# The Live Experiences of Patients' Undergoing Hematopoietic Stem Cell Transplantation

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## ABSTRACT

**Background:** Hematopoietic Stem Cell Transplantation (HSCT) is a critical treatment modality which affects all aspects of the patients' life. Previous studies explored the patients' experiences of HSCT retrospectively. None of the study has specifically explored the experiences of patients during the HSCT process. The current study aimed to explore the live experiences of patients undergoing Hematopoietic Stem Cell Transplantation (HSCT) throughout the process.

**Methods:** Using a qualitative exploratory descriptive research design, 11 participants were included in the study via purposive sampling. Daily diary writing by the patients in response to the semi-structured interview guide was the main strategy of data collection followed by individual interviews and observations, as and when required. Data were analyzed for the theme and sub-themes following the Elo and Kygnas process of inductive qualitative content analysis.

**Results and Conclusion:** The data analysis revealed the sub-themes, "Worries and Apprehensions", "Being Caged", and "Web of Miseries", corroborated by the theme "A leap in the Dark" portraying the participants' overall experience of HSCT. The findings of this study have highlighted the patients' feelings and emotions, and the needs, problems, and challenges specific to each phase of HSCT. The worries and apprehensions in the conditioning and transplant phase were related to the procedural aspects, treatment outcome, and restrains of isolation required in HSCT. The physical debilities were agonizing in the neutropenic phase of HSCT. However, in the engraftment phase, the patients' emotional stress was found reduced due to their recovery from the HSCT. But, their uncertainty about the therapeutic effectiveness of HSCT and disease recurrence was persistent. The study findings emphasize the need for inculcation of empathic behavior by the health care professionals, and call for modifications in the structural, operational, and clinical aspects of HSCT by the health care organizations as vital to making this experience better for the patients.

**Keywords:** Live Experience, Hematopoietic Stem Cell Transplantation, Qualitative Research, Hematologic Diseases, Hematologic Malignancies.

## INTRODUCTION

Cancer is one of the leading causes of morbidity and the second leading cause of mortality worldwide.[1] Among all malignancies, the incidence rate of hematologic malignancy was 1.19 million with nearly 60% fatality in 2018 globally.[2] The world health organization expects a subsequent rise in this burden each year globally.[1]

Chemotherapy is the fundamental therapeutic modality for the treatment of hematologic malignancies.[3] But, patients with refractory or relapsed hematologic malignancies may not be treated with chemotherapy and require bone marrow transplantation also known as hematopoietic stem cell transplantation (HSCT).[4-5] HSCT is the standard life-saving therapy for patients with refractory or relapsed hematologic malignancies (leukemias, lymphomas, myeloproliferative neoplasms, and multiple myeloma), solid tumors (germ cell tumor, sarcoma, and neuroblastoma), and non-malignant disorders (aplastic anemia, fanconi anemia, paroxysmal nocturnal hemoglobinuria, thalassemia and sickle cell disease).[6-7] Although, HSCT remains the last hope for patients with potentially fatal hematologic morbidities, but the prognosis remains uncertain even after going through such an intense treatment modality.[8-9]

HSCT requires prolonged hospitalization in protective isolation under restricted environment.[10] HSCT is divided into five distinct phases namely: Conditioning, Transplant, Neutropenic, Engraftment, and Post-engraftment phase.[4,7] Once the stem cell engraftment gets complete and all the cell lines (WBCs, Haemoglobin, and Platelets) get self-sustained, the patient then gets discharged from the hospital.[7] The average length of patient's hospitalization for HSCT is approximately of three weeks.

Literature indicates that HSCT greatly impacts the patient's quality of life (QOL). Several researchers have assessed the QOL of patients' during HSCT and reported steeper deterioration in the domains of physical, psychological, functional, and social well-being.[10-13] The patients who underwent HSCT perceived it as very difficult process besides bad modality, and reported it as "shadow of death".[14-15] But, all the research studies which explored the patient experiences of HSCT were conducted retrospectively. None of the study specifically explored the patient's experiences as they were undergoing the process of HSCT. Therefore, to address this research gap and fulfill the knowledge gap related to it (if any) in the existing literature, the current study was adapted to explore the live experiences of patients during the entire process of HSCT. The purpose of the study was to explore the live experiences of patients undergoing hematopoietic stem cell transplantation throughout the process, in the context of Pakistan. The current study specifically intended to answer the following questions: 1. What are the patients' feelings and emotions during different phases of HSCT? 2. What problems do the patients face during HSCT? 3. What are the patients' needs when undergoing HSCT?

## METHODS

### Sample and Setting:

A qualitative exploratory descriptive study was conducted at the Joint Commission International Accredited, Quaternary Care Hospital in Pakistan with a capacity of 550 Beds. The selected health care facility performs nearly 50 HSCT procedures annually, with the cost covered by the patients or their health insurance facility. Patients' were approached with the help of the departmental head nurse, who informed the patients about this study upon their hospitalization for HSCT in the Bone Marrow Transplant (BMT) unit, by providing the informed consent containing a brief description of the purpose of research, data collection process, the risk and benefits, and their right to withdraw from the study. The patients, who were willing to participate, were then enrolled in the study.

Using the purposive sampling technique, a total of 13 patients admitted for the HSCT were recruited in this study. However, one participant withdrew from the study after signing the informed consent form of the research study without mentioning any reason, and one participant was excluded because of his inability to comprehend the questions properly. Thus, the final data was collected from 11 participants with achievement of data saturation. The selection criteria were: Adult patients (aged 18 years and above) undergoing HSCT for the first time, able to communicate in either Urdu or English language, and willing to participate in the research study. Patients who were taking antidepressant medications were excluded.

Furthermore, the study was conducted in the BMT unit containing a single-bedded private room for each patient. Each room has an en-suite toilet and bathing facility, a sealed window covered with laminated films, LED television for entertainment, and a couch for the family member to stay with the patient throughout their hospitalization. Each room contained high efficiency particulate air filtration system where a patient is kept in protective isolation during HSCT.

### Data Collection:

The data were collected from the participants between June 2019 to April 2020, using the semi-structured interview guide (Appendix-A). Three researchers (two male and one female) who were not involved in the participants' care collected the data from the participants. The interview guide comprised of open-ended questions with the intent to explore the participants' experiences as well as their needs and challenges while undergoing HSCT. The interview guide was developed following the process of Kallio and colleagues in both English and Urdu language, and was pilot tested with the potential study participants before the data collection.[16] The participants were provided with the choice to respond in the language of their ease.

Daily diary writing by the patient was the main strategy of data collection in this study. The purpose of diary writing was to capture the patient's experience vividly without any recall bias. The participants were provided a list of questions (Appendix-A) along with a diary and pens. The participants were instructed to pen down their responses to the questions in the diary before going to bed daily. Answers to the questions were read by the researchers on the next day and patients' were probed for further clarification of ambiguous concepts. The patient's response to probing was either audio-taped or noted in writing based on patient comfort.

Those patients who felt uncomfortable with writing a diary regularly, the researchers interviewed them using the same questions (Appendix-A) and audio-taped their responses daily in the evening hours. The audio-taped interviews were conducted in the participants' respective rooms in the BMT unit. However, if the participants were unable to provide the data some day because of symptom/s burden, they were enquired about their experience of that particular day on the next day. The field notes were also maintained by the researchers for documenting the substantial observations during the data collection. The data were collected from the conditioning till the engraftment phase of HSCT. The Urdu written responses in the dairy were translated and the audio-taped interviews were transcribed by a professional transcriber who had command on Urdu and English Languages before the analysis.

### Data Analysis:

The data collection and analysis was carried out simultaneously to search for important concepts during data collection.[17] Data were content analyzed manually following the process of qualitative content analysis detailed by Elo and Kygnas.[18] Furthermore, the inductive content analysis approach was used to analyze the data. Firstly, open coding was done where participants' narratives were analyzed using both in-vivo and interpretive codes by the two researchers independently. Another researcher with expertise in qualitative data analysis validated the codes with participants' narratives to reach a consensus. All relevant codes were then categorized and grouped together based on their revelatory meaning to deploy sub-themes and theme to data.

## Trustworthiness:

Anney's strategies for implementing Lincon and Guba's criteria were used in the research process to maintain trustworthiness.[19] The credibility was ensured by maintaining a prolonged engagement with research participants during the data collection; as well as using the probes for clarifications and acquiring deeper insight into the data. Moreover, data was collected by employing triangulation in the data collection strategies (diary writing, individual interviews, and field notes). The dependability of findings was ensured by cross-checking and validating the transcripts with written and audio-taped data. The conformability was established by using the code-recode strategy during data analysis. Moreover, the research findings are supported by excerpts from the participants' narratives. A detailed description of the research process from the data collection to the production of the final report is presented in the study methods for transferability.

## Ethical Considerations:

This study was approved by the Institutional Review Board and Ethics Committee (IRB&EC) of the selected health care facility. The patients, who were willing to participate, were given a brief description of the purpose of the research, the data collection process, the risk and benefits, and their right to withdraw from the study before signing the informed consent. Their write to refusal and withdrawal was respected. For securing the anonymity and confidentiality of the participants, the codes (P1, P2, P3) were used throughout the research process. The safety and confidentiality of information collected were guaranteed by keeping the hard data under lock and key and soft copy in a password protected computer.

## FINDINGS

### Characteristics of Study Participants:

A total of 11 participants were enrolled in this study. In terms of the participants' demographic features, most of the participants' were male, while two third of them were in the young adulthood stage. However, all the women participants' were in their young adulthood stage. With regards to their marital status, education, and occupation most of the participants' were married, had at least graduate degree, and were professional workers as depicted in Table-1.

**Table-1:** ***Demographic Characteristics of Participants***

| Variables | Frequency (n) | Percentage (%) |
|---|---|---|
| | | |
| **Gender** | | |
| Men | 7 | 63.6 |
| Women | 4 | 36.4 |
| | | |
| **Age** | | |
| Young Adulthood (19-40 Years) | 7 | 63.6 |
| Middle Adulthood (41-65 Years) | 4 | 36.4 |
| | | |
| **Marital Status** | | |
| Married | 8 | 72.8 |
| Unmarried | 3 | 27.3 |
| | | |
| **Education** | | |
| Middle Passed | 5 | 45.4 |
| Graduate and Above | 6 | 54.6 |

| | | |
|---|---|---|
| **Occupation and Profession** | | |
| Professional Workers | 5 | 45.4 |
| Non-Working | 3 | 27.3 |
| Retired | 2 | 18.2 |
| Non-Professional Workers | 1 | 9.1 |
| | | |

Referring to the clinical features of the participants' (Table-2), most of the participants' had malignant disorders, while few participants' had non-malignant inherited mutational disorder.  In terms of the type of HSCT, most of the participants' had Autologous HSCT; few of them had Allogeneic HSCT, while one participant had Haploidentical HSCT. The average duration of participants' stay in the BMT unit was of 25 days.

**Table-2:** ***Clinical Characteristics of Participants***

| **Variables** | **Frequency (n)** | **Percentage (%)** |
|---|---|---|
| | | |
| **Disease** | | |
| Malignant | 7 | 63.6 |
| Non-Malignant | 4 | 36.4 |
| | | |
| **Type of HSCT** | | |
| Autologous | 5 | 45.4 |
| Allogeneic | 5 | 45.4 |
| Haplo-Identical | 1 | 9.2 |
| | | |

The data analysis revealed the sub-themes, "Worries and Apprehensions", "Being Caged", and "Web of Miseries", corroborated by the theme "A Leap in the Dark" portraying the participants' overall experience of HSCT. The theme along with subthemes is presented in Table-3, and explained with the support of participants' excerpts.

**Table-3:** ***Theme and Sub-themes of the Findings***

| **Theme** | **Sub-themes** | **Categories** |
|---|---|---|
| **A Leap in the Dark** | **Worries and Apprehension** | Adversity and Challenges |
| | | Lack of Preparedness for HSCT |
| | | Professional Apathy |
| | | Socio-economic Burden |
| | **Being Caged** | Devoid of Natural Environment |
| | | Devoid of Desired Food |

| | | |
|---|---|---|
| | | Devoid of Meeting Family and Friends |
| | **Web of Miseries** | Netting in Physical Debilities |
| | | Dead and Soulless |
| | | Howling in Agony |

## A LEAP IN THE DARK

All the participants shared feelings of uncertainty across their trajectory of HSCT. Considering the level of uncertainty at each phase, the overall transplant experience appeared to be “A leap in the dark”. One of the participants articulated:

Every second you see, you feel the things happening to you one after another. ‘It’s a trial you have jumped in, and whatever will happen now you have to face it. You cannot either step back or stop the trail’ [P3].

The participants’ alluded to the fact that HSCT is the final hope of treatment for their disease. But, they were uncertain and frightened about the outcome of HSCT.

The doctor has told me that you have to go through this process [HSCT] because there isn't any kind of solution except that. You may get success or failure in it, and you may die during the transplant. So, I have this fear of whether fate would be in my favor or not [P4].

## WORRIES AND APPREHENSIONS

Nearly all the participants alluded to the worries and apprehensions that were mainly related to the procedural adversities of HSCT. Moreover, the lack of preparedness for HSCT, professional apathy, and socio-economic strains were also contributing to the participants’ worries and apprehensions during HSCT.

### ***Adversity and Challenges:***

All the participants were scared of the procedures involved in different phases of HSCT such as central line placement, high dose chemotherapy, stem cell harvesting and infusion. They used various descriptions to characterize their experience of different phases of HSCT. In the participants' view, the conditioning phase of HSCT was “the tense and painful phase”, because of the side effects of high-dose chemotherapy. As participant stated, “*Chemotherapy heavy doses are really painful and unbearable sometimes*” [P1]. Likewise, another participant shared, “*I used to feel tense and restless, and have mood swings likely because of the effects of chemo*” [P5].

The participants felt apprehensive in the transplant phase, which involves stem cell harvesting and infusion. They were uncertain about the implications of procedures involved in this phase on their physical well-being, and the longevity of suffering was noticeable in their narratives. The participant expressed:

I have a fear that how much suffering I have to bear in that [stem cell harvesting]. I have a lot of weakness. So, when they will take this blood and stem cells, I might not be able to offer the prayer and go to the washroom [P7].

With regards to stem cell infusion another participant verbalized:

I was feeling scared as to what will happen to me when the blood [stem cells] will be transfused. 'What would happen to my body then?' I don't know whether this will be the last challenge of treatment [P4].

The participants thus recognized them as life-threatening procedures and labeled this phase as “the critical and risky phase” of HSCT. “*The stem cell harvesting and infusion procedure is very critical and risky*” [P1].

For participants, the neutropenic phase of HSCT was “the panicky and dreadful phase”, because of the physical miseries which they experienced in this phase. As participant expressed eloquently:

In bone marrow transplant, the neutropenic phase is really panicky. It's very difficult to face the pains such as headache, nausea, vomiting, diarrhea, mouth ulcers, perianal pain, and body aches. I cannot explain it in words [P10].

However, all the participants felt calm and contented upon the initiation and achievement of stem cell engraftment. They characterized the engraftment phase as “the mitigating, unwinding, and elating phase” of HSCT, because the physical challenges faced by them in the neutropenic phase started subsiding rapidly. Thus, the participants were looking forward to getting freedom from the constraints of isolation. However, their uncertainty about the effect of treatment and disease recurrence was persistent, as reflected in the following excerpts:

I felt happy to hear that ‘your counts have started to rise'. Even I view myself toward betterment, as I don’t have any kind of pain in my body, and heaviness in my head. Previously, I didn’t have the strength to stand up for many days. Now I am standing and walking on my own. I don't need support from anyone. In fact, while walking, I realized that I have regained the stamina which I had earlier [P4].

Similarly, another participant shared:

As compared to the last few days, I am feeling better now, and I wish to go back to my family and home as early as possible. I just pray to God that He would give me a complete cure so that I would not meet with you people [nurses] being a patient again [P5].

***Lack of Preparedness for HSCT:***

Most of the participants revealed that they received a brief overview of HSCT from the physician which they regarded insufficient. “*I wish there was an orientation session or a pamphlet detailing the sequence of the events to unravel*” [P3]. However, two of the participants reported that they educated themselves through web-based videos before their hospitalization for the HSCT.

In comparison with the participants who were able to educate themselves, the participants who had brief information about HSCT experienced more fear, anxiety, and uncertainty, as reflected in the following excerpts:

When I came here, I was really worried and saddened. The staff [Nurse] said to leave the shoes outside, and wear a mask and cap, which made me very fearful. I was thinking that 'what are they going to do to me'. Because I wasn’t aware of all the things [P4].

Likewise, another participant shared:

I am afraid as to what will happen to me. I might have to face a lot of difficulties. I may get unconscious in it [HSCT]. Whether I would regain my consciousness or not? So I have this tension in my mind [P7].

The participants, who were able to educate themselves about the process of HSCT, were found composed and confident in the initial days of their admission to the BMT unit. They knew that the HSCT will not require any major surgical intervention. However, their feelings about the effect and outcome of treatment were similar to the other participants.

Before being admitted to the hospital, I watched a few video clips on the internet regarding the BMT procedure. So that I could prepare myself accordingly, and overcome the unknown fear related to it. I, then, came to know that there isn’t any operation involved in the process. It’s based on medications only, but it has some side effects that would definitely occur [P5].

Contrary to the participants, who have had educated themselves through web-based informational videos and those who had partial information about HSCT, one of the participants' undergoing HSCT for non-malignant hematologic disorder had no idea about specifications and criticality of HSCT procedure. She perceived it as a routine medical treatment, in which she is receiving multiple intravenous infusions and blood transfusions, and remained calm and composed throughout the process of HSCT.

Considering the worries and apprehensions associated with insufficient preparation for HSCT, the participants proposed the informational video for patients' education and psychological preparation, and provided a comprehensive outline for its development.

There must be complete patient-based video information on Bone Marrow Transplant. The video must include all the phases and steps involved in stem cell transplant. The video of the isolation room. How the central line is inserted for BMT? What is chemo? What are the side effects of chemo? How stem cells are infused into the recipient body? How do donors donate the stem cells? What are the risks for the donor? Take the viewpoint of the donor also. The stepwise video presentation will be helpful for training and education, awareness, and mental preparation of new patients [P1].

### ***Professional Apathy:***

All the participants acknowledged the support and assistance provided by the health care professionals with regards to technical chores, assistance and facilitation in the activity of daily living during HSCT. However, accounts of the participants also revealed several aspects of apathy that made them agitated and frustrated during HSCT. Like, few participants faced the neglect of their choice in treatment, irrational imposition of restrictions by the health care professionals, and the threat of treatment discontinuation due to financial issues, on which they resented strongly.

There is a need to curb the wrong practice of staff coming with their own dogma/philosophy superimposing it on you. Like some of the staff may want you to act in a way that is more pious and religious, but other wishes you to watch movies, TV, and use the Internet for entertainment, etc. These uncontrolled sermons of watching movies and having entertainment worry the patients more than helping them [P3].

Likewise, another participant expressed with grief:

One of the staff [Nurse] doesn't clean me. He uses to make me sit in the washroom [commode] and say to me, 'You have to clean it by yourself'. Though I don't have enough strength to do that, but I do it. I really feel dizzy at that time. I am afraid of hitting my head against the wall [P4].

### ***Socio-Economic Burden:***

The participants' elaborated various socio-economic aspects that contributed to their emotional straining during HSCT. Some of the participants highlighted the familial sufferings occurred due to their hospitalization, that made them sad, guilty, and depressed. One of the participants expressed with tears, "*It's very difficult to stay away from my kids all the time, as they are too young to take care of themselves. I made them suffer from my transplant*" [P9].

The participants also highlighted the public perceptions and approach to patient interaction that contributed to their distress, where they usually refer to the negative outcomes. For example, when interacting with the patient instead of quoting examples of those who may have survived, they would say that person was also suffering from this disease and then got expired.

In our society, the patient who suffers from this kind of disease [malignancy], the people highlight the negative aspects only. Like, 'that person was also suffering from this disease. He was in great pain, and now he/she is expired'. Even though there would be other patients who have overcome these diseases [P5].

The participants' thus emphasized the need for coaching the patient throughout the treatment process in order to develop the patient's stamina for coping as well as managing his/her symptoms effectively. "*A graduate Nurse counselor should be appointed for mentoring and guiding the patients through the treatment process, in terms of managing their symptoms*" [P3]. Likewise, another participant articulated:

The hospital should arrange a counseling session of 10 to 15 minutes for the oncology and BMT patients daily. It would not only help the patients in raising their willpower but would also give them the courage for battling the disease [P10].

Few participants also pointed out the emotional fragility of the family members that made them sad and weepy. "*Whenever I use to talk on the video call, my family members get worried to see me this way and start crying. Then I also start to cry by seeing them crying*" [P4].

Moreover, the economic burden of HSCT also contributed to the participants' worries and apprehensions during HSCT. "*I am in great worry regarding the expenses [of HSCT]. All the time I use to think that the money which I have borrowed would be sufficient for my treatment [HSCT] or not*" [P8]. Likewise, another participant elaborated:

For a Pakistani middle-class patient, who gets diagnosed with cancer and is recommended for BMT, it's a shock for the patient and his family. The arrangement of the massive amount of 2.5 million for a middle-class family is not an easy task. Some have to sell their houses, and others may not have anything to sell [P1].

## BEING CAGED

All the participants shared their feelings of "Being Caged" during the trajectory of HSCT. Albeit in different wordings, they alluded to the restrictions which they encountered in protective isolation during HSCT.

I am like a prisoner. A patient is just imprisoned in one particular room. He is unable to see the weather outside. So, I wish I could go outside! Where a person takes fresh air and could fly like a bird [P8].

These restrictions were not only related to their confinement to room, but also to the hospital food, and their ability to meet freely with family and friends. Hence, three sub-sections are used to portray the participants' feelings appropriately.

### *Devoid of Natural Environment:*

All the participants missed the natural environment across the trajectory of HSCT. They recognized protective isolation vital for acquiring health, yet they found it highly oppressive that made them feel bore and suffocated. Therefore, they craved to see the natural environment, to walk outside and to breathe in the fresh air. "*I wish my room could have natural light, and little walking track with some sitting place in the open to see the day turning into night, and night into a bright day, but unfortunately it's not possible here*" [P5]. Unlike other participants, one of the participants had a small window in the room, yet he also expressed the desire for open space:

Though I could see outside by wrapping up the window cover every morning, but I wish I could go outside for a while. Alas, one [patient] lives in the same place, the same room, hears the same voice [Hepa-filter], and even smells the same [P6].

Because of the identified environmental restrictions, patients' perception of time was unduly prolonged. "*I have passed 11 days here [BMT unit]. These 11 days seem like 11 years that I have spent without going outside*" [P2].

The participants also expressed their discomfort for the centrally controlled temperature regulation of patients' rooms. The participant expressed, *"Yesterday, I felt weird kind of suffocation. Although air conditioner is there, but sometimes it gets slow and sometimes it gets fast automatically" [P8].*

The participants thus suggested that, "*There should be a common room for the patient [in BMT unit] other than his own room, where a patient could go and watch outside — the sunshine, rain, and greenery*" [P5], for overcoming the above stated issues and making this experience better for the patients. With regards to temperature regulation, the participant proposed that, "*The patient should be provided with a proper control to the room temperature, so that patient may be able to adjust the temperature according to their need*" [P3].

***Devoid of Desired Food:***

Nearly all the participants were displeased with the food that they were getting from the hospital. They were allowed to eat the hospital-served food only, opted for them by the FNSD staff, which they found tasteless and ridiculous. Thus, they felt helpless and irritated, and regarded the hospitals served food as unappealing and unhealthy.

Food is a very touchy subject at ### [Hospital]. Food is not only tasteless but foolishly planned. Almost every day one has to consume chicken dish—utterly wrong practice, as chicken is a known cause of many health problems. There is no variety in food, like vegetables are not at all included in the patient food menu [P3].

Considering the limitations in HSCT trajectory, the participants proposed that "*The food menu which is being planned for the patients should be shared with them daily so that they could choose from that food menu*" [P5]. Moreover, "*The food should be a mix of both Oriental and English dishes*" [P6].

***Devoid of Meeting Family and Friends:***

All the participants exceedingly missed their family members across their HSCT trajectory. Since patients are kept in protective isolation, so they were unable to meet freely with their family members and friends. This made most of the participants, especially those who were relatively young, feel sad, helpless, and frustrated. Some of them even cried for their loved ones to whom they were most attached.

I use to cry the whole day. I want to meet with my mother. I couldn't find it enough to only talk to my mother and family members on the phone. It's different than sitting and talking directly with them [P2].

Similarly, another participant stated:

I was feeling lonely today. I wanted to meet my daughter, who is just two and a half years old. But, I am helpless in this regard. I don't even talk to her [on phone], because she then gets more disturbed and repeatedly asks me, "Mama where are you?" And I couldn't explain anything to her, because she is too young [P5].

Although, one family member was allowed to stay with the patient, yet at times that person was not necessarily the choice of the patient. As one of the participants expressed, *"My Aunt is staying with me. But, I couldn't talk much with my Aunt, in a way I use to talk with my mother" [P2].* Likewise, another participant refused his son to stay with him saying "*The attendant [family member staying with the patient] should be the one, with whom the patient has a better relationship, closeness, and more understanding*" [P6].

The participants also highlighted the drawbacks in the organizational telecommunication structure that hindered their communication with family and friends. "*I missed my kids. I wish I could have been able to speak to my kids on phone. But, I could not owing to no mobile network signals and lack of availability of the internet [WIFI]*" [P3].

**WEB OF MISERIESAll the participants were confronted with physical challenges, particularly in the neutropenic phase of HSCT, where they found themselves trapped in various physical miseries. They recognized this phase as the most agonizing phase and labeled it as "the panicky and dreadful phase”.**

***Netting in Physical Debilities:***

All the participants experienced various physical debilities during the neutropenic phase. The most distressing physical debilitations were lethargy, mucositis, diarrhea, and pain. These problems affected their functional capability to perform their activities of daily living such as eating, walking, and toileting, and made most of the participants feel dependent, distressed, and disabled.
After the transplant, I had diarrhea, pain, fever, and a weird kind of taste in my mouth. In fact, all these things occurred at the same time, and have shaken me up. I was not in my senses at all. I was unable to predict anything. Like, I used to have urine and motion [diarrhea] on the bed, and I couldn't even realize it. The staff then used to clean me on the bed as I wasn't able to stand, nor feel the strength to sit on my bed too [P4].

***Dead and Soulless:***

The extreme lethargy experienced by the participants during the neutropenic phase made them feel “soulless” and “dead”. As the participant expressed, “*I am feeling extremely lethargic and depressed. My body seems like the dead. I wanted to do some walk, but couldn’t be able to do that*” [P7]. Likewise, another articulated:
I use to lie down on the bed with my very weak and soulless body. I don't feel the strength and energy to come out of my bed. Though I try to do some walking to keep myself active, but my body is not responding affirmatively to that [P5].

***Howling in Agony:***

Most of the participants labeled mucositis, diarrhea, and perianal pain as the most agonizing debilities. The participants pointed out their inability to eat, drink and even speak at times because of mucositis.
I have a lot of pain in my throat. I don't use to talk to anyone. I feel pressure in my throat when I speak with someone, so that creates a lot of pain. Even I feel pain when drinking water or swallowing saliva and tablet too. As soon as I take the medicines, I feel that my eardrums got blasted [P4].

Likewise, the participants labeled diarrhea as a distressing problem that made them feel woeful.
I am feeling irritated. The motions have made it very painful for me. They have made me miserable now. As soon as I drink the water, immediately I hear the sound in my stomach. And, before I could make myself up, I feel that something is coming out [motion] and I had to rush to the washroom [P8].

## DISCUSSION

This study aimed to explore the live experiences of patients undergoing HSCT throughout the process of HSCT. Findings of this study revealed that all the participants were uncertain and emotionally strained throughout their trajectory of HSCT. The patients’ varying emotional and physical response during HSCT is reported in the previous study.[20] But, the patient’s experience of various phases of HSCT were not explored. The current study thus fulfilled this knowledge gap and portrayed the patients’ experience of different phases of HSCT. The patient’s in the current study were vocal because of their strong educational background, thus they used various metaphorical terms to describe their experience of different phases of HSCT. They characterized “conditioning phase” as “tense and painful”, “transplant phase” as “critical and risky”, “neutropenic phase” as “panicky and dreadful”, and “engraftment phase” as “mitigating, unwinding and elating phase” of HSCT.

Existing literature emphasizes the information and education about HSCT as vital in preserving the emotional integrity of patients during HSCT.[12, 21-22] The participants in the current study also recognized the detailed information as helpful for their mental preparation. However, they desired for the authenticated audio-visual information, encompassing the real-life experiences of patients and procedural aspects involved in various phases of HSCT, for better understanding the process of HSCT. The patients' in the current study were clear about their needs, thus they delineated the full outline for developing the informational video for the HSCT patients which can be utilized for further research and in evidence-based nursing projects.

Contrary to the findings reported in the literature as well as affirmed by the participants' of this study, surprisingly one patient in this study, undergoing HSCT for non-malignant hematologic disorder, was found composed throughout her trajectory of HSCT. She had not reported any worry or apprehension pertaining to any of the aspect of HSCT, such as central line placement, high dose chemotherapy, or stem cell infusion. This different finding could be attributed to the fact that the majority of health care decisions for female patients in Pakistan are mainly taken by the male family members such as father, elder brother or husband, where they receive information about the risks and benefits of health care procedures and may not share it with the patient sometimes. In this case, patient's informed consent was also signed by her elder brother. So, this could be the reason that she was not aware of the risks associated with the HSCT treatment. But, due to the time constrain it was not possible for the researcher to wait and find another person with the similar characteristic. Future researcher may make effort to particularly explore this phenomenon further.

Public perceptions and approach to patient interaction were also some factors attributed to patients' worries and apprehensions in this study. Literature also highlights that the Pakistani public regards cancer as a "graveyard illness",[23] which induces psychological distress in cancer patients and affects their morale in battling the cancer. The participants in the current study added to this aspect by emphasizing the need for a daily counseling session to regain hope and courage. They highlighted the additional role of the nurses by desiring to have graduate nurse counselors for coaching the patient throughout the treatment process in order to develop patient's stamina for coping as well as managing his/her symptoms effectively.

The participants in the current study showed strong resentment toward their physical environment and extensively reported the isolation constraints of HSCT as emotionally distressing to them. Except for the neutropenic phase, the emotional stress associated with the isolation constraints remained prominent during the entire trajectory of HSCT. Biagioli and colleagues have reported the window as the source of patients' connectedness to the outside world.[21] But, unlike the findings of the previous study, [21] the participants in this study avouched to have some open space for walking, sitting, and breathing in the fresh air, and seeing the daylight turning into night to find themself connected to the outside world.

Moreover, the deficits in the organization's structural and operational aspects of HSCT treatment, like the inadequate network coverage and ineffective temperature regulation in patients' rooms, and lack of variety in the food made the participants frustrated, bored, and suffocated during the trajectory of HSCT. The unpleasant food provision by the health care facility, improper temperature regulation, and limited space for movement was reported as imminent threats to the healing of patients in the previous study.[21] The patients' in the current study added to this facet by offering the detailed practical solutions for overcoming these problems which the health care organizations can utilize in the planning, execution, establishment, and streamlining the operational aspects of the BMT center.

The presence of family and friends is reported as vital in providing courage and emotional support to the patients during HSCT.[14] Concurrent with the finding of this study,[14] one family member was allowed to stay with the patient during their hospitalization for HSCT in this study. But, the current study identified that mere presence of a family member with the patient does not always help them to cope with the worries and isolation. The presence of a family member only helped the patient if the accompanied person was of the desire of the patient. Moreover, if the person interacting with the patient was emotionally fragile that further added to their emotional strains. Considering this finding, the nurses may play a strong role in identifying an appropriate family member in consultation with the patients and training the family members for their interaction with the patients.

Biagioli and colleagues reported that patients in their study appreciated the health care professionals for providing quality care with advanced competency and sympathizing behavior.[21] Likewise, the participants in the current study also expressed their gratitude to the health care professionals for their clinical competence. However, their narratives also revealed professional apathy which contributed to their emotional distress. They encountered this professional apathy when they were in dire need of emotional support. Finding suggests more attention to the behavioral aspect of health care professionals' preparation in handling the patients' who are dicing with the death. Kahriman and colleagues rightly pointed out that health care professionals need to understand that empathy is not simply understanding and handling patients' verbal expressions, rather it's the identification of patients' potential needs by understanding their feelings and emotions. [24]

## CONCLUSION

The patients undergoing HSCT experience uncertainty and emotional straining with varying intensity in different phases of HSCT. The worries and apprehensions in the conditioning and transplant phase were related to the procedural aspects of HSCT, the outcome of the treatment, and restrains of isolation required in HSCT; that made the participants feel being caged. Whereas, physical debilities were agonizing in the neutropenic phase of HSCT, where patients' found themselves trapped in the web of physical miseries. However, in the engraftment phase, their emotional stress was found reduced as the physical challenges faced by the patients' started subsiding rapidly, and they felt delighted considering their recovery from the HSCT. Thus, they started looking forward to getting freedom from the constraints of isolation. However, their uncertainty about the effect of treatment and disease recurrence was persistent. The patients' in the current study also provided practical solutions and patient-centered interventions to improve the experiences of other HSCT patients'. The inculcation of empathic behavior by the health care professionals, and modifications in the structural, operational, and clinical aspects of HSCT by the health care organizations are recognized as vital to making this experience better for the patients. Thus, overall this research study has made a valuable contribution to the phenomenon of patients' experiences of undergoing HSCT by addressing the knowledge and research gap in the existing literature.

### Recommendations:

Based on the findings of the research study, some of the recommendations have been set forth for health care organizations and clinical practice.

1. Health care organizations must pay consideration to the environmental aspects of the patient treatment in the hospital. Since the patients are supposed to be isolated, so keeping the infection prevention and control considerations in mind, the design of the room should be such that the patients can view the outside weather, roam in little open space, and have adequate coverage of network signals. Likewise, inside the room patient should be able to regulate the temperature of the room easily via remote. Technological facilities such as smart tabs, WIFI, and headphones should also be available in the patient room. Moreover, the hospital's diet menu must be shared with the patients daily, to enable them to get the food of their choice.
2. The patients' needs for religious practices should be assessed and facilitated according to their desire.
3. The transplant team must pay consideration to the pre-transplant patient and family education. Moreover, the family of the patient should receive appropriate training about their interaction with the patient during the HSCT to support the patient appropriately.
4. The patient-based informational video detailing the process of HSCT must be included in the educational module for HSCT patients.
5. The nurses should play an active role in identifying an appropriate family member in consultation with the patients, to stay with the patient during the HSCT.

6. The health care organizations should appoint graduate nurse counselors for mentoring and guiding cancer and HSCT patients during their treatment regimen.
7. The need for empathetic behavior should be repeatedly emphasized through the in-service training sessions, particularly for the health care professionals working in critical and sensitive areas.

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## **Appendix-A:** ***Interview Guide***

| S. No | Questions |
|---|---|
| **1** | How are you feeling today? |
| **2** | How do you describe your stay in the bone marrow transplant unit? |
| **3** | **a)** Is there anything that you wished to have it done today, but were unable to do it? **If yes.**<br>**b)** What was it? |
| **4** | In your view what can be done to help you? |
| **5** | Anything else that you want to mention today? **If Yes.** Please explain/write it down. |