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Elshaimaa Gamal Hasan
Master degree in Pediatric
Nursing, Faculty of Nursing,
Minia University, Egypt

Soheir Abd-Rabou Mohamed
Professor of Pediatric Nursing,
Faculty of Nursing, Cairo
University, Egypt

Sanaa Mahmoud Ahmed
Assistant Professor of
Pediatric Nursing, Faculty of
Nursing, Minia University,
Egypt

Khalid Fathy Riad
Lecturer of Pediatric
Oncology, South Egypt Cancer
Institute, Assiut University,
Egypt

Aml Sayed Ali
Lecturer of Pediatric Nursing,
Faculty of Nursing, Minia
University, Egypt

Corresponding Author:
Elshaimaa Gamal Hasan
Master degree in Pediatric
Nursing, Faculty of Nursing,
Minia University, Egypt

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Knowledge and performance of caregivers having children with cancer undergoing chemotherapy

Elshaimaa Gamal Hasan, Soheir Abd-Rabou Mohamed, Sanaa Mahmoud Ahmed, Khalid Fathy Riad and Aml Sayed Ali

Abstract

Background: Cancer is a leading cause of death for children worldwide. More than 80% of children with cancer are cured in high-income countries, but only 20% are cured in many low-income countries. **Aim of the study was:** To assess the knowledge and performance of caregivers having children with cancer undergoing chemotherapy.

Research design: A descriptive research design was used in the current study.

Sample: A purposive sample of 35 caregivers having children with cancer and undergoing chemotherapy was participated in the study.

Setting: The current study was conducted in the pediatric unit at Minia Oncology Center.

Three Tools were: Tool (I): Structured Interview Sheet: it covered the personal data of the caregivers and the characteristics of the child; Tool (II): Caregivers Knowledge Assessment Sheet and Tool (III): Caregivers Performance Assessment Sheet.

Results: There was lacking in knowledge and performance of Caregivers having children with cancer undergoing chemotherapy. There were no statistically significant relationships between the total mean scores of caregivers' knowledge and total caregivers' practice regarding childhood cancer and chemotherapy as well as their personal data as age, level of education, their children's age, gender and the child's rank in the family ($p > 0.05$).

Conclusion: The study concluded that the overall level of caregivers' knowledge and performance was unsatisfactory. Personal variables have no impact on the knowledge and performance of the caregivers.

Recommendation: The study recommended that developing periodic educational programs and instructions to caregivers having children with cancer undergoing chemotherapy would improve their knowledge and performance regarding childhood cancer and chemotherapy.

Keywords: Childhood cancer, chemotherapy, caregivers, knowledge, performance

1. Introduction

Childhood cancer is a significant public health problem worldwide and is the second leading cause of death after accidents in children ages one to fourteen. Approximately 1,190 children under the age of fifteen are predicted to die from cancer in 2020. Around 11,050 children in the United States under fifteen will be detected with cancer in 2020. Childhood cancer rates have been rising to some extent for the past few decades. Because of significant treatment advances in recent decades, 84% of children with cancer now survive five years or more. Overall, this is a considerable increase since the mid-1970s, when the 5-year survival rate was about 58 percent ^[1].

More than eighty percent of children with cancer are preserved in high-income countries, but in many low-income and middle-income countries (L&MICs), only 20% are cured. The reasons for lesser survival rates in L&MICs include an incapability to attain an accurate diagnosis, inaccessible therapy, abandonment of treatment death from toxicity (side effects), and excess relapse, in part due to lack of access to essential medicines and technologies addressing each of these gaps expands survival and can be highly cost-effective ^[2, 3].

In the study of childhood cancer survivors and health outcomes over the last ten years in Children's Cancer Hospital 57357 Egypt (CCHE), to determine the variations in survival by demographic, and cancer type. A total of 15,997 children with cancer were analyzed; 58% of children were males and 42% of them were females. Nearly half of the children (48%) were in the youngest age group (0-4 years). Fifty-nine percent of the children had solid tumors, and 41% had hematologic malignancies. The most common cancers were leukemia, lymphoma, central nervous system (CNS) tumors, and neuroblastoma. The survival rate was calculated for 14,553 children, representing 92.2% of the full study population ^[4].

Countries crossways the Middle Eastern, North African, and West Asian regions face common difficulties relating to pediatric oncology care provision. Registries are mostly lacking, with the inaccessibility of outcome data. Financial barriers are a common theme, which leading to delays in patient diagnosing, interruptions and abandonment of therapy. Insufficient infrastructure and human resources are shared. The establishment of successful fund raising organizations enhancing services, improving patient access, and leading to outcomes comparable to those in developed countries. Well-designed national registries are crucial for identifying gaps, and exact referral networks are needed to address diagnosis and therapy delays. Programs to facilitate knowledge transfer, and promote advocacy, are required to accelerate progress within the region ^[5].

Recently, Attar, Zagade, and Shinde ^[6]. Documented that childhood cancer is treated with different treatment methods commonly involving chemotherapy, radiotherapy, surgery, immune therapy, stem cell therapy, targeted cell therapy, hormonal therapy, and precision medicine. As reported by Marcdante and kliegman ^[7]; Singaraju, Palaian, Shankar, and Shrestha ^[8], chemotherapy is used in almost all cases of cancer in children. Over 50% of the children with cancer undergoing chemotherapy develop adverse drug reactions (ADRs). Cancer chemotherapeutic agents kill cancerous and the normal rapidly dividing cells, including bone marrow cells, gastrointestinal epithelium, hair follicles, and other side effects. Their main ADRs are nausea and emesis, mucositis, constipation, diarrhea, hematological toxicities, cardiac toxicity, alopecia, gonadal toxicity, pulmonary toxicity, neurotoxicity, and nephrotoxicity. The severity of the adverse effects may vary from mild nausea to life-threatening neutropenia.

According to Tomlinson, Yuan, Cheng, and Hinds ^[9], successful management of symptoms are imperatively attributable to the potential for harmful effects on the child's health and well-being. Children with cancer experience a myriad of symptoms, often occurring as symptom clusters. Symptoms for children with cancer and their families are burdensome, distressing, and often challenging to control. These symptoms result from the condition, its treatment, and associated procedures that can hinder the child's psychosocial and physical development have adverse effects on the child's and family's quality of life. Experiencing frequent and severe symptoms is accompanied by a lower quality of life and may hinder multiple aspects of a child's development.

As documented by Ameringer, Macpherson, and Jibb ^[10], Valizadeh *et al.*, ^[11], chemotherapy's side effects might keep a child from partaking in social interactions, such as playing or being with peers, that are key to facilitating psychosocial development. Symptoms as loss of appetite, nausea, and vomiting lead to inadequate nutritional intake and negatively affecting physical development. Detecting patients' needs is one of the primary steps of the nursing process to plan and implement nursing interventions and prevent late effects.

Leading health care organizations, including the WHO and the American Academy of Pediatrics (AAP), have endorsed that pediatric palliative care (PPC) ought to begin once a severe or life-threatening condition is diagnosed and continue no matter whether or not a child receives treatment aimed toward comfort or cure. Nurse clinicians and scientists were amongst the front runners within the field of

pediatric palliative care within oncology. Several of the early nurse-led studies focused on the perspectives of caregivers caring for their children with incurable cancer. Symptom management is a foundation of PPC, thus supporting the need for the early integration of PPC. ⁽¹²⁾

Family education is an integral and crucial component of nursing care in pediatric oncology; it has recently been identified as a clinical and research priority within the pediatric oncology community. Expert consensus recommendations have been developed to usher the provision of education to families of newly diagnosed patients. Abundant the existing evidence for the provision of patient and family education in pediatric oncology is targeted to the time of initial cancer diagnosis. This underscores the overwhelming quantity of new information that is often provided in parallel with families' need to understand the diagnosis and treatment to provide safe care for the child within the home setting. It also highlights the significant emotional impact of the new cancer diagnosis upon the child and family ^[13].

2. Significance of the study

Cancer is a chief cause of death among children worldwide; it's a life-threatening condition and a significant public health problem for pediatric patients. Globally millions of children die yearly due to cancer. 1,735,350 newly diagnosed cases and 609,640 cancer deaths are projected to occur in the United States ^[14].

The global cancer burden has doubled within the last thirty years of the twentieth century. It is estimated that this will double again between 2000 and 2020 and nearly triple by 2030. The cancer incidence estimate was 113.1/100,000 of the total population in 2012, and 114,98/100,000 of the total population in 2013. Projections to 2050 estimate cancer incidence in Egypt to be 341.169/100,000 of the total population ^[15]. Kamel, Baraka, Khalid, and Ibrahim ^[16] reported that according to the results of Egypt National Cancer Registry, Minia profile, the total number of malignancies reported during 2009, amongst children under the age of 15 years, was 258 cases; these cases represented 5.6% of all incident cancers (total of 4584 patients). Hence, the current study was undertaken to assess caregivers' knowledge and performance regarding the care of children having cancer and undergoing chemotherapy. Results of the current study may help in evaluation of the caregivers' knowledge and performance regarding care of children having cancer. As well as providing guidance and recommendations that should be reflected in pediatric nursing education and practice.

3. Aim of the Study

The current study aimed to assess the knowledge and performance of caregivers having children with cancer undergoing chemotherapy.

4. Research Questions

The current study results answered the following research questions:

What is the level of caregivers' knowledge regarding the care of children having cancer and undergoing chemotherapy?

What is the level of caregivers' performance regarding the care of children having cancer and undergoing chemotherapy?

5. Subjects and Methods

5.1 Research design

A descriptive research design was utilized to achieve the aim of the current study. This design helps describe a situation or an event in exploring and knowing the level of caregivers' knowledge and performance regarding the care of children having cancer and undergoing chemotherapy.

5.2 Subjects

A purposive sample of 35 caregivers having children with cancer and undergoing chemotherapy participated in the current study. According to the statistical equation in which the sample size ranged between 10% to 30% from the total population size, the entire pediatric population admitted to the pediatric oncology unit at Minia Oncology Center was 126 children in 2017.

Inclusion criteria

- Caregivers who have newly diagnosed children with cancer and free from chronic illness as diabetes or renal failure.
- Caregivers who have children and undergoing chemotherapy for the first time.
- Caregivers who agree to participate in the study regardless of their age or educational level.
- Caregivers who have no other child with cancer or any cancer patient receiving chemotherapy.

5.3 Setting

The current study was conducted at the pediatric oncology unit at Minia Oncology Center that is located in Minia city. It serves Minia governorate and affiliated with the Ministry of Health and Population.

5.4 Data collection tools

The following data collection tools were utilized. The researcher developed the tools after reviewing the related literature.

Tool (I): Structured Interview Sheet

It involved 16 questions and classified into two parts

Part I: It contained 11 items that cover the personal data of the caregivers as age, educational level, material status, place of residence, and the number of children in the family. It also comprised the characteristics of the children with cancer and undergoing chemotherapy such as age, gender, and rank within the family.

Part II: It is comprised of five questions covers the current medical history of the children as diagnosis and type of cancer, as well as the duration of illness, medications, and previous hospitalization.

Tool (II): Caregivers' Knowledge Assessment Sheet

It involved 21 questions classified into two parts

Part I: It involved 5 Multiple of Choice Questions (MCQs) to assesses the caregivers' knowledge regarding cancer, including definition, causes, predisposing factors, signs and symptoms, and methods of management.

Part II: It contained 16 MCQs questions to assess caregivers' knowledge regarding chemotherapy, including definition; types; uses, phases; side effects on bone marrow, skin, digestive and respiratory systems; precautions and measures to reduce the side effects.

Tool (III): Caregivers' Performance Assessment Sheet:

It involved 17 MCQs questions to evaluate the caregivers' responses related their performance regarding the care of their children with cancer, such as care of signs and symptoms, e.g., nausea, vomiting, pallor, fatigue, bone or joint pain, infection, and anorexia. Caregivers' responses related their performance was assessed regarding chemotherapy sessions, such as dealing with chemotherapy's side effects, e.g., fever, bleeding tendencies, mucosal ulceration, pain, nausea, and vomiting.

Scoring system: for caregivers' knowledge and performance, two score were given for each correct/complete response, one score was given for the incomplete response, and zero score was given for the wrong answer or the not known/ done one. The total score was converted to 100% and then categorized as following: score ($\geq 50\%$) was considered satisfactory level; meanwhile, caregivers' overall score (less than 50%) was regarded as an unsatisfactory level of knowledge/ or performance. The total caregivers' knowledge score was 42, while 34 scores for the caregiver's total response related to their performance.

5.5 Validity and Reliability

The content validity of the tools was performed by a jury of 5 experts in pediatric nursing and pediatric oncology. Tools were examined for content coverage, clarity, relevance, applicability, wording, length, format, and overall appearance. Based on experts' comments and recommendations, modifications were made. The internal consistency was measured to identify the extent to which the tools measure the same concept and correlate. Cronbach's alpha coefficient was used to assess the tools' internal consistency were .0861 & .910, correspondingly.

5.6 Pilot Study

The pilot study was conducted on 10% (four caregivers having children with cancer and undergoing chemotherapy) who met the inclusion criteria was done to ensure the feasibility, objectivity, applicability, clarity, adequacy, content validity, and internal consistency of the study tools and to determine possible problems in the methodological approach or the tools.

The tools were completed without difficulty, adding support to the validity of the tools. Little modifications were made, e.g., rephrasing and rearrangements of some sentences. Caregivers involved in the pilot study were excluded from the main study sample.

5.7 Ethical Considerations:

Written approval obtained from the Research Ethics Committee of the Faculty of Nursing, Minia University; there was no risk for study subject during application of the current study, oral consent was taken from all caregivers to participate in the study. The researcher explained the study's purpose and nature through direct personal communication before participating in the study.

These data were confidential and were used for the research only. The study followed the common ethical consideration to participate in clinical research, and privacy was assured during data collection. Anonymity and privacy were assured through coding the data, and a caregiver has the right to refuse to participate in the study without any rationale. Children and their caregivers were informed that

participation in the study was voluntary; the researcher also informed the caregivers about their rights to withdraw from the study without giving any reason and without any effect on their children's care.

5.8 Data Collection Procedure

Primary approval was obtained from the Research Ethics Committee, Faculty of Nursing, Minia University. Official permission was obtained from the administrator of Minia Oncology Center and permission from the head of the pediatric oncology unit after explaining the study's aim and nature.

After that, data collection started; the researcher went to Minia oncology center for two days per week. Caregivers were interviewed on individual bases to explain the nature and purpose of the study and obtain personal data about their children's characteristics and current medical history with cancer and undergoing chemotherapy (tool I). The interview took place in the inpatient rooms in the pediatric oncology unit at Minia Oncology Center. Caregivers' knowledge and performance regarding their children's care with cancer and undergoing chemotherapy were assessed using (tools II, III). The duration of the interview was ranged from 25-30 minutes. Data collection was conducted

over twelve months extending from January 2019 till December 2019.

5.9 Statistical Analysis

The collected data was coded, categorized, tabulated, and analyzed using the Statistical Package for Social Science (SPSS) (IBM 25). Descriptive statistics in the form of frequencies, percentages for the qualitative variables, mean and standard deviation for the quantitative variables was used.

Fisher test was used to detect the relation between caregivers' knowledge based on their selected personal variables. Comparisons of means were performed using a paired-sample t-test. Level of significance at $p < 0.05$, 0.001 were used as the cut of value for statistical significance.

6. Results

Regarding caregivers' personal data, the current study results revealed that the highest percentage (45.7%) of the studied caregivers' age was constituted between 35- < 40 years old with mean \pm SD 42.5 ± 5.4 years. All (100%) of caregivers who participated in the current study were mothers. More than half (51.4 %) of them have basic education, and 94.3% lived in rural areas (Table 1).

Table 1: Personal Data of Studied Caregivers in Percentage Distribution (n=35).

Personal data	No	%
Age / years		
35- < 40	16	45.7
40 - < 45	7	20.0
45 - < 50	8	22.9
50- < 55	4	11.4
Mean \pm SD	42.5 \pm 5.4 years	
The degree of closeness to the caregiver:		
Mothers	35	100
Level of education		
Not read and write	10	28.6
Read and write	6	17.1
Basic education	18	51.4
Secondary education	1	2.9
Place of residence		
Urban area	2	5.7
Rural area	33	94.3

Table (2) clarified that 40% of the studied children, their age was ranged from 5 - < 10 years old with mean \pm SD 42.5 ± 5.4 years, and 60% of them were female. More than half

(51.4%) of the children were ranked as the third and more birth order within their families.

Table 2: Characteristics of Studies Children Having Cancer and Undergoing Chemotherapy in Percentage Distribution (n=35).

Personal data	No	%
Age of the child/ years		
1- <5	12	34.3
5 - < 10	14	40.0
10 - 15	9	25.7
Mean \pm SD	7.2 \pm 1.7 years	
Child' gender		
Male	14	40.0
Female	21	60.0
The rank of the child within the family		
First	11	31.4
Second	6	17.2
Third and more	18	51.4

Table (3) showed that 40% % of children have Leukemia followed by lymphoma while 2.9% of them have adrenal

cancer. and 57.1% of them were diagnosed within the last two weeks. The majority (85.7%) of the children didn't have

any cancer-related surgery performed on them. Fever and enlarged lymph nodes were the main symptoms experienced

by children in the current study (22.9% & 20% respectively).

Table 3: Current Medical History of the Studied Children in Percentage Distribution (n=35).

Current medical history	No	%
Type of cancer		
Leukemia	14	40.0
Nervous system cancer	4	11.4
Lymphoma	7	20.0
Adrenal cancer	1	2.9
Kidney cancer	6	17.1
Bone cancer	3	8.6
How long has cancer been discovered?		
Within the past week	15	42.9
Within the last two weeks	20	57.1
Cancer-related surgery performed		
Yes	5	14.3
No	30	85.7
Symptoms		
Fever	8	22.9
Enlarged lymph nodes	7	20.0
Headache or vomiting	2	5.7
Bone or joint pain	2	5.7
Abdominal pain	1	2.9
Fever and enlarged nodes	5	14.3
Fever and pallor	1	2.9
Fever, pallor, and pain	3	8.6
Enlarged nodes and bleeding	4	11.4
Chest pain	1	2.9
Legs edema	1	2.9

Regarding mothers' knowledge, Figure (1): proved that the majority (85.7%) of the caregivers hadn't any knowledge about childhood cancer and chemotherapy.

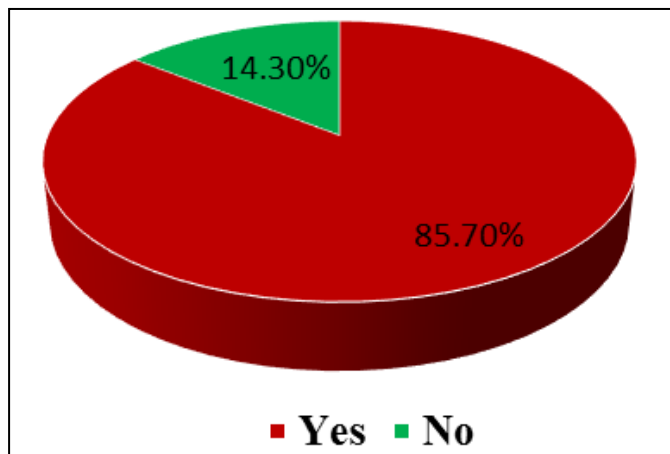


Fig 1: Caregivers' Knowledge about Childhood Cancer and Chemotherapy in Percentage Distribution (N=35).

Regarding the sources of caregivers knowledge about childhood cancer and chemotherapy, figure (2) proved that the caregivers' highest percentage (60%) received their knowledge about childhood cancer and chemotherapy from physicians.

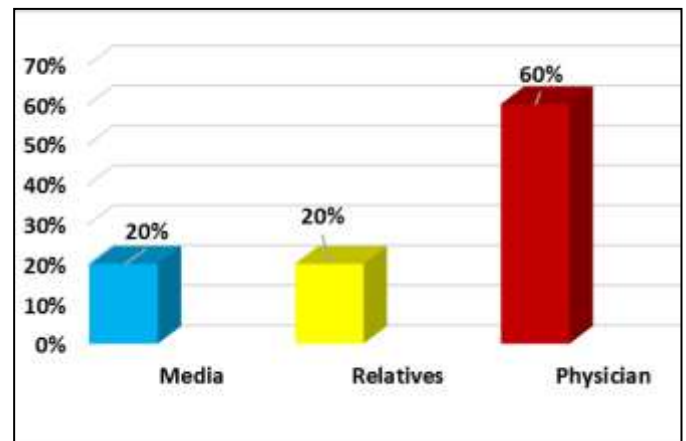


Fig 2: Sources of Caregivers' Knowledge about Childhood Cancer and Chemotherapy in Percentage Distribution (N=5).

Table (4) highlighted that all (100%) of the caregivers don't know the definition of cancer, predisposing factors of childhood cancer, treatment methods, and uses of chemotherapy. The majority (88.6%, 97.1% & 91.4%, respectively) of the caregivers don't know the most common types of cancer in children and its symptoms and cannot define chemotherapy. The total mean score of the caregivers' knowledge was 10.4±4.1.

Table 4: Caregivers' Knowledge about Childhood Cancer and chemotherapy in Percentage Distribution (n= 35)

Caregivers' knowledge	Complete		Incomplete		Don't know	
	No	%	No	%	No	%
Definition of cancer	0	0	0	0	35	100
The most common types of cancer in children	0	0	4	11.4	31	88.6
The common symptoms of childhood cancer	0	0	1	2.9	34	97.1
Predisposing factors of childhood cancer	0	0	0	0	35	100
The different treatment methods for childhood cancer:	0	0	0	0	35	100
Definition of chemotherapy	0	0	3	8.6	32	91.4
Uses of chemotherapy	0	0	0	0	35	100
The different ways to give chemotherapy	0	0	0	0	35	100
All cancers treated with one type of chemotherapy	0	0	0	0	35	100
Total mean score of caregivers' knowledge	10.4±4					

In relation to the caregivers' performance regarding childhood cancer and chemotherapy, table (5) revealed that equal percentages (88.6%) of the caregivers don't know the side effects of chemotherapy on bone marrow, digestive system, skin, and hair and respiratory system. All (100%) of

the caregivers don't know what to do in the case of their children exposed to infection, bleeding, anorexia, vomiting, pain, hair loss, and mouth and throat problems. The total mean score ±SD of the caregivers' responses about performance of chemotherapy was 4.8±0.7.

Table 5: Caregivers' Performance Regarding Chemotherapy in the Pre-test, Post-test, and Follow-up (n= 35).

Caregivers' Performance	Complete		Incomplete		Don't know	
	No	%	No	%	No	%
Side effects on the bone marrow	0	0	4	11.4	31	88.6
Side effects on the digestive system	0	0	4	11.4	31	88.6
Side effects on skin and hair	0	0	4	11.4	31	88.6
Side effects on the respiratory system	0	0	0	0	35	100
Protect the child from infection	0	0	0	0	35	100
Caregivers' responses about conditions that need contact with the physician immediately	0	0	0	0	35	100
Caregivers' responses about performance when the child exposed to bleeding	0	0	0	0	35	100
Caregivers' responses about performance when the child exposed to anorexia	0	0	0	0	35	100
Caregivers' responses about performance when the child exposed to vomiting	0	0	0	0	35	100
Caregivers' responses about performance when the child suffering from pain	0	0	2	5.7	33	94.3
Caregivers' responses about Management of hair loss	0	0	1	2.9	34	97.1
Caregivers' responses about performance when the child exposed to diarrhea	0	0	0	0	35	100
Caregivers' responses about performance when the child exposed to mouth and throat problems	0	0	0	0	35	100
Total mean score of caregivers' responses related to their performance	4.8±0.7					

Table (6) demonstrated that all (100) of the caregivers had an unsatisfactory level of knowledge and performance regarding childhood cancer and chemotherapy.

Table 6: Caregivers' Level of Knowledge and Performance toward Childhood Cancer and Chemotherapy (n = 35)

Items	Satisfactory		Unsatisfactory	
	No	%	No	%
Caregivers' knowledge	0	0	35	100
Caregivers' performance	0	0	35	100

Regarding the relations between the total mean score of caregivers' knowledge related childhood cancer and chemotherapy and their personal data, table (7) illustrated that there were no statistically significant relations between

the total mean scores of caregivers' knowledge regarding childhood cancer and chemotherapy and their age, level of education, social status, place of residence, occupation, and family type (p=>0.05).

Table 7: Relations Between the Total Mean Score ± SD of Caregivers' Knowledge Regarding Cancer and Chemotherapy and Their Personal Data (n= 35).

Personal data	No.	Mean ± SD	Test of significance	
Age / years			t/ F test	P - value
35- < 40	16	6.3 ± .4	1.148	.345 NS
40 - < 45	7	6.1 ± .4		
45 - < 50	8	6.0 ± .0		
50- < 55	4	6.0 ± .0		
Level of education				
Not read and write	10	12.0± .0	1.930	.145 NS
Read and write	6	8.0 ± .0		
Basic education	18	6.3 ± .5		
Secondary education	1	6.0 ± .5		

The social status of the caregiver				
Married	34	12.1 ± .4	.163	.689
Divorced	1	6.0 ± .0		NS
Place of residence				
Urban area	2	6.0 ± .0	.337	.566
Rural area	33	12.2 ± .4		NS
Occupation				
Works outside the home	1	6.0 ± .0	.163	.689
House wife	34	12.2 ± .4		NS

NS= Not statistically significant differences ** Highly statistically significant differences

Regarding the relations between the total mean scores ± SD of caregivers' responses about performance related childhood cancer and chemotherapy and their personal data, table (8) illustrated that there were statistically significant relations between the total mean score ± SD of caregivers' performance and their level of education and type of family

($p < 0.05$). There were no statistically significant relations between the total mean scores ± SD of caregivers' performance regarding childhood cancer and chemotherapy and their age, social status, place of residence, and occupation ($p > 0.05$).

Table 8: Relations between the total mean score of the caregivers' performance regarding cancer and chemotherapy and their personal data (n= 35).

Personal data	No.	Mean ± SD	Test of significance	
Age / years			t/ F test	
35- < 40	16	5.0 ± .9	.518	.673 NS
40 - < 45	7	4.6 ± .8		
45 - < 50	8	4.8 ± .5		
50- < 55	4	4.0 ± .0		
Level of education				
Not read and write	10	4.0 ± .0	3.462	.028*
Read and write	6	4.0 ± .0		
Basic education	18	5.4 ± .9		
Secondary education	1	4.0 ± .0		
The social status of the caregiver				
Married	34	4.8 ± .7	.260	.614 NS
Divorced	1	4.0 ± .0		
Place of residence				
Urban area	2	4.0 ± .0	.540	.468 NS
Rural area	33	4.8 ± .8		
Occupation				
Works outside the home	1	4.0 ± .0	.163	.689 NS
Housewife	34	4.8 ± .8		
Family type				
Extended	25	4.4 ± .5	5.440	.026*
Nuclear	10	5.6 ± 1.1		

NS= Not statistically significant differences * = Statistical significant differences

7. Discussion

The current study results assured that the highest percentage of the studied caregivers age was ranged from 35- < 40 years old, and the mean ±SD of their age was 42.5 ± 5.4 years. All of the caregivers who participated in the current study were mothers. These results supported by a study done by Hamad and Shaker [17] to assess the coping strategies among 54 caregivers of children with acute leukemia in Iraq. The study results proved that caregivers' mean age was 36.53± 7.53 years, and the majority of chief caregivers (87%) were mothers.

The current study results evident that more than half of the caregivers had basic education, and their minority of them did not read and write. The result reflected that higher literacy rates among Egyptian mothers, especially in Upper Egypt. On the same line, the Egypt Demographics Profile [18] assured that females' literacy rate was 65.5% compared to 63.5% in 2016. Accordingly, efforts of governmental and non-governmental organizations should continue to focus on female' education because low levels of literacy can hinder

the economic development of a country in the current rapidly changing, technology-driven world, this; of course, will reflect positively on the health care system as a whole as well as care provided for the sick child.

In a descriptive-correlation study carried out by Khademi *et al.* [19] to assess the caring power of 196 mothers who have a child with cancer and its predictors, the study results concluded that the average age of the mothers was 34.53 years. Similarly, in an Egyptian study conducted by Hassan and Ibrahim [20] to determine the effect of supportive nursing intervention on the burden and coping strategies of 60 caregivers of children with cancer. The results showed that more than ninety percent of primary caregivers were mothers in both groups, and 65% of the total caregivers' ages ranged from 30 to > 35 years. More than one third (38.3%) of studied caregivers have had a technical education, and high education represented thirty-five percent. Ninety percent of mothers of studied cancer children were housewives.

In an Egyptian study was held by Taha, Mohamed,

Mahmoud, and Khaled ^[21] to evaluate the effect of nursing instructions on knowledge and reported-practice of 50 mothers having children with leukemia undergoing chemotherapy. The study results summarized that the highest percentage of mothers' ages ranged from 30 to 35 years and had basic and secondary school education. The vast majority of mothers were married and housewives.

The current study results revealed that the majority of caregivers came from rural areas. This result could be related to the Minia Oncology Center serving children with various types of cancers in the Minia governorate and surrounding rural and semi-urban areas. In the same context, the United Nations Educational, Scientific, and Cultural Organization [UNESCO] ^[22] documented that the rural population was 57% of the total population worldwide. In the same line, Egypt Demographics Profile ^[23] reported that the rural community was 57 % of the total residents, and the rate of urbanization was 1.68 % annual rate of change.

In a cross-sectional study carried out by Motlagh, Mirzaei-Alavijeh, and Hosseini ^[24] to assess the care burden in parents of children with leukemia in Iran, the results demonstrated that the mean age of the parents was 39.45 years. Regarding the educational status, 35.3%, 52.9%, and 11.8% of parents were under diploma, diploma, and academic education, respectively. In the same context, Namazzi, Chege, and Jebet ^[25] conducted a hospital-based cross-sectional descriptive study to assess the caregiver's burden and its associated effect among 74 parents of children who have cancer in Kenya. It was found that one third of the caregivers' age was ranged between 30-39 years old. The majority of them were mothers, and 48.6% of the caregivers attained education up to the secondary level.

Concerning children's characteristics, the current study results clarified that the highest percentage of the studied children age was ranged between 5 - < 10 years old, their mean age \pm SD was 7.2 ± 1.7 years, and nearly two-thirds of them were females. More than half of the children were ranked as the third and more within their families. Forty percent of the studied children were diagnosed with leukemia. These results were in accordance with a study done by Hamad and Shaker ^[17], who found that more than half (52%) of the children were females, and the majority (88.9%) of them were diagnosed with leukemia. On the same perspective, Motlagh *et al.* ^[24] found that the mean age of children with cancer was 5.57 years, 47.1% of the children were female, and 52.9% were male.

Expanding recent literature by the American Cancer Society ^[1] also demonstrated that leukemia is the most significant common in early childhood, peaking between 2 and 4 years of age. There are numerous leukemia types, including acute lymphocytic leukemia (ALL) and acute myeloid leukemia (AML), which start in the bone marrow or blood. Leukemia could cause bone and joint pain, fatigue, weakness, pale skin, bruising, fever, weight loss, and enlarged lymph nodes. Recently, the American Cancer Society ^[1] documented that numerous signs and symptoms of childhood cancer. Common symptoms include fatigue, pale skin, infections and fever, easy bleeding or bruising, shortness of breath, bone or joint pain, loss of appetite, loss of weight, abdominal distention and sometimes headaches, seizures, balance problems, and vomiting. The findings of the current study were in accordance with the above-mentioned empirical evidence and proved that the highest percentage of studied children complained from fever, enlarged lymph

nodes, and bleeding.

The current study results proved that the majority of the caregivers did not give any knowledge about childhood cancer and chemotherapy. These results could be rationalized as the caregivers were not informed about childhood cancer and chemotherapy. These results also showed the urgent need to implement teaching sessions for mothers about that issue for the provision of a safe child's life in all pediatric oncology health care settings.

Concerning mothers' knowledge about childhood cancer and chemotherapy, the current study results revealed that the highest percentages of caregivers didn't know or had incomplete knowledge about cancer and its causes and symptoms. Also, caregivers had incomplete knowledge related to chemotherapy and its side effects. The overall level of caregivers' knowledge about childhood cancer and chemotherapy was unsatisfactory. These results indicate that the caregivers' need for knowledge and instructions about childhood cancer and chemotherapy. The inadequate caregivers' knowledge may exacerbate familial stress and negatively affect their children's clinical outcomes. Adverse events associated with insufficient education may include unexpected medical problems.

As emphasized by Hockenberry and Wilson ^[26], nurses working with children who have cancer have a substantial supporting role in helping the caregivers understand the various therapies, preventing or managing expected side effects or toxicities, and observing for late effects of treatment. Education is a constant feature of the nursing role, especially in new treatments, clinical trials, and home care. Pediatric nurses are influential in helping families avoid seeking unproven and potentially unsafe traditional management methods.

These results were consistent with Taha *et al.* ^[21]; they found that most mothers of children with leukemia had wrong or incomplete knowledge related to etiology, symptoms, and childhood cancer treatment. Besides, the vast majority of the mothers had incomplete items of reported-practice regarding their children's care before, during, and after chemotherapy sessions. Similarly, Mahmoud and Abdelaziz ^[27] evaluated the effect of a psycho-educational training program for 60 parents who have a child with cancer blood on their experience and psychological well-being. The study results summarized that most of the pre-test parents had insufficient knowledge related to the definition, causes, symptoms, and treatment modalities of childhood cancer.

Regionally in Iraq, in a previous study carried out by Obaid, Ajil, and Al-Ganmi ^[28] to assess knowledge about chemotherapy for leukemic child and their 70 mothers, child and child's illness. The study results demonstrated a knowledge deficit of mothers in some aspects related to chemotherapy treatment. Most mothers who have a child with cancer and receiving chemotherapy have a moderate knowledge level.

The newest recommendations indicate that it is crucial to ensure that caregivers understand several fundamental concepts elaborate in caring for a child with cancer within the first days after diagnosis and after discharge following the initial hospital admission, so parents know how and when to seek care at the hospital⁽²⁹⁾. On the contrary, the current study results demonstrated that all caregivers had an unsatisfactory level of knowledge regarding childhood cancer and chemotherapy.

On the same line, Saeed, hamzah, and Nitavid^[30] studied the effectiveness of a structured teaching program on enhancing mothers' knowledge about childcare for children with cancer blood in India. The study results revealed that 38.53% of the mothers had inadequate knowledge, and 34.86% of mothers had moderate knowledge. The same results were attained by Samaan^[31], who assessed mothers' care for their children with leukemia undergoing chemotherapy concluded that 67.5% of the mothers had low total knowledge scores regarding leukemia and chemotherapy. Moreover, 24.4% of the mothers had a fair total score of knowledge. Meanwhile, only 8.1% of them had a good total score of knowledge.

Concerning caregivers' performance provided for their children with cancer, the current study results highlighted that the majority of the caregivers responded that they not able to provide care for their children. Caregivers reported incomplete care for their children as regards the side effects of chemotherapy. The highest percentages were not oriented by the precautions taken to protect the child at home after a chemotherapy session. Inappropriately, all caregivers had an unsatisfactory performance level regarding the care of their children with cancer and undergoing chemotherapy. These results could have a negative impact on their ability to provide proper care for their children.

Similarly, Taha *et al.*^[21] confirmed that 98% and 100% respectively of the mothers don't know the care should be provided for their children before and during chemotherapy. All the mothers who participated in their study had insufficient reported-practice before receiving the nursing instructions.

The current study results clarified that there were no statistically significant relationships between the total mean scores of caregivers' knowledge and total caregivers' practice regarding childhood cancer and chemotherapy and their age, level of education, social status, place of residence, their children's age, and gender and the child's rank in the family ($p > 0.05$). So, it could be concluded that personal variables have no impact on the caregivers' knowledge and performance.

These results were supported by findings of Kaur, Chanu, and Sorte^[32], which assessed the effectiveness of a structured educational program on knowledge regarding home management of side effects of chemotherapy among parents in India. The results illustrated no statistically significant association between knowledge score and their selected demographic variable in terms of age of parents, level of education, age of the child, gender, and child diagnosis. These results are contradicted with Taha *et al.*^[21], they found that there were highly statistically significant positive correlations between mothers' total mean score of knowledge and reported practice and their level of education. These results also contradicted with the study carried by Priya *et al.*^[33]; who found a significant association between knowledge with the child's age and the number of children. In practice, an association was found between the gender of the child and the educational status of the mother.

8. Conclusion

The current study results concluded that there was an obvious lacking in knowledge and performance of the caregivers having children with cancer undergoing chemotherapy. The overall level of caregivers' knowledge

and performance was unsatisfactory. There were no statistically significant relationships between the total mean scores of caregivers' knowledge and performance regarding childhood cancer and chemotherapy and their age, level of education, social status, place of residence, occupation, children's age, gender, and child's rank in the family.

9. Recommendations

The study recommended that;

Development and application of an educational program for caregivers in pediatric oncology units are mandatory to provide a framework for caregivers' role for their children with cancer.

The pediatric oncology health care institutions should establish a committee responsible for teaching children newly diagnosed with cancer and their caregivers about the disease and its management modalities.

Healthcare professionals, including pediatric oncology nurses, should consider developing informational booklets for caregivers to refer to specific cancer varieties and treatment protocols.

There should be arrangements for social programs like mother's meetings etc. by various organizations to increase public awareness about childhood cancer.

This study's replication is warranted; this would enhance opportunities to generalize the findings to other types of pediatric oncological disorders and different pediatric oncology clinical settings.

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