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LEVEL OF AWARENESS AMONG PARENTS AND GUARDIANS ABOUT USHER SYNDROME AND DEAF-BLINDNESS IN LAGOS STATE, NIGERIA

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ABSTRACT

Introduction: Researches have shown that usher syndrome is the leading genetic etiology of congenital deafness combined with progressive vision loss (Deaf-blindness), most parents and guardians of learners with this condition in Nigeria are not of aware that this.
Purpose: This study investigates parents' level of aware of usher syndrome and Deaf-blindness in Lagos State, Nigeria.
Methodology: The study adopted a survey research design of the ex-post facto type. A total of twenty (28) parents/guidance of leaners with deaf-blindness in the 20 Local Government Areas of the State participated in the survey. A self-structured research instrument titled Parents Awareness About Usher Syndrome Scale (PAUSS) was used for data collection. Two (2) research questions were raised to guide the study. Data were analysed using frequency count/percentage and Pearson Product Moment Correlation Coefficient.
Results: Parents and guardians of leaners with Deaf-blindness are not aware of Usher Syndrome as a cause of deaf-blindness 23(82.1%). Also, parents and guardians of learners with Deaf-blindness have low awareness of genetic testing/counseling 21(75.0%).
Conclusion: This study has been able to establish that parents and guardians of learners with deaf-blindness in Lagos state are not aware of the term usher syndrome let alone aware that usher syndrome is the leading cause of Deaf-blindness.
Recommendation: It was recommended among other that parents and guardians of persons with Deaf-blindness should be educated on the causes and prevention of Usher Syndrome and other causes of Deaf-blindness with a view to reducing the incidence of the dual disability in Lagos state and the nation as a whole and that there should be intensive training workshops to equip parents/guidance, other stakeholders and the general public with the knowledge of genetic counseling for the prevention of usher syndrome and Deaf-blindness.

Keywords: Deaf-blindness, usher syndrome, deafness, blindness, parents, awareness, guardians

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PUBLIC INTEREST STATEMENT

This study would expose parents and guardians on the medical condition known as Usher Syndrome as the leading genetic cause of Deaf-blindness. It would sensitize government officials and health policy makers on the need to create awareness on the prevention and management of Usher Syndrome.

INTRODUCTION

Deaf-blindness is a condition in which there is a combination of visual and hearing impairment that causes such a severe communication and other developmental and learning needs that the person(s) cannot be appropriately educated in special education programs designed solely for children and youth with hearing impairment, visual impairment or severe disabilities, without supplementary assistance to address their additional educational needs arising as a result of these dual concurrent disabilities. Persons with Deaf-blindness cannot see themselves or hear the sounds they produce with any part of their bodies- voices, clapping hands or footsteps. This inability to perceive themselves in any other way except with their tactile sense lowers their ability for body awareness, body image, and self-worth. Their inability to participate in the normal activities with their peers with single or no disabilities result in their being avoided and isolated by such peers as they are regarded as strange persons and burdensome to carry along. These factors cause a lot of emotional and psychological distress for such people. Persons with Deaf-blindness tend to become depressed, feel unwanted, and develop withdrawal syndrome, poor self-concepts and very poor social skills. This pathetic situation places the physical and socio-emotional well-being of the affected individuals at risk, and this in turn adversely affects their ability to engage and excel in everyday activities at home, in school and in the larger society.

Etiologies of deaf-blindness across age groups include prenatal infection, prematurity, age-related causes, and genetic causes, with heritable causes estimated to be responsible in 27% of affected individuals (Wittich, Southall, Sikora, Watanabe & Gagné, 2012). Other genetic syndromes significantly affecting hearing and vision include CHARGE syndrome, Heimler syndrome, Norrie's disease, OPA1 variants, Kearns–Sayre syndrome (KSS), Alström syndrome, EXOSC2 variants, and CEP78 variants, among others (Wangtiraumnuay, Alnabi, Tsukikawa, Thau, Capasso, Sharony, Inglehearn, & Levin, 2018). In one study of hard of hearing and deaf children, 11.3% had one or two pathogenic USH alleles, although in the affected individuals with a single allele a second allele was not always identified (Kimberling, Hildebrand, Shearer, & Jensen, 2010). In a separate study of deaf-blind Canadian individuals aged from infancy to 105 years old, 20.9% of instances were attributable to USH based on clinical diagnosis (Wittich et al. 2012).

Deaf-blindness is most often caused by a rare genetic disorder- Usher Syndrome, a heritable, autosomal recessive deafness in the presence of typical features of retinitis pigmentosa. According to Shekerinov, Dashtevska, and Ivanova (2020) stated that Usher Syndrome is a rare syndrome, which typical expressions are hearing loss, retinitis pigmentosa and in some cases impairment of balance and congenital cataract. It is inherited autosomal recessive. Nine genes whose mutations are associated with this condition have been isolated. It is diagnosed on the basis of clinical and genetic testing. The eponym for the condition has been credited to Charles Usher who in 1914 described two variants of the condition. However, the first description of this syndrome was by Albrecht von Graefe in 1858. Clinically, Usher syndrome is grouped into 3 major categories namely, types 1,2 and 3, with types 1 and 2 being most common. Type 1 is associated with congenital profound deafness, speech impairment, vestibular symptoms and childhood-onset retinopathy. Type 2 presents with non-progressive deafness and later onset retinopathy; there are no vestibular symptoms. Type 3 is also associated with non-progressive deafness, adult-onset retinopathy and hypermetropic astigmatism (Friedman, Schultz, Ahmed, Tsilou, & Brewer 2011; Khateb, Kowalewski, & Bedoni, 2018). The Hallgren syndrome is regarded by some authorities as the fourth variety of Usher syndrome; however other researchers feel that it is part of type 1 Usher Syndrome. Features of Hallgren syndrome include congenital progressive. deafness, ataxia and retinopathy (Gregory-Evans, Pennesi & Weleber, 2013).

While reports from developed countries suggest a prevalence of 1:6000, in the absence

of community-based studies, the prevalence of Usher disease in Nigeria is not known. This preventable condition currently affects three major senses in a person's body- hearing, vision and balance, resulting in severe difficulties which impacts the health and general wellbeing of the affected individuals as well as the development of socio-emotional deviations and disorders such as depression, isolation, inferiority complex, low self-esteem, aggression, social skills deficits, fear, frequent outbursts of anger, anxiety, withdrawal syndrome, suicidal tendencies and a high mortality rate. This, coupled with the current mass ignorance about the condition, leads to a sheer wastage of manpower that would be harnessed to enhance national growth and development; and further reduces the standard of living for affected individuals and their families. However, research reports on Usher syndrome in Africa generally are scanty.

According to Nwosu, Ndulue, Ndulue and Uba-obiano (2022), stated that reports from other parts of Africa also suggest a very low prevalence of Usher syndrome – the *raison d'etre* for publishing single case reports. While in the Cameroon it was suggested that Usher syndrome may be a cause of syndromic hearing loss, reports from Mauritania5 and Algeria10 point at consanguinity as an important predisposing factor. In Nigeria, the first report of presumed Usher Syndrome was made about a child by McMoli and Ijaduola in 1981. Abah, Oladigbolu, Samaila, Merral, Ahmed and Abubakar (2011), in a study of students in a special school for the deaf in Kaduna, Nigeria reported that 4 out of 620 students had presumed Usher Syndrome. Nwosu, Ndulue, Ndulue and Uba-Obiano, (2022) also reported that only 2 patients with Usher syndrome were recorded among 37 patients with retinitis pigmentosa seen over a 6-year period. To the best knowledge of these researchers, in all, there are only seven (7) reports of suspected cases of Usher Syndrome in Nigeria published over a 40 years period.

Researches have established the fact that Usher syndrome, clinically and genetically heterogeneous, is the leading genetic cause of combined hearing and vision loss Kimberling, Hildebrand, Shearer and Jensen et al (2010); Machur and Yang (2014). Confirming this, Pater, Green, O'Rielly and Griffin, (2019) stated that usher syndrome is the most common form of inherited deaf-blindness. However, most persons in Nigeria including parents of learners with Deaf-blindness and teachers of learners with hearing impairment and those for the visual impairment who have learners with deaf-blindness in their classroom may not be aware that usher syndrome is the most common form of inherited deaf-blindness. Zurynski, Deverell, and Dalkeith (2017) found that parents and guardians of children with rare conditions report not being connected to appropriate support services, increased burden on the child (and/or their families) to educate their healthcare team, and reduced confidence in clinicians' abilities to provide effective therapy and treatment. As a result, individuals and their families may experience significant psychosocial distress, a lack of support, poor quality of life and reduced capacity to self-advocate (Lopez-Bastida, Oliva-Moreno, Linertova & Serrano-Aguilar, 2016). Parents and carers may also be impacted due to the significant burden of coordination of care required for their child while managing their own grief about the uncertainty of their child's future (Ayton, Galvin, Johansen, O'Hare, and Shapard, 2023).

Medina, Perry, Oza and Kenna (2021) averred that usher syndrome is the leading genetic etiology of congenital deafness combined with progressive vision loss. However, parents may be ignorant of genetic aspects of deaf blindness, neither do they consider genetic testing and counseling before marriage. Advancements in genetic testing have led to Usher syndrome now being diagnosed at a much earlier ages than in the past. This has created an enormous opportunity to provide early interventions to young children before the onset of vision loss, with the goal of giving families and children the skills and capacity to thrive throughout their lives. Despite these developments, many parents of persons with Deaf-blindness in Nigeria seem to know next to nothing as to the genetic testing, in terms of Usher Syndrome and Deaf-blindness.

Study by Ayton, Galvin, Johansen, and O'Hare (2023) assessed awareness of Usher Syndrome amongst allied health clinicians who provide care related to the primarily affected senses of hearing and vision, i.e, optometry, orthoptics and audiology. A prospective cross-sectional online survey of clinicians working in Australian university-affiliated clinics (7 optometry, 1 orthoptics and 4 audiology) was completed between September 2021 and January 2022. Questions were asked about the cause, common symptoms, and awareness of

health professions who manage Usher syndrome. The results revealed that the 27 audiologists, 40 optometrists, and 7 orthoptists who completed the survey included 53 females (71.6%), had an average age of 37 years (range 24-70), and had an average duration of clinical experience of 13 years (range 1-45 years). The majority of respondents correctly identified Usher syndrome as a genetic condition (86%), identified at least two of the affected senses (97%), and identified the progressive nature of the vision and hearing losses (>90%). Awareness of vestibular dysfunction and its characteristics was low, as was knowledge of the key treatment roles that speech pathologists, genetic counselors and geneticists play in the management of Usher Syndrome. The majority of respondents also did not identify important aspects of care within their own discipline. Finding the true etiology of an individual's hearing and visual loss frequently requires genetic testing given similarities in clinical phenotypes across distinct forms of deaf-blindness in children. Furthermore, pinpointing an accurate genetic diagnosis will allow access to clinical trials of genetic therapies as they develop (Pan, Askew, Galvin, Heman-Ackah, Yukako, Indzhykulian, Jodelka, Hastings, Lentz, & Vandenberghe, 2017).

STATEMENT OF THE PROBLEM

Usher syndrome, the most common cause of inherited deaf-blindness, is unlike many other forms of syndromic hereditary hearing loss. Persons with Usher syndrome who are either born deaf or become deaf at an early age also experience vision loss due to progressive retinitis pigmentosa that can become obvious any time from the second decade and lead to legal blindness in their third or fourth decade, making diagnosis difficult due to the subtle changes in visual function over time. This condition results in a reduced ability or total inability to make use of the sense of of vision and hearing. Unfortunately, the incidence of this devastating condition has been reported to be on the rise in Africa and Asia due to mass ignorance among parents and a severe lack of genetic testing and counseling that would enhance prevention. In Nigeria most parents of learners with deaf-blindness may not be aware that usher syndrome is the most common form of inherited/cause of deaf-blindness. These parents may also be ignorant of genetic aspects of deaf blindness, neither do parents consider genetic testing and counseling before marriage. This situation inadvertently places the health of generation yet unborn at risk of contracting the condition as well. This problem propelled the desire for this study which examined the level of awareness among parents about Usher Syndrome in Lagos state, Nigeria.

PURPOSE OF THE STUDY

1. To examine the extent to which parents and guardians of children with Deaf-blindness are aware of Usher Syndrome as a cause of Deaf-blindness in Lagos state.
2. To determine the level of parents and guardians of children with Deaf-blindness awareness of the need for genetic testing and counseling.

RESEARCH QUESTIONS

1. To what extent are parents and guardians of children with Deaf-blindness aware of Usher Syndrome as a cause of Deaf-blindness in Lagos state?
2. To what extent are parents and guardians of children with Deaf-blindness aware of the need for genetic testing and counseling?

METHODOLOGY

Research Design

A descriptive survey research design of the *expo facto* type was used in this study. The study presents a description of event as they occur.

Population and Sample

The population for this study comprised all parents and guardians of persons with Deaf-blindness in Lagos State, Nigeria. Twenty-eight (28) parents and guardians of persons with deaf-blindness were randomly selected for the study in Lagos State and/or reached via media awareness broadcasts. This is due to the fact that the population of parents and guardians of Deaf-blindness are limited compared to persons with a single disability of either hearing or visual impairment. Purposive sampling technique was used to select eighteen (18) special and mainstream schools in Lagos State and/or reached via media awareness broadcasts.

Instrument for Data Collection

The instrument used for this survey is the Parents Awareness About Usher Syndrome Scale (PAUSS). The instrument was self-structured by the researchers with 15 question statements designed to assess the level of awareness about Usher Syndrome and genetic counseling. Specifically, information were elicited in the following areas of awareness: causes of their child deaf-blindness, awareness of causes of Deaf-blindness, medical consultation, awareness of genetic counseling, genetic test and so on. A nominal scale of YES/NO response is elicited from each of the question items. The PAUSS was given to experts in department of special education for face and content validity. Moreover, for content validity of the test, a test blue print was drawn for the items. The instrument was administered to ten (10) parents of students with hearing impairment and 10 parents of those with visual impairment to ensure the reliability of the test. The scores was analysed using analysis of test items measuring the difficulty level and discrimination power. The approach of upper 25% and lower 25% was use for the computation of the discrimination index. For the difficulty index, each test item was computed by dividing the number of testee that gets the item right by the number of testee that takes the test item. The discrimination index for each item was computed by subtracting the upper group score form that of the lower group score and result was divided by the number of testee in the upper or lower group. Using the Cronbach Alpha the reliability of was determined and it was therefore found to be reliable at 0.72.

Procedure for Data Collection

Preliminary visits were made to the selected schools for learners with visual and school s for those with hearing impairment for the study. The purpose of the visits to these schools was to submit the letter of ethical approval from the office of the State Commissioner for Education to carry out the study and to be familiar with the school authorities. They were also intimated with the significance of the study. The research team also explained that there was no possibility of risks to the participants, as anonymity and confidentiality were guaranteed and maintained. At the same time, research team proceeded to identify the learners with both vision and hearing impairment in each school and got their and/or their parents and guardians contacts. Awareness talk-shows were conducted on Radio Lagos and Lagos Television with a view to reach individuals with Deaf-blindness who are presently out of school and/or their family members with our contact details so as to include them in the survey. Next, the team visited the parents and guardians of these leaners with Deaf-blindness so they could respond to the Parents Awareness about Usher Syndrome Scale (PAUSS) in the presence of their children/wards with Deaf-blindness.

Ethical Considerations

Prior to the data collection a letter of ethical approval to carry out the survey in special and mainstream schools in Lagos State was obtained from the office of the State Commissioner for Education.

Method of Data Analysis

The data analysis for this study was carried out using descriptive statistics of frequency count and percentage was used to explain the socio-demographic information of the respondents while t-test was used to test the level of awareness.

RESULTS

Research Question 1: To what extent are parents and guardians of children with Deaf-blindness aware of Usher Syndrome as a cause of Deaf-blindness in Lagos state?

Table 1: Awareness of Usher Syndrome by parents of children with Deaf-blindness

Have you ever heard of ever heard of Usher Syndrome	Frequency	Percentage
No	23	82.1
Yes	5	17.9
Total	28	100.0

Table 1 showed that 23(82.1%) respondents are not aware of Usher Syndrome,

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and 5(17.9%) are aware of the Usher Syndrome. Hence, there is a low extent of awareness among parents of children with Deaf-blindness about Usher Syndrome in the study.

Fig. 1: Pie chart showing the awareness status of usher syndrome by parent with deaf-blindness children

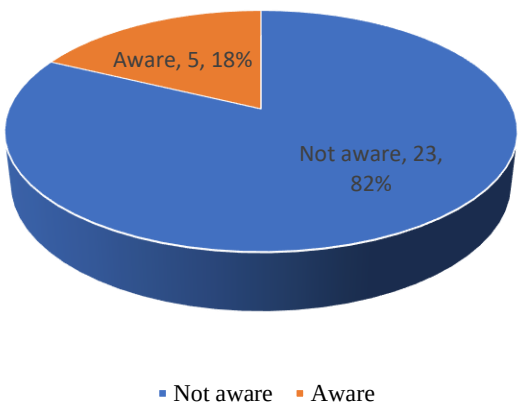

Table 2: Test of norm showing the extent of awareness of Usher Syndrome as a cause of Deaf-blindness in Lagos state among parents of children with Deaf-blindness

Interval	Mean index	Extent of awareness	Frequency	Percentage
0-14	12.3900			
15-28		Low	22	78.6
		High	6	21.4

Table 2 showed the percentage extent of awareness of Usher Syndrome as a cause of Deaf-blindness in Lagos state among parents and guardians of children with Deaf-blindness. 78.6% (n=22) parents had a low extent of awareness, and 21.4% (n=6) had a high extent of awareness. Hence, there is a low extent of awareness of Usher Syndrome as a cause of Deaf-blindness in Lagos state among parents and guardians of children with Deaf-blindness in the study.

In order to ascertain the extent of awareness of Usher Syndrome as a cause of Deaf-blindness in Lagos state among parents and guardians of children with Deaf-blindness, the test of norm was conducted. There are 7 items in the scale that was used to measure awareness of usher syndrome; the 7 items were multiplied with the four measures which gives a score of 28. The division of 28 by 2 (High, and Low) equals 14. Thus, 0-14 indicates that the extent of awareness of the respondent is low, and the scale between 15-28 signifies that the extent of awareness of the respondents is high. The overall mean score is 12.39 which fall between the scales "0-14" indicates that the extent of awareness is of the respondents is low.

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Fig. 2: Pie chart showing the extent of awareness of usher syndrome as a cause of deaf-blindness among Parents of children with deaf-blindness

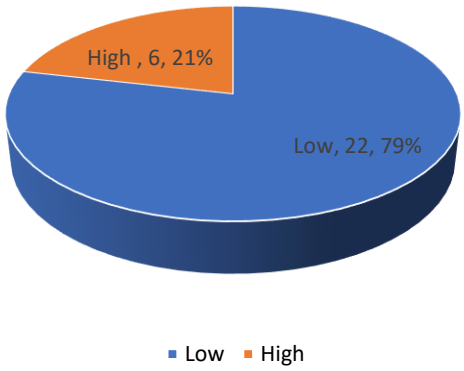

Table 3: Independent t-test showing the difference in the extent of awareness of Usher Syndrome as a cause of Deaf-blindness among male and female parents of children with Deaf-blindness

Awareness of Usher Syndrome	N	Mean	Std. Dev.	Crit-t	Cal-t.	Df	p value
Male	10	11.1824	3.41982	1.96	-.997	26.	320
Female	18	12.0134	2.59826				

Table 3 showed that there is no significant difference in the extent of awareness of Usher Syndrome as a cause of Deaf-blindness among male and female parents and guardians of children with Deaf-blindness (Crit-t = 1.96, Cal.t = -.997, Df = 26, p(0.320)>0.05 level of significance). Hence, female parents did not significantly have a higher form of awareness about usher syndrome than their male counterparts in the study.

Research Question 2: To what extent are parents and guardians of children with Deaf blindness aware of the need for genetic testing and counseling?

Table 4: Awareness on the Need for Genetic Testing and Counseling

Have you ever gone for Genetic Testing/Counseling	Frequency	Percentage
No	21	75.0
Yes	7	25.0
Total	28	100.0

Table 4 showed that 21(75.0%) respondents have not gone for genetic testing/counseling, and 7(25.0%) have gone for genetic testing. Hence, there is a low extent of awareness among parents and guardians of children with Deaf-blindness about genetic testing/counseling in the study.

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Table 5: Test of norm showing the extent of awareness for the need of genetic testing and counseling among parents of children with Deaf-blindness

Interval	Mean index	Extent of awareness of genetic testing	Percentage	Frequency
0-14	13.3412			
15-28		Low	85.7	24
		High	14.3	4

Table 5 showed the percentage extent of awareness for the need of genetic testing and counseling among parents and guardians of children with Deaf-blindness 85.7% (n=24) parents and guardians had a low extent of awareness, and 14.3% (n=4) had a high extent of awareness. Hence, there is a low extent of awareness of awareness for the need of genetic testing and counseling among parents of children with Deaf-blindness in the study.

Fig. 3: Pie chart showing the extent of awareness for the need of genetic testing and counseling among parents of children with deaf-blindness

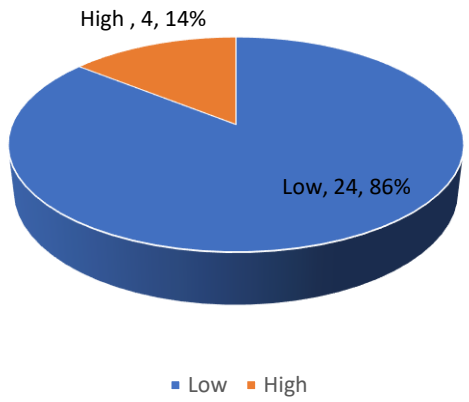

Table 6: Independent t-test showing the difference in the extent of awareness for the need of genetic testing and counseling among parents of children with Deaf-blindness

Awareness of Genetic Testing	N	Mean	Std. Dev.	Crit-t	Cal-t.	Df	p value
Male	10	12.3716	2.1292	1.96	-.631	26	534
Female	18	11.2387	2.1486				

Table 6 showed that there is no significant difference in the extent of awareness for the need of genetic testing and counseling among parents and guardians of children with Deaf-blindness (Crit-t = 1.96, Cal.t = -.631, Df = 26, p(0.534)>0.05 level of significance). Hence, female parents did not significantly have a higher form of awareness for the need of genetic testing and counseling than their male counterparts in the study.

DISCUSSIONS

Awareness of Usher Syndrome by Parents of Children with Deaf-blindness

The findings revealed that there is no significant difference in the extent of awareness of Usher Syndrome as a cause of

Deaf-blindness among male and female parents and guardians of children with Deaf-blindness. Hence, female parents did not significantly have a higher form of awareness about usher syndrome than their male counterparts in the study. The test of norm show a low extent of awareness of Usher Syndrome as a cause of Deaf-blindness in Lagos state among parents and guardians of children with Deaf-blindness in the study. Literature on parents and guardians awareness of Usher Syndrome as a cause of Deaf-blindness is sparse. However, the finding of the present study is in consonance with that of Zurynski, Deverell, and Dalkeith (2017) who found that parents and guardians of children with rare conditions report not being connected to appropriate support services, increased burden on the child (and/or their families) to educate their healthcare team, and reduced confidence in clinicians' abilities to provide effective therapy and treatment. As a result, individuals and their families may experience significant psychosocial distress, a lack of support, poor quality of life and reduced capacity to self-advocate (Lopez-Bastida, Oliva-Moreno, Linertova, Serrano-Aguilar, 2016). Parents and carers may also be impacted due to the significant burden of coordination of care required for their child while managing their own grief about the uncertainty of their child's future (Ayton, Galvin, Johansen, O'Hare & Shapard, 2023).

Awareness on the Need for Genetic Testing and Counseling

The findings indicated that there is no significant difference in the extent of awareness for the need of genetic testing and counseling among parents and guardians of children with Deaf-blindness. Hence, female parents did not significantly have a higher form of awareness for the need of genetic testing and counseling than their male counterparts in the study. This implies that parents and guardians of children with Deaf-blindness are not aware of the need for genetic counseling and counseling. This findings is in line with the finding of study by Ayton, Galvin, Johansen, and O'Hare (2023) assessed awareness of Usher Syndrome amongst allied health clinicians who provide care related to the primarily affected senses of hearing and vision, optometry, orthoptics and audiology. The results revealed that awareness of vestibular dysfunction and its characteristics was low, as was knowledge of the key treatment roles that speech pathologists, genetic counselors and geneticists play in the management of Usher Syndrome. The majority of respondents also did not identify important aspects of care within their own discipline. However, majority of respondents correctly identified Usher syndrome as a genetic condition (86%), identified at least two of the affected senses (97%), and identified the progressive nature of the vision and hearing losses (>90%).

Kimberling, Hildebrand, Shearer and Jensen et al (2010); Machur and Yang (2014) stated that Usher syndrome, clinically and genetically heterogeneous, is the leading genetic cause of combined hearing and vision loss. Also, Pater, Green, O'Rielly and Griffin, (2019) stated that usher syndrome is the most common form of inherited deaf-blindness. Most persons in Nigeria including parents of learners with deaf-blindness are not aware that usher syndrome is the most common form of inherited deaf-blindness. Medina, Perry, Oza and Kenna (2021) averred that usher syndrome is the leading genetic etiology of congenital deafness combined with progressive vision loss. However, parents are ignorant of genetic aspects of deaf blindness, neither do parents consider genetic testing and counseling before marriage. Advancements in genetic testing have led to Usher syndrome now being diagnosed at a much earlier ages than in the past. This has created an enormous opportunity to provide early interventions to young children before the onset of vision loss, with the goal of giving families and children the skills and capacity to thrive throughout their lives. Despite these developments, many parents of persons with Deaf-blindness in Nigeria seem to know next to nothing as to the genetic testing, in terms of Usher Syndrome and Deaf-blindness.

CONCLUSION

This study has been able to establish that parents and guardians of learners with deaf-blindness in Lagos state are not aware of the term usher syndrome as an issue let alone aware that usher syndrome is the common cause of Deaf-blindness. Also, there is a low extent of awareness among these parents and guardians of learners with deaf-blindness about genetic testing/counseling before marriage. The findings of this study can produce the seeds of heart-warming developments if it provokes the initiation of schemes and

programs that would enhance a better understanding Usher syndrome as the leading etiology of Deaf-blindness by all stakeholders with a view to ensuring. It is this awareness that will spark off efforts at preventing and management of Usher Syndrome and other causes of Deaf-blindness with a view to reducing the incidence of the dual disability in Lagos state and the nation as a whole. The study also shows that most parents and guardians are not aware of genetic counseling as most of them are within the low-income class and not educated. The study is a new revelation in the field of special education especially in deaf-blindness research because the findings of this study have added to the existing data on deaf-blindness in Nigeria and collection of data bank.

RECOMMENDATIONS

On the basis of the findings and general experience in the course of the study, the following recommendations are hereby made:

1. Parents and guardians of persons with Deaf-blindness should be educated on the causes and prevention of Usher Syndrome and other causes of Deaf-blindness with a view to reducing the incidence of the dual disability in Lagos state and the nation as a whole.
2. There should be intensive training workshops to equip parents and guardians, other stakeholders and the general public with the knowledge of genetic counseling for the prevention of usher syndrome and Deaf-blindness.
3. There is the need for massive awareness campaign to reach individuals with Deaf-blindness who are hidden in their homes by their family members with the wrong notion that they cannot live meaningful and productive lives with their twin disability.
4. The Lagos State Office for Disability Affairs, in conjunction with the Ministry of Education, should design a scheme that would enhance the training of the first interveners and specialists in the education of individuals with Deaf-blindness in Lagos State and the nation.

Conflict of Interest

The authors declare that there is no conflict of interest.

Acknowledgement

We wish to acknowledge the immeasurable contributions of the Disability Rights Fund to the actualization of this project for the benefit of individuals with Deaf-blindness in Nigeria who had been extremely marginalized all over the nation until the present day.

Disclaimer Statement

This is an original work they carried out by the authors as parts of advocacy efforts for Nigerians with Deaf-blindness which has not been previously published. The results thereof are based on the views and experiences of the participants.

Authors Bio-note

Solomon Olakunle OKELOLA is the Founding Executive Director of Lionheart Ability Leaders International Foundation (LALIF), a non-governmental organization in Nigeria for people with disability. He is a graduate of Department of Special Education, University of Ibadan, Ibadan, Oyo State where he bagged Bachelor in Education (Special Education) and Master Degree in Special Education and Rehabilitation Science, University of Ibadan, Ibadan, Oyo State. As an individual with Deaf-blindness, he strong advocates for early detection of Usher Syndrome, the world's leading etiology of Deaf-blindness and more training and awareness in the mainstream schools.

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Authors' Level of Contributions

Friday Ovie Azanor did the final proof reading, editing and presentation of the article in the format required by the publisher. reviewed and updated the literature of this work in the form it is published and assisted in discussion of findings.

Solomo Olakunle Okelola was involved in the proof reading and editing of the work. He also assisted with collection of letter of ethical approval from the office of the Lagos State Commissioner for Education. Both authors were involved in conceptualization and data collection.

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