# Experience of families of children and adolescents submitted to Hematopoietic Stem Cell Transplantation

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## ABSTRACT

A descriptive study with a qualitative approach to describe how families of children and adolescents submitted to Hematopoietic Stem Cell Transplantation went through this experience. We conducted semi-structured interviews with 16 relatives of children and adolescents submitted to transplantation between December of 2014 to March of 2015 at the bone marrow transplantation service at a university hospital located at the South of Brazil. We analyzed the data with steps described by Creswell, with the support of the software IRAMUTEQ. From this analysis, the emerging categories were: the mother as an active subject in the transplantation process; family experience with the transplantation; transplantation impact for the child and/or adolescent; and, transplantation: from fear to hope. Considering our results, it is possible to ponderate about the care provided by the nursing team, becoming indispensable for these professionals to plan assistance focused not only on the patient but the whole family nucleus.

**Descriptors:** Hematopoietic Stem Cell Transplantation; Family; Child; Adolescent; Pediatric Nursing.

## INTRODUCTION

The Hematopoietic Stem Cell Transplantation (HSCT) is a therapy that aims to substitute the compromised auto-immune system by a healthy system, capable of producing new blood cells after high doses of immunosuppression, resulted from chemotherapy and/or radiotherapy. It is indicated for benign and advanced malignant diseases or life threatening, as hematologic diseases, solid tumors and auto-immune disorders of congenital or not origin(1).

This therapy lets the organism susceptible to many risks, as infections and complications in various organs, including the risk of death. The risks related to the transplantation added to the specific situations that patients and their families experience, lead the family nucleus to a diversified trajectory of challenges(2). Within these challenges, there is the care provided to the patient for an extended period, requiring a reorganization of the family routine to meet this new necessity.

The HSCT and the hospitalization also include modifications in habits and routines for the child or adolescent and their family, as changes in the patient's diet, rigorous hygiene, the environment and the socialization, which aims to avoid possible infections(3).

The experience of having a disease in the family can cause unexpected changes in habits and routines. Besides, it can lead to other conditions from an organic and emotional source. In pediatrics, the child is part of an inter-dependency structure that is the family, and when the child is ill, the entire family nucleus is involved in the process(4-5).

Within so many changes, there is the possibility of transplantation that is a tranquilizing factor when facing the impact caused by the diagnosis, but, it is surrounded by high expectations. Contrasting feelings like happiness, hope, insecurity, and fear appears with the possibility of the therapeutic success or failure(2,6).

Considering the nursing team importance during all transplantation steps, especially in guiding families for post-discharge care, and considering all changes faced by families of children and adolescents submitted to HSCT; nurses need to recognize these changes and how the transplantation modifies the experience of families, so they can plan attention focused on the needs of this family nucleus.

About the nursing Brazilian studies related to HSCT, the primary research objects are the quality of life of the transplanted patient in various transplantation phases and about types of HSCT, nursing care and assistance to the transplanted patient and, the transplantation repercussion in biopsychosocial aspects for patients and their families.

An integrative review addressing the crisis experienced by relatives of patients submitted to HSCT selected 25 articles that addressed the theme, however, only one study was Brazilian(7). Considering that new studies emerged in the last decade discussing this issue, national studies addressing the family experience are still insufficient to deeply understand this object.

Based on the exposed, our study aimed to describe the experience of families of children and adolescents submitted to the Hematopoietic Stem Cell Transplantation.

## METHODS

We conducted a qualitative descriptive study in a Service of Hematopoietic Stem Cell Transplantation at the South of Brazil, during December of 2015 to March of 2015.

From 22 families that attended the following inclusion criteria: to be related to a child or adolescent who went through a transplantation and was in ambulatorial accompaniment for 15 days after hospital discharge until 180 days after the transplantation and, to have accompanied the patient during and/or after the transplantation; 16 members from 15 families of patients submitted to Hematopoietic Stem Cell Transplantation participated in this study. The exclusion criterion was to be a relative younger than 18 years.

Regarding the level of kinship from the 16 study participants, 11 were mothers (68.75%); four were fathers (25%) and one aunt (6.25%). The age group varied from 27 to 54 years. About the family origin, nine were from the South of Brazil (60%), three from the Northeast region (20%), two from the Central-West region (13.4%) and, one from the Southeast (6.6%).

We collected data using a semi-structured interview conducted with the following guiding question: “How was for you and for your family to experience the Hematopoietic Stem Cell Transplantation?”

We audio-recorded the interviews, and researchers transcribed and analyzed them according to Creswell steps(8) described as follows:

- Material organization and preparation for analysis: the interviews were fully transcribed, characterized by a code of not allowing participant’s identification and organized in corpus format.
- Reading of all data: in this step, we apprehended information and reflected on their general meaning, through the reading of interviews.
- Detailed analysis of the textual body through a coding process with the support of the software *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* – IRAMUTEQ. This software allows statistical analysis using texts and tables, individuals or words. To use the software in qualitative studies aims for direct data analysis and the reduction of study biases. The IRAMUTEQ offers many analysis methods, as the Descendent Hierarchical Classification, utilized in this study, which classifies text segments according to their specific words(9).
- Use of codification to generate categories: we defined the study categories from the analysis of text segments grouped by the software connected to the meaning of words that ordinate classes.
- The presentation of results with interconnected themes: the categories emerged from themes coming from the analysis of classes organized by the software, and exemplified by participant’s speeches;
- Data interpretation: the results were discussed through the convergence and divergence with the literature, to meet the study objective.

This study pertains to the project “Social Support Network to Families of Children and Adolescents Submitted to Hematopoietic Stem Cell Transplantation”, analyzed by the Ethics in Research Committee of the Health Sciences Sector from Universidade Federal do Paraná, approved protocol nº 726.145, and the co-participant institution also approved it. We preserved participant’s anonymity in the results by identifying and coding relatives according to the chronological order of interviews (Int 1, Int 2, Int 3…).

## RESULTS

The software IRAMUTEQ processed the textual body composed of interviews, obtaining 54 text segments, with the use of 41 (75.93%). From the classification of text segments according to the vocabulary, we obtained four classes. The class codification resulted in four empirical categories denominated: the mother as an active subject in the HSCT process, family experience with the HSCT, the HSCT impact for the child or adolescent, and, HSCT: from fear to hope. We exemplify the relationship between categories in the following dendrogram (Figure 1):

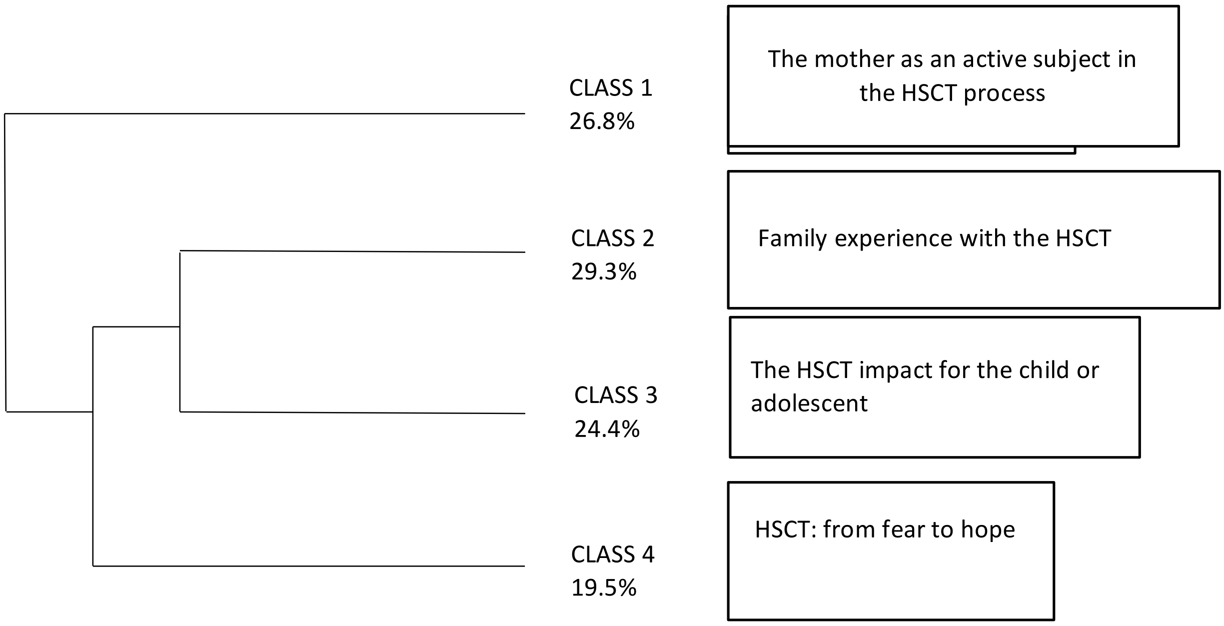

**Figure 1:** Dendrogram of classes and words provided by the software IRAMUTEQ. Curitiba, PR, Brazil, 2016.

## Family experience with the HSCT

We ordinated participant's speeches according to the words: to experience, family, HSCT, hard, thing, fear, to think, to hope, to wait, to diagnose, child, adolescent, to stay, and to imagine.

In this category, we found the form and feelings that families experienced the child's or adolescent's HSCT. One of the families reveals tension caused by unawareness about the therapy and all experiences related to it.

*We imagined one thousand things, but we did not imagine how is to be in a hospital, to experiment all that, all that tension. It was a bit tense, let's say a lot tense, to experience the transplantation.* (Int 14)

Families acquire knowledge about the HSCT while experiencing the therapy.

*To experience the HSCT was a learning process because I (father) did not know about the HSCT.* (Int.4)

*To us (family), to experience her transplantation was good and a bit scary, because we did not know for sure how it would be. When we came to the first consultation, we learned about the whole reality, of what could happen.* (Int. 13)

## HSCT: from fear to hope

We ordinated participant's speeches according to the words: bone marrow, to achieve, to think, to happen, it happened, then, easy, to give, no and, stay.

In this category, families present feelings of fear and tension before the transplantation. During therapy, these feelings are transformed into hope of survival and cure for transplanted children and adolescents, as shown by the following speeches:

*We thought that if we didn't do the transplantation, the worse could happen and we did it, at least we were trying. The transplantation was very hopeful. We had so much faith that everything would go well. (Int. 13)*

*[...] I (mother) started to deconstruct the idea that I had about the transplantation being that seven-headed monster, I've started to see the transplantation with other eyes. (Int. 15)*

## The HSCT impact for the child and/or adolescent

We ordinated participant's speeches according to the words: to pass, thanks, God, to eat, time and he/she, being the words "he" and "she" referring to transplanted children and/or adolescents in their relative's testimonials during the interview.

This category shows how children and adolescents have their lives influenced by the HSCT. Its repercussion might be psychological, due to frustrated expectations of something that did not happen, or biological, caused by the therapy, underlying disease or complications, according to the following speeches:

*Last time she was hospitalized to insert the catheter, and it didn't work out. We had expectations, and we knew that possibly, she would pass it with the transplantation, but it was harder than I (mother) thought. (Int. 2)*

*She had complications as the graft disease; she went on a little of everything, she had nausea, vomit, diarrhea, eating issues. (Int. 2)*

*It was hard, at the same time, it was good because she recovered a lot. In the beginning, we were really fearful, it was so hard, but everything went well, Thanks to God.It's hard because of the changes, she couldn't eat. (Int. 10)*

## The mother as an active subject in the HSCT process

We ordinated participant's speeches according to the words: city, to want, to bring, to say, to appear, to know, donator, to say, mother, yet, the city of the transplantation service, to resolve, no, exam, to come and hospital.

In this category, the data showed the maternal figure as an active subject facing the need of a decision during the HSCT process. The mother acquires more knowledge about the therapy during the transplantation experience, to subsidize decisions required during her child's treatment, according to the following testimonials:

*I've started an Internet campaign by Facebook because I always used to make campaigns to raise blood and bone marrow donations, but then I've begun to do campaigns for donators to update their data. I've started to act in a pro-active manner for the transplantation to happen. (Int. 15)*

*We decided to stay in Curitiba, I (mother) started to go to the hospital to know about the outspread, if there was a donator, if the donator was compatible, which level of compatibility and, some of those times, I've spoken to people that had gone through the transplantation. (Int.15)*

## DISCUSSION

The study shows changes in family care provided to the transplanted child or adolescent. Before the disease, care was directed to meet the needs of child development. After the transplantation, these care became complex, intense and full-time, requiring a different structure and family dynamics. Such particular care requires daily effort to organize and perform, intended to preserve health, life, and therapeutic success. Considering this situation, many changes occur in families' lives so they can cope with the treatment. Studies show dynamic family modifications in the care for patients of Hematopoietic Stem Cell Transplantation(10-11).

During therapy, relatives start to break barriers to accepting HSCT, recurring to faith as a coping resource(5). During the transplantation, families acquire knowledge to subsidize care and for the decision-making process. But this process also includes a change of feelings for these relatives, who initially presented fear of the risks involving the HSCT, becoming hope for a cure perspective, grounded not only in science but also in spirituality.Thus, faith can be an important coping resource for relatives during the HSCT(12).

Relatives go through moments of fear, uncertainties, and insecurities moved by doubts of the treatment success, the fear of complications and the life and death dualism(12-13). However, the HSCT comes as an alternative to the previous situation of living with a chronic and possibly fatal disease and, therefore, it brings a hope of an uncertain future(11-13).

During this whole process, the expectation of death and hopelessness, conditioned by the diagnosis conception and the need for transplantation, are surpassed by the expectation of cure and life renovation. The search for spiritual refuge supports this change, once the treatment does not totally guarantee cure neither the patient's life. Thus, faith is a coping resource(6-14). Our study reports anxiety, concern and fear, present in families' lives caused by the risk brought by the child's disease and therapy. Studies demonstrate families coping with these feelings in the HSCT experience(6-15).

These feelings become much more evident after their arrival to the HSCT service. Even if the treatment brings risks, the expectation of the therapeutic success is kept positive, demonstrating the existence of conflicting feelings. In agreement with such result, a study about parents' experience with the cancer diagnosis of their child assessed that 44% of parents could not overcome the sorrow feeling. This study suggests that overcoming these feelings could be associated with the parents' resilience to cope with their child's disease(16).

The transplant also influences the affective and emotional dimensions of children and adolescents submitted to this therapy, because they present the same feelings described by their families during this period(17-18).

In our study, testimonials express situations and feelings related to different moments of the transplantation, especially the negative or positive ones referring to its repercussions, as shown in the literature(4-16). The literature corroborates with this data and points that the HSCT impacts the child's or adolescent's life with signs and symptoms from the transplantation or even from the underlying disease(19).

Thus, changes are necessary, especially the ones related to eating and hygiene. Participants expressed these changes when reporting issues related to the family's concern with eating after the HSCT. There is a particular attention for the child not to eat anything outside of the house, and the need for the child's hygiene requiring constant care. A study confirms such results when listing as necessary attention the prevention of infection post-HSCT: washing hands, hygiene, use of masks, restriction of contact with sick people, diet care, and hospital attention when hyperthermia occurs. It is important to highlight the need to meet infection prevention measures as exposed above, considering the patient's immunity decrease(20).

About the maternal role, our data agrees with the literature(19-21), as most children and/or adolescents have their mothers as their companion. The maternal figure develops the primary carer role during hospitalizations, assuming exclusive dedication to the sick child.

In our study, the mother as primary carer for the transplanted child or adolescent is responsible for the decision-making about their care. For this decision-making process, the mother searches for knowledge from health professionals and with relatives of other children or adolescents who went through the same therapy. A study about factors associated with the family management during the coping process in infant chronic conditions also found that most family carers were mothers (66.4%)(22).

Our results showed that mothers centralize care and its management, as the HSCT implicates the imminent risk of death, thus, they need to monitor the environment where their child is, considering the care offered to minimize the risks involved. Thus, the mother assumes the direct care for the transplanted child, because she believes that she can provide a better quality attention and less risk of death.

The results still show resignations by the main caregiver as a resource to cope with the HSCT. In this case, the mother changes her lifestyle and compromises with a new role according to the singular care that her child needs. In testimonials from this study, we found that the relevant part of this process is the quality of the therapeutic result to benefit the patient's quality of life. A study of coping from caregivers of children with cancer in a chemotherapy process corroborates with this data, which presents resignation when totally dedicating themselves to the caregiver role, abandoning their previous routine(23).

In our findings, we observed that the mother could change her previous routine and to abdicate of everything that used to give her pleasure and to be responsible for caring for the transplanted child/adolescent, avoiding to delegate this function to others. The mother considers that like this, her child will be well assisted, increasing possibilities for a cure. But, in life-threatening situations, she prevents herself from living in the same house and even of offering care to protect the child's well-being. A study about caregivers who assist children with cancer in a chemotherapy process elected that within the coping ways, mothers use resignation and abnegation, and the study concluded that caregivers leave everything to care for their child, including their life if this was possible(23).

Another study, about the experience of parents of children with Fanconi's anemia, confirms the need parents have to receive medical information and to be part of the decision-making process about the treatment indications for their child.For parents, it is critical to know about their child's disease and the implemented therapy, because from the information provided by health professionals or from parent's research, the feelings of insecurity and guilt can be reduced(24).

The results of our study show that the mother/caregiver assumes the control about decisions related to her child's care and therapy, aiming for a better quality of life for the child/adolescent. Therefore, for a subject to become active in the decision-making process, there is a need for caregivers to obtain more knowledge about their child's therapy.

## CONCLUSION

Our study identified that families of children and adolescents submitted to HSCT arrive at the transplantation service with little knowledge about this treatment, making it difficult for the family to go through this experience. The experience of participants' relatives in this study is permeated by ambiguous feelings, as the fear caused by all risks that involve the transplantation becomes a hope for a cure for the transplanted. We verified that during this process, the transplanted has his life biologically and psychologically affected due to the underlying disease or the treatment's adverse effects, that alters their family's routine. Besides, because they are the primary caregivers for their children, mothers require more knowledge to subsidize the decision-making process about the treatment and care provided to the patient.

Considering the results of our study, it is possible to reflect about the care given by the nursing team. It becomes indispensable for these professionals to plan assistance focused not only on the patient but in the whole family nucleus. For that, they need to recognize all experiences lived by these families during this period, to provide necessary information and to promote autonomy to families so they can subsidize the decision-making process about their child's treatment.

Future studies can investigate the experience in other phases of the HSCT, for example, during the admission period or with populations in other transplantation services.

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