

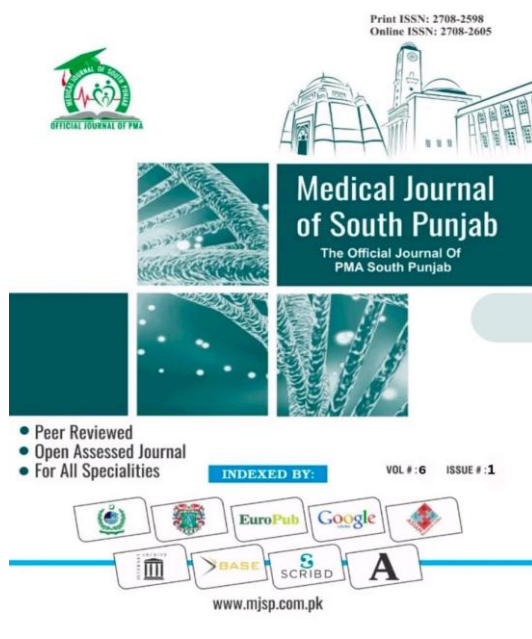
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## Coping Strategies of Patient's Undergoing Hematopoietic Stem Cell Transplantation in Pakistan

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## Coping Strategies of Patient's Undergoing Hematopoietic Stem Cell Transplantation in Pakistan

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### ABSTRACT

**Objective:** The study was conducted in the BMT unit at Quaternary Care Hospital in Pakistan, from February 2019 to April 2020.

**Methods:** 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 Kyngas process of inductive qualitative content analysis.

**Results:** The data analysis revealed seven categories, including “Spirituality and Faith,” “Familial and Social Support,” “Walking,” “Seeking and Sharing Information,” “Rationalization and Optimism,” “Remarks of Encouragement,” and “Days Count Down,” that describe the specified coping strategies used by the patients during HSCT.

**Conclusion:** The study findings revealed that the patients in Pakistan cope with physical and psychological hardships during HSCT primarily by relying on spiritual and religious practices. Moreover, the remarks of encouragement, familial and social support, walking, rationalization and optimism, and day’s countdown strategy also helped the patients preserve their emotional integrity.

**Keywords:** Bone Marrow Transplant, Coping Strategies, Hematopoietic Stem Cell Transplantation, Hematologic Malignancies, Qualitative Research.

## 1. INTRODUCTION

Cancer is one of preeminent cause of universal morbidity, and second major cause of universal mortality.<sup>1</sup> Among

cancer, the universal incidence rate of hematologic malignancies in Pakistan was approximately 1.19 million in 2018.<sup>2</sup> However, the mortality rate of hematologic malignancies was nearly 60% of the reported hematologic malignancy incidences in 2018 globally.<sup>2</sup> The only therapeutic modalities which are used in the treatment of hematologic malignancies are chemotherapy and bone marrow transplantation;<sup>3-5</sup> thus, limiting the scope of therapeutic treatment in their management. Moreover, these therapeutic modalities are extremely expensive that most of people lack access to the treatment of hematologic malignancies, which makes them the highly fatal morbidities. Hence, they are perceived as incurable and grave-yard illnesses in Pakistan.<sup>6</sup> This perception about hematologic malignancies interferes with psychological and emotional well-being of persons' and can induce psychological distress.<sup>6</sup>

Nearly 70,000 HSCT's were carried out in a year globally, and are expected to rise each year.<sup>7,8</sup> Nearly 1900 HSCT's have been carried out in Pakistan since its initiation at the national level in the year 1995.<sup>9</sup> Their number in Pakistan are also expected to rise each year because of subsequent increase in the incidences of hematologic malignancies and the number of stem cell transplant centers in the country.<sup>9</sup>

Several research studies have assessed the impact of HSCT on quality of life of patients' both during and following HSCT modality. These studies have identified worsen QOL in each domain of their well-being, predominantly in the physical, psychological and functional domains.<sup>3,11-14</sup> The commonly reported physical impacts during HSCT include nausea, vomiting, diarrhoea, fatigue, mouth sores, loss of appetite, hair loss, and infections.<sup>15</sup> The socio-economic impacts of HSCT include economic

hardship and social isolation.<sup>3,10,13,14</sup> All these potential impacts of HSCT affect the patients' psychological domain and provoke or exacerbate psychological distress. Consequently, it affects the quality of life and well-being of patients' across the HSCT trajectory.<sup>13,15</sup>

Some of the research studies explored the strategies used by the patients to cope with or overcome the psychological hardships associated with Hematologic disorders and HSCT. These studies have identified various strategies such as attribution, denial and avoidance, acceptance of fate, reliance on faith, seeking treatment, gathering information, seeking family and social support, comparing with something else, positive thinking and optimism, distracting one's attention, patience and resignation, and use of religious/spiritual resources.<sup>16-18</sup> But, none of the research study was found to have explored the coping strategies of HSCT patients within the context of Pakistan. The existing literature highlights that the patients' coping strategies may vary according to contextual factors, and emphasizes the need to conduct research studies in different countries.<sup>16,19</sup> Therefore, the current study was adapted to explore the coping strategies used by the patients' during HSCT, specifically in the context of Pakistan.

## 2. METHODOLOGY

The study was conducted in the Bone Marrow Transplant (BMT) unit at Quaternary Care Hospital in Pakistan, from February 2019 to April 2020. The BMT unit of selected health care facility contains 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.

Using the purposive sampling technique, a total of 11 patients admitted for the HSCT were recruited in this study with achievement of data saturation. The selection criteria were: Adult patients (aged 18 years and above) undergoing HSCT, 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.

Patients' were approached with the help of the departmental head nurse 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.

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.<sup>20</sup> Two researchers (Male and Female) who were not involved in the participants' care collected the data from the participants. 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 responses vividly without any recall bias. The participants were provided a list of questions (Table-1) 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 (Table-1) 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 activities 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 diary were translated and the audio-taped interviews were transcribed by a professional transcriber who had command on Urdu and English Languages before the analysis.

### 3. RESULTS

The data collection and analysis was carried out simultaneously to search for important concepts during data collection.<sup>21</sup> Data were content analyzed manually following the process of qualitative content analysis detailed by Elo and Kygnas.<sup>22</sup> 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 theme and sub-themes to data.

Anney's strategies for implementing Lincon and Guba's criteria were used in the research process to maintain trustworthiness.<sup>23</sup> 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.

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.

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 (%) |
|----------------------------------|---------------|----------------|
|                                  |               |                |
| <b>Gender</b>                    |               |                |
| Men                              | 7             | 63.6           |
| Women                            | 4             | 36.4           |
|                                  |               |                |
| <b>Age</b>                       |               |                |
| Young Adulthood (19-40 Years)    | 7             | 63.6           |
| Middle Adulthood (41-65 Years)   | 4             | 36.4           |
|                                  |               |                |
| <b>Marital Status</b>            |               |                |
| Married                          | 8             | 72.8           |
| Unmarried                        | 3             | 27.3           |
|                                  |               |                |
| <b>Education</b>                 |               |                |
| Middle Passed                    | 5             | 45.4           |
| Graduate and Above               | 6             | 54.6           |
|                                  |               |                |
| <b>Occupation and Profession</b> |               |                |
| 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 participants' average stay in the BMT unit was of 25 days.

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

| Variables | Frequency (n) | Percentage (%) |
|-----------|---------------|----------------|
|-----------|---------------|----------------|

|                     |   |      |
|---------------------|---|------|
|                     |   |      |
| <b>Disease</b>      |   |      |
| Malignant           | 7 | 63.6 |
| Non-Malignant       | 4 | 36.4 |
|                     |   |      |
| <b>Type of HSCT</b> |   |      |
| Autologous          | 5 | 45.4 |
| Allogeneic          | 5 | 45.4 |
| Haplo-Identical     | 1 | 9.2  |

#### 4. DISCUSSION

This study aimed to explore the patients' coping strategies while undergoing hematopoietic stem cell transplantation, in the context of Pakistan. Findings of this study revealed that all the participants' used various strategies to cope with isolation, and deal with the physical and psychological hardships across the HSCT trajectory. These strategies helped the patients to stay optimistic and hopeful, and keep themselves relaxed, motivated, and composed during HSCT.

Spirituality was the only ray of hope which helped the patients' in sailing through the physical and psychological hardships in each phase of HSCT. Unlike the previous study the participants' were not inclined to hear music.<sup>24</sup> This could be due to fact that all of them were Muslims, and they relied extensively on religious or spiritual practices. They believed that the life, death, disease, and health are controlled by the Almighty Allah. Medical treatment was viewed as source of help, but the ultimate cure and healing was rested with Almighty Allah. In their view, religious practices were one way to seek the Almighty mercy. This finding is in line with the previous researches involving Muslim population, which indicated that Muslim patients believes that all challenges, pains, and hardships comes from the God and there will be reward for it.<sup>16,17</sup> Moreover, Alaloul and colleagues further reported that the Muslim patients' extensively rely on religious practices to minimize the negative consequences of the HSCT procedure.<sup>17</sup>

The various religious practices performed by the patients' and their family members such as reciting and listening various Surah of Holy Quran, and then blowing it on the body have offered them the peace and comfort specifically in the pancytopenia phase of HSCT. The participants' believed that Holy Quran contains the cure for every disease, and they used various verses of Holy Quran for getting relief from various physical debilities. The participants' thus emphasized the inclusion of Quran Therapy in the treatment regimen of HSCT. Previous studies conducted in Iran and Saudi Arabia has also highlighted listening to the recitation of the Holy Quran vital for patients' healing and comforting their soul.<sup>17,18</sup>

The participants in the current study also used various spiritual rituals performed by them or their family members for healing during HSCT. These rituals include Praying, performing Istikhara, visiting Shrines, and eating and drinking Ajwa (specific type of dates) and Aab-e-Zam Zam (holy water). Praying or supplication was performed by the patients' and their family members to seek the help of God for their life protection and speedy recovery during HSCT. The patients in previous studies conducted in Saudi Arabia and Brazil also used Supplication or Praying to invoke God and seek His help and guidance.<sup>17,18</sup> However, the family members of patients in the current study additionally visited Shrines for Praying to seek the help of spiritual healers in invoking God for patients' cure and recovery from HSCT. Moreover, the patients' also performed Istikhara (a special type of prayer to seek the help of God in choosing the better of two things where one needs to choose one of them) to seek the help and guidance of God before opting for HSCT to guess the treatment success in the curing their disease. The patients' also used spiritual diet including Ajwa and Aab-e-Zam Zam for

the symptomatic relief and getting cure of their disease during HSCT.

In addition to spirituality, the remarks of encouragement used by the health care professionals' in the pancytopenia phase was also regarded one of the coping strategy by the participants'. They asserted that the encouraging remarks of the health care professionals' help the patients' to sail through the difficulties with courage and patience. This finding signifies the nurses' expertise and preparation for dealing with such patients'.

The presence of family and friends is reported as critical during HSCT as they provide courage and emotional support to patients' while undergoing HSCT.<sup>25</sup> This gives them the hope for cure and alleviates their psychological stress.<sup>3,24</sup> The participants' in the current study has also found the organized visits of their family and friends helpful for coping with the isolation constrains and emotional stress. Moreover, one family member was allowed to stay with the patient throughout their hospitalization. But, findings of the current study reveals that mere the presence of the family member with the patient does not always help to cope with the worries and isolation. The presence of family member helped the participants' if: (a) the accompanied person was of the desire of the patient (b) the accompanied person was bold and courageous. Considering this finding, the nurses may play strong role in identifying an appropriate family member in consultation with the patients', and training the family members for their interaction with the patients'.

Previous studies reported various activities which were used by the patients' in mitigating the isolation, such as walking, watching TV, using computers and smart phones, listening music and reading books.<sup>24,26</sup> The participants' in the current study also used some of these activities. However, concurrent with the study of

Walpole and colleagues, walking was most preferred activity among the participants' of the current study.<sup>26</sup> They found it helpful not only for maintaining their physical strength, but also for psychological freshness.

Existing literature emphasizes that the information and education about HSCT preserve the emotional integrity of patients', and keep them motivated in undergoing HSCT with hope and courage.<sup>12,16,24</sup> The participants' in the current study used various sources including former patients' and their families, health care professionals, and accessing the information on web for seeking the information related to HSCT. They recognized seeking and sharing of information pertinent to the procedural aspects of HSCT as helpful for their mental preparation, overcoming the fear, and staying relaxed. However, they desired for the detailed patients' based audio-visual information to develop the better understanding about the process of HSCT.

Although not explicitly reported in the literature, the participants' in the current study also used "days count down" as a strategy to cope with isolation. They have had the information about the expected duration of their treatment. Hence, they anticipate being freed from the cage of isolation by using the days count down.

## 5. CONCLUSION

This study explored the coping strategies of patients undergoing hematopoietic stem cell transplantation in Pakistan. Participants used various strategies to cope with isolation and physical and psychological hardships during HSCT. They used spiritual practices like reciting the Holy Quran and performing Istikhara to stay hopeful and motivated. They believed that the ultimate cure and healing rested with Allah. Spiritual rituals like praying, visiting shrines, and taking Ajwa and Aab-e-Zam Zam were also important. Participants also used health

care professional's remarks of encouragement, rationalization and optimism, familial and social support to cope with isolation and emotional stress. Walking was the most preferred activity for maintaining physical strength and psychological freshness. Information and education about HSCT were crucial for patients' emotional integrity and motivation. Participants sought information from former patients, their families, healthcare professionals, and the internet for better understanding. They also used the "days count down" strategy, anticipating being freed from isolation by knowing the expected treatment duration.

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