

# Enclosed by Others: Post Haematopoietic Stem Cell Transplantation Patients Experience-A Phenomenological Study

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## ABSTRACT

**Introduction:** Haematopoietic Stem Cell Transplantation (HSCT) has been considered as final treatment strategy for many diseases. Many quantitative studies have been conducted regarding the difficulties that these patients experience after the procedure with the focus being on negative side effects.

**Aim:** This study was conducted to explore lived experiences of Iranian patients after haematopoietic stem cell transplantation.

**Materials and Methods:** A qualitative design method was used in this study. Based on the philosophical perspective of the naturalistic and the phenomenological approach, Van Manen's method of doing phenomenological study was used in this study. Six patients who had undergone HSCT at least six months ago, older than 18 years and able to communicate participated in the

study. Semi-structured interviews were conducted. Data was analysed by using MaxQDA 10.

**Results:** Participants experienced isolation from social, occupational and emotional activities and stated that they are being excessively controlled by their family members. So main theme was "Enclosed by others" and "Excessive care and excessive support" were the two subthemes.

**Conclusion:** It is vital to pay attention to patients feeling of independence when taking care of themselves and to reduce unnecessary support by others. Educating nurses and families of these patients about different aspects of supportive behaviours are required. Also, different types of supportive and unsupportive behaviours should be included in nurses curriculum.

**Keywords:** Haematopoietic stem cell transplants, Nursing, Phenomenology

## INTRODUCTION

In recent decades, HSCT has been considered as final treatment strategy for many diseases [1,2]. Now-a-days, HSCT has been performed in more than 500 centres in 50 countries and approximately 50000 patients received haematopoietic stem cell transplant [3,4]. Iran is one of the leading countries, having its first HSCT centre launched in 1990 and ever since there has been a fast growth of HSCT centres across the country [5]. It is estimated that by the end of 2016 more than 8224 patients in 14 hospitals have undergone HSCT. HSCT being a time consuming and long procedure, many patients experience physical, psychological, social and financial burden as side effects [6].

Many quantitative studies have been conducted regarding the difficulties that these patients experience after the procedure with the focus being on negative side effects [7], but there are still many facets of this subject which require further research, including investigating patients problems, nursing supporting services for patients and establishing HSCT manuals and guidelines [8]. Given the unique experience of these patients, investigation of these experiences could assist nurses and healthcare personnel to provide better care and consequently, to improve patients coping abilities and recovery [6,9]; Also, apprehension of these experiences could assist the nurses to provide better assistant for patients during hospitalisation period [10].

One phenomenological study, suggested patients undergoing allogeneic HSCT experienced imminence of illness with existential crisis. These patients mentioned many challenges, including fighting for their survival [11]. In another study, in the United Kingdom, patients noticed changes in their appearance and these changes could lead to isolation of patients and low self-esteem [12]. In Australia, experiences of these patients showed that after the transplantation their emotional, spiritual, psychological and physical

conditions changed dramatically and were not the same as before the transplantation [13].

These experiences are affected by the illness context, culture, health and treatment, personal point of view, personality and cultural and religious views [3,14]. Given the religious background and strong family ties in Iranian culture [15], and also the fact that as of today no study has been conducted regarding the experiences that these patients endure; recognition of these experiences are helpful in developing new strategies to improve care provided for these patients. Therefore, this study was conducted to explore the experiences of Iranian patients after haematopoietic stem cell transplantation.

## MATERIALS AND METHODS

### Study Design

This study was a qualitative study based on the philosophical perspective of the naturalistic and the phenomenological approach. Van Manen M method of doing phenomenological study was used in this study [16]. This study was done in September 2017 to March 2018 in Shariati hospital in Tehran.

### Participants

**Inclusion criteria:** Be literate and be able to communicate verbally. Participants should be at least 18 years old and with HSCT done at least six month ago [Table/Fig-1].

### Setting

This study was conducted in haematology, oncology, and HSCT centre of Shariati Hospital which is the leading and referral HSCT centre in Iran. This centre has three haematopoietic cell transplantation wards with 30 beds, one children haematopoietic

S. No.	Age (Years)	Sex	Marital status	Education	Occupation	Month passed since transplantation	Place of residence	Type of transplant
1	56	Male	Married	Master's degree	Employee	156	Tehran	allogeneic
2	35	Female	Married	Diploma	Housewife	6	Varamin	allogeneic
3	22	Male	Single	Diploma	Employee	6	Mashhad	allogeneic
4	30	Male	Married	Associate degree	Militant	18	Qazvin	allogeneic
5	40	Male	Married	Diploma	Employee	16	Tehran	allogeneic
6	31	Female	Married	Bachelor's degree	Employee	21	Taleghan	autologous

**[Table/Fig-1]:** Patients demographics.

cell transplantation ward with 11 beds and a Post HSCT ward with 8 beds. This centre also has three haematology and oncology wards with 48 beds where patients are hospitalised before transplantation procedure.

## Data Collection

Patients demographics are mentioned in [Table/Fig-1]. Semi structured interviews were used for data collection. Interview questions are depicted in [Table/Fig-2]. Place and time of interview were organised by patient approval. All of the interviews were conducted by the first author, in hospital environment. The researcher has an experience of ten years in the field. Interviews had mean duration of 40 minutes. All of the interviews were audiotaped with permission from the patients and after listening to interviews for a couple of times, they were written in text. Sampling was stopped when no new theme was encountered during analysis [Table/Fig-2].

Please describe your life story after haematopoietic stem cell transplantation?
What does come to your mind when you hear the word "haematopoietic stem cell transplantation"?
How does your life look like after haematopoietic stem cell transplantation?

**[Table/Fig-2]:** Interview questions.

## DATA ANALYSIS

Data analysis was conducted via Van Manen M method [16], using MaxQDA 10 software.

At the first step after thoughtful perception of post HSCT patients we formulated phenomenological question. In the second step, after collecting data through conducting interviews and reviewing literature [9,17,18], it was attempted to investigate the phenomena, as experienced by the patient. In the third step, the interviews were listened to and the audio files were transcribed. Transcriptions were double-checked to prevent errors in data transfer and with a comprehensive and optional approach, the transcripts were read and the main theme was identified as endurance.

In the fourth step, researchers described and interpreted the experiences of patients accurately and elegantly by reflecting the patient's expressions. In the fifth step by considering main questions and monitoring performance, it was attempted to establish a strong connection with the phenomena and in the last step; we repeatedly referred to the whole and part of the context.

To ensure the value of qualitative data and reliability of results, four criteria of Lincoln and Guba were used. These four criteria are: 1) Credibility; 2) Dependability; 3) Conformability; and 4) Transferability [19,20].

In this study, purposive sampling was used. Moreover, to achieve rich data maximum variation sampling strategy was used to confirm their validity, all of the results were reviewed by supervisor and advisor professors and to confirm the results, two of them were randomly presented to participants. With accurate description of the environment and participants and by presenting samples of participant's statements, effort was made to facilitate the conveyance of the results of the study. Credibility of the study was ensured by submitting to advice of experts and keeping related documents and by conducting the study according to Van Manen M methodology.

## Ethical Consideration

Ethical approval was obtained from ethics committee of research deputy of Tehran university of medical sciences and haematology, oncology and haematopoietic cell transplantation centre with license number IR.TUMS.FNM.REC.1396.2211. Before commencement of data collection, aim of the study was explained to participants. Verbal and written consent was obtained from the participants to be interviewed and their voice recorded. Participants were assured that their decision regarding their participation in the study would not interfere with their treatment process. They were also allowed to leave the study if they desired. The researcher's phone number was given to participants for additional questions and information.

## RESULTS

"Enclosed by others" was the main theme of this study. Participants experienced isolation from social, occupational and emotional activities and stated that they are being excessively controlled by their family members. This theme included two subthemes: excessive care and excessive support.

### Excessive Care

Excessive care refers to the rather restrictive cares patients receive after the transplantation and as a necessity of treatment process. After transplantation procedure patients will be isolated in hospital and their homes for a while to prevent risk of infection and this isolation gives rise to negative psychological effects in patients.

One of the participants stated: "You know that humans are social beings, but I was isolated in a room and I felt that I'm getting prepared to meet death. I felt a gradual disconnection from the world and thought that after leaving this room, I would die."

Separation from family members brings about feeling of loneliness in patients. One of the patients stated: "Most of the times I would see my children standing on the other side of the glass windows. I wanted to give them a hug but I knew that it was harmful for me. Sometimes I wondered what would happen if I go and gave my children hugs, in worst case scenario I would die, at least I hugged my children once more before my death. I think this intense care is not necessary and doctors overstate these cautions. Why should I not be able to meet my children?"

Participants regarded these intensive cares unnecessary and intolerable and believed that it would create a feeling of alienation from other human beings.

One of participants stated that: "We are also humans, we have passion and emotions, I like to go out with my friends again but I'm not able to. After the transplantation I felt that I have become another human being and I should suppress these emotions."

Excessive care not only isolates the patients from their family, but also affects the connection between the patients with their society. One of the participants stated: "I wanted to visit the holy shrine after being released from the hospital, but then I was notified that I will not be able to visit there for quite a while, and this made me sad."

Also, patients have restrictions for walking around in public areas of the hospital and these limitations would exacerbate their feeling of being different. A participant said: "I only go out for medical purposes because I have to wear a mask the whole time. In my hometown

people look at me differently and this makes me uncomfortable, but I have to get used to it. I wish I could take off the mask as soon as possible. Sometimes I take off the mask and would not care for what may happen, why I should wear it anyway, hundreds of people are coughing and I would not shake hands with anyone or talk to anyone and I won't wear the mask."

Participants mention the changes in their diet as another limitation. For instance one of the participants said: "I can't eat all types of food, I would like to eat some type of food but I should not."

Another participant which points out that transplantation affects all aspects of life, says: "Since our medical situation has higher priority, we are deprived of many things and there are not much activities that we are able to do."

### Excessive Support

Another subtheme is excessive support. A participant said: "People that are diagnosed with illness and treated by transplantation will be ignored by their families and the family members would assume that they are not able to perform daily chores. For instance they would not allow us to lift heavy objects, whereas time has passed and we have recovered."

Another participant said: "After the procedure I am treated differently in my workplace and even my boss says that I am not fitted to do physical tasks, because my family members have told me and also others repeatedly that I am not able to do tasks as before."

Regarding excessive support and the feeling of losing independence, one of the participants said: "I am always being looked after by my family to see where I'm going, who I'm going with and they are always trying to control me."

Escorting patients during treatment period is considered excessive support and a participant mentioned that: "There is always someone accompanying me and I am losing my independence."

Excessive love and care was something that participants regarded as pointless care and one of them said: "We are not asking not to be loved or to be loved excessively, most people have a pointless feeling of love toward us."

Another participant said: "Although I was still able to do my job, they made me to retire even though it was not my retirement time. Now I feel like a burden for my family."

## DISCUSSION

The present study was conducted to explain experiences of patients that undergone haematopoietic stem cell transplantation. Experience of Isolation was the main finding concluded from the study which explains the experiences that these patients go through. This theme is comprised of two subthemes: Excessive care and excessive support. With excessive support and treatment, participants saw themselves as being isolated and after going through lots of stress and anxiety and waiting for transplantation and treatment process, they experienced a high degree of isolation. When the treatment was over, relatives of the patients unwillingly separated them from society and by treating them as a special person and showing excessive love and sympathy, induced a feeling of independence in patients. In a study, unsupportive behaviour of patient's relatives limited their feeling of independence while physical assistance, willingness for listening, having positive attitude and praying were considered supportive care [21].

In our study, being alone in an isolated room was hard to endure for some of the participants and being away from family members made the treatment period to look more prolonged and in a way; they saw this situation as if they were preparing to die. In a study it was shown that isolation could worsen the feeling of confinement and dying and increase emotional damage [13]. Other studies have also shown that long periods of isolation and disengagement in social activities, would

harm the self-esteem of patients [12,22,23]. During isolation, unique and proper psychological support is required and since priorities, life quality and values of patients may alter after transplantation, supportive care must be in harmony with new conditions.

Paying attention to physical appearance, is a reminiscent of illness and treatment period for patients and would damage patients self-esteem [21]. Also in present study, attending physical appearance and using facial mask which draws other people's attention, was considered a limitation for social engagement by patients.

Taking extreme precautions and looking for supportive care programs for patients, may cause the patients to feel that they are being excessively controlled and supported [24]. Although studies have shown that social support has its effects on mortality of patients, but the quality of support is an essential factor and affects the outcome. These supports are two sided and they may act in either positive or negative way and this demonstrates that all types of social support are not necessarily effective and their quality is the factor which influences mortality of HSCT patients [25,26]. Participants of present study also mentioned this issue and saw it as excessive support and a participant labeled it as sympathy and said: "We do not need excessive love nor no love at all, most people show unnecessary love and sympathy toward us". Another participant said: "Society has this misconception toward us that we are not able to work and are in need of full time rest." Studies have proven that as a result of these misunderstandings and misguided behaviours, patient's self-esteem would suffer and they will feel unhappy [27].

In present study, low self-esteem as a consequence of support of others was one of the post-transplantation experiences for patients, and presence of a family member during all stages of treatment and during follow-ups was considered as unnecessary dependency. Patients saw independency during post-transplantation follow-ups as a mean for higher self-esteem and well-being.

Considering experiences of patients, clarity on needed support and a good definition of excessive support are highly required to impede difficulties that these patients go through and to prevent damages that affect their independency and self care.

## LIMITATION

The small sample size and the nature of the study limited the generalisability of the findings. However, as with all qualitative studies, the intention of the results was not generalisation.

## CONCLUSION

Despite proper care and support, patients receiving stem cell transplantation felt isolation. It is vital to pay attention to patients feeling of independence when taking care of them and to reduce unnecessary support by others. Educating nurses and families of these patients about different aspects of supportive behaviours are required. Also, different types of supportive and unsupportive behaviours should be included in nurses' curriculum. Further studies are required to give an exact definition of support for these patients by drawing the line between necessary and unnecessary support and to determine quality of these supports. This study highlighted the sensitivity of supporting behaviours for HSCT patients and their opinion about these supports. Further research is required to explain the reason behind unsupportive behaviours and to understand their different subtypes and also to define different kinds of proper supportive behaviours suitable for patients.

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FINANCIAL OR OTHER COMPETING INTERESTS: None.

Date of Submission: **May 25, 2018**

Date of Peer Review: **Jul 09, 2018**

Date of Acceptance: **Aug 20, 2018**

Date of Publishing: **Jan 01, 2019**