

Life in Limbo: Experiences of Iranian Hematopoietic Stem Cell Transplantation Recipient Patients and Nurses in a Qualitative Study

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ABSTRACT

Background: This study explored the state of hematopoietic stem cell transplantation (HSCT) recipient patients and problems experienced by them and nurse about these state and problems, in Iran.

Methods: Qualitative content analysis was used for analyzing semi-structured interviews with 12 HSCT recipient patients and 18 nurses.

Results: Three main categories described the HSCT state and problems: shadow of death, living with uncertainty, and immersion in problems. Patients treated with risk variety in continuity with probability of death. The patients lived with uncertainty. Consequently these resulted immersion in problems with four sub-categories including: (a) Physical problems, (b) money worries, (c) life disturbances, and (d) emotional strain.

Conclusion: HSCT patients live in a state of limbo between life and death with multidimensional problems. Establish centers for supporting and educating of patients and their families, education of health care providers, enhancement of public knowledge about HSCT along with allocating more budgets to take care of these patients can help patients for passing from this limbo.

KEY WORDS: Limbo; Uncertainty; Hematopoietic stem cell transplantation

INTRODUCTION

HSCT is a complex treatment modality which is performed in various life-threatening diseases like malignant and benign blood and immune system disorders.¹ With science and research advancements, HSCT is gaining more popularity as 50,000 HSCTs are performed annually worldwide.² While efforts are toward HSCT success, HSCT is not always successful and may end in death. A study

reported a death rate of 36% following HSCT.³ Moreover, HSCT is a long-term and lengthy process⁴ during which patients receive chemotherapy and suffer chemotherapy-related toxicity, HSCT process and its complications. As a reason, patients experience various physical, social, psychological and emotional stresses⁵⁻⁸ and become vulnerable.⁵ The HSCT patients suffer serious consequences of HSCT along with uncertainty in survival.⁶ In this situation, the patient is unable to determine or

assign a definitive value to illness-related events or is not able to accurately predict outcomes.⁹

In Iran, the incidence of transplantable diseases is estimated 1500 patients per year and since the establishment of the transplantation center in Iran in 1991 the HSCT numbers and rates has increased yearly.^{10, 11} According to the protocol, before HSCT is performed, patients are referred to the Legal Medicine Organization where they are informed of the success and failure rates of HSCT which puts them in a difficult and uncertain dilemma, resulting in a great deal of stress and emotional burden¹² which affects their psychological coping as well as illness-related outcomes and consequences.¹³

Need to remember that the health care professionals often fail to understand the depth of traumatic nature of transplant and as result poorer compliance and higher morbidity occurred.⁵ Thus better assessment and describing the state of HSCT patients and considering that in practice will effective in reducing the complications and as a results HSCT success. A good deal of emphasis has been placed on considering the experience and determining the needs and priorities of the patients,¹² especially in unique nature of the HSCT experience.⁵ With regard to the effect of culture on patients' perceived problems and uncertainty¹² and due to the fact that no investigation has been performed in this regard in Iran, and majority of HSCT researches were focused on Medication, we found it useful to conduct a qualitative research on this topic. Evaluation of the patients' experience can further clarify the state of patients and problems they experience in this process.

Since HSCT is a time-consuming process and authors, during the years of service, witnessed frequent hospitalizations of HSCT patients and the continued encounter of the nurses with these patients, even long after discharge, evaluation of the nurses' viewpoints regarding the patients' state, situation and problems along with the assessment of patients' experiences can help to elucidate their status and problems better. Therefore, this study was conducted with the aim of describing the HSCT patients' state and problems in the Iranian culture considering the experiences of HSCT patients and nurses. Recognition of these patients' state and problems can be useful in different areas such as

healthcare, policies and support programs to ensure HSCT success.

MATERIALS AND METHODS

Design

A qualitative method using content analysis approach was undertaken using collection and analysis of in-depth interviews.

Setting

The present study was conducted in the main national HSCT center is based in Shariati hospital in Iran. The center has 4 HSCT wards and two hematology-oncology wards that some patients before and after HSCT are hospitalized in order to preparation for HSCT or treatment complications of HSCT. A total of 3170 first HSCT were carried out in this center.¹⁰

Total of nurses in all these wards were 67 graduate (B.Sc.) clinical nurses. All of nurses worked full time (Minimum 35 h per week) and were directly responsible for HSCT patient care.

Participants

The participants consisted of 12 HSCT patients and 18 nurses. They were selected by using purposive sampling. Inclusion criteria for patient participants (PP) were 18 years or older, able to participate physically and mentally, speak in Persian and undertaken HSCT recently or years ago. For nurses these criteria were at least 1 year of work experience with HSCT patients and willingness to participate. The nurse participants (NP) helped the researcher to select the patients based on the inclusion criteria.

The mean age of the HSCT patients was 35.8 (range: 20-61), 6 male and 6 female. All nurses were female with average age of 37.4 years (range: 25-53 years) and experiences in dealing with HSCT patient ranged between 1 till 21 years with a mean of 9 years. Table 1 shows the characteristics of the participants.

Data collection

Interviews with participants were scheduled between December 2011 and August 2012. All

interviews were conducted by one of the Authors in Persian after an appointment for the interviews. Each interview lasted between 30–120 min with intervals convenient to participants.

Firstly, some questions were asked based on the general aim of the study. Based on the participants' answers and during the data analysis, other questions were emerged and mentioned in the following interviews. Table 2 shows example of

main interview questions. The interviews were audio-recorded and transcribed verbatim. Data collection was done concurrently with data analysis with the development of categories related to the reality of HSCT patients' state and problems. Saturation was achieved when no new information was gained from the interviews.

Table 1 Characteristic of Participants

| Nurses | | Patients | |
|-------------------------------|---------------------------------|---------------------|--|
| Mean(range) | N | Mean(range) | N |
| Age in year | 37.4(25-53) | Age in year | 35.8(20-61) |
| HSCT work Experiences in year | 9(1-21) | HSCT Duration range | 15 days - 13 year |
| Sex | Female 18 Male 0 | Sex | Female 6 Male 6 |
| Wards | hematology -oncology and HSCT 6 | Disease | Acute Lymphoid Leukemia 3 Acute Myeloid Leukemia 3 Chronic lymphocytic leukemia 1 Aplastic anemia 2 Hodgkin's lymphoma 2 Non-Hodgkin Lymphoma 1 |
| | | HSCT Type | Allogene 10 AutoLog 2 |

Table 2 Examples of Main Questions from the Interview Guide

| |
|--|
| Patients |
| How are you describing your state in HSCT? |
| What kind of problems do you had with HSCT (before, during and after)? |
| Nurses |
| How are you describing your patients' states when dealing with? |
| What kind of problems do HSCT patients had? |

Data Analysis

The researchers reviewed each text interview several times, in order to gain a whole description of the data. Relevant parts of the text referring to patients' state and problems were identified. Line-by-line coding was done. Codes with a similar content were grouped together. The subcategories were identified based on comparing their similarities and differences. The subcategories were

then coded to reduce them into categories describing patients' state and problems.

Regarding rigor, research team discussed and interpreted the findings until agreement was reached. Some of the participants (nurses and patients) verify the accuracy of results and validate the congruity of findings with their experiences. These items enhanced the credibility of data. To increase the dependability, one of the researchers collected and analyzed the data and the other researchers checked and verified the results.

Participants were selected by considering to maximum variation in terms of work experience in nurses; and gender, age, and HSCT duration in HSCT patients to provide transferability.

Ethical consideration

The Participants were assured that participation was entirely voluntary. All of participants provided informed consent.

RESULTS

Data analysis showed three main categories including shadow of death, living with uncertainty and immersion in problems describing the situations of HSCT patients in Iran. These tree categories were around the main topic of life in limbo as mentioned by one nurse during describing HSCT state: "Transplant is the last thread of hope that patients cling to. Patient life in limbo, it is unknown that patients stay alive from transplantation." [NP4]

Shadow of Death

The life of these patients is always endangered with a lot of risks and threats. Various risks threaten these patients for a long time with probability of death. This category had three sub-categories of risk variety, risk continuity and death probability.

Risk Variety

These patients' lives are always at stake; bleeding, infection, GVHD, and relapse are the most eminent risks that threaten their lives. One of the nurses mentioned: "These patients may have no white cells at times and therefore become prone to infections. Fungal infections are a disaster. When they start to receive antifungal treatment, their bone marrow develops problems. Patients are so prone to bleeding that we do not have time to do platelet count. If you don't take care of it soon and fast, the patient may start on internal bleeding." [NP1]

The development of GVHD in allogeneic HSCT patients is another risk that may result in death in high stages. An experienced nurse said: "Nothing can be done for some GVHDs, like liver, in high stages." [NP7]

The disease may relapse after HSCT in some patients. Relapse means restarting all treatment cycles and facing all associated risks. A nurse stated: "We have a patient now with post-transplant relapse. The doctor says nothing can be done." [NP8]

Risk Continuity

HSCT is a lengthy process and the high risk conditions of the patients continue for a long time, from before transplant to long after it. In this regard, one of the nurses said: "Their problems continue forever. They have already overcome a lot of problems when they become hospitalized for transplant but the story continues even after it. Some develop transplant complications after discharge. I have seen patients who struggle with the complications for years and years and eventually die." [NP1]

Death Probability

HSCT patients faced to death from beginning HSCT until years after discharge. It is possible that patients died in HSCT wards during hospitalization or years after transplantation. One nurse mentioned: "Unfortunately death is a possibility for every patient." [NP10]

Another nurse said: "I had a patient, a kid, who was hospitalized in this ward for two months because of HSCT complications and was discharged with good condition, but his condition deteriorated two days later at home in the middle of the night and expired." [NP8]

Living with Uncertainty

These patients live with uncertainty and many of them deal with indeterminate and uncertain situations. Many situations like preparation of lab tests, finding a donor for transplantation or platelet, human leukocyte antigen (HLA) matching of donor and recipient, and receiving HSCT require the patients to wait with anxiety. A patient stated: "When I was told that there was 30% possibility that my brother's or sister's cells did not match, I really became stressed. I did not know what do. I could not sleep at night and tossed and turned in bed until 4 in the morning every night. I constantly

asked myself what I could do. If the cells did not match me what can I do.”[PP6]

A nurse mentioned her experience with a patient who was hospitalized in an isolated room in the HSCT ward, waiting for his blood count to rise. She said that her patient was said: “When one is in this room, his wishes change with what others wish. Other people, who are out, have “other-side-of-the-window wishes, we have this-side-of-the-window wishes. All we wait for is to see what our count is today, if it is above 1000 or below, how far we are from recovery or death.”[NP4]

Immersion in Problems

HSCT patients have different problems in many aspects. Four sub-categories described this category: (a) Physical problems, (b) money worries, (c) life disturbances, and (d) emotional strain.

Physical Problems

Participants mentioned various physical problems, from chemotherapy complications to HSCT side effects and change in body image. A nurse mentioned: “Patients have many physical problems: Oral ulcers, hair loss, nausea, vomiting, vaginal ulcers, skin discoloration, fever, pain, weakness, fatigue, dark skin.” [NP10]

A patient who had received transplant 11 months ago stated: “I couldn’t eat for about 4 months. The moment I ate, I threw up everything. I also could not sleep for 5-6 months. I was in pain. I had urine infection and went to the toilet many times in the night.”[PP2]

Money Worries

Financial issues are one of the most important problems to Iranian patients. Transplant is a very costly treatment. A patient from a far city who was hospitalized for relapse complained about the heavy costs: “Drugs and tests are very expensive. One cannot really afford them. I had to move to the suburbs of Tehran because the rents were very high.”[PP5]

Another patient who was transplanted for lymphoma stated: “One who has this disease should receive medications and care for free. It is not fair to worry both about the disease and the costs.

Financial problems put a lot of pressure on us. One who has this disease should not be pressed for money worries.”[PP8]

Life Disturbances

These patients experience a sudden change in their life course. A patient who was hospitalized for HSCT stated: “My life has turned upside down. It has totally changed 180 degrees.”[PP9]

Patients experience many limitations in their daily lives including limitations in diet, transportation, occupation, marriage, etc. a patient who was transplanted 11 months ago stated: “When I was transplanted, my wife was pregnant. My son is now about 11 months old. I did not go anywhere near him for nine months. I sat in front of him, at a distance of 1.5 to 2 meters, and just looked at him from far away, couldn’t kiss him, hug him, or give him love. It was very hard. I cannot have home-made bread and home-grown grapes and eggs. Of vegetables, I can only have bananas. When I have a cold, I really suffer because I cannot use any drugs.” [PP2]

Different problem resulting from HSCT puts the patient and his/her family under a lot of pressure, sometimes leading to family disruption. A nurse said: “I had a 20-year-old patient. She had a child, too. She responded to treatment and was recovered in 20 days. When she went home, her husband told her that she was sick and he did not want her anymore. He wanted to marry again. They took her child from her and she returned in a poor and pitiful state. She did not feel well. She was depressed and hopeless. She told us that her husband wanted to divorce her and took her child from her. She said she did not want to live and eventually died after a while.”[NP5]

Emotional Strain

HSCT patients exhibit different emotional reactions to their situations. They experience anxiety, fear and panic while receiving treatment and dealing with unfamiliar circumstances. A patient stated his fear when he first entered the transplant ward: “When I entered the ward, I was scared to death. I wondered what was going to

happen next and believed that there was no way out.”[PP7]

Patients worry about many issues like transplant success, financial problems, their future, family and children. A nurse said: “Some patients even ask about the number of their cells. How many platelets do I have today? What is my white count? What if my transplant does not take? They are really worried.” [NP3]

The disease and HSCT complications cause these patients to be angry and aggressive. They have nightmares about their disease, their condition and even about other patients who they have met during their HSCT. One patient said: “At first I was going crazy, I shrieked so much. I could not tolerate anything. I have no one to listen to me. I now hate the hospital. I see nightmares. I see other patients who I met in the hospital in my nightmares.”[PP9]

Developing a difficult-to-treat disease and lengthy treatment courses make patient to think as to the reason why they caught the disease. In some cases, patients develop a feeling of guilt. A patient said: “I always think why this happened to me. I asked the Lord to forgive me. I said to God I did not pray but was always thankful to you.”[PP8]

Illness and transplant affect patients’ education, occupation, marriage, children, income and many other issues. The future is full of ambiguity and uncertainty to them, resulting in frustration and hopelessness. A nurse stated: “Some patients, especially young ones, come in with very low spirits. You can see it from their behavior. For example, I ask about their grades, university, work, or what they want to do in the future but all they say is that they have no future.” [NP1]

HSCT patient suffer loneliness as well. A patient who was transplanted 2.5 years ago and was hospitalized for relapse said: “A bad thing about transplant is loneliness. It is very hard to pass time alone in the transplant room. It makes you tired, depressed, and leaves you with no spirits at all.”[PP5]

Sometimes, the patients do not like to talk about their illnesses and problems for some reasons: to afraid of having transplanted disease in public and to avoid unnatural and fake compassion expressed by the people around them. They marked from others around them. Some patients believe that

people attribute their illness to committing sins. A patient who was transplanted 6 months ago and was hospitalized for GVHD: “Once I saw a movie. An old man’s wife died and he remarried. He had a son from the first marriage and a daughter from the second. The son swindled him out of all his money and left nothing for his sister but then got larynx cancer. I was upset and asked myself all these patients who get cancer and receive transplant, so they are all sinners. It is obvious when people see these movies, they look at me differently. They wonder what sin I have committed to deserve it.” [PP8]

The patients become abandoned and lonely following the lengthy process of transplant. In the beginning of the treatment and hospitalization, the patient’s family usually pays a lot of attention to the patient but as time goes by, the support and attention fade. A patient describes this matter and said: “Gradually others will separate themselves and leave you. Relatives and friends cut the relationships and keep distance from you. You are not the person who you were. They leave you. ” [PP9]

DISCUSSION

Transplant is the last thread of hope that patients cling to in order to survive but it is not always successful. The patients’ lives are endangered with different threats in different stages of HSCT which may result in death. Many studies have evaluated mortality in HSCT patients due to the side effects of treatment during hospitalization or even years after HSCT ¹⁴⁻¹⁷ and have considered these side effects as the most challenging aspect of HSCT. ¹⁸⁻²⁰ Therefore death cast a shadow in HSCT life.

In addition patients were in a state of uncertainty most of the time. Uncertainty reported in different illnesses like cancer ²¹⁻²³ and chronic diseases such as systemic lupus erythematosus ^{24, 25} and ensues when illness and healthcare intervention events, such as diagnosis, symptoms, treatments, and prognosis, are not distinct, available, specific, and familiar. In this condition, the patients are unable to cognitively categorize them sufficiently. ^{26, 27} HSCT patients, through Legal Medicine Organization, know that HSCT is not always successful which results in more uncertainty in them. Also HSCT

patients encounter to this situation many times because of long duration and chronic nature of HSCT. Some studies noted that the severity of this situation varies in different illnesses; for example, in contrast to acute diseases in which uncertainty does not last long, it is constant in chronic illnesses.²⁷

HSCT patients face numerous problems and difficulties in different aspects as the consequences of the risks they are exposed to and uncertainty. These patients immerse in problems. Their physical problems begin during hospitalization or after discharge. Other studies have also reported a variety of early and delayed physical problems in HSCT patients including chemotherapy complications and HSCT side effects.^{7, 28, 29}

Financial issues are one of the most important and eminent problems.^{15, 29, 30} Although the costs of HSCT are covered by insurance companies and the board of trustees in Iran,³¹ indirect and collateral expenses like the costs of frequent hospitalizations, several lab tests, medications, outpatient clinic visits, transportation, accommodation, special diets and disability of the patients are beyond them; this issue has also been reported by other studies.^{7, 32}

Patients' lives change following HSCT and they experience many limitations. HSCT affects family relationships and results in divorce in many patients. Studies have shown low levels of marital satisfaction following HSCT.³³ On the other hand, the prolonged process of hospitalization and recovery in HSCT and associated problems may lead to changes in patients' interactions and relationships with others.⁷

Findings indicated emotional strain in HSCT patients. Various studies have reported stress, anxiety, fear, depression, despair and hopelessness following HSCT or years after it^{5, 7, 34, 35} and have addressed their predisposing factors such as financial problems, loss of control and role, fear of death and relapse.⁷ Uncertainty could also act as an underlying and predisposing factor as uncertainty is known as a stressor with a major impact on the patients and their illnesses. Also, some patients believed that negligence in performing religious duties and paying for their sins were reasons for their current conditions and this result a feeling of guilt, blame and shame as noted in some patients like cancer patients.^{36, 37}

The stigma attached to HSCT was another strain that patients experience, that may increase the stress and negative effect associated with illness.³⁷ The stigma has also been reported in other patients, especially cancer patients^{38, 39} and bone marrow transplantation patient.^{7, 40} Our findings also indicated that after some time and when problems became more serious, the family members and friends gradually left the patient, giving the patient a feeling of abandonment; the same issue has also been noted in cancer patients.³⁸

In summary, HSCT patients experience multi dimensional, various, and extensive problems in a context of uncertainty and shadow of death. The state described as life in limbo. Education and emotional support, maintain and enhancing hope in these patients, and adopting proper coping strategies in these patients will help them to overcome HSCT-related problems and complications and consequently limbo situation.

CONCLUSION

The results of our study showed that HSCT patients live in a state between life and death with all complications of HSCT. Considering the increasing trend of HSCT and its lengthy process, attention to remove and reduce these problems is one of the top priorities in providing these patients with comprehensive care. Considering the aforementioned will enhance the quality of care and success rate of HSCT. Establishing centers with the aim of supporting these patients, providing them with necessary information regarding their situation, counseling psychotherapy, and helping them to be accepted are highly recommended along with their families.

Helping healthcare providers to develop an insight into HSCT patients' problems and uncertain status, educating them on strategies to reduce these problems can significantly reduce the difficulties that these patients experience. Moreover, enhancement public knowledge and awareness regarding HSCT and the peculiar conditions of these patients, and allocating more budgets to take care of their requirements can alleviate some of their numerous problems and passing HSCT limbo with success.

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