Needs and Problems of children Undergoing chemotherapy and their Caregivers: An assessment study

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Abstract

Background: Cancer is a group of diseases characterized by uncontrolled growth and spread of abnormal cells. If has been categorized as a chronic disease that is characterized as a prolonged course, which does not resolve spontaneously and for which a complete cure is rarely achieved.so, this study aimed to assess needs and problems of children undergoing chemotherapy and their caregivers. Design: A descriptive study exploratory design was used to conduct this study. Subject: A purposive sample composed of 100 children undergoing chemotherapy. Settings: this study was carried out in Oncology Units in Children Hospital affiliated to Ain Shams University Hospitals and Minia Oncology Center over six months. Tools: two tools were used to collect necessary data, Interview questionnaire sheet and children' needs and problems sheet. Result: more than two thirds of the studied caregivers had unsatisfactory level of total knowledge while this study revealed that more than third of studied children had high needs. Also, more than half of studied children had severe problems related to cancer and chemotherapy. Conclusion: Based on the results of the current study, it can be concluded that, more than half of studied children had high total needs of psychological & social, cognitive & mental, and medical needs and less than two thirds of them had severe problems related to cancer and chemotherapy. Moreover, it was found that three quarters of the studied caregivers had unsatisfactory level of total knowledge about cancer and chemotherapy. In addition, there was highly statistically positive correlation between the needs of the studied children and their problems. Also, there was statistically positive correlation between the knowledge of the studied caregivers and the needs and problems of their children. **Recommendation:** Further research study is recommended to assess needs and problem of children undergoing chemotherapy and their caregiver.

Keywords: Children, Caregiver, Chemotherapy, Needs, Problems.

Introduction:

Cancer is the 2nd leading cause of death among children, following only injuries.. Childhood cancers include many that also occur in adults. Leukemia is by far the most common, representing about 33% of childhood cancers, brain tumors represent about 25%, lymphomas represent about 8%, and certain bone cancers (osteosarcoma and Ewing sarcoma. Bone Tumors represent about 4% (Steliarova-Foucher et al., 2017).

Controlling pain is an important part of treating children with cancer. Pain is not something that the child has to "put up with." Children will feel stronger and better during treatment if they don't have pain. Pain can

suppress the immune system, increase the time it takes the body to heal, interfere with sleep, and increase the chances of depression (National Cancer Institute, 2015).

Common short term side effects of chemotherapy include: tiredness and weakness, feeling or being sick, sore mouth, allergic reactions, anemia (low red blood cell counts), increased risk of bleeding, these are different for every child. But some possible long term side effects of chemotherapy include: fertility problems, bone problems, changes in how the kidneys and heart work, growth problems, a risk of developing a second cancer (Hellman & Rosenberg, 2015).

Neurotoxic effects of chemotherapeutic agents are common and include neuropathy, coagul-opathy causing stroke or cerebral sinovenous thrombosis, encephala-opathy, seizures, cerebellar dysfunction, myelopathy, neuro-psychologic difficulties, numbness in the hands or feet, burning sensation in hands or feet, difficulty of movement, disequilibrium, blurred vision, pain during walking (Sun & Cooper, 2018).

Caregivers can develop physical symptoms, like tiredness and trouble sleeping. This is more likely to be a problem for caregivers who aren't able to get the support they need, and who don't take care of themselves – especially those who try to press forward alone, even as their own quality of life suffers. Caring for someone going through cancer treatment can be demanding, but being good at it can give you a sense of meaning and pride. These good feelings can help provide the strength and endurance to continue in the role for as long as needed (American Cancer Society, 2019).

Significance of the study:

Cancer now agreed to be accruable disease especially with rapid development in medicine and technology. Most cancers in children, like those in adults, are thought to develop as a result of mutations ingnes that lead to uncontrolled cell growth and even tally cancer. However, environmental causes of childhood cancer have been difficult to determine what children might have been exposed to early in their development (Bhakta et al., 2019)

Cancer- treatment as chemo-therapy, radiotherapy, bone marrow transplantation and biological therapy cause problems in children, which adversely influence daily life activities and quality of life (Sklar et al., 2018)

Aim of the study:

This study aims to assess needs and problems of children undergoing chemotherapy and their caregivers.

Research questions:

What are the needs and problems of children undergoing chemotherapy and their caregiver?

Subjects and Methods:

I. Technical design Research Design:

A descriptive exploratory design was used to conduct this study.

Research Settings:

The study was carried out at the inpatient Oncology Units in Children Hospital affiliated to Ain Shams University Hospitals and Minia Oncology Center.

Subjects:

- 1- A purposive sample composed of 100 children undergoing chemotherapy who admitted to the previously mentioned settings over six months period.
- 2- Second subject was composed of (100) family caregivers for their children undergoing chemo-therapy who admitted to the previously mentioned settings over six months period.

Tools of the study:

I- Interview questionnaire sheet:

Part1: It was concerned with characteristics of study subjects;

- **a-** Characteristics of children which include gender, level of education, ranking and residence.
- **b-** Characteristics of caregiver which include relationship to child, age, educational level and job.
- Part 2: History of the disease in children which include diagnosis, duration of chemotherapy and family history of cancer.
- **Part 3:** It was concerned with knowledge of caregivers related to cancer and chemotherapy and consisted of 15 questions.

Scoring system:

The caregivers' answers were checked with model key answer ,each complete correct

answer was scored as two scores, incomplete correct was scored as one score and the wrong answer or unknown were was scored as zero .These scores were summed up and converted into percentage . The total scores of the questions was 30 marks which equal 100% and accordingly the caregivers' knowledge was classified into 2 categories:

- **Satisfactory** knowledge if total score >60%.
- **Unsatisfactory** knowledge if total score < 60%

II- children' needs and problems sheet:

Part1: It was concerned with needs of children and consisted of four domains(33sentences) as physiological needs, psychological and social needs, cognitive and mental needs and medical needs.

Scoring system:

Children' needs sheet was consisted of **33** sentences, each sentance was rating by likert rating scale as always (2), sometimes (1) and never (0). These scores were summed up and were converted into a percentage score and accordingly the total children' needs was classified into 3 categories:

- Low if total score (1-11)
- Moderate if total score (12-23)
- **High** if total score (24- 33)

Part 2: It was concerned with problems of children and consisted of eight domains as general problems, digestive problems, neurological problems, urinary problems, skin, nails and hair problems, psychological problems, mental problems and social problems.

Scoring system:

The total score of children' problem sheet were 52 degree which equal 100%, each sentence was answered by "yes" was given one score and "no" was given zero score. These scores were summed up and were converted into a percentage score, accordingly the total

children' problems was classified into 3 categories:

- Mild if total score (1-17)
- Moderate if total score (18-35)
- Severe if total score (36-52)

Validity and Reliability:

- Validity was ascertained by a group of experts in pediatric nursing (5) professor. Their opinions elicited regarding the format, layout, consistency, accuracy and relevancy of the tools. Reliability analysis by measuring of internal consistency of the tool through Cronbach's Alpha test.

Items	Cronbach alpha
Interview	0.801
questionnaire sheet	
Children needs and	0.823
problems sheet	

Operational Design: Preparatory Phase:

This phase included reviewing of literature related to needs and problems of children undergoing chemotherapy and their Caregivers. This served to develop the study tools for data collection. During this phase, the researcher also visited the selected places to get acquainted with the personnel and the study settings. Development of the tools was under supervisors' guidance and experts' opinions were considered.

Ethical Considerations:

The research approval was obtained from scientific ethical research committee Faculty of Nursing Ain shams university before starting the study. The researcher was clarified the objectives and aim of the study to caregivers included in the study before starting and Verbal approval was obtained from them. They secured that all the gathered data was confidential and used for research purpose only. The caregivers were informed that they were allowed to choose to participate or not in the study and they had the right to withdrawal from the study at any time.

Pilot Study:

The pilot study was carried out on ten children and their caregivers those represent

10% of subjects at children hospital affiliated to Ain shams university hospitals and Minia oncology center in order to test the applicability of the constructed tools and the clarity of the questions related to needs and problems of children undergoing chemotherapy and their Caregivers. Also, The pilot study had served to estimate the time needed for each subject to fill in the questionnaire. According to the results of the pilot, no corrections and omissions of items were performed, so the children and caregivers were included in the study sample.

Fieldwork:

The actual field work started from first of May 2019 to the end of October 2019. The researcher firstly met with the caregivers at the previously mentioned settings, explained the purpose of the study after introducing herself. Then, individual interviewing was done after obtaining verbal consent to participate. The researcher was visiting the study setting 3days / week (Saturday, Sunday and Monday) at morning shift (8a.m-2p.m) and afternoon shift (2pm-8pm) by rotation to collect data. The questionnaire was filled by caregivers which take 30-35 minutes and the assessment sheet was filled by the researcher in 20-30 minutes.

III.Administrative Design:

An approval was obtained from the Medical Director of Children Hospital affiliated to Ain shams University and Minia Oncology Center. A letter was issued to them from the Dean of the Faculty of Nursing, Ain shams University in order to obtain their permissior and cooperation.

IV.Statistical Design:

Data collected from the studied sample was revised, coded and entered using Personal Computer (PC). Computerized data entry and statistical analysis were fulfilled using the Statistical Package for Social Sciences (SPSS) version 22. Data were presented using descriptive statistics in the form of frequencies, percentages. Chi-square test (X²) was used for

comparisons between qualitative variables. Spearman correlation measures the strength and direction of association between two ranked variables.

Significance of the results:

- Highly significant at p-value < 0.01.
- Statistically significant was considered at p-value < 0.05
- Non-significant at p-value ≥ 0.05

Results:

Table (1): demonstrates that more than half of studied children (56%) and (55%) aged between 6-< 12 years with mean 8-56 \pm 1.94 and were male respectively. As regard children educational level and their ranking, it was found that more than one third of them (44%) and (37%) stage and ranked as a second child in the family. Also nearly two thirds of studied children (63%) lived in rural area.

Table (2): shows that more than half (53%) of the studied caregivers their age ranged between 30-< 40 years, the mean of age of them was 34.9 ± 7.05 . As regard to kinship relationship to child. The majority (85%) of the studied caregivers were mother. In relation to the educational level of the studied caregivers, it was found that, (50%) of them had secondary education, and more than three quarters of them (76%) were not working.

Figure (1): shows that, more than two thirds (70%) of the studied caregivers had unsatisfactory level of total knowledge about cancer and chemotherapy.

Figure (2): shows that, 56% of the studied children had high total needs, while 30% and 14% of them had moderate needs and low needs.

Table (3): reveals that more than half of studied children (60%) had severe problems related to cancer and chemotherapy.

Table (4): reveals that, there is highly statistically significant relation between total knowledge about cancer and chemotherapy of the studied caregivers and their age, educational level and family history of chemotherapy at (P = < 0.01). Also, there is statistically significant relation with their kinship relationship to child and job at (P = < 0.05).

Table (1): Distribution of the Studied Children According to their Characteristics (n=100).

Items	No	%		
Age (year)				
<6	20	20		
6<12	56	56		
12≤18	24	24		
$\overline{\chi}_{\pm \text{S.D}}$	8.56 ± 1	8.56 ± 1.94		
Gender				
Male	55	55		
Female	45	45		
Education level				
Nursery	35	35		
Primary	44	44		
Preparatory	13	13		
Secondary	8	8		
Ranking				
First	20	20		
Second	37	37		
Third	25	25		
Fourth & more	18	18		
Residence				
Urban	37	37		
Rural	63	63		

Table (2): Distribution of the Studied Caregivers According to their characteristics (n=100).

Items	No	%
Age (year)		
< 20	5	5
20 -< 30	22	22
30 -<40	53	53
≥ 40	20	20
$\overline{\chi}_{\pm}$ S.D	34.9 ± 7.05	
Kinship relationship to child		
Mother	85	85
Father	5	5
Sister / Brother	8	8
Grandfather / Grandmother	2	2
Educational level		
Illiterate	16	16
Read and write	24	24
Secondary education	50	50
University education	8	8
Other	2	20
Job		
Working	24	24
Not working	76	76

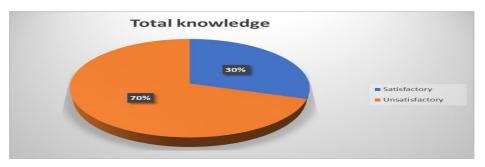


Figure (1): Distribution of percentage the Studied Caregivers According to their Total Knowledge (n=100).

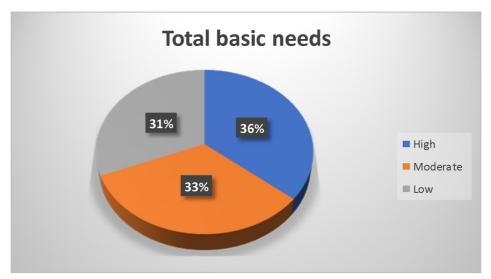


Figure (2): Number and Percentage Distribution of the Studied Children According to their Total Basic Needs (n=100).

Table (3): Distribution of the Studied Children According to their Total Problems (n=100).

Total problems.	No	%
Severe	60	60
Moderate	22	22
Mild	18	18

Table (4): Relation Between Characteristics of the Studied Caregivers and their Total Knowledge

Kilowieuge.						
	Total knowledge				\mathbf{X}^2	
T4	(n=30) (n=70)		Unsatisfactory		/Fisher Exact test	P-
Items				Value		
	N	%	N	%		
Kinship relationship to child						
Mother	25	29.5	60	70.5		
Father	2	40	3	60	10.15	0.04*
Sister / Brother	3	37.5	5	62.5	10.13	0.04
Grandfather / Grandmother	0	0.0	2	100		
Age (year)						
< 20	0	0.0	5	100		
20 -< 30	1	4.5	21	95.5		
30 -<40	27	50.9	26	49.1	24.17	.000**
≥ 40	2	10	18	90		
Educational level						
Illiterate	0	0.0	16	100		
Read and write	2	8.40	22	91.6		
Secondary education	18	36	32	64		
University education	8	100	0	0.0	25.94	.000**
Other	2	100	0	0.0		
Job						
Working	22	91.6	2	8.40	14.10	0.01*
Not working	8	10.5	68	89.5	14.19	0.01*
Family history of chemotherapy						
Yes	18	100	0	0.0	26.72	.000**
No	12	14.6	70	85.4	26.73	.000***

*significant at p < 0.05. **highly significant at p < 0.01

Discussion

Regarding to characteristics of children who received chemotherapy there were more than half of children were male and aged between 6to 12 years ,about two fifth of them in second stage of disease.

The study finding is respected by **Uzun & Kucuk (2019)** who fond, in a very recent study in titled"side effects of chemotherapy in children with cancer" that children with cancer, more than half of children were male, approximately one third of them were aged 6-10 years,

In relation to caregiver's characteristics the current study finding indicated that, majority of caregiver were Mothers, and more than half of caregiver ages between 30 <40 years old. This result could be attributed to; in our society the mothers have responsibility of their children caring especially during illness.

Similar findings was supported by study of Hasan et al. (2012) who carried out a study in titled "Assessment of Home Care Management for Caregiver's having Leukemic Adolescent Patient" and found that about one third of caregiver's age were between (39-48)years old. Also, this finding was supported by study of El-Sawy et al. (2013) who carried out a study in titled" Knowledge and Home Practices of Caregivers Having Children with Leukemia Attending National Cancer Institute Cairo University" and found that more than half of the family caregivers were mothers of the children.

In relation to caregiver's education level and working the current study reported that half of them have secondary education level and most of them didn't work. This result may be due to the education in Egypt is compulsory until completion of the basic education stage and main occupation of females in our society was housewives

Meanwhile, the present study revealed that more than half of children were Leukemia. On the same line the study carried out by Nair et al. (2017) who carried out a study in titled "Parents' Knowledge and Attitude Regarding Their Child's Cancer " and found that the majority of children with cancer were leukemia.

Regarding to **total basic needs of children** the present study displayed that approximately less than three fifth of children with chemotherapy were high level of basic needs, Moreover, less than one third of them were moderate level of basic needs, while few of them were low level of basic needs.

This result may be due to; chemotherapy adversely affects the general condition of children who receive it, which necessitates their need for help most basic daily activity and needs.

In this regard **Stevens et al. (2012)** emphasized that, the diagnosis of *cancer* in a *child* is one of the most stressful events that can happen to a family. Younger *children* need their parents to cope with *basic* fears and *basic* desires. Depending on the *child's* developmental level, special *needs* have to be met in the context of the family (parents, siblings) and the enlarged social environment (friends, school, health care workers. Each phase of treatment has its own characteristics that contribute to the reactions of parents and children.

Regarding to studied children total problems undergoing chemotherapy treatment, the present study findings stated that, more than half of them suffered from severe problems, while minority of children suffered from mild problems from chemotherapy treatment. This result could be attributed to deficit in an integrated psychosocial programs support for pediatric patients and their parents by a multidisciplinary team work including pediatric oncologist, psychiatrist, social worker and a specialized nurse is a must to help them realize and cope with the stresses

they face, answer their questions, listen to them patiently, help them to express their emotions, give explanations, advice, and support.

Similar findings were reported by study of Krull et al. (2013) who carried out a study in titled"Chemotherapy-related changes in central nervous system phospholipids and neurocognitive function in childhood acute lymphoblastic leukemia "and found that the use of high doses of chemotherapy drugs for treatment of cancer children has led to large number of symptoms or problems caused by those drugs. On the same line another study by Arslan et al. (2013) who carried out a study in titled "Quality of Life and Chemotherapy-related **Symptoms** Children Undergoing Turkish Cancer Chemotherapy" and found chemotherapeutic drugs can cause symptoms that can seriously affect quality of life in children.

Regarding to relation between characteristics of caregivers and their total knowledge the present study findings stated that, highly statistically significant relation between caregiver total knowledge about cancer and chemotherapy and their age, educational level and family history of chemotherapy, while there were statistically significant relation with their kinship relationship to child and job

This findings was supported by study of Al-Jauissy (2010) who carried out a study in titled "Health care needs of Jordanian caregivers of patients with cancer receiving chemotherapy on an outpatient basis" and found that half of participated caregiver were secondary school graduate and could read and write.

In congruent with present study findings the study of **Sharpe et al.**, (2005) who carried out a study in titled " The relationship between available support, unmet needs and caregiver burden in patients with advanced cancer" and found that highly significantly association

between caregivers' knowledge and their level of education. Most important variables associated with insufficient knowledge were low educational level, This was more supported by **Othman et al.**, (2011) who carried out a study in titled"Psychological distress and associated factors in parents of children with cancer" reported that parents with higher level of education showed better cancer knowledge.

Conclusion:

Based on the results of the present study, it can be concluded that:

This study revealed that more than half of studied children had high level of psychological & social needs, cognitive & mental needs and medical needs, regarding their total basic needs respectively. Moreover half of them had high level of psychological needs. Also more than half of studied children had severe problems related to cancer and chemotherapy.

Recommendation:

In the light of the findings of the current study the following recommendations are suggested:

- Further studies about needs and problems of children undergoing chemotherapy with increasing sample size and different settings.
- Preparation of educational program for caregivers about needs and problems of children undergoing chemotherapy.
- Child classes have to be encouraged in oncology center to acquire knowledge regarding chemotherapy.
- Further studies to detect the predictive factors affecting needs and problems of children undergoing chemotherapy.

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