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Health Needs and Problems among Children Post Bone Marrow Transplantation

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Abstract

Background: Post the transplantation; children report high levels of somatic distress, mood disturbance, nausea and pain, and fatigue and malaise. In the first 4–6 months post BMT, children are still susceptible to infections and need to live with restrictions. **Aim:** This study aim was to assess health needs and problems among children post bone marrow transplantation. **Design:** Descriptive research design was utilized in this study. **Setting:** The outpatient clinic at Naser Institute- Egypt, this unit considered the biggest unit for BMT in Egypt. **Sample**: all children had BMT at 2015 which equal 72 children after discharge from BMT until one year. **Tools: :** Interviewing questionnaire consist of: children and caregivers socio-demographic characteristic, caregivers' general knowledge and practice about bone marrow transplantation, child health needs and problems post bone marrow transplantation. **Results:** Regarding child needs post bone marrow transplantation, near to half of them achieved their needs post bone marrow transplantation regarding safety and security at school followed by more than one third of them achieved their needs regarding personal hygiene then nutritional pattern and sleep pattern. Regarding children present health problems, near to one fifth of children have urinary system problems followed by digestive systems and skin problems, and then the minority them have cardiovascular system and behavioral and psychological problems. **Conclusion**: more than two third of the caregiver's have satisfactory knowledge level about bone marrow transplantation, all of them caring their children by correctly practices, the vast majority of the caregivers' have a good compliance toward follow-up system with the medical team, and there was no a statistically significant difference between caregiver's knowledge and socio-demographic characteristics of the caregivers except number of children in the family. **Recommendation:** Carrying out rehabilitation program for the patients and their caregivers to be performed properly during the rehabilitation period.

Key words: Health needs, Health problems, Post bone marrow transplantation**.**

Introduction

Bone marrow is a semi-solid tissue which may be found within the spongy or cancellous portions of bones. Human marrow produces approximately 500 billion blood cells per day, which join the systemic circulation via permeable vasculature sinusoids within the medullary cavity **(Arulrajah et al., 2012)**. All types of hematopoietic cells, including both myeloid and lymphoid lineages, are created in bone marrow; however, lymphoid cells must migrate to other lymphoid organs (e.g. thymus)

in order to complete maturation **(Elemam, Hannawiand, and Maghazachi, 2017).**

The total population in Egypt in 2007 is 75 million with only eight transplant centers performing about 210 transplants per year. The biggest center is at the Nasser Institute, which contains 20 cabins equipped with high efficiency particulate air (HEPA) filters, positive pressure and vertical laminar air flow. Around 170 transplants perform per year; 80% of the transplants are allogeneic and 20% autologous. The transplant rate in Egypt is about 2.8transplants per million, compared to an average of 30–42 transplants per million in developed countries **(Mahmoud et al., 2008)**.

The caregiver engages to develop a comprehensive care plan specific to the needs of the children. The caregiver seeks to understand the children with respect to health status, abilities, and priorities. Caregiver and chronic illness a 'caregiver' has been defined as an unpaid caregivers who helps children cope with disease or illness. Caregiver in the context of chronic illness has largely been studied in the fields of geriatrics and pediatrics **(Katie et al., 2016)**.

Caregiver of children post BMT are often required to deliver home-based interventions. They must continuously monitor their children's health, advocate for appropriate health care, be prepared for episodes of infection and other life threatening complications, attend frequent hospital appointments and convey information to health care professionals, caregiver, relatives and teachers. The ability of caregivers to manage care can impact on the children's child development and medical management (**Caocci , La Nasa, and D'Aloja, 2011)**.

Post the transplantation; children report high levels of somatic distress, mood disturbance, nausea and pain, and fatigue and malaise. In the first 4–6 months post BMT, children are still susceptible to infections and need to live with restrictions. BMT has a profound impact on the lives of children and caregiver, both pre BMT, during hospitalization and post transplantation. Caregivers are faced with the need to provide both physical and emotional care for their children during a long and stressful period **(Mccarthy et al., 2012)**.

Community health nurses are faced with challenges when assessing bio-psychosocial concerns post BMT. nurses responded that a lack of time was the greatest barrier to providing bio-psychosocial care in oncology settings If bio-psychosocial assessment is to become the standard of care, efficient tools are needed to screen children and documentation of this assessment needs to be incorporated into the medical record **(*Babalola* et al., 2017).** Bio-psychosocial care is important not only to children but also to the caregiver providing that care. Children consistently report having significant informational and emotional needs **(Heinze et al., 2015)**.

Significance of the study

The total number of transplants in Egypt performed till June 2007 is 1362; 80% of the cases are allogeneic and 20% autologous and the team is registered in the Center for International Blood and Marrow Transplant Research ***(Bone Marrow Transplantation,* 2010).** Children are now surviving hematopoietic stem-cell transplantation (HSCT) and require structured long-term follow-up care. The number of long-term survivors of childhood HSCT will continue to increase. According to **Kimberly et al., 2009 & Journal of hospice (2011)**

studied long-term outcomes of autologous hematopoietic-cell transplantation (HCT) for advanced Hodgkin (HL) and non-Hodgkin lymphoma (NHL) done at the Medical College of Wisconsin found that caregiver has been associated with improved survival at 1 year after transplantation (75%) versus patients without a dedicated caregiver (26%)

Aim of the study

The aim of this study was to assess health needs and problems among children post bone marrow transplantation through:

1. Identifying caregiver's knowledge about bone marrow transplantation.
2. Assessing caregiver's practices toward care the child post bone marrow transplantation.
3. Recognizing child health needs and problems.

Research Questions

1. Is there a relation between caregiver's knowledge and their socio demographic characteristics?
2. Is there a relation between caregiver's knowledge and practices toward care the child post bone marrow transplantation?

Subjects and Methods

Research design

A descriptive research design was utilized in this study to conduct the study aim.

Setting:

The study was conducted at Bone Marrow Transplantation (BMT) outpatient clinic at Naser Institute-Egypt, this unit considered the biggest unit for BMT in Egypt.

Subjects:

The subjects of this study composed of all children had BMT at 2015 which equal 72 children with their caregivers.

Inclusion criteria:

1. After discharge from BMT until one year.
2. Their age from 6-18 years.
3. Children accompanied by their caregivers which living with them in the same home.

Tool of data collection

one tool was used in this study for data collection

Interview questionnaire form was designed by the investigator and written in simple Arabic language based on scientific literature review to assess data about the following:

Part I: Children and Caregivers socio-demographic characteristic was used to assess socio-demographic characteristics (children characteristics as age, gender, school stage, and child ranking; caregivers' socio-demographic characteristics as age, relationships, level of education, occupation, number of children in the family, residence, and income).

Part II: **A: Caregivers' knowledge about bone marrow transplantation** to assess knowledge of caregivers about bone marrow transplantation. It included 20 questions such as meaning of bone marrow, site, types of bone marrow transplantation, and complication post bone marrow transplantation. **Caregivers' knowledge about autologous transplantation** to caregivers' who children do autologous transplantation, which included 5 questions such as the process, indication, stem cell separation, the advantage, and

the most common problems of autologous transplantation. Also, **Caregivers' knowledge about allogeneic transplantation** to caregivers' who children do allogeneic transplantation, which included 5 questions such as the concept, indication, stem cell separation, the advantage, the most common problems of autologous transplantation, and GVHD

❖ **Scoring system**

Each correct answer took one score and the wrong answer or do not know response took (zero). These scores were summed-up and converted into a percent score. If scores < 50% means incorrect knowledge, ≥ 50 % correct knowledge

Part III: Caregivers' practices toward care the child post bone marrow transplantation was to assess practices of caregivers about bone marrow transplantation. It included 52 questions such as poor appetite, vomiting and nausea, diarrhea, mouth ulcers and swallowing difficulties, changes in taste, prevent infection and food hygiene was measured by done or not done.

❖ **Scoring system:**

Each done practice took one score, and not done practice took (zero). It contained 52 questions. These scores were summed-up and converted into a percent score. If scores < 60% means not done practices, If scores ≥ 60% done correctly practices.

Part IV: Child needs and problems post bone marrow transplantation such as physical needs (included nutritional patterns (11 items), elimination pattern (2 items), personal hygiene (2 items), sleep habits (4 items), activity and movement (5 items)), safety and security needs (divided into at home (5 items), outside the house (2 items) and at school (4 items)) and psychological and social needs (included 11 items) while physical problems included digestive system (10 problems), respiratory system (6 problems), urinary system (5 problems), cardiovascular system (5 problems) central nervous system (4 problems) skin (6 problems) motor system (4 problems) and behavioral and psychological problems (6 problems).

❖ **Scoring system**

For health needs: each achieved needs took one scores, and didn't achieve needs took (zero). These scores were summed-up and converted into a percent score < 60% means not achieved, if scores ≥ 60% means achieved health needs.

While for health problems scoring was by using Likert scale never (zero), sometimes (1 score), always (2 scores). These scores were summed-up and converted into a percent score.

II. Operational Design:

The operational design for this study consisted of three phases, namely preparatory phase, pilot study, and fieldwork.

Preparatory Phase

This phase included reviewing of literature related to health needs and problems among children post bone marrow transplantation by using books, articles, journals, and internet. This served to develop the study tools for data collection. During this phase, the investigator also visited the selected places to get acquainted with the personnel and the study settings. Development of the tools was under supervisors' guidance and expert's opinions were considered.

Pilot Study

A pilot study was conducted on 10% of total sample of caregivers to test availability of study sample and clarity of the study tools. The pilot has also served to estimate the time needed for each subject to fill in the questions. According to the results of the pilot, some corrections and omissions of items were performed as needed. They were excluded in the main study subjects during the actual collection of data. The process of pilot study took one week (from 1/2 to 7/2) in Feb. 2016.

Validity and Reliability

The tools of the study were given to a group of five experts in the community health nursing at faculty of Nursing; Ain Shams University was elicited regarding the format, layout, consistency, accuracy, and relevancy of the tools.

Reliability of the tool was performed to confirm validity of tool and calculated statistically. The internal consistency measured to identify the extent to which the items of the tool measure the same concept and correlate with each other by Cronbach's alpha test were .70, .71, .689, and .714 respectively.

Fieldwork

The official permission was obtained from scientific research department, medical and nursing director of outpatient clinic of Naser Institute -Egypt. A letter was issued to them from the Faculty of Nursing, Ain-Shams University, explaining the aim of the study in order to obtain their permission and cooperation. The investigator first met with the caregivers of children post bone marrow transplantation attended to the outpatient clinic explained the purpose of the study after introducing himself. The caregivers were assured that information collected treated confidentially, and it used only for the purpose of the research. Then, individual interviewing was done after obtaining the consent to participate. The investigator was visiting the study setting 2 days / weekly **(Saturday, Sunday)** at morning shift 1- 2 caregiver / 2 days for 6 months from the period of 15 March, to 19 September 2017 to collect data and implement this study. The purposes of the study were explained to the caregiver and took 20-25 minutes nearly to complete the interview.

III. Administrative Design:

An official Approval obtained through an issued letter from the Dean of the Faculty of Nursing, Ain Shams University to Directors of the outpatient clinics of Naser Institute- Egypt. The investigator then met the hospital director and explained the purpose and the methods of the data collection.

Ethical Consideration

Verbal approval was obtained from the caregivers before inclusion in the study; a clear and simple explanation was given according to their level of understanding. They secured that all the gathered data was confidential and used for research purpose only. They informed also that they are allowed to choose to participate or not in the study and they have the right to withdraw from the study at any time and this is not affect the care or treatment they received from hospital.

IV. Statistical Design

Statistical analysis was done by using Statistical Package for the Social Science (SPSS 20.0). Quality control was done at the stages of coding and data entry. Data were presented by using descriptive statistics in the form of frequencies and percentage for qualitative variables. Chi square (X^2) was used to test the association between two qualitative variables or to detect differences between two or more proportions and the sample size large. Fisher's exact test used to test the association between two qualitative variables or to detect differences between two or more proportions and the sample size is small. Graphs were done for data visualization using Microsoft Excel. Inferential statistical tests of significance such as independent t-test were used to identify group differences and the relations among the study variables.

Results

Table (1): Distribution of children related to their socio-demographic characteristics (n = 72)

Socio-demographic characteristics of the child	No.(n= 72)	%
Age / year		
6 - < 12	42	58.3
12 - 18	30	41.7
Gender		
Male	43	59.7
Female	29	40.3
School stage		
Primary	40	55.6
Preparatory	12	16.7
Secondary	20	27.7
Child ranking		
Single child	12	16.7
First	18	25.0
Middle	19	26.4
The last	23	31.9

Table (1): showed that 58.3% of children aged between 6 - < 12 years, 59.7% of them were males, 55.6% of them in primary school and 31.9% of them were the last child in their family.

Table (2): Distribution of caregivers according to their Socio-demographic characteristics (n = 72).

Socio-demographic characteristics of the caregiver	No. (n= 72)	%
Age / year		
< 19 years	2	2.8
19 - < 29	16	22.2
29 - < 39	34	47.2
39 - < 49	20	27.8
Relationship		
Father	11	15.3
Mother	54	75.0
Another (grandmother/ father, uncle).	7	9.7
Level of education		
Can not read or write	11	15.3
Read and write	25	34.7
Average education	33	45.8
Higher education	3	4.2
Occupation		
Working	35	48.6
Not working	37	51.4
No. of children in the family		
One	12	16.7
Two	30	41.7
Three	24	33.3
Four	6	8.3
Residence		
Urban	49	68.1
Rural	23	31.9
Income		
Sufficient	9	12.5
Insufficient	63	87.5

Table (2): presented that 47.2% of caregivers aged were ranged between 29- < 39 years, 75.0% of caregivers were mothers, 45.8 % of them have average education, 51.4% not working, 41.7% of them had two child in their family, 68.1% of them lives in urban area and 87.5% of caregivers suffering from insufficient income

Figure (1): Distribution of the caregivers according to their total score of their knowledge (n = 72).

figure (1): illustrated that 68.1 % of caregivers had correct knowledge level about bone marrow transplantation and 31.9% of them had incorrect knowledge level.

Figure (2): Distribution of the caregivers according to their total score of their practices (n = 72).

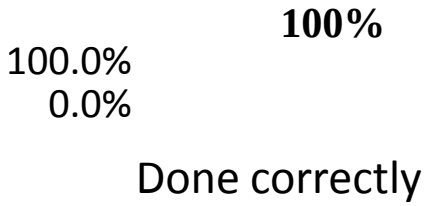

Figure (2): illustrated that 100% of caregivers had done correctly practice level for post-transplantation complications at home.

Table (3): Distribution of the caregiver according to achievement score level regarding to their child health needs post bone marrow transplantation (n = 72).

Needs	no.	%
Physical needs		
Nutrition pattern	26	36.1
Elimination pattern	8	11.1
Personal hygiene	28	39.0
Sleep pattern	26	36.1
Activity and movement	22	30.6
Safety and security needs		
At home	19	26.4
Outside the house	12	16.7
At school	30	41.7
Social and psychological needs	4	5.6

Table (3): demonstrated that 41.7% of child achieved their needs post bone marrow transplantation regarding safety and security at school followed by 39.0% of them achieved their needs regarding personal hygiene then 36.1% related to nutritional pattern and sleep pattern.

Table (4): Distribution of the children according to their present health problem (n = 72).

Problems	No.	%
(A)- Physical Problems		
- Problems of digestive system	12	16.7
- Respiratory problems	3	4.2
- Urinary system problems	14	19.4
- Problems of the cardiovascular system	11	15.3
- Problems of the central nervous system	1	1.4
- Skin problems	12	16.7
- Problems of the motor system	4	5.6
(B)- Behavioral and psychological problems	11	15.3

Table (4): indicated that 19.4% of children had urinary system problems followed by 16.7% of them had digestive systems and skin problems, and then 15.3% of them had cardiovascular system and behavioral and psychological problems.

Table (5): Relation between caregiver's knowledge and their socio-demographic characteristics (n = 72).

socio-demographic characteristics of the caregiver	Incorrect (n= 23)		Correct (n= 49)		Fisher Exact Test	*P* – value
	No.	%	No.	%		
< 19 years						
19 - < 29	0	.0	2	4.1	4.924	.177 NS
29 - < 39	4	17.4	12	24.5		
39 - < 49	15	65.2	19	38.8		
Relationship	4	17.4	16	32.7		
Father						
Mother	4	17.4	7	14.3	1.151	.562 NS
Another (grandmother/ father, uncle).	18	78.3	36	73.5		
Level of education	1	4.3	6	12.2		
Not read or write						
Read and write	5	21.7	6	12.2	4.815	.186 NS
Average education	5	21.7	20	40.8		
Higher education	13	56.5	20	40.8		
Occupation	0	.0	3	6.1		
Working						
Not working	10	43.5	25	51.0	X^2 .356	.550 NS
No. of children in the family	13	56.5	24	49.0		
One						
Two	2	8.7	10	20.4	20.635	.000**
Three	5	21.7	25	51.0		
Four	16	69.6	8	16.3		
Residence	0	.0	6	12.2		
Urban						
Rural	19	82.6	30	61.2	X^2 3.292	.070 NS
Income	4	17.4	19	38.8		
Sufficient						
Insufficient	19	82.6	44	89.8	X^2 .739	.390 NS
< 19 years	4	17.4	5	10.2		

NS= not statistical significant * P – value ≤ 0.05 ** P – value ≤ 0.01

Table (5): presented that there was no a statistically significant difference between caregiver's knowledge and socio-demographic characteristics of the caregivers except withnnumber of children in the family in which P – value ≤ 0.000.

Table (6): Relation between caregiver's knowledge and practices toward care the child post bone marrow transplantation

Total practice score	Total knowledge score		t	*P* - value
	Mean ± SD			
	Incorrect(n= 23)	Correct(n= 49)		
Practice score	43.9 ± 2.2	44.8 ± 2.9	1.288	.202 NS

NS= not statistical significant

Table (6): presented that there was no statistically significant difference between mean scores of caregiver's knowledge and total practice score toward care the child post bone marrow transplantation in which P – value ≤ 0.202.

Discussion

Bone marrow transplantation (BMT) is an aggressive medical procedure associated with high mortality and morbidity rates. For children and adolescents with some life-threatening pediatric cancers, blood diseases, and metabolic disorders, BMT may represent the best or the only viable treatment option after disease relapse and failure of more conventional treatments ***(Davidov et al., 2018)***.

Regarding socio-demographic characteristics of children **(Table 1)** the present study showed that more than half of children were male, aged

between 6 - < 12 years, in primary school and slightly less than one third of them were the last child in their family.

Regarding socio-demographic characteristics of caregivers the study results illustrated that less than half of them aged between 29- < 39 years and had average education. Also the three quarters of them were mothers; slightly more than half of them not working, slightly more than two fifth of them had two child in their family, more than two third of them lives in urban area and the majority of them their income were insufficient. The mothers had a sense of responsibility than peers especially regarding caring of their children.

Regarding the total knowledge of the caregivers about bone marrow transplantation **(Figure 1)** the present study illustrated that more than two third of the caregivers had correct knowledge level about bone marrow transplantation and less than one third of them have incorrect knowledge level. This may be due to good health education about the bone marrow transplantation before going to do it. This result comes in the line with those of the study of ***Yen-Michael and Cushing***, (***2016)*** in a very recent study who discussed autologous stem cell mobilization and collection done at Weill Cornell Medical College, USA found that their caregivers had to join rehabilitation program before transplantation and had to know the majority of what is related to bone marrow transplantation and rehabilitation and how to handle the complications, they must be aware and have adequate knowledge.

Concerning the total practice of the caregivers about bone marrow transplantation **(Figure 2)** the present study illustrated that all of caregivers had done correctly practice level for post-transplantation complications at home.

Regarding caregiver achievement score level regarding child needs post bone marrow transplantation

(Table 3) the present study showed that slightly more than two fifth of child achieved their needs post bone marrow transplantation regarding safety and security at school followed by slightly less than two fifth of them achieved their needs regarding personal hygiene then more than one third related to nutritional pattern and sleep pattern. This result were confirmed with ***Ragheb et al. (2016),*** who stated that 36.7% of the patient were independent to do activity of daily living. and contraindicated with ***Mohamed, et al, (2015)*** who studied care provided to patients who underwent autologous bone marrow transpantation during the rehabilitation period and mentioned that about two third of the total patients were totally depended on caregiver in performing of daily living activity while one third were partially depended on the caregivers.

Regarding child health problem **(Table 4)** the present study indicated that less than one fifth of children had problems in one or more of the following system "urinary system, digestive systems and skin, and cardiovascular system and behavioral and psychological status. This result come in the line with ***Mohamed, et al, (2015)*** who stated that Less than one fifth from the total study sample suffered tachycardia, about half hyperthermia, about one third tachypnea and about one third hypertension

Regarding the relation between caregiver's knowledge and their socio-demographic characteristics **(Table 5)** the present study showed that there no a statistically significant difference between caregiver's knowledge and socio-demographic characteristics of the caregivers except number of children in the family in which P – value ≤ 0.000. This attributed to small number of study sample had received complete health education and information about the bone marrow transplantation and its preparation.

Regarding the relation between caregiver's knowledge and practices toward care the child post bone marrow transplantation **(Table 6)** the present study illustrated that there was no statistically significant difference between mean scores of caregiver's knowledge and total practice score toward care the child post bone marrow transplantation in which P – value $\leq$ 0.202. this result were contradicted with ***Ragheb et al.(2016)*** who mentioned that there were highly statistical significant differences between pre and post program of family caregivers" practices related to care for diarrhea/constipation, anemia, avoidance of infection, fever, stomatitis and management of pain. Also this result come inconsistent with ***Ahmed et al, (2016)*** who studied about follow up care for 100 family caregivers and their patients with leukemia undergoing in Egypt, they reported that there was highly statistically significant difference related to caring of their side effects of chemotherapy pre, post and follow up program implementation.

Conclusion

Based on the findings, of the current study the following conclusions can be drawn: more than two third of the caregiver's have satisfactory knowledge level about bone marrow transplantation and all of them caring their children by correctly practices. Also, slightly more than two fifth of child achieved their needs post bone marrow transplantation regarding safety and security at school followed by slightly less than two fifth of them achieved their needs regarding personal hygiene then more than one third related to nutritional pattern and sleep pattern and less than one fifth of children had problems in one or more of the following system "urinary system, digestive systems and skin, and cardiovascular system and behavioral and psychological status.

In additional, there no a statistically significant difference between caregiver's knowledge and socio-demographic characteristics of the caregivers except number of children in the and no statistically significant difference between mean scores of caregiver's knowledge and total practice score toward care the child post bone marrow transplantation. Also, there was no a statistically significant difference between caregiver's knowledge and socio-demographic characteristics of the caregivers except number of children in the family.

Recommendations

- Carrying out rehabilitation program for the patients and their caregivers to be performed properly during the rehabilitation period at caner hospitals.
- A need for a written discharge plan including a resource manual for family members and availability of phone line number to contact in emergency situations.

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