

Suggestion Guidelines for Caregivers Having Children With Wilms'tumor

Amal Kamal, Randa Mohamed Adly, Zeinab Fathy

Pediatric Nursing Department – Faculty of Nursing- Ain Shams University

ABSTRACT

Aim of study, is to assess the role of caregivers having children with Wilms'tumor, design suggestion guidelines for caregivers having children with Wilms'tumor and disseminate a guideline booklet for parent having children with Wilms' tumor based on need assessment. **Design:** A descriptive design. **Setting:** The study was conducted at outpatient clinic and inpatient departments in Children's Cancer Hospital (57357). **Subject:** The study sample was a purposive sample involved of 80 children suffering from Wilms'tumor, both sex, aged from one day to less than or equal 15 years accompanied with their caregivers. **Tools of data collection:** A pre-designed questionnaire to assess caregivers' knowledge and practices regarding to their children with Wilms'tumor: **Results:** The present study revealed that, the mean age of the studied children (3.51 ± 2.97). The greatest majority of the studied caregivers were mothers. There was a statistical significant difference between educational level of the caregivers and their level of knowledge P-value (0.013). There was a statistical significant difference between working condition of the caregivers and their level of practices P-value (0.001). **Conclusion:** The level of knowledge & practices were ranged from poor to an average level among the great majority of the studied caregivers. Therefore, there is a need for the guidelines to support them in care of their children with Wilms'tumor. **Recommendations:** It could be recommended: Continuous assessment for the level of knowledge & practices of caregivers for children with Wilms'tumor, implementation programs for caregivers having children with Wilms'tumor to keep them updated with health education about care of their children.

Key words: Wilms'tumor- Caregivers- Children- Knowledge- Practices

Introduction

Wilms'tumor (Nephroblastoma) is a type of cancer that starts in the kidneys. It is the most common type of kidney cancer in children, named after Max Wilms, a German doctor who wrote one of the first medical articles about the disease in 1899 (American Cancer Society, 2014).

Wilms'tumor is a type of cancer develops from cells in the kidney. It mainly affects children, most probably between 3 to 4 years old. In most cases, it affects only one or two kidneys (unilateral or bilateral). The most common sign of Wilms'tumor include a swelling or a hard mass in the abdomen. Risk factors for Wilms'tumor development include young children, family history of Wilms'tumor, certain genetic syndromes (e.g. WAGR syndrome) and birth defects. Diagnosis of Wilms'tumor needs chest X-ray,

chest CT scan and bone scan to determine whether the tumor was disseminated beyond the kidneys which helps to determine the treatment options (Surgery, chemotherapy & radiotherapy) (Cone et al., 2016).

Nephroblastoma (Wilms'tumor) is a malignant tumor that rises from metanephric mesoderm cell of the upper pole of the kidney. It accounts for 20% of solid tumor in childhood, associated with congenital anomalies such as aniridia (lack of color in the iris), cryptorchidism, hypospadias, pseudo hermaphroditism, cystic kidney, hemangioma, and talipes disorder. Some children with disorder have a deletion on chromosome 11. Without therapy, metastatic spread by bloodstream is most often to lung, regional lymph nodes, liver, bone, and eventually brain (McClean & Castellino, 2008 and Pillitteri, 2010).

Pediatric oncology nurses are essential contributors to the successful diagnosis, treatment, and cure of children with cancer. As a member of the multidisciplinary care team, the nurse works with physicians, social workers, child life specialists, psychologists, and other specialists to provide comprehensive care for the child and family. Innovative technologies require the nurses caring for children with cancer become experts in critical care management as well as in the provision of the psychological support to the child and family (Marilyn et al., 2016)

The caregiver is defined as the person who most often helps the child with cancer and the main (primary) caregiver is a spouse, partner, parent, or an adult child. When family is not around, close friends, co-workers, or neighbors may fill this role. The role caregiver toward their children with Wilms' tumor is very important role in maintaining the child's health start during and after hospitalization as well as care for the child with chemotherapy and its complication (Brown and Brown, 2014).

Subjects and Methods

This is a descriptive study aimed to assess the role of caregivers having children with Wilms'tumor at Children's Cancer Hospital (57357).

Subjects and Methods are discussed according to the following designs:

I-Technical design.

II-Operational design.

III-Administrative design .

IV-Statistical design.

I-Technical design:

The technical design for this study includes research design, research setting, subjects and tools of data collection.

Research Design:

A descriptive design was utilized for this study.

Research Setting:

The study was conducted at both the Out-Patient clinic and In- Patient pediatric departments at Children's Cancer Hospital (57357). Where, the hospital is considered as the highest admission rate of children suffering from Wilms'tumor.

Research Subjects:

Purposive Sample including 80 children with inclusion criteria were suffering from Wilms'tumor, both sex, aged from one day to less than or equal age 15 years, postoperative, start session of chemotherapy, radiotherapy and free from chronic illness and their accompanying caregivers regardless their characteristics.

Ethical consideration:

Verbal approval was obtained from the studied caregivers accompanying with their children before inclusion in the study; a clear and simple explanation was given according to their level of understanding, physical and mental readiness. They secured that, all the gathered data was confidential and used for research purpose.

Tools of data collection:

Tools were developed and utilized by the researcher to collect data in the current study, it included:

A structure interviewing questionnaire sheet. It was developed by the researcher after reviewing the current related literature. It was written in simple Arabic language to suit the understanding level of the studied caregivers. It was consisted of three parts:

Part 1: It concerned with the characteristics of the studied children (the child's age, gender, ranking, residence and duration of the disease). Also, it included data about the studied caregivers (age, gender, residence, educational level, occupation and family socioeconomic standard).

Part 2: The knowledge of the caregivers about Wilms'tumor (Definition, causes, signs, symptoms, management and the complications).

Part 3: Caregivers' reported practices related to care of their children with Wilms'tumor during chemotherapy and its complication as (alopecia, vomiting, anorexia, oral mucositis, fever and low immunity).

Questions were in the form of open, closed ended multiple choices. Each questionnaire sheet was filled on spot

individually. Time consumed for completion of each form was around 60-90 minutes according to caregivers' knowledge and practice.

Scoring system:

A scoring system was developed by the researcher to obtain the outcome of caregivers' knowledge, according to the answers obtained from caregivers, zero degree was given to each incorrect answer, one degree was given to each correct but incomplete answer and two degree was given to each correct and complete answer. Accordingly, their knowledge & practices were categorized into either Poor (Score < 50%), average (Score 50 < 75%) and good level of knowledge & practices (Score 75 ≤ 100%).

II. Operational Design:

Preparatory phase

A review of the past, current related literature covering various aspects of the research problem was done by using available books, articles, magazines, and periodicals to be acquainted with the research problem, and to develop the study tools. Tool content validity and reliability ascertained by five nursing staff expertise from pediatric field.

Pilot study:

A pilot study was carried out at December 2012, involving 10% of the expected study sample (8 children suffering from Wilms'tumor & their caregivers) to test the validity of the study tools, the result of the data obtained from the pilot study helped in modifications of study tools where items were correct, omitted and added as necessary. All the children involved in the pilot study were excluded from the study sample.

Field Work:

The actual field work was carried out over 6 month from the first week of January (2013) up to the end of June (2013). The researcher was available in the study setting four days / weekly at morning shift (2 days in inpatient & 2 days in outpatient).

Aim of the study and its expected outcome expressed/ described by the researcher, each caregiver was interviewed individually to gather the necessary data. The total time required fulfil the questionnaire was ranging from 60-90 minutes. The researcher checked each sheet after the caregivers had completed it, to be sure that no missing information were present. The researcher filled the data from illiterate caregivers after asking them.

III. Administrative Design:

An official permission to carry out the study was obtained from administrator of 57357 hospitals through an issued letter from the Dean of Faculty of Nursing/ Ain Shams University to conduct the study.

IV. Statistical Design:

Data collected from the studied sample was revised, coded and entered using computer. Data entry and statistical analysis were fulfilled using the Statistical Package for Social Sciences (SPSS). Data were presented using descriptive statistics in the form of number, percentages, mean, stander deviation, T-test & p-value.

Significance of the results:

-Non –significant (NS)

If $P > 0.05$

-Significant(S)

If $P < 0.05$

Result

Table (1) Number and Percentage Distribution of the Studied Children according to their Characteristics. (n=80)

Child's characteristics	N	%
Age in years:		
<5 Years	56	70.00
5 - < 10 Years	18	22.50
10 - ≤15 Years	6	7.50
(Mean±SD)	3.51±2.97	
Gender:		
Male	32	40.00
Female	48	60.00
Resident:		
Urban	28	35.00
Rural	52	65.00
Child's ranking:		
First	24	30.00
Second	23	28.75
Third	13	16.25
Fourth	20	25.00

Table (2): Number and Percentage Distribution of The Studied Caregivers according to Their Characteristics. (n=80)

Caregivers' characteristic	N	%
The assigned caregivers:		
Mother	74	92.50
Father	2	2.50
Grandparents	3	3.75
Relatives	1	1.25
Age of the caregivers:		
< 20 Years	3	3.75
20-<30 Years	28	35.00
30-<40 Years	48	60.00
>40 Years	1	1.25
Education level:		
Illiterate	23	28.75
Read & write	41	51.25
Highly educated	16	20.00
Working:		
Work	16	20.00
Not work	64	80.00
Parents are relatives:		
Yes	13	16.25
No	67	83.75

Figure (1): Percentage Distribution of the Studied Caregivers according to their Knowledge about Signs & Symptoms. (n=80).

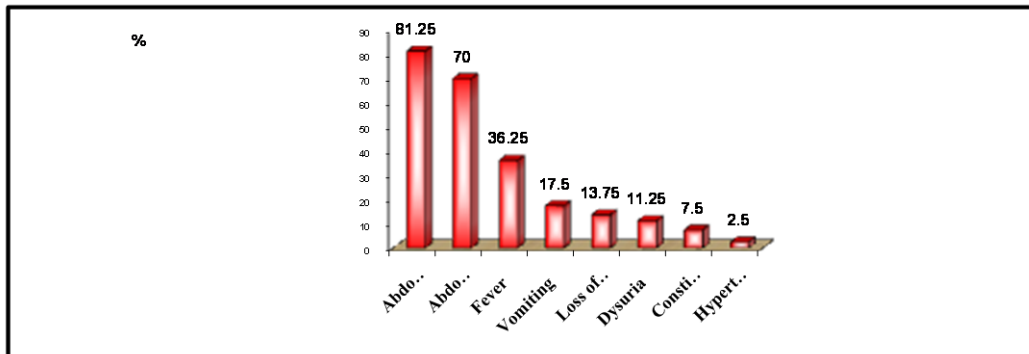


Figure (2): Percentage Distribution of the Studied Caregivers according to their Knowledge about Protocol of Treatment (n=80).

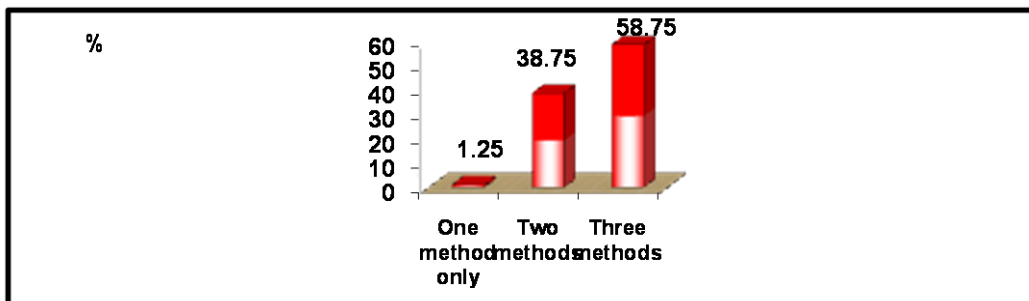


Figure (3): Percentage Distribution of the Studied Caregivers according to their total level of Knowledge and Practices. (n=80)

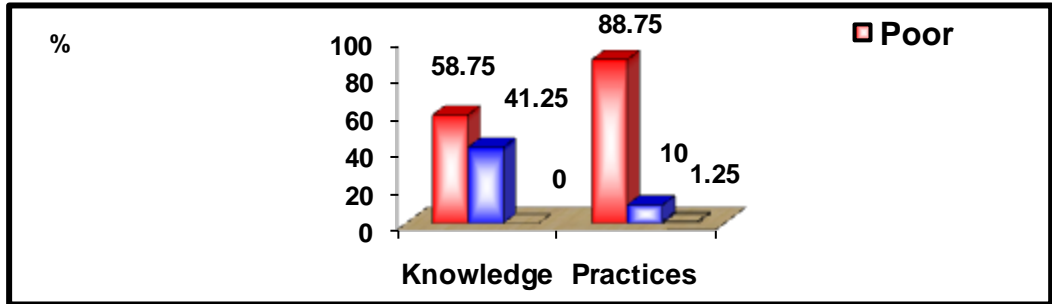


Table (3): Relations between Caregivers' Total Knowledge and their Characteristics. (n=80)

Caregivers' characteristic		Knowledge			Test	
		Mean	SD		t	P-value
Age of the caregivers	< 20 Years	15	0	.830	.82	0.4
	20-<30 Years	8	2			
	30-<40 Years	8	2			
	>40 Years	19	0			
Education level	Illiterate	3	2	.639	.13*	0.0
	Read & write	1	2			
	Highly educated	6	2			
Working	Work	6	2	.848	.06*	0.0
	Not work	4	2			
Family history of cancer	Yes	1	2	.057	.55	0.9
	No	9	2			

* Significant

Table (4): Relations between Caregivers' Total Practices and their Characteristics. (n=80)

Caregivers' characteristic		Practices			Test	
			Mean	SD	t	P-value
Age of the caregivers	< 20 Years		28.667	9.504	0.388	0.762
	20-<30 Years	8	35.429	12.139		
	30-<40 Years	8	36.125	12.578		
	>40 Years		40.000	0.000		
Education level	Illiterate	3	28.261	10.319	13.112	<0.001*
	Educated	1	35.732	7.603		
	Highly educated	6	46.063	16.587		
Working	Work	6	45.438	14.380	3.894	<0.001*
	Not work	4	33.203	10.354		
Family history of cancer	Yes	1	35.667	12.893	0.007	0.994
	No	9	35.644	12.068		

*Significant

Table (1): As regards the characteristics of the studied children, this table showed that, less than three quarter (70%) of them aged <5 years with mean age (3.51+2.97) years old, while two thirds (60%) of them were female, more than two thirds (65%) of them were lived in rural area & in addition to one third (30%) of them were ranked as the first child in the family.

Table (2): As regards the characteristics of the studied caregivers, this table showed that, the greatest majority (92.50%) of the caregivers were mothers. Near to two thirds (60%) of them were in age group between 30 <40 years, the majority (80%) of the caregivers were not work and more than half (51.25%) of them can read & write and the parents were not relatives among (83.75%) of the studied children.

Figure (1): Concerning the caregivers' knowledge about the signs & symptoms, as observed from this table that, abdominal edema, abdominal pain, fever, vomiting, loss of appetite, dysuria, constipation, & hypertension were mentioned by 81.25%, 70%, 36.25%, 17.50%, 13.75%, 11.25% 7.50%, & 2.50 % respectively.

Figure (2): In relation to caregivers' knowledge regarding the treatment of Wilms'tumor it is observed from this figure that, near two thirds (58.75%) of them knew that, the protocol of treatment divided into three methods (surgical, chemotherapy & radiotherapy).while 38.75% ,1.25% of them know(two methods & one method) respectively.

Figure (3): As regards to the total level of knowledge and practices of caregivers, this table showed that, more than half (58.75%) of them had poor level of knowledge about Wilms'tumor. While, only 41.25% of them had an average knowledge. Also, this table illustrated that the majority (88.75%) of them had poor level of practices. While, only 10% of them had an average level of practices.

Table (16): Regarding to the relation between the caregivers' total level of knowledge and their characteristics, this table showed that, statistical significant differences between educational level and their level of knowledge p-value was 0.013. As well, statistical significant differences between their level of knowledge and their working condition p-value was obvious in this table 0.006.

Table (17): Regarding to the relation between the caregivers' total level of practices and their characteristics, this table showed that, statistical significant differences between their educational level and the level of practices of them p-value <0.001. As well, statistical significant differences between their working condition and their level of practices p-value was observed in this table, <0.001.

Discussion

Wilms'tumor is the most common cancer in children that start in the kidneys. About 9 of 10 kidney cancers in children are Wilms'tumor. It becomes quite large before they are noticed. Even if a doctor thinks a child might have a cancer such as Wilms'tumor based on a physical exam or imaging tests, they can't be certain until a sample of the tumor is looked at under a microscope (**American Cancer Society, 2016**).

Table (1): as regards the characteristics of the studied children, this finding clarified that, less than three quarter of them aged less

than 5 years, with mean age (3.51-+2.97), two thirds of them were females, slightly less than one third of them were ranked as the first child and more than two thirds were from rural area. This result could be attributed to exposure of the child to pesticides in rural area and the presence of contaminated water, low educational level, poor sanitation and poor medical care facilities.

This study finding was supported by the study of **Dome, et al., (2016)** who studies treatment of anaplastic histology Wilms'tumor: Results from the fifth National Wilms'tumor Study Group, mentioned that Wilms' tumors are most common in young children, with the average age being about 3 to 4 years. They are less common in older children, and are rare in adult's children. Girls have a slightly higher risk of Wilms'tumor than boys.

Table (2): As regards the characteristics of the studied caregivers, this table showed that, the greatest majority of the caregivers were mothers. Nearly to two thirds of them were in age group between 30 less than 40 years, in addition to the majority of the caregivers had not work and more than half of them can read & write and the parents were not relatives among the majority of them. This study was in accordance with the study of **Dome, et al., (2016)**, who mentioned that, the majority of the studied sample of caregivers were from the age group 30-40 and attached with their children inside the hospital. This result could be attributed to in our society the mother is a main caregiver, the core of house and is responsible for all family specially her children resulting from our culture.

Figure (1): Concerning the caregivers' knowledge according to signs & symptoms, as observed that the majority of them mentioned that, abdominal edema, abdominal pain, fever, vomiting, loss of appetite, dysuria, constipation & hypertension were

from the common signs & symptoms of the disease. This study finding was in agree with the study of National Cancer Data Base, **Juane, et al., (2016)**, is a hospital-based cancer registry jointly sponsored by the American Cancer Society (ACS) and the American College of Surgeons, and includes approximately three quarters of all malignant cancers children with Wilms' tumor in the United States for more information regarding the classification and signs and symptoms caregivers' knowledge regarding wilms' tumor.

Figure e (2): In relation to caregivers' knowledge regarding treatment of Wilms'tumor it is observed in this study finding the greatest majority of them had mentioned that, the treatment is surgical, chemotherapy and while near two thirds of them knew that, the protocol of treatment divided into three ways (surgical, chemotherapy & radiotherapy). Also, more than half of them reported laboratory tests are the most common identified investigation.

This study was highly supported by **Anna, (2016)**; the study of American Society of Clinical Oncology related Pediatric Cancer Survivorship: Research and Clinical Care mentioned that caregivers recognized that their children with cancer might be cured by adding chemotherapy to surgery and radiation. Studies reported that caregivers understood the protocol of treatment divided into three ways (surgical, chemotherapy & radiotherapy). This result could be attributed to Wilms'tumor is a multimodal treatment of pediatric solid tumor.

Figure (3):As regards to the total level of knowledge and practices of caregivers for children with Wilms'tumor, this finding showed that, more than half of them had poor level of knowledge about Wilms'tumor. While more than one third of them had an average knowledge. In addition to the majority of them had poor level of practices, while only one fifth of them had an average level of practices. This study supported by

the study of **Turkman, (2015)** who study QOL of children undergoing of chemotherapy in Ain Shams University and institute of cancer, mentioned that the majority of the mothers of the children had unsatisfactory total level of knowledge and practices regarding their children suffering from cancer . It could be attributed to educational level of caregivers and poverty especially in rural area.

Table (3): Regarding to the relation between the caregivers' total level of knowledge and their characteristics, This finding showed that, significant differences between educational level and the level of knowledge of them 0.013& significant differences between working and the level of knowledge of them 0.006. This study finding were highly supported by the study of **Ouda and Tantawi, (2015)**, who study Assessment of Parent and Children Satisfaction about Primary Nursing care Assessment in Children Cancer Hospital (CCH) 57357, mentioned that significant differences between educational level, working condition and their level of knowledge.

Table (4): Regarding to the relation between the caregivers' total level of practices and their characteristics, This finding showed that, significant differences between educational level and the level of practices of them 0.001 & significant differences between working and the level of practices of them 0.001. This study finding was similar to the study of **Robison, (2014)** who study childhood cancer in the United States. A geographical analysis of cases from the Pediatric cooperative clinical trials groups, mentioned that working of mother let her to be more practicing and giving care to their children.

Conclusion:

The level of knowledge & practices were ranged from poor to an average level among the great majority of the studied caregivers. Therefore, there is a need for the

guidelines to support them in care of their children with Wilms'tumor.

Recommendations:

It could be recommended: Continuous assessment for the level of knowledge & practices of caregivers for children with Wilms'tumor, implementation programs for caregivers having children with Wilms'tumor to keep them updated with health education about care of their children.

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