

Caregivers Knowledge of Post Autologous Bone Marrow Transplantation Patients at Home

¹Asmaa Farouk Mohamed, ² Nawal Soliman,, ³ Hemat Abd-El-Moneem El-Sayed, Asmaa Talaat

¹ M.Sc.N., Community Health Nursing, ² & ³ Professors of Community Health Nursing, Faculty of Nursing - Ain Shams University-Egypt

Abstract

Background: Autologous bone marrow transplantation is an intervention for a variety of life-threatening diseases. Stem cells transplantation procedures continue to be improved, making transplantation a treatment option for many patients. The unique and intensive nature of this treatment requires distinctive knowledge and care during and post the entire transplant course. **Aim to** assess the knowledge of the caregivers of post autologous bone marrow transplantation patients at home. **Research Design:** A descriptive study. **Sample:** A convenient sample was comprised a total number of 143 patients, during the six months attend the follow up clinic at bone marrow transplantation unit. **Setting:** The study was conducted at outpatient follow-up clinics, bone marrow transplantation unit in Sheikh Zayed Specialized Hospital, National Oncology Institute, and Nasser Institute. **Tools:** Two tools were used for data collection. **First tool:** A self-administered questionnaire of patients and their caregivers' demographic data. **Second tool:** Caregivers' knowledge toward post autologous bone marrow transplantation patients at home. **Results:** This study indicated that, most of caregivers of the studied sample were totally need to improve their knowledge, and there were significant association between caregivers' demography and their knowledge. **Conclusion:** Caregivers had poor knowledge of post autologous bone marrow transplantation. **Recommendation:** Although caregivers had adequate knowledge on some aspects, gaps were identified. There is a need for educational interventions and discharge plan to upgrade knowledge, post autologous bone marrow transplantation patient at home.

Keywords: Caregivers- autologous bone marrow transplantation- home.

Introduction

Bone marrow transplantation, formerly a highly experimental, rarely used procedure, has become a fairly common and accepted treatment. Bone marrow transplant (BMT) has evolved over the past two decades from an experimental treatment modality to the treatment of choice for certain malignant and non-malignant hematological disorders. Bone marrow transplant (BMT) is, however, a risky procedure, with attendant side effects and complications. Many of these are serious; some can be life-threatening (Grimm, et al., 2017).

A stem cell transplant is a procedure that replaces unhealthy blood-forming cells with healthy ones. Blood and marrow stem cells are transplanted for the treatment of blood cancer. Certain other marrow disorders are also treated with transplantation, and many of the principles are the same. For some patients, this complex procedure offers a curative treatment option (Majhail, 2016). The bone marrow is a tissue that is found in the center of bones, such as the back of the hips, and the breastbone. These areas are very rich in bone marrow and so are used for obtaining bone marrow for tests or for harvesting (Majed, 2018).

The success of a transplant depends on appropriate timing. Compared with other treatments, earlier treatment often improves the likelihood of success and survival (**Frey et al, 2015**). A record number of bone marrow transplantation is 36 469 patients (15 765 allogeneic (43%), 20 704 autologous (57%)) were reported by 656 centers in 47 countries to the 2017 survey. Trends include continued growth in transplant activity, more so in Eastern European countries than in the west; a continued increase in the use of haploidentical family donors (by 25%) and slower growth for unrelated donor. The use of cord blood as a stem cell source has decreased again in 2017 (**Taha, 2018**).

A caregiver is part of the health care team, he is the person who helps the patient post autologous bone marrow transplant. Most often, the main caregiver is a spouse, or an adult, also includes the medical staff. A good caregiver is often the one person who knows everything that is going on with the patient. The patient has to be involved in planning his care; help the patient do his part to get better. Caring for someone going through cancer treatment is a demanding role (**Mittelman, 2019**). Patients with an identified caregivers demonstrated a survival rate of 75% at one year following transplant (**Majed, 2018**).

Significance of the study

Bone marrow transplantation in Egypt started in 1989 on a narrow scale. In 1997, the transplant rate increased dramatically with the opening of the unit at Nasser Institute. The total number of transplants performed till June 2017 is 136200; around 80% of the cases are allogeneic and 20% autologous (**Taha, 2018**).

According to the medical records, 204 cases were found in **Sheikh Zyed Specialized Hospital**, 153 cases were found in **National Oncology Institute**, and 134

cases were found **Nasser Institute**. of which autologous bone marrow transplantation were carried out last year. Their ages vary between 21-50 years old. The main source of care and support for patients are received by their families as caregivers at home. Having access to this support is important for the patients' outcomes.

Aim of the study

The study aims to assess the care provided to patients who underwent autologous bone marrow transplantation during rehabilitation period through:

1- Assessing knowledge of patients and care givers related to bone marrow transplantation.

Research questions:

- 1- Do caregiver have knowledge regarding patients' needs post autologous bone marrow transplantation at home?
- 2- Are there a relation between caregivers' demographic data and caregivers' knowledge?

Subject and Methods

Research Design:

This is a descriptive analytic study was carried out to assess knowledge of the caregivers of post autologous bone marrow transplantation at home.

Setting:

This study was conducted in Bone Marrow Transplantation unit at outpatient follow-up clinics Sheikh zayed Specialized Hospital, National oncology, and Nasser institute.

Sampling:

Adults patients their aged range between 21-50 years old post autologous bone marrow transplantation who were attending the follow up clinic the total number of the sample 143 as follow (43 patients from Sheikh zayed Specialized Hospital, 51 patients from National Oncology Institute, and 49 patients from Nasser Institute) at Autologous Bone Marrow Transplantation unit for 6 months

period. Criteria of selection was literate patients and accompany with one of his or her caregiver.

Data was collected using the following tools:

First tool: A Self-administered Questionnaire

Assessing demographic characteristics of patients and their caregivers.

This tool was developed by the investigator, based on reviewing related literatures and experts opinions, written in Arabic language. This part includes closed ended questions : such as age, gender, marital status, level of education, monthly income, residence place. type of relationship with the patient, and time of care given to the patient.

Second tool: Assessing knowledge of the caregivers toward caring of patients, This tool was developed by the investigator, based on reviewing related literatures and experts opinions, written in Arabic language. This part includes closed ended questions : as regards early identification of problems such as fever, dietary requirements, signs of infection, tendency of bleeding, post-transplant medications, following up regiments, etc.....

Scoring system for caregivers' knowledge of post autologous bone marrow transplantation patient at home:

Zero to one, correct = 1 & incorrect =0. The total score for all items was 9 items and categorized into three levels as followings:

- Poor 0-3
- Average 4-6
- Good 7-9

Content validity and reliability:

It was be ascertained by group of experts in community health nursing. Their opinions were elicited regarding the format

layout, consistency, accuracy and relevancy of the tools.

Administration design and Ethical Consideration:

An official written letter approval to conduct this study obtained from the dean of Faculty of Nursing, Ain Shams University to the director of Sheikh Zayed Specialist Hospital, director of national oncology institute, and Nasser institute. In addition, an oral consent was obtained from each participant, and was assured that anonymity and confidentiality would be guaranteed and the right to withdrawing from the study at any time.

Operational Design:

Preparatory Phase

A review of literature was done regarding current and past available literature, covering the various aspects of the problem, using text books, articles, magazines and internet search. This was necessary for the researcher to get aquatinted with, and oriented about aspects of the research problems, as well as to assist in development of data collection tools.

Field work:

The actual process of data collection was carried out in the period from February 2019 to July 2019 the researcher present at three days /weekly nearly about 2 hours /day (Sunday, Wednesday and Friday) meeting and discuss the title and the aim of the study and taking permission for collecting data from the patients. The investigator started by introducing herself, and explaining the purpose of the study, then distributed the questionnaire sheet after clear explaining the way to fill it out and wait until all the patients complete the questionnaire. Demographic characteristics for the patients and caregivers took about 10 minutes patients past and current medical history questionnaire took about 15 minutes.

Patients and caregivers knowledge took about 15 minutes.

Results:

Table (1): Shows that, the mean age of the studied patients was (36.8 ± 15.1) years, in relation to gender, 53.1% were males, and 67.1% were married, while 58% had 3-4 children, as regards educational level 42% of them had university education. Concerning occupation, 37.8% were employees, with 70.6% had sufficient monthly income.

Table (2): Illustrates that, the mean age of the studied caregivers was (34.7 ± 16.2) years. 68.5% of the caregivers were females. Regarding Kin-relation with the patient 26.6% were their wives. Related to educational level 41.9 % of the studied sample were secondary education. In relation to the marital status, 41.9% were married, Concerning of job 34.3% were employees, and 76.9% of time of care were full time.

Table (3): demonstrates that 30.1% from the total study sample had poor knowledge about type of bone marrow

transplantation, 44.8% had poor knowledge in meaning of autologous bone marrow transplantation, 58.8% of the caregivers had poor knowledge of type of nutrition , and 41.3% had average knowledge in right way of cooking. As regard side effect of chemotherapy 41.3% of the study sample had average knowledge.

Figure (1): Elaborates that 41.5% of the total sample of the patients post autologous bone marrow transplantation had average knowledge, and 33.1% were poor in knowledge, while 25.4% were good in knowledge.

Table (4): Demonstrates that there was no statistical significant association between gender of the caregivers with the caregivers' knowledge at $P > 0.05$. Meanwhile, there was a statistical significant association between the caregivers 'level of education and job with the caregivers' knowledge, where respectively at $P < 0.05$. In addition, this table elaborates that there is a highly statistical significant association between the caregivers' age and caregivers' knowledge at $P < 0.001$.

Table (1): Distribution of the patients post autologous bone marrow transplantation patients at home according to their demographic characteristics (N=143).

Patients' demographic characteristics		(N=143)	
		N	%
Age:			
21 < 30 yrs.		38	26.6
30 < 40 yrs.		57	39.9
40 - 50 yrs.		48	33.5
Mean ± SD		36.8 ± 15.1	
Gender:			
Male		76	53.1
Female		67	46.9
Marital status			
Single		19	13.3
Married		96	67.1
Divorced		12	8.4
Widow		16	11.2
Number of children			
Non		21	14.7
1-2		34	23.8
3 – 4		83	58
>4		5	3.5
Educational level:			
Does not Read or write		7	4.9
Read & write		3	2.1
Primary		19	13.3
Secondary		54	37.7
University		60	42
Occupation			
Jobless		14	9.8
Employee		87	60.8
Housewife		42	29.4
Monthly income			
Sufficient		101	70.6
Not sufficient		42	29.4

Table (2): Distribution of the Caregivers according to their demographic characteristics (N=143).

Caregivers' demographic characteristics	(N=143)	
	N	%
Age		
20 < 30 yrs.	23	16.1
30 < yrs	64	44.8
40 - 50 yrs	56	39.1
Mean ± SD	34.7 ± 16.2	
Gender:		
Male	45	31.5
Female	98	68.5
Kin-relation		
Mother	15	10.4
Father	7	4.9
Husband	6	4.2
Wife	38	26.6
Son	19	13.3
Daughter	14	9.8
Brother	2	1.4
Sister	19	13.3
Relatives	9	6.3
Friend	8	5.6
Nurse	6	4.2
Educational level:		
Primary	55	38.5
Secondary	60	41.9
University	28	19.6
Marital status		
Single	28	19.6
Married	60	41.9
Divorced	29	20.3
Widow	26	18.2
Occupation		
Jobless	21	14.7
Employee	88	61.5
Housewife	34	23.8
Time of care		
Full time	110	76.9
Part time	33	23.1

Table (3): Distribution of the caregivers according to their knowledge about post autologous bone marrow transplantation and side effects of chemotherapy (N=143).

Knowledge about	Good		Average		Poor	
	N	%	N	%	N	%
Type of bone marrow transplantation	45	31.4	55	38.5	43	30.1
Meaning of autologous bone marrow transplantation	39	27.3	40	27.9	64	44.8
Type of nutrition	26	18.1	33	23.1	84	58.8
Right way of cooking	37	25.9	59	41.3	47	32.8
Side effect of chemotherapy	37	25.9	59	41.3	47	32.8

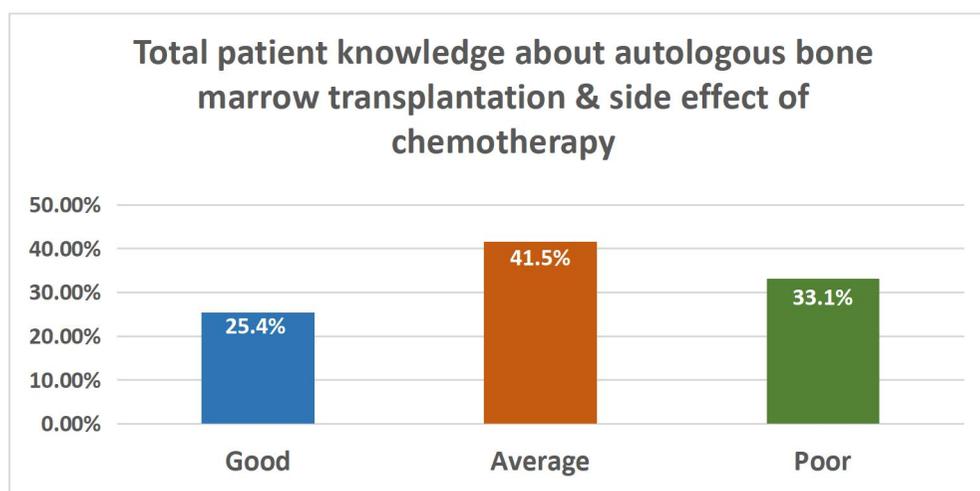


Figure (1): Distribution of the patients according to their total knowledge about autologous bone marrow transplantation side effects of chemotherapy (N=143).

Table (4): Relation between the patients' knowledge about autologous Bone Marrow Transplantation and their socio-demographic characteristics (N=143).

Items	Good		Average		Poor		X ²	P
	N	%	N	%	N	%		
Caregivers' knowledge about Autologous Bone Marrow Transplantation								
Caregivers' socio-demographic								
Age							40.951	**
20 < 30 yrs.	8	5.6	6	4.1	9	6.3	df=4	P <0.001
30 < yrs	6	4.1	25	17.4	33	23.2		
40 - 50 yrs	18	12.6	23	16.2	15	10.5		
Gender								
Male	14	9.8	13	9.1	18	12.6	1.021	P>0.05
Female	23	16.1	27	18.9	48	33.6	df=2	
Educational level								
Primary	10	6.9	16	11.2	29	20.3		*
Secondary	10	6.9	11	7.7	39	27.2	16.722	P<0.05
University	7	4.8	9	6.3	12	8.4	df=6	
Job								
Jobless	5	3.5	10	6.9	6	4.1	15.929	*
Employee	26	18.1	43	30.1	19	13.3	df=8	P <0.05
Housewife	9	6.3	16	11.1	9	6.3		

*Significant **highly significant

Discussion:

The current study illustrated that almost two fifth of the patients of the studied sample their aged was between 30<40years, and around the half were males. These results are in agreement with **Abo Elsaad, (2015)**, who reported in his study in Monofya governorate that around two fifth of the studied patients' age were between 30<40 years, and more than half were males. This study also agrees with the study of **Taha, (2018)** who reported in his study in Nasser institute hospital that two fifth of the studied patients' age were between 31<40 years of his study sample and almost half were males.

Regarding marital status around two third were married, and above half of patients had between 3-4 children. Concerning educational level around two fifth had university education and two third were employees with two third had sufficient monthly income. These results are in agreement with **Taha, (2018)** who

reported in his study in Nasser institute hospital that marital status of the sample of his study nearly two third were married, and almost half of patients had between 3-4 children. In relation to educational level about two fifth had university education and almost two third were employees with about two third had sufficient monthly income.

This study consisting with **Ahmed, et al., (2016)** on their study in National oncology institute in Cairo that the highest percentage of them had secondary school, and were farmers, due to almost of the patients from country side, in addition, the majority had insufficient monthly outcome, the investigator found that there were differences between patients monthly income due to their work does not afford enough income (**Table 1**).

Regarding the demographic characteristics of the caregivers (**Table 2**) the present study showed that, around two fifth their age above 30 years, and around two third of the caregivers were females. Regarding patients' kin-relation above

quarter were their wives. This study was in agreement with *Ahmed, et al., (2016)* on their study in National oncology institute In Cairo found that the highest percentage of the studied caregivers' age was above 30 years, almost two fifth of the caregivers were females. Beside Kin-relation with the patient, the majority were their wives.

This study also agrees with *Farouk, et al., (2015)* who reported in his study in Cairo the caregiver as part of the health care team, is the person who helps the patient post autologous bone marrow transplant. Most often the main caregiver is a spouse, or family member, and the majority of them were giving care full time. This study was in agreement with *Fouad (2016)* who reported in his study in fayom governorate that less than half of his studied sample were their wives, the majority of the caregivers staying at the same place of the patients, and care were giving along 24 hours. In accordance to *Hassan, et al., (2016)* who argued in his study in Nasser institute hospital that nearly half of the sample were aged above 45 years, and majority of them were females. Patients' kin- relation one third were mothers.

Related to educational level almost two fifth of the studied sample were secondary education. In relation to the marital status, approximately two fifth were married, Concerning of job about one third were employees, and almost three quarters of time of care were full time. This study contradicted with the study of *Hassan, et al., (2016)* who reported in his study in Nasser institute hospital that level of their education almost half of the total sample of caregivers were essential education. In relation to the marital status, about three quarters were married, regarding of occupation the majority were house wives, and time of care were full time.

Regarding knowledge of the patients (**Table 3**) the present study showed that one third had poor knowledge about type of bone marrow transplantation, and less than

half did not know the meaning of autologous bone marrow transplantation, Also the table displays that above half of the studied sample had poor knowledge in type of nutrition. About two fifth had average knowledge concerning right way of cooking, and side effect of the chemotherapy, and this due to there is no appropriate discharge plan, beside the hospital does not provide rehabilitation program for the patients and their caregivers, to get the needed information after discharge and staying at home.

This result contradicted with the study of *Sala, et al., (2016)* founded that in his study in Ohio patients had to join rehabilitation program before transplantation and had to know the majority of what related to bone marrow transplantation and rehabilitation and how to handle the complications, they must be aware and have adequate knowledge.

This study were also in contrary with the present study as *Freedman et al., (2015)* who reported in his study in Stanford hospital patients and their caregivers had satisfactory level of total knowledge related to chemotherapy side effect, his study revealed that total knowledge of the patients and their caregivers were satisfactory exceed three quarter of total knowledge.

Total patients knowledge about autologous bone marrow transplantation and side effects of chemotherapy revealed one third of them had poor knowledge (Figure 1). While caregivers knowledge were about half was poor (Figure 2), this study were in contrary with Freedman et al, (2015) who reported patients and their caregivers had satisfactory level of total knowledge related to chemotherapy side effect, his study revealed that total knowledge of the patients and their caregivers were satisfactory exceed three quarter of total knowledge.

There was a statistical significant (Table 4) association between the caregivers' level of education and job with the caregivers' knowledge with agreement of *Beschorner and Jones, (2016)* in this study revealed that there was a statistical significant association between the clients , level of education and job with the caregivers' knowledge. Also the present study showed that there was a highly statistical significant association between the caregivers' age with the caregivers' knowledge This result contradicted with the study done by *Walker,, et al., (2018)* who reported in his study there was no significant relation between caregivers' age and their knowledge.

Conclusion:

This study revealed that caregivers knowledge almost half of them had poor knowledge, one third had average, and less than fifth had good knowledge and there were significant association between caregivers' demography and their knowledge.

Recommendations

The findings of this present study, suggested the following recommendations: Health education programs before going to bone marrow transplantation for patients and their caregivers about nutrition, self-care. Providing practical guidance on every related patient's health issues regarding side effect of chemotherapy. Providing the patients and their caregivers with health education about complication that might happen post autologous bone marrow transplantation at home.

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