



Pathways to Care for Children with Mental Disorders and Epilepsy Attending Specialist Clinics in Nigeria

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Authors' contributions

This work was carried out in collaboration among all authors. Authors TB - A and AA designed the study, performed the statistical analysis, wrote the protocol and wrote the first draft of the manuscript. Authors IL and OO managed the analyses of the study. Author AA managed the literature searches. All authors read and approved the final manuscript.

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ABSTRACT

Aims: This study set out to identify and compare the pathways to care for children and adolescents presenting at child psychiatry and paediatric neurology clinics in South West Nigeria.

Study Design: This was a comparative cross sectional study.

Place and Duration of Study: Departments of Child and Adolescent Psychiatry and Paediatrics, University College Hospital Ibadan, Nigeria between February and May 2017.

Methodology: A sociodemographic questionnaire and the World Health Organization's (WHO) pathway encounter form were used to assess 114 participants (57 in each group) recruited sequentially into the study. Kaplan meier survival analysis was used to compare time to seeking orthodox and specialist care between the two groups, and Atlas Ti software was used to analyse qualitative responses about barriers to accessing care.

Results: There were slightly more males than females in both groups, and the mean age of participants was 9.87 years (SD =5.52). Participants in the paediatric neurology group were

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significantly more likely to access orthodox care at their first level of contact than their child psychiatry counterparts {41 (71.93%) vs. 18 (31.58%); $P < 0.001$ }. There were significant differences in the median survival time to accessing orthodox medical care between the two groups: {paediatric neurology 8 weeks (IQR =23.79) vs. child psychiatry 192 weeks (IQR =80; $P < 0.001$ }. There was however no significant difference in median survival time to specialist care between the two groups. Lack of finances, frequently having to take time off work, and long distances to the hospital were the major barriers to accessing orthodox medical care in both groups.

Conclusions: Our findings suggest a need for continuous advocacy to promote better access to orthodox healthcare for youths with psychiatric and neurological disorders in the developing world context.

Keywords: Pathways to care; children; epilepsy; mental health; Nigeria.

1. INTRODUCTION

Globally, a substantial proportion of disease burden has been attributed to mental, neurological and substance use disorders [1]. These disorders often begin in childhood or adolescence, and the treatment gap is high [2,3]. Mental and behavioural disorders occur among one in five children, and 50% of adult mental disorders have an onset around the age of 14 years. In addition, 75% of adult mental disorders start before the age of 24 years [3]. Mental health disorders often co- occur with neurological disorders such as epilepsy [4, 5] and both disorders are highly stigmatised by the society [6]. Epilepsy is the most common neurological disorder affecting children worldwide [7], and it is estimated that 80 - 90% of people with epilepsy in developing countries do not receive treatment, majority of whom are likely to be children and adolescents [8, 9, 10].

Pathways to care often represent a mixture of available & accessible health care resources as well as belief systems of the population [11]. Many persons living with neuropsychiatric disorders delay seeking care from formal health facilities. Their trajectories to care vary, and are often guided by societal beliefs about the cause of the disorder. In many parts of the world especially in low and middle income countries (LMICs) these disorders are often attributed to spiritual and cultural factors [12, 13, 14]. Previous studies on pathways to care in LMICs have shown that a high proportion of patients with mental disorders first seek care from traditional and religious healers with significant delays in accessing care along the line [15].

For children and adolescents, the factors that determine pathways to care are multiple and complex. Many communities do not have accessible healthcare services designated for

children, and the decision of how, when and where to seek to care help depends on the guardian and not the child [8]. Studies across Nigeria have found that about a third of children and adolescents with mental health problems had received care from a traditional/religious healer before accessing mental health services [16, 17, 18]. While there are few studies on the pathways to care for children with epilepsy, a study of 175 children with epilepsy in Ibadan, Nigeria reported that 56.6% of the caregivers gave a history of complementary and alternative medicine (CAM) use such as herbal preparations (39.4%), spiritual/prayer healing (34.3%), scarifications (17.1%) and special vitamins (6.1%). Approximately 40% of the participants had received these treatments before seeking orthodox care [19]. Another community study in northern Nigeria also found that all subjects identified were currently using alternative/traditional treatment as the sole method of treatment, and only 21% had used orthodox treatments in the past [8].

Despite the similarities in the burden, treatment gap and stigma associated with both epilepsy and child psychiatry disorders, there is a paucity of data comparing the pathways to care among youth with these disorders. The first facility tailored to the needs of children with mental disorders opened just 2 decades ago in Nigeria [20]. On the other hand, services for children with neurological disorders such as epilepsy have been running for over 50 years. Would there be a difference in pathways to these two services? In planning for services for children with neuropsychiatric disorders in Nigeria, a country of over 200 million where children and adolescents make up almost 50% of the population, it is important to identify pathways and timing to care so that relevant interventions can be put in place. This study therefore set out to identify and compare the pathways to care in

children with epilepsy and psychiatric disorders presenting to paediatric neurology and child psychiatry clinics in Ibadan, Southwest Nigeria. The perceived barriers to accessing care were also documented.

2. MATERIALS AND METHODS

This was a comparative cross-sectional study. Using a sample size formula for comparing 2 independent proportions, power was set at 80% & alpha at 5%, and a minimum sample size of 52 participants in each group was calculated. This was increased to 57 to adjust for non - responders. The study sites were the specialist child psychiatry and paediatric neurology clinics of the University College Hospital Ibadan, Nigeria. The University College Hospital, Ibadan is the foremost tertiary health facility in the country located in the city of Ibadan, with a population of about 5 million. The hospital receives referrals from all over Nigeria.

The child psychiatric service commenced in the year 2000 as a single clinic to cater to the needs of children and adolescents with mental health concerns in the Hospital. This service is the second such service to cater to the needs of children and adolescents with mental disorders in Nigeria. The service has since grown into two specialist clinics per week (a general child & adolescent clinic, and a clinic for neurodevelopment concerns), a consultation liaison service, an inpatient service, a school mental health service, and services within the juvenile justice system. The paediatric neurology service was established in 1962, and is a unit within the hospital's Paediatrics department which has several specialized units.

A socio-demographic questionnaire [21] and the World Health Organization's (WHO) pathway encounter form were used for this study. The WHO pathway encounter form was designed to collect data on the referral paths which patients take in the course of their illness until they present at specialist mental health services [22]. Two open-ended questions were added to determine perceptions on barriers to care, and suggestions for improving the existing care facilities.

A purposive sampling technique was used to select consecutive participants over a 13-week period from the two clinics. Inclusion criteria included age less than 19 years and a primary diagnosis of a mental disorder (from the child

psychiatry clinic) or epilepsy (from the paediatric neurology clinic). Children and adolescents who were acutely ill were excluded from the study. Ethical approval to carry out this study was obtained from the University College Hospital Ibadan (UI/UCH Ethics Review Board). Informed written consent was obtained from parents or caregivers after careful explanation of the study. All data collected from participants was kept confidential.

The questionnaires were administered to consecutive patient guardians over a 13 week period. Epilepsy was defined as the separate occurrence of two or more unprovoked seizures, or one unprovoked seizure when the risk for another is known to be high (>60%) [23]. The diagnosis of epilepsy was based on history from a reliable eyewitness account and EEG findings. A detailed account of the seizures was obtained from an eyewitness. All diagnoses of epilepsy were made by a consultant child neurologist. All patients presenting at the child psychiatry clinic also had a comprehensive assessment, and diagnoses were made by a consultant child and adolescent psychiatrist according to the ICD 10 diagnostic criteria.

Data entry and analysis was done using the statistical package for the social sciences version 20. Socio-demographic, clinical variables and pathways were analysed using frequencies and chi – square statistics. Kaplan meier survival analysis was used to compare time to seeking medical and specialist care between the two groups. Level of significance was set at 5%. Computer assisted theme generation from the open ended questions on barriers to care was conducted using the Atlas Ti software.

3. RESULTS

3.1 Sociodemographic Characteristics of the Study Population

A total of 114 study participants, 33 (56%) males and 50 (44%) females were recruited into the study. There were 57 participants in each group. In the paediatric neurology group there were 33 (57.9%) males, and 24 (42.1%) females, while in the child psychiatry group there were 31(54.4%) males and 26 (45.6%) females. There were no differences in the male : female ratios of the two groups. The mean age of all the participants was 9.87 years (SD=5.52). The ages of participants with epilepsy ranged from 8 months to 18 years with a mean age of 7 years (SD=4.85), while

those with mental disorders ranged from 2 to 18 years with a mean age of 12.74 years (SD=4.61). This difference was statistically significant at $P < 0.001$ (See Table 1). There were no significant differences in the religion and educational status of participants' parents between the two groups. See Table 1.

3.2 Clinical Characteristics

Generalized epilepsy was diagnosed in 44 (77.2%) of the paediatric neurology group while partial epilepsy was diagnosed in 13 (22.8%). Generalised epilepsy was made up of the

following categories: generalised tonic clonic 61.4% (n =35), absence seizures 5.3% (n = 3), atonic seizures 1.8% (n =1), and myoclonic epilepsy 8.8% (n = 5). Overall, 6 (10.6%) of the participants in the paediatric neurology group also had an associated psychiatric diagnosis. ADHD was present in 3 (5.3%) participants, and intellectual disability in 3 (5.3%). Among those in the child psychiatry group, 16 (28.1%) had neurodevelopmental disorders, 25 (43.9%) had psychotic & bipolar disorders, 8 (14%) had depression, anxiety and related disorders, 6 (10.5%) had disruptive disorders, and 2 (3.5%)

Table 1. Socio-demographic characteristics of the study participants

Variable	Paediatric Neurology n (%)	Child Psychiatry n (%)	X ² (P-value)
Age (years)			
0-10	43 (75.4)	17 (29.8)	23.785 (<0.001)
11-18	14 (24.6)	40 (70.2)	
Gender			
Male	33 (57.9)	31 (54.4)	0.142 (0.706)
Female	24 (42.1)	26 (45.6)	
Present Class			
Pre-Primary/Primary	25 (65.8)	8 (17.8)	19.976 (<0.001)
Secondary & above	11 (28.9)	33 (73.3)	
Special school	2 (5.3)	4 (8.9)	
Age Appropriate to class			
Yes	26 (68.4)	28 (58.3)	0.924 (0.336)
No	12 (31.6)	20 (41.7)	
Primary Guardian			
Biological parent	52 (91.2)	50 (87.7)	4.309 (0.116)
Adult Relative	5 (8.8)	4 (7.0)	
Non-Relative adult*	0 (0.0)	3 (5.3)	
Parental status			
Both Parent Alive	52 (92.9)	40 (72.7)	9.906 (0.019)
Single Parent	4 (7.1)	12 (21.8)	
Orphan	0 (0.0)	2 (3.6)	
Not Reported	0 (0.0)	1 (1.8)	
Father's Level of Education			
No Formal Education	0 (0.0)	1 (1.8)	2.781 (0.427)
Primary School	1 (1.8)	3 (5.5)	
Secondary School	15 (26.3)	12 (21.8)	
Post-secondary & University	41 (71.9)	39 (70.9)	
Mother's Level of Education			
No Formal Education	0 (0.0)	2 (3.6)	5.674 (0.129)
Primary School	2 (3.5)	6 (10.7)	
Secondary School	19 (33.3)	14 (25.0)	
Post-secondary & University	36 (63.2)	34 (60.7)	
Religion			
Christianity	36 (64.3)	41 (74.5)	1.347 (0.241)
Islam	20 (35.7)	14 (25.5)	

Non-relative adult* – school matron, non governmental organizations, paid carers

had other psychiatry disorders. Sixteen participants (28.1%) in the child psychiatry group also had associated epilepsy.

3.3 Pathways to Care

In the paediatric neurology group, 6 (10.5%) participants had visited religious healers and 41 (71.7%) had visited primary and secondary level clinics & hospitals at the first level of contact. In the child psychiatry group 31(54.4%) had visited religious healers and 18 (31.6%) had visited primary and secondary level clinics & hospitals at the first level of contact. This difference was statistically significant ($P < 0.001$) (See Table 2). There were no significant differences between the two groups at the second level of contact ($P = 0.09$). At the third level of contact, 1 (4.4%) and 21 (91.3%) of the participants in the paediatric neurology group had visited religious healers and hospital specialists respectively. In the child psychiatry group, 4(16.7%) and 9(37.5%) had visited religious healers and hospital specialists respectively. This difference was also statistically significant, $P = 0.001$.

3.3.1 Time between onset of symptoms and the time taken to seek intervention at a medical or specialist facility

The median survival time to seeking specialist care for the paediatric neurology group was 156 weeks ($IQR = 30.86$) while that for the child psychiatry group was 192 weeks ($IQR = 96.50$). This difference was not statistically significant ($P = 0.06$). The median survival time to seeking any form of medical care in the paediatric neurology group was 8 weeks ($IQR = 23.79$) while in the child psychiatry group the median survival time to seeking medical care was 192 weeks ($IQR = 80$). This difference was statistically significant ($P < 0.001$). See Table 3.

3.3.2 Barriers to accessing health care services

Barriers to accessing care identified in the two groups fell into 3 broad themes: personal, work - related and hospital. Personal issues included difficulties with finances, poor family support, and poor health of guardians. Work - related issues were problems with getting time off from work repeatedly. Hospital related issues included long distances from participants' homes to the hospital, stress of navigating hospital facilities, and poor attitudes of hospital staff. See Table 4.

Table 2. Pathways to care for children & adolescents presenting at paediatric neurology & child psychiatry clinics

Event	Variable	Paediatric Neurology N (%)	Child Psychiatry N (%)	χ^2 (P- value)
Pathways to Care	First Contact			
	<i>Religious healer</i>	6 (10.53)	31 (54.39)	26.080 (<0.001)
	<i>Specialist Care Primary/secondary level clinics /hospitals</i>	41 (71.93)	18 (31.58)	
	Second Contact			
	<i>Religious healer</i>	16 (34.04)	14 (27.45)	4.792 (0.091)
	<i>Specialist Care Primary/secondary level clinics /hospitals</i>	22 (46.81) 9 (19.15)	17 (33.33) 20 (39.22)	
	Third contact			
	<i>Religious healer</i>	1 (4.35)	4 (16.67)	14.919 (<0.001)
	<i>Specialist Care Primary/secondary level clinics /hospitals</i>	21 (91.30) 1 (4.35)	9 (37.50) 11 (45.83)	

Table 3. Summary statistics & test of equality of the survival distribution of time taken (weeks) by caregivers after onset of illness symptoms to seek healthcare at a health facility

Time	Group	Mean	Median	Mode	Range	Interquartile Range	Median Survival Time (weeks)	Std Error	Chi-square	P-value
A	Paed Neuro	29.42	2.00	0.14	311.86	23.79	156.00	53.82	3.53	0.060
	Child Psych	94.82	6.00	4.00	779.86	80.00	192.00	84.52		
B	Paed Neuro	29.42	2.00	53.00	311.86	23.79	8.00	2.75	23.19	<0.001
	Child Psych	94.82	6.00	52.00	779.86	80.00	192.00	79.64		

Time A– Time taken to seek care at a specialist facility; Time B - Time taken to seek care at a medical facility

Table 4. Guardians' perceptions of barriers to accessing health care

Theme	Paediatric Neurology n =43 (%)	Child Psychiatry n = 38 (%)	Example
Personal			
Poor Parental Health	0(0.0)	2 (5.3)	<i>'Mother has not been feeling fine'</i> <i>'Lack of funds'</i> <i>'We had to trek a bit before we took a cab to clinic because we didn't have enough money'</i>
Financial Difficulties	16 (37.2)	22 (57.9)	
Lack of Family support	2 (4.7)	1(2.6)	<i>'Father did not give permission'</i>
Work			
Frequent absences from work	16 (37.2)	5 (13.2)	<i>'Its like cancelling the whole day's work'</i>
Hospital			
Distance	2 (4.7)	4 (10.5)	<i>'The distance to the hospital is stressful'</i>
Stress of navigating facility	5 (11.5)	4 (10.5)	<i>'Delays at the hospital'</i> <i>'They take one's time unnecessarily'</i>
Poor staff attitudes	2 (4.7)	0 (0.0)	<i>'Staff are not accommodating'</i>

4. DISCUSSION

This study aimed to identify and compare pathways to care among children and adolescents presenting with epilepsy at a paediatric neurology clinic, and mental disorders at a child psychiatry clinic in Ibadan, South West Nigeria. The demographic profile of the participants revealed slightly more males than females in the two groups. Previous studies in low and middle-income countries (LMIC) countries have found that epilepsy is commoner in boys [8, 24]. Females are found to have a marginally lower incidence of epilepsy and unprovoked seizures than males due to a lesser exposure to risk factors for lesional epilepsy and acute symptomatic seizures [25]. For the child psychiatry group, the slight overabundance of males is also not surprising as the most common diagnosis found was neurodevelopmental disorders. This diagnosis is known to be commoner in boys than girls [3]. There was also a significant difference in the mean age between the two groups. Subjects with epilepsy were significantly younger than those with mental disorders. This is also not surprising as epilepsy has an early age of onset usually in the first decade of life, [26] while the onset of child psychiatry disorders increases in adolescence [3].

There were significant differences in the reported pathways to care between the two groups. At the

first level of contact, over 70% of participants with epilepsy had sought orthodox medical care through primary or secondary health care facilities and private clinics. However, for children with mental disorders only a third (31.6%) received any form of orthodox medical care at their first level of contact. Over half (54.4%) of the participants with mental disorders were taken to traditional and religious healers at their first level of contact while only 10% of participants with epilepsy had the same. By the 3rd level of contact, over 90% of the participants with epilepsy had accessed specialist care while significantly less than two-thirds of participants with mental disorders had done the same. The time to specialist care was not different between the two groups but the time to medical care was significantly different, with participants in the epilepsy group accessing medical care in a median survival period of 8 weeks (IQR =23.79) compared to 192 weeks in children with mental disorders (IQR =80; P < 0.001). In the few reports on pathways to care for children with epilepsy in the developing world, a study in Ibadan, Nigeria reported that only 40% of children had received alternative treatments before orthodox care was sought [19]. Another study of caregivers of children with nodding syndrome (a rare form of epilepsy found in some regions of Africa), found that 78% sought care first from an orthodox health facility [27].

These taken together with our findings suggest that while both disorders have cultural and spiritual beliefs about aetiology, childhood epilepsy may be viewed more as a biomedical problem when compared to mental disorders leading guardians to access medical care earlier. What could be responsible for this? First is the clinical presentation of the disorders. Epilepsy is dramatic with prominent physical symptoms such as falling, jerking and loss of consciousness. Psychiatric disorders tend to be more behavioural with less physical manifestations. The length of availability of existing services may also be a contributing factor. Paediatric neurology services in this context have existed for almost half a century, while child psychiatry services have only existed for about 2 decades. It is therefore expected that there would be greater knowledge and awareness of the symptoms and treatments for epilepsy when compared with child mental health disorders. The long delay to seeking medical care in the child psychiatry group may have serious implications on the long term outcomes of children with child mental health disorders, as longer duration of untreated illness has been associated with poorer prognosis and outcomes.

Major barriers to accessing care mentioned by participants were finances and repeated absences from work. Many families in this context still have to pay out of pocket for health services and thus cannot afford to miss work repeatedly. Esiegbe et al, [8] in northern Nigeria reported that low cost and easy availability of traditional healers were one of the strong factors that led guardians to seek help for their children from these providers. Other barriers mentioned in this study included long distances to the hospital, long waiting times at hospitals, and poor attitudes of medical personnel. These are similar to the barriers reported in a qualitative study [28] among adults with mental disorders and epilepsy from Liberia, Nepal and Uganda; all which serve as pointer to the poor state of health services in many parts of the developing world.

While it is encouraging that youth with epilepsy are able to access orthodox medical care early in the course of help - seeking, our findings suggest a need for greater advocacy for youth with child mental health disorders to be able to do the same. This is particularly important as there tends to be a comorbidity between the two types of disorders [4]. With the introduction of the WHO mental health gap action plan (mhGAP) in many LMICs including Nigeria, [29] capacity is being

built at all levels of the health care system to effectively manage these common conditions. However in order to further bridge the treatment gap, there is also a need for improving the recognition and management of these disorders within community child settings such as schools.

The strengths of this study are its comparative nature for two important, often comorbid disorders among children and adolescents. However the study is limited by the relatively small sample size. Data was based on prior events, and is subject to recall bias. There is also a need for further in - depth exploration of the barriers to accessing care to supplement the findings from the short open - ended questions used in this study.

5. CONCLUSION

This study showed that there were significant differences in the pathways to care between children with epilepsy presenting to paediatric neurology and children with mental disorders presenting to child psychiatry clinics in Ibadan, Nigeria. Those in the first group were more likely to access early orthodox care, despite similar reported challenges encountered in the process. There is a need for increased advocacy in the recognition and management of neuropsychiatric disorders with emphasis on reducing delays to accessing care for the millions of affected children in the community.

CONSENT

All authors declare that written informed consent was obtained from the study participants.

ETHICAL APPROVAL

This study was approved by the University of Ibadan/University College Hospital Ethics committee with ethics approval number: UI/EC/17/0046

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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