

Knowledge and Home Practices of Caregivers Having Children with Leukemia Attending National Cancer Institute Cairo University

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Abstract

Children with leukemia usually suffer from many health problems and complications as a result of the disease process or the course of treatment.

Aim of the Study: Was to assess the knowledge and home practices of family caregivers having children with leukemia.

Design: Descriptive correlational research design was utilized in this study.

Setting: The study was conducted at the out-patient clinic of the Pediatric Oncology Department at the National Cancer Institute (NCI), Cairo University.

Sample: A sample of 192 family caregivers of newly diagnosed children with leukemia between the ages of 6-12 years of age who were receiving chemotherapy.

Tools for Data Collection: Three tools were used. 1- Structured interviewing sheet: It had three parts: a. Sociodemographic characteristic of the children as: Age, gender, education, child rank, etc... b. Sociodemographic characteristic of the caregivers as: Age, gender, education, etc... c. Disease information: Family history of cancer, types of treatment taken, etc... 2- Knowledge questionnaire sheet consisted of 24 questions related to the caregiver's knowledge as disease definition, causes, signs and symptoms, etc... 3- Practice questionnaire sheet consisted of 27 questions related to the caregiver's practices such as care of symptoms and side effects of chemotherapy, etc...

Results: More than two third of caregivers had partially satisfactory knowledge and practice scores concerning home care, dealing with disease and side effects of treatments. A statistically significant positive correlation was found between total knowledge and total practice scores of family caregivers. A statistically significant correlation was found between total knowledge & practice scores and caregiver's education, income, place of residence, number of children in the family and duration of care.

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Conclusion: The study concluded that, the majority of caregivers had lack of knowledge and practices regarding care of their children with leukemia.

Recommendation: Based on the study results it is recommended to develop a health education programs tailored to improve knowledge and home care practices of caregivers having children with leukemia.

Key Words: *Family caregivers — Children with leukemia — Knowledge — Practice.*

Introduction

CANCERS account for approximately 14% of all deaths worldwide, estimated 12.66 million new cancer cases and 7.56 million deaths occurred in 2011 worldwide [1]. It is the leading cause of death in the developed world and the second leading cause of death in the developing world [2]. As the world's population continues to grow and age, the burden of cancer will inevitably increase, even if current incidence rates remain the same. More than half of all cancers worldwide are already diagnosed in the developing countries, and without intervention this proportion is predicted to rise in the coming decades. By 2030, there will be almost 21.4 million new cases diagnosed annually and that there will be over 13.2 million deaths from cancer [3]. The three most common childhood cancers are leukemia (34%), brain tumors (23%), and lymphomas (12%) [3].

Diagnosis of cancer in a child or teenager is a devastating blow to the parents, siblings, and others who love the child. Cancer creates an instant crisis in the lives of the whole family. Normal daily life stops, parents must be away from work so they can be with their child [4]. The preparation of family caregivers must begin in the hospital and should only be concluded when the family caregiver demonstrates cognitive and instrumental skills to

provide care and a fluid integrative identity [5]. Caregivers need to perform complex medical tasks, supervise patients, make decisions, solve problems, provide emotional support and comfort, and coordinate care. Using these skills, caregivers administer medications, plan and provide meals, handle medical equipment, and provide direct care such as wound care and lifting and turning [6].

The ability of the family caregiver to provide quality care and contribute to the management of chronic disease is a vital health care resource. Health care providers should be supportive of family caregivers and help them acquire knowledge and skills in order to maximize quality care. Providers need to help family caregivers develop problem-solving, organizational, and communication skills [7]. Health professionals need to help family members acquire skills, caregivers for leukemic children require knowledge, skills, and judgment to carry out the tasks of care for patients, and research has shown that caregivers who feel prepared to deliver care (i.e., have the knowledge and skills needed) have less burden [8].

Significance of the study:

According to WHO, (2006) death rates from leukemia among Egyptian children accounted for 5.1 per 100,000 and Egypt was ranked the 28th Arab Country having leukemia among children [9]. Home caregivers play an increasingly important role in providing health services for family members. Although many studies have been done to measure burden and related concepts, few studies have examined holistically the caregiving experiences about knowledge and practice of care for sick child [10].

The capacity of family caregivers to take on the care of the person with cancer may have a significant influence on both health outcomes and cost in terms of readmission rates and the use of inpatient facilities [11]. Children with leukemia suffer from many health problems and complications as a result of the disease process or the course of treatment. The more knowledge and skills caregiver's have, the more skillful they become in managing their children illness, so this study aimed at assessing the knowledge and practices of caregivers having children with leukemia.

Definition of term:

Caregiver:

Caregiver is an individual in a cancer child's life who provides continuous assistance, care & support for the child at home.

Aim of the study:

The present study aimed at assessing knowledge and home practices of caregivers having children with leukemia.

Research Questions:

- 1- What are the knowledge of caregivers about Leukemia?
- 2- What are the practices that caregivers do for their children at home?

Material and Methods

Research design:

A descriptive correlational research design was utilized in this study.

Setting:

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

Sample selection:

Convenient sample was used to collect data pertinent to the study. Data was collected within 6 month (from September 2011 to February 2012). The total number of the sample after 6 month was 192 caregivers.

Inclusion criteria:

- Caregivers of children between 6-12 years (school age).
- Newly diagnosed cases with Leukemia at least 6 month before the study.
- Receiving chemotherapy.

Tools for data collection:

Three tools were used in this study:

- 1- A structured interviewing sheet was developed by the investigator to collect data about:
 - *Sociodemographic characteristic of the child:* Age, gender, education, duration of disease, no of sibling and child rank.
 - *Sociodemographic characteristic of the caregivers:* Age, gender, education, occupation, marital status, income, place of resident, relative degree and duration of responsibilities.
 - *Disease information:* Family history of cancer, types of treatment, presence of another child having chronic illness and health insurance for sick child, etc...

- 2- Knowledge questionnaire sheet consisted of 24 items related to the caregiver's knowledge such as disease definition, causes, signs and symptoms,

complications, high risk group, treatment, side effects of treatments, etc...

Regarding knowledge scores, complete correct answer was given two points, incomplete answer given one points, and incorrect answer was given zero. The total scores of the knowledge section were (34 points): Unsatisfactory level of knowledge from (17-20), satisfactory level of knowledge from (21-25) and good level of knowledge score from (26-34) points.

3- Practice questionnaire sheet consisted of 27 items related to the caregiver's practices such as care of symptoms and side effects of chemotherapy as mucositis, nausea and vomiting, diarrhea, infection, anemia, fatigue, bleeding, fever, anorexia, food preparation, etc...

For practice section scores, complete correct answer was given two points, incomplete answer given one points, and incorrect answer was given zero. The total score of the practice section was (64 points): Poor level of practice from (32-37), fair level of practice from (38-48) and good level of practice scores from (49-64) point.

Ethical and legal consideration:

- Human subject approval was taken from the board the faculty of nursing, Cairo University as well as the director of National Cancer Institute and director of the outpatient clinic.

- All ethical issues of the research were maintained. The purpose, specific objectives, anticipated benefits and the method of the study were carefully explained to each eligible subject.

- The investigator emphasized that, participation in the study is entirely voluntary; and their rights were secured; anonymity and confidentiality was assured through coding the data.

- Written consent was taken from caregivers who accept to be included in the study.

Tools validity:

Tools were submitted to a panel of five experts in field of community health nursing to test the content validity. Modifications were carried out according to the panel judgment on clarity of sentences and appropriateness of content.

Pilot study:

A pilot study was carried out on 10% of the total sample to check clarity of items and determine the feasibility of the study.

Procedure:

The entire research tools for data collection and proposal was submitted to the ethical committee in the faculty of nursing, initial approval was obtained on 27-7-2011 for data collection. An official permission was obtained from the director of the National Cancer Institute, the director of the out-patient clinic and the head nurse. The investigator explained the aim of the study to each caregiver to gain their cooperation to share in the study. Interviewing the caregiver took place at the waiting room beside the clinic. Written consent was obtained from caregivers who accept to participate in the study. The interviewing sheet took around 30-45 minutes to be filled. Data was collected within 6 month from September 2011 to February 2012: 2 days/week from 9-lpm.

Statistical analysis:

Collected data were coded and tabulated using personal computer. Statistical Package for Social Science (SPSS windows) version 11.5. Was used. Descriptive as well as inferential statistics were used to answer research question. Statistical significance was considered at p-value less than 0.05.

Results

Regarding the socio-demographic characteristics of the children, results revealed that, the mean age of children with leukemia was 9.06 ± 2.17 years; two thirds of the children (62.5%) were males. Almost two third of the children (60.4%) had the disease from 6-10 months while 39.6% of them had the disease for more than 10 months (Table 1). Regarding the socio-demographic characteristics of the caregivers, more than half (55.8%) of the caregivers aged from 35 to less than 45 with a mean age 37.46 ± 6.56 years, about sixty percent (59.4%) of the caregivers were females and 41.4% had secondary school education, 27.1% could not read and write and 20.8% had primary school education.

Regarding marital status of the caregivers, the majority (90.1%) were married. More than half of the caregivers (55.2%) were from urban areas, and about one third (31.6%) of the caregivers were house wives, while 28.2% were employed. More than half of the caregivers (52.1%) had a monthly income ranging from 400 to 800 L.E (Table 2). As revealed in Table (3), more than two third of the caregivers (69.8%) had partially satisfactory knowledge and practice scores regarding general knowledge and practice scores regarding general knowledge about leukemia and home care, where 30.2%, 8.3% had satisfactory knowledge and practice

scores respectively (Research questions answered). Table (4) indicated a statistically significant positive correlation between total knowledge and total practice scores of the caregivers ($r=0.39, p=0.00$).

A statistically significant positive correlation was found between the caregiver's level of education and their knowledge and practice scores regarding leukemia ($r=.69, p=0.00$ & $r=0.36, p=0.00$ respectively). Also a statistically significant positive correlation was found between the caregiver's place of residence and their knowledge and practice scores regarding leukemia ($r=0.4, p=.00$ & $r=0.27, p=0.00$ respectively). There was a statistically significant positive correlation between the caregiver's monthly income and their knowledge and practice total scores ($r=0.53, p=0.00$ & $r=0.22$ & $p=0.02$) respectively. Results of the current study also indicated a statistically significant negative correlation between the caregiver's number of children and their knowledge and practice total scores ($r=-0.3, p=0.00$ & $r=-0.3, p=0.00$) respectively. No statistically significant correlation was found between the caregiver's sex or age in relation to their knowledge and practice total scores (Table 5).

Table (1): Percentage distributions of the socio-demographic characteristic of the children regarding their age, sex, duration of disease numbers of children and child rank (n=192).

Variables	Socio-demographic characteristic of the children	
	No.	Frequency
Age/year:		
5-7	75	39.1
8-10	49	25.5
<10 years	68	35.4
X±SD	9.06±2.17	
Sex:		
Male	120	62.5
Female	72	37.5
Duration of disease/months:		
6-10	116	60.4
<10	76	39.6
X±SD	8.20±2.22	
No of sibling:		
1-3	106	55.3
4-6	82	42.7
<6	1	0.5
Single child	3	1.6
Child rank:		
1-2	114	59.4
3-4	71	37
5-6	7	3.6

Table (2): Percentage distributions of socio-demographic characteristic of the family caregivers regarding their age, sex, educational level, marital status and Place of resident (n=192).

Variables	Family caregivers	
	No.	Frequency
Age/year:		
>25	4	2
25>35	54	28.1
35 >45	107	55.8
45>55	27	14.1
X±SD	37.46±6.56	
Sex:		
Male	78	40.6
Female	114	59.4
Educational level:		
Unable to read and write	52	27.1
Primary	40	20.8
Secondary	79	41.4
University	20	10.4
Graduate studies	1	0.5
Marital status:		
Single	5	2.6
Married	173	90.1
Widow	7	3.6
Divorced	7	3.6
Place of resident:		
Rural	86	44.8
Urban	106	55.2

Table (3): Percentage distributions of the total knowledge and home practice scores for caregivers having children with leukemia (n=192).

Variables	Knowledge		Practices	
	No.	Frequency	No.	Frequency
Unsatisfactory	0	0	43	22.4
Partially satisfactory	134	69.8	133	69.3
Satisfactory	58	30.2	16	8.3
Total	192	100.0	192	100.0

Table (4): Correlation between the total knowledge and the total home practice scores of the family caregivers having children with leukemia.

Study variable	Knowledge	
	r	P
Practices	0.39	0.00*

*Correlation is significant at the 0.05 level (2-tailed).

Table (5): Correlation between the total knowledge and practice scores and sociodemographic characteristic of the caregivers.

Socio-demographic characteristics	Knowledge		Practices	
	<i>r</i>	<i>P</i>	<i>r</i>	<i>P</i>
Age	0.1	0.16	0.3	0.6
Sex	0.3	0.6	0.1	0.1
Education	0.69	0.00**	0.36	0.00**
Resident	0.4	0.00**	0.27	0.00**
Income	0.53	0.00**	0.22	0.02**
Number of children	-0.3	0.00**	-0.3	0.00**

**Correlation is significant at the 0.05 level (2-tailed).

Discussion

The capacity of family caregivers to take on the care of the person with cancer may have a significant influence on both health outcomes and cost in terms of readmission rates and the use of inpatient facilities [6]. The aim of the study was to assess knowledge and home practices of caregivers having children with leukemia.

Socio-demographic characteristics of children with leukemia and their family caregivers:

Regarding the socio-demographic characteristics of children with leukemia, results of the current study indicated that, two thirds of the children with leukemia were boys. This finding were in agreement with Howlader et al., [12] who reported that, incidence rates for all types of leukemia were higher among males than females. Also Farouk et al., [13] who conducted a study on 40 leukemic Egyptian children at the National Cancer Institute, Cairo University found, male to female ratio of leukemia to be 1.86: 1 in childhood. Regarding children age, results of the current study indicated that, more than one third of the children aged from 5-7 years, while one third aged more than 10 years, and one fourth aged from 8-10 years. The same result was revealed from Farouk et al., [13] who reported that, leukemia developed in children between one and ten years of age, although it can occur at any age.

Concerning family caregiver's age, results of the current study indicated that, more than half of them aged from 35>45 years and this result was consistent with National Alliance for Caregiving, [14] which reported that, the average age of caregivers was 48 years and about 51% of caregivers in USA were between the ages of 18 and 49 years. The study done by Saeui et al., [15] on 30 caregivers of children with leukemia at the Queen Sirikit

National Institute of Child Health, Bangkok found that, the majority of caregivers age ranged from 20-30 years and 31-40 years. This age is consider the capable age for providing care for sick members in the family.

Results of the current study indicated that, more than half of the family caregivers were females and mothers of the children. These results were supported by many studies as Scarpelli et al., [16] who conducted a study on 190 family caregivers of children with cancer at Pediatric Hematology/Oncology Centers in Brazil and found that, most of the family caregivers were females and mothers of their children. Also Hasan, Hussein & Hashim, [17] studied 80 caregivers at Nanakali Hospital for Blood Disease in Iraq and revealed that, the majority of family caregivers were females. Sitaresmi et al., [18] found that, more than two third of the family caregivers were females. This could be related to the fact that mothers are the first caregivers for sick child at home especially in Egyptian culture and they usually have more and close contact with the sick child and take most of responsibilities.

More than quarter of the family caregivers were unable to read and write while, one fifth had primary school and less than half of the family caregivers had secondary school education. This result was supported by Bahy-Eldin, [19] who conducted a study on 50 caregivers of children with leukemia in pediatric oncology department at the National Cancer Institute, Cairo University found that, the majority of caregivers were illiterate or had primary education which may affect the understanding of disease and treatment process or following physician's instructions and may indirectly affect health status of their leukemic children. This may be related to the number of females in this study and also most of female in Egypt are less educated especially in rural area due to socio-economic geographical factors and gender disparities continue to affect access to primary education as reported by Unicef, [26].

Regarding marital status of the caregivers, the majority of the caregivers were married. These results were in agreement with Al-Jauissy, [20] who conducted a study on 82 caregivers at outpatient chemotherapy clinic in Jordan found that, the majority of the family caregivers were married. The same result also revealed from Hasan, Hussein & Hashim, [17] who found that, the majority of the family caregivers to be married and have another children and responsible about whole family.

Concerning the place of residence, more than half of the family caregivers were from urban areas. This result contradicted the study done by the National Alliance for Caregiving, [21] in USA which indicated that caregivers were equally distributed among urban and rural areas. In contrast to the study results, Al-Jauissy, [20] conducted a study on Jordanian caregivers found that, most of caregiver were coming from rural areas. The difference between the two studies could be related to the sample selection at the time of data collection and the cancer institute at urban area.

Regarding total knowledge and practice total scores of the caregivers, more than two third of the family caregivers gained partially satisfactory knowledge and practice total scores while the minority gained satisfactory knowledge and practice scores regarding care of their children with leukemia at home. This result stand in position with Hasan, Hussein & Hashim, [17] who revealed that, the majority of caregivers had deficient knowledge regarding causes, symptoms, complication and treatment of the leukemia and the majority of caregivers had poor practice regarding complications and side effects of chemotherapy. On the same line, Geleson et al., [22] carried out a study at the chemotherapy outpatient clinic of the pediatric oncology institute in Brazil and indicated that, family caregivers of cancer patients had lack of knowledge & practice and needed orientations about the disease, it is dangerous signs and side effects of chemotherapy and relevant actions. Also Saeui et al., [15] reported that, family caregivers having lack of knowledge and competence in caring for acute leukemia in children undergoing chemotherapy. This could be related to caregiver's lower educational level, income and place of residence plus lack of awareness regarding leukemia and improper health education programs about their children condition from health care providers.

A highly statistically significant positive correlation was found between family caregiver's total knowledge scores and their total practice scores. These results mean that, the family caregiver's knowledge had an effect on their practices and the more knowledge they have, the better home practice they provide. This result was supported by Fouad, [23] who conducted a study on 140 caregivers at child clinic of metabolic disorder in preventive medicine center Abo EI-Reesh, Cairo university hospital and reported that, family caregiver's knowledge had an impact on their practices. This is true because when family caregivers are provided with basic knowledge about their children condition, prognosis, various treatment approaches and

side effects of treatment this will help them in practicing healthy behaviors regarding their children with leukemia.

No statistically significant correlation was found between the caregiver's sex in relation to their knowledge regarding leukemia and their home practices. This result was supported by Patistea & Babatsikou, [25] who conducted a study on 71 parents of children with leukemia at Health Visiting Department, Technological Educational Institution of Athens, Greece who reported that, no statistically significant differences were found between the two sexes. This could be related to the number of female caregivers in the study.

Also, no statistically significant correlation was found between the caregiver's age in relation to their knowledge regarding leukemia and their home practices. These results were contradicted with the results of the study done by Fouad, [23] who revealed that, there was a highly statistically significant negative correlation between the caregiver's ages in relation to their home practices. This is a fact of life that health declines with age and caregiver's activities and ability to provide care for their children will be decrease by the age.

There was a highly statistically significant positive correlation between the caregiver's educational level and total knowledge scores regarding leukemia. Also a positive correlation was found between the caregiver's educational level and their home care practices. This result was supported by Hasan, Hussein & Hashim, [17] and Fouad, [23] who found that, there was highly statistically significantly correlation between caregivers' knowledge and practices and their level of education. The higher the educational level of the caregivers the more knowledgeable they become about leukemia and the better their home care practices will be for their children.

A positive correlation was found between the caregiver's knowledge and home practice in relation to their residency areas. This result was in agreement with Scarpelli et al., [16] who reported that, the place of residency was associated with sufficient knowledge and practices for mothers providing care for their children. This could be related to caregiver's education among rural areas, where in rural areas most of people are not educated or have only basic education. Also they didn't have sufficient knowledge about their children conditions may be due to improper health education from health care provider and limited resources in rural areas.

There was a highly statistically significant positive correlation between the caregivers' income and their knowledge and home practices total scores regarding their children with leukemia where the higher the caregivers' income, the more knowledge they had about leukemia and the better home care practices. These results were supported by Hasan, Hussein & Hashim, [17] who found that, most of the caregivers living in low socioeconomic status and facing financial difficulties usually face more financial problems after the diagnosis of leukemia and this directly influences their knowledge and practices. On the same line, Byers, Wolf & Bauer, [24] who conducted a study on American caregivers and reported a statistically significant difference among parents who had different income and different education level of their leukemic child. With sufficient income, there will be availability of money to travel to more than one hospital for diagnosis, making more investigation, follow-up and getting appropriate treatment and medications. Also having enough money allows caregivers to demonstrate better and healthy practices and getting more knowledge about leukemia and treatment from specialized doctors. While low socioeconomic status associated with a high mortality due to delay diagnoses and treatments.

Conclusion: The current study concluded that, there was a lack of family caregiver's knowledge regarding leukemia and home practices for their children with leukemia.

Recommendations: Based on the study results, the following recommendations are suggested:

- 1- Health education program for family caregivers of children having leukemia to prepare them with the needed knowledge and skills so they can provide appropriate home care for their children.
- 2- Prepare a protocol of home care for children having leukemia to help caregivers to provide appropriate home care.

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