

Parents' Experiences of their Children Bone Marrow Transplantation: A Qualitative Study

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Abstract

Introduction: It is an unfamiliar, frightening and stressful experience for the parents of a child who is undergoing bone marrow transplantation. It is impossible to propose an effective caring method without considering all dimensions related to such experience.

Objective: The purpose of this study was to describe and understand the lived experiences of parents whose children were undergoing bone marrow transplantation process. .

Methods: This research was a phenomenological study in which parents of 6 children with bone marrow transplantation were participated. Data collection method was semi- structured and profound, in-depth, face to face interviews. Data then were analyzed using interpretative phenomenological approach.

Results: Four major themes emerged from the data: 1) pending between dread and hope of the transplantation result, 2) exalting spirituality, 3) worry about circumstantial difficulties, and finally 4) life lessons learned.

Conclusion: During bone marrow transplantation process, parents of the children who undergoing transplantation, are experiencing a lot of problems, affections, difficulties, dreads, tensions, emotional conflictions and at the same time they learn a lot.

Implications for Practice: It should be acknowledged for nurses to be more sensitive to pay attention to parents' needs during their children bone marrow transplantation. Nurses need to recognize the power of spiritual factors which may help parents in coping with circumstantial difficulties of the bone marrow transplantation.

Key words: Parents Experiences, Bone Marrow Transplantation, Nursing, Phenomenology.

Introduction

The experience of bone marrow transplantation is (BMT) an unfamiliar, frightening and stressful experience for the parents of children who undergoing bone marrow transplantation. It is essential for medical team to enter into this experienced world during the hospitalization period. It is almost impossible to propose an effective and desirable nursing care, without analysis and studying this experience. So the first step in caring and treatment is to know this phenomena and this

will happen only by getting closer to the patient and his family, discovery of their experienced world, analysis of situation and then proposing useful caring suggestions, according to the situation.

BMT is an appropriate treatment method for treating most of children's disease such as hematological malignancies and bone marrow failure syndrome. Today with the accomplished improvements in clinical supportive and psychological cares of patients and their families, the number of mortality is decreased so much.(1)

Although this method potentially is therapeutic, related diagnostic procedures cause different physical and psychological disorders.(2)

Results of researches in different cultures shows that in despite of supportive care, child's BMT process is a very worrying and stressful experience for his parents.(3,4) Some of its reasons are severity of the disease, indeterminate prognosis, complications and risks of procedure, isolation of patients and long lasting hospitalization period.(5) On the other hand some other elements like family and financial pressures, feeling guilty, feeling of loneliness and hopelessness and dread of recurrent of illness can make this period a very difficult one for the parents.

Also parents feel so inability and weakness while watching their child's suffering from pain and the body condition changes; they face lots of problems for expressing their feelings regarding their children and of course in performing their parental role. In this situation it's very hard and tensional for them to make decision about their child situation. These pressures cause both physical and psychological inconveniences and led to mood disorders, behavioral rupture, negative effect on parents' social performance, their self confidence, marital relationship and well-being.(3, 4)

Research results also show that child's anxiety and adaptation levels, acceptance of illness and its treatments is correlated with parents' behaviors with their child. Also there is a close relation between child's adaptation and parent's psychological health and solace.(6, 7)

Based on evidences, parental factors have effective and important prognosis for child's adaptation with BMT period.(8) So by getting more information on parent's experience, psychological pressures, effective supportive factors during transplantation process, and by scheduling and implementing appropriate educational, caring and supportive programs to control and adjust the tensional factors, we can help the child to get adapted to treatment and improve child's and his family's quality of life.

Regarding the spesific cultural features of Iran , the nature of family relationship , the traditional nature of the society and considering the fact that the society of Iran is family –centered and the lack of research evidences which address the importance and necessity of cultural issues in nursing care – specially for the patients who were undergoing bone marrow transplantation –this research has been done to describe and understand the lived experiences of parents whose children were undergoing bone marrow transplantation.

Purpose: The aim was to describe and understand the lived experiences of parents whose children were undergoing BMT process. With discovering the meanings of parents' experiences we will be able to identify its aspects and characteristics as well as to understand parents' major problems in order to propose proper nursing care plan based on the available real evidences.

Methods and materials

This qualitative study was conducted using an interpretative phenomenological approach. The result of phenomenological inquiry reveals meaning embedded in experience.(9) Phenomenological methods were selected for the study because they permit insight into and understanding of people's experiences from which a broad overview of the phenomena under study can be structured.(10)

Participants: Participant selection was based on purposeful sampling with maximum variation which was going on, till the moment, when there was no new data, actually it continued until data saturation. Obviously in qualitative researches the quality of data is more important than the number of samples.(11)

The inclusion criteria for the study were as follows: parents who had a child with a history of blood malignancy and who were able to understand and communicate in Farsi. In total the parents of 6 children who undergoing bone marrow transplantation admitted in the BMT ward of Dr. Shariati Hospital related to Tehran University of Medical Sciences (TUMS) were participated in this study.

Data collection Methods: In this study the main method of collecting information was semi-structured and profound face to face interviews with participants. These dialogs were so explicit and individually. Data collection took place between the periods of January to April 2009, and was carried out by first and second authors.All interviews were tape recorded and then transcribed verbatim.

Data Analysis: The analyzing method in this study was hermeneutic approach, in which the experiences of participants were clearly identified.12

All transcribed recorded interviews coded and analyzed immediately to get the reply for the next interviews and show the quality of data. Each interview was coded and analyzed before going on to the next one. After the transcripts were carefully and thoroughly read and reread line by line, key

sentences and concepts were highlighted and coded. In the next stage, the meaningful units and initial themes in the data were identified and grouped into themes. Coding is a process for categorizing qualitative data. Qualitative methods involve transcribing material (usually interview transcripts), coding data into themes, and drawing conclusions regarding the phenomena based on these theme¹³.

The interviews were followed Diekelmann well known process of analysis. According to Diekelmann, Allen, and Tanner (1989) analysis is typically done by an interpretive team and involves seven steps: (a) reading the interviews to obtain an overall understanding; (b) writing interpretive summaries and coding for emerging themes; (c) analyzing selected transcripts as a group to identify themes; (d) returning to the text or to the participants to clarify disagreements in interpretation and writing a composite analysis for each text; (e) comparing and contrasting texts to identify and describe shared practices and common meanings; (f) identifying patterns that link the themes; and (g) eliciting responses and suggestions from team members.(12, 14)

Ethical consideration: This research was the result of the approved research project of the Hematology-Oncology and BMT Research Center of TUMS.

Explaining the goal of the research to the participants, signing informed consent forms, and getting necessary commitment for delivering the results of the study in case of the participants request as well as keeping their name confidential and being authorized to dispense in any level of research, were the ethical considerations of this study.

Findings: Findings of this research are actually from the point of view of the parents whose children were undergoing bone marrow transplantation. Some demographic characteristics of these children and their disorder type were summarized in table No.1.

Four major themes emerged from the data: 1) pending between dread and hope of the transplantation result, 2) exalting spirituality, 3) worry about circumstantial difficulties, and finally 4) life lessons learned.

One of the major issues which were obvious almost in all interviews was the parents dread and hope of the child transplantation results. They were more afraid of rejection of transplantation, complications of treatment, recurrent and death, ability of child's body to resistance, condition of donor.

Table- 1: Characteristics of children who were undergoing BMT

Participant	Hematology Disorder Type	Sex	Age	Residence
N=1	Thalassemia	M	10	Town
N=2	Hodgkin	M	17	Town
N=3	Acute Lymphoblastic Leukemia	M	14	Village
N=4	Acute Lymphoblastic Leukemia	F	13	Village
N=5	Thalassemia	F	6	Town
N=6	Chronic Myelogenous Leukemia	F	8	Village

In the other side the parents were also hopeful about the complete recovery of their child, getting positive response from treatments and getting over the difficulties.

"I was so worried, I was confused, I was just thinking, what's going to happen to him/her. I was also worried about my other child (donor) who was waiting alone in down floor. I wish no problem would occur, next door room's children is in bad condition, what if my child reject the transplantation and becomes like him. "

"I'm worried about whether my child's body can tolerate all these high dose chemotherapy? I hope his defiance power and endurance will increase. "

"I was so worried about the rejection of transplantation, while he was rejecting the platelets and every thing was mixed up, I was feeling so bad, I thought there is no hope. "

"I had a good feeling, I was hopeful that we would achieve good results."

"We just have one hope, curing of our child."

Increasing of spirituality among the parents during their children transplantation, growth of their trust in God, believing in saints and leaving all issues to God's will, was very interesting.

"I was trying to calm myself with Quran and calling the saints, I was convincing myself with these things and hoping that God will help".

"I trust in God".

"During Azan(pray time), I was telling my child, to raise his hands and pray for yourself as well as all other children who are hospitalized here".

"You should surrender everything to God; it will be OK, Amen".

"During this period I was always trying to calm myself with Quran and calling out the saints, I was convincing myself that God will help".

All the parents in this research were experiencing different levels of worries and difficulties of transplantation circumstances. Concerns of caring at

home, financial problems, provision of dwelling in Tehran (capital city) for future follow ups and unfamiliarity with the hospital and city environments, high costs of transplantation process, dissatisfaction from long waiting period before BMT, problems regarding to difficulties of strict ward rules (allowing just one parent for taking care of the admitted child) and also dissatisfaction regarding lack of providing enough information were the most common worrying issues mentioned by the parents.

"Now we have dwelling problem, we are looking for a house, rents here are so high, transplantation itself is so costly, once it happened that we didn't have money even for taxi fair to go and get our child's results of lab. test."

"My child wanted so much to play or chat with other children; I wish there were such possibility".

"He wants his father; it would be great if they allow fathers to come in once or twice a week, it's no use to visit from other side of window".

"I'm more concerned about home care, what are we going to do in a twenty m² home".

"We endured so much difficulty to reach to the stage of bone marrow transplantation".

"We faced a lot of problems regarding donors, because we didn't have any relative in Tehran to get the necessary lab. Tests, and then once we find a donor, we had to go in the row of transplantation again and by the time it was our transplantation turn, the validity of lab. Testes were expired".

"Generally, they act so poor in giving information, while you are coming to clinic (before hospitalization), They are not giving any information about the ward, I've asked everything one by one by myself, there were no one to explain".

"We are depressed, I cannot bear the retainer to snuff me after all, first day we were late for fifteen minutes, they asked me severely for more explanation about that, does fifteen minutes creating this much problems"?

"We thought we will face problems for provision of medicines, thank God, charities sponsor the expenses, and we don't have financial problems".

"Those who are coming here should be very patient, I was so stressful in the beginning, and I caught cold sore from extreme stress, now it is eight days that we are here, I try to think this is the first day, it will pass like a thunderbolt".

"Now it is very difficult in the ward, we are unfamiliar, she (child) was crying so much in the beginning, now she is better, but still crying. It's difficult to bath her alone, someone should look out

for her all the time, and otherwise she may drop from the bed".

"Loneliness was hurting so much, I was all alone with my child, the atmosphere was also closed, and it was very difficult for me".

On the other hand most of the parents, attended to this research, could have learned lots of fruitful lessons during BMT process. They mentioned that BMT and its surrounding difficulties are in such a great scale, that daily regular problems looks meaningless.

For example we can refer to below cases: Transplantation and a new life, transplantation and ignoring daily life negligible issues, to value health, transplantation and a new birth.

"Transplantation is like a new life for us".

"Transplantation was an experience, maybe I learned to live better, little things are not important, being healthy is much better than having lots of unimportant things we usually think of, health is the most important thing".

"I feel like I'm going to give birth to my child once again, a new birth for her".

Discussions

What were scrutinized during this study were actually the experiences of the parents whose children were undergoing BMT. In this study, parent's experiences were classified into four major themes: dread and hope of transplantation, exalting spirituality, worry about circumstantial difficulties and life lesson learned.

The findings showed that the BMT and following treatments can cause psychological pressures for patients and their families such as worry about the success of treatment, financial problems due to high cost of treatment, future follow ups challenges and unfamiliarity with the hospital and city environments, and long waiting period before BMT. Also child's condition can cause severe emotional reactions, separation reactions, and increase of pessimism about the results of treatment. In line with other studies during the first stages of hospitalization, the children and their parents are facing lots of psychological pressure.(8, 15-16)

One of the major findings of this study was the experience of dread and hope of parents during the hospitalization period and transplantation of their children.

In line with the Oppenheim et al. (2002) study about the experiences and impressions of the parents of children undergoing BMT, most participant parents were declining with frightening thoughts, and wanted to forget everything. Some of them said,

they are in extreme crisis and also most of these parents were not satisfied with their parental role and were feeling hopeless and guilty.(5)

Jane et al. (2005) in similar study showed that parents are more concentrated on treatment, and improvement of their children is the most important aspect of their life. Getting negative response from treatment was creating psychological pressure and receiving good results could cause happiness to parents.(8)

One of the other results of this study was the great influence of spirituality and religious beliefs on adaptation of parents during their children transplantation. Most of the parents were seeking help from God and saints and were trying to calm themselves by praying.

Jane et al. (2005) also stated in their study that most of the parents were using adaptive mechanism such as, religious beliefs, advising the child to adapt, and asking supports from wife for getting adapted to difficult situations.(8) Most parents of this study were also praying for their children which were making them calmer.

Phipps et al. (2005) in their study upon the effective psychological factors in measuring amount of stress in children who undergoing BMT, emphasized that parents stress are mostly influenced by their children's anxiety level, and their adaptation level to BMT process, so applying effective programs in order to improve the children's coping with BMT can lead to decreasing of their parents stress. Also child's body condition before hospitalization is one of the factors that specify parents' anxiety level.(6)

Jane et al. (2005) in their research results denoted that mothers have explained their ailment by sentences like "She is so young, she is having a lot of pain during chemotherapy, she is alone, and we are so worried".(8) In this study, mothers also have said "while the child is hospitalized we do worry about our other children, who are staying with our relatives, our life is broken in two". Also most of the parents are facing financial problems during their child's transplantation, and most of the parents have to leave their job for taking care of their child. Families have to change their dwelling in order to be closer to hospital, they are not concentrated upon their jobs during working hours, and their expenses go up.

With considering the findings of current study and results of previous studies, anxiety and worrying is one of the major problems of parents whose children undergoing BMT, that can have negative effect on their physical and psychological health status. In Phipps, et al(2005) study, parents stated

that their social and supportive first levels are nurses and during isolation period they have received emotional supports from them.(6)

Therefore nurses should have special emphasis on this issue, and should appliance trainings before, during and after transplantation, creating an atmosphere that, parents can share their feelings and emotions, persuasion of parents, using religious beliefs, training other family members so that they can support the parents, and at the end benefit from psychological consultations.

Oppenheim et al. (2002) study results also showed that isolation and problems related to the long lasting hospitalization are the major problems of parents of children that undergoing BMT.(5)

Heath (1997) study upon 32 parents of children that undergoing BMT; showed that most of the parents are using different mechanisms in adaptation with such difficult situation.(16)

Explanations of parents about their children transplantation were so different from each others. Some resembled it to second life, some to a new child birth and some others to an experience for better living.

In Stubblefield and Murray (1998) study, transplantation consider as second chance of living from the parent's prospect.(17)

In this research one of the major themes was lessons parents learned during the experiencing of such difficult situation. They mentioned that the hardness of the situation taught them to be real about most small things trough their life. Most conditions around us are less valuable which we react them. We became more realistic about our surrounding environment and we are surprised when see some people's impatience and intolerance. In line with this study Kessler (2002) study results denoted that positive changes result in a feeling of life satisfaction that is believed to be greater among cancer survivors than for people in general.(18)

Also it is reported that when patients with cancer adjust, they change their perception of what is important in life, so as to keep their psychological well-being at a high level.(19-20)

Implications for clinical practice: It is also important for nurses to be more sensitive to pay attention to parents' needs during their children BMT. Nurses need to recognize the power of spiritual factors which may help parents in coping with circumstantial difficulties of the BMT.

According to the findings of this study, taking help from religious beliefs, and planning programs to improving of the BMT children parents' patience

and tolerance. Planning interventions for supporting them during this process should be considered in the nursing care plan.

Limitations: A major limitation of this study was the severe tiredness of the parents during the BMT period and it led to less involvement in data collection. Since the BMT is a hard, boring and difficult process, this influenced the parents' abilities for depth of the interviews. We had to do more sessions and short interviews instead of preferred ones. Although the findings of a qualitative study cannot be generalized, but they raise important clinical nursing issues for consideration.

Conclusion

During BMT process, parents of the children who are undergoing transplantation, are experiencing a lot of problems, affections, difficulties, fears, tensions, emotional conflicts and at the same time they learn a lot. Besides concentrating on taking care of patients, nurses should consider identified issues to improve parents' conditions during the caring process.

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