

## Views of patients undergo hematopoietic stem cell transplantation on their basic needs

Leila Sayadi<sup>1</sup>, Fateme Jafaraghaee<sup>2</sup>, Alireza Jeddian<sup>3</sup>, Mahboobe Kafaei Atrian<sup>4</sup>, Azam Akbari<sup>5</sup>, Farhood Tootoonchian<sup>6</sup>

<sup>1</sup>PhD candidate, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran.

<sup>2</sup>PhD candidate, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran.

<sup>3</sup>MD, Hematology-Oncology and stem cell transplantation research center, Shariati Hospital, Tehran University of Medical Sciences, Tehran, Iran.

<sup>4</sup>MSc, School of Nursing and Midwifery, Kashan University of Medical Science, Kashan, Iran.

<sup>5</sup>Msc Nursing, Guilan University of Medical Sciences, School of Nursing and Midwifery, Guilan, Iran.

<sup>6</sup>MD, Hematology-Oncology and stem cell transplantation research center, Shariati Hospital, Tehran University of Medical Sciences, Tehran, Iran.

**Corresponding author:** Fateme Jafaraghaee, PhD candidate, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran

Email: fja\_a80@yahoo.com

Tell: 09111361338

### Abstract

**Background:** Today, hematopoietic stem cells transplantation (HSCT) has been accepted as a therapeutic approach and is widely applied in many patients with disorders of hematopoietic systems or patients with malignancies. Concomitant use of this therapeutic approach with long term chemotherapeutic procedures and hospitalization requires special care. This study was conducted to examine basic needs of patients after HSCT.

**Methods:** In this study, 171 hospitalized patients were selected after transplantation, using convenience sampling method. They completed a questionnaire formulated on the basis of Yura and Walsh Theory of Basic Needs.

**Results:** Most of the needs reported in the areas of vital functions, functional health status, and reaction to functional health status were chills (76.8%), insomnia (68.5%), and dissatisfaction with changes of lifestyle/habits (53.6%), respectively. Furthermore, 94.1% of the patients were aware of their disease.

**Conclusion:** This study identified a broad spectrum of the needs in HSCT patients. Given the importance of determining needs to reach thorough nursing care, paying attention to the provided list can facilitate the achievement of the goals of the care program for these patients.

**Keywords:** Hematopoietic stem cell transplantation, Needs assessment.

Received: 2, Jan, 2013

Accepted: 24, Mar, 2013

### Introduction

Today, HSCT is considered as a standard treatment for many patients with congenital or acquired disorders of hematopoietic system or patients with malignancies. The use of this therapeutic approach has expanded over the past two decades and has been associated with massive technological changes<sup>1</sup>. In patients with malignancy, this therapeutic approach is performed to relieve the bone marrow from the fatal effects of chemotherapy and to allow more extensive chemotherapy for patients' recovery. Meanwhile, in patients with non-malignant diseases, this approach is used to replace an insufficient and damaged bone marrow<sup>2</sup>. HSCT is an invasive therapeutic approach which

develops specific physical, psychological, social, and emotional conditions in patients. Acceptance of this widespread invasive approach and its associated side effects, the need to be in isolation, prognosis, and uncertain conditions of patients develop a situation which makes the patients to be dependent on others, especially health care personnel, more than ever<sup>3</sup>. Understanding patients' basic needs and trying to obviate them are among the objectives of caregivers. New therapeutic and healthcare approaches have caused a considerable decrease in the risk of graft versus host disease, modification of the pre-graft chemotherapeutic regimens in order to reduce the side effects and toxicity, and early diagnosis of infections in

order to treat them with proper medications. All these measures lead to patients' more survival after transplantation<sup>4</sup>.

HSCT patients have special needs and problems and identifying and attending to these needs will have a significant impact on their care and recovery. That is why obviating patients' basic needs is the basis of care and the primary task is to identify them<sup>5, 6</sup>. Discussions and investigations on patients' needs must be regarded as key tools by caregivers in order to manage a physical, psychological, and social support<sup>7</sup>.

Maslow presented the most recognized categorization for human's basic needs in 1943. In his theory, Maslow determined the basic needs which were common in all humans regardless of their age, sex, race, social class, and health status. According to this theory, basic needs include physiologic needs, safety, belonging, respecting, and finally, self-actualization<sup>5, 6</sup>. Nursing theorists such as Henderson, Orlando, King, Roger, Abdullah, Yura & Walsh and Roper based their theories on human basic needs<sup>5, 6, 8</sup>. The disease-induced stress influences satisfaction of basic needs in different ways. Therefore, patients need to be helped and cared by others especially by nurses who play the main role in helping patients to meet their needs<sup>9-12</sup>.

The work overload and lack of appropriate management of staffing in different wards cause most of the attention to be paid to investigating and satisfying therapeutic needs and fulfilling medical orders. Therefore, many needs may be ignored that can result in unfavorable outcomes. This problem requires more attention in patients with more critical needs<sup>13</sup>.

A review of literature showed that little research has been done on the needs of patients admitted to HSCT wards. Most of the studies are based on determining needs of patients with cancers. A study in England reported the needs of 110 patients with various cancers. The patients had introduced 27 needs, of which, the top five needs including care, treatment, and health information were well satisfied by the medical team. The needs which were paid the least attention by the medical team included receiving information about genetics and changes in lifestyle, concerns about recurrence

or spread of the disease, and the need for parking one's automobile near medical centers. In the above study, sex (females), age (younger patients), having an informal caregiver, and the cancer site affected the patients' needs<sup>7</sup>.

Another study examined the unmet needs of 219 men with cancer. On average, 3 unmet needs were reported by the patients. The frequently reported unmet needs included physical needs (80%), daily life activities (53.3%), nutrition (46.1%), and psychological needs (32.5%). Younger men had physical, economical, and therapeutic unmet needs<sup>14</sup>. A qualitative study explored the met and unmet needs of terminal cancer patients. Results of the study showed that the most frequent unmet needs were symptom control (62.8%), occupational functioning (62.1%), and emotional support (51.7%). The least frequent needs reported by the patients included personal care, financial support, and emotional closeness<sup>15</sup>.

HSCT patients have too many problems in satisfying their needs especially physical and psychological needs which are vital for them, and also the high treatment costs due to long hospital stay in HSCT wards, which can be due to improper care. These problems can affect patients' recovery. If the provided care is aimed at resolving the problems and satisfying the needs based on identified problems of patients, it will have positive effects on patients, society, and also nursing personnel. This study was conducted to determine patients' view about their basic needs in HSCT wards. In this study, two fundamental questions were supposed to be answered: What are the basic needs of patients after HSCT? And, what are the most and the least frequently reported needs in patients admitted in HSCT wards?

## Methods

This descriptive cross-sectional study was performed in bone marrow transplantation (BMT) wards of Shariati hospital (Tehran-Iran). Shariati is a reference hospital and most of the patients throughout the country are referred to this hospital for HSCT. Mean of admission days calculated as 26.4 days. Mean number of nurses in each working shift was 4 and the caring approach based on team method was provided by registered nurses. The sample size

was calculated with 95% confidence and 171 patients were selected using convenience sampling method. The female and male patients with any occupation, level of education, and marital status were included in the study upon their consent. Before completing the questionnaire, patients read a written informed consent and signed it. All the participants were conscious and able to communicate verbally in Persian, and they were spending their last admission week in HSCT ward while completing the questionnaire.

The structured questionnaire was adopted from Louri et al. (1993) which was based on Yura and Walsh Theory of Basic Needs<sup>16</sup>. This instrument consisted of demographic information and questions relevant to the basic needs. The first part of the questionnaire included questions about some personal specifications and information such as sex, age, marital status, number of admission days in HSCT ward, level of education, and occupational status. The second part of the questionnaire involved 4 main areas as follows:

1. Vital functions: circulation, respiration, regulation of body temperature.
2. Functional health status: sleep, rest, nutrition, elimination, swallowing, mobility, skin, sexuality, sense perception, pain, cognitive process, and communication
3. Reaction to functional health status: feeling/emotions, relationships, personality, belief system/religious sense, coping, mental stability, activity and safety/compliance.
4. Environmental needs: information and hospital process.

There were 3 columns entitled Never, Sometimes, and Often in front of each question about vital functions, functional health status, and reaction to functional health status, and 2 responses of Yes and No in front of each question about environmental needs.

Validity of the questionnaire was confirmed by content validity. The calculated reliability based on the Spearman-Brown formula was 90%.

The data were gathered in autumn and winter 2010 by the first researcher. Once the preliminary details about the objective of the study were provided to the studied units, the questionnaire was submitted to them upon their consent to participate in the study. If a participant did not have adequate literacy or

was not willing to read the questionnaire, the researcher would read the questions and mark the answers.

In order to analyze the data, the data collected through the questionnaire were encoded and analyzed using descriptive statistics.

To analyze the needs statistically, Sometimes and Often choices were regarded as Yes option. In this respect, values obtained from Sometimes and Often choices were added together and the resulting value was put in Yes option. Problems that were experienced sometimes or often, at least by 50% of the patients were considered as basic needs.

The patients' view about the most and the least frequent needs and the table for frequency distribution on the basis of the highest percentage to the lowest percentage of needs that were experienced at least by 50% of the patients were determined in each area. The researchers observed ethical issues by obtaining permission from the head of the university hospital and the head of BMT wards to perform the study, providing full explanation of the objective of the study to the participants, making the participation voluntary, and keeping confidentiality and security of the information collected from the participants.

## Results

The results showed that most of the participants aged 18-28 years (50.6%), and 58% were male, 57.1% were married, 42.6% were employed, and 39.6% had high school diploma. Of the participants, 58.6% had undergone allogeneic transplantation and 66.6% of them were admitted in HSCT wards for 20 to 29 days. All the study samples underwent chemotherapy in the study wards. Specifications of the study sample are provided in detail in tables 1 and 2.

In this study, the patients introduced various needs in each area of the basic needs. They mentioned 6 major needs in the area of vital functions, 11 needs in the area of functional health status, and 4 major needs in the area of the reaction to functional health status. These needs and the relevant areas are described in table 3.

Number of unmet needs which were most frequently reported by the samples was 21. These needs were related to all three areas mostly to the functional health status. Table 4

shows the most frequent unmet needs of patients.

**Table 1: Demographics definitions**

	N (%)
<b>Age(year)</b>	
18-28	80(46.8)
29-39	50(29.2)
40-49	28(16.4)
50-59	7(4.1)
>60	6(3.5)
<b>Sex</b>	
male	98(57.3)
female	73(42.7)
<b>Marital stature</b>	
married	98(57.3)
single	70(40.9)
Widow	3(1.8)
<b>Employment</b>	
Unemployed	61(35.7)
Household	44(25.7)
Employed	66(38.6)
<b>Level of Education</b>	
Primary	56(32.6)
Diploma	69(40.4)
University	46(27)
<b>Type of disease</b>	
Acute myeloid	58(33.9)
Acute lymphocytic	42(24.6)
Chronic myeloid	9(5.3)
Hodgkin	24(14)
Lymphoma	25(14.6)
Myelodisplasia	3(1.8)
Multiple Myeloma	10(5.8)
<b>HSCT Type</b>	
allogenic	104(60.8)
autolog	67(39.2)
<b>Length of stay(day)</b>	
4 – 9	1(0.6)
10 – 19	9(5.3)
20 – 29	120(70.2)
30 - 39	34(19.9)
40 – 49	5(2.9)
50 – 59	2(1.1)

**Table 2: frequency and percentage of most reported HSCT patients' needs in main areas**

Frequency(%)
--------------

<b>Vital function</b>	
Circulation	
<b>Weakness</b>	128(76.2)
Respiration	
<b>Cough</b>	102(60.7)
Regulation of body temperature	
<b>Cold Feet</b>	91(53.8)
<b>Feeling cold generally</b>	98(59.4)
<b>Chills</b>	129(76.8)
<b>Night time perspiration</b>	92(55.8)
Functional health status	
Rest/sleep	
<b>Insomnia</b>	113(68.5)
<b>Fatigue</b>	112(67.5)
<b>Napping during the day</b>	126(76.4)
Nutrition	
<b>Anorexia</b>	150(89.8)
<b>Weight Loss</b>	121(76.1)
<b>Hunger</b>	110(66.3)
<b>Cracked Lips</b>	134(79.8)
Elimination	
<b>Diarrhea</b>	123(73.7)
Pain/Well Being	
<b>Pain</b>	94(57.3)
<b>Illness feeling</b>	112(66.7)
<b>Nausea and vomiting</b>	128(75.7)
Reaction to functional health status	
Personality	
<b>Changes of life style/ habits</b>	89(53.6)
Belief system/Religious sense	
<b>Have been punished with your illness</b>	86(51.5)
Coping	
<b>Difficulties in accepting present situation</b>	84(50.3)
Safety/Compliance	
<b>Difficulties in complying with the treatment</b>	81(50.3)

**Table 3: frequency and percentage of most reported HSCT patients' needs**

Unmet needs	N (%)
Anorexia	150(89.8)
cracked lips	134(79.8)
Chills	129(76.8)
weakness	128(76.2)
Nausea and vomiting	128(75.7)
Napping during the day	126(76.4)
Diarrhea	123(73.7)

Weight Loss	121(76.1)
Insomnia	113(68.5)
fatigue	112(67.5)
illness feeling	112(66.7)
hunger	110(66.3)
cough	102(60.7)
Feeling cold generally	98(59.4)
Pain	94(57.3)
Night time perspiration	92(55.8)
cold feet	91(53.8)
Changes of life style/your habits	89(53.6)
Have been punished with your illness	86(51.5)
Difficulty in accepting present situation	84(50.3)
Difficulties in complying with the treatment	81(50.3)

## Discussions

According to the patients' answers in the area of vital functions, the patients had problems with the physiological need for oxygenation such as weakness and coughing and with the need for temperature regulation; they had problems such as chills, feeling cold generally, night time perspiration, and cold feet. The incidence of these problems may be due to the high risk of infection in the patients that arise from the degree and duration of neutropenic period, suppression of the entire immune system, destroyed mucous barrier, central venous catheter and also the infectious condition of the donor. The patients are prone to be infected with bacterial and viral infections which cause fever, chills, coughs, and sweating<sup>4, 18-20</sup>. Cold feet and feeling cold generally are conditions that may happen due to taking antibiotic and disappearance of fever and also due to weakness.

In respect of rest/sleep, problems such as napping during the day, insomnia, and fatigue throughout the day were reported. It is obvious that these patients do not have a normal sleep due to anxiety and fear. Issues of concern affect the sleep process; therefore, sleep confounding factors must be limited during HSCT process. In this respect, lights and noises must be reduced. Moreover, fatigue is one of the prevalent side effects of HSCT<sup>4</sup>.

In respect of nutrition needs, anorexia, cracked lips, weight loss, and hunger were reported. Cracked lips may happen following mucositis which usually starts 48-72 hours after chemotherapy and sometimes lasts up to the recovery of neutropenic period<sup>4, 19</sup> or 21 days after BMT<sup>17</sup>. Mucositis affects oral and esophageal mucosa and causes enteritis and diarrhea and consequently, failure of food absorption. Mucositis can disturb the absorption of food, liquids, and medications, therefore, patients feel hungry and need to supply calories intravenously<sup>4, 19, 20</sup>. Mucositis, esophagitis, and diarrhea result in poor absorption of food and liquids from the gastrointestinal tract<sup>4</sup>. Other problems influencing patients' nutrition status were nausea and vomiting which were related to the feeling of well-being<sup>4, 17, 19, 20</sup>.

Diarrhea was reported as a problem for most of participants. In patients undergoing HSCT, diarrhea is secondary to toxic effects of chemotherapy and intestinal inflammation. The intestinal inflammation is exacerbated by infection and graft-versus-host disease (GVHD)<sup>4, 19</sup>. The diarrhea resulting from destruction of rapidly dividing cells of intestines occurs in 75% of patients undergoing chemotherapy<sup>17</sup>. Diarrhea occurs in almost 50-70% of BMT recipients and depends on several factors including long admission in the hospital and taking antibiotics for infections and can be a life-threatening toxicity<sup>17, 21</sup>.

In relation to pain/ well-being, the results showed that the study patients experienced problems such as nausea and vomiting, illness feeling, and pain. In these patients, chemotherapy and antibiotics, opioids, and other medications may cause nausea and vomiting. Moreover, GVHD in the upper GI is generally presented with nausea. Nausea and vomiting occur within 24 hours after chemotherapy and lasts up to 48 hours. Sometimes, they occur even more than 24 hours after chemotherapy, for example, 2-3 days later<sup>11</sup>. Herpes simplex virus infection, cytomegalovirus, adenovirus, helicobacter, and fungal infections are common among these patients that may exacerbate gastrointestinal complications and nausea and vomiting. Vomiting is usually accompanied with weight loss which influences satisfaction of patients' nutrition needs<sup>17, 19</sup>.

Furthermore, the patients felt pain that not only disturbs obviation of the need for release from pain, but also disturbs obviation of many basic needs of the patients. Researchers have shown that patients who receive new bone marrow cells may suffer pains around the kidneys and also may have prevalent feelings of illness, discomfort, and pain<sup>4</sup>.

In respect of belief system/religious sense related to the area of the reaction to functional health status, patients felt that they have been punished with their illness. Based on the expressions related to personality, patients' problem was changes in lifestyle/habits. A study on the stressful factors in patients undergoing BMT showed that the most stressful factors in those patients were concerns about changes in lifestyle that arouse from the long period of treatment<sup>22</sup>. This problem might be due to the isolation of patients in the ward, limited visits, inability to have visitors except through glass walls, and long admission in the ward.

The patients found it difficult to cope with the disease. Researchers have explained that acceptance or non-acceptance of the disease determines the coping styles with the disease and the incidence of physical symptoms like pain, nausea, and vomiting<sup>23</sup>. In this study, it is clear that not accepting the treatment plan or having problem with compliance played a role in failure to cope with the disease.

Another problem reported by the patients in respect of safety/compliance was the difficulty in complying with the treatment plan. Evidences show that when patients are aware of their diagnosed cancer or of the fact that they must undergo BMT, they will have problem in deciding about the treatment due to their high stress that has arisen from their condition<sup>23</sup>.

In respect of the needs for information, the results showed that although the participants were aware of their disease, they did not know how to care themselves.

It seemed that patients especially those undergoing BMT were more curious about their disease because of the criticality of the disease and consequently had more information in this regard and intended to know more about self-care in order to be recovered soon and prevent relapse of the disease.

## Conclusion

The present study was conducted to determine the basic needs of patients admitted to HSCT wards. This study showed that the patients admitted to these wards had various needs in areas of vital functions, functional health status, reaction to functional health status, and information. The results showed that the patients admitted to HSCT wards have specific needs which are due to long-term conditions of admission, severe condition of the disease, not much satisfactory prognosis, and staying away from family and friends. In this respect, paying more attention to patients' needs and executing intervention programs on the basis of a thorough understanding of the patients' basic needs can facilitate passing through this stage and yield more favorable outcomes for the patients. As determining the needs is one of the most important tasks of nurses, the results of this study is a guideline for nurses and caregivers in order to know the problems and needs of patients more accurately and be aware of the existing weaknesses and shortcomings and try to resolve them.

In this study, the needs were determined according to the patients' view. Some physical and psychological conditions influenced the way of answering the questions that could be considered as a limitation of the study. Moreover, the study was performed in one medical center. Although it is known as the most significant center for HSCT in Iran and most of the patients are referred to this center, limitation of the place of the study may have affected the results.

## Acknowledgement

The authors gratefully thank all the participants for their participation in this study. This study was part of a research supported by Islamic Azad University Lahijan Branch and Hematology and oncology research center in Tehran University of Medical Sciences. We would like to express our sincere gratitude to these centers.

## References

1. Gratwohl A, Baldomero H, Aljurf M, Pasquini MC, Bouzas LF, Yoshimi A, et al, 2010. Hematopoietic Stem Cell Transplantation: A Global Perspective. *JAMA*; 2010. 303(16): 1617-1624.

2. Saria, MG and Gosselin-Acomb, TK. Hematopoietic Stem Cell Transplantation: Implications for critical care nurses. *Clin J Oncol Nurs*; 2007. 11(1): 53-63.
3. Fife, BL., Huster, GA., Cornetta, KG., Kennedy, VN., Akard, LP and Broun, ER. Longitudinal Study of adaptation to the stress of bone marrow transplantation. *J Clin Oncol*; 2000. 18: 1539-1549
4. Cant AJ, Galloway A, Jackson G. *Practical Hematopoietic Stem Cell Transplantation*. Massachusetts: Blackwell; 2007.
5. Louri S, Lepisto M, Kappeli S. Patients Needs in Hospital : nurses and patients views. *J Adv Nurs*; 1997. 25(2):339-46.
6. Kim HS, Kollak I. *Nursing Theories Conceptual Philosophical Foundations* New York: Springer; 2006.
7. Morrison V, Henderson BJ, Zinovieff F, Davies G, Cartmell R, Hall A, et al. Common, important, and unmet needs of cancer outpatients. *Eur J Oncol Nurs*; 2012. 16: 115-123
8. Minshull J, Ross K, Turner J. The Human Needs Model of Nursing. *J Adv Nurs*; 1986. 11:643- 9.
9. Taylor G, Lillis G, Lemone P. *Fundamental of Nursing the Art and Science of Nursing Care*. Philadelphia: Lippincott; 2007.
10. Potter P, Perry A. *Fundamental of Nursing Concepts Process and Practice*. Philadelphia: Mosby; 2005.
11. Kozier B, et al. *Fundamental of Nursing*. New York: Addison Wesley; 2007.
12. Slater P, McCormack B. Determining older people's needs for care by Registered Nurses: the Nursing Needs Assessment Tool. *J Adv Nurs*; 2005. 52(6):601-8.
13. Sayadi L. Comparing the nurses and patients views about patients basic needs in coronary care units (Thesis), Guilan University of Medical Sciences; 1999.
14. Hwang SS, Chang VT, Cogswell J, Alejandro Y, Osenenko P, Morales E, et al. Study of unmet needs in symptomatic veterans with advanced cancer: incidence, independent predictors and unmet needs outcome model. *J pain symptom manage*; 2004. 28: 421-432.
15. Morasso G, Capelli M, Viterbori P, Leo SD, Alberisio A, Costantini M. Psychological and symptom distress in terminal ill cancer patients with met and unmet needs. *J pain symptom manage*; 1999. 17: 402-409.
16. Louri S, Lepisto M, Kappeli S. Needs of Finnish and Swiss Patients in Hospital. *Hoitotied*; 1995. 7(5):199-205.
17. Mousavi, A. *Nursing care Protocol in HSCT, inward, chemotherapy and discharge*. Research Centre of Hematology and Oncology, Tehran University of Medical Sciences; 2006.
18. Morris EC, Thomson KJ. Bone marrow and stem cell transplantation. *Transplantation and transfusion*; 2009. 37(3):168-71.
19. Antin JH, Raley DY. *Manual of Stem Cell and Bone Marrow Transplantation*. New York: Cambridge University Press; 2009.
20. Appelbaum FR, Forman SJ, Negrin RS, Blume KG. *Thomas' Hematopoietic Cell Transplantation*. USA: Wiley-Blackwell; 2004.
21. Bevans M, Tierney DK, Burgunder M, Castro K, Ford R, Miller M, et al. *Hematopoietic Stem Cell Transplantation Nursing: A Practice Variation Study*. *Oncol Nurs Forum*; 2009. 36(6).
22. Heinonen H, Volin L, Zevon MA, Uutela A, Barrick C, Ruutu T. Stress among allogeneic bone marrow transplantation patients. *Patient Educ Couns*; 2005. 5a6: 62-71
23. Carvalho ECd, Gonçalves PG, Bontempo APM, Soler VM. Interpersonal Needs Expressed by Patients during Bone Marrow Transplantation. *Cancer Nurs*; 2000. 23(6):462-7.