

Health Needs and Problems among Children Post Bone Marrow Transplantation

Thesis

Submitted for the requirement of Master Degree in Nursing
Science “Community Health Nursing”

By

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(B.Sc Nursing, 2010)

Faculty of Nursing
Ain Shams University
2018

Health Needs and Problems among Children Post Bone Marrow Transplantation

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2018



Acknowledgments

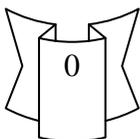
Thanks to our merciful Allah for the various and numerous blessing, best owed for us. Thanks to Allah for once more for enabling me to prepare this thesis, hoping that it may be useful for all those who will need it.

*I would like to express my deep thanks and gratitude to **Prof. Seham Guirguis Ragheb**, Professor of Community Health Nursing, Faculty of Nursing, Ain-shams University, for her kind, supervision, sincere help and patient, in conducting this work. She gives me a lot of valuable time in tabulating and discussing the results.*

*Words are not enough to convey my sincerity towards **dr. Shimaa Fathy Mikky** Lecturer of Community Health Nursing, Faculty of Nursing, Ain-shams University, for her help, support, creative comments and generous advice during the conduction of this thesis.*

I would like to express my gratitude to all who helped me in fulfilling my aims and carrying out my responsibilities towards research especially the caregivers and thier children and health team in out patients clinics at Naser Institute- Egypt.

Hasan Khaled Hasan.



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List of Abbreviations

BMT	Bone Marrow Transplantation
GVHD	Graft-Versus Host Disease
GVT	Graft-Versus-Tumor
HRQoL	Health-Related Quality Of Life
HSCs	Hematopoietic Stem Cells
HSCT	Hematopoietic Stem Cell Transplantation
HSV	Herpes Simples Virus
MSCs	Mesenchymal Stem Cells
MUDs	Matched Unrelated Donors
PBSCs	Peripheral Blood Stem Cells
PTSD	Posttraumatic Stress Disorder
VZV	Varicella Zoster Virus
CMV	Cucumber Mosaic Virus
EBV	Epstein Barr Virus
HRQoL	Health Related Quality of Life



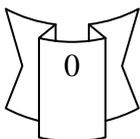
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By

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Background: Post Bone Marrow transplantation; children report high levels of somatic distress, mood disturbance, nausea and pain, and fatigue and malaise. In the first 4–6 months post bone marrow transplantation, children are still susceptible to infections and need to live with restrictions. 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. **Sample:** all children had bone marrow transplantation at 2016 which equal 72 children after discharge from bone marrow transplantation 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 had urinary system problems followed by digestive systems and skin problems. **Conclusion:** more than two third of the caregiver's had satisfactory knowledge level, all of them caring their children by correctly practices, the vast majority of the caregivers' had 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 at cancer hospitals such as, 57357 Hospital, and the National Cancer Institute in Cairo.

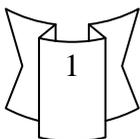
Keywords: Health needs, Health problems, Post bone marrow transplantation



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 (**Harrison, et al., 2015**).

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. A ‘caregiver’ has been defined as an unpaid child 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**).

Caregivers have a vital role in supporting people with managing their medications at home. A child living post BMT may have a complex medication regime with multiple medications and doses at different times of the day. Caregivers may assist in managing medications in many ways. Medications might include tablet, but also cremes, injections or liquid medications (**Cohen et al., 2013**).

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 et al., 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 psychosocial concerns post BMT. Nurses responded that a lack of time was the greatest barrier to providing psychosocial care in oncology settings. If 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 (**Bresters et al., 2017**). 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 transplant rate in Egypt is about 2.8 transplants per million, compared to an average of 30–42 transplants per million in developed countries. The total number of transplants 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. Caregiver burden is a vital investment in one of the most important allies to the healthcare team during the BMT process. The presence of a caregiver has been associated with improved survival at 1 year after transplantation (75%) versus patients without a



dedicated caregiver (26%) (Kimberiy et al., 2009 & **Journal of hospice 2011**).

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.
4. Assessing caregiver's compliance related to follow up system.
5. Assessing home environment.

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?
3. Is there a relation between caregiver's knowledge and compliance to follow up system?
4. Is there a relation between caregiver's practices and health needs & problems among children post bone marrow transplantation?