

Role of Family Care Givers Regarding Care of their Children Suffering from Acute Lymphoblast Leukemia

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Abstract

Background: Child hood Leukemia is a broad term that refers to a group of malignant diseases of the bone marrow and lymphatic system. Burden is one of the issues that are faced by primary family care giver. Meanwhile, they experience frustration in performing tasks, isolation and failure due to inadequate education about the disease and inadequate information support. **Aim:** Assess role of family care givers regarding care of their children suffering from Acute Lymphoblast Leukemia (ALL). **Design:** Descriptive exploratory design. **Setting:** The current study was conducted at In-Patient Pediatric Hematology departments affiliated to Children's Cancer Hospital (57357). **Subjects:** A convenience sample composed of 40 family care givers for children suffering from ALL attending the above-mentioned setting with exclusion of terminally ill children. **Tools:** Two tools were used for data collection; **First tool:** Assessment sheet for the family care givers. **Second tool:** Observational checklists. **Results:** The current study revealed that the mean age of the studied family care givers was 33.31 ± 7.05 years, half of them were in the age group range $30 < 40$ years, Also, the results of study showed that the mean age of the studied children was 6.68 ± 3.66 and less than two-thirds of them were males. Also, it was found that almost the majority of the family care givers had poor level of knowledge. and more than three quarters had un satisfactory level of actual practices. **Conclusion:** The current study results concluded that almost the majority of the family care givers had poor level of knowledge and the majority of them had un satisfactory level of practice regarding care of their children suffering from ALL. **Recommendation:** Designing and implementing an educational intervention for family care givers to enhance their role regarding care of their children with ALL.

Keywords: Acute Lymphatic leukemia, Pediatric, Nursing, family care givers, Knowledge, Practice.

Introduction:

Cancer is a process of uncontrolled abnormal cell growth. Under normal circumstances, cells are formed, mature, carry out their intended function, and then die. New cells constantly regenerated in the body to replace those cells and to maintain normal cellular function (Abeloff and Martin, 2020).

Acute Lymphoblast Leukemia (ALL) is the most common hematologic malignancy in children and accounts for approximately around 80% of leukemia among children aged 0–14 years. Around the world, annual incidence of ALL is 1 in 60,000 peoples with 75% of children less than 15 years old (Curado, 2019). Advances in treatment have improved the outlook for

survival for children who were well diagnosed with leukemia that can help to ensure a positive outcome for ill children with leukemia and pediatric patients respond well to treatment, particularly chemotherapy and/or radiation (Ebra, 2020).

According to the research department at the Children's Cancer Hospital 57357 in Egypt (2020), it was reported that, the total number of children with ALL who enrolled from 2017 until the end of 2020 was 1947 children with an average of 486 new cases / year. Males are affected twice as often as females (Children's Cancer Hospital in Egypt 57357, 2020).

The family care givers can play an important role as a team member of the health care delivery team of their children suffering from ALL. family care givers have three essential roles which are; protecting their children from harm, promoting emotional as well as physical health, enforcing boundaries to ensure their children's safety and optimizing their children's development (**Devizzi et al., 2018**).

Care givers coping with their children suffering from leukemia is difficult, whereas they need to react adaptively to stressful situations and threatening life events (**Cortis, & Laccy, 2020**). Caregivers and health care professionals should be aware for the abnormal signs in a leukemic child, such as; fatigue, anemia, infection, bleeding, bruising, petechiae, thrombocytopenia, bone pain, joint pain, headache, seizures, and vomiting. Parents are overwhelmed with many questions about their children's condition. Every effort should be made to keep the family close to the child and include the parents into the child's plan of care, if these efforts will help the child and family to cope positively with the disease and its management (**Zimmermann et al., 2019**).

Significance of the Study:

In Egypt, Leukemia is the most common childhood malignancy. It accounts for 30% of all cancers diagnosed in children less than 15 years of age. The annual incidence is approximately four cases per 100,000 children per year (**Jamal et al., 2020**). ALL constitutes 30% of all pediatric malignancy and 70% of pediatric leukemia (**Shalaby et al., 2020**).

The care givers are usually the main care givers for their children suffering from acute lymphoblastic leukemia. They must be knowledgeable and competent in caring for their children, which consequently affects the care provided to their children. Therefore, the present study conducted to assess the role of family caregivers regarding care of their children suffering from acute lymphoblast leukemia.

According to the annual report of the research department of CCHE in 2020, there are 500 children were diagnosed as ALL and some of complaining from cancer related complications. this study would be of great value

for while, the present study may shed the light to the deficit needs related knowledge and practice family care givers having children suffering from ALL.

The aim of the study:

The current study aims assess the role of family care givers regarding care of their children suffering from acute lymphoblastic leukemia at children's cancer hospital (57357).

Research questions:

1- What's family care givers' knowledge regarding care of their children suffering from acute lymphoblastic leukemia?

2- What's family care givers' actual practices regarding care of their children suffering from acute lymphoblastic leukemia?

Technical design

Research Design:

A descriptive design was utilized to conduct the study

Research Setting:

The study was conducted at In-Patient Pediatric Hematology departments affiliated to Children's Cancer Hospital (57357). Where the hospital is being with the highest admission rate of children suffering from ALL all over Egypt.

Research Subjects:

The study sample involved a purposive sample composed of 40 family care givers for children suffering from ALL attending the above-mentioned setting with exclusion of terminally ill children.

Two tools were used for data collection:

Tools of Data Collection: two tools were used

The tools of data collection were designed in the light of relevant literatures, written in simple Arabic language and consisted of :

Tool (1) Assessment sheet for the family care givers to gather data in relation to:

Part 1: Characteristics of the studied sample:

- Characteristics of the studied children including; age, gender, level of education, child is ranking, in addition, data about the diseases history in child cause of admission, duration of illness and type of treatment.
- Characteristics of the studied family care givers included; age, level of education and work. Status.

Part 2: Concerning family care givers' knowledge regarding care of their children suffering from ALL, included the following:

- Family care givers' knowledge regarding ALL including definition, causes, signs, symptoms, complications, diagnosis and component of blood & function.
- Family care givers' knowledge regarding chemotherapy including goal, route of administration and complications.
- Knowledge of family care givers about children's care of related complications such as definition, causes, signs, complications and care.

Scoring System:

According to family care givers' knowledge answers each correct answer had score 2 degree and both incorrect answer and do not know had 1 degree. Accordingly, the total level of studied family care givers' knowledge was categorized into three levels: Poor ($< 50\%$) & average ($50 - < 75\%$) and good ($75 \leq 100\%$).

Tool (2) Observational Checklists:

The observational checklists were adopted from Gaylene et al., (2019), Shieh et al., (2018), Edmonds, (2015) & Baraff, (2018), it was used to assess the actual family care givers' practices regarding care of their children suffering from ALL at Children's Cancer Hospital (57357). Four observational checklists

were used including; hand washing, mouth care, cold compresses and axillary temperature measurement. Each family caregiver was observed during the actual care for his/ her child.

- Hand washing procedure consisted of 10 steps.
- Mouth care procedure consisted of 16 steps.
- Cold compress procedure consisted of 9 steps.
- Axillary temperature procedure consisted of 9 steps.

Scoring system:

According to family care givers' actual practices, each step was scored as "One" grade if the step is done correctly and scored "Zero" if the step was not done or done incorrectly. The total scores were ranged from "0-44" grades according to the family caregivers' actual practice they were classified into:

- atisfactory level of practice (more than and equal $60\% = > 26$ grads)
- nsatisfactory level of practice (less than $60\% = \leq 26$ grads).

Validity:

The tools of the current study were judged by a panel of five experts and professors of pediatric nursing. The necessary modifications were done according to experts' opinions to ensure the validity of the content.

Reliability:

The reliability of the tools was tested by using Cronbach's Alpha, the reliability of the Assessment sheet for the family care givers tool was 0.98 and for Observational checklists tool was 0.840 with good reliability. The reliability of the practice scale was 0.804.

Ethical considerations:

Ethical approval granted from the Scientific Research Ethical Committee from Faculty of Nursing, Ain Shams University, In

57357 Children Cancer Hospital Egypt as a in process to gain the approval to conduct the study, the researcher explained the aim and the nature of the study in Scientific Medical Advisory Committee (SMAC) to gain their acceptance and support. Additionally, the researcher obtained approval from the Institutional Review Board (IRB) at the data collection setting. To conducted the study, the medical and nursing directors of the In- Patient Department gave their official permissions. Informed consent was obtained from the family care givers prior to data collection. The family care givers were informed about the purpose and the explained outcome of the study.

Operational design:

The operational design included a preparatory phase, pilot study, and field work.

Preparatory phase

A review of the past and current related literature covering various aspects of the research problem was done by using available books, articles, periodicals and magazines to be acquainted with the research problem to develop the study tools and content.

Pilot study:

A pilot study was carried out on 10% (4 family care givers) of the total study sample. The result of the data obtained from the pilot study helped in removing some repeated questions related knowledge to avoid duplication of questions and then all family care givers involved in the pilot study were included in the study sample.

Field Work

The actual fieldwork was carried out over 6 months from the beginning of January till the end of August 2021. The researcher was available in the study setting five days/ week from Sunday to Thursday at morning shift from 9:00 a.m. to 4:00 p.m. at In- Patient Department Children's Cancer Hospital Egypt.

The researcher intrduced herself to each family care giver and gave complet back ground about the study, purpose of the study and its

expectations were explained by the researcher to the studied family care givers before starting interviewing and data collection. The questionnaire was filled in by the family care givers. The researcher herself fulfilled the interviewing questionnaire for the illiterate family care givers.

The researcher used the pre-constructed tools in collecting the data about family care givers' knowledge and actual practices regarding care of their children suffering from All. The time needed for filling the knowledge questionnaire sheets ranged from 20-30 minute while the required time for observational checklist ranged from 30-45 minute. The average numbers of interviewed family care givers were 5-6 family care givers per day. At the beginning of interview.

Administrative design:

An official permission to carry out the study was obtained through an issued letter from the dean of the faculty of nursing, Ain Shams University to the medical and nursing directors of the previously mentioned outcomes of the study to obtain their approval to conduct the study.

Statistical Design:

The data obtained was organized, analyzed, and presented in the form of tables and figures using the Statistical Package for Social Sciences (SPSS) Version 20. Qualitative variables were presented in the form of frequencies and percentages; quantitative variables were presented in the form of mean and SD.

Result

Table 1: This table indicated that, less than two thirds (62.5) of the studied children's age was ranged from 2-< 6 years with mean \pm SD (6.68 ± 3.66). Moreover, less than two thirds children (62.5%) were males. Also, half (50.0%) of them were in primary school. In addition, to less than one-third (30.0%) of them were ranked as second child in their families.

Table (2) According to the causes of admission and type of treatment of the studied children, this table illustrates that, half (50%) of children were admitted because of complications related to management therapy. Also chemotherapy was the most common types of treatment among 50% of the studied children

Table 3: As regards the characteristics of the studied family care givers this table shows that, the mean age of the studied family care givers was (33.31 ± 7.05), regarding their educational qualification, it was found that more than one third (37.5%) of them were graduated from secondary technical school. In relation to their work status, three quarters (75%) of the studied family care givers were working.

Figure (1): illustrated that more than two thirds (68.1%) of the studied family care givers had poor knowledge about ALL while, one half (50.0%) of them had poor knowledge regarding to chemotherapy. Moreover, this figure clarified that, more than half (59.7%) of

the studied family care givers had poor knowledge, regarding to complications related to health problems of ALL.

Table (4) As regards family care givers their total level of knowledge regarding care of their children suffering from ALL this table shows that, almost majority (80.0%) of studied family care givers had a poor level of knowledge. While the minority (7.5%) of them had good level of knowledge.

This figure (2) showed that, the majority (86.1%) of the studied family care givers had not done hand washing with un satisfactory performance, while near quarter (20.8%) of them performed satisfactory practice regarding mouth care.

Table 5: As regards family care givers their total actual level of practice regarding care of their children with ALL. This table shows that, three quarters (75.0%) of studied family care givers had un satisfactory level.

Table 1: Number and percentage distribution of the studied children according to their characteristics (n=40).

Characteristics	No.	%
Age (years)		
< 1	5	12.5
< 3	10	25.0
< 6	25	62.5
$\bar{X} \pm SD$	6.68± 3.66	
Gender		
Male	25	62.5
Femal	15	37.5
Level of education		
Read and write	5	12.5
Primary school	20	50.0
Preparatory school	5	12.5
Secondary school	10	25.0
Ranking		
First	5	12.5
Second	12	30.0
Third	8	20.0
Fourth	10	25.0
Fifth	5	12.5

Table (2): Number and percentage distribution of the studied children according to their causes of their admission and type of treatment (n=40).

Items	No.	%
Causes of admission		
Receiving chemotherapy	10	25.0
Complications related to management therapy	20	50.0
Investigations & follow-up	5	12.5
Complications from treatment	5	12.5
Types of treatment		
Chemotherapy	20	50.0
Medical therapy (other than chemotherapy)	10	25.0
Surgical procedure	4	10.0
Specialist treatment	6	15.0

Table (3): Number and percentage distribution of the studied family care givers according to their characteristics (n=40).

n=40).

Characteristics	No.	%
Age (years)		
20- < 30	5	12.5
30- < 40	20	50.0
40 - < 50	10	25.0
50 ≤ 60	5	12.5
\bar{X} + SD	33.31+ 7.05	
Level of education		
Illiterate	5	12.5
Read and write	10	25.0
Secondary technical school	15	37.5
Bachelor	10	25.0
Work status		
Working	30	75.0
Not Working	10	25.0

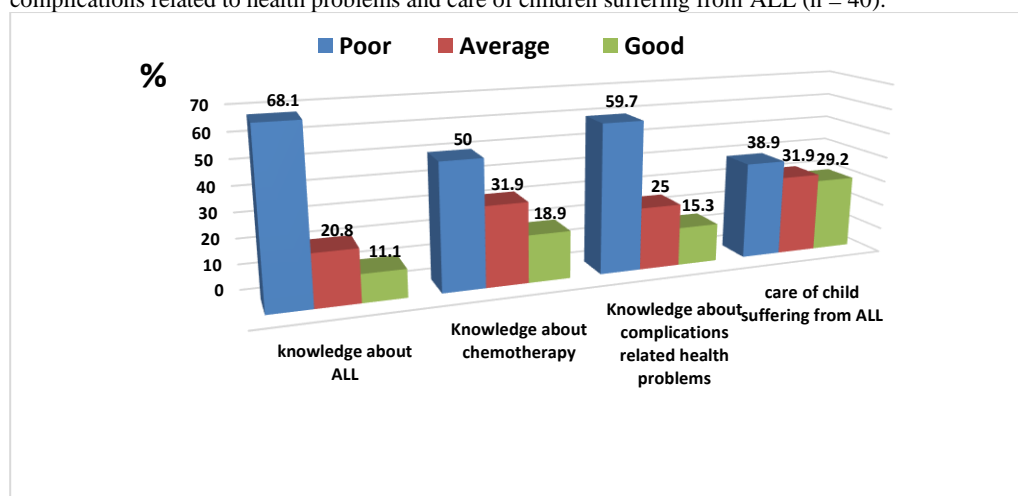
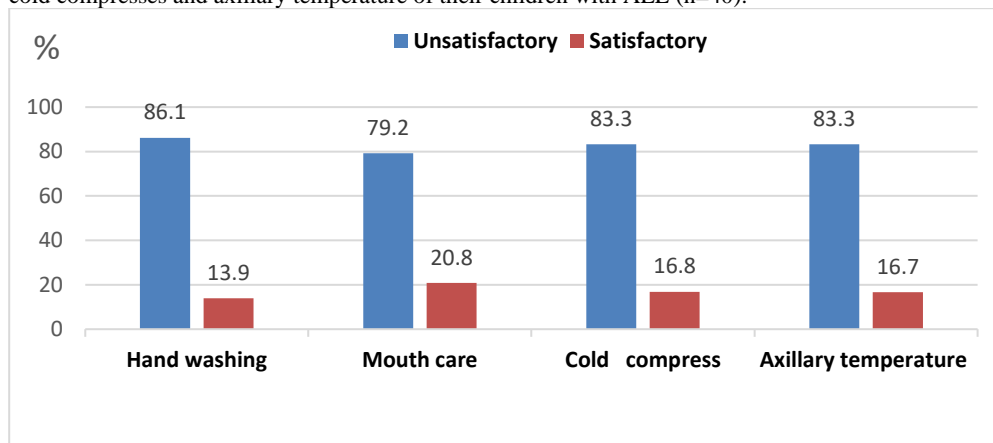
Figure (1): Distribution of the studied family care givers regarding their knowledge about ALL, chemotherapy, complications related to health problems and care of children suffering from ALL (n = 40).

Table (4): Distribution of the studied family care givers according to their total level of knowledge regarding care of their children suffering from ALL (n=40).

Total level of knowledge	No.	%
Good (Score $75 \leq 100\%$)	3	7.5
Average (Score $50 < 75\%$)	5	12.5
Poor (Score $< 50\%$)	32	80.0

Figure (2): Distribution of the studied family care givers actual practice regarding hand washing, mouth care, cold compresses and axillary temperature of their children with ALL (n=40).**Table (5):** Distribution of the studied family care givers according to their total actual level of practices regarding care of their children with ALL (n=40).

Total actual practices	No.	%
Satisfactory (more than 60%)	10	25.0
Unsatisfactory (less than 60%)	30	75.0

Discussion:

Childhood leukemia in general can be viewed as chronic illness with uncertain outcomes, remissions are common and recurrence may occur. Moreover, The family care givers should be more aware of the complexities and unique physical and emotional needs of their child with leukemia (Donna et al., 2020).

The family care givers can play an important role as a team member of the health care delivery team of their children suffering from ALL. family care givers have three essential roles which are; to protect their children from harm, promoting emotional as well as

physical health, enforcing boundaries to ensure their children's safety and optimizing their children's development (Devizzi et al., 2019).

The result of the present study revealed that, less than two thirds (62.5) of the studied children's age was ranged from 1-< 6 years. The present study result was contrasted with Abdelhamed, (2018), in study entitled "Discharge plan for mothers of children suffering from leukaemia" who performed study to, more than half of the studied children's age were between 2 <18 years. As mentioned by Parkin et al., (2018), in study entitled "Integration of the national comprehensive cancer network (NCCN) distress screening tool as a guidepost for telephonic oncology case

management" and showed that, ALL is a relatively rare disease in children aged less than 15 years. From researcher experience, it is clear that diagnosis of ALL is commonly discovered during this age period of children's life.

Regarding children's gender, less than two thirds of the studied children were males. the result matched with **James et al., (2018)** who performed a study to entitled "Factors associated with health-related quality of life in pediatric cancer survivors" it was mentioned that was more common among males than females.

Regarding type of treatment for children suffering from ALL, the result of the current study revealed that ,half of the studied children were admitted due to complications related to management therapy and receiving chemotherapy. The result of the current study is in agreement with **Frew et al., (2016)**, who conducted a study titled "Duration treatment protocol designed for children with leukemia in developing countries" reported that chemotherapy is the initial treatment of choice for most children suffering from ALL. There are no surgical options, due to systemic distribution of the malignant cells. Also, **National Comprehensive Cancer Network [NCCN] (2018)**, who conducted a study titled, "Impact of educational health program on quality of life for family care givers of cancer children receiving chemotherapy" found that, most of the children with ALL receiving chemotherapy,

Concerning the characteristics of the studied family care givers the present study revealed that, half of the studied family care givers at the age group from 30 to 40 years. The current results are supported by **Abdul-Kareem et al. (2021)**, who studied titled "Mother's practice of knowledge concerning their children less than five years with upper respiratory tract infections " and reported that, the highest percentage of age was among mothers at age group 18-30 year.

Concerning on level of education, the present study illustrated that, more than third of studied family caregivers had secondary technical school and three quarters were working. This result in supported by **Bham et al. (2016)**, in study entitled "Knowledge, attitude

and practice of mothers on acute respiratory infection in children under five years" while it was found that, the majority of the study participants had secondary technical school and three quarters were working. Also congruent with **Amuka et al. (2020)** who conducted study entitled "Knowledge, perceptions and practices of care givers on pneumonia among children aged below 5 Years in Migori County Referral Hospital, Kenya" and showed that, half of studied mother had intermediate level of education.

As regards to total knowledge of the studied family care givers regarding care of their children suffering from ALL, the results of the current study revealed that the, more than two thirds of them were had poor knowledge about ALL while, one half of them had poor knowledge regarding to chemotherapy. Moreover, more than half of the studied family care givers had poor knowledge, regarding to complications related to health problems of ALL. From the researchers' point of view, these reflect a lack of knowledge regarding ALL, care and chemotherapy. This result is in agreement with **(Gaber, et al., (2018)**, who stated in the study conducted at Cairo University titled with the effect of care givers knowledge on patient among leukemic children undergoing chemotherapy, it was found that, not enough knowledge about care.

Concerning the studied family care givers' total level of knowledge regarding care of their children suffering from ALL, the findings of the current study clarified that, almost majority of them were having poor level of knowledge. From the researcher' point of view, this result might be due to characteristics of family care givers as most of them with secondary technical school education and working. And children newly diagnose, However, the stuted children were selected with criteria of newly diagnosed. Therfoore, the knwlodge level was poor while, this considered a new experenceses for the care givers besides, the focuses of the health care team on the disease management aspects and missing their roles as health educator's knowledge part. The present result parallel to **Abozed et al. (2017)**, who conducted a study titled "Effectiveness of learning package application on the use of antibiotics for mothers

of children with upper respiratory tract infection" and reported that, majority of the studied mothers had poor level of knowledge. On other hand, the result not supported with the study that carried out by **Mutalik & Raje (2020)**, who conducted a study titled "Study to assess the knowledge, attitude, and practice about acute respiratory infections among school going children and their parents in rural Maharashtra" and reported that, two thirds of mothers had poor knowledge about acute respiratory infection.

On investigating family care givers total actual practice regarding care of their children suffering from ALL the finding of the current study reported that, most of studied family care givers performed the procedures unsatisfactory regarding hand washing, cold compresses and measuring axillary temperature. While more than near quarter had the done oral care procedure satisfactory. The current results are supported by **Sustrami et al (2023)**, who studied titled "Role of mothers of children With Cancer" and showed that, most of the studied mothers has incompetent level of care of practice regarding to their children suffering from cancer about hand washing, mouth care, cold compresses and axillary temperature.

Concerning total actual level of practices regarding care of their children suffering from ALL, the finding of the current study reported that, most of them had un satisfactory levels of actual practice. The present study were inconsistent with **Hooshangi et al., (2017)**, under title "Knowledge, attitude and practice of students of Gonabad University of Medical Sciences toward famous methods of complementary and alternative medicine" who reported that, less than two thirds of the studied women had good level of total actual practices. From the researcher's point of view, these reason for this may be that the new diagnosis so family caregivers do not have enough information about the diseases. family care givers knowing the diagnosis recently and information about the disease is weak affects the practical part.

Conclusion:

Based on the study findings it was concluded that, almost the majority of the care givers had poor level of knowledge and the

majority of the studied them had un satisfactory level of actual practices regarding care of their children suffering from ALL

Recommendation:

According to the study findings, the following recommendations are suggested:

- Designing and implementing an educational intervention for family care givers to enhance their role regarding care of their children with ALL
- Development of a guideline leaflet for family care givers of children with ALL to guide them in care.
- Continuous evaluation and monitoring for level of care givers' knowledge and practice regarding care of their children with ALL.
- Replication of the study using a larger probability sample from different pediatric oncology departments to generalize the study results.

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