

Mothers' Health Care of their Children with Leukemia

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Abstract: Children having leukemic usually suffer from many health problem as a result of the disease process. **The purpose of the study was** to assess knowledge and practices provided by mothers for the care of their children having leukemia. **Research design:** A descriptive research design was utilized to conduct this study. **Setting:** The present study was conducted at out- patient clinic of pediatric oncology in the National Cancer Institute at Cairo University. **Sample:** A simple random sample was used to collect the total number of the sample was 366 mothers. **One instrument was used;** A) structured interviewing questionnaire it had four parts: 1. Demographic characteristic of the children, 2. Demographic characteristics of the mothers, 3. Exposure of the mothers to risk factors of leukemia, 4. Medical history of the disease as past and present history. B). Mothers' knowledge questionnaire sheet, C). Reported practices questionnaire sheet. **Results:** 64.2% of studied sample had poor knowledge, 83.3% had satisfactory total reported practices. Conclusion: An approximately two thirds of mothers (64.2%) had poor knowledge. Where more than three quarters of them had satisfactory practices (83.3%).**Recommendation:** Health education programs for mothers who having children with leukemia to prepare them with needed knowledge and skills. This study can be applied on a larger sample at other setting.

Key words: Leukemia, Knowledge, Practices.

Introduction

Childhood is a period of play, physical, mental, social, emotional growth, and development, creation, hyperactivity, stress, strain, responsible to school and educational environment. School age constitutes a big sector of the population. The children are a god's gift for a family, child has been more vital, gentle, joyous, trustful, curious, courageous and more innovative than adult, children bring happiness and makes a family a whole, children health have to be family health (James et al., 2015).

Leukemia is a cancer of bone marrow characterized by over production of abnormal white blood cells that range from very primitive and immature to nearly normal. The abnormal cells cannot defend the body against microorganisms and tissue injuries. Leukemia has three major effects; increased number of abnormal, immature leukocytes; accumulations of

these cells within the lymph nodes, spleen, and other organs. Treatment of leukemia is increasing the overall the last 5-year survival rates for childhood cancers are approximately 80%, cancer is still the second leading cause of death(following accidents) in children aged from 8-18 years old (Leukemia and Lymphoma Society, 2017).

A community health nurse plays a critical role to educate family members, friends, school personnel and healthcare providers about possible long-term and late effects of treatment, guide the parent to help the leukemic child to live within normal life between the family and their peers, and communicate with teachers about the child's need. The well-being of the community served is the community health nurse's primary goal and is achieved through the education of community members on health practices and disease prevention, the

basic element of community health nursing are promotion of healthful living, prevention of health problems, treatment of disorders and rehabilitation (Follin et al., 2014).

Significance of the study

Leukemia is a cancer of bone marrow, the soft inner part of bones where new blood cells are made, leukemia account for approximately 14% of all deaths worldwide, estimated 12.66 million new cancer cases and 7.56 million deaths occurred in 2011 worldwide, and it is the second leading death in developed world. By 2030, there will be almost 21.4 million new cases annually diagnosed (James et al., 2015).

Leukemia developed in 352,000 people globally and caused 265,000 deaths. It is the most common type of cancer in children. With three quarters of leukemia cases in children being the acute lymphoblastic type. It occurs more commonly in the developed world (American cancer society, 2017).

In Egypt, childhood leukemia is the most common childhood malignancy, it represents 33.2% of all childhood malignancies, and those children represent 73.3% of all leukemic children in National Cancer Institute, Cairo University. More than 65 million mothers play a major role in maximizing the health and quality of life of individuals with acute and chronic leukemia (National cancer institute, 2018). A recent forecast modeling study for mothers' health care of their children with leukemia.

Purpose

The purpose of this study was to assess the knowledge and practices are provided by mothers for the care of their children having leukemia.

1. Assessing the mothers' knowledge regarding to leukemia.

2. Assessing the mothers' practices regarding to care of their leukemic children.

Research Questions:

1. What is the level of mothers' knowledge score regarding leukemia?
2. What is the level of mothers' practices for the care of their children having leukemia?

Subjects and Methods

Research Design: -

A descriptive research design was utilized to conduct this study.

Setting:-

The present study was conducted at out-patient clinic of pediatric oncology at National Cancer Institute Cairo University.

Sampling:-

Simple random sample was used in this study. The total number of children diagnosed with leukemia was 4320. The size was determined according to the following equation

$$n = \frac{N}{1+N(e)^2}$$

Criteria of the sample: Children should range from 5-14 years.

Instruments:

Instrument one:-A structured interview questionnaire it is developed by the researcher to collect data about characteristics of the sample it included three parts:

- 1) **Part A:** It included four parts:
 - Demographic characteristic of the children,

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- The socio characteristic of the mothers' as, Age, education, occupation, etc.....
- Exposure of the mothers to risk factors of leukemia,
- Medical history of the disease as past and present history.

2) **Part B.** Mothers' knowledge about meaning of leukemia, diagnosis of leukemia, treatments, etc.....

3) **Part C.** Mothers reported practices for the care of their children with leukemia such as care of symptoms and side effects of chemotherapy as bleeding, nausea and vomiting, hyperthermia, infection, etc.....

Results

Table (1): Distributions of studied children regarding their demographic characteristics (n=366).

Demographic Characteristics of the children	No	%
Age /year		
5 -	142	38.8
8 -	114	31.1
11+	110	30.1
Mean &SD	9.3±2.6	
Gender		
Male	237	64.8
Female	129	35.2
Residence		
Rural	263	71.9
Urban	103	28.1
Education		
Can't Read & Write	90	24.6
Read & Write	70	19.1
Primary	147	40.2
Preparatory	59	16.1
Birth order		
First	95	25.0
Second	138	44.4
Third or more	133	30.6

Table (1): Showed that, 38.8% of the children aged from 5-8 years old with the mean age (9.3±2.6) years, and 64.8% were males, while 71.9% were

living in rural areas, 40.2 % had primary education, and 44.4 % leukemic children were the second child in birth order.

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Table (2): Distribution of studied mothers regarding their demographic characteristics
(n= 366).

Demographic Characteristics of mothers	NO	%
Age/ Year		
18 –	60	16.4
25 –	161	44.0
32 +	145	39.6
Mean &SD	29.8±6.1	
Marital status		
Married	232	63.4
Widow	56	15.3
Divorced	78	21.3
Occupation		
Worker	183	50.0
Not working	183	50.0

Table (2): Demonstrated that, 44.0% of the mothers aged from 25-32 years with mean age 29.8±6.1, 63.4% of mothers were married and equal percent 50.0 % between worker and not working mothers.

Table (3): Distribution of studied mothers regarding to their exposure of risk factors of leukemia (n= 366).

Exposure the mothers to the risk factors of leukemia	NO	%
Exposure to radiation in the first trimester of pregnancy		
Yes	166	45.4
No	200	54.6
Parents' consanguinity		
Yes	159	43.4
No	207	56.6
Mothers smoking		
Yes	0	0.0
No	366	100.0
Exposed to smoke at home		
Yes	259	70.8
No	107	29.2

Table (3): Demonstrated that, 54.6% of the mothers were not exposed to radiation in the first trimester of pregnancy, 56.6 % had no consanguinity, while all mothers didn't smoke and 70.8 % had exposed to smoke at home.

Table (4): Distribution of studied mothers regarding their knowledge about leukemia (n=366).

Mothers knowledge about Leukemia	Correct Complete		Correct Incomplete		Incorrect	
	No.	%	No.	%	No.	%
Leukemia						
Meaning	154	42.1	72	19.7	140	38.2
Predisposing factors	16	4.4	217	59.3	133	36.3
Types	21	5.7	130	35.5	215	58.8
Commonly affected age group	245	66.9	0	0.0	121	33.1
Symptoms	156	42.6	130	35.5	80	21.9
General complications	48	13.1	238	65.0	80	21.9
Prevention	41	11.2	176	48.1	149	40.7
Infection						
Predisposing factors of infection	132	36.1	198	54.1	36	9.8
Symptoms of infection	55	15.0	269	73.5	42	11.5
Normal body temperature	205	56.0	0	0.0	161	44.0
Sites of measurement	250	68.3	0	0.0	116	31.7
Sites of cold compresses	183	50.0	146	39.9	37	10.1
Anemia						
Meaning of anemia	291	79.5	0	0.0	75	20.5
Symptoms of anemia	167	45.6	163	44.5	36	9.9

Table (4): Illustrated that, 42.1% of mothers had correct complete knowledge regarding meaning of leukemia, 59.3% had correct incomplete knowledge regarding to predisposing factors, 58.8 % had incorrect knowledge regarding to types, 66.9 % had correct complete regarding to commonly affected age group, 42.6 % had correct complete knowledge regarding to symptoms, 83.1 % had correct incomplete knowledge regarding to complications, 65.0% had correct incomplete knowledge regarding to general complications of leukemia, 48.1% had correct incomplete knowledge regarding to prevention of

leukemia, 54.1% had correct incomplete knowledge regarding to predisposing factors of infection, 73.5% had correct incomplete knowledge regarding to symptoms of infection, 56.0% had correct complete knowledge regarding to normal body temperature, 68.3% had correct complete knowledge regarding to sites of measurement, 50.0% had correct complete knowledge regarding to sites of cold compresses, 79.5% had correct complete knowledge regarding to meaning of anemia, and 45.6% had correct complete knowledge regarding to symptoms of anemia.

Table (5): Distribution of studied mothers regarding to their knowledge about investigations of leukemia (n=366).

Mothers knowledge about investigation	Correct Complete		Correct Incomplete		Incorrect	
	No.	%	No.	%	No.	%
Types	83	22.7	265	72.4	18	4.9
Care before any procedure	84	23.0	147	40.2	135	36.8
Importance of bone marrow aspiration	76	20.8	230	62.8	60	16.4
Mothers' role after bone marrow aspiration	90	24.6	195	53.3	81	22.1
Importance of complete blood picture	80	21.9	240	65.6	46	12.5
Mothers' role after aspiration of blood sample	107	29.2	146	39.9	113	30.9

Table (5): Indicated that, 72.4% of mothers had correct incomplete knowledge regarding to types of leukemia investigation, 40.2% had correct incomplete knowledge regarding to care before any procedure, 62.8% had correct incomplete knowledge regarding to aim of bone marrow aspiration, 53.3% had correct

incomplete knowledge regarding to mothers role after bone marrow aspiration, 65.6% had correct incomplete knowledge regarding to aim of complete blood picture, and 39.9% had correct incomplete knowledge regarding to mothers role after aspiration of blood sample

Table (6): Distribution of studied mothers regarding to their knowledge about leukemia treatment (n=366).

Mothers knowledge about Treatment	Correct Complete		Correct Incomplete		Incorrect	
	No.	%	No.	%	No.	%
Types of treatment	99	27.0	240	65.6	27	7.4
Aim of chemotherapy	48	13.1	297	81.1	21	5.8
Routes of chemotherapy	18	4.9	77	21.0	271	74.1
Places of receiving chemotherapy	102	27.9	252	68.9	12	3.2
Complications of chemotherapy	93	25.5	261	71.3	12	3.2
Meaning of bone marrow transplantation	182	49.7	0	0.0	184	50.3
Source for bone marrow donation	14	3.9	200	54.6	152	41.5
Aim of blood transfusion	272	74.3	0	0.0	94	25.7
Mothers' role during blood transfusion	67	18.3	166	45.4	133	36.3
Time of disease relapse	16	4.4	120	32.8	230	62.8
Symptoms of relapse	118	32.2	0	0.0	248	67.8
Contraindicated drugs	49	13.4	181	49.4	136	37.2
Dangerous signs be reported immediately	85	23.2	212	57.9	69	18.9

Table (6): Demonstrated that, 65.6% of mothers had correct incomplete knowledge regarding to types of leukemia treatment, 81.1% had correct incomplete knowledge regarding to aim of chemotherapy, 74.1% had incorrect knowledge regarding to rout of chemotherapy, 68.9% had correct incomplete knowledge regarding to places of receiving chemotherapy, 71.3% had correct incomplete knowledge regarding to complication of chemotherapy, 50.3% had incorrect knowledge regarding to meaning of bone marrow transplantation, 54.6% had correct incomplete knowledge regarding to source of bone marrow

donation, 74.3% had correct complete knowledge regarding to aim of blood transfusion, 45.4% had correct incomplete knowledge regarding to mothers role during blood transfusion, 75.9% had correct incomplete knowledge regarding to aim of follow up after stop of drugs, 62.8% had incorrect knowledge regarding to time of disease relapse, 67.8% had incorrect knowledge regarding to symptoms of relapse , 49.4% had correct incomplete knowledge regarding to contraindicated drugs, and 57.9% had correct incomplete knowledge regarding to dangerous signs be reported immediately.

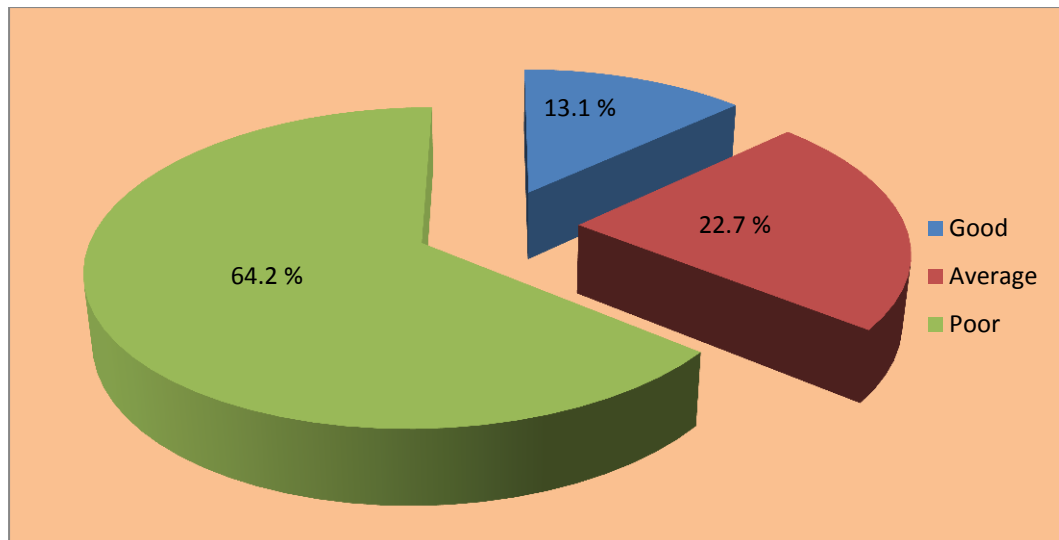


Figure 1: Illustrates that 64.2% of studied sample had poor knowledge score about leukemia, investigations, treatments, where as 22.7% had average knowledge score and 13.1% had good knowledge score.

Table (7A): Distribution of studied mothers regarding their reported practices about leukemia management (n=366).

Mother's practices regarding to leukemia	Done complete		Done incomplete		Not done	
	No.	%	No.	%	No.	%
Child follow up	302	82.6	0	0.0	64	17.4
Give the medications at home	198	54.1	101	27.6	67	18.3
Give the medications according to five right	75	20.5	119	32.5	172	47.0
Care of hyperthermia	84	23.0	0	0.0	282	77.0
Prevent of infection	104	28.4	250	68.3	12	3.3
Prevent of bleeding	93	25.4	225	61.5	48	13.1
Care of epistaxis	105	28.7	244	66.7	17	4.6
Manage of pain	35	9.6	306	83.6	25	6.8
Care of teeth and mouth inflammation	49	13.4	258	70.5	59	16.1
Manage of anorexia	62	16.9	285	77.9	19	5.2

Table (7A): Revealed that, 82.6% of mothers did regular child follow up, 54.1% gave medication at home, 47.0% didn't follow five rights of medication, 77.0% didn't care of hyperthermia, 61.5% did incomplete prevent of bleeding, 66.7% cared incomplete of epistaxis, 83.6% did management of pain incomplete, 70.5% did care of teeth and mouth inflammation incomplete, and 77.9% did management of anorexia incomplete

Table (7B): Distribution of studied mothers regarding their reported practices about leukemia management (n=366).

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Mother's practices regarding to leukemia	Done complete		Done incomplete		Not done	
	No.	%	No.	%	No.	%
Care of nausea & vomiting	74	20.2	243	66.4	49	13.4
Encourage the child to eat	85	23.2	272	74.4	9	2.4
Manage of anemia	59	16.1	301	82.2	6	1.7
manage of fatigue	63	17.3	294	80.3	9	2.4
Manage of diarrhea	135	36.9	222	60.7	9	2.4
Manage of constipation	152	41.5	205	56.1	9	2.4
Care of skin inflammation	120	32.8	232	63.4	14	3.8
Care of alopecia	160	43.7	164	44.8	42	11.5
Care of urine changes	92	25.1	203	55.5	71	19.4
Training the child to future follow up	199	54.4	0	0.0	167	45.6
Forms of child follow up	148	40.4	117	32.0	101	27.6

Table (7B): Revealed that, 66.4% did care of nausea and vomiting incomplete, 74.4% did encourage the child to eat, 82.2% did manage of anemia incomplete, 80.3% managed of fatigue incomplete, 60.7% did manage of diarrhea incomplete, 56.1% did

incomplete manage of constipation, 63.4% incomplete cared of skin inflammation, 44.8% incomplete cared of alopecia, 55.5% incomplete cared of urine changes, and 54.4% o did trained the child to future follow up.

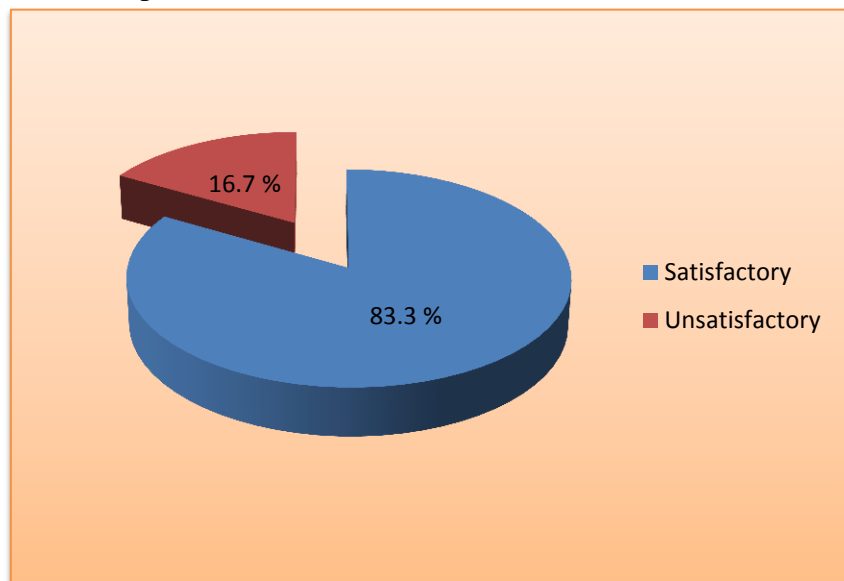


Figure 2: Reveals that, more than three quarters of study sample 83.3% had satisfactory practices score

regarding care of their children with leukemia while, 16.7% had unsatisfactory practices score.

Table (8): Characteristics of mother having different levels of knowledge about leukemia.

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Demographic characteristics of mothers'	Poor (n=235)		Average (n=83)		Good (n=48)		X ²	p-value
	No	%	No	%	No	%		
Age/Years								
18-	32	13.6	21	25.3	7	14.6	16.71	0.000
22-	106	45.1	25	30.1	30	62.5		
32+	97	41.3	37	44.6	11	22.9		
Education								
Can't read & Write	52	22.1	21	25.3	0	0.0	114.7	0.000
Read & Write	54	23.0	11	13.3	1	2.1		
Primary & Preparatory	44	18.7	25	30.1	0	0.0		
Secondary	64	27.2	5	6.0	16	33.3		
University	21	8.9	21	25.3	31	64.6		
Marital status								
Married	130	55.3	58	69.9	44	91.7	48.45	0.000
Widow	33	14.0	22	26.5	1	2.1		
Divorced	72	30.6	3	3.6	3	6.3		
Occupation								
Worker	115	48.9	25	30.1	43	89.6	43.31	0.000
Not working	120	51.1	58	69.9	5	10.4		
Parents' consanguinity								
Yes	99	42.1	40	48.2	20	41.7	0.98	0.61
No	136	57.9	43	51.8	28	58.3		

Table 8 reveals there was highly statistically significant difference between knowledge of mothers having

different ages, education, marital status and occupation.

Discussion

As regards total knowledge score of the studied mothers, this study showed nearly two third of studied sample had poor knowledge score about leukemia, investigations, and treatments (Figure 1). This finding was agreed with American Cancer Society, (2017) which mentioned in a similar study that most of mothers were poorly informed about the treatment and investigation of leukemia. This result indicated with Hani, et al., (2016) who found that, the majority (90%) of caregivers had deficient knowledge about treatments

and investigations of leukemia. On the same line, Gelesson et al., (2016) who conducted a study on 11 caregivers of children with cancer at chemotherapy outpatient clinic of the pediatric oncology institute of Sao Paulo, Brazil and indicated that, family caregivers of cancer patients had lack of knowledge and needed orientations about the disease.

Also National Comprehensive Cancer Network, (2016) which reported that, family caregivers had lack of knowledge of acute leukemia in

children undergoing chemotherapy. These results may be related to mother's educational level, place of residence and improper health education programs about their children condition from health care providers.

Concerning follow up for the child the study showed that, more than two third of mothers reported that, there were regular follow up for the children (Table 9A). This result was supported with Leukemia and Lymphoma Society, (2017) who stated that, follow up regimen or chemotherapy protocol was based on the child's type of leukemia and condition and the mothers should discuss with the physician the chemotherapy protocol and any variations in treatment.

Regarding mothers' knowledge about gave medication of the child at home, study result demonstrated that, more than half of mothers gave medication to their children; on the other hand less than half of mothers reported that, they didn't don five right of medication. This finding was in agreement with Gelesson et al., (2016) who showed that, the most of caregivers gave the medication to their leukemic children. This may be due to the frequent questions of mothers about medication. The study indicated that, more than three quarters of the mothers didn't care of hyperthermia. This result finding was agreed with WHO, (2017) who showed that, caregiver's action in case of hyperthermia was hurrying to hospital immediately because they were afraid from child convulsion. This may be due to mothers' educational level.

Regarding to mothers practices about prevention of infection, more than half of mothers' done incomplete prevent the infection. This result was supported with Michele et al., (2016) who revealed that, the majority of family caregivers were avoiding child's

contact with ill people and avoid staying in crowded and dusty areas was a measure to prevent child infection. This could be related to the frequent instructions that given to the mothers about measures to prevent child infection from physician and nurses.

The finding of present study revealed that the highest percentage of mothers did manage of epistaxis. This finding was in agreement with James et al., (2015) who found that, most of the caregiver in New York City knows to manage their children suffering from leukemia in developed countries. This may be related to lack of health education about home care of epistaxis or to mothers' fear that their children will lose a lot of blood and that these children are already anemic and this reflect on their health condition and the regularity of their chemotherapy session.

Regarding to management of pain, the finding of the present study revealed that, the majority of mothers had done incomplete. These findings were in agreement with Martinet al., (2016) who indicated that, to relief bone pain, warm compresses should be applied at the site of pain, massage site of pain, and administer analgesic according to doctor order.

As regards care of teeth and mouth inflammation, the finding of the present study showed that, more than two third of studied mothers had done incomplete. According to American Cancer Society, (2016) which found that, the most of caregivers use soft tooth brush and encourage rising mouth with warm water and take her child for regular dental checkup in case of teeth decay. This may be due to the mothers fear from teeth bleeding as these children had the tendency to bleed.

In relation to mothers' practices about anorexia management the present study found that, three fifths of the studied mothers had done incomplete. This

finding was supported by National Cancer Institute, (2018) mentioned that, there were many theories about the cause of anorexia in cancer patient, alteration in taste manifested by increased salty, sour and metallic taste lead to decreased appetite and decreased nutritional intake. This side effect could be caused by administration of chemotherapy agents. As regarding to care of nausea and vomiting, the present study revealed that more than three fifths of studied mothers had done incomplete (Table 9B). This finding was indicated with Leukemia and Lymphoma Society, (2017) which revealed that, the measures of care in case of nausea and vomiting should include offering small frequent meals and allowing the child to drink water and fluids between meals. In addition fatty, greasy or fried spicy and hot food should be avoided, limit the child's activity as well as avoid favorite food when the child is nauseated.

As regards constipation management, the present study reported that, more than half of studied mothers had done incomplete. This result was agreed with Fouad, (2013) who found that, administering fruits and vegetables, plenty of fluids and providing foods rich in fibers as cereals and bread to treat constipation. This may be related to administering plenty of fluids is the most common and simple known measure of care.

Regarding to care of skin inflammation practices, the finding of the present study revealed that, less than two third of studied mothers had done incomplete practices about skin inflammation. This finding was supported by Health Professional Version, (2016) which mentioned that, the majority of caregivers had adequate knowledge about care of skin inflammation and the measures of care include hand washing before contacting

the child, exposing site of inflammation to air to dry, drying skin with compression and applying ointment according to doctor order and caring of children's nutrition. This may because it was the treatment usually prescribed when mothers report to doctors about their children's skin inflammation and to mothers' believes especially in rural area, that medication is the best for treating any disease.

As regards care of alopecia and, the present study showed that less than half of studied mothers had done incomplete. This finding were in agreed with Zaki & Soke, (2015) who found that, the majority of family caregivers had adequate knowledge score about care of alopecia, and found that washing the child's head, wearing a scarf or hat or wig and avoid the use of hair pains are measures of care of alopecia. This may be explained in the light of children's psychological feeling with their hair loss and they want to hide their scolded head and cover it.

On accessing relation between mothers' knowledge and their demographic characteristics, the present study indicated that, there was highly statistically significant difference between mother's knowledge and their age, education, marital status, and occupation ($P = 0.000$). On other hand, there were no statistically significant differences between mother's knowledge and their parent's consanguinity ($P=0.610$) (Table 9). This result was supported by Fouad, (2013) and Hassan et al., (2015) who reported a highly statistically significantly between caregivers' knowledge and their age, education, marital status, and occupation. These finding were not in accordance with those of Oncology Nursing Society (ONS), (2017) which mentioned in USA that were no statistically significantly between caregivers' knowledge and their age, education,

marital status. This difference could be related to different communities and types of health care services.

Conclusion

Based on the results of the present study and research question, the following can be concluded:

More than three fifths of the mothers had poor knowledge score about leukemia, investigations, and treatments. More than three quarters of study sample had satisfactory reported practices score regarding to care of their leukemic children?

Recommendations

In the light of the result of present study, the following recommendations are suggested:

- Develop a health education programs for mothers who having leukemic children to prepare them with needed knowledge and skills and improve the public awareness about the early warning signs and symptoms of leukemia.
- Providing Pediatric Oncology Clinic with power point presentation showing mothers' principle steps for caring child with leukemia.
- Further researches should be conducted on a larger scope to explore more about the nursing strategies for caring of the child with leukemia.

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