#### Mothers Care for their Children Suffering from Retinoblastoma

# Heba Abd-Elnnaby Salem<sup>1</sup>, Ebtisam Mohamed Abd Elaal<sup>2</sup> and Basma Mohamed Abd Elrahman <sup>3</sup>

<sup>(1)</sup>B.Sc. Nursing (2005), Faculty of Nursing, Tanta University, Egypt, (2) Professor of Community Health Nursing, Faculty of Nursing, Benha University, Egypt and <sup>(3)</sup> Lecturer of Community Health Nursing, Faculty of Nursing, Benha University, Egypt

#### Abstract

Background: Retinoblastoma is a malignant (cancerous) tumor that occurs in the retina of the eye. Mothers are expected to be extensively care giver of their child at home. a higher level of nursing tasks under taken by mothers. Aim of the study: Was to assess mothers care of their children suffering from retinoblastoma. Research design: A descriptive research design was utilized in this study. Setting: The study was conducted at Oncology Outpatient Clinics at Rod Al-Farag Hospital in Cairo City. Sample: Purposive sample of 50 mothers having children with retinoblastoma. Tools of data collection: A structured interviewing questionnaire was used to assess a): Mothers demographic characteristics and personal characteristics of children b): Medical history of children suffering from retinoblastoma c): Mothers knowledge about retinoblastoma and d): Practices of the studied mothers to care of their children with retinoblastoma. Results: 14% of studied mothers had good knowledge level about retinoblastoma, 54% of them had average knowledge level and 32% had poor knowledge level about retinoblastoma. 58% of studied mothers had satisfactory practices level while 42 % of them had unsatisfactory practices level regarding to total practices level toward their children suffering from retinoblastoma. Conclusion: There were a highly statistically significant relation between the mothers' total knowledge level and level of education and there were a statistically significant relations between total practices level of the studied mothers and age, level of education, marital status and income and there was a statistically significant relation between studied mothers total knowledge level and their total practices level. Recommendations: Health educational program for mothers to improve their knowledge and practices regarding care for their children with retinoblastoma.

Keywords: Children, Mothers' care, Retinoblastoma

#### Introduction

Retinoblastoma is a type of eye cancer that affects the retina and causes tumors (clumps of cells) to grow in the retina. Nerve cells in the retina sense light and send images to the brain and allow children to see. Retinoblastoma happens when nerve cells grow out of control and the eye can't communicate with the brain (Garibotto, 2019).

Retinoblastoma is considered the 6th most common cancer in children, it accounts for 3–4% of all pediatric tumors in developed countries. It occurs at any age and most cases are in children usually between the ages of 0 and 5 years. 40% of them will get the disease for hereditary reasons so in case of retinoblastoma history in the parents' families; the child must be checked by an ophthalmologist right after birth. The remaining 60% will get the disease because of a certain gene mutation during the early stages of intrauterine development of the baby. Globally, about 100 in one million births develop retinoblastoma, and it is estimated that around 9,000 children are newly affected each year (Ahmed, et al., 2019).

Most cases of retinoblastoma are caused by a genetic mutation (a change in a The two common form gene). of retinoblastoma are heritable retinoblastoma sporadic retinoblastoma. Heritable and retinoblastoma can happen when a child inherits a mutation (change in a gene) from a parent. Often, the baby will be born with retinoblastoma. Most of these children will develop retinoblastoma before the age of one year. Sporadic retinoblastoma occurs when a gene mutation happens in early childhood, usually after one year of age and affecting just one eye (Xie et al., 2021).

The most common early sign of retinoblastoma is leukocoria (a cloudy white pupil). In bright light, the pupil can look silvery or yellow. Normally when shine a light in the eye, the pupil (the dark spot in the center of the eye) looks red because of the blood vessels in the back of the eye. In an eye with retinoblastoma the pupil often appears white or pink instead this white glare of the eye may be noticed by the mothers after a flash photograph is taken. Sometimes the eyes don't appear to look in the same direction, a condition often called lazy eye. Other signs and symptoms include deterioration of vision, a painful, red and irritated eye with glaucoma, and faltering growth or delayed development (Kaliki, 2021).

Treatments for retinoblastoma include enucleation, intravenous chemotherapy (with focal therapy (laser therapy, cryotherapy), intra-arterial chemotherapy with focal therapy, and focal therapy alone when tumors are small at diagnosis (**Manrique et al.**, 2021). Complication of retinoblastoma includes partial or total blindness to one or both eyes. Also children are at high risk of retinal detachment and glaucoma. Although most children with retinoblastoma have one eye affected, it is possible for the cancer to spread to the other eye or to other parts of the body, in particular the brain, lungs, and bone. The metastasis, or spreading of the cancer, rarely occurs. If there is metastasis, the spread of the disease is usually seen 1 to 2 years after treatment of the original tumor (Rajan et al., 2021).

Mothers expected to be are extensively care giver at home for their children suffering from retinoblastoma. mothers under take a higher level of nursing tasks and assumed primary responsibility for carrying out the children nursing care procedures such as primary eye care which includes eye clinical activities that are manipulated by mothers or referral of children with eye disease, eye medications as drops instillation, ointment applications, hot and cold applications and eye exercise (Cain & Fanshawe, 2021).

Community Health Nurse (CHN) should provide explanation for mothers about the disease process and how to cope with the rapid changes that occur. A two-way communication with the family members must be provided, providing information and listening to their doubts and sharing information can help the mothers to understand the situation and directly influence their decision-making and skill acquisition. When mothers know about their child's illness feel more control of the situation they face, and the feelings of guilt and insecurity decrease (Amador et al., 2021).

## Significance of the study:

The Egyptian National cancer Institute (NCI) reported that retinoblastoma children's

represented 3% of all NCI pediatric tumor patients (1067) in 2001 and a similar 3% of 6279 diagnosed patients during the period from 2002 to 2010. Retinoblastoma showed a relative frequency of 1.9% age standardized rates by site and gender in Egyptian children under age 15 years was 3 per million. Considering an expected retinoblastoma incidence of 1 per 15,000-16,600 live birth and an annual increase of population by 2.1 million we can infer that the number of new retinoblastoma patients in Egypt ranges between 120 and 140 patients annually it could be roughly estimated that Children Cancer Hospital Egypt receives annually around 40-50% of the total retinoblastoma children in the country (Elzomor et al., 2015).

According to statistics of the Mobilization and Statistics Office of the Rod Al-Farag Hospital in Egypt for the year 2019/2020, the number of children diagnosed with retinoblastoma 146 cases (**Rod Al-Farag Statistics Office, 2019**).

## Aim of the study

The aim of the study was to assess mothers care of their children suffering from retinoblastoma.

## **Research Question:-**

**1**-What is the mothers knowledge regarding retinoblastoma?

**2**-What are the mother's practices regarding care of their children suffering from retinoblastoma?

**3-**Is there are a relation between knowledge and practices of mothers with children suffering from retinoblastoma?

**4-**Is there are a relation between practices and demographic characteristics of mothers with children suffering from retinoblastoma?

### Subjects and Method

#### **Research design:**

A descriptive study design was utilized to conduct the study.

#### Setting:

This study was conducted at Oncology Outpatient Clinics at Rod Al-Farag Hospital as a large number of children with retinoblastoma were attending to this setting. **Sampling:** 

Purposive sample was used in carrying out this study. All mothers of children suffering from retinoblastoma attending to the previously mentioned setting were included through a period of six months, (N=50 mother). The sample was chosen according to the following criteria.

a): Age of child from1-15 year.

b): All children free from other chronic disease.

#### Tools of data collection:

An interviewing questionnaire was used to collect the data: It was developed by the investigator and revised by the supervisor staff, based on reviewing related literatures and it was written in simple clear Arabic language: It comprised of four parts:

**First part:** It was concerned with: **A**-Demographic characteristics of the mothers of children suffering from retinoblastoma. It included eight closed ended questions (multiple choice types) as age, level of education, marital status, occupation

**B-** Personal characteristics of children suffering from retinoblastoma involved in the study. It included three closed ended questions (multiple choice types) as age, gender and child ranking among siblings.

**Second part:** It was concerned with medical history of children suffering from retinoblastoma.

**A-** Past medical history of children suffering from retinoblastoma. It included gestational age, labor problem for child, types of problem at birth, child weight at birth, child hospitalized after birth, causes of hospitalization, age when symptoms appear, history of cancer, congenital anomalies and surgical operation.

**B-** Present medical history of children suffering from retinoblastoma. It included type of retinoblastoma, retinoblastoma effects, child age during the enucleation, noticing vision problems, type of vision problem and type of treatment.

C- Family history of children involved in the study. It included mothers' pregnancy complication, mothers' complication during birth, other siblings with retinoblastoma, relatives with retinoblastoma and relative relation between the parents.

Third part: It was concerned with: Mothers' knowledge regarding to retinoblastoma as meaning, causes, signs and symptoms, types of retinoblastoma, diagnosis. Scoring system:-

The scoring system for mothers knowledge was calculated as follows, (2) correct and complete knowledge, (1) correct and incomplete knowledge and (0) don't know answer.

The total score of knowledge = 22

The total knowledge score was considered good if the score of the total knowledge  $\geq$  75% (>17 points), while considered average if it equals 50-75% (11-17 points) and considered poor if it is <50% (<11 points).

**Fourth part:** It was concerned with mothers' practices regarding to their children suffering from retinoblastoma.

A-Mother's reported practices regarding to care of their children suffering from

retinoblastoma which included eight procedures the as following (personal hygiene, eye cleaning, wound dressing after enucleation, applying eye drops, removal of prosthetic eye, fixing the prosthetic eye, caring of the prosthetic and eye environmental safety).

**B**-Mother's reported practices to manage the side effects of chemotherapy for children with retinoblastoma which included five items as the following (fever, Constipation, Diarrhea, Nausea and vomiting and Alopecia).

## Scoring system:

The scoring system for mother's practices was calculated as: as (1) score for done and (0) for not done.

The total practices score = 80

The total practices score was considered satisfactory if the score  $\geq 75 \%$  ( $\geq 60$  points) and considered unsatisfactory if it <75 % (< 60 points).

# Content validity and reliability of the tool:

The tool validity was done by five of Faculty's Staff Nursing Experts from the Community Health Nursing Specialists who reviewed the tools for clarity, relevance, comprehensiveness; understanding, applicability and easiness for implementation, according to their opinion minor modification were carried.

Reliability was applied by the investigator for testing the internal constancy of the tool, by administration of the same tool to the same subjects; the tool reliability was done by Cronbach Alpha test. Cronbach alpha for knowledge was 0.830. A Cronbach Alpha for practices was 0.929.

## Ethical consideration:

All ethical issues were assured; oral consent has been obtained from each mother before conducting the interview and given them a brief explanation about the purpose of the study. They were also reassured that all information gathered would be treated confidentially and used only for the purpose of the study. Mothers were also informed about their right to withdraw from the study at any time without giving any reasons.

## **Pilot study:**

The pilot study was carried out on 10% (5 mothers) of the sample size. The pilot study was aimed to assess the tool clarity, applicability and objectivity. As well as to estimate the time needed to fill each sheet and to identify any possible obstacles that may hinder the data collection. No modification was done, so the pilot study sample was included to the total sample.

## Field work:

The actual field work was carried out 6 months which started over a period of from the beginning of May 2021 to the end of October 2021. The study was carried out in the Oncology Outpatient Clinics at Rod Al-Farag Hospital. The investigator interviewed the mothers having children with retinoblastoma to assess their knowledge and practices at the outpatient waiting area. The investigator visited the previously mentioned setting one day per week (Wednesday) from 9:00 am to 12:00 mid-day to collect the data and cover the study sample. The average time needed for the sheet was around 30-45 minutes; the mothers average number interviewed at the Out-Patient Clinics were 1-2 mothers/day depending on their responses to the interviewers.

## Statistical analysis:

Statistical analysis was done by using the Statistical Package for Social Science (SPSS) version 21. All data were collected, revised, coded, organized, tabulated and analyzed using frequencies, numbers and percentages. Data were presented in the form of tables and figures. Quantitative data was presented by mean  $(x^{-})$  and standard deviation (SD). Qualitative data was presented in the form frequency distribution tables, number and percentages. It was analyzed by Chi-square test ( $x^2$ ) to detect the relation between the variables of the study. Also (P- value) used to determine statistical significance as: Not significant P value > 0.05 Significant P- value  $\leq 0.05$ Highly significant P-value  $\leq 0.001$ 

## **Results:**

**Table (1)**: Shows demographic characteristics of studied mothers, 60% aged 30 < 40 years old with mean age  $32.18\pm6.31$ . Regarding to level of education 70% of the mothers had middle education while 86% of the mothers were married, and 82% of them not working. Regarding family monthly income 80% of the studied mothers had adequate income and 56.0 % of them were living in rural areas.

**Table (2):** Shows personal characteristics of included children, 58% of studied children aged from 1-5 years old with mean age 5.80±4.05. Regarding to child's gender, 56% of them were females and 54% of them were the first child among siblings.

 
 Table (3):
 Describes past medical
history of the children, 76% of children had 40 weeks of gestational age. Regarding to labor problem 60% of the child didn't have labor problems and 24% of them had trouble breathing. Regarding child weight at birth, 64% of the children born with normal weight. About 54% of the children were hospitalized after birth and 32% of them hospitalized because of pathological jaundice. Regarding child age when symptoms appear 48% of them were  $\geq$  3 years. Also all of the children didn't have history of cancer, and 82% of them didn't have any congenital anomalies, while 62% of the children performed surgeries related to the disease.

**Figure (1):** Clears that 14% of studied mothers had good knowledge level about retinoblastoma, 54% of them had average knowledge level and 32% had poor knowledge level about retinoblastoma.

**Figure (2):** Shows that 58% of studied mothers had satisfactory practices level while 42 % of them had unsatisfactory practices level regarding to total practices for their children suffering from retinoblastoma

**Table (4):** Shows that there were a highly statistically significant relation between the mothers' total knowledge level and level of education ( $P \le 0.001$ ) and there were a statistically significant relation between the mothers' total knowledge and the age and occupation (P- value  $\le 0.05$ ). While

there were no statistically significant relation between the mothers' total knowledge level and marital status, residence and income (Pvalue > 0.05).

**Table (5):** Shows that there were a statistically significant relations between total practices level of the studied mothers and age, level of education, marital status and income (P- value < 0.05). While there were no a statistically significant relations between the studied mothers total practices level and their occupation, and residence (P- value > 0.05).

**Table (6):** Shows that there is a statistically significant relation between studied mothers total knowledge level and their total practices level (p- value < 0.05).



#### Mothers Care for their Children Suffering from Retinoblastoma

Demographic characteristics	No.	%
Age in years		
20 < 30	17	34.0
30 < 40	30	60.0
$\geq 40$	3	6.0
Min –Max	21-45	•
Mean ±SD	32.18±6.	.31
Level of education		
Don't read and write	3	6.0
Basic education	6	12.0
Middle education	35	70.0
University education and above	6	12.0
Marital status		
Married	43	86.0
Divorced	4	8.0
Widowed	3	6.0
Occupation		
Working	9	18.0
Not working	41	82.0
Residence		
Urban	22	44.0
Rural	28	56.0
Family monthly income		
Adequate	40	80.0
In adequate	10	20.0

Table (1): Frequency distribution of studied mothers regarding to their demographic characteristics (n=50).

Table (2): Frequency distribution of children suffering from retinoblastoma regarding to their personal characteristics (n=50).

Personal characteristics	No.	%					
Age in year							
1-5	29	58.0					
6-10	10	20.0					
11-15	11	22.0					
Min –Max	2-14						
Mean ±SD	5.80±4.05						
Gender							
Male	22	44.0					
Female	28	56.0					
Child ranking among siblings							
First	27	54.0					
Second	14	28.0					
Third and more	9	18.0					



# Heba Abd-Elnnaby, Ebtisam Mohamed and Basma Mohamed

Child past medical history	No.	%	
Gestational age	1100	,,,	
40 weeks	38	76.0	
Less than 40 weeks	12	24.0	
Labor problem for child	12	24.0	
Yes	20	40.0	
No	30	60.0	
Types of problem at birth (n=20).	11	22.0	
Blood problems	11	22.0	
Eye problems	3	6.0	
Congenital anomalies	6	12.0	
Trouble breathing	12	24.0	
Child weight at birth			
Normal	32	64.0	
Less than normal	15	30.0	
More than normal	3	6.0	
Child hospitalized after birth?			
Yes	27	54.0	
No	23	46.0	
Causes of hospitalization (n=27). *			
Low birth weight	12	24.0	
Respiratory problem	14	28.0	
Pathological jaundice	16	32.0	
Age when symptoms appear		·	
6 month	6	12.0	
One year	16	32.0	
Two years	4	8.0	
$\geq$ 3 years	24	48.0	
Min –Max	2-	-5	
Mean ±SD	3.92±1.14		
History of cancer	•		
No	50	100.0	
Congenital anomalies	•		
Yes	9	18.0	
No	41	82.0	
Surgical operation	1		
Disease-related operations	31	62.0	
Operations not related to the disease	12	24.0	
No surgery was performed	7	14.0	

Table (3): Frequency distribution of children regarding to their past medical history(n=50).

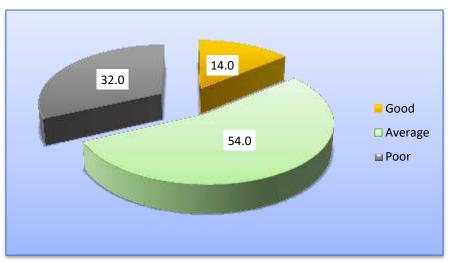


Figure (1): Percentage distribution of studied mothers regarding to their total knowledge level about retinoblastoma (n=50).

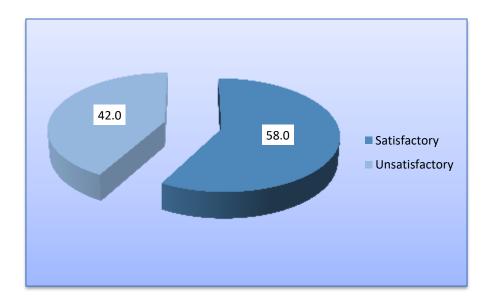


Figure (2): Percentage distribution of studied mother regarding their total practices level for their children suffering from retinoblastoma (n=50).



Table (4): Relation between total knowledge level and demographic characteristics among studied mothers (n=50).

	Total knowledge level							
Demographic characteristics	Poor knowledge (n=16)		Average knowledge (n=27)		Good knowledge (n=7).		X <sup>2</sup>	P-value
	No.	%	No.	%	No.	%		
Age in years					-			
20 < 30	1	6.3	14	51.9	2	28.6		
30 < 40	15	93.8	11	40.7	4	57.1	12.782	.012*
$\geq$ 40	0	0.0	2	7.4	1	14.3		
Level of education					-			
Don't read and write	2	12.5	1	3.7	0	0.0	28.883	
Basic education	2	12.5	4	14.8	0	0.0		.000**
Middle education	12	75.0	21	77.8	2	28.6		
University education	0	0.0	1	3.7	5	71.4		
and more	0	0.0	1	5.7	5	/1.4		
Marital status								
Married	11	68.8	26	96.3	6	85.7		
Divorced	3	18.8	1	3.7	0	0.0	7.928	0.094
Widowed	2	12.5	0	0.0	1	14.3		
Occupation								
Working	0	0.0	7	25.9	2	28.6	7.86	0.020*
Not working	16	100.0	20	74.1	5	71.4	7.80	0.020*
Residence								
Urban	8	50.0	13	48.1	1	14.3	2.931	0.231
Rural	8	50.0	14	51.9	6	85.7	2.751	
Monthly income								
Adequate	11	68.8	23	85.2	6	85.7	1.862	0.394
In adequate	5	31.3	4	14.8	1	14.3	1.002	0.394

# Mothers Care for their Children Suffering from Retinoblastoma

Table (5): Relation between demographic characteristics and total practices level among studied mothers (n=50).

Demographic characteristics	Unsatisfactory (n=21).		Satisfactory (n=	X <sup>2</sup>	P- valu e	
characteristics	No.	%	No.	%		e
Age in year						
20 < 30	4	19.0	13	44.8		.027
30 < 40	17	81.0	13	44.8	7.202	.027
$\geq$ 40	0	0.0	3	10.3		-
Level of education						
Don't read and write	3	14.3	0	0.0		.034 *
Basic education	3	14.3	3	10.3		
Middle education	12	57.1	23	79.3	8.656	
University education and	3	14.3	3	10.3		
more	5	14.5	5	10.5		
Marital status						
Married	18	85.7	25	86.2		.030 *
Divorced	0	0.0	4	13.8	7.04	
Widowed	3	14.3	0	0.0		
Occupation						
Working	3	14.3	6	20.7	0.338	0.56
Not working	18	85.7	23	79.3	0.558	1
Residence						
Urban	6	28.6	16	55.2	3.498	0.06
Rural	15	71.4	13	44.8	5.498	1
Monthly income		•	•			•
Adequate	20	95.2	20	69.0	5.055	.022
In adequate	1	4.8	9	31.0	5.255	*

Table (6): Relation between total knowledge level and total practices level among studied mothers (n=50).

		Total practio	X <sup>2</sup>	P- value		
Total knowledge level	Unsatisfactory (n=21).				Satisfactory (n=29).	
	No.	%	No.	%		
Poor knowledge (n=16)	1	4.8	15	51.7		
Average knowledge (n=27)	15	71.4	12	41.4	12.92	0.002*
Good knowledge (n=7)	5	23.8	2	6.9		



#### **Discussion:**

Regarding demographic the characteristics of the studied mothers of children suffering from retinoblastoma, the present study showed that, less than two third of the studied mothers aged 30 < 40 years old with mean age 32.18±6.31 and less than three quarters of them had middle education,. These findings in accordance with Saad et al.(2020), who studied "Assessment of home accident among children with retinoblastoma in Egypt" (n=100), and reported that less than two third (62%) of the studied sample were in between 30: 40 years old with the mean age of  $32.33\pm$ 4,601 and less than half (47%) of the studied sample had diploma

Concerning the personal characteristics of children suffering from retinoblastoma, the present study showed that, less than three fifths of studied children aged from 1-5 years old with mean age 5.80±4.05. This findings come in accordance with Handavani et al. (2021), who studied "Treatment outcome of children with retinoblastoma in a tertiary care referral hospital in Indonesia" (n=61), and reported that majority (81%) of children are younger than 5 years old at diagnosis, the average age at diagnosis is 2 years. Also this findings was supported by Van Dijk et al. (2017), who studied "Health-related quality of life of child and adolescent retinoblastoma survivors in the Netherlands" (n=65), and reported that the majority of children (79%) were in between 1-5 year, the proportion of female were more than male.

Concerning the past medical history of children suffering from retinoblastoma, the present study illustrated that slightly more than three quarters of children had 40 weeks of gestational age and more than three fifths of them had no problem during labor. These findings in accordance with **Fabian et al.** (2021), who studied " Sex, gender, and retinoblastoma: analysis of 4351 patients from 153 countries" (n=4351), who stated that less than three fifth (58%) of the studied children had normal birth and free from any complication. This might be related to the effective antenatal care and effective infant care during child birth

The present study showed that less than one fifth of studied mothers had good knowledge level about retinoblastoma, more than half of them had average knowledge level and less than one third of them had poor knowledge level about retinoblastoma,. These findings come in line with Mohammed et al. (2018), who studied "Assessment of mothers' role in care of ophthalmological problems in their children in Egypt"(n=300), and reported that three quarters(75%) of the studied sample had unsatisfactory knowledge regarding eye problem and one quarter (25%) of them had satisfactory knowledge. This might be related absence of health education about to retinoblastoma that affect negatively in the mothers awareness regarding retinoblastoma. Also these findings were supported by Hill et al. (2018), who studied "Knowledge, experiences and attitudes concerning genetics among retinoblastoma survivors and parents" (n=15), and reported that the studied sample had poor knowledge regarding retinoblastoma and need more health education.

The present study showed that, more than half of studied mothers had satisfactory practices regarding to care of their children suffering from retinoblastoma. This finding confirmed by **Saad et al. (2020),** (n=100), who reported that less than two thirds of the parents (65%) had inadequate practices regarding children with retinoblastoma. This might be due to effective training from the health care providers toward mothers about retinoblastoma.

Regarding the relation between total knowledge level and demographic characteristics among studied mothers, the current study showed that there were a highly statistically significant relation between the mothers' total knowledge level and level of education and there were a statistically significant relation between the mothers' total knowledge and the age and occupation (pvalue < 0.05). This result in the line with Handayani et al. (2021), (n=61), who reported that there statistically significant relation between the parents knowledge level and demographic data. This might be due to education effect on mother's ability to acquire knowledge and more older mothers had more experiences.

The present study showed that there were a statistically significant relations between total practices level of the studied mothers and age, level of education, marital status and income (p- value < 0.05). This result disagreed with Sukati et al. (2018), who studied "Knowledge and practices of parents about child eye health care in the public sector in Swaziland" (n=173), and reported that no significant association was found between level of education and practices regarding eve conditions affecting children. This might be due to that high level education had good impact on studied sample practices and older mothers had more experiences which may be reflected on their practices.

The present study showed that there is a statistically significant relation between studied mothers total knowledge level and their total practices level (p- value < 0.05), This finding was confirmed by Mohammed et al. (2018), (n=300), who reported that there were a statistically significant differences between the studied sample knowledge and practices. Also this finding was confirmed by Ahmed et al. (2019), (N=100), who reported that the relation between parents" total knowledge and total practices was highly statistically significant (P<0.001). This might be due to that the mothers acquired knowledge from health care providers affect their practices also might be due to that the knowledge play an important role in changing behavior leading to change of practice

## **Conclusion:**

Regarding to mothers knowledge less than one fifth of studied mothers had good knowledge level, more than one half of them had average knowledge level and less than one third of them had poor knowledge level about retinoblastoma. While more than one half of studied mothers had satisfactory practices levels and less than one half of them had unsatisfactory practices level regarding to total practices levels. There was a highly statistically significant relation between the mothers total knowledge level and level of education and a statistically significant relation between the mothers total knowledge and the age and occupation. Also there were a statistically significant relations between total practices level of the studied mothers and age, level of education, marital status and income. While there were no a statistically significant relations between the studied mothers total practices level and their occupation, and residence. There is a



statistically significant relation between studied mothers total knowledge level and their total practices level.

# Recommendations

**1-** Health educational program for mothers to improve their knowledge and practices regarding care for their children with retinoblastoma.

**2-**Distributed guidance brochure or handouts including information about community resources and comprehensive care needs.

**3-**Mother's class during follow up visits to trained them about child care.

**4-**Further studies: Health educational program for mothers having child with retinoblastoma **References**:

Ahmed, S., Ahmed, H., Mohammed, M., Shelil, A., and Elzomor, H. (2019). Prevention of Home Accident Among children with Retinoblastoma, Egyptian Journal of Health Care; 52 (4): 530-535.

Amador, C., Shah, R., Tormanen, K.,<br/>Ghiam, S., Saghizadeh, M.,Arumugaswami, V., and Ljubimov, A. V.<br/>(2021). Systemic diseases and the<br/>cornea, Experimental Eye Research: 204,<br/>108455.

**Cain, M, and Fanshawe, M. (2021).** From Emotional Crisis to Empowerment: The Journey of two Mothers, Infants & Young Children; 34(3): 225-240.

El Zomor, H., Nour, R., Alieldin, A., Taha, H., Montasr, M. M., Moussa, E.m and Alfaar, A. S. (2015). Clinical presentation of intraocular retinoblastoma; 5-year hospitalbased registry in Egypt, Journal of the Egyptian National Cancer Institute; 27(4): 195-203.

Fabian, I., Khetan, V., Stacey, A., Foster,A., Ademola-Popoola, S., Berry, J.and

**Kaliki, S. (2021).** Sex, gender, and retinoblastoma: analysis of 4351 patients from 153 countries, Eye: 1-7.

**Garibotto, F. (2019).** Diffuse Anterior Retinoblastoma: A Challenging Case Report with Psychological Implications, Universal Journal of Oncology; 2 (1): 1-5.

Handayani, K., Indraswari, B., Sitaresmi, M., Mulatsih, S., Widjajanta, P., Kors and W. Mostert, S. (2021). Treatment Outcome of Children with Retinoblastoma in a Tertiary Care Referral Hospital in Indonesia, Asian Pacific journal of cancer prevention: APJCP; 22(5): 1613.

Hill, J., Gedleh, A., Lee, S., Hougham,K and Dimaras, H. (2018). Knowledge, experiences and attitudes concerning genetics among retinoblastoma survivors and parents, European journal of human genetics; 26(4): 505-517.

**Kaliki, S. (2021).** Aqueous seeding in intraocular retinoblastoma: A review, Clinical & Experimental Ophthalmology; 49(6): 606-614.

Mohamed, A., Abd Al-Moniem, I., Shalaby, L.,and Elsayed, S. (2018). Effect of discharge plan for children undergoing chemotherapy and their caregivers on improving practice and coping pattern. Unpublished Doctorate Thesis, Faculty of Nursing, Ain Shams University: 99-103.

Manrique, M., Akinbolue, D., Madigan, W., and Bregman, J. (2021). Update on the Treatment of Retinoblastoma, NeoReviews; 22(7): 423-437.

Rajan, R., Kim, U., Maitray, A., Jena, S., and Sen, S. (2021). A Rare Case of Acute Hemorrhagic Retinopathy Following Intravitreal Melphalan Injection for Persistent Vitreous Seeds in Retinoblastoma, Journal of Vitreoretinal Diseases, 24741264211024147.

```
Rod Al-Farag Statistics Office, (2019).
```

Saad, S., Mohammed, H., Elhusseiny, A., and Elzomor, H. (2020). Assessment of Home Accident Among children with Retinoblastoma, Egyptian Journal of Health Care; 11(2): 155-169.

Sukati, V., Moodley, V., and Mashige, K. (2018). Knowledge and practices of parents about child eye health care in the public sector in Swaziland. African Journal of Primary Health Care and Family Medicine; 10(1): 1-13.

Van Dijk, J., Huisman, J., Moll, A., Schouten-van Meeteren, A., Bezemer, P., Ringens, P. and Imhof, S. (2017). Healthrelated quality of life of child and adolescent retinoblastoma survivors in the Netherlands, Health and Quality of Life Outcomes; 5(1): 1-8.

Xie, M., Gu, X., Jia, R., and Ge, S. (2021). Publication Trends of Research on Retinoblastoma During 2001–2021: A 20-Year Bibliometric Analysis, Frontiers in Medicine, 8: 7



رعاية الأمهات لأطفالهن الذين يعانون من ورم شبكية العين

هبه عبدالنبي سالم البسطويسي – ابتسام محد عبدالعال- بسمه محد عبدالرحمن

ينشأ ورم شبكية العين في الطبقة الداخلية للعين ( الشبكية ) والذي يتم تشخيصه في السنوات القليلة الأولى من حياة الطفل ، ويؤثر على ما يقرب من ١ لكل ١٦٠٠٠ مولود حي. ويعد هذا الورم أكثر أنواع السرطانات الأولية شبوعًا بالعين في جميع أنحاء العالم، كما يؤثر على الأطفال من جميع الأجناس ، أو لاد وبنات على حد وفي حاله تأخر العلاج يتطور الورم ويعيق الرؤية ويؤدي إلى خطر انتشار المرض. لذلك هدفت هذه الدراسة الي تقييم ر عاية الأمهات لأطفالهن الذين يعانون من ورم شبكية العين. وقد أجريت هذه الدراسة في العيادات الخارجية للأورام بمستشفى رمد روض الفرج بالقاهرة تم استخدام عينة غرضيه في هذه الدراسة في العيادات الخارجية الذين حضروا للمستشفى رمد روض الفرج بالقاهرة تم استخدام عينة غرضيه في هذه الدراسة وتم اخذ جميع الأمهات الذين حضروا للمستشفى السابق ذكرها بصرف النظر عن خصائصهن ولديهن أطفال مصابين بورم شبكية العين. وعيث اسفرت النتائج بان أقل من خُمس الأمهات مستوى معلوماتهم جيد تجاه ورم شبكية العين بينما كان لدي أكثر من نصف الأمهات الخاصات للدراسة ممارسات مرضيه وتوجد علاقة ذات دلالة إحصائية بين معلومات الأمهات ومستوى التعليم والعمر والوظيفة . بينما لا توجد علاقة ذات دلالة إحصائية بين معلومات الأمهات ومستوى التعليم والمار الخرائية والدخل الشهري ، كما توجد علاقة ذات دلالة إحصائية بين معلومات الأمهات ومستوى التعليم والعمر والوظيفة . بينما لا توجد علاقة ذات دلالة إحصائية بين معلومات الأمهات ومستوى التعليم والحالة الاجتماعية والدخل الشهري ، كما توجد علاقة ذات دلالة إحصائية بين معلومات الأمهات والعمر ومستوى التعليم والحالة الإحتماعية والدخل الشهري . بينما لا توجد علاقة ذات دلالة إحصائية بين معلومات الأمهات ما سنوى المهات الخامية والدخل الشهري ، كما توجد علاقة ذات دلالة إحصائية بين معلومات الأمهات والعمر ومستوى التعليم والحالة الاجتماعية والدخل الشهري . بينما لا توجد علاقة ذات دلالة إحصائية بين مستوى مارسات الأمهات والوطيفة ومحل الألمامه وأيضا توجد علاقة ذات دلالة إحصائية بين معلومات الأمهات و

