

## Rehabilitation Program for Caregivers about Patients' Post Autologous Bone Marrow Transplantation

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**Abstract:** Autologous stem cell transplant can be a curative therapy to restore normal hematopoiesis after myeloablative treatments in patients with malignancies.

**Aim:** To evaluate the effect of rehabilitation program for caregivers about patients' post autologous bone marrow transplantation

**Research Design:** A quasi-experimental design was used.

**Setting:** The study was conducted in Sheikh Zayed Specialized Hospital at Oncology Outpatient Clinic of Bone Marrow Transplantation Unit.

**Sample:** A purposive sample comprised; a total number of 60 patients, their age ranged from 21 to 50 years, free from any other chronic disease and the caregivers are living with the patients in the same home.

**Tools:** Two tools were used for data collection.

**First tool:** An interviewing autologous bone marrow transplantation questionnaire for the patients and their caregivers was divided into five parts;

**Including:** Socio-demographic data, knowledge of caregivers regarding autologous bone marrow transplant and side effect of chemotherapy, family caregivers' practices according to their providing care related to post bone marrow transplantation, signs and symptoms, activities of daily living for patients and home environmental sanitation for the patients.

**Second tool:** deals with physical examination assessment of the patients from head to toe.

**Results:** 61.7% of patients aged 30- <40 years, and 68.3 % were female. Regarding the type of relationship with the patients, 48.3% were the mother, 58.3% of patients who underwent autologous bone marrow transplantation had a sanitary environment and there were highly statistically significant differences between caregivers' knowledge and practices pre/post program.

**Conclusion:** There were highly statistically significant differences between family caregivers' total knowledge, their practices, as well as their total caregivers' knowledge, practices and patients' independency level pre/post rehabilitation program. .

**Recommendations:** Counseling for family caregivers of patients who underwent autologous bone marrow transplantation and 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:** Autologous bone marrow transplantation, family caregivers, rehabilitation program, sanitary environment, activities of daily living and instrumental daily living activities.

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### I. Introduction

Bone marrow is the spongy liquid tissue in the center of some bones. It has a rich supply of stem cells, and its main job is to make blood cells that circulate in your body. The bones of the pelvis (hip) have the most marrow and contain large numbers of stem cells. For this reason, cells from the pelvic bone are used most often for a bone marrow transplant. Enough marrow must be removed to collect a large number of healthy stem cells.<sup>[1]</sup>

Stem cells make the three main types of blood cells: red blood cells, white blood cells, and platelets, there is a need for all of these types of blood cells to keep alive. For these blood cells to do their jobs, there is a need to have enough of each type in blood. 'Transplant' means taking tissue from one place and putting it somewhere else. In this case the cells are collected from patient blood, frozen and stored, and then given back to him after the high-dose treatment. There are three types of transplants a patient can receive, depending upon where the stem cells come from Allogeneic transplant, the donor is someone other than the patient. It can be a family member or someone other than a family member. An umbilical cord blood transplant is also a type of allogeneic transplant. In autologous transplant, the donor is the patient himself. They are returned to the patient

after the chemotherapy is given for the underlying disease. Syngeneic transplant in which the donor is an identical twin with a genetically identical bone marrow. This is also considered an 'allogeneic' transplant.<sup>[2]. [3]</sup>

Autologous stem cell transplant can be a curative therapy to restore normal hematopoiesis after myeloablative treatments in patients with lymphocytic malignancies, such as multiple myeloma (MM), non-Hodgkin lymphoma (NHL), Hodgkin lymphoma, and other malignancies. Mobilized hematopoietic stem/progenitor cells (HSPCs) collected by apheresis are the predominant source of stem cells for autologous and allogeneic transplant because of their higher yield and the decreased procedural risk compared with bone marrow (BM) harvest. Patients who have had many cycles of high-dose chemotherapy and/or radiation may have a significantly reduced BM reserve and a poor autologous yield after attempted stem cell mobilization.<sup>[4]</sup>

After discharge, in the rehabilitation period, some patients have physical or mental health problems. These ongoing needs must be managed by following up in the hospital by health team and at home by caregiver as family support which is very important. Transplant patients are still followed closely during rehabilitation. Patient may need weekly exams along with things like blood tests, chest X-rays, bone marrow tests, or spinal taps. During early rehabilitation, patient also might need blood and platelet transfusions, antibiotics, or other treatments. The exams are frequent at first, may be even every day, but will be needed less often if things are going well. It can take 6 to 12 months, or even longer, for blood counts to get close to normal and patient immune system to work well. Some problems might show up even a year or more after the stem cells are infused. Physical problems are usually from the chemo and/or radiation treatment.<sup>[5]</sup>

Informal caregivers (ICs), also referred to as family caregivers in the extent literature, include parents, partners, siblings, children and friends who are intimately involved in the patient's care and play a critical role in the recovery from hematopoietic stem cell transplantation (HSCT). In the majority of cases, an IC is a required and critical element of the HSCT process. ICs of patients receiving outpatient HSCTs prepare their homes to avoid potential infectious complications, and are responsible for the administration of medications, monitoring of vital signs, and intake and output of fluids. Additionally, while ICs of patients receiving inpatient HSCTs are often tasked with the transportation of the patient to the treatment center multiple times a week after discharge, ICs of outpatient HSCT patients may be required to facilitate daily visits.<sup>[6]</sup>

Uncertainty and need for more information were major underlying themes noted across the early bone marrow transplants (BMTs) trajectory. Caregivers reported feeling overwhelmed and juggling multiple roles, including (a) "interpreter," which included obtaining and translating medical information to their partner, family, and social network; (b) "organizer," which the most challenging aspects of their role were to "be strong" for included arranging and coordinating medical appointments (pre- and post-BMT) for the patient, but also juggling the needs of immediate and extended family members; and (c) "clinician," which included assessing and identifying changes in their significant other, with many reporting that they had to be "vigilant" about or "on top of" any changes. Caregivers also reported "everyone and finding balance".<sup>[7]</sup>

### **1. 1. Significance of the Study:**

Approximately 50 000 people undergo BMTs each year worldwide. With the move to more outpatient and home care, family caregivers are playing an ever-increasing role. However, there is little information regarding the needs and well-being of caregivers of individuals undergoing BMT. In Egypt, according to medical records of Sheikh Zayed Specialized Hospital, (2013). 390 cases of autologous transplant were carried out during the last 3 years in bone marrow transplantation unit. 75% of individuals receiving autologous transplants were between the ages of 21-50 years. The main source of support for patients is often their family as having access to this support which is important for patient outcomes.<sup>[8]</sup>

The community health nurse role includes assessing patients' needs to identify expectations of the patients and anticipate impact on family, providing psychosocial support and education during rehabilitation. Assessment and interventions are needed to support the sexual dysfunction and infertility as are major concern, monitoring the patient's condition with thorough physical assessments, assisting the patients and families to take responsibility for establishing, maintaining, and improving their health by adding to their knowledge and ability to influence health determinants. Specific information on how family can carry out these roles during rehabilitation encourages the adoption of health beliefs, attitudes, and behaviors that contribute to the overall health of the population.<sup>[9]</sup>

### **1. 2. Aim of the study:**

The aim of this study was to evaluate the effect of rehabilitation program for caregivers about patients' post autologous bone marrow transplantation through:

- 1- Assessing family caregivers' knowledge and practices about autologous bone marrow transplantation.
- 2- Assessing patients regarding dependency level.
- 3- Designing and implementing rehabilitation program for caregivers' and patients' needs.
- 4- Evaluating the effect of the rehabilitation program on improving caregivers' knowledge, and practices related to autologous bone marrow transplantation.

### **1.3. Research hypothesis:**

The rehabilitation program will improve caregivers' knowledge and practices related to autologous bone marrow transplantation and also restore dependency level of patients toward daily living activities.

## **II. Subjects and Methods**

**2.1. Research design:** A quasi-experimental design was used with pre, post tests in order to achieve the aim of the study.

**2.2. Setting:** This study was conducted in the Sheikh Zayed Specialized Hospital at Oncology Clinic of Bone Marrow Transplantation Unit, Six October Governorate, Egypt. This clinic is considered the biggest clinic for autologous BMT in Egypt.

**2.3. Subjects:** A purposive sample was selected; the total number of patients post autologous bone marrow transplantation attending to the Oncology Clinic at the selected setting in the year 2015 was (1200). The total number of the sample included in the study represented 5%, i.e. equal 60 patients with their caregivers attending within 5 months at follow up clinic, according to inclusive criteria: Patient's age between 21-50 years, both male and female, free from any other chronic disease and the caregivers are living with the patients in the same home. In addition, 7 patients and their direct caregivers were chosen randomly to conduct the pilot study. The interview was arranged after the first follow up to the Oncology Clinic.

### **2.4. Study Tools:**

Two tools were used in this study for data collection:

**First tool:** An interviewing autologous bone marrow transplantation questionnaire developed by the researchers from review of literature using magazines, it was used pre/post implementation of the program, which included the following parts:

**Part I - a.** It was used to assess the socio-demographic characteristics of the patient. It included 7 closed-ended questions regarding age, gender, educational level, occupation, marital status, income and treatment cost.

**b.** It was used to assess the socio-demographic characteristics of the caregivers. It included 9 closed-ended questions regarding age, gender, educational level, occupation, marital status, place of accommodation, residence, relative degree, time of care giving and type of family.

**Part II -** Family caregivers' knowledge about post autologous bone marrow transplantation and side effects of the chemotherapy, it included the meaning of autologous bone marrow transplantation, types, medical investigations, dietary requirements, post-transplant medications, side effect of chemotherapy.

**Scoring system for knowledge:** The score ranged in multiple choice questions and open-ended questions from zero to one; correct = 1 and incorrect = 0. The total score for all items was 9 and categorized into three levels as followings: Poor 0-3, Average 4-6 and Good 7-9. The caregivers' knowledge was considered satisfactory if the percent score was 50% or more and unsatisfactory if the score was less than 50%.

**Part III -** Family caregivers' practices according to their provided care related to post bone marrow transplantation signs and symptoms such as; vomiting, diarrhea/ constipation, anemia, infection, fever, bleeding, stomatitis and pain.

**Scoring system for practice:** The scoring system ranged from one score for the done, and zero for not done. The total grades were 36 for 36 statements equal 100%. The caregivers' practices were categorized into done practices if the percent score was 60% or more, and not done if less than 60%.

**Part IV -** Assessing environmental sanitation for the patient at home through asking questions:

It included items related to isolated room, ventilation, lighting, walls and floor of the room, bathroom, changing bed sheet, sewage, utensils, smoking and pest free method.

**Scoring system for environmental sanitation:** The items were categorized into low level, moderate level, and high level and scored as 0, 1, and 2, respectively. For each part, the scores of the items were summed-up and the total scores were 68 grades 34 items, equal 100%. The home environment is considered sanitary if the percent score was 60% or more and unsanitary if percent less than 60%.

**Part V - Activities of daily living and instrumental daily living activities scale for the patients** as regards; hygiene, dressing, housekeeping, toileting, transferring, sleeping, shopping, eating, medication administration, following up in the clinic and following doctor instructions. This scale was adopted from **Katz**,<sup>[10]</sup> and modified by the researchers.

**Scoring system:** It was graded according to daily activities of the patients post autologous bone marrow transplantation. The score ranged from zero to 3, Independent = 3, Partial assistance = 2, Dependent = 1. The total score for 24 items was 72 and categorized into 3 levels as following; Independent = 49- 72, Partial assistance = 25-48 and Dependent = 0-24

**Second Tool: Physical examination for the patients (pre program):** Assessment of body mass index, calculated according to the following equation:  $BMI = \text{weight (kg)} / \text{Height (m)}^2$ .

**Scoring system of body mass index according to Siston,**<sup>[11]</sup>

Body mass index was categorized as follow: Underweight <18.5, Normal weight 18.5–25, Overweight 25–30 and Obese >30.

As regards the autologous patients from head to toe using form adopted from of **Bickley & Szilagyi**,<sup>[12]</sup> **It include** : Assessing vital signs, body examination from head to toe, by using inspection, palpation, percussion and auscultation.

Normal range for vital signs: Pulse: 60-100 b/m, Respiration: 14-24 b/m, Blood pressure: 120/80 mm/Hg ± 20 and Temperature: 36.5-37.5 C.

**Validity and Reliability:** The validity of the tools was ascertained by five experts, (three of them were community health nursing, faculty of nursing and another two were oncologist, faculty of medicine), Ain Shames University who reviewed the instruments for content accuracy. The reliability test of translated version was established by using the Cronbach alpha and Pearson correlation which showed good internal consistency construct validity Cronbach alpha = (0.887).

### **2.5. Pilot study:**

A pilot study was carried out before starting data collection, and 7 patients & their care givers were chosen randomly from previous mentioned setting. It was done to estimate the time required for filling out the tools and also to check the clarity, applicability, relevance of the questions. Based on the results of the pilot study, the necessary modifications were done; these patients were excluded from the study.

### **2.6. Operational Design:**

#### **Field work:**

- An official permission to conduct the study was obtained from the Director of Sheikh Zayed Specialized Hospital. In order to obtain their agreement and cooperation, a formal letter was issued by the Dean of Faculty of Nursing, Ain Shams University, explaining the aim of the study.
- Preparation of data collection tools was carried out over a period of one month beginning from end of August 2015 to end of September 2015, after being revised from experts to test their validity.
- The application of the rehabilitation program, done by the researchers, lasted for 6 months from the beginning of October 2015 to end of March 2016; three days/week (Sundays, Tuesdays & Wednesdays), in the previous unit from 9.00 a.m. to 2.00 p.m. The questionnaire took about 45 minutes to be filled in by the researchers and included about (8-15 patients & their care givers). The rehabilitation program was applied for caregivers and for the patients; they were met few times because they had low immunity and to avoid contact with others. The intervention was applied in five sessions (2 sessions for theory and 3 sessions for practices).

## **III. Nursing Intervention Program Development Phases**

**Phase 1:** A pre-program assessment tool, using the previous interviewing questionnaire for data collection from caregivers and physical examination for the patients. This phase aimed at improving caregivers' knowledge and practices toward autologous bone marrow transplantation at home during the rehabilitation period and patients' dependency level

**Phase 2:** The rehabilitation program was designed by the researchers based on results obtained from the pre-program assessment tools. It was revised and modified based on related literature, and socio-demographic aspects of the study sample to cover family caregivers' knowledge and practices toward their patients having autologous bone marrow transplantation during the rehabilitation period at home and follow up at hospital.

**The general objective of the program:** To improve caregivers' knowledge, practices and to restore dependency level of patients toward daily living activities.

The theoretical part of the program was presented in two sessions as lectures, and discussions, followed by the second part which consisted of three subsequent sessions for caregivers' practices regarding their providing care related to post bone marrow transplantation signs and symptoms, and patients' activities of daily living during the rehabilitation period.

#### **Implementation of the program:**

**Through group discussion, the researchers discussed with the caregivers the theoretical and practical parts, which included the following items:**

Knowledge included the meaning of autologous bone marrow transplantation, type, laboratory investigations, type of medication used, type of proper diet, content and components of proper food and side effects of chemotherapy.

**The contents of the practical part was given through asking questions that included:** Care of side effects of chemotherapy as; bleeding from nose, diarrhea, change of color skin, avoidance of infection, fever, constipation/diarrhea, vomiting, stomatitis and management of pain, and dealing with daily living activities

DLAs such as, feeding, bathing, personal hygiene, transfer, walking, toileting, clothing and dressing, and medical care.

Each session started by the objectives, taking into consideration using simple and clear Arabic language. Different methods were used such as lectures and interaction. Effective media used for conveying information was as follows: power point by laptop, posters, and using the doll for care of bleeding and bathing.

**Phase 3:** Implementation was done in Sheikh Zayed Specialized Hospital at Oncology Clinic of Bone Marrow Transplantation Unit, Six October Governorate, Egypt in the waiting area after the patient being examined by a physician at follow up visits.

Methods of teaching: included; discussions, role play, followed by demonstration and re-demonstration using simple Arabic language for family caregivers. As well, audio-visual aids were used such as posters, leaflets and a booklet.

#### **Phase 4: Evaluation phase:**

Evaluation of the rehabilitation program was done immediately after completing the program implementation by using the same pre-program tools to evaluate the effect of rehabilitation program on caregivers' knowledge and practices related to autologous bone marrow transplantation and dependency level of patients toward daily living activities and instrumental activities of daily living.

#### **Ethical Considerations:**

The necessary approval from the administrative authority of the Sheikh Zayed Specialized Hospital was taken after issuing an official letter from the Dean of Faculty of Nursing, Ain Shames University. An informed consent to participate in the current study was taken after the purpose of the study was clearly explained to each caregiver. Confidentiality of obtained personal data, as well as the respect of participant's privacy was totally ensured. A summary of the program was explained to caregivers who voluntarily agreed to participate in the study and caregivers were informed that they can withdraw from the study at any time without giving any reason.

#### **Statistical Design:**

Data entry was done using Epi-info, version 6.04 computer software package, while statistical analysis was done using the statistical package for social sciences (SPSS), version 21.0. Quality control was done at the stages of coding and data entry. Data were presented using descriptive statistics in the form of frequencies and percentages for qualitative variables. Qualitative variables were compared using Chi-square test (X<sup>2</sup>). The significance of the results was considered as not significant, if  $P > 0.05$ ; significant, if  $P < 0.05$ ; and highly significant, if  $P < 0.001$ .

### **IV. Results**

**Table (1):** reported that, 61.7% of patients aged 31-<40 years, and 68.3% were female. Regarding to educational level 46.7% was secondary school. The table also showed that 28.33% of them were employee, 45.0% of the sample were married, and related to monthly income 61.7% had insufficient income and all were under governmental payment for the treatment.

**Table (2):** showed that 30.0% of sample of caregivers aged between 20-<30years, and 78.4% of the caregivers were female. Regarding the type of relationship with the patients 48.3% were mothers. The table also recorded level of education, 55.0% of the sample was essential education, and 41.7 % of them were housewife. All the caregivers accommodated with the patients, 84.4% of them were giving care full time, 53.3% live in urban areas. And, 63.3% was living in nuclear families.

**Table (3):** presented patients' health status. As regards patients' body mass index, 53.3% had normal weight, 38.4% and 39% of the patients had abnormal pulse and respiration, 36.6% of them had abnormal blood pressure, 55.0% had hyperthermia. Also the same table mentioned that 43.3% of the patients were using vision aid, while 30.0% had mouth cracked. Regarding the dental status, 46.7% of the patients had missing teeth, 23.3% had pale oral mucosa. This table shows also that 40.0% of the patients had dysphagia, and 25.0% had productive cough. Regarding hemorrhoids, 36.7% of the patients had superficial hemorrhoids. This table showed also that 55.0% of the patients had normal amount of urine.

**Table (4):** Showed that regarding environmental sanitation at home 58.3% of patients who underwent autologous bone marrow transplantation had a sanitary environment, while for 41.7%, it was an unsanitary environment.

**Table (5):** Stated that there were highly statistically significant differences between pre and post program implementation in relation to family caregivers' knowledge about the meaning of autologous bone marrow transplantation, type, lab. investigations, scan investigations, type of receiving the medicine, type of nutrition, content of food, and side effects of chemotherapy. The same table presented that there was a highly statistically

significant difference between pre and post implementation of the program related to their total knowledge, however, there was an insignificant difference in relation to right way of cooking.

**Table (6):** reported 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. The same table recorded that there was highly statistically significant difference between pre and post implementation of the program related to their total practices, however, insignificant statistical differences were detected in relation to vomiting, nausea and bleeding from nose.

**Table (7):** showed that there were highly statistically significant differences between pre and post implementation of the program related to patients' total independency level regarding activities of daily living and instrumental activities of daily living with P-value <0.001.

**Fig. (1):** illustrated that there was a highly statistically significant relation between total caregivers' knowledge about autologous bone marrow transplantation and their practices pre/post rehabilitation program with P- value <0.001.

**Fig. (2):** indicated that there was a highly statistically significant relation between total caregivers' knowledge about autologous bone marrow transplantation and patients' independency level pre/post rehabilitation program with P-value <0.001.

**Fig. (3):** revealed that there was a highly statistically significant relation related to total caregivers' practices according to care provided related to post bone marrow transplantation signs and symptoms and patients' independency level pre/post rehabilitation program with P-value <0.001.

**Table (1):** Distribution of the patients who underwent autologous bone marrow transplantation according to their socio-demographic characteristics (n=60).

Items	(n=60)	
	No	%
<b>Age (in year):</b>		
21-< 30yrs.	10	16.7
30- < 40yrs	37	61.7
40-50 yrs	13	21.6
<b>Gender:</b>		
Male	19	31.7
Female	41	68.3
<b>Educational level:</b>		
University	20	33.3
Secondary	28	46.7
Primary	11	18.3
Illiterate	1	1.7
<b>Occupation:</b>		
Professional	14	23.33
Employee	17	28.33
Jobless	11	18.33
Housewife	18	30.0
<b>Marital status</b>		
Married	27	45.0
Single	15	25.0
Widow	11	18.3
Divorced	7	11.7
<b>Income</b>		
sufficient	23	38.3
Insufficient	37	61.7
<b>Treatment cost</b>		
Governmental payment	60	100

**Table (2):** Distribution of the caregivers according to their socio-demographic characteristics (n=60).

Items	(n=60)	
	No	%
<b>Age</b>		
20- <30	18	30.0
30- <40	14	23.3
40- <50	17	28.3
50+	11	18.4
<b>Gender</b>		
Female	47	78.4
Male	13	21.6
<b>Type of relationship</b>		
Mother	29	48.3
Husband	5	8.3

Sister	13	21.7
Wife	13	21.7
<b>Level of education</b>		
Illiterate	6	10.0
Basic education	33	55.0
High school	20	35.0
<b>Occupation:</b>		
Professional	5	8.3
Employee	13	21.7
Jobless	17	28.3
Housewife	25	41.7
<b>Place of accommodation</b>		
With the patient	60	100.0
<b>Time of care giving</b>		
Full time	50	84.4
Part time	10	16.6
<b>Residence</b>		
Urban	32	53.3
Rural	28	46.7
<b>Type of family</b>		
Nuclear family	38	63.3
Extended family	22	36.7

**Table (3):** Distribution of the patients who underwent autologous bone marrow transplantation according to their health status (n=60).

Items	n=60	
	No	%
<b>Body mass index</b>		
Under weight <18.5	13	21.7
Normal weight 18.5–25	32	53.3
Overweight 25–30	12	20.0
Obesity >30	3	5.0
<b>Pulse</b>		
Tachycardia	10	16.7
Bradycardia	13	21.7
<b>Respiration</b>		
Tachypnea	17	27.7
Bradypnea	7	11.5
<b>Blood pressure</b>		
Hypertension	50	28.3
Hypotension	5	8.3
Hyperthermia	33	55.0
Use vision aid	26	43.3
<b>Ear-Hearing</b>		
Hearing aid	2	3.3
Deaf	1	1.7
<b>Mouth</b>		
Cracked	18	30.0
Cyanotic	6	10.0
<b>Dental</b>		
Caries	14	23.3
Missing teeth	28	46.7
Bleeding gum	17	28.3
White patches	27	45.0
<b>Oral mucosa</b>		
Dry	23	38.3
Pale	14	23.3
Dysphagia	24	40.0
<b>Skin</b>		
Dry	19	31.7
Cool	7	11.7
Clammy	8	13.3
Nonproductive cough	22	36.7
Productive cough	15	25.0
<b>Abdomen</b>		
Hard	17	28.3
Distended	13	21.7
Tender	5	8.3
<b>Hemorrhoids</b>		
Superficial	22	36.7
Deep	13	21.7
Bleeding	13	21.7

Urine amount	No	%
Above normal	12	20.0
Below normal	15	25.0

N.B.: Total items are not mutually exclusive

**Table (4):** Distribution of the patients who underwent autologous bone marrow transplantation, according to their environmental sanitation (n=60).

Items	No	%		
<b>Isolated room</b>				
Yes	38	63.3		
No	22	36.7		
<b>Good ventilation</b>				
Yes	29	48.3		
No	31	51.7		
<b>Good lighting</b>				
Yes	36	60.0		
No	24	40.0		
<b>Walls of the room</b>				
Painted	27	45.0		
Not painted	33	55.0		
<b>Floor of the room</b>				
Ceramic	38	63.3		
On cement	22	36.7		
<b>Cleaning bathroom</b>				
Regularly everyday	23	38.3		
Not regularly everyday	37	61.7		
<b>Changing bed sheet</b>				
Regularly everyday	29	48.3		
Not regularly everyday	31	51.7		
<b>Sewage</b>				
Healthy sewage	46	76.7		
Unhealthy sewage	14	23.3		
<b>Eating utensils</b>				
Cleaned by boiling	32	53.3		
Ordinary cleaning	28	46.7		
<b>Smoking family member</b>				
Yes	21	35.0		
No	39	65.0		
<b>Smoking patient</b>				
Yes	0	0.0		
No	60	100.0		
<b>Pest free method</b>				
Yes	31	51.7		
No	29	48.3		
<b>Total environmental score</b>	Sanitation (60%+)		Insanitation (<60%)	
	No.	%	No.	%
	35	58.3	25	41.7

According to the research hypothesis:

**Table (5):** Distribution of family caregivers according to their total satisfactory level of knowledge about autologous pre / post program (N=60).

Items	Pre- program		Post-program		Chi-square	
	No	%	No	%	X <sup>2</sup>	P-value
Meaning of autologous bone marrow transplantation	12	20.0	52	86.7	53.571	<0.001
Type of bone marrow transplantation	11	18.3	46	76.7	40.936	<0.001
Lab. Investigations	3	5.0	55	91.7	90.234	<0.001
Scan investigations	10	16.7	48	80.0	48.187	<0.001
Type of receiving the medicine under doctor prescription	20	33.3	44	73.3	19.286	<0.001
Type of nutrition	27	45.0	50	83.3	19.173	<0.001
Right way of cooking	30	50.0	40	66.7	3.429	>0.064
Content of food	9	15.0	56	93.3	74.148	<0.001
Side effects of chemotherapy	18	30.0	45	75.0	24.361	<0.001
Total satisfactory knowledge	15	25.0	48	80.0	36.391	<0.001



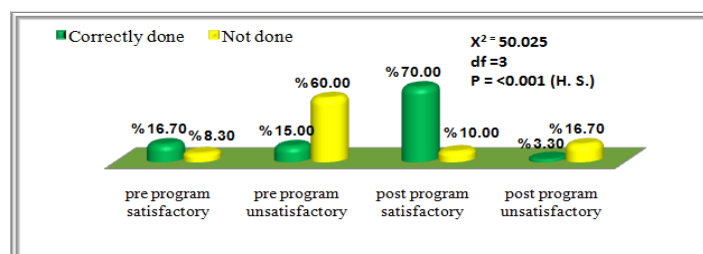
**Table (6):** Distribution of caregivers about their total correctly done practices related to caring for their patients with autologous bone marrow transplantation pre/post program (n =60)

Items	Caregivers (n=60)					
	Pre		Post		Chi-square	
	No	%	No	%	X <sup>2</sup>	P-value
Vomiting/ nausea	30	50.0	38	63.3	2.172	>0.141
Diarrhea/ constipation	17	28.3	45	75.0	26.162	<0.001
Anemia	10	16.7	49	81.7	50.714	<0.001
Avoidance of infection	13	21.7	44	73.3	32.114	<0.001
Fever	16	26.7	50	83.3	38.923	<0.001
Bleeding from nose	33	55.0	43	71.7	3.589	>0.058
Stomatitis	19	31.7	39	65.0	13.348	<0.001
Management of pain	21	35.0	37	61.7	8.543	<0.011
<b>Total correctly done practices</b>	19	31.7	44	73.3	20.886	<0.011

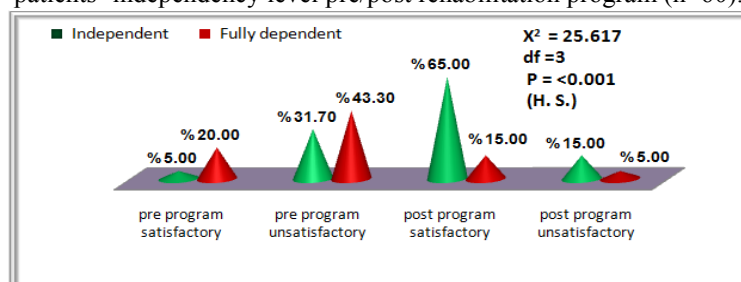
**Table (7):** Distribution of patients who underwent autologous bone marrow transplantation according to their independency level towards activities of daily living and instrumental activities of daily living pre/post program (n=60).

Items	Pre-program		Post-program		Chi-square	
	No.	%	No.	%	X <sup>2</sup>	P-value
<b>Personal Hygiene:</b> Bathing, washing face and hands, mouth wash, cut nails and comb hair	30	50.0	38	63.3	2.172	>0.141
<b>Wearing clothes:</b> Wearing upper/ lower part clothes and wearing shoes	49	81.7	60	100.0	12.110	<0.001
<b>Housekeeping:</b> Making the bed, cleaning the house and laundry	39	65.0	42	70.0	0.342	>0.559
<b>Food:</b> Buying food, preparing the food, eating foods and drinking	19	31.7	44	73.3	20.886	<0.001
<b>Going to the bathroom</b>	8	13.3	55	91.7	73.818	<0.001
<b>Transferring:</b> Walking and doing exercises on bed	15	25.0	50	83.3	41.119	<0.001
<b>Sleeping:</b> Sleeping at night regularly, taking a nap and waking up	25	41.7	45	75.0	13.714	<0.001
<b>Following up in the clinic</b>	23	38.3	59	98.3	49.910	<0.001
<b>Medication administration</b>	16	26.7	49	81.7	36.554	<0.001
<b>Shopping</b>	0	0.0	38	63.3	55.610	<0.001
<b>Following doctor instructions</b>	20	33.3	47	78.3	24.635	<0.001
<b>Total independency level</b>	22	36.7	48	80.0	23.177	<0.001

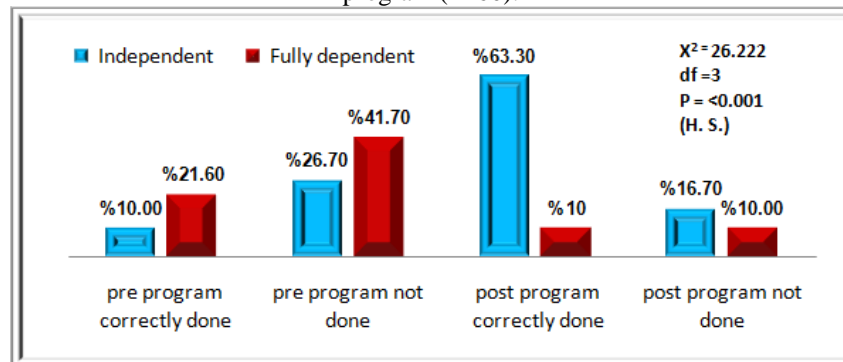
**Fig. (1):** Relation between the total caregivers' knowledge about autologous bone marrow transplantation and their practices pre/post rehabilitation program (n=60).



**Fig (2):** Relation between the total caregivers' knowledge about autologous bone marrow transplantation and patients' independency level pre/post rehabilitation program (n=60).



**Fig (3):** Relation between the total caregivers' practices and patients' independency level pre/post rehabilitation program (n=60).



## V. Discussion

Concerning the patients' socio-demographic characteristics, the current study result showed that slightly more than three fifth of the patients their age ranged between 30-<40 years, and more than two third were female. These results are in agreement with **Taha** <sup>[13]</sup>, who recorded that two third of his sample aged 31-40 years and about half of the studied sample were female. Regarding to educational level, less than half were secondary school, and married. In this respect, **Mohammed** <sup>[14]</sup> argued that above half of his sample were married. This table also reported that more than three fifth had insufficient income. These study findings are consistent with **Hasan et al.** <sup>[15]</sup>, who conducted a study on 80 family caregivers at the Nanakali Hospital for blood disease in Iraq and found that the highest percentage of them get less than 1200 dinar monthly. According to cost of treatment the same table revealed that all the patients were under governmental payment for the treatment. This study result was in agreement with **Yoost and Crawford** <sup>[16]</sup>, who reported that paying cost of treatment was government beside donation.

Concerning the family caregivers' socio-demographic characteristics, the finding of the present study revealed that less than one third of the caregivers were aged between 20- <30 years, and more than three quarter of the caregivers were female. This study was in agreement with **Lowsky and Negrin** <sup>[17]</sup>, who in their study found that, more than half of the sample were above 25, and around two third of the sample were female. As for type of relationship, with the patients, this study result revealed that less than half were mother. This could be related to the fact that mothers are the first caregivers for sick patient at home, especially in Egyptian culture and they usually have more and close contact, with the sick patient and take most of the responsibilities. About level of caregivers' education, more than half of the studied sample of caregivers had basic education. All the caregivers accommodated with the patients, and the majority of them were given care full time. This study results were in agreement with **Leather** <sup>[18]</sup>, who reported that less than half of his studied caregivers was mother; the majority of the caregivers were staying at the same place of the patients, and care was given along 24 hours.

Considering patients' health status, the current study results revealed that the patients' body mass index, for more than half was normal weight. Less than one fifth from the studied sample suffered from tachycardia, more than half of the patients had hyperthermia, and more than one fourth suffered from tachypnea and hypertension, less than one third had mouth cracked. These results agreed with those of a study carried out by **Abd El Fattah et al.**, <sup>[19]</sup> who conducted a study in the Faculty of Nursing, Ain Shams University, Cairo, Egypt, 100 mothers' adjustment related their children with Leukemia, they reported that due to chemotherapy side effects, above half of his studied sample had hyperthermia due to infection, also study revealed that about one third had hypertension. Those patients suffered long time because of chemotherapy side effect which led to dysphagia. These results could be attributed to short and long side effects of chemotherapy, beside signs and symptoms of autologous bone marrow transplantation.

The current study revealed that, slightly more than two fifth of patients were living in an insanitary home environment. This result agreed with **Freyer et al.** <sup>[20]</sup>, whose concerns about the patient with leukemia led to an examination of the family caregivers' ability to understand the treatment and its likely effects and side effects at Sweden, they reported that home safety is a major concern for persons living with patients having autologous bone marrow transplantation, because much direct care is provided at home. This result could be attributed to that less than half of patients were living in rural and slum areas added to that more than one third was living in extended families.

Regarding knowledge of caregivers about post autologous bone marrow transplantation, the present study result showed that there were highly statistically significant differences between pre and post program of family caregivers' knowledge about the meaning of autologous bone marrow transplantation, the type, lab. investigations, scan investigations, type of receiving the medicine, type of nutrition, content of food, and side

effects of chemotherapy. The same table presented that there were highly statistically significant differences between pre and post implementation of the program related to their total knowledge. These results contradicted with those of the study of **Yen-Michael and Cushing** <sup>[21]</sup> who in a very recent study 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. From the researchers' point of view, a good caregiver is often the person, who knows everything that is going on with the patient. The patient has to be involved in planning his care, as this will help doing his/her part to get better. Caring for someone going through cancer treatment is a demanding role.

As regards caregivers' practices related to caring for their patients post autologous bone marrow transplantation the current study results mentioned that there were highly statistically 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. The same table revealed that there was a highly statistically significant difference between pre and post implementation of the program related to their total practices. These results were supported by those of a study done by **Ahmed et al.** <sup>[22]</sup>, 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.

According to patients' independency level towards activities of daily living and instrumental activities of daily living post autologous bone marrow transplantation, the finding showed that less than two third of the patients who were dependent pre program intervention changed to more than three fourth being independent post program implementation. This result contradicted with that of the study done by **Champlin** <sup>[9]</sup>, which revealed that the majority of the patients were depending on their caregivers and concluded that family caregivers perform all aspects of care, such as meal preparation, cleaning and housekeeping activities, as well, providing shopping of goods for patient post autologous bone marrow transplantation.

Regarding to relation between the total caregivers' knowledge about autologous bone marrow transplantation and caregivers' practices, pre/post the study result revealed that there were highly statistically significant differences related to total caregivers' knowledge about autologous bone marrow transplantation and their practices pre/post rehabilitation program. This result was supported by **Fouad** <sup>[23]</sup>, who studied family caregivers' knowledge and practices of children with phenylketonuria at Cairo Governorate, and reported that caregivers' knowledge had an impact on their practices. From the researchers' point of view, this is true because caregivers were provided with basic knowledge about their patients' condition, prognosis, various treatment approaches and side effects of treatment by the health team in Sheikh Zayed Specialized Hospital. Besides a booklet of rehabilitation program was offered to them which assisted them in practicing healthy behaviors regarding their patients with autologous bone marrow transplantation.

The relation between caregivers' knowledge related to autologous bone marrow transplantation and patients' independency level the result of this study was also investigated that there was a highly statistically significant difference related to total caregivers' knowledge about autologous bone marrow transplantation and patients' independency level pre/post rehabilitation program. This result agreed with **Farouk et al.** <sup>[24]</sup>, whose study on 130 patients who underwent autologous bone marrow transplantation, in Egypt, displayed that there was highly statistically significant association between the total patients' knowledge about autologous bone marrow transplantation and total activity of daily living and care provided to the patients by caregivers ( $P > 0.001$ ).

Considering the relation between caregivers' practices and patients' independency level pre/post rehabilitation program, the result of this study showed that there was a highly statistically significant difference related to total caregivers' practices in providing care related to post bone marrow transplantation signs and symptoms and patients' independency level pre /post rehabilitation program. This result is on line with **Ahmed et al.** <sup>[22]</sup>, study, which revealed that there was a highly statistically significant difference between total caregivers' practices and total patients' independency regarding their daily living activities at pre/post and follow up program ( $P < 0.001$ ).

There was improvement in all items, for activities of daily living towards their patients who underwent autologous bone marrow transplantation. This could be due to the current social situation in the Egyptian society, having a strong kin-relationship between patients who underwent autologous bone marrow transplantation and family caregivers, and also a feeling of responsibility toward them.

## **VI. Conclusion**

Based on the results of the current study, and the research hypothesis the following can be concluded:

There was a highly statistically significant difference between family caregivers' total knowledge, and their practices pre/post rehabilitation program, as well as total caregivers' knowledge about autologous bone marrow transplantation and patients' independency level pre/post rehabilitation program. There was also a

highly statistically significant difference related to total caregivers' practices according to care provided related to post bone marrow transplantation signs and symptoms and patients' independency level pre/post rehabilitation program ( $P < 0.001$ ).

## VII. Recommendations

Based on the results of the present study, and research hypothesis, the following recommendations are suggested:

- Counseling and nursing intervention for family caregivers of patients who underwent autologous bone marrow transplantation about:
  - \* Daily living activities, especially personal hygiene
  - \* Providing posters, booklets, and leaflets for family caregivers, which describe care.
  - \* Periodic physical examination and screening for early identification and detection of health problems and prompt intervention.
  - \* Providing practical guidance on every health issue regarding side effects of chemotherapy.
- 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.
- 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.

## References

- [1] **National Cancer Institute. (2016):** Bone marrow transplantation and peripheral blood stem cell transplantation. Accessed at: [www.cancer.gov/cancertopics/factsheet/Therapy/bone-marrow-transplant](http://www.cancer.gov/cancertopics/factsheet/Therapy/bone-marrow-transplant) in April 4, 2016.
- [2] **Thomas, S. (2009):** Autologous transplant patient guide. Psychosocial adjustment and quality of life among multiple myeloma patients undergoing evaluation for autologous stem cell transplantation, (6<sup>th</sup> ed.). California, USA, UNC Cancer Care. P.33.
- [3] **Harrison, N., Mitterbauer, M., & Tobudic, S. (2015):** Incidence and characteristics of invasive fungal diseases in allogeneic hematopoietic stem cell transplant recipients: A retrospective cohort study. *BMC Infect Dis.*;15:584.
- [4] **US Department of Health and Human Services. (2016):** Blood cell transplant. Donation Frequently Asked Questions. Accessed at: [http://bloodcell.transplant.hrsa.gov/donor/donating/donation\\_faqs/in](http://bloodcell.transplant.hrsa.gov/donor/donating/donation_faqs/in) April 4, 2016.
- [5] **Frey, P., Stinson, T., & Siston A. (2012):** Lack of caregivers limits use of outpatient hematopoietic stem cell transplant program. *Bone Marrow Transplant.* (4<sup>th</sup> ed.). USA: California, p. 741.
- [6] **Foster, L.W., McLellan, L., Rybicki, L., Dabney, J., Copelan, E., & Bolwell, B. (2013):** Validating the positive impact of in-hospital lay care-partner support on patient survival in allogeneic BMT: A prospective study. *Bone Marrow Transplant*; 48: 671–677.
- [7] **Sautter, J.M., Tulsy, J.A., Johnson, K.S., Olsen, M.K., Burton-Chase, A.M., and Hoff, J. (2014):** Caregiver experience during advanced chronic illness and last year of life. *J Am Geriatr Soc*; 62: 1082–1090.
- [8] **Young, L.R. (2013):** A Family perspective on a program for bone marrow transplantation of adults. *Journal of Oncology Nursing*;11:287.
- [9] **Champlin, R. (2014):** Hematopoietic cellular transplantation. *Cancer Medicine.* (6th ed.). Hamilton, Ontario:BC, Decker Inc., pp. 1019-1036.
- [10] **Katz, S. (1983):** Assessing self maintenance “activities of daily living, mobility and instrumental activities of daily living. *J Am Geriatr. Soc.*; 31:721-727.
- [11] **Siston, C.S. (2012):** Textbook of medical-surgical nursing. (11<sup>th</sup> ed.). Philadelphia, USA: Brunner & Suddarth's, Lippincott., pp.74-77.
- [12] **Bickley, L. S., & Szilagy, P. G. (2009):** Bates' guide to physical examination and history taking (8<sup>th</sup> ed.). Philadelphia: Lippincott Williams & Wilkins, pp. 60-67.
- [13] **Taha, M. (2013):** Cancer patients underwent bone marrow transplantation. *European Journal of Oncology Nursing*;14:278.
- [14] **Mohammed, T. (2014):** 20th century, chemistry, health and medicine. *Journal of the American Association*; 288 (14): 1567.
- [15] **Hasan, S., Hussein, K., & Al-Ani, M. (2013):** Assessment of home care management for caregivers having leukemic adolescent patient in Erbil City, *Kufa Journal for Nursing Sciences.* 2(1):5.
- [16] **Yoost, B., & Crawford, L. (2015):** *Fundamental of nursing : Active learning for collaborative practice.* (1st ed.), New York Mosby. P.1002.
- [17] **Lowsky, R., & Negrin, R.S. (2012):** Principles of hematopoietic cell transplantation. In: Lichtman MA, Kipps TJ, Seligsohn U, Kaushansky K, Prchal JT, (eds.). *Williams Hematology.* (8th ed.) pp. 245-249.
- [18] **Leather, H. (2013):** Drug interactions in the hematopoietic stem cell transplant (HSCT) recipient: What every transplantee needs to know. *Bone Marrow Transplantation*; 33: 137–152.
- [19] **Abd El Fattah, N. M., Abd El Hakim, H. A., Guirguis, S. R., & Ibrahim, H. A. (2012):** Health needs of children with leukemia and their families adjustment. Master Degree in Community Health Nursing, Faculty of Nursing, Ain Shams University. pp. 79-82.
- [20] **Freyer, A.C., Wendt, L.V., & Klang, B. (2013):** Informational needs in families after their child's mild head injury. *Patient Edu. Couns.*70 (2): 251-255.
- [21] **Yen-Michael, S. H., & Cushing, M. M. (2016):** Autologous stem cell mobilization and collection. *Hematol Oncol Clin N Am*; 30: 573–589.
- [22] **Ahmed, W. M., Abd El Hakim, H. A., Guirguis, S. R., & Abd El Moneem, H. E. (2016):** Follow up care for family caregivers and patients with leukemia undergoing. Doctorate Degree. Faculty of Nursing, Ain Shams University, pp. 111-113.
- [23] **Fouad, R., (2013):** Family caregivers' knowledge and practice of children with PKU. Master Degree in Nursing Science, Community Health Nursing, Faculty of Nursing, Cairo University.
- [24] **Farouk, A. M., Abd El Mobydy, S. R., & Abd El Moneem, H. E. (2015):** Care provided to patients who underwent autologous bone marrow transplantation during the rehabilitation period. Master Degree in Community Health Nursing, Faculty of Nursing, Ain Shams University, p. 130.