Assessment of Home Care Management for Caregiver's having Leukemic Adolescent Patient in Erbil city

***Shukir Saleem Hasan **Kareema Ahmed Hussein *** Mouroge Hashim Al-Ani**

***M.sc. Pediatric Nursing Assist Lecturer, College of Nursing, Hawler Medical University**

****PhD. Pediatric Nursing Assist Professor, College of Nursing, Hawler Medical University**

***** PhD. Pediatric Medicine , Assist Professor, College of Medcine, Hawler Medical University**

ABSTRACT:

Background and Objectives: Children with leukemia may experience physical, psychological, cognitive and neuropsychological effects. The caregiver is the main provider of physical and emotional support for the patient. The aim of the study was to assess caregivers' home care management regarding their adolescent leukemic patient and association with their socio-demographic characteristic.

Subjects and Methods: A descriptive study was carried out in Nanakali Hospital for Blood Disease in Erbil city from 1st /Nov. 2010 to 1st /Feb. /2011. Eighty caregivers face to face interviewed for assessing their knowledge and practices regarding their adolescent leukemic patients were selected.

Results: The study shows the majority of caregiver had deficit knowledge regarding cause of leukemia and nutrition to reduce fatigue for adolescent leukemic, and shows the majority of caregivers had poor practices regarding preparing meals and snakes, with poor practice regarding oral hygiene. And the study shows there were a significant association between caregiver's knowledge and: level of education, residency areas, and highly significant association between caregivers' knowledge and practice with their socio-economic status.

Conclusion and Recommendation: This study shows that the caregivers who are having adolescent leukemia patients had deficit in knowledge and low practices regarding home care management. The study recommended providing information and guidance to caregivers through health educational intervention regarding home care management for leukemia.

Key word: Caregiver, Home Care, Management, Adolescent, leukemic

INTRODUCTION

Leukemia is the most common malignancy that affects children, accounting for approximately a third of cancer diagnoses[1, 2]. Leukemia in Iraq is accounting 6.35/100,000 of Iraqi population[3]. Nanakali Hospital for Blood Disease/ Erbil registered more than 400 leukemic childhood patients in 2010.

Leukemia is a significant public health and life-threatening problem for pediatric cancer patients [4]. More than half of all women provide care an ill person at some point in their lives and most of caregivers are mother's child[5]. At home the caregiver is the main provider of physical and emotional support for the patient. Informal caregivers are mostly the patient's spouse, partner or closest relatives, and females are more tuned to the caring function at home [6]. Home care is a good choice for many adolescent who have cancer [7]. As family caregivers provide more care for cancer patients, who report poorer health outcomes compared with those individuals without cancer [8]. Healthcare professionals should encourage parents to seek care at a pediatric cancer center and to ask about clinical trials if the issue is not raised. This is particularly important for older children and adolescents [9]. Health education is primarily preventative and aims to increase knowledge, thus enabling informed choice in addressing issues that affect health and well-being [10].

Indeed there is a few nursing studies which focusing on oncology pediatric nurses in Kurdistan Region-Iraq. Supports and guidelines for caregivers who give care to improve the quality of life of adolescent leukemic patient, with adequate knowledge and practice toward complications may be arise before, during and after treatments to reduce mortality rate among leukemic patients, minimize hospitalization, and the burden of the treatment. The study attempts to assess the association between socio-demographic characteristics with their knowledge and practices of caregivers regarding home care management for adolescent leukemic patient in Nanakali Hospital for Blood Disease/ Erbil city.

SUBJECTS AND METHODS:

A descriptive study was conducted in Nanakali Hospital for Blood Disease in Erbil City, from /1st /Nov. / 2010 to /1st /Feb. /2011/. Eighty caregivers who have adolescent leukemic patient between 10 to 19 years old were selected to participate in the study. To achieve the aim of the study, questionnaire was designed and translated to Kurdish language; and it is divided in to two main parts the first part was to identify the socio-demographic characteristics and the second part was a checklist; this checklist was composed of two main domains. First domain is to assess caregivers' knowledge regarding the disease and it consists of (18) questions, items are rated between (1) for Yes (18) score, and (2) for No (36) score. The second domain was assessing caregivers practice it contains (22) questions which are used to assess their home practices, items are rated between (1) for Yes (22) score, and (2) for No (44) score. Formal permission approval was obtained from both Erbil Health Director and Nanakali Hospital for Blood Disease and ethical consent was obtained form participants. Data was collected through direct interviews with caregivers by investigators. The statistical package for social science (SPSS version 17) was used to determine the frequency, percentage, mean score, standard deviation and Chi-square test to measure the significant association between different variables p-value measured form ≤ 0.05 to 0.01.

RESULTS: The result of the study shows that the majority (71.3%) of caregivers were mothers, their ages (38.6%) were above 41 years old, (46.2%) were illiterate, (76.3%) were housewives, (78.8%) were married, (66.2%) of them were living from rural areas, and (72.5%) having low SES **(Table, 1).** The study shows that (90%) of caregivers having deficit knowledge regarding the causes of leukemia, (85%) of caregivers were had poor knowledge regarding psycho-social aspects, and (80%) had deficit knowledge regarding importance of nutrient to reduce fatigue, and (96.25%, 92.5%) of caregivers were having poor home practice regarding preparation the meals and characteristic of snake meal respectively,(93.75%) of them did not encourage their leukemic adolescent to drink a plenty of fluid, (92.5%) of them poor practices regarding managing constipation, (92.5%) of them not encourage their leukemic adolescent to brushing teeth with a very soft toothbrush **(Table 2and 3).** The study shows significantly association between caregivers' knowledge and: level of education (p-value 0.025), residency areas (p-value 0.021), and there was a highly significant association between knowledge and practice with socio economic status (SES) (p-value 0.002) and (0.000) respectively (**Table 4 and 5).**

Table 1: Socio-demographic characteristic of caregivers:

Items	No.	%
Who is caregiver		
Mother	57	71.3
Father	4	5
Both parents	7	8.8
Sister	1	1.2
Brother	8	10
Aunt	3	3.7
Age of caregiver		
18-23	6	7.5
24-29	3	3.8
30-35	19	23.8
36-41	21	26.3
41 and above	31	38.6
Level of education		
Illiterate	37	46.2
Can read and write	24	30
Graduate primary school	8	10
Graduate secondary school	2	2.5
Graduate preparatory school	4	5
Graduate institute and college	5	6.3
Occupation of caregiver		
Governorate employee	9	11.2
Private employee	9	11.2
Housewife	61	76.3
Retired	1	1.3
Marital status of caregiver		
Single	9	11.2
married	63	78.8
Widowed	8	10
Residency of caregiver		
Urban	27	33.8
Rural	53	66.2
Socio-Economic Status (SES)		
Low SES	58	72.5
Middle SES	20	25
High SES	2	2.5
Total	80	100

Table 2: Caregivers' knowledge regarding leukemic disease

	Items	No	%	Yes	%	MS	SD
1	Leukemia is a disease which is called blood cancer.	45	56.25	35	43.75	1.43	0.499
2	The exactly causes of leukemia is still unknown.	72	**90**	8	10	1.1	0.301
3	The definite diagnosis is made a by bone marrow examination.	61	76.25	19	23.75	1.23	0.428
4	The most common symptom of leukemia is pallor.	53	66.25	27	33.75	1.33	0.475
5	Long bone pain is another symptom.	62	77.5	18	22.5	1.22	0.420
6	Leukemia can be treated by ordinary antibiotics.	59	73.75	21	26.25	1.26	0.442
7	Leukemia can be treated only by chemotherapy.	55	68.75	25	31.25	1.31	0.466
8	Bone marrow transplantation can sometimes save patient's life.	64	80	16	20	1.2	0.402
9	Common side effects of chemotherapeutic agents are nausea and vomiting.	60	75	20	25	1.25	0.435
10	Alopecia results from chemotherapy treatment.	53	66.25	27	33.75	1.33	0.475
11	Chemotherapy can cause mouth ulcers.	63	78.75	17	21.25	1.21	0.411
12	Fatigue is a result of the disease process.	57	71.25	23	28.75	1.28	0.455
13	Poor diet increases fatigue.	64	**80**	16	20	1.2	0.402
14	Good diet can reduce the fatigue.	64	**80**	16	20	1.2	0.402
15	Psychological stress is common among leukemic patients.	68	**85**	12	15	1.15	0.359
16	Social isolation can be a result of the leukemia disease.	63	78.75	17	21.25	1.21	0.411
17	Leukemia is a disease which needs repeated hospitalization.	57	71.25	23	28.75	1.28	0.455
18	Leukemia is a disease which needs specific treatment.	57	71.25	23	28.75	1.28	0.455

Table 3: Caregivers practices regarding leukemia disease.

ID	Items	No	%	Yes	%	MS	SD
1	Hand washing before and after preparing food.	34	42.5	46	57.5	1.57	0.497
2	Small meals and snacks when he/she has nausea.	77	**96.25**	3	3.75	1.03	0.191
3	Encourage to 5 or 6 small meals and snacks instead 3 large meals.	74	**92.5**	7	8.75	1.07	0.265
4	Avoid eating big meal before sleep.	6	7.5	73	**91.25**	1.08	0.284
5	Give large amount of fresh fruit and vegetables.	44	55	36	45	1.45	0.500
6	Choose foods that are moist, soft and easy to chew and swallow.	73	**91.25**	7	8.75	1.08	0.284
7	Avoid fatty diet when the patient has diarrhea.	71	88.75	9	11.25	1.11	0.317
8	Encourage to drink 8 to 12 cups of clear liquids each day.	75	**93.75**	5	6.25	1.06	0.243
9	Advice fiber diet when the patient has constipation.	74	**92.5**	6	7.5	1.07	0.265
10	Avoid patient’s contact with ill people.	33	41.25	47	58.75	1.58	0.495
11	Avoid staying in crowded and dusty areas.	37	46.25	43	53.75	1.53	0.501
12	Encourage to reduce the use of caffeine and nicotine.	67	83.75	13	16.25	1.16	0.371
13	Avoid sharp and hard material forms.	60	75	20	25	1.25	0.435
14	Avoid direct sunlight.	70	87.5	10	12.5	1.12	0.332
15	Encourage to wear a hat or a cap for alopecia.	58	72.5	22	27.5	1.27	0.449
16	Check the mouth and tongue every day.	69	86.25	11	13.75	1.13	0.346
17	Encourage brushing teeth, gums, and tongue after each meal and at bed time.	70	87.5	10	12.5	1.12	0.332
18	Encourage brushing teeth with a very soft toothbrush.	74	**92.5**	6	7.5	1.07	0.265
19	Encourage adequate sleep of at least 8 hour each night.	63	78.75	17	21.25	1.21	0.411
20	Encourage deep breathing when feeling anxiety, and depression.	70	87.5	10	12.5	1.12	0.332
21	Encourage exercise.	70	87.5	10	12.5	1.12	0.332
22	Encourage social activity.	61	76.25	19	23.75	1.23	0.428

Table 4: Association between caregivers' knowledge and some of socio-demographic characteristics.

Knowledge						
Score / **Level of education**	**No**		**Yes**		**Total**	
	N	%	N	%	N	%
Illiterate	32	40	5	6.25	37	46.25
Can read and write	22	27.5	2	2.5	24	30
Graduate primary school	5	6.25	3	3.75	8	10
Graduate secondary school	2	2.5	0	0	2	2.5
Graduate preparatory school	2	2.5	2	2.5	4	5
Graduate institute and college	2	2.5	3	3.75	5	6.25
Total	**65**	**81.25**	**14**	17.5	80	100
p-value = 0.025		df= 5			X^2 = 12.832^a	

Score / **Residency of caregiver**	**No**		**Yes**		**Total**	
	No.	%	No.	%	No.	%
Urban	**18**	22.5	9	11.25	**27**	33.75
Rural	47	58.75	6	7.5	53	66.25
Total	65	81.25	14	17.5	**80**	100
p-value = 0.021		df= 1			X^2 = 5.689^a	

Score / SES	**No**		**Yes**		**Total**	
	No.	%	No.	%	No.	%
Low SES	**51**	63.75	**7**	8.75	**58**	72.5
Middle SES	14	17.5	5	6.25	19	23.75
High SES	1	1.25	2	2.5	3	3.75
Total	**65**	81.25	**14**	17.5	**80**	100
p-value = 0.002		df= 2			X^2= 12.028^a	

Table5: Association between caregivers' practice and their socio-economic status

Practice						
Score SES	**No**		**Yes**		**Total**	
	No.	%	No.	%	No.	%
Low SES	**56**	70	**2**	2.5	58	72.5
Middle SES	16	20	4	5	20	25
High SES	0	0	2	2.5	2	2.5
Total	**72**	90	**8**	10	80	100
p-value = 0.000		df= 2			X^2= 22.989[a]	

DISCUSSION:

Our study indicated that the most (71.3%) of the caregivers were mothers adolescent, that was in agreement with a study in Thailand mentioned that the majority of caregivers who care leukemic patient were mothers [5]. The majority of Indonesian leukemic caregivers (76%) were child's mother[11], other study was conducted in Brazil shows caregivers were patient's mother[12]. The caregivers are mostly the patient's spouse, partner or closest relatives, and females are more tuned to the caring function at home[4,6].

The present study reveals that (31%) of caregiver's age were between (39-48) years old, the mothers in this age should have good experience for caring to their children, this result was in agreement with a study which conducted in Jordan and founded that the caregivers age was between 19 to 50 years old [13].

With regards to caregivers level of education the study shows that approximately half of participant (46.2%) were illiterate and (30%) have 1 to 6 years of formal education, this emphasizes that majority (74.2) of caregiver having low level of education regarding caring their leukemic adolescent. Alexander reported that the majority of parents were not much educated, and he found that (25%) were illiterate and (45%) have their education till grade 10 [14]. This was in disagreement with a study which was conducted on Jordanians' caregivers and found that the education level of participants ranged from (2 to 18) years [13], (46.7%) were secondary school graduate and could read and write[15], (63.7%) could read and write [12.]

Most (76.3%) of caregivers' occupation were housewives. This result indicated that the main occupation of females in our society was housewives. This result was supported by Al-Jauissy who found that the majority (78.1%) of participants of caregivers were females[13].

And majority (78.8%) of caregivers were married; it indicated that the caregivers have other roles at home regarding caring other siblings that was in an agreement with a study done in Jordan which was found that (70.7%) were married [13].

With respects to the residency areas our result found that most (66.2%) of caregiver were coming form rural areas, and the study notes the distance between caregivers residency area and the hospital that is approximately 200 Kilometres. This result supported by Al-Jauissy who is found that the distance between participants' home and hospital ranged from 20 to 60 miles, and the average time required to travel from home to hospital that was 64 minutes [13,15].

Our finding result shows that (72.3%) of caregivers living with low SES. A study conducted in Thailand which mentioned that the majority of cancer caregivers were belonged to the lower SES class[5]. The concerns relating to the family's well-being change in role and responsibilities, relocation, travelling, difficulty arranging blood and its products, and financial difficulties are facing after the diagnosis of leukemia[14]. And disagreed with a study on Brazilian cancer caregivers were living with intermediate SES [12].

Our finding shows that (90 %,) of caregivers have deficient knowledge regarding causes and symptoms of the disease, and (80%) have deficit knowledge regarding the importance of nutrients, and (85%) also have deficit knowledge about the psycho-social

aspects during supporting, and managing the leukemia patients respectively. Knowledge of the specific diagnosis and details of treatment can help caregivers to provide good caring, and implement appropriate interventions. Parents differ in how much information they need or feel they can handle about the disease[15]. However, less than 50% of parents raise such topics, and parents report that only 15% to 20% of physicians assess the family's psychosocial issues [14.]

Our result shows the majority of caregivers have poor practice regarding the preparing small meals and snacks when they have nausea, and encourage their patient to 5 to 6 small meals and snacks instead 3 big meals respectively, the (93.75%) have poor practice regarding necessity of fluids, while (92.5%) of them had very poor practice regarding their complication such as constipation and oral ulcer. International cancer institute has been encouraging caregivers to provide home management regarding the needs of adolescent leukemic patient which are including fiber diet, fluid, oral hygiene and constipation management[16]. (92.5%) of caregivers have deficit practices to encourage their leukemic adolescent from brushing teeth, gums, and tongue after each meal and at bed time. Oral health influences both the development and severity of treatment related mucositis[17]. Some of persons with cancer interfere with the ability to chew, swallow, or digest food [18].

The study shows highly significantly association between caregivers' knowledge and level of education (p-value 0.025). Most important variables associated with insufficient knowledge were low educational level [15]. **Lack of knowledge regarding pediatric management of symptom-relief is one of the barriers,** several resources are available to help patients and their families become more knowledgeable about cancer and treatment options, gain support from nurses, and obtain help with practical concerns [14] And supported by Publica stated that the poorer knowledge, attitude and practice of mothers with hospitalized children may have lack caring[17]. Some studies reported that the caregivers assume approximately 50%–55% of the total care required for patients with cancer at home. The education and support needs of caregivers should be considered when designing home care plans for cancer patients[15].

There is highly significant association (p-value 0.021) between caregiver's knowledge and their residency areas. This result was in agreement with the study conducted in Brazil who indicated that the place of residency was associated with sufficient knowledge and practices for mothers providing care for their children [12]. There is highly significant association between SES and caregivers' knowledge and practices (p-value 0.002 and 0.000) respectively. The specific qualities, or basic care giving skills, and knowledge of the caregiver affect the child's survival, health, growth, and security for exploration and learning [5]. In another study indicated that there were statistically significant differences among parents who had different income and different education level of their leukemic child at $p<0.001$ [13]. These people, due to less resources and larger family size face a lot of problems relating to economic circumstances, change in role and responsibilities and accommodation away from home. In India, (60.2%) of these children comes from low economic status families[19]. And the majority of leukemia child caregiver belonged to Low SES and low knowledge and practice[9]. Low SES is associated with a high mortality due to later diagnoses and less aggressive treatments for cancer [20].

CONCLUSION: Our study found that the majority of caregivers were housewife, illiterate, married, rural sitting, low SES. And they have deficient knowledge and poor child care skill. This study recommends updating health interventional program to improve their knowledge and practices.

REFERENCES

1. Tomlinson D, and Kline NE. pediatric oncology nursing- Advanced clinical handbook, Springer-Verlag Berlin Heidelberg, Printed in Germany 2003, pp. 2-23,162-190
2. Behrman RE, Kingman RM, and Jenson HB. Nelson text book of pediatric. Tubingen DG, and Bleyer A. The leukemia, Chapter 487 in book. The leukemia. 17edition, sanders, printed in China 2004, pp, 1694-1697.

3. IRAQI CANCER BOARD. Iraqi cancer registry 2005, Ministry of health, Iraqi cancer registry center, Iraqi_cancerboard@yahoo.com. BAGHDAD – IRAQ. 2008. Table 2 page 20.
4. Saeui W, Chintanadilo N, Sriussadaporn P, Sanasuttipun W. The Effects of an Empowerment Program on the Competence of Caregivers in Caring for Preschool Children with Acute Leukemia Undergoing Chemotherapy *J Nurs Sci* 2009 Vol.27 No.2 S1 May-Aug.
5. American Cancer Society. Cancer facts and figures. Atlanta GA, Author. Grunberg SM, Deuson RR, Mavros P, Geling O, Hansen M, Cruciani G , and et al. 2004. Incidence of chemotherapy-induced nausea and emesis after modern antiemetics. Cancer, 2008, 100(10), 2261–2268.
6. Blum D. Care giving for Your Loved One with Cancer, cancer care helps and hope, 2008, www.cancercare.org. pp 1-20.
7. Grov E K, Dahl A A, Moum T and Fossa S D. Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase, Annals of Oncology 2003 Vol, 16: 1183–1191, doi: 10.1093/annonc/mdi210, annonc.oxfordjournals.org by Shukir S. Shwani on April 3, 2010.
8. McMillan S C, Small B J, Weitzner M, Schonwetter R, Tittle M, Moody L and et al. Impact of coping skills intervention with family caregivers of hospice patients with cancer. Cancer, 2006 Vol(106), Issue 1, pages 214–222, 1 January. doi: 10.1002/cncr.21367.
9. Iqbal A and Siddiqui Kh S. DEPRESSION AMONG PARENTS OF CHILDREN WITH ACUTE LYMPHOBLASTIC LEUKEMIA, Shaukat Khanum Memorial Cancer Hospital and Research Centre, Lahore. Pakistan, 2010, pp 1-4.
10. Stiff PJ. The Challenges of Oral Mucositis and Its Therapy, J Support Oncol 2004;2(2):70–72, www.SupportiveOncology.net.
11. Sitaresmi M N, Mostert S, Gundy Ch, Sutary M , and Veerman A JP. Health related quality of life assessment in Indonesian childhood acute lymphoblastic leukemia, 2008 , Health and Quality of Life Outcomes, This article is available from: http://www.hqlo.com/content/6/1/96.
12. Scarpelli AC, Paiva S M, Pordeus I A, Ramos-Jorge M L, Varni J W and Allison P J. Measurement properties of the Brazilian version of the Pediatric Quality of Life Inventory (PedsQL™) cancer module scale, Health and Quality of Life

Outcomes 2008, 6:7 doi:10.1186/1477-7323-6-7, This article is available from: http://www.hqlo.com/ content/6/1/7.

13. Al-Jauissy MS. Health care needs of Jordanian caregivers of patients with cancer receiving on an outpatient basis, Eastern Mediterranean Health Journal, Oct 2010, Vol 16 No. 10. pp. 1-8.
14. Alexander LL. Childhood Leukemias and Lymphomas, CME Resource • September 29, 2009 , pp 1-95 www.NetCE.com.
15. Sharpe L. The relationship between available support, unmet needs and caregiver burden in patients with advanced cancer and their carers. Psycho-Oncology, 2005, 14:102 –114.
16. National cancer institute. Chemotherapy and you: support for people cancer, side effects and Ways to Manage Them, US national cancer institute, 2011 www.cancer.gov. P 1.
17. Gates RA, and Fink RM. Oncology Nursing Secrets, third edition, Mosbey elesevier, Newjersy, (2008) P 398, 410, 483.
18. Lanhgorne ME, Fulton JS, and Otto ShE. Oncology Nursing, fifth edition, Mosbey Elesvier, (2001) printed in United States of America, pp, 505-607.
19. Publica C. The medical caregiver to a population based sample of children with leukemia, lancet J, Vol. 1999, No. 176, p.1128.
20. Byers TE, Wolf HJ, Bauer KR. The impact of socioeconomic status on survival after cancer in the United States. Cancer. 2008; 112:382-391.