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Parents' Perception regarding their Children Suffering from Acute Lymphoblastic Leukemia at Nasser Institute Hospital

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Abstract

Background: Acute lymphoblastic leukemia is a common cancer and life-threatening malignancy affects children health physically, psychologically and socially wellbeing over the world. Aim of the study: To assess parents' perception regarding their children suffering from acute lymphoblastic leukemia at Nasser Institute hospital. Setting: the study was carried out at pediatric cancer outpatient clinic at Nasser institute hospital. Sample: Convenience sample compromised 179 parents' had children suffering from acute lymphoblastic leukemia. Tool: A structured interview questionnaire consists of 4 parts Demographic characteristic of parents' and child, child medical history, parents' knowledge regarding acute lymphoblastic leukemia and Parents' reported practices regarding care of their children suffering from acute lymphoblastic leukemia. Results: 44.1 % of the studied parents had poor total knowledge and 31.8% of parents had fair level of knowledge regarding acute lymphoblastic leukemia. Also 58.2% of the studied parents had inadequate level of total reported practices, while 41.8% of parents had adequate level of practices regarding care of acute lymphoblastic leukemia child. Conclusion: More than two fifths of studied parents had poor total knowledge regarding acute lymphoblastic leukemia. Also more than half of the studied parents had inadequate total level of reported practices regarding care of their children suffering from acute lymphoblastic leukemia, there was a significant statistical positive correlation between total level of knowledge and total level of reported practices among the studied parents. **Recommendation:** Develop and implement health educational program to increase awareness and practices of parents about acute lymphoblastic leukemia.

Keywords: Acute lymphoblastic leukemia, Children, Parents perception.

Introduction

Leukemia is a malignancy of white blood cells that begins in the hematopoietic stem cells in the bone marrow. As the cancer cells increase, the bone marrow can no longer make adequate numbers of normal white blood cells, red blood cells, and platelets. Childhood Leukemia is the most common type of cancer among children. Nearly 39% of cancer-induced childhood deaths are attributable to leukemia in the United States (Cui et al., 2023).

Acute lymphoblastic leukemia (ALL) primarily affects young children (2–4 years of age), although it is also seen in adolescents and young adults. In this disease, too many stem cells differentiate into lymphoblast leading to the excessive overproduction of leukocytes, which cannot fight infections and a decreased number of circulating, healthy white and red blood cells (Radadiya et al., 2020).

Leukemia has two main types include lymphocytic leukemia and myeloid leukemia which subtypes to acute and chronic. The differences between subtypes are related to the kind of blood cells that are affected and the multiple rates of progressions. ALL represent about 75% of all pediatric leukemia cases and is five times more common than acute myeloid leukemia worldwide (Tilaoui et al., 2022).

The etiology of childhood acute lymphoblastic leukemia is still poorly understood to date, a few chromosomal and genetic abnormalities exposure to high-dose ionizing radiation prior chemotherapy, and high or low birth weight, growing

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body of research has targeted parental environmental and occupational exposures including pesticides and lifestyle factors (e.g., diet, coffee, alcohol consumption (Frederiksen et al., 2020).

Significance of the study

Childhood leukemia represents the most commonly diagnosed malignancy in children. About 80% of childhood leukemia diagnoses are caused by acute lymphoblastic leukemia, while about 15-20% of leukemia is Myeloid Leukemia. The incidence rate of ALL is 42 cases per million children, with a peak incidence in early childhood between ages 1 and 4 being nearly 100 cases per million. Incidence rates are higher in boys compared to girls up to the age of 19. Leukemia was the 15th most commonly diagnosed cancer and the 11th leading cause of cancer death globally, In Egypt, Childhood leukemia represents 35.6% of all incidents of childhood cancer (Vahedi et al., 2023).

Aim of the Study

The aim of this study was to assess parents' perception regarding their children suffering from acute lymphoblastic leukemia at Nasser institute hospital through the following objectives:

1. Assessing parents' knowledge regarding their children suffering from acute lymphoblastic leukemia.

2. Appraising parents' reported practices regarding care of their children suffering from acute lymphoblastic leukemia.

3. Determining relation between parents' knowledge and practices regarding acute lymphoblastic leukemia and their demographic characteristics.

Research questions:

1. What are the parents' knowledge regarding acute lymphoblastic leukemia?

2. What are parents' reported practices regarding care of their children suffering from acute lymphoblastic leukemia?

3. Is there relation between parents' knowledge and reported practices regarding acute lymphoblastic leukemia and their demographic characteristics?

Subjects and Methods

Research design:

A descriptive research design was used in this study.

Setting:

The study was conducted at outpatient clinic of pediatric cancer in Nasser institute Hospital

Sampling:

A Convenient sample compromised 179 parents' had children suffering from acute lymphoblastic leukemia

Tool for data collection:

A structured interview questionnaire: it consisted of four parts:

Part 1: Demographic characteristic of parents' included 8 questions as age, sex, educational level, marital status, occupation, monthly income, place of residence and what is the source of parental information about acute lymphoblastic leukemia and children demographic characteristic included 4 questions as age, sex, school grade and ranking between siblings.

Part 2: Child medical history includes:

(A) Present history included 3 questions as child current complains, when the complain start and follow up time.

(B) Past medical history included 5 questions as: Does the child suffer from any health problem before, if the answer is yes, what is the health problem, has the child had surgery before, if yes, then what is it and when was the child's surgery performed.

(C) Family medical history included 4 questions as is there a degree of kinship between the parents', if yes, what is it. are there cases in the family of other types of cancer and if found. who is it Part 3: Parents' knowledge regarding acute lymphoblastic leukemia included 10 questions as meaning of acute lymphoblastic leukemia, causes of acute lymphoblastic leukemia, symptoms of lymphoblastic leukemia, diagnostic methods of acute lymphoblastic leukemia, complications of acute lymphoblastic leukemia, the ways to treat acute lymphoblastic leukemia, the warning signs that calls the doctor visit immediately, the ways of preventing the





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disease, the health precaution that must be taken to care for a child with lymphoblastic leukemia and the importance of following up for the child.

Scoring system for parent's knowledge:

It was composed of 10 questions = 20 points categorized as:

- Complete correct answer =2 points
- Incomplete correct answer = 1 point
- Don't know = 0
- Total parents knowledge were ranged from 0-20 points and Classified as the following:
 - Poor knowledge < 50% = (< 10 points)
 - Fair knowledge $50 <75\% = (10 \le 15 \text{ points})$
 - Good knowledge $\geq 75\% = (\geq 15)$

Part 4: Parents' reported practices regarding care of their children suffering from acute lymphoblastic leukemia adapted from (El-Sawy et al., 2013), and modified by investigator included 6 main practices that subdivided into:

- 1. When giving medication included 2 questions as which you must make sure before giving treatment and the measures you take when giving injection to child
- 2. How to deal with the medication side effects included 9 questions as in case of appearing warning signs for the child, when a child bleed, to keep the child from bleeding, to protect the child from repeated infections, to reduce nausea and vomiting for the child, when the child temperature rises, to reduce anemia in the child, reduce child fatigue and to treat diarrhea
- 3. Parent practices regarding the correct nutrition of the child included 2 questions as how to prepare healthy meals for the child and in case of anorexia in child
- 4. Parental practices toward pain felt by the child and how control it included one question as when child feels pain.
- 5. Practices toward the child personal hygiene included 2 questions as practices used to care for the mouth and teeth of the child and practices followed for personal hygiene
- 6. Parents practices toward psychological state of the child included one question as help the child overcome negative feeling at home.

Scoring system for parents reported practices:

- It composed of 17 questions was scored as following:

- Always = 2 points
- Sometimes = 1 point
- Never = 0

The total score of parents reported practices were ranged from 0- 34 categorized as follows:

*Adequate if the score $\geq 60\%$ (≥ 20 points)

* Inadequate if the score < 60% (< 20 points)

Validity:

The developed tool was formulated and submitted to 3 expertises in Community Health Nursing, Helwan University to measures the validity of the tool and the necessary modifications were done accordingly as paraphrasing to sentences.

Tool reliability:

To assess reliability, the study tools were tested by the pilot subjects at first session and retested after 2 weeks a test – retest reliability for calculating cronbach alpha Parents in this study found to be 0.85 'knowledge item and 0.89 for Parents' reported practices items.

Ethical considerations:

An official permission to conduct the proposed study was obtained from the Scientific Research Ethics Committee, Faculty of Nursing, Helwan University. Participation in the study was voluntary and subjects were given complete full information about the study and their role before signing the informed consent. The ethical considerations include explaining the purpose and nature of the study, stating the possibility to withdraw at any time. Confidentiality of the information where it would not be accessed by any other party without taking permission of the participants. Ethics, values culture and beliefs were respected.





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II. Operational design:

Included preparatory phase, content validity, pilot study and field work.

Preparatory phase:

A review of past, current, national and international related literature and theoretical knowledge of various aspect of the study helpful in designing and processing of data collection tools were available books, journals, internet and article.

Pilot study:

The pilot study has been conducted to test clarity, applicability and understandability of the tool. It has been conducted on 10% (18) of parents. The results of the pilot helped in refining the interview questionnaire and to schedule the time framework. No modifications has been done so, the participants of the pilot were included in the main study sample.

Field work:

Data were collected through 3 months from beginning of July until end of September 2023

- The investigator introduced herself to participants, explained the aim of the study and its implications and how to fill in the knowledge questionnaire and ensure their cooperation.
- Informal consent was obtained from the participants. Interviewing participants was carried out in medicine outpatient clinic at private room, Aswan University Hospital.
- The questionnaire takes about 15-20 minutes to completed.
- Data was collected through two days (Saturday, Monday) per week from 9 A.M to 2 P.M 2 days. About 5 to 8 parents of acute lymphoblastic leukemia children per day.
- The questionnaire sheet was completed by the investigator from each participants.

III. Administrative designs:

An official permission was obtained was obtained from Dean of Faculty of Nursing, Helwan University and official permission was obtained from the director of the Nasser Institute hospital for conducting this study. This letter included a permission to collect the necessary and explain the purpose and nature of the study.

IV-Statistical Item:

Data collected from the studied sample was revised, coded, and entered using Personal Computer. Computerized data entry and statistical analysis were fulfilled using the Statistical Package for the Social Science (SPSS), version 24 for analysis. Data were presented using descriptive statistics in the form of frequencies, percentage Chi-square test X2 was used for comparisons between qualitative variable. Spearman correlation

measures the strength and direction of association between two ranked variables. Also used mean standard deviation (SD).

Significance of the results:

P-value < 0.001= Highly Significant (HS).

P-value $\leq 0.05 =$ Significant (S).

P-value > 0.05= Non-Significant (NS).





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Table (1): Frequency Distribution of the Studied Parents according to their Demographic Characteristics (n=179)

Parents demographic characteristics	No	%			
Age (years)					
20 - < 30	37	20.7			
30 - < 40	56	31.3			
40 -50	86	48.0			
Mean ± SD	37.21±6.35				
Sex					
Male	51	28.5			
Female	128	71.5			
Educational level					
No read & write	4	2.2			
Read and write	9	5.0			
Basic education	37	20.7			
Secondary education	94	52.5			
University education or more	35	19.6			
Marital status					
Married	156	87.2			
Divorced	14	7.8			
Widowed	9	5.0			
Occupation					
Employee	60	33.5			
Unemployed/ House wife	119	66.5			
Monthly income					
Not enough	114	63.7			
Enough	54	30.2			
Enough and save	11	6.1			
Place of residence					
Rural	101	56.4			
Urban	78	43.6			

Table (1): Shows that, 48.0% of the studied parents were in age group 40 -50 years old with mean age 37.21±6.35 years and 71.5% of them were females. Also, 52.5% of them had secondary education and 87.2% of them were married. Additionally, 66.5% of them were unemployed/ house wife and 63.7% of them reported not enough monthly income and 56.4 of them lived in rural areas.





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Table 2: Frequency Distribution of the Studied	d Child Demographic Characteristics (n= 179).
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Child demographic characteristics	No.	%					
Child age (years)							
6 -< 9	71	39.7					
9 -< 12	36	20.1					
12 -15	72	40.2					
Sex	·	·					
Male	129	72.1					
Female	50	27.9					
School grade							
1-3 primary	65	36.3					
4- 6 primary	42	23.5					
1-3 preparatory	72	40.2					
Ranking between sibling							
The first	29	16.2					
The second	35	19.6					
The third	58	32.4					
The fourth	57	31.8					

Table (2): Shows that, 40.2% of the studied child was in age group 12 -15 years and 72.1% of them were males' child. Also, 40.2% of them were in 1-3 preparatory and 32.4% of them were the third child between siblings.

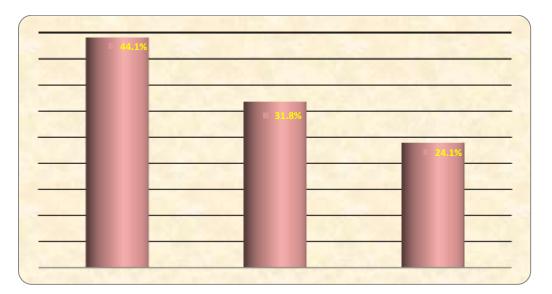


Figure (1): Percentage Distribution of the Studied Parents Total Level of Knowledge regarding Acute Lymphoblastic Leukemia (n=179).

Figure (1): Illustrates that, 44.1% of the studied parents had poor total knowledge level and 31.8% of them had fair level of total knowledge while, 24.1% of them had good level of total knowledge regarding acute lymphoblastic leukemia.





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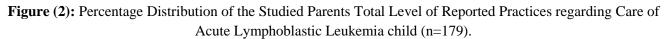


Figure (2): Illustrates that, 58.2% of the studied parents had inadequate total level of reported practices and 41.8% of them had adequate total level of reported practices regarding care of acute lymphoblastic leukemia child.

Table (3): Relation between Demographic Characteristics of the Studied Parents and their Total Level of Knowledge (n=179).

Demographic characteristics		Total level of knowledge							
		Poor (n=79)		Fair (n=57)		Good (n=43)		\mathbf{X}^2	P-value
		No	%	No	%	No	%		
Age (years)	20 < 30	8	4.5	14	7.8	15	8.4		*0.011
	30 < 40	28	15.6	14	7.8	14	7.8	3.064	S))
	40 -50	43	24.0	29	16.2	14	7.8		((8
Sex	Male	22	12.3	14	7.8	15	8.4	1.311	0.519
	Female	57	31.8	43	20.0	28	15.6	1.311	NS))
Educational level	No read & write	4	2.2	0	0.0	0	0.0	4.192	
	Read and write	9	5.0	0	0.0	0	0.0		*0 002
	Basic	14	7.8	15	8.4	8	4.5		*0.003 S))
	Secondary	45	25.1	45	19.6	14	7.8		
	University	7	3.9	7	3.9	21	11.7		
Marital status	Married	77	43.0	41	22.9	38	21.2	7.914	0.637
	Divorced	0	0.0	14	7.8	0	0.0		0.037 (NS)
	Widowed	2	1.1	2	1.1	5	2.8		(113)
Occupation	Employee	26	14.5	17	9.5	17 9.5 1.061 0.500			
	Unemployed/ House wife	53	29.6	40	22.3	26	14.5		0.588 (NS)
	Enough	12	6.7	27	15.1	15	8.4	7.213	0.254
	Not enough	62	34.6	27	15.1	25	14.0		0.354
	Enough and save	5	2.8	3	1.7	3	1.7	1	(NS)
Residence	Rural	44	42.6	36	20.1	21	11.7	2.075	0.002*
	Urban	35	19.6	21	11.7	22	12.3	2.075	(S)





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Table (3): Shows that, there was a significant statistical relation between age, educational level and residence of the studied parents and their total level of knowledge P-value = 0.011, 0.003 and 0.002 respectively. While, there was no significant statistical relation between sex, marital status, occupation and monthly income of the studied parents and their total level of knowledge P-value = 0.519, 0.637, 0.588 and 0.354 respectively.

Table (4): Relation between Demographic Characteristics of the Studied Parents and their Total Level of Reported Practices (n=179)

			Total reported practices					
Demographic characteristics		Adequate (n=75)		Inadequate (n= 104)		\mathbf{X}^2	P-value	
		No	%	No	%			
Age (years)	20 < 30	12	6.7	25	14.0		0.006*	
	30 < 40	24	13.4	32	17.9	1.804	S))	
	40 -50	39	21.8	47	26.3		3))	
Sex	Male	20	11.2	31	17.3	0.211	*0.037	
	Female	55	30.7	73	40.8	0.211	S))	
Educational level	No read & write	1	0.6	3	1.7			
	Read and write	5	2.8	4	2.2		0.739 (NS)	
	Basic	13	7.3	24	13.4	1.981		
	Secondary	41	22.9	53	29.6		(115)	
	University	15	8.4	20	11.2			
Marital status	Married	69	38.5	87	48.6	3.030 0.22 (NS		0.220
	Divorced	3	1.7	11	6.1			
	Widowed	3	1.7	6	3.4		(115)	
Occupation	Employee	26	14.5	34	19.0	0.076	0.453	
	Unemployed/ House wife	49	27.4	70	39.1		0.453 (NS)	
Monthly income	Enough	21	11.7	33	18.4	0.375	0.042* (S)	
	Not enough	51	28.5	63	35.2			
	Enough and save	3	1.7	8	4.5			
Residence	Rural	45	25.1	56	31.3	0.671	0.447	
	Urban	30	16.8	48	26.8		(NS)	

 X^{2} test= Chi-Square test P-value > 0.05= Non-significant (NS) *P-value ≤ 0.05 = Significant (S)

Table (4): Shows that, there was a significant statistical relation between age, sex, and monthly income of the studied parents and their total level of reported practices P-value = 0.006, 0.037 and 0.042 respectively. While, there was no significant statistical relation between, educational level, marital status, occupation and residence of the studied parents and their total level of reported practices P-value = 0.739, 0.220, 0.453 and 0.447 respectively.





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Table (5): Correlation between Total Level of Knowledge and Total Level of Reported Practices among the Studied Parents (n=179).

Variables	Total level of knowledge				
	r	P-value			
Total level of reported practices	0.628	0.019* (S)			

Table (5): Shows that, there was a significant statistical positive correlation between total level of knowledge and total level of practices among the studied parents P-value = 0.019.

Discussion:

Acute lymphoblastic leukemia is a cancer of children blood forming tissues, including bone marrow and the lymphatic system. Usually, it has an impact on white blood cells which normally act as potent infection fighters. While leukemia can occur at any age, the mutations that cause childhood leukemia often differ from those that cause adult leukemia. Childhood leukemia arises from blood progenitors that begin developing before birth (Mendoza & Magee, 2023). Childhood leukemia is a persistent global health issue representing nearly one-third of all pediatric cancers. The worldwide incidence rate of childhood leukemia is approximately 17.3 new cases per 100,000 children (Onyije et al., 2022).

Regarding demographic characteristics of the studied parents, the finding of the present study indicated that nearly half of the studied parents were in age group 40 -50 years, with mean age 37.21 ± 6.35 years and less than three quarters of them were female (table1).

The present findings were agreed with the study done by Hamad and Shaker, (2019) conducted a study to assess" The coping strategies among caregivers of children with acute leukemia " in Iraq (n=54). The study results proved that caregivers mean age was 36.53 ± 7.53 years, and 74.1% of caregivers were female. In addition, These findings were disagreed with Yacoub et al., (2023), who conducted a study about "Psychological Problems and Coping Patterns among Parents of Children with Leukemia" in Kaluobia Governorate (n=100), reported that 32% of the studied parents had 40 years, 60% of them were female.

The present finding revealed that more than half of the studied parents were had secondary education and more than four fifth of them were married.

These findings were consistent with the study carried out by Motlagh et al., (2019) titled "Assess the care burden in parents of children with leukemia" in Iran (n=187), showed that 52.9% were secondary education, 11.8% of them were university education and 84% of participant were married

Also, the present finding revealed that more than two thirds of studied parent were unemployed / house wife and three fifths of them had not enough monthly income and more than half of them lived in rural area.

These findings were agreed with a study conducted by Yacoub et al., (2023), revealed that 64% of them were not working and 58.7% of them lived in rural area. Also, these findings were inconsistent with the study performed by Ochoa et al., (2023), in USA who studied "Barriers and facilitators of Hispanic/Latino parents care giving for a childhood cancer survivor: a qualitative study ",and reported that 33.3% of the participants had enough monthly income, In addition the study showed that 29.4% of the sample from rural areas.





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Regarding demographic characteristics of the studied children, the finding of the present study indicated that two fifths of the studied children were in age group 12 -15 years and less than three quarters of them were male (table 2).

This finding was disagreed with Al-Buraiki et al., (2021), who conducted their study about ^{*}Association of parental, child, and environmental factors with the occurrence of childhood leukemia" in upper Egypt (n=170) and showed that the most affected age group was children 5 years or younger, 30% of them were male. Also these results were disagreed with a study done by Hamad and Shaker, (2019), who found that 52% of the children were females and 88.9% of them were diagnosed with leukemia.

Regarding school grade of the studied children, the finding of the present study indicated more than two fifths were from 1 -3 preparatory grade and nearly one third were the third child between their sibling. This finding were disagreed with Yacoub et al., (2023), who revealed that 46% of children were at preschool age, and 44% of children were the first children between their siblings.

Regarding total knowledge level of studied parents, the finding of this study indicated that more than two fifths of the studied parents had poor total knowledge level, nearly one third of the studied sample had fair total knowledge level and more than one fifth of them had good level of total knowledge level (figure 1)

These findings were disagreed with the study performed by Elfattah et al., (2017), founded that, 64.2% of studied sample had poor knowledge level about leukemia, 22.7% had average knowledge level and 13.1% had good knowledge level.

From investigator point of view, this might be due to decrease health education to parents about leukemia disease, parent didn't read about the disease and unavailability of information source that increase parent knowledge.

These findings were consistent with the study conducted by Saeed et al., (2019), in India, about \cdot studied the effectiveness of a structured teaching program on enhancing mothers' knowledge about childcare for children with cancer blood " (n=70). The study results revealed 38.53% of the mothers had inadequate knowledge, and 34.86% of mothers had moderate knowledge.

From the investigator point of view, this might be related to the decrease educational level of studied parents and lack of health education about leukemia diseases and hematology cancer.

Regarding parents reported practices about care of acute lymphoblastic leukemia, the present study showed that more than half of the parents had inadequate total level of reported practices and two fifths of them had adequate total level of reported practices regarding care of acute lymphoblastic leukemia child (figure 2).

This study inconsistent with the study carried out by Elfattah et al., (2017), reveals that, 83.3% of study sample had satisfactory practices score regarding care of their children with leukemia while, 16.7% had unsatisfactory practices score regarding care of their children with leukemia.

From investigator point of view this may due to decrease parents knowledge and training about how to deal with leukemia child and its care.

The present findings showed that there was significant statistical relation between educational level and residence of the parents and their total knowledge level, while there was no significant statistical relation their marital status, occupation and total level of parents' knowledge regarding leukemia (table 3).

These findings were disagreed with the study conducted by Yacoub et al., (2023) showed that, there was statistically significant relation between total level of parents knowledge regarding leukemia and their marital status and occupation, while there is no statistically significant relation between total level of parent knowledge regarding leukemia and their educational level and residence.





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The present study showed that, there was significant statistical relation between age and sex of the studied parent and their total level of reported practices (table 4).

These findings were disagreed with the study conducted by Hoa et al., (2020), who stated that no statistically significant relation was found between the primary caregivers' age and gender with their practices.

The present study revealed that, no significant statistically relation between their total reported practices and educational level of the studied parents.

These result were inconsistent with the study result carried out by Hasan et al., (2020), illustrated that there were statistically significant relations between the total mean score of mothers' performance and their level of education.

From investigator point of view, this inconsistent confirm that parents practices affected by educational level and parents education help them to read more about disease and be more skillful about care of their children.

Regarding correlation between total level of knowledge and total level of reported practices, the current study showed that, there was significant statistical positive correlation between the total level of knowledge and total level of reported practices among the studied parents (P-value=0.019) (table 5).

These findings were agreed with the study conducted by Taha et al., (2019) showed, that there was statistically significant positive correlations between mothers' total level of knowledge and total level of reported practices p=<0.001 respectively.

From investigator point of view, this agreed is proof that parents can't had good practices and care toward their children without knowledge.

Conclusion:

Based on the present study results and answering research questions. The following can be concluded:

More than two fifths of the studied parents had poor total knowledge level, nearly one third of the studied sample had fair total knowledge level and more than one fifth of them had good level of total knowledge level.

More than half of the parents had inadequate total level of reported practices and two fifths of them had adequate total level of reported practices regarding care of acute lymphoblastic leukemia child.

There was significant statistical relation between educational level and residence of the parents and their total knowledge level, while there was no significant statistical relation their marital status, occupation and total level of parents' knowledge regarding leukemia. Also, no significant statistically relation between their total reported practices and educational level of the studied parents. In addition, there was significant statistical positive correlation between the total level of knowledge and total level of reported practices among the studied parents.

Recommendations

- * Develop and implement health educational program to increase awareness and practices of parents about acute lymphoblastic leukemia.
- * Booklets and posters should be available at pediatric outpatient clinics to guidance all parent about leukemia disease.
- * Regular periodic interviews between health team and the parents to provide opportunity for parents ask questions.
- * Further research on large sample of parents to assess their perception regarding acute lymphoblastic leukemia and other setting is needed.

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