which supports previous studies' findings (Ångström-Brännström *et al.*, 2008; Modry-Mandell, 2008; Prchal & Landolt, 2012). For example, according to Modry-Mandell's (2008), bone marrow transplantation leads to improvement in sibling relationships, as they develop more real and deeper friendships, which is manifested by their desire to be more helpful by sharing their feelings and serving as a source of companionship when the ill sibling is lonely. Although many studies have discussed deepening family relationships during treatment and child hospitalization, it should be noted that many other studies have reported paradoxical findings, and highlighted disruption of family relationships and devastation of the entire family due to numerous factors, including prolonged hospitalization of the child, and consequently, changed family roles and impacts on marital relationships. Parents become exhausted and endure numerous tensions because of the sick child's physical and emotional problems, handling of siblings, and also dealing with financial concerns (Barrera *et al.*, 2000; Björk, 2008; Fletcher, 2010). It is evident that the more a family is close knit and supportive, the less likely distress is experienced throughout the HSCT process (Phipps *et al.*, 2005). In line with other studies (Wu *et al.*, 2005; Fletcher, 2010), the importance of the supportive role of mothers was also foregrounded in this study. It is difficult to simultaneously be the mother of a child with a life-threatening disease, a supportive caregiver, and deal with the emotional burdens of the child's condition, as well maintain a stable home life (Barrera *et al.*, 2000; Young *et al.*, 2002; Phipps *et al.*, 2005; Vrijmoet-Wiersma *et al.*, 2009; Fletcher, 2010).

Our findings also demonstrated that one of the main concerns of children was coping with loneliness and being apart from family members and their toys or possessions, which was due to the obligatory isolation and certain restrictions to prevent infection transmission. The results were supported by other researches (Davies *et al.*, 2002; Epstein *et al.*, 2004; Ångström-Brännström *et al.*, 2008); however, some studies reported that it is important for school-aged children to be in touch with their friends to deal with feelings of loneliness and to overcome emotional distresses during hospitalization (Ream *et al.*, 2006; Björk, 2008).

One of the most commonly mentioned experiences in the narratives was fear, which varied in nature. The children experienced fear for different reasons, depending on their age and condition. Younger children spoke of their medical fears, which have been discussed in similar studies (McCarthy *et al.*, 1998; Anderzén-Carlsson *et al.*, 2007b; Forsner *et al.*, 2009). Medical fears, loneliness, parental concerns, uncertainty, and loss of control have been reported as the fears mainly associated with hospitalization. As discussed in this study, fear could be a consequence of awareness of parental emotions and concerns, typically for older children. Accordingly, the emotional state of the family influences the child's emotions and experienced feelings (Anderzén-Carlsson *et al.*, 2007a). In order to address medical fears, it has been suggested that these be addressed in adjusted conditions and preferably in the presence of a child life specialist. It is believed that playing, especially role play using dolls, has a significant impact on children's distraction, and consequently, their fear management (McCarthy *et al.*, 1998; Forsner *et al.*, 2009).

According to the narratives, most of the children were unhappy with the lack of information about their condition, and especially of the HSCT process. Similar studies have reported that a lack of information might lead to uncertainty and more emotional burden for both children and their parents (Wu *et al.*, 2005; Hummelinck & Pollock, 2006; Aein *et al.*, 2009; Asadi *et al.*, 2011). For example, some studies revealed that seeking information about their condition or of invasive procedures is an important coping strategy for both children and adults who suffer a life-threatening disease (Farsi *et al.*, 2010; Weinstein & Henrich, 2013). Although providing children with information makes them calmer and more relaxed (Björk, 2008), their developmental status and psychological state should be considered before communication and provision of information. In similar conditions, there is an emphasis on providing information about what will be done and what should be expected prior to the commencement of the procedures (McCarthy *et al.*, 1998). As reported in other studies (Anderzén-Carlsson *et al.*, 2007b; Ångström-Brännström *et al.*, 2008), nurses' and other health providers' kind, supportive, and considerate manners are appreciated by children, and also by their parents, and help them face difficulties. In fact, establishing effective communication with the children, being close and friendly to them, as well as sensitive to their needs, concerns, and expectations, are the most emphasized prerequisites for providing emotional, supportive care (Epstein *et al.*, 2004; Aein *et al.*, 2009; Weinstein & Henrich, 2013).

Study limitations and strengths

This study has some limitations; due to the nature of their disease and complications of the treatment, most of the children were weak and felt tired. Therefore, the researchers made some adjustments to conduct shorter interviews, often in two sessions, if necessary. Also, because the study was based on the participants' subjective views in a specific context, the results of this research should not be generalized. The researchers acknowledge the broad age range of the children in this study as a limitation. Future research should

focus on including more defined and limited age groups to gain a more comprehensive understanding of children's experiences, and to discover their developmental needs and expectations more specifically. However, there were several strengths to this study. First, the inclusion of the children themselves and exploration of their feelings and experiences through their narrated stories, rather than parents or healthcare professionals, because despite nurses' duty to seek the views of children and discovering their experiences and expectations, children's voices are mostly unheard in nursing practice (Watson, 2008). Second, data collection was performed when the children were hospitalized, which provided an opportunity to describe currently-experienced feelings in detail.

Conclusion

In this qualitative study, children's experiences during the HSCT process were reported. Voices, which are not heard often, were heard. The findings revealed some of the children's positive and negative experiences, including happiness following transplantation and associated difficulties. It also showed that closeness of family members resulted in desirable therapeutic outcomes.

Because it was a qualitative study based on subjective views, these accounts could be used as a helpful source to better understand the experiences, feelings, concerns, and expectations of children who undergo the HSCT process. It is essential for nurses to be acquainted with the experiences of these children to be able to promote professional pediatric care. This study addressed the gap in the knowledge of children's experiences and challenges suffered in the HSCT process. Awareness of these experiences can help to develop more professional interventions to provide children with holistic care during their hospitalization. That is, the findings of the present study give nurses the opportunity to focus on the main concerns and expectations of these children, and to identify their emotional support priorities to deliver more comprehensive nursing care. It is also recommended that further research in different contexts is conducted to gain a greater understanding of the pediatric HSCT process from children's perspectives, worldwide.

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CONTRIBUTIONS

Study Design: AM, ANN, MA.
Data Collection: AM, MA.
Manuscript Writing: AM, ANN.

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