

Original Research Article

AWARENESS AND KNOWLEDGE OF RETINOBLASTOMA AMONG PREGNANT WOMEN IN A SPECIALIST HOSPITAL IN NIGERIA.

ABSTRACT

Background: Retinoblastoma is a rare, curable but deadly intra ocular tumor affecting usually children under 5 years of age. Awareness, early detection and treatment determine vision preservation and patient's survival. In low- and middle-income countries majority of children present very late because of poor awareness of early signs of retinoblastoma.

Aim: To determine the awareness and knowledge of retinoblastoma among pregnant women in Anambra State, Nigeria.

Methods: This study was a cross sectional study that was carried out among 246 antenatal attendee in a private specialist hospital in Anambra state between March 2023 to August 2023. It was done using a pretested, self-administered and interviewer-administered questionnaire which included 25 well-structured questions concerning awareness of retinoblastoma. Data obtained were analyzed using IBM SPSS version 26 statistical package. Participants' responses were anonymized and analyzed. Continuous variables were analyzed while bivariate analysis was done using chi-square while binary logistic regression analysis was performed to identify factors associated with retinoblastoma awareness. The test of significant was p-value <0.05.

Results

Comment [u1]: Is the questionnaire validated?

Two hundred and forty six women participated in this survey. Of the women who participated in this survey, 84.2% reported not having heard of retinoblastoma. The majority heard it via health workers (40.0%). However, majority of the participants do not know that retinoblastoma can affect children (49.3%), or can be inherited from parents (63.3%). Multivariate logistic regression analysis identified two variables that might influence retinoblastoma awareness: occupation (trader) of the husband (adjusted odds ratio (aOR) = 2.63, 95% CI = 1.07-6.49; $p=0.035$) and childbearing (aOR=5.83, 95% CI = 1.14-9.20; $p=0.046$).

Conclusion

Nigerian pregnant women had appallingly low levels of awareness and information of retinoblastoma during pregnancy. There was a correlation between the participants' level of knowledge about retinoblastoma and their husband's occupation, and having children. These results could lead to improved ophthalmic practices and the development of successful public health programmes, ultimately benefiting the health of Nigerian pregnant women and children. It will take more research to examine this connection.

INTRODUCTION

Retinoblastoma is the most common pediatric eye cancer in children, accounting for about 2.5%–4% of all pediatric cancers in high-income countries and usually presents very early in life [1]. Though this condition is curable, it can lead to blindness and even death if not detected early and treated appropriately [2, 3]. The key to good treatment outcomes is determined by early detection, improved awareness of retinoblastoma and recognition of its early signs by both the

health professionals and the general public as well as eye screening of children under 5 years of age [4, 5].

Retinoblastoma may be familial, but can also occur sporadically [6]. The heritable type may be bilateral while the sporadic type is commonly unilateral [7]. The common presenting symptoms of retinoblastoma are deviating eyes and leukocoria especially in high income countries whereas in Africa and other low income countries, retinoblastoma patients often present with proptosis as a result of late diagnosis and presentation [2]. Several factors are responsible for late presentation in Africa. These include lower national income level, poor awareness of retinoblastoma among health professionals and the general public particularly among mothers, cultural beliefs which hinder acceptance of eye care services, poor access to modern quality retinoblastoma services, non-availability of tertiary cancer centers and lack of routine eye screening of children [3,8-12].

The high burden of morbidity and mortality from retinoblastoma in Africa have been attributed to very low level of its awareness and late presentation [8]. Because retinoblastoma is known to present usually in the first few years after birth, if pregnant women become increasingly aware and knowledgeable of retinoblastoma, this will enhance early detection and treatment of retinoblastoma thereby reducing its morbidity and mortality[13]. In addition, although only about 23 cases has been reported in adult [14], only one case in pregnancy has been reported [15]. However, Takahashi *et al.* reported one case which presented six months post-partum in a 26-year old female and had acute presentation with photopsia, diminution of vision and field defect [16]]. Retinoblastoma remains the most common intraocular tumour in childhood; occurring before the age of two years and rarely after the age of four years. The present study

therefore is aimed at assessing the awareness of retinoblastoma among pregnant women living in Nigeria.

MATERIALS AND METHODS

Study design: The study is a cross-sectional study.

Study setting: The study was conducted at Grace Specialist Hospital Onitsha, Anambra State, Nigeria. It has consultant Obstetricians and Gynaecologists, nurses and lab scientists among other health workers. It serves as a referral centre for patients from within Anambra, parts of Imo, Enugu, Abia, Ebonyi and Delta states

Study population: The study population were pregnant women attending antenatal care at Grace Specialist Hospital Onitsha, Anambra State, Nigeria. Women included in the study were consenting booked women who must have attended three or more antenatal care in the hospital. Those excluded were unbooked women, women with medical complication of pregnancy and those in labour or any pregnancy and labour complication.

Data collection and study instrument: The participants were recruited between March 2023 and August 2023. The data was collected by two trained registrars in ophthalmology. The survey consisted of 25 well-structured questions concerning awareness of retinoblastoma. Demographic information included sex, age, residence, marital status, childbearing, occupation, and family income. A pretested questionnaire was administered to consenting pregnant women.

Comment [u2]: Diagnosed case of RB to be mentioned or criteria for inclusion?

Information like age, marital status, and place of residence, educational level, parity, annual income, occupation, awareness and knowledge of Rb will be collected and analyzed.

Data Processing and Statistical Analysis

Results were reported as number (percentage). The relationships of age, gender, marital status, occupation, childbearing, number of children, and family monthly income with women's awareness regarding retinoblastoma were analyzed by chi-square tests.

All statistical analyses were performed using SPSS version 26.0 statistical software IBM Corporation, with a two-sided p -value <0.05 considered statistically significant. All collected data were entered into Excel spreadsheet. The cleaned data was exported to SPSS version 26.0 statistical software IBM Corporation for analysis. Continuous variables were represented using mean, median and standard deviation, while categorical variables were described by frequency and proportion; and presented using tables and figures. It should be able to classify the dependent variable. What constitute a good and bad knowledge should be well outlined. The criteria for making diagnosis should be well outlined. It should be such that any researcher can repeat the study.

Ethical consideration

The study protocol was approved by the Chukwuemeka Odumegwu Ojukwu University Teaching Hospital, Amaku, Awka, Ethics Committee, with approval number: COOUTH/CMAC/ETH.C/Vol.1/FN:04/261. A letter of permission was also obtained from the Management of Grace Specialist Hospital, Onitsha. The confidentiality of the collected data was assured during data collection and anonymity of the study participants were kept during analysis.

RESULTS

Two hundred and forty six women participated in this survey, including 106 and 110 women in each of the two age groups, consisting of women in their 20s, 30s, respectively. Their demographic characteristics are presented in Table 1. Majority (97.2%) of the women were married (97.2%) and traders (37.0%). Majority of the women live in monthly income between 11.31USD and 31.42 USD.

Table 2 shows the participants awareness and knowledge of retinoblastoma, while Figure 1 shows a pie chart showing the knowledge of retinoblastoma. Of the women who participated in this survey, 84.2% reported not having heard of retinoblastoma. The majority heard it via health workers (40.0%), followed by other means (25.0%). However, majority (49.3%) of the participants do not know that retinoblastoma can affect children, while 26.0% do not believe that that it affect children. Also, majority (63.3%) of the participants do not know that retinoblastoma can be inherited from parents, while 24.3% do not believe that that it can be can be inherited from parents.

However, majority (93.9%) of the participants do not know any symptoms or signs of retinoblastoma. Most of the participants do not know any symptom they will observe in the child's eye to suspect that the child has retinoblastoma. Majority (68.2%) do not believe that retinoblastoma can cause any complications.

The participants' knowledge of the presentation and treatment of retinoblastoma is shown in Table 3. When asked on the complications they think a patient with retinoblastoma may have, majority (40.4%) of the participants did not know, while 51.6% believed that retinoblastoma can be diagnosed shortly after birth. Majority (80.9%) of the participants believed that all children should be routinely screened for retinoblastoma before symptoms appear in the eye. Most 86.2% do not know that treatment can be free in any tertiary cancer center, in Nigeria

Table 4 shows the descriptive analysis of knowledge of retinoblastoma. Overall, uninterestingly, poor knowledge were observed in the knowledge of retinoblastoma (84.2%), affects children(91.9%), can be inherited from parents(92.7%), number of eyes usually affected (93.9%), symptoms of retinoblastoma (98.4%), and signs to notice on the child to suspect retinoblastoma (88.2%).

The association between degree of knowledge and socio demographic characteristics of participants is shown in Table 5. Univariable analysis found that the degree of knowledge of retinoblastoma were all associated with occupation of the participants ($p < 0.001$), occupation of the husband ($p = 0.010$), and childbearing ($p = 0.021$). Table 6 shows the multivariate binary logistic regression showing the association between awareness of retinoblastoma and associated risk factors. Multivariate logistic regression analysis identified two variables that might influence

retinoblastoma awareness: occupation (trader) of the husband (adjusted odds ratio (aOR) = 2.63, 95% CI = 1.07-6.49; p=0.035) and childbearing (aOR=5.83, 95% CI = 1.14-9.20; p=0.046).

Table 1: Descriptive analysis of socio demographics.

Variables	Frequency (n=246)	Percentages %
Age		
20-29	106	43.1
30-39	110	44.7
40-49	22	8.9
50-59	7	2.9
60 and above	1	0.4
Gender		
Female	246	100.0
Males	0	0.0
Marital status		
Divorced	1	0.4
Married	239	97.2
Single	6	2.4
Occupation		
Artisan	33	13.4
Business	38	15.4
Civil servant	30	12.2
Not working	15	6.1
Others	2	0.8
Professional	14	5.7
Student	23	9.4
Trader	91	37.0
Occupation of husband (n=76)		
Artisan	10	13.2
Business	2	2.6
Civil servant	7	9.2
Clergy	1	1.3
Others	2	2.6
Trader	54	71.1
Do you have children		
No	46	18.7
Yes	200	81.3
How many children (n=200)		
Four and above	46	23.0
One	72	36.0
Three	37	18.5
Two	45	22.5
Contact with large number of children		

No	15	6.1
Yes	231	93.9
Monthly income (USD)(n=211)		
62.85-125.69	6	2.8
11.31 or less	56	26.5
11.31-31.42	110	52.1
125.69 and above	5	2.4
31.42-62.85	34	16.1

1USD=1591.17Naira. Those 50 years and above got pregnant via IVF.

Table 2: Participants awareness and knowledge of retinoblastoma.

Variables	Frequency (n=246)	Percentages %
Heard about retinoblastoma		
No	207	84.2
Yes	39	15.8
If yes, how (n=20)		
Health worker	8	40.0
Others	5	25.0
Radio/TV and social media	3	15.0
Social media	4	20.0
Does it affect children (n=77)		
Don't know	38	49.3
No	19	24.7
Yes	20	26.0
Can it be inherited from parents (n=226)		
I don't know	143	63.3
No	55	24.3
Sporadic (not familiar)	10	4.4
Yes	18	8.0
How many eyes are usually affected		
Affects one eye only	17	6.9
Can affect both eyes	15	6.1
I don't know	214	87.0
Do you know any signs of retinoblastoma (n=65)		
No	61	93.9
Yes	4	6.1
What are the signs that you may notice on the child's eye to suspect he/she has retinoblastoma? (n=199)		
Redness association with swelling	27	13.6
Deviation of eye	2	1.0
I don't know	148	74.4
Protrusion of the eye	15	7.5
White patch on the black eye	7	3.5
Do you think that the emergence of any of the above signs requires a visit to a doctor as soon as possible		
I don't know	76	30.9
No	27	11.0

Yes	143	58.1
Do think retinoblastoma causes complication (n=66)		
No	45	68.2
Yes	21	31.8

Table 3: Participants' knowledge of the presentation and treatment of retinoblastoma

Variables	Frequency (n=246)	Percentages %
What complications do you think a patient with retinoblastoma may have (n=342)		
Eye removal	101	29.5
Death	7	2.0
I don't know	138	40.4
Severe visual loss or blindness	96	28.1
When can retinoblastoma be diagnosed (n=155)		
At the age of one year or older	48	31.0
Before 1 year of age	27	17.4
Shortly after birth	80	51.6
Do you think that all children should be routinely screened for retinoblastoma before symptoms appear in the eye		
I don't know	26	10.6
No	21	8.5
Yes	199	80.9
If any child was diagnosed to have retinoblastoma do you think it is important to examine all new born in that family		
I don't know	39	15.9
No	26	10.5
Yes	181	73.6
Do you have or know a tertiary cancer center in Nigeria		
I don't know	104	42.3
No	123	50.0
Yes	19	7.7
If there is any tertiary cancer center, is treatment there for free		
I don't know	212	86.2
No	26	10.6
Yes	8	3.2
If you noticed ocular problems with your child, which healthcare provider do you consult		
General practitioner	14	5.7
Ophthalmologist	231	93.9
Optometrist	1	0.4

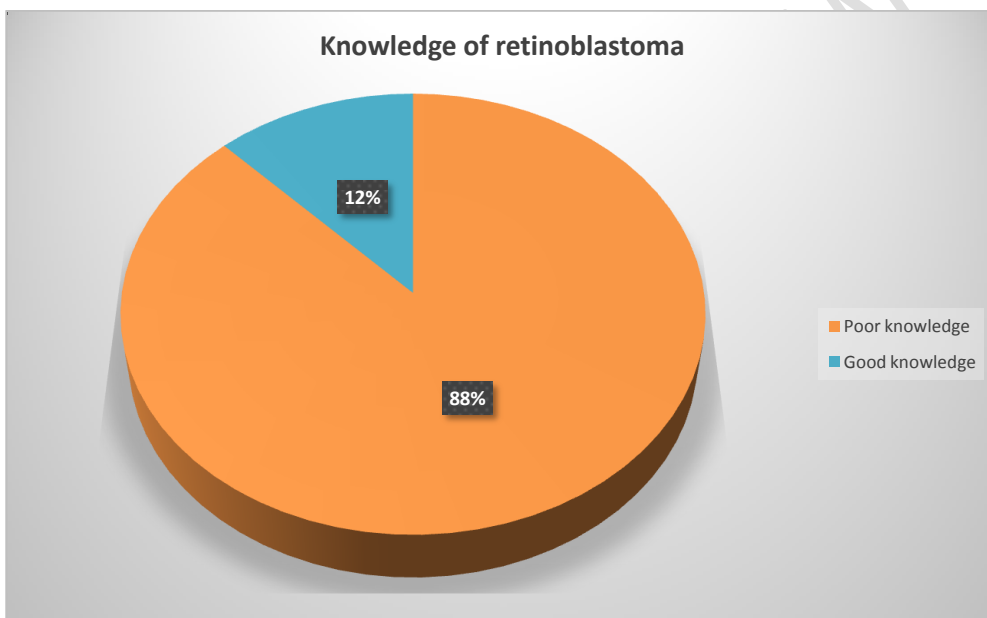


Fig 1: A pie chart showing the knowledge of retinoblastoma.

Table 4: Descriptive analysis of knowledge of retinoblastoma

Variables	Frequency (n=246)	Percentages %
Heard about retinoblastoma		
Good knowledge	39	15.8
Poor knowledge	207	84.2
Does it affect children		
Good knowledge	20	8.1
Poor knowledge	226	91.9
Can it be inherited from parents		
Good knowledge	18	7.3
Poor knowledge	228	92.7
How many eyes are usually affected		
Good knowledge	15	6.1
Poor knowledge	231	93.9
Do you know any signs of retinoblastoma		
Good knowledge	4	1.6
Poor knowledge	242	98.4
Signs that you may notice on the child's eye to suspect he/she has retinoblastoma		
Good knowledge	29	11.8
Poor knowledge	217	88.2
Does the emergence of any of the above signs requires a visit to a doctor as soon as possible		
Good knowledge	143	58.1
Poor knowledge	103	41.9
Do you think retinoblastoma causes complication		
Good knowledge	21	8.5
Poor knowledge	225	91.5
What complications do you think a patient with retinoblastoma may have		
Good knowledge	108	43.9
Poor knowledge	138	56.1
When can retinoblastoma be diagnosed		
Good knowledge	128	52.0

Poor knowledge	118	48.0
Do you think that all children should be routinely screened for retinoblastoma before symptoms appear in the eye		
Good knowledge	199	80.9
Poor knowledge	47	19.1
If any child was diagnosed to have retinoblastoma do you think it is important to examine all new born in that family		
Good knowledge	181	73.6
Poor knowledge	65	26.4
If you noticed ocular problems with your child, which healthcare provider do you consult		
Good knowledge	231	93.9
Poor knowledge	15	6.1

Table 5: Association between degree of knowledge and socio demographic characteristics of participants

Socio demographics vs	Degree of knowledge		X ²	p-value
	Good knowledge	Poor knowledge		
Age				
20-29	8 (26.7)	98 (45.4)		
30-39	18 (60.0)	92 (42.6)	4.133	0.388
40-49	3 (10.0)	19 (8.8)		
50-59	1 (3.3)	6 (2.8)		
60 and above	0 (0.0)	1 (0.5)		
Gender				
Female	30 (100.0)	216 (100.0)	-	-
Males	-	-		
Marital status				
Divorced	0 (0.0)	1 (0.5)		
Married	28 (93.3)	211 (97.7)	2.693	0.260
Single	2 (6.7)	4 (1.8)		
Occupation				
Artisan	2 (6.7)	31 (14.4)		
Business	1 (3.3)	37 (17.1)		
Civil servant	5 (16.7)	25 (11.5)		
Not working	1 (3.3)	14 (6.5)	28.416	<0.001*
Others	0 (0.0)	2 (0.9)		
Professional	7 (23.3)	7 (3.2)		
Student	0 (0.0)	23 (10.7)		
Trader	14 (46.7)	77 (35.7)		
Occupation of husband (n=76)				
Artisan	1 (6.2)	9 (15.0)		
Business	2 (12.5)	0 (0.0)		
Civil servant	3 (18.8)	4 (6.7)	15.145	0.010*
Clergy	1 (6.2)	0 (0.0)		
Others	0 (0.0)	2 (3.3)		
Trader	9 (56.3)	45 (75.0)		
Do you have children				
No	1 (3.3)	45 (20.8)	5.306	0.021*
Yes	29 (96.7)	171 (79.2)		
How many children (n=200)				
Four and above	9 (31.0)	37 (21.6)		
One	8 (27.6)	64 (37.4)	1.688	0.640
Three	5 (17.2)	32 (18.7)		
Two	7 (24.1)	38 (22.2)		
Contact with large number of children				
No	1 (3.3)	14 (6.5)	0.455	0.500
Yes	29 (96.7)	202 (93.5)		

Monthly income(USD) (n=211)				
62.85-125.69	0 (0.0)	6 (3.3)		
11.31 or less	3 (10.0)	53 (29.3)	7.976	0.092
11.31-31.42	20 (66.7)	90 (49.7)		
125.69 and above	0 (0.0)	5 (2.8)		
31.42-62.85	7 (23.3)	27 (14.9)		

1USD=1591.1 naira

Table 6: Multivariate binary logistic regression showing the association between awareness of retinoblastoma and associated risk factors

Associated factors	Adjusted Odds Ratio	95% Confidence Interval (lower-upper)	P-value
Occupation of woman			
Artisan	1.0	-	-
Business	3.46	(0.09-34.65)	0.621
Civil servant	1.91	(0.16-14.98)	0.219
Not working	2.85	(0.18-19.83)	0.808
Others	2.77	(0.58-1.07)	0.311
Professional	1.01	(0.96-1.05)	0.552
Student	4.92	(1.86-7.99)	0.091
Trader	1.87	(0.45-2.65)	0.053
Occupation of husband			
Artisan	1.0	-	-
Business	0.97	(0.20-4.75)	0.978
Civil servant	2.01	(0.54-7.31)	0.295
Clergy	1.21	(0.18-5.28)	1.000
Others	0.51	(0.02-2.19)	0.627
Trader	2.63	(1.07-6.49)	0.035*
Presence of children			
No	1.0	-	-
Yes	5.83	(1.14-9.20)	0.046*
Age group (years)			

20-29	1.0	-	-
30-39	1.67	(0.12-8.92)	0.213
40-49	0.86	(0.36-2.05)	0.743
50-59	2.21	(0.44-6.81)	0.330
60 and above			
Marital status			
Divorced	1.0	-	-
Married	1.86	(0.36-8.05)	0.912
Single	1.21	(0.94-4.81)	0.371
Monthly income			
Less than 18,000 (ref)	1.0		-
18,000-49,999	2.97	(0.20-9.75)	0.291
50,000-99,999	1.01	(0.54-7.31)	0.295
100,000-199,999	2.21	(0.18-5.28)	0.819
200,000 and above	3.51	(0.02-2.19)	0.921

(ref) - reference category, Associated risk factors included in the model at p -value <0.05 , controlled for age, marital status, and monthly income.

Discussion

The current study shed light on Nigerian pregnant women's knowledge of retinoblastoma and its contributing factors. In the current study, 84.2% of pregnant women in Nigeria who participated in the survey said they were unaware about retinoblastoma. It is noteworthy that most participants learned about retinoblastoma via medical professionals, despite the fact that most are unaware that the disease can be inherited from parents or impact children. A multivariate analysis revealed a correlation between the participants' level of retinoblastoma awareness and their husband's occupation (trader) and having children.

Just 15.8% of the pregnant women in this study were aware of retinoblastoma. This contradicts earlier research conducted in Western nations [3, 17]. This is significantly less than the 29.8% found in a previous study conducted by Naser et al. [3] in three Arab countries (Iraq, Jordan, and Saudi Arabia) that evaluated healthcare professionals' and the general public's knowledge of retinoblastoma in terms of presentation, risk factors, diagnosis timing, and complications. Contrarily, a recent study by Elfalah et al. that examined the effects of changing the curriculum for teaching medical students about retinoblastoma awareness revealed that, despite the fact that most of them had significantly less knowledge about the disease's diagnosis, the majority of them scored higher on important questions like knowing that retinoblastoma is a fatal illness that requires immediate treatment [17].

The degree of knowledge about retinoblastoma in this study was found to be correlated with the participants' husband's occupation, and childbearing; however, it was not impacted by age, marital status, childbearing, and number of children, family monthly income, or the husband's occupation. However, a prior study by Naser et al. [3] found that participants who were older than 50, married, had completed secondary education, were employed as professionals in the industry, had more than four children, and stated that they did not have frequent contact with children were less likely to be aware of the symptoms, risk factors, timing of diagnosis, and complications associated with retinoblastoma.

The current study did, however, also shed light on how little our study population knows and understands about retinoblastoma. People are typically unaware of the danger of eye cancer because it is a rare disease. Raising awareness about retinoblastoma is a noble endeavour, and all

medical and nursing staff should give special consideration to any eye ailment. Attempts ought to focus on raising retinoblastoma awareness among the general public and medical professionals [3]. In order to promote early diagnosis of retinoblastoma, policymakers must raise public awareness of the condition, undertake awareness campaigns, enhance healthcare practitioners' screening abilities, and provide them with appropriate screening and diagnostic resources [3].

As far as we are aware, this study is the first to evaluate Nigerian pregnant women's awareness of retinoblastoma. However, this study had a number of drawbacks, such as the manual data gathering method that only allowed those who were physically there to participate. In order to ascertain pregnant women in Nigeria's true awareness of retinoblastoma, future studies may employ random sampling. Although knowledge has not been strongly associated to the occurrence of retinoblastoma in childhood, follow-up studies could offer longitudinal data and investigate the relationship between real knowledge of retinoblastoma and infant's retinoblastoma. By increasing knowledge about retinoblastoma, more women may inform doctors and ophthalmologists about the risks associated with the disease in young patients.

CONCLUSION

Nigerian pregnant women had appallingly low levels of awareness and information of retinoblastoma during pregnancy. There was a correlation between the participants' level of knowledge about retinoblastoma and their husband's occupation, and having children. Finding out how much information Nigerian women know about retinoblastoma might help us better understand how common it is and how it affects both the health of women and their unborn

children. These results could lead to improved ophthalmic practices and the development of successful public health programmes, ultimately benefiting the health of Nigerian pregnant women and children. It will take more research to examine this connection.

Ethical Statement

Ethical approval was obtained from the Chukwuemeka Odumegwu Ojukwu University Teaching Hospital, Awka, with identification number COOUTH/CMAC/ETH.C/VOL.1/FN:04/261.

. Permission letter was granted from the authority of Grace Specialist Hospital Onitsha, Nigeria.

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UNDER PEER REVIEW

