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Assessment of chemotherapy safe handling among mothers of children with cancer at home

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Abstract---Chemotherapy poses a threat due to its genotoxicity, carcinogenicity, teratogenicity, organ toxicity, and adverse effects on infertility. mothers who administer chemotherapy at home may face these side effects. This study aimed to assess chemotherapy safe handling among mothers of children with cancer at home. Descriptive design was utilized. This study was conducted at the outpatient and inpatient of pediatric oncology departments in Children Cancer Hospital (57357). Sample: 200 mothers were selected. They administer and handle chemotherapy at home. Tools included a structured interviewing questionnaire and self-reported checklist sheets for assessing mothers' knowledge and reported practices. Results: revealed that, 30% of mothers had satisfactory level knowledge, 96.5% of them had poor level of practice. Conclusion: Most of the mothers had school education, aged from thirty to less than forty years, were living in urban, had unsatisfactory total level of knowledge and poor practice level accompanied by lack of awareness regarding safe handling of chemotherapy. A highly statistically significant correlation found between mothers' awareness and each of their total knowledge, reported practices. Recommendation: Establish a system of return – back extra -chemotherapy and related -waste to the hospital pharmacy by mothers of children with cancer should be one of the future plans.

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Keywords---chemotherapy, cancer, children, handling, home, mothers.

Introduction

Cancer increases globally and constitutes the leading cause of death worldwide. It has a large impact on both children and caregivers' lives, often resulting in increased levels of tension, pressure, and psychological diseases, and a decline of personal welfare and well-being. (1).In children, cancer is considered the second leading cause of death; approximately 300,000 cases of cancer are diagnosed in children and teens under the age of 19 every year worldwide. Moreover, there are an estimated 80,000 deaths annually from childhood cancer, approximately half of childhood cancers are lymphoma and leukemia beside that leukemia is the most common form of childhood cancer. (2).

Chemotherapy remains as a standard treatment for cancer besides radiotherapy and surgery; owing to the advances in chemotherapy treatment modalities, it can be administered at home. (3). Chemotherapy is hazardous, whether in intravenous or oral forms. In oral chemotherapy, some of the traditional responsibilities of health care providers have been shifted to children's mothers. So, it is clear that administering chemotherapy without direct supervision from oncology nurse or other health care providers has a potential safety risk. (4). In several published studies had approved that exposures to hazardous drugs can cause both acute and chronic health effects such as skin rashes, adverse reproductive outcomes including spontaneous abortions, infertility, congenital malformations, possibly leukemia and other types of cancers. The health risk depends on how much exposure a mother has to these drugs and how toxic they are. (5).

Mothers are the most common caregiver who stays during hospitalization with their children with cancer. Concerning with the care of their sick children, the mothers may be directly or indirectly exposed to the hazards related to oral chemotherapy, which are continuously administered for months and even years from the children's excreta which is contaminated with chemotherapy or its active metabolites. These hazardous may be represented in carcinogenicity, mutagenicity, and embryo-fetal toxicities. Additionally, mothers may be indirectly exposed to chemotherapy during administration or handling through inhalation, ingestion, or absorption. (6).

Significance of the study

Recently, according to the data base for scientific research in the study setting, Children Cancer Hospital Egypt CCHE (57357), a total of 4,366 children having cancer were enrolled from 2016 till the end of 2017 and 3401 of them receives chemotherapy at home orally and intramuscularly. (7). Therefore, it is important to assess chemotherapy safe handling among mothers of children with cancer at home.

Aim of the study

To assess chemotherapy safe handling among mothers of children with cancer at their home.

Research questions

- What are the mothers' knowledge and reported practices regarding to the safe handling of chemotherapy for their children with cancer?
- Is there a relation between the mothers' characteristics, and their knowledge and reported practices regarding to safe handling of chemotherapy for their children with cancer?

Research design

A descriptive design was utilized in the current study

Setting

The current study was conducted in outpatient and inpatient departments affiliated to Children Cancer Hospital Cairo (57357), Egypt.

Sample

A purposive sample of 200 mothers of child receiving chemotherapy at home from both genders aged from 2 month up to 18 years, diagnosed with cancer and admitted to children cancer hospital in Cairo, Egypt during the study period of 6 months (July until December 2016).

Tools for data collection

It was constructed by the researcher after referring to several guidelines and studies Tool (I): A structure Interview Questionnaire Sheet: Part one: personal characteristics data as the studied children age, gender, residence, etc... and the studied mothers' mothers' age, education, and job. Part two: contained seven dimensions (59) questions to the studied mothers' knowledge about safe handling of chemotherapy at home. Scoring system of knowledge: each question was given a score from zero to 1 in which zero indicated wrong answer or I don't know, while 1 indicated correct answer. All scores were summed with a higher score indicating satisfactory knowledge as follow: A score of zero to 35(<60%) indicated unsatisfactory total score. A score of 36 to 59(>60%) indicated satisfactory total score

Tool II: Self-reported checklist

to assess mothers' reported practice of handling and administering of chemotherapeutic medications at their home. It consisted of sixteen statements to be checked by the researcher if it carried out by the participants or not scoring system of practice: Each statement was given a score of one if the action is made correctly and zero if not done incorrectly. The total score was equal 16 equal to

100%. Total practice score was classified as the following: Satisfactory: ≥ 60% of total practice score (10-16). Unsatisfactory: < 60% of total practice score (zero-9)

Content validity and reliability

Content validity was checked before the pilot study and the actual data collection through distribution of the tools to three expertise in the field of the study (oncologist and pharmacist) from the Children's Cancer Hospital in Egypt (**57357** CCHE) who were recommended by its Scientific Medical Advisory Committee (SMAC), appropriateness, relevance, clarity and completeness of the tool. Modifications and minimal changes were applied as required. The internal consistency reliability was acceptable (α=0.82 for knowledge and α=0.76 for practice)

Protection of ethical and human rights

In an approval document memo dated 2016, the institutional review board of 57357, Egypt, approved this study. Before the study volunteers were included, the study's purpose, design, and anticipated results were described to them. The subjects were told that the study was safe and that all the information collected would only be utilized for that reason. Each subject gave their written consent to take part in the investigation. They had the option to leave the study, and anonymity and confidentiality were protected.

Procedure

Throughout the study, all of the mothers were contacted when their children were admitted to the inpatient or outpatient area, depending on where they would receive their therapy. This occurred between the hours of 12 p.m. and 2 p.m. on weekdays (July until December 2016). After each mother had been informed of the study's goal, each mother gave her written agreement to participate in the study. All participants were given an introduction by the researcher, who then informed them that any information gathered would be kept private and utilized only for the duration of the study. Their child's care would not be impacted either. The researcher highlighted that participation in the study was voluntary and that participants' identity was ensured by data coding. After that, a face-to-face interview was conducted where the researcher read the mothers the questions and categories of possible answers before recording their responses on the questionnaire and the reported practice list. This was done to make sure that all questions and responses were understood as we had intended.

Results

Table 1
Number and percentages distribution of children regarding their characteristics (n=200)

Variable	N	%
Child Age		
<1	13	6.5%

1-<3	36	18%
3-<6	62	31%
6-<12	72	36%
12-<18	17	8.5%
	M± SD 4.34 ± 1.093 year	
Educational level		
Not registered	100	50%
Nursery/Kinder grade	12	6%
Primary/preparatory	84	42%
Secondary	4	2%
Total	200	100%

As regards the characteristics of the studied children, this table indicates that 36% of children aged between 6 to less than 12 years, 31% of them aged 3 to less than 6 years and 18% aged between 1 to less than 3 years while 8.5% aged between 12 to less than 18 years with M± SD = 4.34 ± 1.093. Regarding educational level of children, 50% of them were not registered yet, while only 2% were secondary school.

Table 2
Number and percentages distribution of mothers according to their characteristics (n=200)

Variable	N	%
		Mother's Age
20-<30	71	35.5%
30-<40	112	56%
40-<50	17	8.5%
	M ± SD 4.34 ± 1.093	
	Educational level	
Illiterate	16	8%
Read and write	6	3%
School Education	105	52.5%
Bachelor	71	35.5%
Other (master's degree)	2	1%
Total	200	100%

As regard mothers' characteristics this table illustrates that 56% of mothers aged between 30 to less than 40 years with M± SD = 4.34 ± 1.093 years mothers' educational level was school education in 52.5% of them while 11% were illiterate or just read and write.

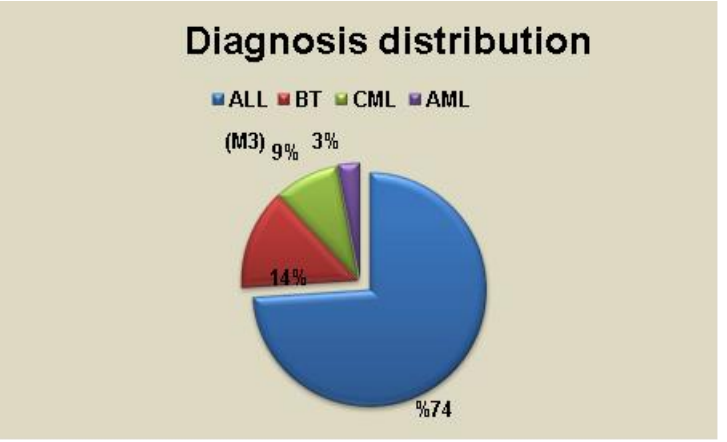

Figure 1. Fig. 4 Percentage distribution of children according to their diagnosis (n=200)

Figure (1) reveals that 74%, 14%, 9 %, and 3% of the studied children arediagnosed as acute lymphoblastic leukemia (ALL), brain tumor (BT), chronic myeloid leukemia and acute myeloid leukemia (AMLM3) respectively.

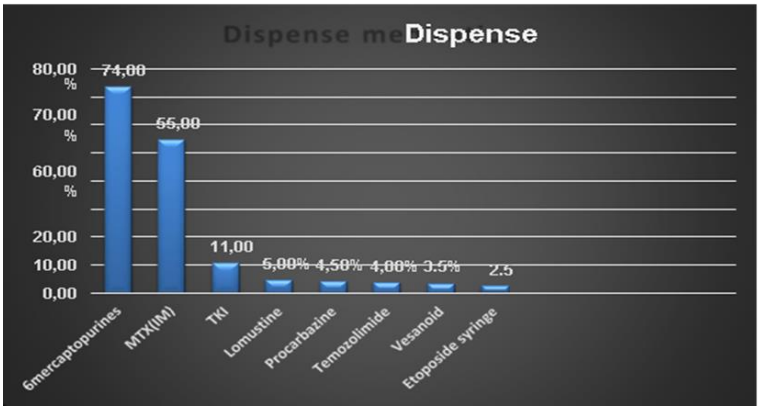

Figure 2. Percentage distribution of the studied children according to their dispensed home chemotherapy (n=200)

Responses are not mutually exclusive

Figure (2) revealed that, 6 –mercaptopurine is dispensed for 74% of the studied children; methotrexate via intramuscular injection (MTX IM) is dispensed for 55% of them beside oral 6 – mercaptopurine (6-MP), while 11% are on Tyrosine kinase inhibitors (TKI).

Table 3
Frequency distribution of mothers' knowledge about chemotherapy protocol of administration &related precautions at home (n=200)

Mothers 'knowledge about chemotherapy protocol	Know		Don't know	
	N	%	N	%
Protocol of chemotherapy administration				
Recommended time for administration	138	69	62	31
Frequency of chemotherapy	198	99	2	1
Precautions against chemotherapy administration				
Interaction with certain type of Food	126	63	74	37
- Interaction with certain type of Medication	52	26	148	74
- Precautions required while Administration	11	5.5	189	94.5

Table (3) illustrates that, 69 % and 99 % of the studied mothers are oriented with the recommended time for giving chemotherapy and its frequency respectively. As regards the precautions against chemotherapy administration, it is found that 94.5% of the studied mothers do not know the precautions required during administering chemotherapy while 74% of them do not know that chemotherapy interacts with certain type of medication.

Table 4
Frequency distribution of mothers' knowledge about their role regarding chemotherapy administration at home (n=200)

Mothers' role	Know		Don't know	
	N	%	N	%
Giving the oral dose	56	28%	144	72%
Actions toward missed doses of chemotherapy	38	19%	162	81%
Vomiting the dose within half an hour of administration	81	40.5%	119	59.5%
Manifestation must report/Dangerous signs	128	64%	72	36%
Chemotherapy side effects identifying	141	70.5%	59	29.5%

Table (4) In relation to the studied mothers' knowledge regards their role during chemotherapy administration, this table reveals that 72%, 81%& 59.5% of the studied mothers do not know their required actions towards giving oral dose, missed doses while 70.5% of the studied mothers could identify the common side effects of chemotherapy.

Table 5
Frequency distribution of the studied mothers' knowledge about waste disposal of chemotherapy (n=200)

Waste disposal of chemotherapy	Know		Don't know	
	No	%	No	%
Co-personnel responsible for safe chemotherapy waste disposal	5	2.5	195	97.5
- Dangers of unsafe chemotherapy waste disposal	2	1	198	99
- Disposal of chemotherapy residuals	7	3.5	193	96.5
- Disposal of used syringes of chemotherapy	1	0.5	199	99.5
- Disposal of empty chemotherapy Bags	1	0.5	199	99.5
- Disposal of single used equipment	1	0.5	199	99.5
-Disposal of the child's body fluids (vomiting, urine, stool)	4	2	196	98

In relation to the studied mothers' knowledge as regards waste disposal of chemotherapy, this table reveals that 97.5%, 99% & 99.5% of the studied mothers do not know the co-personnel for safe disposal of chemotherapy, the dangers of un safe disposal of chemotherapeutic waste and the safe and correct actions and disposal of empty chemotherapeutic bags/ containers respectively, while only 0.5 % and 2% of the studied mothers know the safe disposal and handling of chemotherapy single used equipment and their child's body fluids (vomiting, urine, and stool).

Figure 3
Frequency distribution of the studied mothers according to their total knowledge and reported practices about chemotherapy safe handling at home (n=200)

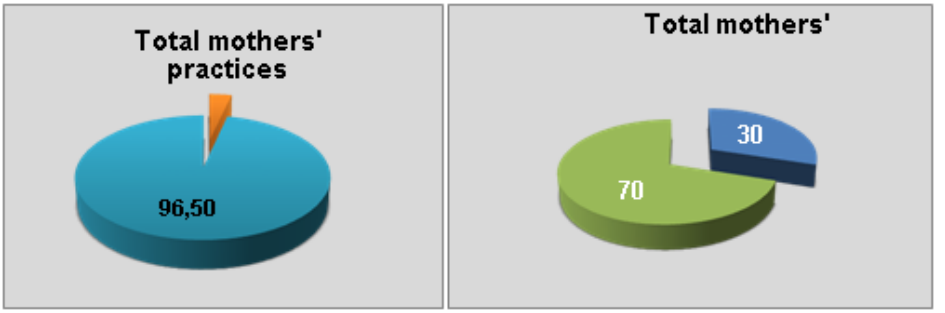

Figure (3) revealed that, 30% of the studied mothers have satisfactory levels of total knowledge; while 96.5% of them have poor level of total reported practices regards safe handling of chemotherapy at home.

Table 6
Frequency distribution of mothers according to their reported practices regards safe handling chemotherapy at home (n=200)

Items	Done		Not done	
	N	%	N	%
Wash hands	30	15%	170	85%
Wear (PPE)	10	5%	190	95%
Discard unused equipment into special waste bag.	5	2.5	195	97.5%
Wash equipment with soap & water.	7	3.5%	193	96.5%
Wash gloves before removing	0	0%	200	100%
Remove all PPE, throw into special waste bags.	0	0%	200	100%
Clean table with soap and water.	0	0%	200	100%
Wash hands with soap and water	3	1.5%	197	97%
Monitor child for side effects	3	1.5%	197	98.5%
Return residuals chemotherapy to hospital pharmacy	5	2.5%	195	97.5%

Concerning the studied mothers' reported practices regards safe handling of chemotherapy, this table denotes that 15%, 5 %&1.5% of the studied mothers report that they wash their hands, wear personal protective equipment (PPE) before administering chemotherapy, wash their hands after administering chemotherapy and monitor their child for side effects respectively, while 97.5% & 98.5% of mothers reported that they do not return chemotherapy related-residuals to the hospital's pharmacy.

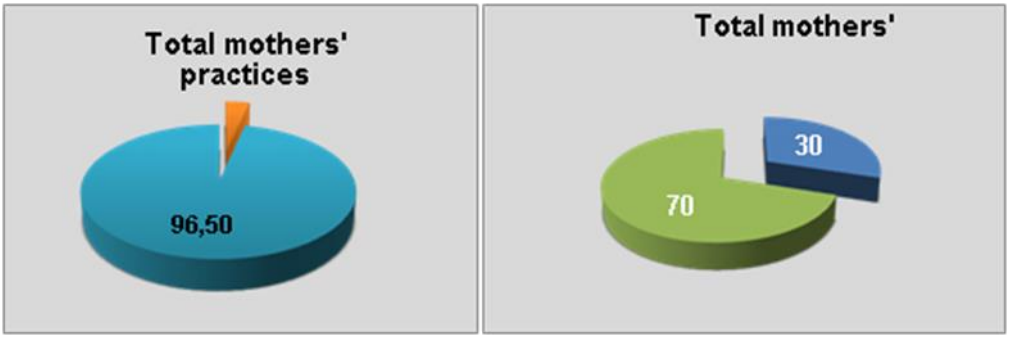

Figure 4. Frequency distribution of the studied mothers according to their total reported practices regards safe handling chemotherapy at home (n=200)

Figure 4 showed that the total level of the mothers' knowledge and reported practices, this figure reveals that 30% of the mothers have satisfactory level of total knowledge, while 96.5% of them have poor level of total reported practices regards safe handling of chemotherapy at home.

Table 7
Correlation between mothers' awareness and their total knowledge, practice

Variables	Mother's awareness	
	r	P
Total knowledge	0.2	0.008*
Total practice	0.3	0.0001*

This table (7) reveals that a very high statistically significant correlation was found between the studied mothers' awareness and each of their total level of knowledge and reported practices at the level with ***p= 0.008 and 0.0001.

Table 8
Correlation between total mothers' knowledge, practices regard safe handling of chemotherapy

	Knowledge	
	R	*P*
Reported practice	0.36	0.0001*

There was a high statistically significance correlation * (p< 0.0001) between the studied mothers' knowledge & their reported practice

Discussion

Chemotherapy affects both diseased and non-cancerous cells, making them both mutagenic and carcinogenic as a result. Cancer medications are dangerous for women who may come into contact with them during daily activities, as well as for healthcare professionals and children (leading in secondary malignancies) (8). Among the possible risky activities in chemotherapy handling are chemotherapy transportation, storage, spillage management, waste disposal and patients' excreta handling. In the study setting there is neither policy related to safe handling of chemotherapy at patients' home, nor system to collect chemotherapeutic wastage; therefore, the present study aimed to assess chemotherapy safe handling among mothers of children with cancer at their home (9). Regarding to the studied children characteristics, the current study results revealed that the mean age of the studied children was 4.34 ± 1.093 years, while more than one-half of the studied children were males. This was in agreement with (10,13) who conducted a study to evaluate the adherence to oral 6-mercaptopurine (6MP) maintenance chemotherapy for childhood acute leukemia in Egypt and found that the mean age of the studied children was 5.03 ± 3.24 years while about half of them were males.

Concerning the studied children's diagnosis, the present study results revealed most of the studied children were diagnosed as Acute Lymphoblastic Leukemia (ALL), while about one fifth of them were diagnosed as brain tumor (BT) and the most of dispensed home chemotherapy in the study setting are 6–mercaptopurine (6-MP) and intramuscular methotrexate injection. This is because the treatment of ALL mainly depends on oral 6 – mercaptopurine (6-MP) and intramuscular

methotrexate injection and oral chemotherapy is used in treatment of some types of brain tumors. Dispensing intramuscular injection of chemotherapy outside the hospital could be source of needle stick injury and environmental hazards.

As regards the studied mothers' characteristics, the result of the current study showed that the most of the studied mothers' mean age was 32.3±6 years, had school education and about half of them live in rural, while the minority of them was illiterate or just read and write. This may be related to most of female in Egypt are less educated especially in rural area due to socio-economic, geographical factors and gender disparities as reported by (11) This result is in agreement with (12) who studied knowledge and home practices of caregivers having children with leukemia and found that more than half of the caregivers aged from 35 to less than 45, less than half of the family care-givers had secondary school education, while more than half of them were from urban areas. Meanwhile, this finding is contraindicated with (10,13) who found that forty percent of the studied caregivers were not educated, forty- fife percent had low and moderate educational level and fifteen percent had high educated level.

By investigating the studied mothers' knowledge about chemotherapy administration and the related precautions at home, it was found that most of the studied mothers were oriented with the recommended time for giving chemotherapy, but the most of them did not know the precautions required during administering chemotherapy while about three-quarters of them didn't know that chemotherapy interacts with certain type of medication. This result may be due to pharmacist's instructions focus on chemotherapy administration time, while missing/ not paying attention to educate them about chemotherapy related precautions. This finding was in agreement with (14) who investigated challenges of children with cancer and their mothers in Iran and found that the main challenge among mothers of children with cancer was the inadequate knowledge of disease, treatment, and complications.

Concerning the studied mothers' knowledge as regards their role during chemotherapy administration, it was found that most of the studied mothers did not know what to do in case their child vomited his dose of chemotherapy, how to give the dose properly, and their actions towards missed doses of chemotherapy while the most of them knew the side effects of chemotherapy. This result is supported by (15) who conducted a study to update the oncology nursing society chemotherapy administration safety standards and to highlight standards for pediatric oncology and addressed that parents of pediatrics with cancer should be provided with documented verbal and written or electronic information as part of an education process before the first administration of treatment of each treatment plan. This educational information should include patient's diagnosis, schedule of treatment administration, drug names and supportive medications, drug-drug and drug-food interactions, and plan for missed doses, potential long-term and short-term adverse effects of therapy, symptoms that require the parents to contact the health care setting or to seek immediate attention, symptoms or events that require immediate discontinuation of oral or other self-administered treatments.

Regarding to the studied mothers' awareness as regards safe handling of chemotherapy, the current study revealed that all the studied mothers mentioned that they had received patient health education related to their received chemotherapy, and the most of mothers mentioned that they received instructions as regards administrations of chemotherapy. But on the other hand, nonetheless, was received related to wearing PPE, storage, waste disposal, spill handling. This could be due to the pharmacist is the main co-personal for chemotherapy education in the study setting and their main focus is on time, frequency of chemotherapy and its related side effects. This result came in accordance with (16), who conducted a study for an understanding the current disposal practices and relevance of the various routes of unused entry to the environment in Malta and Ireland and found that seven percent of Maltaze and one – fifth of Irish respondents had ever been advised on the best way for medication disposal. In addition, (17) who conducted a study to examine the behavior of individuals with respect to the disposal of expired and unused medications in Riyadh, Saudi Arabia and demonstrated that a low percentage of respondents had ever received information regarding correct medication disposal and added that respondents weren't aware of the consequences of keeping expired medication at home. In similar to (18), who reported that persons who dispensed the medicines to the participants did not often provide proper information on storage and disposal of medicines.

Concerning the studied mothers' reported practices as regards chemotherapy safe handling, the current study illustrated that, less than one fifth, five percent and the minority respectively of the studied mothers reported that they washed their hands before administering chemotherapy, wore personal protective equipment (PPE) before administering chemotherapy, and washed their hands after administering chemotherapy. On the other side, the most of them reported that they didn't return chemotherapy residuals or its related waste to the hospital's pharmacy. On the same line this result is supported with a study done by (19) who found that about one fifth of responders reported that they did not utilize protective gear during preparation of oral chemotherapy and the majority of them disposed medication waste with regular garbage or poured down the sink. Similarly, the study conducted in Ghana by (20), about assessment of pharmaceutical waste management at selected hospitals and homes and found that less than five percent of the participants return the medication to the pharmacy.

Regarding the studied mothers' total level of knowledge and reported practices, the current study revealed that less than one- third of the studied mothers had satisfactory total level of knowledge; while the most of them had poor total level reported practice regards safe handling of chemotherapy at home. This result could be related to the studied mothers' low educational level, society culture, plus lack of awareness regarding safe handling of chemotherapy and inadequate health education about related – safe administration from health care providers in the study setting. This finding was supported by (21), who studied the meaning of neutropenia and homecare needs according to caregivers of children with cancer 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. Meanwhile, (22), who

investigated the effects of an empowerment program on the competence of caregivers in caring for preschool children with acute leukemia undergoing chemotherapy and reported that, family caregivers had lack of knowledge and competence.

In relation to the correlation between the studied mothers' awareness about safe handling of chemotherapy at home and their total knowledge, this study revealed that there was a very - high statistically significant correlation between the studied mothers' awareness and each of their total level of knowledge and reported practices. This result is supported with (23) who conducted a study to determine patients' medications disposal methods and their awareness of the pharmacy medications take back program and found that most of the respondents with information on medication disposal were significantly more willing to return the medication to pharmacy. Regarding the correlation between mothers' total level of knowledge and practices regards safe handling of chemotherapy, it was found that there was a very high statistically significance correlation between the studied mothers' knowledge & their practice. These results mean that, the mothers' knowledge had an effect on their practices and the more knowledge they have, the better home practice they provide. This finding was supported by (12, 23) who found that a highly statistically significant positive correlation was found between family caregiver's total knowledge scores and their total practice scores.

Conflict of Interest: No conflict of interest

Conclusion

most of the mothers had unsatisfactory total level of knowledge and poor practice level accompanied by lack of awareness regarding safe handling of chemotherapy. A highly statistically significant correlation was found between mothers' awareness and each of their total knowledge, reported practices. Meanwhile, there was a statistically significant relation between the studied mothers' level of education and their total knowledge, also between their age and their total practices.

Recommendation

- Establish a structured patient's education and training on home chemotherapy transport, storage, administration, disposal, and spill
- Design educational materials for home chemotherapy transport, storage, administration, disposal, and spill for mothers and nurses.
- Establish a system of return –back extra -chemotherapy and related -waste to the hospital pharmacy by mothers of children with cancer should be one of the futures.

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