

## **Assessment of Knowledge and Reported Practice of Mothers Having Children with Cancer and Undergoing Chemotherapy**

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### **ABSTRACT**

**Background:** Cancer is a life threatening illness that involves emotional distress, fear of the unknown and changes in life priorities for the child and family. It is at a significant risk of depression for mothers because of the frequent stressful diagnostic tests, treatments and side effects of treatments. **Aim:** Assessof knowledge and reported practice of mothers having children with cancer and undergoing chemotherapy. **Design:** A descriptive research design was used in the study. **Data collection:** a purposive sample of **50** mothers and their children with cancer at inpatient and out- patient departments at Oncology Institute in Mansoura City. **Tools:** An interview questionnaire form to collect data about socio-demographic characteristics for studied mothers and their children, assessment of knowledge related childhood cancer and chemotherapy sheet and reported practice of mothers related to care of their children who undergoing chemotherapy sheet. **Results:** revealed that, only 14% of mothers had satisfactory knowledge related childhood cancer and chemotherapy .In relation to total reported practice, only 34.0% of the studied mothers had total reported practice related to side effects management of chemotherapy. **The study recommended:** developing frequent educational training programs for mothers of children with cancer about care of their children who undergoing chemotherapy through updated posters, booklets and brochures and a repeat of this research on a large sample and in various places in Egypt for improving mother's knowledge and practice.

**Key Words:** *Mother's knowledge & practice, childhood cancer, chemotherapy.*

## INTRODUCTION

Childhood cancer is usually defined as a malignant disease that is diagnosed up to 16 years of age and results when the body fails to regulate cell production, and occurs a proliferation and spread of abnormal cells (*Michel et al. 2010*). The causes of childhood cancer are unknown and the most common types of childhood cancer are leukemia, lymphoma (including both Hodgkin and non-Hodgkin), brain and other central nervous system tumors, neuroblastoma, Wilms tumor, retinoblastoma, bone cancer (including osteosarcoma and Ewing sarcoma) (*Hockenberry and Wilson, 2011; Pillitteri and Funk, 2007*).

The mothers play important roles where children with cancer are often limited in their opportunities to develop independence and autonomy, the limitations come from restrictions placed by treatment regimens and therapy-related complications; therefore, mothers can promote their children to be more comfortable through prevention of infection, regular activity, skincare, emotional support. So that mothers should be informed in a manner that can understand the nature of the disease, its causes, treatment, complications and prognosis (*Elsayed and Mahmoud, 2012*).

### AIM OF STUDY:

Assessment of knowledge and reported practice of mothers having children with cancer and undergoing chemotherapy.

### SUBJECTS AND METHODS:

**Research Design:** A descriptive research design was utilized in the conduct of the study.

**Setting:** The study was carried out at pediatric inpatient and outpatient departments at Oncology Institute in Mansoura City.

**Subjects:** A purposive sample of 50 mothers and their children were used in the study according to inclusion criteria which were mothers should be accompanying child during chemotherapy at the study setting; children have any type of childhood cancer; children were from both genders; they were undergoing chemotherapy and received at least two doses.

### Tools of data collection:-

Three different tools for data collection were used in this study as following:

#### **Tool (I): Structured Interview Questionnaire Sheet:**

Upon inclusion in the study sample, each mother was interviewed individually. The questionnaire was designed by researcher after reviewing related literature, it was

designed in Arabic language to suit understanding of the study subjects .It consisted of the following parts.

**Part (1):**

This covered the socio demographic characteristics of studied children such as age, gender, birth order and educational attainment.

**Part (2):**

This part was covered the socio demographic characteristics of mother's such as age, educational level, residence and income, as well as family size.

**Tool (II): Assessment of mother's knowledge about childhood cancer and chemotherapy sheet:**

This tool was intended to assess mother's knowledge about cancer such as definition, risk factors, symptoms, and spread of disease, investigations, complications, and treatment. It also had questions for mother's knowledge about chemotherapy definition, duration, routes, action, and side effects, in addition to dealing with child under chemotherapy and the home precautions.

**Scoring:**

For each question, a correct answer was scored 1 and zero for incorrect answer. For each area of knowledge, the score items were summed-up and the total divided by the number of items, giving mean scores for the part. These scores were converted into percent score. Knowledge was considered satisfactory if percent score was 50 % or more and unsatisfactory if less than 50 %.

**Tool (III): Assessment of mother's reported practice sheet.** This tool was aimed at assessing mother's reported practice while caring for their children with cancer. It involved questions about the care provided for side effects as bone marrow, skin, and gastrointestinal, respiratory, urinary, muscle-skeletal, neurological and psychological side effects of chemotherapy. The mother was asked whether the steps of care for each side effect was done or not done.

**Scoring:**

The steps reported to be done were scored (1) and the items not done were scored (0) for each area, the scores of the items were summed-up and the total divided by the number of the items, giving a mean score for the part. These scores were converted into percent scores. The reported practice was considered adequate if the percent score was 60% or more and inadequate if less than 60%.

**Methods of study**

- An official permission was obtained from the directors of oncology institute in Mansoura city through an official formal letters from the Dean of The Faculty of Nursing Port Said University.
- The tools were tested for their content validity and clarity by seven experts in nursing and medical pediatrics and oncology for face and content validation. The tools were then adjusted based upon their recommendations.

- Informed consent was obtained from each mother in the study after explaining its purpose and importance. Confidentiality of the information was assured by the researcher.
- A pilot study was carried out after review of data collection tools by seven experts. It was applied on 10% of study sample (five mothers and their children). The purposes of the pilot study were to test the applicability, clarify, feasibility and modification of the data collection tools.

Statistical analysis of data:Up completion of data collection, variables included in the structured interview sheet, were coded prior to computerized data entry. The raw data were coded and transformed into coding sheets. The results were checked. Then, the data were entered using SPSS 20.0 statistical software package. Output drafts were checked against the revised coded data for typing and spelling mistakes. Finally, analysis and interpretation of data were conducted.

## **RESULTS:**

**Table (1):** demonstrates socio-demographic characteristics of the studied children with cancer, children's age ranged between six and sixteen years, the highest percent of them were males (60.0%). Slightly more than one-third of them (42.0%) were first born. As for their educational level, approximately two-thirds (68.0%) were in the primary level, whereas only 4.0% were in secondary education.

**Table (2):** shows socio-demographic characteristics for mothers of studied children with cancer, it illustrates that mother's age ranged between 25 and 55 years, with median 35. They mostly had secondary education (64.0%), and the majority of them (90.0%) were housewives.

**Table (3):** shows the studied mother's knowledge about childhood cancer, it was observed that less than half of studied mothers (42.0%) had satisfactory knowledge related to definition of childhood cancer. While 2.0% of them had satisfactory knowledge related to risk factor and spread of disease.

**Table (4):** reveals studied mother's knowledge about chemotherapy. It illustrated that 42.0% of studied mothers had satisfactory knowledge related to home precaution. On the other hand, none of them (0.0%) had satisfactory knowledge related to definition of chemotherapy and factors which determine the duration of chemotherapy. In relation to total knowledge of studied mothers, majority of studied mothers (86.0%) had unsatisfactory knowledge related to childhood cancer and chemotherapy.

**Table (5):** demonstrates reported practice of the studied mothers related to care of children who are undergoing chemotherapy. It clarified that 12.0% of studied mothers had adequate reported practice related to children's psychological disturbance and only 2.0% of them had adequate reported practice related to GIT, bone marrow, respiratory and neurological disturbance.

**Table (6):** presents the correlation between knowledge and practice scores and child and family characteristics throughout study phases. It indicated a knowledge scores had weak statistically significant positive correlation with the duration of their children's disease (0.310), while a weak statistically significant negative correlation between mother's practice score and their age ( $r=-0.01$ ).

**Table (1):** Socio-demographic characteristics of studied children with cancer.

Socio-demographic Characteristics	N = (50)	%
<b>Age (years):</b>		
<12	34	68.0
12+	16	32.0
Range	6.0-16.0	
Mean± SD	9.5±3.2	
Median	8.5	
<b>Gender:</b>		
Male	30	60.0
Female	20	40.0
<b>Birth Order:</b>		
First	21	42.0
Second	20	40.0
Third	6	12.0
Fourth	3	6.0
<b>Level of Education:</b>		
Primary level	34	68.0
Preparatory level	14	28.0
Secondary level	2	4.0

**Table (2):** Socio-demographic characteristics of the studied mothers of children with cancer.

<b>Socio-demographic Characteristics</b>	<b>(n= 50 )</b>	<b>%</b>
<b>Mothers Age (years):</b>		
<35	22	44.0
35+	28	56.0
Range	25.0-55.0	
Mean± SD	35.6±7.4	
Median	35	
<b>Mothers Education:</b>		
Basic education ( primary& preparatory)	3	6.0
Secondary education	32	64.0
University education	15	30.0
<b>Mother's job:</b>		
House wives	45	90.0
Employed mothers	5	10.0
<b>Residence:</b>		
Urban	26	52.0
Rural	24	48.0
<b>Family size</b>		
<5	8	16.0
5+	42	84.0
Range	3.0-6.0	
Mean ±SD	5.0±0.6	
Median	5.00	
<b>Income</b>		
Sufficient	4	8.0
Insufficient	46	92.0

**Table (3):** knowledge of studied mothers about childhood cancer.

<b>knowledge of studied mothers about childhood cancer</b>	<b>(n= 50 )</b>	<b>%</b>
Definition	21	42.0
Risk factors	1	2.0
Symptoms	2	4.0
Spread of disease	1	2.0
Investigation	5	10.0
Complications	4	8.0
Treatment	6	12.0

**Table (4):** knowledge of studied mothers about chemotherapy.

<b>Mother's knowledge about chemotherapy</b>	<b>(n= 50 )</b>	<b>%</b>
Definitionof chemotherapy	0	0.0
Factors that determine the duration of chemotherapy.	0	0.0
Routes of chemotherapy.	6	12.0
Effective of chemotherapy.	5	10.0
Side effects	20	40.0
Dealing with child before chemotherapy	10	20.0
Dealing with child during chemotherapy	5	10.0
Dealing with child after chemotherapy	10	20.0
Home precautions	21	42.0
<b>Total knowledge about childhood cancer and chemotherapy:</b>		
Satisfactory	7	14.0
Unsatisfactory	43	86.0

**Table (5):** Reported practice of the studied mothers related to care of children who undergoing chemotherapy .

<b>Total reported practice</b>	<b>(n= 50 )</b>	<b>%</b>
GIT disturbance	1	2.0
Skin dryness	2	4.0
Bone marrow disturbance	1	2.0
Pyrexia	3	6.0
Respiratory disturbance	1	2.0
Urinary disturbance	0	0.0
Musculoskeletal disturbance	2	4.0
Neurological disturbance	1	2.0
Psychological disturbance	6	12.0
<b>Total reported practice:</b>		
Adequate	17	34.0
In adequate	33	66.0

**Table (6):** Correlation between knowledge and reported practice scores and child and family characteristics.

Children and family characteristics	Spearman's rank correlation coefficient	
	(n=50)	
	Knowledge	Practice
Practice	.400**	1.00
Child age.	0.01	-0.01
Birth order.	0.09	-0.01
Child education.	-0.03	0.02
Duration of cancer.	.310*	0.17
Duration of chemotherapy	-0.26	-0.03
Mother age.	0.10	0.02
Mother education.	0.23	-0.02
Father education.	0.13	-0.11

(\*) Statistically significant at  $p < 0.05$  . (\*\*) statistically significant at  $p < 0.01$

## DISCUSSION:

Cancer, characterized by uncontrolled division of cell and metastasis, is one of the major causes of mortality among adolescents (*Mojtaba, 2012*). The family caregivers, especially the mothers, of these children are in challenging (*Markward et al., 2013*). The oncology nurses have important roles in supporting these mothers with necessary information to improve the health satisfaction and quality of life of their children (*Ricci & Kyle, 2009*). The present study was carried out to assess knowledge and reported practice of mothers having children with cancer and undergoing chemotherapy.

The study was carried out on 50 mothers and their children with cancer and undergoing chemotherapy. The sample had a higher percentage of male gender in childhood cancer. In agreement with this, *Bae et al. (2016)* reported that the incidence of cancer among boys was 1.2 than in girls, which is very close to our ratio. On the same line, *Darre et al. (2016)*, in Togo, found that the male /to female ratio of children with cancer was 1.4. Although more than two-fifth of the children in the present study were firstborn, research provide no strong evidence of a relation between birth order and the occurrence of cancer (*Schuz et al., 2015*).

The findings revealed major deficiencies in these mothers' knowledge concerning cancer and complications, risk factors, spread, and symptoms as well as the various aspects of chemotherapy. This lack of information would pose threats on the care of the children, in addition to being stressful for the mothers who do not know how to help. Similar but less information gaps were identified by *Van Dijk-Lokkart, et al. (2015)* in their study, the authors highlighted the importance of improving parents' knowledge about cancer, treatment, potential late effects and necessary follow up in

order to reassure them-selves and motivate their children to participate in regular follow-up. This indicates that information administered to them by health care providers was insufficient and could not meet their actual needs. In line with this, **Gorete et al. (2007)** reported that mothers obtained their information and explanations about childhood cancer from various sources, mainly doctors and nurses. These foregoing present study findings are in agreement with those of **Rodrigues et al. (2010)** who demonstrated a lack of mothers' information about childhood cancer, and recommended an educational intervention based on identification of mothers' information needs during the hospitalization with their children in order to understand the disease nature to be able to support their children.

The current study was also aimed at assessing the reported practices of the mothers of children with cancer. The findings indicated marked deficiencies in mothers' practices. This was evident in dealing with the problems resulting from the disease itself, and/or its treatment by chemotherapy, and affecting all body systems. The result is also in partial agreement with a study in Sweden, which demonstrated high satisfaction of parents of children with cancer with personalized intervention, but the impact on their practices was minimal, and this was attributed to bias in sampling (**Ringner et al., 2014**). Other studies reported inadequate mothers' practices in the care of their children with cancer due to the severity of side effects of chemotherapy such as gastrointestinal, respiratory, neurological and psychological disturbance (**Duignan et al., 2014**), (**Long et al., 2014**) & (**Santa Maria et al., 2014**).

## **CONCLUSION:**

Based on the findings of the present study, it was concluded that major deficiencies in knowledge and reported practice of mothers having children with cancer and undergoing chemotherapy.

## **RECOMMENDATIONS:**

Based on the findings of the present study, the following recommendations are to be considered: Health teaching and counseling programs should be provided for mothers of children with cancer and undergoing chemotherapy to decrease burden on them and make them the focus of the health care team through updated posters and brochures that help improve their knowledge and then releases improve care for their children who suffering from cancer and undergoing chemotherapy.

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participate in a combined physical and psychosocial intervention program: Quality of Life in Motion. Psychooncology; 24(4):465-71.

## تقييم معلومات ومهارات الأمهات اللاتي لديهن أطفال يعانون من السرطان والخاضعين للعلاج الكيماوي

دعاء بهيج أنور عقل ، نبيله حسن على عبد الله ، أمل أحمد خليل مرسى ، محمد محمد أحمد المزاحى

### الخلاصة

تهدف هذه الدراسة الوصفية إلي تقييم معلومات ومهارات الأمهات اللاتي لديهن أطفال يعانون من السرطان والخاضعين للعلاج الكيماوي وقد أجريت هذه الدراسة في معهد الأورام بالمنصورة في العيادات الخارجية وقسم الداخلي للأطفال وشملت العينة ٥٠ من الأمهات و أطفالهن المصابين بالسرطان والخاضعين للعلاج الكيماوي أثناء فترة جمع البيانات. كما استخدمت ثلاثة أدوات لجمع البيانات من الأمهات: الأداة الأولى وهي استمارة استبيان مصممة بواسطة الباحث وتحتوى على البيانات الشخصية والاجتماعية للطفل والأسرة، الأداة الثانية وتشمل معلومات خاصة بمرض السرطان والعلاج الكيماوي ،أما الأداة الثالثة فهي تشمل مهارات الأمهات المرتبطة برعايتها لطفلها الذي يعاني من السرطان والخاضع للعلاج الكيماوي. ولقد أوضحت الدراسة ان ١٤% فقط من الأمهات لديهن معلومات كافية مرتبطة بسرطان الطفولة والعلاج الكيماوي وان ٣٤% منهن فقط لديهن مهارات مرتبطة برعاية أطفالهن الخاضع للعلاج الكيماوي . لذا فقد أوصت الدراسة لأقامة برامج تعليمية بصفة مستمرة لهؤلاء الأمهات وتكرار هذا البحث على عينة كبيرة و في أماكن مختلفة في مصر وجعل أمهات الأطفال المصابين بالسرطان محور اهتمام فريق الرعاية الصحية من خلال النشرات المحدثه والملصقات و الكتيبات التي تساعد علي تحسين معلوماتهن ومن ثم تحسين الحالة الصحية لأطفالهن .

**الكلمات المرشدة:** معلومات ومهارات الأمهات – سرطان الطفولة - علاج كيماوي