

## Effect of Health Educational Program on the Performance of Home Caregivers of Children with Cancer about Side Effects of Chemotherapy

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### Abstract

**Background:** Children and families impacted by cancer generally face debilitating, unpleasant, and often difficult-to-manage symptoms. Symptom management is a basis of potentially preventable complications (ppc), which supports the need for early incorporation of ppc. **Aim:** assess the effectiveness of health educational program on the performance of home caregivers of children with cancer about side effects of chemotherapy. **Research Design:** A Quasi-experimental research design was utilized in this research. **Subjects:** Included a purposive sampling of 124 home caregivers of children with cancer at pediatric outpatient clinic at Sohag Oncology Institute in Sohag City. **Tools of data collection:** Two tools included Tool I: A structured Interviewing Questionnaire Sheet (demographic data of the home caregivers and their children, home caregiver's knowledge on side effects of chemotherapy), Tool (II): observational checklist to assess the skill of the home caregivers of children with cancer. **Results:** The majority of the studied caregivers (88.7%) had poor knowledge while only (2.4%) of them had good knowledge before health educational program compared to fifty-six percent of them (56.5%) had good knowledge after implementation of health educational program. A statistically significant difference was present between the pretest and posttest scores of the caregiver total knowledge and practice regarding the side effects of chemotherapy. **Conclusion:** Caregivers' knowledge as well as practices related to the side effects of chemotherapy were enhanced after the implementation of health educational program. **Recommendations:** Oncology nurses and experts should think about creating instructional booklets for caregivers to reference various kinds of cancer and treatment methods.

**Keywords:** Children; chemotherapy; Caregivers' performance & health educational program

### Introduction:

Childhood cancer is second in terms of causes of death for children after accidents, making it a major global public health concern. According to the global survey, both developed and developing countries have childhood cancer rates that are higher than 80–85%. An estimated 400,000 children and teenagers aged 0 to 19 worldwide are predicted to have cancer every year. (National Cancer Institute (NCI, 2023).

A cancer diagnosis can result in abnormal cell growth, the disease's ability to spread to neighboring tissues, and, if treatment is not taken, the eventual death of the illness. Cancer is primarily caused by one cell. When normal cells become cancerous, they become aberrant, useless, and damage organs and tissues in the body. The most frequent cancers in children include brain tumors, lymphomas, leukemias, and solid

tumors including Wilms tumors and neuroblastoma. Leukemia accounts for around 33% of childhood cancer cases, with brain tumors (25%), lymphomas (8%), and bone tumors (4%). In this regard, leukemia is by far the most prevalent. (American Cancer Society (ACS, 2019).

Children's Cancer Hospital 57357 Egypt (CCHE) has been studying the health outcomes of pediatric cancer survivors over the past ten years in order to ascertain the differences in survival by cancer type and population. 15,997 children with cancer in all were examined; 42% were female and 58% were male. Of the children, the lowest age group (0–4 years) had the biggest percentage (48%) of them. 49 percent of the kids had hematologic malignancies, and 59 percent had solid tumors. The most frequent cancers were neuroblastoma, leukemia, lymphoma, and tumors of the central nervous system (CNS). 14,553

children, or 92.2% of the total research group, had their survival rate determined (Soliman et al., 2019).

The primary factors influencing treatment for children malignancies are the cancer's type and stage. Radiation therapy, chemotherapy, and surgery are all part of the treatment. Chemotherapy is always the first treatment utilized in most situations, and other therapies are performed as needed (Marcdante and kliegman, 2019). Chemotherapy, usually known as drug therapy, is the use of medications to treat cancer. Chemotherapy can affect cancer cells throughout the body, while radiation therapy and surgery only target and destroy cancer cells in specific regions of the body. Chemotherapy eliminates cancer cells that have traveled to distant regions of the body from the original tumor. (National Cancer Institute, NCI, 2023).

Chemotherapy is the initial line of treatment for over 70% of children worldwide who have been diagnosed with cancer. Chemotherapy medications can impact healthy and normal cells because they kill rapidly growing cells, which is how cancer cells proliferate. Side effects result when healthy cells are damaged. The therapy process includes side effects, which are not harmful. Damage to the bone marrow's blood-forming cells, hair follicles, and the mouth, digestive tract, and reproductive system are the most frequent adverse effects. Certain chemotherapy medications can harm cells in the nervous system, kidneys, bladder, heart, and lungs. (National Cancer Institute (NCI), 2018, Uzun and Kucuk, 2019)

Children who receive cancer treatment, including chemotherapy, radiation therapy, and surgery, face a variety of challenges. Some of the side effects include anemia, decreased appetite, bleeding, constipation, diarrhea, tiredness, losing hair, an infection, changes in the mouth and throat, nausea and vomiting, abnormalities in the skin and nails, neurocognitive problems, and sexual dysfunction (Bhakta, et al., 2019).

Effective symptom management is critical due to the risk of negative implications for the child's health and overall well-being. Children with cancer endure a variety of symptoms, which often show as clusters. Children and families afflicted by cancer

often face debilitating, unpleasant, and difficult-to-manage symptoms. These symptoms are caused by the illness, its treatment, and related procedures, which may impede the child's physical and psychological development, as well as the quality of life for the child and family. Experiencing severe symptoms on a regular basis reduces one's quality of life and can hamper a child's development in various ways (Tomlinson et al., 2020).

Nurse clinicians and scientists were at the forefront of pediatric palliative care in oncology. Several early nurse-led research focused on the experiences of mothers caring for children with terminal cancer. Symptom management is a basis of PPC, supporting the need for its early incorporation (Newman et al., 2020).

Family education must be an integral part of nursing care. The pediatric oncology community has recently identified it as a clinical and scientific priority. Expert consensus has been established to develop guidelines for educating families of newly diagnosed patients. A vast amount of data suggests that patient and family education in pediatric oncology should start as soon as a child is diagnosed with cancer. This demonstrates the deluge of new information that is regularly presented, yet families must be aware of the diagnosis and course of therapy in order to provide safe care at home. It also underlines the severe emotional toll that the children and families (Haugen et al., 2020)

#### **Significance of the study**

Chemotherapy is used to treat almost all childhood cancers. Over 50% of children with cancer who undergo chemotherapy suffer undesirable medication responses. (Singaraju, et al., 2020)

Caregivers are the children's only hope of preserving their physical, emotional, and psychological well-being and providing ongoing support to enrich their lives. Caregivers are said to improve their understanding about treatment side effect in order to deliver appropriate care for the children. According to a report, caregivers should have extensive understanding of complication control strategies in order to improve children's progress. (American Cancer Society, 2019) As a result, the researcher chooses to deliver

**Operational definition:**

**Health education** refers to deliberately designed learning experiences that include some sort of communication and are meant to enhance health literacy, involving acquiring information and developing life skills that benefit individual and community health.

**Performance** refers to home caregivers' knowledge and practice in controlling their children's side effects related to chemotherapy administration.

**Chemotherapy side effects** are secondary and usually adverse reactions linked with chemotherapy administration. The most common side effects include fatigue, hair loss, easy bruising and bleeding, infection, anemia, nausea, vomiting, appetite changes, constipation, Diarrhea, Mouth, tongue, and throat problems such as sores and pain with swallowing and Skin and nail changes such as dry skin and color change.

**Caregivers of children with Cancer:** Caregivers can be either a mother, father, or a family member who cares for a child diagnosed with cancer and is undergoing the cycles of chemotherapy.

**Aim of the study****General aim of the study:**

- Examine the effectiveness of a health educational program on the performance of home caregivers of children with cancer about the side effects of chemotherapy.

**Specific objectives of the study are:**

1. Assess knowledge of home caregivers of children with cancer about side effects of chemotherapy.
2. Assess practice of home caregivers of children with cancer about side effects of chemotherapy.
3. Designing, implementing, and evaluating the effect of a health education program on developing the performance of home caregivers of children with cancer about the side effects of chemotherapy.

**Research hypothesis**

1. Implementing the program will increase home caregivers' knowledge.
2. Implementing the program will improve practices of home caregivers.

3. There will be a statistically significant association between home caregivers' performance before and after program implementation.

**Research design:**

This study used a quasi-experimental approach (one group before and after the test). A quasi-experiment is an empirical interventional study that estimates the causal effect of an intervention (health education program) on the target population without random assignment.

**Research settings:**

Sohag Oncology Institute is located in Mubarak Medical City, West Sohag District, near the One Day Education Hospital in Sohag Governorate. It serves all people of the Sohag and Qena governorates. It has an affiliation with the Ministry of Health. It offers general and specialized medical services, including outpatient clinics, radiotherapy, chemotherapy, blood transfusions, CT scans, MRI scans, and PET scans. The study was conducted at the pediatric outpatient clinic on the first floor of the Oncology Institute, which has a patient waiting area next to it.

**Subject:**

Purposive sample 124 home caregivers of children with cancer at previously mentioned settings. The sample was estimated using the following equation:

$$n = \frac{[DEFF * Np(1-p)]}{[(d^2/Z^2(1-\alpha/2)^*(N-1) + p*(1-p))]}$$

$$DEFF \text{ (Design effect)} = 1$$

$$N \text{ (population)} = 1150$$

$$p \text{ (Hypothesized \%)} = 10\% \pm 5$$

$$d \text{ (tolerated margin of error)} = 0.05$$

$$Z \text{ (level of confidence)} = 1.96$$

$$\alpha \text{ (Alpha)} = 0.05$$

$$n = \frac{[1 * 1150 * 8\% \pm 5 (1 - 10\% \pm 5)]}{[(0.05)^2 / (1.96)^2 - 0.05 * (1150 - 1) + 10\% \pm 5 (1 - 10\% \pm 5)]}$$

n= 124 home caregivers were selected according to the following criteria for inclusion and exclusion.

**Inclusion Criteria:**

1. Caregivers of children with cancer who wish to participate in the study.
2. Caregivers of children with cancer who are receiving chemotherapy.

**Exclusion Criteria**

1. Caregivers of children with cancer who have participated in any educational program on chemotherapy side effects within the last six months.
2. Caregivers with hearing and speech impairments.

#### Tools for data collection:

Data was collected using the following tools during the pre/post-educational program.

#### Tool I: A structured Interviewing Questionnaire:

The researchers made this instrument based on the scientific literature study (Hasan et al, 2020) and was designed in Arabic language for data collecting. It consists of three parts:

**Part 1: Demographic data of the home caregivers** such as age, gender, education status, occupational status, family history of cancer.

**Part (2): Demographic data of the children with cancer included** age, gender, family history of cancer and type of diagnosis, duration of illness from the period of diagnosis and type of treatment.

**Part (3): Home caregiver's knowledge on side-effects of chemotherapy** it consisted of 39 multiple choice questions as define cancer, define chemotherapy, the action and uses of chemotherapy drugs, methods of administration, routes of chemotherapy administration, side effects of chemotherapy administration related to anemia, appetite changes, bleeding, constipation, diarrhea, fatigue, hair loss, infection, mouth and throat changes, nausea and vomiting, skin and nail changes and nutrition for children with cancer.

**Total knowledge score was classified as** The correct response received a (1) grade, whilst the erroneous response received a (0). These scores were combined to give a percentage score. As a result, the overall score ranged from 0 to 39. Mothers' knowledge was categorized as follows:

- **Poor knowledge** (< 50%)
- **Fair knowledge** (50% - 75%).
- **Good knowledge** (> 75%).

**Tool (II): An observational checklist** was derived from (Hasan et al, 2020) and modified by investigators to measure the

skills of home caregivers of children with cancer. It consisted of twenty-eight (28) items separated into four aspects:

Items (chemotherapy sides effect)	Control measures
Infection	Hand washing – 7 steps
Diarrhea	ORS preparation – 7 steps
Oral ulcer	Salt water gargle – 7 steps
Fever	Tepid sponging – 7 steps

#### Scoring system:

A score of (1) was assigned to the action that was completed, while a score of (0) was assigned to the action that was not completed. These scores were totaled and translated into a percentage. As a result, the overall level of recorded practices was determined as follows:

- Score  $0 < 50\%$  indicated to unsatisfactory level of reported practices.
- Score  $\geq 50\%$  referred to satisfactory level of reported practices.

#### Tools validity and reliability:

The study's tools were validated by seven specialists in Pediatric and Community Health Nursing, which was from Sohag University's Faculty of Nursing. Every member was assess the tool's content and structural design to ensure the item's completeness and clarity. All comments and ideas were considered, and some statements were reworded and sequenced accordingly.

**Reliability:** The researchers employed the test-retest approach to assess the tools' internal reliability and consistency. It was completed before data collection began during the pilot study. Cranach's alpha for knowledge was 0.928, and 0.843 for practice.

#### Ethical considerations:

Official permission was received from the Faculty of Nursing, Sohag University's ethical committee was approved on the

research by No (158) on February 12th, 2024, and the director of Sohag Oncology Institute; all gave their official consent and permission prior to the study's conduct. Furthermore, after the researchers discussed the goal of the study and promised them that confidentiality would be respected during the trial, all home care providers verbally agreed to participate. All participants were advised that their information would be kept confidential and used purely for research reasons, that their participation in the study was entirely voluntary, and that they could withdraw at any time.

#### **Field work:**

The study was carried out in the following four stages:

#### **I- Assessment stage (pre planning stage):**

Initially, the researchers interviewed each home caregiver, introduced herself to the participants in the study, and obtained their verbal consent to participate in the study after talking about the study's goal. The home caregivers were then asked to complete a structured interviewing questionnaire form separately for the purpose of collecting information from the baseline. It took about 30-40 minutes to finish each interview questionnaire, and the pre-test period took one month from the start of data collection. It also helped in identifying knowledge and practice gaps among home caregivers, providing more information, and establishing a health education program depending on outcomes.

#### **II- Planning stage:**

The researchers designed the educational program based on assessment data, pilot study, and relevant literature (Ignatavicius et al., 2024; Thomas, 2024; Cheever and Hinkle, 2018). The educational program was established as a booklet to address recognized demands, requirements, and weaknesses. The program is divided into two parts:

- the educational theoretical part, which covered cancer and common chemotherapy side effects in the first four sessions.
- The educational practical part involved oral rehydration solution preparation, hand

washing, saltwater gargling, and tepid sponging practices during the last sessions. All of the home caregivers were given the same booklet content, and the sessions were shown to the home caregivers using a laptop, a booklet, and a baby dolly. In addition, the teaching program's technique was determined by selecting a suitable teaching method (a lecture, small-group discussion, role play, demonstration, and remonstrations) and the appropriate teaching medium (handouts, dolls, audiovisual material, hand washing, and ORS preparation materials).

#### **III- Implementation stage:**

The study lasted for seven months, from October 2023 until the end of April 2024. Data was gathered by conducting interviews with caregivers at the selected pediatric outpatient clinic at the Sohag Oncology Institute in Sohag City. The researchers were present three days per week (Saturday, Monday, and Tuesday) from 9:00 a.m. to 2:00 p.m. to collect data using the instruments stated previously.

The investigated home caregiver (124 caregivers) was separated into 20 groups, with each group consisting of 6-7 caregivers. The study was done in pediatric outpatient. The total number of sessions for the group was two every day, with six sessions per week. Each month, four groups were implemented.

The program lasted six hours, divided into six sessions. The duration of each session is 60 minutes, including the periods of discussion. Every session began with a recap of the previous session, an explanation of the next one's aims, and taking into consideration the use of simple language to suit the level of the caregivers. A schedule for home caregivers was prepared, outlining the date, time, place, themes, and duration of each session. Two researchers gathered information.

The researchers continued to reinforce her acquired knowledge, answering any questions that were offered and providing feedback. All of the home caregivers were cooperative with the researchers, and at the end of each session, the caregivers participated in a discussion to correct any misunderstanding.

The researcher designed six sessions, which were carried out for each group as follows:

1. The first session covered an overview of about cancer and chemotherapy, the action of chemotherapy, its uses, routes of administration of chemotherapy, and the most common adverse effects of chemotherapy.
2. The second session included theoretical topics such as anemia, bleeding, fatigue, and their signs, symptoms, and management.
3. The third session consisted of theoretical issues such as hair loss, nail, and skin changes, as well as their causes, signs, symptoms, and management.
4. The fourth session emphasized theoretical topics around appetite changes and constipation, in addition to their causes, signs, symptoms, management, and diet for children with cancer.
5. The fifth session contained both the theoretical and practical aspects of nausea, vomiting, and diarrhea, including signs, symptoms, and management, as well as oral rehydration solution preparation and hand washing.
6. The sixth session discussed theoretical and practical parts of infection, mouth and throat changes, involving signs, symptoms, and management, in addition to saltwater gargle and tepid sponging.

#### **Evaluation stage:**

The performance of each group was evaluated three months after the program was implemented. Post-tests were administered using the same data gathering instruments as pretests.

#### **Statistical analysis:**

The collected data was organized, classified, coded, tabulated, and analyzed using the Statistical Package for Social Sciences (SPSS) V.26. Data was presented in tables and charts using numbers, percentages, averages, and standard deviations. The McNemar test was used to demonstrate the difference before and after intervention. To determine the relationship between variables, the Chi-square test was used. The T-test was employed to compare the means of the variables. P-values <0.05 are regarded statistically significant, whereas <0.01 are extremely significant.

#### **Limitation of the Study:**

- ❖ Inadequate nationwide studies have been conducted to study the current research issue.

- ❖ The investigator was unable to generalize the findings as the sample size is small.

#### **Results:**

**Table 1** revealed that over one third of the home caregivers (38.7 %) were between the ages of 31 and 35, with a mean SD age of  $31.24 \pm 7.23$  years old. All of the home caregivers were mothers, the most (91.1%) of them was mothers, 52.4% of the home care givers were from rural areas, and the majority (84.7%) of them was married. Over one-third (33.9%) of home caregivers were illiterate. The table also showed that almost three-quarters (83.1%) were housewives and 62.1% were extended families. Concerning family income, the table showed that almost three quarters (83.9%) of the home care givers reported not enough for their expenditures.

**Table 2** illustrated that as regard children's characteristics the study illustrated that more than (58.1%) were between the ages of 6 and 10, with a mean SD age of  $9.12 \pm 8.23$  years old. Over half (56.5%) were male while 35.5% were ranked as the second child. The table also showed that 46.8% of children had uncertain family history, more than one third (39.5%) were diagnosed with cancer for less one month and all of the children had receiving chemotherapy treatment.

**Figure 1** demonstrates that leukemia was the most prevalent type of cancer in children, followed by myeloma, which accounts for 46.8% and 25.0%, respectively. **Figure 2** shows that only 2.4% of participants had a good knowledge of the side effects chemotherapy prior to the program's introduction, compared to 56.5% afterward. There was a statistically significant difference in the participants' overall knowledge before and after the program's execution. ( $P = .001^{**}$ ). This figure represented the first research hypothesis.

**Table 3** showed that 87.9% of caregivers had unsatisfactory practice before the test, which decreased to 11.3% after the test. There was a statistically significant variance between pretest and posttest, indicating that home caregivers' practices improved following the adoption of a health education program. This table indicated to the second research hypothesis.

**Table 4** shows that there was a difference of statistical significance between total levels of knowledge and educational level, occupational status, and family income in pre and post-test P= (0.001, 0.001, 0.001, 0.001, 0.001& 0.001) respectively, as well as a statistically significant difference between total levels of knowledge and the age of the home care givers and types of family in pre-test p= (0.001 & 0.003\*\*).

**Table 5** indicates that there was a statistically significant variation between the level of practice, age of home care givers, educational status, types of family, and family income in the pre-test at P= (0.001, 0.001, 0.003, and 0.001).

**Figure 3** revealed a significant relationship between the whole score of knowledge and total score of practice of home care caregivers regarding chemotherapy side effects in the initial test and post-test (p= (0.001& 0.001), accordingly).

### Result:

**Table 1: The distribution for the investigated home caregivers based on their demographic characteristics (n=124)**

demographic characteristics of home caregivers:	N	%
<b>Age of the home caregivers:</b>		
• 20-25years	21	16.9
• 26-30years	15	12.1
• 31-35years	48	38.7
• 36-40years	32	25.8
• >40years	8	6.5
<b>Age (mean± SD)</b>	<b>31.24±7.23</b>	
<b>Gender of home caregiver:</b>		
• mothers	124	100.0
<b>The kinship to patient:</b>		
• Mother	113	91.1
• Sister	11	8.9
<b>Residence:</b>		
• Rural	65	52.4
• Urban	59	47.6
<b>Marital status:</b>		
• Single	6	4.8
• Married	105	84.7
• divorce	11	8.9
• Widow	2	1.6
<b>Educational status:</b>		
• Illiterate	42	33.9
• Read and write	21	16.9
• Primary education	16	12.9
• Preparatory education	13	10.5
• Secondary education	18	14.5
• University education	14	11.3
<b>Occupational status:</b>		
• Work	21	16.9
• Housewives	103	83.1
<b>Types of family:</b>		
• Nuclear	47	37.9
• Extended	77	62.1
<b>Family income:</b>		
• Enough	20	16.1
• Not enough	104	83.9

Table (2) Distribution of children's attributes (n=124):

Children attributes	N	%
<b>Child's age (years)</b>		
• 1-5 years old	1	0.8
• 6-10	72	58.1
• 11-15	37	29.8
• 16-19	14	11.3
<b>Age (mean <math>\pm</math>SD)</b>	<b>9.12<math>\pm</math>8.23</b>	
<b>Gender of child</b>		
• Male	70	56.5
• Female	54	43.5
<b>Rank of child:</b>		
• First	16	12.9
• Second	44	35.5
• Third	34	27.4
• More than Fourth	30	24.2
<b>Family history of cancer:</b>		
• Father	36	29.0
• Mother	30	24.2
• Uncertain	58	46.8
<b>Duration of illness from the period of diagnosis:</b>		
• < one month	49	39.5
• 1-< 4 month	41	33.1
• 4-< 6 month	34	27.4
<b>Type of treatment:</b>		
• Chemotherapy	124	100 %

Figure (1) displays the distribution of children based on their diagnoses (n=124):

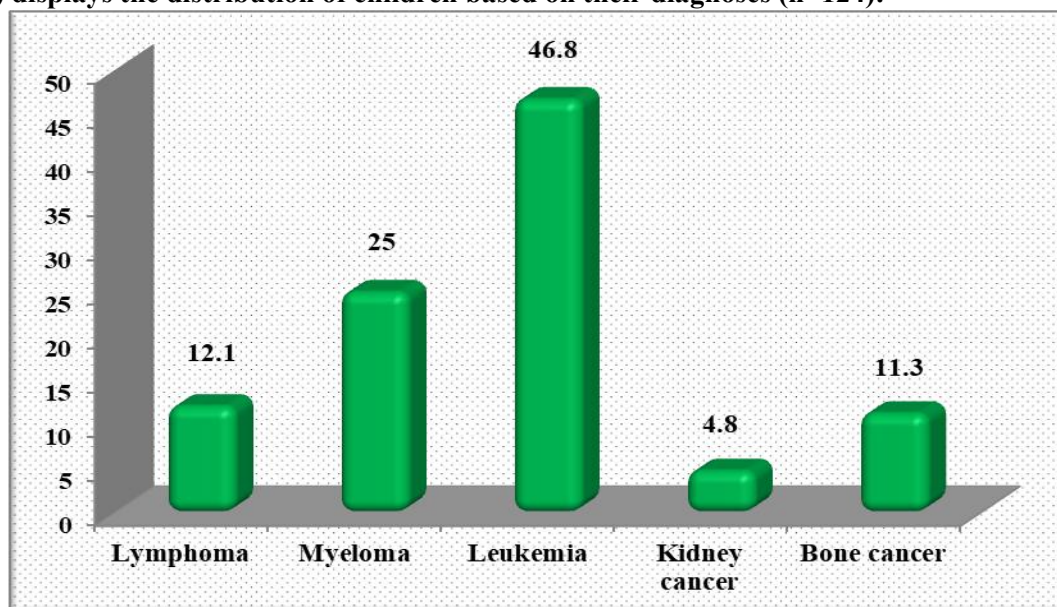
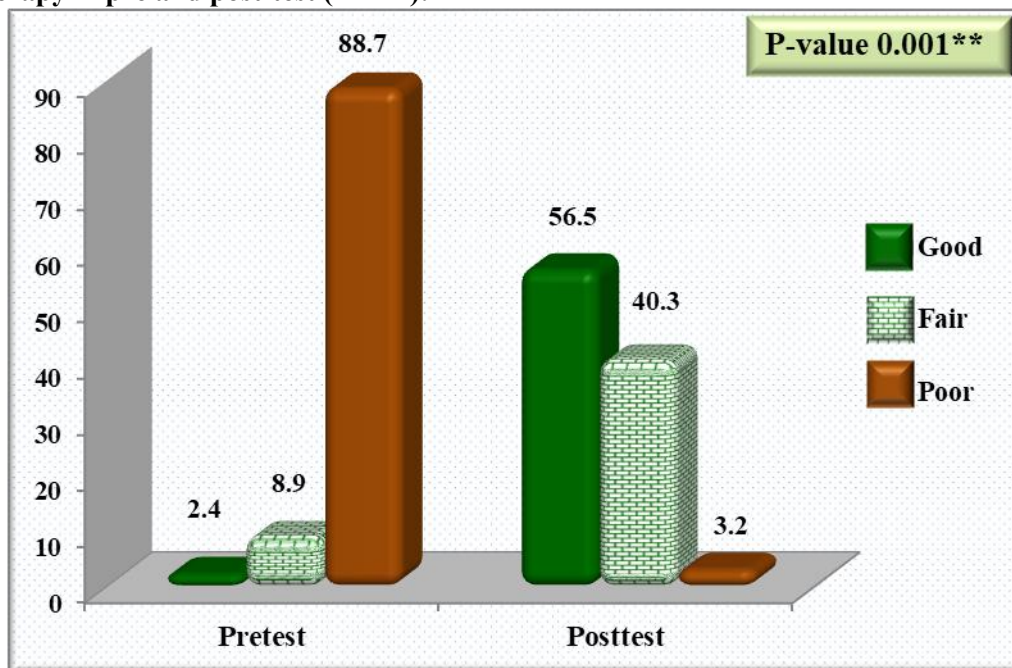




Figure (2) clarifies distribution of the studied caregivers based on their total knowledge about side effects of chemotherapy in pre and post-test (n=124):



McNemar test

(\*\*) Highly statistically significant difference

Poor knowledge: <50% of overall score.

Fair degree of knowledge: 50%-75% of total score

Good knowledge: greater than 75% of the total knowledge.

Table (3) illustrates the allocation of the study home caregivers according to their practices score on side effects of chemotherapy in pre and post-test (n=124):

Items	Practices score about side effects of chemotherapy				P-value
	Pre-test		Post-test		
	N	%	N	%	
<b>Hand washing:</b>					0.001**
• Satisfactory	36	29.0	96	77.4	
• Unsatisfactory	88	71.0	28	22.6	
<b>Oral Rehydration Solution preparation:</b>					0.001**
• Satisfactory	22	17.7	106	85.5	
• Unsatisfactory	102	82.3	18	14.5	
<b>Salt water gargle</b>					0.001**
• Satisfactory	3	2.4	120	96.8	
• Unsatisfactory	121	97.6	4	3.2	
<b>Tepid sponging</b>					0.001**
• Satisfactory	2	1.6	110	88.7	
• Unsatisfactory	122	98.4	14	11.3	
<b>Total practices</b>					0.001**
• Satisfactory	15	12.1	110	88.7	
• Unsatisfactory	109	87.9	14	11.3	

(\*\*) highly statistically significant difference

.Unsatisfactory degree of practice 0 < 50 % of the total grade

Satisfactory practices ≥ 50 % all of the score.

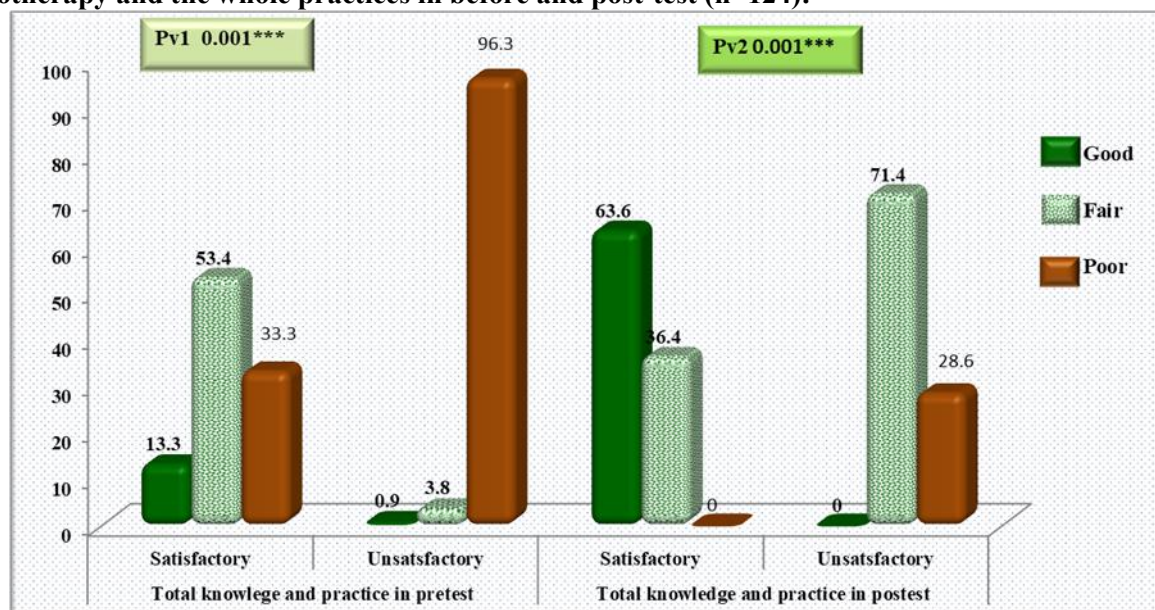
**Table (4) Relation between the studied home care giver's demographic data and total knowledge about side effects of chemotherapy in pre and post-test (n=124):**

Demographic data	Total knowledge about side effects of chemotherapy							P-value
	Pre-test			P-value	Post-test			
	N(%) 3	N(%) 11	N(%) 110		N(%) 70	N(%) 50	N(%) 4	
<b>Age of the home care givers:</b> <ul style="list-style-type: none"> <li>• 20-25years</li> <li>• 26-30years</li> <li>• 31-35years</li> <li>• 36-40years</li> <li>• &gt;40years</li> </ul>	0(0.0) 0(0.0) 0(0.0) 0(0.0) 3(100.0)	0(0.0) 2(18.2) 4(36.3) 3(27.3) 2(18.2)	21(19.1) 13(11.8) 44(40.0) 29(26.4) 3(2.7)	<b>0.001*</b>	10(14.3) 9(12.8) 28(40.0) 18(25.7) 5(7.1)	10(20.0) 6(12.0) 19(38.0) 12(24.0) 3(6.0)	1(25.0) 0(0.0) 1(25.0) 2(50.0) 0(0.0)	0.948
<b>The kinship to patient:</b> <ul style="list-style-type: none"> <li>• Mother</li> <li>• Sister</li> </ul>	3(100.0) 0(0.0)	11(100.0) 0(0.0)	99(90.0) 11(10.0)	0.464	64(91.4) 6(8.6)	46(92.0) 4(8.0)	3(75.0) 1(25.0)	0.511
<b>Residence:</b> <ul style="list-style-type: none"> <li>• Rural</li> <li>• Urban</li> </ul>	0(0.0) 3(100.0)	4(36.4) 7(63.6)	61(55.5) 49(44.5)	0.089	33(47.1) 37(52.9)	28(56.0) 22(44.0)	4(100.0) 0(0.0)	0.097
<b>Marital status:</b> <ul style="list-style-type: none"> <li>• Single</li> <li>• Married</li> <li>• divorce</li> <li>• Widow</li> </ul>	0(0.0) 3(100.0) 0(0.0) 0(0.0)	0(0.0) 11(100.0) 0(0.0) 0(0.0)	6(5.5) 91(82.7) 11(10.0) 2(1.8)	0.827	2(2.9) 60(85.7) 8(11.4) 0(0.0)	3(6.0) 43(86.0) 2(4.0) 2(4.0)	1(25.0) 2(50.0) 1(25.0) 0(0.0)	0.100
<b>Educational status:</b> <ul style="list-style-type: none"> <li>• Illiterate</li> <li>• Read and write</li> <li>• Primary education</li> <li>• Preparatory education</li> <li>• Secondary education</li> <li>• University education</li> </ul>	0(0.0) 0(0.0) 0(0.0) 0(0.0) 3(100.0)	0(0.0) 0(0.0) 0(0.0) 0(0.0) 8(72.7)	42(38.3) 21(19.1) 16(14.5) 13(11.8) 15(13.6) 3(2.7)	<b>0.001*</b>	16(22.9) 13(18.6) 4(5.7) 10(14.3) 15(21.4) 12(17.1)	25(50.0) 7(14.0) 12(24.0) 2(4.0) 2(4.0) 2(4.0)	1(25.0) 1(25.0) 0(0.0) 1(25.0) 1(25.0) 0(0.0)	<b>0.001*</b>
<b>Occupational status:</b> <ul style="list-style-type: none"> <li>• Work</li> <li>• Housewives</li> </ul>	0(0.0) 3(100.0)	7(63.6) 4(36.4)	14(12.7) 96(87.3)	<b>0.001*</b>	19(27.1) 51(72.9)	0(0.0) 50(100.0)	2(50.0) 2(50.0)	<b>0.001*</b>
<b>Types of family:</b> <ul style="list-style-type: none"> <li>• Nuclear</li> <li>• Extended</li> </ul>	3(100.0) 0(0.0)	8(72.7) 3(27.3)	36(32.7) 74(67.3)	<b>0.003*</b>	28(40.0) 42(60.0)	18(36.0) 32(64.0)	1(25.0) 3(75.0)	0.782
<b>Family income:</b> <ul style="list-style-type: none"> <li>• Enough</li> <li>• Not enough</li> </ul>	0(0.0) 3(100.0)	6(54.5) 5(45.5)	14(12.7) 96(87.3)	<b>0.001*</b>	20(28.6) 50(71.4)	0(0.0) 50(100.0)	0(0.0) 4(100.0)	<b>0.001*</b>

Table (5) suggests the relationship between home caregivers' total practices to chemotherapy side effects and their characteristics in pre and post-test (n=124):

Personal data	Total practices regarding side effects of chemotherapy									
	Pre-test				p-value	Post-test				p-value
	Satisfactory (15)		Unsatisfactory (109)			Satisfactory (110)		Unsatisfactory (14)		
	N	%	N	%	N	%	N	%		
<b>Age of the home care givers:</b>	0	0.0	21	19.3	<b>0.001**</b>	18	16.4	3	21.4	0.371
• 20-25years	2	13.3	13	11.9		13	11.8	2	14.3	
• 26-30years	2	13.3	46	42.2		45	40.9	3	21.4	
• 31-35years	7	46.7	25	22.9		26	23.6	6	42.9	
• 36-40years	4	26.7	4	3.7		8	7.3	0	0.0	
• >40years										
<b>The kinship to patient:</b>					<b>0.517</b>					0.809
• Mother	13	86.7	100	91.7		100	90.9	13	92.9	
• Sister	2	13.3	9	8.3		10	9.1	1	7.1	
<b>Residence:</b>					0.114					0.847
• Rural	5	33.3	60	55.0		58	52.7	7	50.0	
• Urban	10	66.7	49	45.0		52	47.3	7	50.0	
<b>Marital status:</b>					0.684					0.923
• Single	0	0.0	6	5.5		5	4.5	1	7.1	
• Married	13	86.7	92	84.4		93	84.5	12	85.7	
• divorce	2	13.3	9	8.3		10	9.1	1	7.1	
• Widow	0	0.0	2	1.8		2	1.8	0	0.0	
<b>Educational status:</b>					<b>0.001**</b>					0.370
• Illiterate	0	0.0	42	38.4		34	30.9	8	57.1	
• Read and write	0	0.0	21	19.3		20	18.2	1	7.1	
• Primary education	0	0.0	16	14.7		14	12.7	2	14.3	
• Preparatory education	2	13.3	11	10.1		12	10.9	1	7.1	
• Secondary education	3	20.0	15	13.8		16	14.5	2	14.3	
• University education	10	66.7	4	3.7		14	12.7	0	0.0	
<b>Occupational status:</b>					0.284					0.779
• Work	4	26.7	17	15.6		19	17.3	2	14.3	
• Housewives	11	73.3	92	84.4		91	82.7	12	85.7	
<b>Types of family:</b>					<b>0.003**</b>					0.858
• Nuclear	11	73.3	36	33.0		42	38.2	5	35.7	
• Extended	4	26.7	73	67.0		68	61.8	9	64.3	
<b>Family income:</b>					<b>0.001**</b>					0.081
• Enough	7	46.7	13	11.9		20	18.2	0	0.0	
• Not enough	8	53.3	96	88.1		90	81.8	14	100.0	

**Fig (3) Relation between the evaluated home caregiver's overall knowledge regards side effects of chemotherapy and the whole practices in before and post-test (n=124):**



**PV1 (between total knowledge and total practices in pre-test)**

**PV2 (between total knowledge and total practices in post-test)**

**(\*\*) highly statistically significant difference**

### **Discussion:**

A child diagnosed with cancer and undergoing chemotherapy treatment may be the parent's most difficult task. Education to parents on how to care for a child having cancer therapy aids in the overall improvement of the child. (Singaraju, et al., 2020)

The current study aimed to evaluate effectiveness of health educational program on the performance of home caregivers of children with cancer about side effects of chemotherapy

The current study results assured that over one third of the home caregivers (38.7 %) were between the ages of 31 and 35, with a mean SD age of  $31.24 \pm 7.23$  years old. All of the home caregiver was female, more than half (52.4%) of the home caregivers were from rural areas. Over one-third (33.9%) of home caregivers were illiterate. This study is consistent with a correlational-descriptive investigation conducted by **Khademi et al. (2019)** to analyze the caring power of 196 women whose a child having cancer and its predictors, with the findings indicating that the mothers' average age was 34.53 years. Similarly, **Hassan and Ibrahim (2018)** performed an Egyptian study to assess the impact of supporting nursing interventions

on the burden and coping methods of 60 mothers of cancer children. The findings revealed that in both categories, more than 90% of the primary caregivers were mothers, with 65% of total mothers aged 30 to 35 years or older. Ninety the majority of the mothers who studied cancer children were housewives. Also, **Hamad and Shaker (2019)** conducted a research investigation to analyze coping techniques among 54 mothers who had children with acute leukemia in Iraq. The study found that mothers had a mean age of  $36.53 \pm 7.53$  years.

In an Egyptian research done by **Taha et al., (2019)** to examine the impact of nursing guidelines on knowledge and reported-practice of 50 mothers had child with leukemia receiving chemotherapy. The study findings concluded that the highest percent of mothers' ages were from 30 to 35 years. The great majority of mothers were married and housewives.

This result could be related to the Sohag oncology Institute in Sohag city is serving children with different types of cancers in the Sohag governorate and surrounding rural and semi-urban areas. In the same context, **the United Nations Educational, Scientific, and Cultural Organization [UNESCO] (2017)** reported that rural

populations accounted for 57% of the total global population. In the same way, 49.4 percent of Egypt's population is female, compared to 50.6 percent of males. At the beginning of 2024, 43.2 percent of Egypt's population resided in cities, while 56.8 percent lived in rural regions (**Data reportal Digital Egypt, 2024**).

In contrast, **Hassan et al., 2020** accomplished an Egyptian study to measure the knowledge and performance of mothers who have children with cancer and are receiving chemotherapy. The study's findings revealed that more than half of the women had a basic education, whereas the minority did not read or write. **Hassan and Ibrahim (2018)** found that more than one-third (38.3%) of studied mothers had a technical education, with high education accounting for 35%.

As regard children's characteristics the current study illustrated that more than (58.1%) were between the ages of 6 and 10, with a mean SD age of  $9.12 \pm 8.23$  years old. Over half (56.5%) were male while 35.5% were ranked as the second child. The table also showed that 46.8% of children had uncertain family history, more than one third (39.5%) were diagnosed with cancer for less one month and all of the children had receiving chemotherapy treatment. The most common types of Cancer among children are leukemia followed by myeloma which constitute 46.8% and 25.0% respectively. These results are consistent with a study conducted by **Hamad and Shaker (2019)**, who discovered that 52% of the youngsters were female, with the majority (88.9%) being diagnosed with leukemia. Similarly, **Motlagh, Mirzaei-Alavijeh, and Hosseini (2019)** noticed that the average age for children diagnosed with cancer was 5.57 years, with 47.1% being female and 52.9% male.

**The American Cancer Society (2020)** updated on recent literature and observed that leukemia is the most frequent in early children, peaking between the ages of 2 and 4. There are various forms of leukemia, including acute lymphocytic leukemia (ALL) and acute myeloid leukemia (AML), that begin in the bone marrow or blood. Leukemia may result in bone and joint pain, weariness, weakness, pale complexion,

bruises, fever, weight loss, and swollen lymph nodes.

**The results of the current study** revealed that the vast minority (2.4%) of the participants had good level of knowledge about side effects of chemotherapy prior to the implementation of the program, compared to more than half (56.5%) of them having a good knowledge level post-implementation. These findings could be attributed to the caregivers' lack of knowledge regarding children cancer and chemotherapy. These research results also highlighted the critical necessity to establish caregiver education sessions in all pediatric oncology health care settings. Insufficient mothers' understanding may increase family stress and worsen their children's clinical results and adverse occurrences connected with insufficient education may include unforeseen medical difficulties.

According to **Hockenberry and Wilson (2019)**, nurses working with children with cancer play an important role in assisting mothers in understanding the various therapies, preventing or managing predicted side effects or toxicities, and monitoring for late effects of treatment. Education is an ongoing aspect of the nursing profession, particularly in new treatments, clinical trials, and home care. Nurse practitioners have vital role in assisting families prevent using unproven and potentially harmful traditional management methods. These findings correspond with those of **Hassan et al. (2020)**, who found that caregivers had limited awareness of chemotherapy and its negative effects. The general degree of knowledge among caregivers about children cancer and treatment was inadequate.

These findings are congruent with those of **Taha et al. (2019)**, who's discovered that the majority of mothers of children with leukemia had incorrect or insufficient knowledge of the genesis, symptoms, and treatment options for childhood cancer. Furthermore, the vast majority of mothers documented items that are unfinished of stated practice for the children's care before, during, and after chemotherapy treatments. Similarly, **Mahmoud and Abd Elaziz (2015)** investigated the impact of a psych

educational training course for 60 parents of children with cancer blood on their experience and psychological well-being. The results of the investigation proved that the majority of pre-test parents lacked information about the definition, causes, symptoms, and treatment options for children cancer.

In a previous study carried out regionally in Iraq, **Obaid, Ajil, and Al-Ganmi (2014)** evaluated knowledge about chemotherapy for leukemic children and their 70 mothers, as well as the relationship between the mother's knowledge and demographic characteristics for mothers, children, and children's illnesses. The research's results displayed a knowledge deficit among mothers in various parts of chemotherapy treatment.

According to the most recent recommendations, it is essential that mothers understand a number of basic principles associated with 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 hospital care (**Jackson, Liang, Frydenberg, Higgins, and Murphy, 2016**).

Similarly, **Saeed, Hamzah, and Nitavid (2019)** explored the effectiveness of a structured education program in India to improve mothers' awareness of childcare for children with cancer blood. The study's findings indicate that 38.53% of mothers lacked expertise, while 34.86% had moderate understanding. The same results were attained by **Samaan (2020)**, who evaluated mothers' care for their children with leukaemia during chemotherapy, found that 67.5% of the mothers had low the entire knowledge levels on leukaemia and chemotherapy. Furthermore, 24.4% of mothers got a fair total knowledge score. Furthermore, just 8.1% of them achieved a high overall knowledge score.

Concerning caregiver's practices for their children with cancer, **the current study** illustrated that the majority (87.9 %) of the home caregivers had unsatisfactory practices prior to program implementation compared to 11.3% post-implementation. There is highly statistically significant difference between pre-test and post-test, the home caregiver's practices were

improved after implementation of health educational program. Unsatisfactory practices of caregivers could have a negative impact on their ability to provide proper care for their children so that educational programs. **Hassan et al. (2020)** conducted the same research, finding that the majority of mothers were unable to care for their infants. Mothers claimed that their children were not receiving adequate care for chemotherapy-related side effects. The biggest percentages weren't aware of the steps taken to protect the youngster at home following a chemotherapy treatment. All mothers performed poorly when it came to caring for their cancer-stricken children who were undergoing chemotherapy.

In a comparable manner **Taha et al. (2019)** found that 98% and 100% of mothers are unaware of the care that must be given to their children before to and throughout chemotherapy. All of the mothers in the research had insufficient documented practice prior to getting nursing instructions. The current study found a statistically significant variance between total levels of knowledge and educational level, occupational status, and family income in pre- and post-tests, as well as a statistically significant difference between total levels of knowledge and age of home caregivers and family type in pre-test. In the pre-test, there was a statistically significant association between degree of practice and age of home caregivers, as well as educational status, type of family, and family income.

The current study found a significant connection between the total score of knowledge and total score of practice of home care providers regarding chemotherapy side effects in pre-test and post-test. As a result, it is possible to assume that mothers' practice is influenced positively by their personal expertise. Caregivers' age, education, and income all have an impact on their performance when dealing with chemotherapy side effects.

In a similar manner **Taha et al. (2019)** discovered highly statistically significant positive connections between mothers' total mean score of knowledge and reported practice and their educational degree. These findings are also aligned with those of **Priya et al. (2019)**, who discovered a

substantial relationship between knowledge, child age, and number of children. In practice, there was a relationship identified between the child's gender and the mother's educational status.

In accordance with **Hassan et al., 2020**, there were no statistically significant connections between the total mean scores of mothers' knowledge and total mothers' 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 ( $p > 0.05$ ). These findings were additionally disputed by **Kaur, Chanu, and Sorte (2017)**, who evaluated the efficacy of a structured educational program on parents' understanding of home management of chemotherapy side effects in India. The findings revealed no statistically significant relationship between knowledge score and selected demographic variables such as parent age, level of education, child age, gender, and child diagnosis.

#### Conclusion:

The results of the current research reveal a clear lack of knowledge and practice among caregivers of children with cancer receiving chemotherapy with regard to chemotherapy side effects. There was a statistically significant variation between total level of knowledge and educational level, occupational status, and family income in pre and post-tests, as well as a statistically significant distinction between the whole levels for knowledge and age of home caregivers and type of family in preliminary tests. In a pre-test, there is also a significant association between degree of practice and age of home caregivers, as well as educational status, type of family, and household income. In addition, there was a significantly positive association between home caregivers' total score of knowledge and total score of practice about chemotherapy side effects in both the pre and post-test.

**Recommendations:** The study recommended that;

- Replicating the study is crucial for generalizing its findings to different pediatric oncology treatment settings.

- Oncology nurses and experts should think about creating instructional booklets for caregivers to reference various kinds of cancer and treatment methods.
- Raise public awareness of pediatric cancer through programs like as caregivers and meetings organized by various groups.
- Establishing and carrying out an instructional educational programs for caregivers in pediatric oncology units improves cancer care for children.
- Pediatric oncology facilities should establish a committee to educate newly diagnosed cancer patients and their caregivers on the disease and treatment options.

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