

Description and interpretation of the lived experience of hematopoietic stem cell transplantation, focusing on before, during, and after transplantation: A hermeneutic phenomenological approach

Masoume Rambod (✉ rambodma@yahoo.com)

Shiraz University of Medical Sciences

Nilofar Pasyar

Shiraz University of Medical Sciences

Ladan Zarshenas

Shiraz University of Medical Sciences

Shahpar Bagheri

Shiraz University of Medical Sciences

Mani Ramzi

Shiraz University of Medical Sciences

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Abstract

Purpose: This study aimed at description and interpretation of the lived experience of Hematopoietic Stem Cell Transplantation (HSCT) as a novel therapeutic option in hematologic cancers.

Methods: This hermeneutic phenomenological study was conducted on 13 individuals who had undergone HSCT. The participants were selected using purposeful sampling. In-depth interview was used and data analysis was conducted using van Manen's methodological framework.

Results: Three themes emerged in this study, including "bewilderment in the shadow of hope", "emerging dream of budding", and "entering the calm beach". Bewilderment in the shadow of hope consisted of four subthemes, namely "strange and shocking news", "searching for information accomplished with psychological distress", "having some misconceptions", and "finding a chance for survival". In addition, five subthemes of "chemotherapy as a root of transplantation", "immersing in the psychological burden", "shining light of life", "waiting for successful transplantation", and "living with positive feelings" emerged from "emerging dream of budding". Finally, "entering the calm beach" consisted of "resilience in spite of physical burden", "constant attention to blood cells count", "conducting careful self-care", "having family support", "strong relationship with God", and "valuable rebirth and continuation of life".

Conclusion: Being informed about the need for HSCT was shocking and led to psychological distress and misconceptions before HSCT performance. However, entrance of stem cells into the body shined the light of life and the participants spent their hospitalization period with positive feelings. After HSCT, psychosocial and spiritual interventions are suggested to be provided to improve calm life among individuals.

Introduction

Hematological malignancies are comparatively common cancers which have several different risk factors such as positive family history, previous exposure to radiation (Kuznetsova et al., 2016), maternal exposure to passive smoke, etc. (Edraki and Rambod, 2011). Hematological malignancies and their treatment, including chemotherapy, may lead to some complications, such as mucositis (Mansouri et al., 2012; Rambod et al., 2018), sleep disturbance, pain (Rambod et al., 2019), fatigue (Pearce et al., 2017; Rambod et al., 2019), diarrhea, and constipation (Pearce et al., 2017). Additionally, this treatment may not be successful and recurrent cancer may occur. Hematopoietic Stem Cell Transplantation (HSCT), as a novel and appropriate therapeutic strategy, has been used in various cancers, such as multiple myeloma, leukemia, and lymphoma (Brunner, 2018). It is a promising treatment, which increases the survival of cancer patients (Chapman et al., 2013). Nonetheless, patients might experience several physical, psychological, and social complications as a result of HSCT, which might affect their quality of life (Bevans, 2010; Marques et al., 2018). The patients who had stayed in the hospital reported that the HSCT process was full of stress and worries. For example, being in the isolation room was one of the stressors. The patients indicated that toleration of isolation was very hard for them, because isolation led to

loneliness and interrupted their communication (Biagioli et al., 2016; Nørskov et al., 2015). Although the dimensions of quality of life gradually improved in the participants a year after HSCT, they had several symptoms that could affect their family functions. For instance, cardiovascular diseases, taking drugs, and Graft Versus Host Disease (GVHD) might affect their physical and psychological dimensions of life and decrease their sexual health (Li et al., 2015). Yet, the most common psychological issue in these patients was fear from recurrent cancers (Sarkar et al., 2014).

Review of the literature on the lived experience of HSCT revealed limited qualitative studies in this field (Liang et al., 2014; Zamanzadeh et al., 2013). As an example, Zamanzadeh et al. conducted a qualitative study on the lived experience of HSCT and interviewed HSCT patients and nurses. They made use of content analysis, which showed three main categories as follows: "shadow of death, living with uncertainty, and immersion in problems" (Zamanzadeh et al., 2013). In order to access the rich experience of a phenomenon, in-depth interviews with the participants undergoing HSCT were crucial. However, interviewing the nurses was not needed. Moreover, using a phenomenological approach was essential to access the lived experience of HSCT, but content analysis might not be effective in getting oriented, strong, rich, and deep information.

In another study, grounded theory approach was used on the "perceived threat" concept in HSCT and the concept was explored as "inattention to the signs and symptoms, doubt and anxiety, perception of danger and time limitation, and change of life condition" (Farsi et al., 2013). In another study with meta-synthesis approach on one of the experiences of HSCT (the experience of isolation), isolation was found as a source of suffering leading to relationship with oneself and communicating with others via the Internet (Biagioli et al., 2017).

Liang et al. conducted a study on the lived experience of individuals 100 days to one year after HSCT. The phenomenological approach was employed and the data were analyzed using the Giorgi approach. The results revealed six themes, namely "interference of symptoms, interruption of important development tasks, low self-value, unbreakable shackles, support networking, and living in the moment" (Liang et al., 2014). The Giorgi approach was a descriptive data analysis method, while a hermeneutic phenomenological study would be crucial for description and interpretation of the lived experience of HSCT. Hermeneutics is a philosophy for interpretation of the meaning a phenomena (Van Manen, 2001), such as the lived experience of HSCT, and is an approach for reflection on the lived experience of human life (Van Manen, 2014). Review of the literature revealed no studies on the lived experience of HSCT using the hermeneutic phenomenological approach. Therefore, the present study aims at description and interpretation of the lived experience of HSCT focusing on before, during, and after HSCT. This study has been focused on the meaning and interpretation of the lived experience of HSCT.

Methods

Design

This was a hermeneutic phenomenological study.

Setting

This study was conducted in the hematology and oncology unit in Motahari clinic and the stem cell transplantation ward in Namazi hospital.

Participants

The study was conducted on 13 HSCT participants selected using purposeful sampling. The inclusion criteria of the study were aging 18 years and above, having been on HSCT at least 20 days ago, having rich experience regarding HSCT, speaking Persian, being able to communicate and express their thoughts and feelings, and being willing to talk about one's experiences. The individuals who had previous cognitive impairments were excluded from the study.

Measurements

The data were collected using semi-structured interviews. The criteria for having rich experience regarding HSCT were being in the hospital, passage of seven days from chemotherapy, passage of a one-day rest between chemotherapy and transplantation, undergoing HSCT, passage of at least 20 days from transplantation, and still staying in the hospital or being discharged home.

This study was conducted based on the six steps of Van Manen's approach (Van Manen, 2001). This approach was used to describe and interpret the lived experience of HSCT. In the first stage of Van Manen's approach, the phenomenon (HSCT experience) was determined. In the second stage, investigation on the lived experience was conducted using in-depth semi-structured interviews with the participants who had undergone HSCT. The participants were asked "what is the meaning of HSCT in your life?". The interview questions have been presented in Table 1. The interviews provided the researchers with the opportunity to listen to the HSCT experiences. The interviews were performed in a private and silent room. The time and place of the interviews were arranged based on the participants' comfort. The interviews lasted for approximately 30-60 minutes. The participants were required to explain the nature of HSCT from their experiences. Then, the interviews were recorded and transcribed. Data collection was continued until oriented, strong, rich, and deep information was achieved (Van Manen, 2001, 2014). In the third stage, reflection on the essential themes was done. To achieve the meaning of HSCT, thematic analysis was used. In this step, holistic, selective, and line-by-line reading of the transcripts was used to explore the meaning essence of this experience (Van Manen, 2014). In the fourth stage, the phenomenon was described by the art of writing and rewriting. In the fifth stage, a strong and oriented relation was maintained with the lived experience of HSCT, and the study question was focused. In the sixth stage, in order to provide balance in the research context by considering the parts and the

whole, the main study question was considered and reflection and interpretation of the transcripts were carried out (Van Manen, 2014).

Table 1

Interview questions among the participants undergoing hematopoietic stem cell transplantation

- 1) Explain about your daily life?
- 2) What does it look like living with hematopoietic stem cell transplantation in transplant recipients?
- 3) How do you see yourself in this world and among other people?
- 4) How do you feel about living with a hematopoietic stem cell transplant?
- 5) What comes to your mind when you think about living with a hematopoietic stem cell transplant?
- 6) Is there anything else that you feel is important and you should talk about?

Ethical consideration

This study was approved by the Ethic Committee of Shiraz University of Medical Sciences (IR.SUMS.REC.1397.755, 10 November 2018). The study was also approved by the managers of Motahari clinic and Namazi hospital. Moreover, written informed consent forms were obtained from the participants. At first, the study objectives and methods were explained to the participants. Then, they were ascertained that the data would be used anonymously and that participation/non-participation in the study was voluntary. They were also reassured that they could withdraw from the study at any time and place.

Results

This study was conducted on 13 participants (nine males and four females). The mean age of the participants was 36 years. Among the participants, three (23.07%) were known cases of lymphoma and the others (76.92%) had leukemia.

The lived experience of HSCT meant “bewilderment in the shadow of hope”, “emerging dream of budding”, and “entering the calm beach”. The themes and subthemes of the lived experiences of HSCT have been presented in Table 2.

Table 2

The lived experiences of hematopoietic stem cell transplantation

Themes	Subthemes
1. Bewilderment in the shadow of hope	1.1. Strange and shocking news 1.2. Searching for information accomplished with psychological distress 1.3. Having some misconceptions 1.4. Finding a chance for survival
2. Emerging dream of budding	2.1. Chemotherapy as a root of transplantation 2.2. Immersing in the psychological burden 2.3. Shining light of life 2.4. Waiting for successful transplantation 2.5. Living with positive feelings
3. Entering the calm beach	3.1. Resilience in spite of the physical burden 3.2. Constant attention to blood cells count 3.3. Conducting careful self-care 3.4. Having family support 3.5. Strong relationship with God 3.6. Valuable rebirth and continuation of life

1. Bewilderment in the shadow of hope

1.1. Strange and shocking news

The phrase “stem cells transplantation” was first strange and terrifying for the participants. When they first heard about the need for HSCT from a hematologist, they were shocked. They got out of control and were bewildered. Participant 1 said:

The first time that I heard about the need for transplantation, I was shocked and felt tremor in my body.

1.2. Searching for information accomplished with psychological distress

In this state, the participants listened to the physician's description of the transplantation and searched for information on how HSCT would be performed. However, they felt fearful, anxious, and worried regarding HSCT. Participant 6 stated:

Those days, I was scared. I was always thinking I was going to die.... I was sad. I said: God, what is transplantation and how is it done! I was worried whether I would find a transplantation donor! I bargained with myself regarding performing or not performing the transplantation.

1.3. Having some misconceptions

The days before HSCT, the participants had misconceptions regarding how HSCT would be performed. They imagined that their bones would be cut and the graft would be inserted. Participant 10 maintained: *I thought that the bones would be pierced for transplantation.* Participant 7 also said: *I thought that some parts of the patient's body were removed and replaced by the donor's body.*

1.4. Finding a chance for survival

After many days, the participants found themselves in a world where the novel treatment had helped them have a chance for survival. Therefore, HSCT was accepted using hope and spirituality. The patients passed the hard days before transplantation by hoping to be healthy. Participant 10 mentioned:

The doctor told me that I had to undergo blood cells transplantation. As I heard a 20-year-old man had undergone transplantation and was healthy, I also accepted to have transplantation... I trusted in God. I believed whatever God wanted would happen. So, I had no fears and followed the transplantation planning.

2. Emerging dream of budding

2.1. Chemotherapy as a root of transplantation

In the transplantation ward, first the participants underwent a seven-day high dose chemotherapy. These days started with the complications of chemotherapy. The participants reported nausea, vomiting, diarrhea, anorexia, pain, sleep disturbance, fatigue, numbness, and suicidal thoughts. Participant 2 said:

During the chemotherapy period, I had nausea, fever, dizziness, and sleep disturbance. I lost my appetite. I also had shortage of breath. ... I got bored during the chemotherapy period. When I had severe nausea, I had suicidal thoughts ... As I had diarrhea, I was sick.

2.2. Immersing in the psychological burden

Sometimes, the participants had psychological issues and were depressed as a result of the long duration of hospitalization. They also felt lonely and socially isolated. Participant 5 maintained:

As I had not seen my child for several days, I felt depressed and lonely. I did not like anyone to come to my room. I hated the phone ringtone, it annoyed me. ... When I looked out of the window, I felt I was in a prison. I did not like to look out of the window.

2.3. Shining light of life

After the chemotherapy days and the one-day rest, the golden moment; i.e., the “stem cells transplantation day”, was over. During stem cell injection that lasted from 1.5 to 5 hours, the participants looked at the stem cells and talked to each drop with stress and hope. When the stem cells entered their bodies, they felt pressure, numbness, and fatigue. Energy also entered their legs and fingers, and fatigue came out of their bodies gradually. They became happy after all. That day was enjoyable, with all details remaining in their minds. In fact, hope for living was emerged. Participant 9 said:

Stem cells transplantation is like planting a small tree with a root and waiting for a branch and leaf.... I am like a crashed machine that has been repaired. Now, everything is fine and my life will continue. It is like a rebirth.

2.4. Waiting for successful transplantation

During the days after transplantation, although the participants were happy, they were still stressful and concerned about the success of the transplantation. Participant 6 stated:

I was waiting for the results of the lab tests. I repeatedly asked myself whether or not the transplantation would be successful. I was always stressed and worried. So, I thought about it all the time.

2.5. Living with positive feelings

In the HSCT ward, the participants lived in a room where only nurses, doctors, and sometimes a family member were there. The participants tolerated those days using perceived social support, spirituality, and hope. Participant 11 said:

The nurses gave me some information. They told me to watch TV, use my cellphone, and use virtual networking. The doctors looked at my lab tests every day and said that my blood cells were good.... I perceived that I was very important for them.

Participant 5 maintained:

When I was in the hospital, I said my prayers. I believed that God would help me be healthy. I thanked God that there were those doctors, nurses, and transplantation facilities.

During the days of hospitalization, the participants were hopeful. They were hopeful that the days of illness would end and they would get back to healthy days. Life expectancy and hope for the future were brighter and bolder during their daily lives. As platelets and blood cells rose, life expectancy doubled, as well. Participant 3 said:

I was hopeful for myself and the other patients. You know, the transplantation is a hope. I hope for life.

3. Entering the calm beach

After discharge from the hospital, the participants arrived at the calm beach. On this beach, they coped with their life challenges through social support, spirituality, and hope. They performed self-care.

3.1. Resilience in spite of the physical burden

In this step, the participants were resilient against the physical burden, including nausea, bone pain, hot flashes, gait impairment, recurrent colds, and mucosal dryness. Participant 5 who had undergone transplantation four years ago maintained:

I have bone and leg pain, but I ignore it. Look at me, I am 26 years old, believe me. Anyone who sees me asks me whether I am 40-50 years old, because my skin is full of dark brown pigments and it seems that my face and all my body cells have been destroyed. Dry and burning eyes suffer me. My body mucosa is dry, but these don't matter. ... Sometimes I walk with a cane. I got osteoporosis because of corticosteroid drugs, but I tolerate it.

3.2. Constant attention to blood cells count

The participants paid attention to their blood cells counts. Participant 13 maintained:

When I came back home from the hospital, my whole blood cells count was increasing gradually. Now my platelet count is 160,000. My white and red blood cells have increased, as well. But as soon as I get common cold, my whole blood cells count goes down. Of course, now my whole blood cells are within the normal range.

3.3. Conducting careful self-care

After transplantation and at home, self-care was important. In order to maintain health, the participants followed health tips, such as avoiding being in public and wearing a mask and gloves. They also avoided

contact with people who had infectious diseases. Considering self-care, participant 1 stated:

A limited number of people come to my house. I communicate with my family members via telephone. I follow up treatments. I go to the doctor regularly to show my lab tests... Even though I feel hot when I wear gloves or choked when I wear a mask, I still wear them. I have to take care of myself.

3.4. Having family support

During the days following the transplantation and for several years later, the participants reported high levels of family support. Participant 11 mentioned:

My sister and her husband come to the clinic with me for visiting the hematologist. If someone catches a cold at home, s/he will wear a mask. ...My mom does all my housework. She tells me not to get out of the house; she says she will buy anything I want for me.

3.5. Strong relationship with God

During these days and months, the participants continued to ask God for help and talk to God about maintaining health. Participant 3 who had been at home for 40 days said:

I believe in God in my life. If you are resilient yourself, God will help you.... I always ask God to help me get back to the days before the illness.

3.6. Valuable rebirth and continuation of life

At home, the participants knew the value of life. They thought life was more important than anything else and that their lives were brighter than ever before. They were happy to see their children grew up.

Participant 4 who had been transplanted several years ago stated:

Now, I see life better than before. I appreciate life so much. To me, the important thing is that I'm living. I'm grateful for my brother who was my donor.

They looked forward to the future and saw transplantation as a rebirth. They hoped that everything would be fine in future. They hoped they would be healthy and able to find a job. Participant 12 mentioned:

To me, the future is clear. I hope everything would be good. I hope I would be healthy and my blood cells count would be normal. ... I hope for life.

Discussion

This study revealed the lived experiences of HSCT; i.e., “bewilderment in the shadow of hope”, “emerging dream of budding”, and “entering the calm beach”. These themes were completely unique. One study showed the lived experience of HSCT as shadow of death, living with uncertainty, and immersion in problems (Zamanzadeh et al., 2013). Thus, the lived experiences of HSCT using the hermeneutic phenomenological approach described and interpreted this phenomenon and increased our understanding of the meaning of HSCT, which is appropriate for clinical care.

The days before transplantation, the hematologist’s suggestion regarding the need for HSCT was strange and shocking for the participants. They searched for some information about what it was and how it would be done. This period of time was full of psychological distress and misconceptions regarding HSCT. They felt fearful, anxious, and worried regarding HSCT. They thought that the bones would be cut and the graft would be inserted. Finally, however, the participants found HSCT as a chance for survival and welcomed it by hope and spirituality. Review of the literature revealed no studies exploring this period of HSCT. In a study on HSCT, only the concept of “uncertainty” was revealed in this period. It was reported that finding a transplantation donor with matching human leukocyte antigen was a stressor in this period and that the patients did not know whether they would find the donor or not (Zamanzadeh et al., 2013).

In the HSCT ward, high dose chemotherapy as a root of transplantation had some physical complications. Similarly, researchers indicated that chemotherapy led to side effects and changed the participants’ body images (Zamanzadeh et al., 2013). Physical issues, such as nausea, pain, fever, weakness, dark brown pigments on the skin, and fatigue, were also common during and after the chemotherapy course, which was consistent with the findings of the present investigation (Zamanzadeh et al., 2013).

In the current study, living in the isolation room for a long time immersed the participants in the psychological burden. Similarly, it has been shown that isolation room as a source of suffering led to “loneliness, lack of freedom, and psychological distress” (Biagioli et al., 2017).

The present study results indicated that entrance of stem cells into the body shined the light of life. It also gave energy to the participants and caused fatigue to get out of their bodies gradually. That day was enjoyable and they became happy. Review of the literature revealed no articles focusing on the “transplantation day”. Therefore, the obtained information was novel. The days after HSCT, the participants waited for the success of the transplantation. They spent their hospitalization days by positive feelings, such as perceived social support, spirituality, and hope. These results were not exactly reported in the previous studies. Only one study demonstrated that relationship with others using the Internet service was important and that the participants needed more social support during the isolation period (Biagioli et al., 2017).

After discharge from the hospital and at home, the participants had resilience in spite of the physical burden. They paid attention to their blood cells count constantly and conducted self-care carefully. They received family support and had a strong relationship with God. They thought that rebirth was valuable and life would continue and enjoyed their lives. Therefore, it seemed that they experienced well-being. On

the contrary, a prior research indicated that although the participant had lower levels of physical problems, they reported many issues against returning to normal life (Poloméni et al., 2016). Other researchers also disclosed that their participants experienced various physical distresses, low levels of self-worth, and distress of rejection (Liang et al., 2014). These findings showed that physical problems annoyed the participants and had negative impacts on their psychological health. However, the present study participants had resilience and did self-care. In fact, living a new life was more important for them. They thought that rebirth was valuable and life would continue, leading them to enjoying their lives. In the same vein, Amonoo et al. reported that family support and hope for cure and returning to the normal and healthy life were the positive psychological concepts that the participants used after HSCT (Amonoo et al., 2019). In the current study, the participants were grateful for their donors. Amonoo et al. also showed that the participants who had undergone HSCT used gratitude, optimism, and determination (Amonoo et al., 2019). Another study also indicated that the HSCT participants were very grateful to their family members (Poloméni et al., 2016).

In the present study, the participants' lives were full of spirituality before, during, and after HSCT. They had strong relationships with God and thanked God that there were those doctors, nurses, and transplantation facilities. These findings were also novel and not reported in any study on the lived experiences of HSCT individuals. In a previous study on the spiritual well-being of HSCT, patients maintained that HSCT had a large positive impact on their spiritual well-being (Sinclair et al., 2015).

The strong point of the present study was making use of the hermeneutic phenomenological approach that described and interpreted the real lived experiences of HSCT. However, the data might be not generalized to other HSCT participants.

This study had some implications in clinical and community settings. The need for HSCT was shocking for the participants and led to psychological distress and misconceptions before HSCT. This showed the lack of knowledge regarding HSCT and the need for psychological planning. Therefore, providing some educational and psychological interventions is suggested in this step. Besides, individuals are recommended to share their experiences regarding the "emerging dream of budding" to patients with hematologic cancer, thereby encouraging them to undergo HSCT as soon as possible. After HSCT and at home, providing psychosocial and spiritual interventions are suggested to improve the calm lives of HSCT individuals.

Conclusion

The essence of the lived experiences of HSCT was "bewilderment in the shadow of hope", "emerging dream of budding", and "entering the calm beach". After strange and shocking information about the need for HSCT, the participants searched for some information. Irrespective of psychological distress and misconceptions, a chance for survival, hope, and spirituality led to the performance of HSCT. Similarly, in spite of the physical complications of chemotherapy and psychological burden, entrance of stem cells into the body shined the light of life and the participants spent their hospitalization days with positive

feelings. At home, the participants had resilience in spite of the physical burden using perceived family support and strong relationships with God. They did self-care constantly, as well. They thought that rebirth was valuable and life would continue. Moreover, the HSCT process was full of spirituality.

Declarations

Funding

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Conflict of interest

None declared.

Ethical approval

This study was approved by the Ethics Committee of Shiraz University of Medical Sciences (IR.SUMS.REC.1397.755, 10 November 2018).

Authors' contributions

Masoume Rambod, Nilofer Pasyar, Ladan Zarshenas, Shahpar Bagheri, and Mani Ramzi contributed to this study. All the authors participated in conceptualization, design, drafting, reading, and revising the manuscript and approval of the study. Masoume Rambod, Ladan Zarshenas, Shahpar Bagheri participated in data collection management. Masoume Rambod, Nilofer Pasyar collaborated in data analysis and interpretation.

Consent to participate

Written consent forms were signed by the patients. The interview were coded and the study data were collected anonymously. In addition, the patients were assured about the confidentiality of their data and the voluntary nature of the study.

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