COMPARISONS OF PATHWAYS TO CARE FOR CHILDHOOD EPILEPSY AND CHILDHOOD PSYCHIATRY DISORDERS AMONG CHILDREN AND ADOLESCENTS IN IBADAN, NIGERIA

BY

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DECLARATION

I hereby declare that this project entitled "Pathways to Care among Children and Adolescents in Ibadan, Nigeria: Comparisons between Childhood Epilepsy and Childhood Psychiatric Disorders" is a result of my own original work and has not been submitted either wholly or in part to any other institution for the award of another degree or diploma.

This research project is submitted in part of fulfilment of the requirements for the award of Master of Science in Child and Adolescent Mental Health at the University of Ibadan.

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CERTIFICATION

This is to certify that conduct of this study and the preparation of the thesis were carried out by ADEBAYO ADEOLA OLUWANIFEMI in the CENTRE FOR CHILD AND ADOLESCENT MENTAL HEALTH, UNIVERSITY OF IBADAN under my supervision.

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DEDICATION

I dedicate this research work to Almighty God and to my mother who took the whole responsibility of a man and also to all caregivers who partook in this study.

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LIST OF ABBREVIATIONS (Acronyms)

CCAMH: Centre for Child and Adolescent Mental Health

WHO: World Health Organization

UCH: University College Hospital

SPSS: Statistical Package for Social Sciences

IQR: Inter Quartile Range

HRQOL: Health Related Quality Of Life

OR: Odds Ratio

CI: Confident Interval

CAM: Complementary and Alternative Medicines

ABSTRACT

Background

Epilepsy and child psychiatry disorders are very common in the developing world and contribute to the burden of diseases among young people in this region. It is estimated that 80% of children with epilepsy live in resource poor countries; likewise 10-20% of children and adolescents suffer from mental illness. Also these disorders often overlap and majority of the patients do not have access to the much needed specialist care.

In Nigeria, studies have shown different pathways of mental health services which revealed that it is either majority of the subjects had not received any care prior to presentation at hospital or majority of the subject had initially received treatment from a traditional or religious healer. However not much is known about pathways to epilepsy health care services. This study therefore set out to determine the pathway to care for children presenting at a neurology clinic and to evaluate similarities and differences between pathways to child psychiatric services and neurology services.

Methodology

In this comparative cross-sectional study, data was collected over 13 weeks from 114 participants and their caregivers attending the Paediatrics Neurology Clinic; and the Child and Adolescent Mental Health Clinic of the University College Hospital, Ibadan and a private clinic (The New World Clinic). A comparative two proportional sampling size formula was used to derive my sample size. Participants who met the inclusion criteria were selected using a purposive sampling technique. A socio-demographic questionnaire was used to obtain background information from the participants, while a modified version of the WHO Encounter form and the Data Extraction form was used to collect data about participants' visits to the various research sites. Data was cleaned and coded where appropriate. Data entry and analysis was done using the Statistical Package for the Social Sciences version 20 (S.P.S.S 20). Socio-demographic and clinical variables were analysed and presented in frequencies or percentages. The Chi-square test was used to determine association between categorical socio-demographic and clinical variables and the type of pathway taken. Kaplan Meier Survival

analysis was applied for the analysis of time to the actual act of seeking help for medical services by the caregiver, and the exact time to seek help will be determined. Cox regression analysis was used to check whether the socio-demographic variables were related to the time taken to seek an intervention. Computer assisted theme generation from the qualitative data was conducted using ATLAS Ti software.

The statistical level of significance was set at 5% ($p<0.05$).

Results

There were 34 (57.9%) males, and 24 (24.1%) females in the epilepsy group, while 31(54.4%) were males and 26 (45.6%) were females in the child psychiatry group. The participants' ages ranged from 8 months to 18 years. Generalized tonic clonic epilepsy, seen in 46 (80.7%) was the most common type of epilepsy in the epilepsy group while neurodevelopmental disorders 30 (52.6%) was the most common in the psychiatric group.

The medical pathway was accessed by 41 (72.0%) of caregivers of children and adolescents with epilepsy as their first contact into help seeking while 24 (42.1%) of caregivers of children and adolescents with psychiatric disorders sought help from non-medical pathway (religious leaders) as their first contact to care. This difference was statistically significant at $p<0.001$.

The median time taken to seek any type of help after onset of symptom was 29.42 weeks (IQR 30.86) for childhood epilepsy while it took 94.82 weeks (IQR 96.50) for childhood psychiatry disorders. The median time taken to seek at the tertiary facility was 52 weeks (IQR 124.00) for childhood epilepsy while it took 48 weeks (IQR 91.00) for childhood psychiatry disorders.

The main barriers to care identified by the study participants were family issues, financial constraints, work related issues. Hospital related themes included long distance to the clinic, hospital stress and delay at the hospital

Conclusion

This study revealed various forms of pathways to care for both disorders. The most frequently used intervention for childhood epilepsy, was to access care in a hospital setting while for childhood psychiatric disorder, it was to access care in a non-medical pathway which is in keeping with most studies. The main barriers identified in this study were family issues, financial constraints and work related issues. Adjusting clinic time and increasing mental health talk through advocacy would go a long way in improving access to the available child and adolescent mental health services.

Key Words: Pathway to care, help seeking, epilepsy, child and adolescent psychiatric disorder, barrier to care, determinant of care.

(Word count: 742)

CHAPTER ONE

INTRODUCTION

1.1 Background to the Study

Psychiatry and neurological disorders pose one of the greatest threats to public health (Tarun Dua 2006). It has thus become apparent that unless immediate action is taken globally, these disorders are expected to become unmanageable problem in all countries (Tarun Dua 2006). Epilepsy is the most common neurological disorder affecting children, and the greatest burden of childhood epilepsy is found in the developing countries of the world (Lagunju et al. 2012). Similarly mental health problems affect 10-20% of children and adolescents worldwide (Kieling et al. 2011). Epilepsy is associated with a wide treatment gap among children living with this disease in the developing countries and they face the added burden of stigmatization, strong myths, and cultural beliefs about the disease and harmful traditional practices geared toward the treatment of epilepsy (Lagunju et al. 2012). Despite mental health of children and adolescents being a leading cause of health-related disability in this age group and their long lasting effects throughout life, their needs are neglected, especially in low-income and middle-income countries (Kieling et al. 2011). Studies have shown links between childhood epilepsy and psychiatric disorders.

Pathway studies have been used to investigate how people use services (including time on the pathway) and the role of careers (Sorketti 2013). Despite the limited services available for mental and neurological disorders, they are often under-utilized because of widespread ignorance and supernatural beliefs about the aetiology of mental illnesses (Abdulmalik et al. 2012). Studies have shown that mental health services are sought as a last resort in Nigeria, resulting in delayed treatment (Aneibu and Ekwueme 2009; Lasebikan et al.2012). Help-seeking also known as pathways, in mental setting has been characterized primarily as an adaptive coping response to mental health problems which comprises a search for assistance from external sources (Rickwood et al. 2012).

1.2 Statement of the Problem

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In sub-Saharan Africa, traditional and faith healers provide competing services alongside biomedical professionals (Ikwuka et al. 2016). Children and adolescent living with either epilepsy or mental health problems are well identified in resource-poor countries (Lagunju et al. 2012). This may be associated with delays in reaching specialized mental health services, and hence with longer duration of untreated illness (Ikwuka et al. 2016). Traditional and faith healers play an important role alongside biomedical professionals, frequently seen in traditionalist (collectivist) societies of the developing world such as Nigeria, where studies indicate that the majority of patients have consulted traditional and spiritual healers before their eventual arrival at a conventional psychiatric facility(Aghukwa 2012). A study carried out in Nigeria showed that up to 68% and 75% of respondents who believed in a medical or genetic cause of illness, respectively, reported seeking a psychiatric consultation within six months of onset, and about 70% who believed in supernatural forces reported seeking psychiatric consultation five years after onset or later among adolescents and adults (p<.05) (Aghukwa 2012).

Epilepsy is the most common serious neurological disorder and is one of the world's most prevalent non-communicable diseases (Scott et al. 2001). Studies have shown caregivers use of complementary and alternative medicines (CAM) in seeking treatment for childhood epilepsy disorders. Lagunju in a study of 175 children with epilepsy carried out at the UCH, reported that ninety nine (56.6%) of the caregivers gave a history of CAM use. The forms of CAM used were herbal preparations (39.4%), spiritual/prayer healing (34.3%), scarifications (17.1%) and special vitamins (6.1%). Seventy (40%) of the 175 children had received CAM ever before seeking Western Medicine for the treatment of epilepsy. Of the 99 children with history of CAM use, 33 (33.3%) continued to use CAM in combination with the prescribed anti-epileptic drug (AED) (Lagunju 2013).

Children with epilepsy have a lower performance in school than other pupils, including those suffering from other chronic diseases that affect their attendance at school. The burdens produced by epilepsy go beyond the individuals affected by the condition (Scott et al. 2001).
There is limited availability of mental health services in Nigeria, and indeed most of Africa. Available services are also often under-utilized because of widespread ignorance and super-natural beliefs about the aetiology of mental illnesses. The consequence, therefore, is a long and

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tedious pathway to care for the individual with a mental illness, especially children and adolescents (Abdulmalik et al. 2012).

Socio-culturally, most Africans, regardless of their level of education, believe in the supernatural causality of mental health issues (Odejide et al. 1989) and studies have shown that southwestern Nigerian public preferred alternatives (spiritual/traditional healers) to Western medicine for the treatment of mental illness (Adewuya et al. 2009).

1.3 Justification and relevance of the Study

Children and adolescents are particularly vulnerable as they partake of but usually do not initiate help seeking, but can only seek care, at the discretion and through the pathways that the parents may choose (Abdulmalik et al. 2012). Pathway studies have been used to investigate how people use services including time on the pathway and the role of care givers (Osungbade et al. 2011). Studies have shown that the use of complementary and alternative medicines (CAM) has been on the increase worldwide (Lagunju 2013).

Globally, people with mental illness are challenged twice; on one hand, they struggle with the symptoms and disabilities that result from the disease and on the other, they are stereotyped and prejudiced due to misconceptions about mental illness (Corrigan 2002). As a result, people with mental illness are robbed of the opportunities that define a good quality life: good jobs, safe housing, satisfactory health care, and affiliation with a diverse group of people.(Corrigan 2002). Stigma has been described as one of the most important factors hindering the early identification of symptoms of these disorders (Thornicroft et al. 2007). Among the underlying reasons of delays are; absence of services and programs which leads to late diagnosis and treatment of mental disorders, stigma and the belief that mental health issues are untreatable with orthodox medical interventions (Gureje et al. 2000).

Studies show that caregivers of mentally ill children experience various psychological and emotional, social, and economic challenges (Ambikile et al. 2012). On the other hand, prompt diagnosis and treatment of children with health challenges can reduce mortality, lower anxiety, minimize complaints and reduce hospital stay in many diseases (Kamau et al. 2017) and also affect caregivers health positively.

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Consequently, people with epilepsy continue to be stigmatized and have a lower quality of life than people with other chronic illnesses. However, bridging the treatment gap and reducing the burden of epilepsy early improves their quality of life and affecting their families positively(Scott et al. 2001).

It is therefore pertinent to find out the sources of delay in the receipt of care among patients with childhood epilepsy and psychiatry disorders. This will help to reduce the gap experienced in accessing care and support in childhood epilepsy and psychiatry disorders by putting in place policies that will help reduce the barriers.

The information obtained from this study would be of use to policymakers and non-governmental organizations interested in increasing children's access to childhood epilepsy care and mental health services.

It will also help in providing considerable strategies on how to reduce barriers related to accessing of care about these disorders in addition to structural barriers.

1.4   Research Questions:

1. What are the various pathways of care for children with epilepsy and psychiatric disorders?

2. What are the socio-demographic and clinical factors associated with pathways to care for patients with childhood epilepsy and childhood psychiatric disorders?

3. How long does it take the patient with childhood epilepsy and the one with childhood psychiatric disorders to access care?

4. What are the perceived challenges experienced while seeking to access care through hospital services?

5. What are the caregivers' perceptions towards possible measures to improve access to care?

1.5   Aims and objectives of the study
1.5.1 The overall aim of this study is:

To determine guardian-reported pathways and barriers to receipt of care among children with epilepsy as well as those with psychiatric disorders in Ibadan, South West Nigeria.

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The specific objectives of the study were:

1. To identify the various pathways of care for children with epilepsy and psychiatry disorders.

2. To determine the socio-demographic and clinical factors associated with pathways to care for patients with childhood epilepsy and those with childhood psychiatry disorders.

3. To compare the time spent to access orthodox care between patients with childhood epilepsy and patients with childhood psychiatry disorders.

4. To identify the perceived challenges experienced while seeking to access care to hospital services by their caregivers.

5. To identify caregivers perceptions towards measures to improve access to care.

1.6   Null Hypothesis

1.   There is no significant difference between pathways to care among childhood epilepsy and childhood psychiatric disorders

2.   There is no significant difference in the time spent seeking alternative care between childhood epilepsy and psychiatric disorders

3.   There is no significant difference in the socio-demographic and clinical factors associated with the pathways to care for childhood epilepsy and psychiatric disorders.

1.7   Primary Outcome measure

It identified the pathways used in accessing care for childhood epilepsy and psychiatry disorders; (the similarities and differences in pathways to care).

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CHAPTER TWO

LITERATURE REVIEW

2.1 Pathways to care: Definitions

The aim of a clinical pathway is to improve the quality of care, reduce risks, increase patient satisfaction and increase the efficiency in the use of resources (De Bleser et al. 2006). In mental health context, help-seeking is an adaptive coping process (and respective timeframe) in an attempt to obtain external assistance (the source and type of assistance that is sought) to deal with a mental health concern (the type of mental health problem for which help is being sought) (Rickwood et al. 2012).

2.2 Pathways to care definitions, conceptual models their application to Health and it's similarities to the Nigerian Health system

There are different studies that have shown different patterns to patient's pathways in decision making to access care as well as the factors that guide patients to health care professionals.

2.2.1 The Parallel Process Model

It is also known as "the Common-Sense Model of self-regulation. This model was developed by Howard Leventhal and his colleagues; the key construct within the parallel process model is the idea of illness representations or 'lay' beliefs about illness. These representations integrate with the normative guidelines that people hold, enabling them to make sense of their symptoms and guide any coping actions. They described five components of these illness representations: *(1) Identity*: the label or name given to the condition and the symptoms that 'appear' to go with it. It can be argued that people like to have a label for their symptoms (for legitimization) (Lau et al. 1983).

(2) Cause: the individualistic ideas about the perceived cause of the condition, which may not be completely bio medically accurate. These representations will be based on information gathered from personal experience as well as the opinions and discourses of significant others,

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health professionals and media sources, reflecting issues such as stress, and other pathogens (Lau et al. 1983).

(3) Time-line: the predictive belief about how long the condition might last, i.e. is it acute or is it going to be chronic? These beliefs will be re-evaluated as time progresses (Lau et al. 1983).

(4) Consequences: the individual beliefs about the consequences of the condition and how this will impact them physically and socially (Lau et al. 1983).

(5) Curability/controllability: the beliefs about whether the condition can be cured or kept under control and the degree to which the individual plays a part in achieving this. It is likely that other factors influence the proposed pathway from representation to outcome via coping (Hale et al. 2007). This model has been used for various chronic and common illnesses (Lau et al. 1983, McAndrew et al. 2008).

2.2.2 Conceptual Pathway Model

This model can also be referred to as "The Casual Mechanism" which throws enlightenment on factors that are beyond limited health literacy (the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions) shown by studies, but other factors that are associated with worse health outcome.

The causal mechanisms of the health literacy-health outcomes relationship are due not only to patient-level characteristics, but also to those attributes of the health care system.

This model describes *the systemic, interactional, and self-care mechanisms* by which limited health literacy is most likely to lead to worse health outcomes.

(1) The Systematic: It deals with how the financial structure of medical insurance which is not organized to command fewer logistical barriers to care, also the rules and regulations of how to use health plans vary, and it is easy to misunderstand what services are covered and how to use various types of programmes. Similarly, health programme do not comprehensively manage the flow of information that commonly has to be processed separately for medical, pharmacy, and dental benefits – if one has coverage. Furthermore,

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rule changes situations where doctors are shifted out of network and medications are dropped from formularies this frequently befuddle clinicians and patients alike (Paasche-Orlow et al. 2007).

(2) Patient-Provider Interaction: Patient factors. Knowing less about a disease may have broad ramifications on how patients with limited literacy interact with their providers. Patients may or may not have insight into the fact that they do not know very much about their condition. Beyond the issue of how shame might lead some people with low health literacy to avoid asking questions from their clinicians, low literacy may be associated more generally with worse patient activation. In addition, low literacy has been linked to worse mental health functioning and worse depression. *Provider factors.* Providers tend to be unaware of their patients' limited literacy. However, it is not clear that even with such knowledge providers should always be able to communicate with their patients in a manner that the patients understands. (Paasche-Orlow et al. 2007).

(3) Self-Care: Patient factors. People with limited health literacy have been found not only to have lower levels of disease specific knowledge, but also to know less of the practical and instrumental knowledge critical to self-management. Self-management requires not only the knowledge of what to do but also the will and capacity to carry out the health care plan. A critical element of successful self-management is medication adherence (Paasche-Orlow et al. 2007).

2.2.3 Mediating Factors of Pathways

This study looks extensively into other factors that can actually determine a patient's decision to access care and services. The study suggests other mediating factors, such as desire to participate in care and health knowledge which are: *Extrinsic factors.* Self-management is now the accepted term used to describe the day-to-day decisions and activities that patients, with the help of loved ones, engage in to live with and control their illnesses. Patients need to interpret their symptoms and make decisions. Similarly, patients contend with competing and confusing health messages from the news, the public health sector, and direct- to-consumer advertising. Patients with chronic disease are commonly in the position of needing to monitor their condition and adjust their

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therapy. Because patients with low health literacy are less able to understand their disease and symptoms or to know how to monitor their disease (DeWalt et al. 2004).

2.2.4   Linkage of primary health care models

These models incorporate a cost effective model for increasing access to mental health care at the primary care level in Nigeria. These models need to be incorporated religiously to get improvement in the fields of these disorders.

- i.   Enhancement model: It is refer to the training of primary care workers to recognize, diagnose and treat epilepsy and psychiatry disorders, and carry out other epilepsy and psychiatry services independently for children and adolescent care (Omigbodun 2001).

- ii.   Linkage model: It occurs when epilepsy and psychiatry professionals leave their hospital bases to provide epilepsy and psychiatry services in primary care setting for children and adolescents care (Omigbodun 2001).

2.2.5   Alternate care system models

Involving traditional health care systems into modern health care system may also improve treatment accessibility. This has been incorporated before as a way of maximizing epilepsy and psychiatry services for the community (Jilek 1971) and various models exist for working together with traditional healers (Freeman et al. 1992).

- i.   In a "task-shifting" model,   traditional healers may be incorporated into existing mental health services by co-opting their penetrance and cultural acceptability to deliver conventional treatment. For example, they may administer medication to patients in rural areas, or be trained to deliver other psychiatrysupport96 (Freeman et al. 1992, Campbell-Hall et al. 2010). While this task-shifting approach may expand the reach of epilepsy and psychiatry services in poorly resourced countries, it makes little use of healers' unique skills and specific advantages, which should rather be acknowledged and built on.

- ii.   In a collaborative model, traditional healers and conventional practitioners remain autonomous and independent, but co-operate fully, for example by

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referring patients to each other or consulting on complex cases. In a fully integrated model, traditional healers and conventional services would be blended into a new hybrid system such that patients need not choose one over the other. Treatment approaches would be similarly integrated. For example, a culturally relevant explanation may be given for why someone is depressed, followed by the necessary ritual and a prescription for an antidepressant (Oye Gureje et al. 2015).

2.3 Mental and Neurological Disorders

Neurological disorder is an unpredictable disease that can manifest itself in seizures, brain damage and cognitive and psychiatric disabilities, although some people with epilepsy can have a relatively normal life (De Boer et al. 2013). The majority of patients with epilepsy that begins in childhood will become free of seizures by adulthood. Those who do not enter remission have an increased risk of death. Although patients with uncomplicated epilepsy have a favorable long-term medical prognosis, they are more likely to have lower levels of education and employment than the general population and less likely to marry or have children, even if they have been seizure-free without medication for many years (Sillanpää et al. 1998). In the area of mental health services research, children and youth represent a sadly neglected majority. There is a major gap in our knowledge of and service provision for mental health problems among children and young people (Ustün 1999). Mental disorders account for a large proportion of the disease burden in young people in all societies. Most mental disorders begin during youth (12-24 years of age), although they are often first detected later in life. Poor mental health is strongly related to other health and developmental concerns in young people notably lower educational achievements, substance abuse, violence, and poor reproductive and sexual health. The effectiveness of some interventions for some mental disorders in this age-group has been established, although more research is urgently needed to improve the range of affordable and feasible interventions, since most mental-health needs in young people are unmet, even in high-income countries. It is estimated that 80% of the world's 33 million children with epilepsy live in resource-poor countries of the world (Lagunju et al. 2012). Evidence suggests that considerable levels of mental health

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problems exist among children and adolescents in sub-Saharan Africa; 1 in 7 children and adolescents have significant difficulties, with 1 in 10 (9.5%) having a specific psychiatric disorder (Cortina et al. 2012). Children with epilepsy are at increased risk for mental health problems in comparison with the general population (Davies et al. 2003). Several studies have reported that over 90% of people with epilepsy in developing countries do not receive appropriate treatment for their condition, a phenomenon known as the treatment anticonvulsant therapy, and cost is only one of a number of reasons for this (Shorvon et al. 1988).Key challenges to addressing mental-health needs include the shortage of mental-health professionals, the fairly low capacity and motivation of non-specialist health workers to provide quality mental-health services to young people, and the stigma associated with mental disorder. We propose a population-based, youth focused model, explicitly integrating mental health with other youth health and welfare expertise. Addressing young people's mental-health needs is crucial if they are to fulfil their potential and contribute fully to the development of their communities (Patel et al. 2007). It may be said that epilepsy presents people with health problems, and they also have to cope with a wide range of psychosocial difficulties that affect almost every aspect of their lives (De Boer 2002). In a nationally representative sample, children with seizures were at increased risk for mental health, developmental, and physical comorbidities, increasing needs for care coordination and specialized services (Russ et al. 2012). Children with epilepsy are at increased risk for mental health problems in comparison with the general population and with children with chronic illnesses not involving the central nervous system (Davies et al. 2003). Children with epilepsy are known to have high rates of mental health problems thus, the role of seizures in the development of these problems is not known primarily because of difficulties in separating the effects of seizures from the three other potential causal factors: (a) poor child and family response to the condition, (b) side effects of antiepileptic medication, and (c) neurological dysfunction causing both the seizures and the behavioral problems although cross-sectional studies focusing on children with chronic epilepsy show associations between behavior problems and each of these causal factors (Austin et al. 2002).

2.4 Epilepsy Prevalence and Public Health Burden

Epilepsy accounts for 0.5% of the global burden of disease, with more than 50 million people affected worldwide; 80% of them are in developing regions (Alhazzani et al. 2016). The majority

of the 50 million people with epilepsy live in developing countries, with a prevalence rate of five to 10 people per 1000. The disease poses an enormous psychological, social and economic burden on patients (Tanywe et al. 2016). People with epilepsy are among the most vulnerable in any society because the disease is misunderstood and often stigmatizing. Thus, many patients and their families are reluctant to admit that they suffer from epilepsy. This in turn affects public policy in terms of patient care, early diagnosis, medical research, advocacy, cure and their very lives (De Boer et al. 2013). Stigma and exclusion are common features of epilepsy in both the developed and developing countries and a major contributor to the burden associated with the condition. Reducing the stigma of epilepsy is more like reducing its impact and so improving quality of life. The social consequences of having epilepsy can be enormous and it varies from country to country, based on cultural differences and economic circumstances. The most significant problems people with epilepsy encounter in daily life often are not related to the severity of the condition, but stem from concepts of epilepsy held by the general public (de Boer 2010).

Epilepsy affects people of all ages, sex, races, nations and social class (Tanywe et al. 2016). Childhood epilepsy adversely impacts quality of life and same, comorbid behavioral problems have been identified as major contributors to reduced quality of life in children with epilepsy (Johnson et al. 2004). Access to mental health care services by persons living with severe mental disorders and epilepsy remains low in these three post conflict countries (Uganda, Liberia and Nepal) (Kisa et al. 2016). The reasons contributing to it are multi-faceted ranging from systemic, familial, community and individual. It is imperative that policies and programming address: negative attitudes and stigma from health care workers and community, regular provision of medicines and other supplies, enhancement of health care workers skills. Ultimately reducing the accessibility gap will also require use of expert clients and families to strengthen the treatment coalition (Kisa et al. 2016).

2.5 Mental Health Prevalence and Public Health Burden

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The global burden of mental disorders highlights the magnitude of the problem as loss of life years in terms of human productivity as well as social functioning (Ustün 1999). A major contributory factor to poor mental health outcome in Africa is delayed presentation for care and treatment (Kohn et al. 2004). There is limited access to mental health services in Nigeria, and indeed most of Africa (Abdulmalik et al. 2012). Available services are also often under-utilized because of widespread ignorance and supernatural beliefs about the etiology of mental illnesses (Abdulmalik et al. 2012). Thus elucidating pathways to care and the potential barriers that delay access to early interventions is a priority, particularly within contexts characterized by limited mental health resources (Morgan et al. 2006, O'Callaghan et al. 2010).

Mental health has long been neglected in health and public health practice-much as persons with mental disorders have been segregated and seen as different, unreal, and incurable (Kohn et al. 2004). A study was carried out in Sub-Saharan and the study shows apparent inter-regional differences. For example, six studies from countries (Ethiopia, South Africa, Zimbabwe)other than Nigeria reported that 50 % or more of their participants attended formal health services as their initial health provider, while this was the case in only three of the eight studies from Nigeria (Burns et al. 2015). In contrast, all five studies reporting a majority of participants attending traditional and religious healers as their initial providers, were from Nigeria (Burns et al. 2015).

There is good evidence for a considerable mental health treatment gap in low- and middle-income countries due to a lack of adequate infrastructure, human resources and treatment options (Kohn et al. 2004). Mental health services are poorly developed (Gureje et al. 2000). The treatment gap for serious mental disorders across low-income countries is estimated to be 89% (de Menil et al. 2015).

Today we can effectively treat many mental disorders. We have come a long way in being able to diagnose and treat the majority of people suffering from these illnesses, and treatments for mental disorders are better studied and more efficacious than those for many other common chronic human ailments. The main challenge now is to bridge the gap between science and service (Ustün 1999). Health services should be designed in such a way that it effectively in the real world. One key to accomplishing this is to conceptualize mental disorders as long-term and often recurrent conditions and to design disease management strategies accordingly (Kreyenbuhl et al. 2010). In spite of all these arguments (the burden, the gap, and the availability of cost-effective

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interventions) still there is not enough clarity and understanding about the obstacles that actually prevent low and middle income countries to improve mental health. The strong resistance to change and innovation to mental health care in most countries of the world have not been examined carefully. Some "reasons" to explain the fact that too little is happening in mental health in spite of the evidence, something effective can be done, have been provided: stigma about mental disorders prevent people to be treated, primary health care doctors are not properly equipped in recognizing and managing mild and moderate mental disorders (Evidence et al. 2006).

2.6 Beliefs and attitudes towards Epilepsy and Mental Health disorders

People living with epilepsy believed that the disease was caused by factors such as fever, demonic power, beatings, witchcraft, curses and God (Tanywe et al. 2016). Patients also had differing views as to whether the disease was contagious or hereditary. They indicated that the disease manifested as seizures, triggered by fever, stress, depression and anger (Tanywe et al. 2016). People living with epilepsy usually have both negative and positive experiences in their social relationships. The negative experiences were linked to the social, psychological and economic burden of the disease on patients, whereas the social support they got from friends, peers, family and community members were the positive aspects (Tanywe et al. 2016). Often epilepsy is not called by its name. For instance, in Africa, it is called the "burns disease," as a result of people falling into an open fire and not being helped for fear of their saliva contaminating others. For very similar reasons, in Asia it may be called "the drowning disease," and in the western world, "the hidden disease." (De Boer 2002).

In 1996, a study of carried out in Malay on aetiology of mental illness among 134 Malay patients. About 53% of the patients attributed their illnesses to supernatural agents. Witchcraft and possession by evil spirits were regarded as common causes of illness. Belief in supernatural causes of mental illness was not significantly associated with age, gender, level of education or occupation of the patients. Patients who believed in supernatural causes of mental illness were also found to show poor drug compliance (Razali et al. 1996).

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A study was conducted on the levels and experiences of harassment of people with mental health problems in the community compared with those of the general population and result shows that harassment in the community was found to be twice as common for individuals with mental health problems (41%) than for those in the general population (15%). The harassment commonly involved verbal abuse referring to the individual's mental health problems and was committed primarily by teenagers and neighbours (Berzins et al. 2003).

According to a study carried out in Nigeria to determine the knowledge and attitudes of a representative community sample shows that Most respondents expressed the view that substance misuse (alcohol or drugs, but mainly the latter) could result in mental illness, the next most commonly endorsed cause of mental illness was a belief that it could be due to possession by evil spirits. Following this, trauma, stress and heredity were about equally ascribed as possible causes. Only about one in ten respondents believed that biological factors respondents believed that biological factors or brain disease could be the cause of mental illness. Confirming a stronger belief in supernatural causation, over 9% thought supernatural causation, over 9% thought mental illness could result from punishment from God, whereas only about 6% thought poverty could cause mental illness.

The views about mental illness were generally negative. People with mental illness were believed to be mentally retarded, to be a public nuisance and to be retarded, to be a public nuisance and to be dangerous. It also shows that most respondents were unwilling to have social interactions with someone with mental illness. Most would be afraid to have a conversation would be afraid to have a conversation and would be disturbed to work with a person with mental illness. Only a few would be willing to maintain a friendship and fewer still would consider marrying such a person apart from evidence of a somewhat more liberal attitude of men and those residing in urban areas (Gureje, Lasebikan et al. 2005). Negative attitude to mental illness seems to be highly prevalent across many different groups in the community (Gureje et al. 2005)

2.7 Factors Affecting Pathways to care: Sociodemographic, Clinical Barriers and Facilitators

Studies have shown factors accompanying delay in seeking health care services. This article describes one such method through a model, which is the Cultural Formulation model, (It consists

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of five components, assessing cultural identity, cultural explanations of the illness, cultural factors related to the psychosocial environment and levels of functioning, cultural elements of the clinician–patient relationship, and the overall impact of culture on diagnosis and care), talking about culture has been a major factor on how and whether people access health care services (Lewis-Fernández et al. 2002). Parental awareness of child symptoms, parental perception of problems is the key initial step in the help-seeking process, but nevertheless, there are some factors such as the type and severity of disorders, parental perceptions, child age and gender, and family and social background factors determine which affected children access services (Sayal 2006). This study has shown that pathways to mental health care are influenced by multiple factors, including conventions governing referral systems, relationships between mental health services and other sources of help, and the availability and accessibility of mental health agencies and other agencies offering assistance (Gater et al. 1991). According to a family study carried out on Pathways to Mental Health Care for Children and Youth in Rural Communities highlighted personal facilitators to access and utilization of mental health services, which are word of mouth "It was serendipitous that families discovered ways to access services for their children. Families find out themselves. e.g I learned about Dr L. from a lady I work with who has two kids with disabilities" and advocacy (Boydell et al. 2006).

There are a number of factors contributing to the treatment gap for epilepsy in sub-Saharan Africa which are:

1. Inadequate supplies and costs of anti-epileptic medications
2. Lack of primary health workers trained to diagnose and treat epilepsy
3. Limited access to health facilities particularly in rural areas
4. Social stigma, misinformation, and traditional beliefs.
5. Limited opportunities for specialty training in neurology. (Chin 2012)

One cause frequently mentioned in literature is the influence of cultural beliefs on diagnosis and proper treatment (Meinardi et al. 2001).

This study identified a number of possible facilitators of help-seeking. These included emotional competence, knowledge, positive attitudes towards seeking professional help, social encouragement, and the availability of established and trusted relationships with professionals such as general practitioners (Rickwood et al. 2007).

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CHAPTER THREE

METHODOLOGY

3.1   Study Location

Located in South West Nigeria, Ibadan the site for the study is the third largest populated city in Nigeria which the metropolis consists of five urban and six rural local government areas. The study sites were two hospitals: the University College Hospital (UCH) (both Paediatrics Neurology Clinic and Child and Adolescent Psychiatric Clinic) and the New World Clinic (a private health facility).

The University College Hospital is a tertiary facility in Ibadan, which was officially opened to the public on 20th November 1957.The hospital is strategically located in Ibadan, then the largest city in West Africa which is also the seat of the first University in Nigeria.

It caters for many specialties. Paediatrics neurology and Child and Adolescent Mental Health have both in-patient and outpatient facilities. The Child and Adolescent Mental health Clinic is a multi-disciplinary centre within the University of Ibadan that caters primarily for the needs of Africa and the developing world in the areas of training, research and service in Child and Adolescent Mental Health (CAMH). Paediatrics neurology clinic started in 1962. Paediatrics Neurology has grown over the years from a unit in the department of surgery to become a full-fledged department of the hospital.

The New World Clinic is a private mental health facility established in 1993 primarily for Adults but children and adolescents are often seen there with psychiatric illnesses. It is located at Molete, Ibadan. Oyo State. It is run by a consultant psychiatrist and they attend to about 20 children and adolescents in a month.

3.2   Study Design

This was a comparative cross-sectional design investigating pathways to care among childhood epilepsy and psychiatric disorders.

3.3   Study Population

The study targeted at children and adolescents aged 0-18 years receiving services at the study sites and their guardians**.**

3.4   Sample Size

The sample size was derived using this formula for comparing both proportions;

$$n = \frac{(Z_\alpha + Z_\beta)^2 \, (P_1 \, (1 - P_1) + P_2 \, (1 - P_2) \,)}{(P_1 - P_2)^2}$$

Z_α = Standard normal deviation corresponding to a two sided level of significance of 5% (1.96)

Z_β = Standard normal deviation corresponding to a power of 80% (0.84)

P_1 = Proportion of outcome in group 1 (50%) (Lwanga SK 1991)

P_2 = Proportion of outcome in group 2 (70%)

n = 52 (number of participants) adjusted for non-response = n/(1-10%)

n= 57 (in each group).

3.5   Sampling Technique

Purposive sampling technique was used to select those who met the inclusion criteria over the 13 weeks of data collection. Purposive sampling is a type of probability sampling technique where the participants are selected based on their willingness to participate having met the inclusion criteria (Tongco 2007). This method was used based on the short period allocated for data collection.

3.5.1 Inclusion criteria:

1. Caregivers of children and adolescents aged 18years and below, with childhood epilepsy and psychiatry disorder.

2. Informed consent

3.5.2 Exclusion criteria:

1. Caregivers of children who are too acutely ill to participate in the study.

3.5.3 Data collection method:

A mixed method was used in this study (both qualitative and quantitative methods).

3.6   Study Instruments

Three instruments were used for this study. These included a socio-demographic questionnaire, the World Health Organization Pathway Encounter, Data Extraction Form. Details about the contents of each instrument are provided below. Informed consent form was also translated into Yoruba language for native study participants.

3.6.1 Modified Socio-demographic questionnaire:

This consists of questions relating to demographic characteristics modified from a previous adolescent study in this region (Omigbodun et al. 2008). This questionnaire was modified to capture data such as age, gender, religion, educational background of the child and the guardian.

3.6.2 Modified WHO Encounter Form:

The WHO Pathway Encounter form was developed for used for a multi-centre collaborative study in Eastern Europe (GATER et al. 2005). It has been used before on Nigerian adult population (Aghukwa 2012). It is a semi-structured questionnaire designed to collect data on the referral paths which patients take in the course of the illness, how long it takes to pass various modes in the path and how long it takes caregivers to present refer patient for services.
In this study the form was modified to add on questions on both epilepsy and psychiatry disorders. Also on the caregiver's belief as to the cause of the child's illness, as well as barriers to care at the various care points on the pathway.

3.6.3 Data Extraction Form:

It is a review of case notes made by doctors for both epilepsy and psychiatry disorders and also report of electroencephalogram (EEG) for epilepsy patients. The case note was used to extract data on diagnosis and other relevant data from the patient's note. Epilepsy disorders diagnosis was as a result of the clinical diagnosis and EEG report.

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Figure 3.1: Data collection Procedure Flowchart:

Data collection flow chart by a study done in Kenya was incorporated (Kamau et al. 2017)

```
┌─────────────────────────────────┐
│ Participants   selected   by   purposive │
│ sampling techniques              │
└─────────────────────────────────┘
              │
              ▼
┌──────────────────────────┐      ┌──────────────────────────────┐
│ Study procedure and informed │ ──► │ Met exclusion criteria.       │
│ consent explained         │      │ Thanked and excluded from     │
│                           │      │ the study.                    │
└──────────────────────────┘      └──────────────────────────────┘
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┌─────────────────────────────────┐
│ Met inclusion criteria.         │
│ Socio-demographic questionnaire & │
│ Encounter form administered to  │
│ guardian.                       │
└─────────────────────────────────┘
                │
                ▼
        ┌─────────────────────────┐
        │ Thanked for participation. │
        │ Data analysis.           │
        └─────────────────────────┘
```
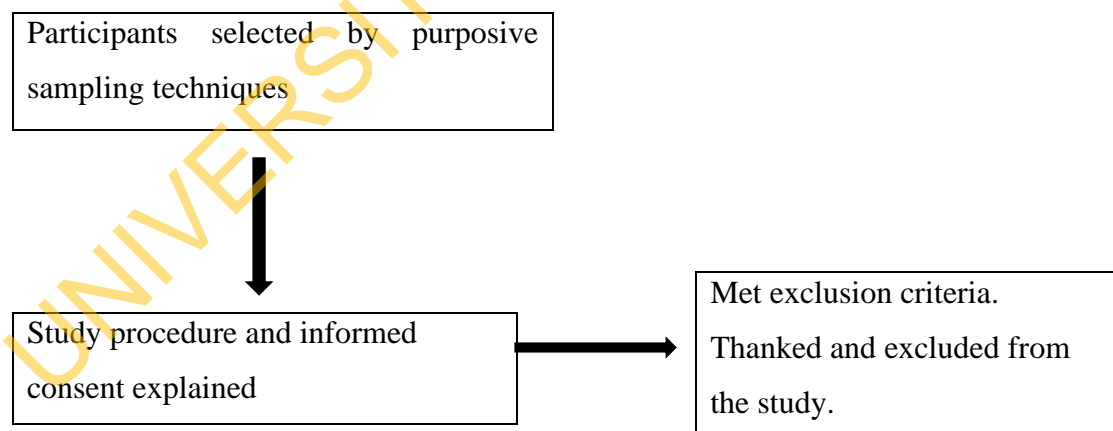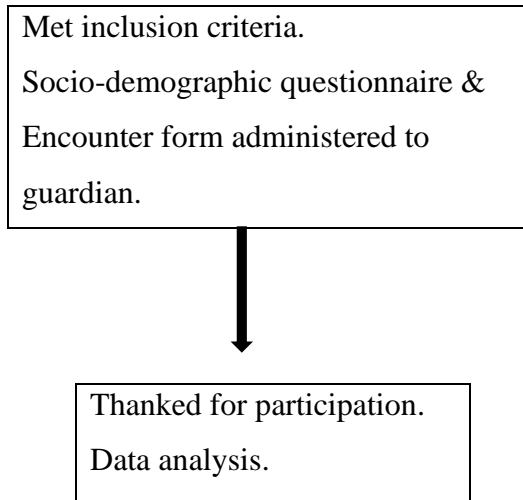
3.7   Data Management:

Data was cleaned and coded where appropriate and entered into a computer. Data entry and analysis was done using the Statistical Package for the Social Sciences version 20 (S.P.S.S 20). Socio-demographic and clinical variables were analysed and presented in frequencies or percentages. The Chi-square test was used to determine association between categorical socio-demographic and clinical variables and the type of pathway taken.

Kaplan Meier Survival analysis was applied for the analysis of time to the actual act of seeking help for medical services by the caregiver, and the exact time to seek help will be determined. Cox regression analysis was used to check whether the socio-demographic variables were related to the time taken to seek an intervention.

Computer assisted theme generation from the qualitative data was conducted using ATLAS Ti software.

The statistical level of significance was set at 5% ($p<0.05$).

3.8   Ethical Consideration:

Ethical approval to carry out this study was obtained from the University College Hospital Ibadan Ethics Review Board. All data collected from participants was kept confidential.

3.8.1 Consent

Informed written consent was obtained from the parent/caregivers after careful explanation of the study. It was made clear to participants that they could withdraw from the study at any time they so desired.

3.8.1 Voluntariness

It was made clear to the guardians that participation was strictly voluntary and the acquired information would be used for research purposes and that failure to consent would not affect their treatment at the hospital in any way. It was made clear to participants that anyone could withdraw from the study at any time so desired.

3.8.2 Beneficence to participants

There were no material gains to them from the study, and the main benefit to the participant was the projected improvement of service after. It was made clear that one could withdraw from the study at any time if they so desired.

3.8.3 Non-maleficence to participants

Participants who do not give their consent would not at any cost neither will it hinder them from receiving fair hospital services. Likewise those who consent to participate in the research, would neither receive financial gain nor gift in the course of this study.

3.8.4 Confidentiality

The study participants were assured of anonymity with no name or any form of identification that can be linked to them. Respective information gotten from participants were strictly used for the purpose of this study.

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CHAPTER FOUR

RESULTS

The findings from this study are presented in five sections. The first section gives a general description of the socio demographic and clinical characteristics of the study participants. The second section outlines the pathways to care of both groups of participants. The third section describes the socio-demographic and clinical factors associated with the pathways to care for both children with epilepsy and children with mental health problems. Sections four and five describe the perceived challenges experienced by patients and caregivers during the health care seeking process and their suggestions on ways to improve services for both the paediatrics neurology clinic and child and adolescent mental health services.

4.1: General description of the study sample

4.1.1: Socio demographic characteristics

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There were a total of 114 study participants enrolled into the study. Fifty seven study participants in each group for both childhood epilepsy and childhood psychiatry disorders. The mean age of all participants was 9.9 (SD=5.52) years.

The ages of the participants who presented at the paediatrics neurology clinic ranged from 8 months to 18 years with a mean age of 7.0 (SD=4.85) years while those of children presenting at the child Psychiatry clinic ranged from 2 to 18 years with a mean age of 12.74 (SD=4.61) years.

There were 33 (57.9%) males, and 24 (42.1%) females in the epilepsy group, while 31(54.4%) were males and 26 (45.6%) were females in the child psychiatry group. There was no difference in the male: female ratio between the two groups. See Table 1

Majority (75%) of the children in the epilepsy group were below 10 years while, majority (70.1%) in the psychiatry group were above 10 years old. This difference was statistically significant at p=<0.001. See Table 1

Majority (65.8%) in the epilepsy group were in pre-primary/primary class while, majority in the child psychiatry group (73.3%) were in secondary school. This difference was statistically significant at p<0.001. See Table 1 below.

Table 1: Socio-demographic characteristics of the study participants

Variable	Epilepsy group n (%)	Child Psychiatry group n (%)	X² (P-value)
Age group (years)			
0-5	27 (47.4)	4 (7.0)	31.728 (<0.001)
6-10	16 (28.1)	13 (22.8)	
11-15	10 (17.5)	19 (33.3)	
16-18	4 (7.0)	21 (36.8)	
Total	57 (100.0)	57 (100.0)	
Gender			
Male	33 (57.9)	31 (54.4)	0.142 (0.706)
Female	24 (42.1)	26 (45.6)	
Total	57 (100.0)	57 (100.0)	
Attending School			
Yes	37 (67.3)	45 (78.9)	1.945 (0.163)
No	18 (32.7)	12 (21.1)	
Total	57 (100.0)	57 (100.0)	
Present Class			
Pre-Primary/Primary	25 (65.8)	8 (17.8)	19.976 (<0.001)
Secondary & above	11 (28.9)	33 (73.3)	
*Others**	2 (5.3)	4 (8.9)	
Total	38 (100.0)	45 (100.0)	

*Others – Special School, Significant at (P<0.05)

4.1.2 Family Characteristics of the study participants

The primary guardians of both groups were majorly their biological parents; 52(91.2%) in the (childhood epilepsy and 50(87.7%) in the child psychiatry group had.

52(92.9%) the children in the epilepsy group had both parents alive but only 40(74.1%) in the child psychiatry group had both parents alive. This difference was statistically significant at P=0.004. (Table 2).

Fathers of children in the child psychiatry group were more likely to be unemployed than fathers of children in the epilepsy group (14.3% vs 100%). This difference was statistically significant at P=0.013. (Table 2).

There was no statistically significant difference in religion and educational status of parents between the two groups. See Table 2.

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Table 2: Family characteristics of the Study participants

Variable	Epilepsy group n (%)	Psychiatry Disorder n (%)	X^2 (P-value)
N=114			
Primary Guardian			
Biological parent	52 (91.2)	50 (87.7)	0.373(0.542)
Non-biological parent	5(8.8)	7(12.3)	
Total	57(100)	57(100)	
Parental status			
Both Parents Alive	52 (92.9)	40 (74.1)	8.111(0.004)
Single parent or orphan	4(7.1)	15(27.3)	
Total	56(100.0)*	55(100.0)*	
Father's Highest Level of Education			
Secondary school and below	16(28.1)	16(29.1)	0.043(0.836)
Post-secondary & University	41(71.9)	39(70.9)	
Total	57 (100.0)	55 (100.0)*	
Father's Occupation			
Professional	26 (45.6)	22 (39.3)	8.764 (0.013)
Non-professional	31 (54.4)	26 (46.4)	
Not Employed	0 (0.0)	8 (14.3)	
Total	57 (100.0)	56 (100.0)*	
Mother's Highest Level of Education			
Secondary & below	21(36.8)	23(40.4)	0.148(0.700)
Post-secondary & University	36 (63.2)	34 (60.7)	
Total	57 (100.0)	57 (100.0)	
Mother's Occupation			
Professional	21 (36.8)	17 (29.8)	0.650 (0.722)
Non-professional	31 (54.4)	34 (59.6)	
Not Employed	5 (8.8)	6 (10.5)	
Total	57 (100.0)	57 (100.0)	
Religion			
Christianity	36 (64.3)	41 (74.5)	1.717 (0.424)
Islam	20 (35.7)	14 (25.45)	
Total	57 (100.0)	57 (100.0)	

Professional – Up to University degree and job specification; Non-Professional – Requires little or no formal education

Asteric(*)- missing values, Significant at (P<0.05)

4.1.3 Neurological and Psychiatry Disorders in the Pediatric Neurology group study sample

Tables 3a and3b display the clinical characteristics of the 57 patients seen at the paediatrics neurology clinic.

Generalized epilepsy was the most common type of epilepsy disorder presenting at the paediatrics neurology clinic during this study 46 (80.7%), followed by partial epilepsy with 11(19.3%). See Tables 3a and 3b below.

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Table 3a: Types of Paediatric Neurological Disorders and Psychiatry Disorders in the Paediatric Neurology group of 57 study participants

Disorders	Number	%
Generalized Tonic Epilepsy		
Generalized Tonic Clonic Epilepsy	35	61.4
Absence Epilepsy	3	5.3
Atonic Epilepsy	1	1.8
Multifocal Epilepsy	2	3.5
Myoclonic Epilepsy	5	8.8
Partial Epilepsy		
Simple Partial Epilepsy	3	5.3
Complex Partial Epilepsy	8	14.0

The disorders are been classified with the use of clinical diagnosis combined with EEG report.

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Table 3b: Patterns of Neurological and Psychiatry Disorders among study participants presenting at Paediatrics neurology clinic

Disorders	Number	%
Generalized Tonic Epilepsy	46	80.7
Partial Epilepsy	11	19.3
Total	57	100

4.1.3 Psychiatry Disorders in the childhood psychiatry group

Neuro-developmental disorders were the most common type of psychiatry disorder presenting at the clinic during this study 30(52.6%), followed by psychotic disorders with 17(29.8%). Depression was diagnosed in 5(8.8 %) of the children and adolescents while Disruptive Disorders were diagnosed in 3(5.3%). See Tables 4a and 4b below.

Table 4b Frequency Distribution of types of Psychiatry disorders in the Psychiatry group of 57 study participants

Disorders	Frequency Number	%
Psychotic disorders and bipolar disorders		
Psychotic disorder	3	5.3
Bipolar disorders	5	8.8
Schizophrenia	7	12.3
Depression, Anxiety and related disorders		
Depression	3	5.3
Depressive psychosis	1	1.8
Adjustment disorder	1	1.8
Post traumatic stress disorder	1	1.8
Obsessive compulsive disorder	1	1.8
Somatoform Pain Disorder	1	1.8
Disruptive disorders		
Attention Deficit Hyperactivity Disorder	2	3.5
Conduct Disorder	1	1.8
Neurodevelopmental disorders		
Autism spectrum disorder	5	8.8
Intellectual disability	23	40.4
Others		
Substance use disorders	1	1.8
Organic mental disorders	1	1.8
Delayed developmental milestone	1	1.8

Table 4b: Frequency Distribution of Psychiatry disorders in Childhood Psychiatry group

Disorders	Number	%
Psychotics disorders and bipolar disorders	17	29.8
Depression, anxiety, and related disorders	5	8.8
Disruptive disorders	3	5.3
Neuro-developmental disorders	30	52.6
Others Psychiatry disorders	2	3.5
Total	57	100

4.2 Pathway to care for children with Epilepsy and Psychiatry disorders

Forty one of the children and adolescents (72.0%) out of fifty seven who presented at the paediatrics neurology clinic on account of epilepsy sought help in a private or public hospital while 24 (42.1%) of children and adolescents who had psychiatry disorders out of fifty seven first sought help from their religious leaders. This difference was statistically significant at p<0.001.

For the second intervention, 22 (46.8%) of caregivers of childhood epilepsy out of forty seven sought help from tertiary a facility while 20 (39.3%) of children with psychiatry disorders out of fifty one sought help in private or public hospitals. This difference was statistically significant at P<0.001. See table 5 below

There was also a statistical significant difference in the place of seeking a third intervention with 21(91.3%) of caregivers of childhood epilepsy seeking help from a tertiary facility while only 11(45.8%) sought help in private or public hospital for caregivers of childhood psychiatry disorders (P<0.001). See Table 5 below.

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Table 5: Pathways to care for childhood Epilepsy and childhood Psychiatry disorders after the onset of symptoms

	N=114		
Variable	**Epilepsy n (%)**	**Psychiatry Disorder n (%)**	**X² (P-value)**
First intervention			
Religious leaders	2 (3.5)	24 (42.1)	47.864 (<0.001)
Traditional healer	2 (3.5)	7 (12.3)	
Tertiary facility	10 (17.5)	8 (14.0)	
Other hospitals/Clinics	41 (72.0)	18 (31.6)	
Others	2 (3.5)	0 (0.0)	
Total	57 (100.0)	57 (100.0)	
Second intervention			
Religious leaders	4 (8.5)	4 (7.8)	32.964 (<0.001)
Traditional healer	10 (21.3)	5 (9.8)	
Tertiary facility	22 (46.8)	17 (33.3)	
Other hospitals/Clinics	9 (19.1)	20 (39.3)	
Others	2 (4.3)	5 (9.8)	
Total	47 (100.0)	51 (100.0)	
Third intervention			
Religious leaders	0 (0.0)	2 (8.3)	20.845 (<0.001)
Traditional healer	1 (4.3)	2 (8.3)	
Tertiary facility	21 (91.3)	9 (37.5)	
Other hospitals/Clinics	1 (4.3)	11 (45.8)	
Total	23 (100.0)	24 (100.0)	

Others – Medical Laboratory; Neighbourhood Nurse; Chemist, significant at (p<0.05)
Other hospitals/Clinics – Public hospitals; Private hospital; Primary health care

4.2.1 Initiators of contact for the various care sought after the onset of symptoms by study participants

Thirty eight (71.7%) of the caregivers of children and adolescents who had epilepsy while 25(48.1%) of children and adolescents who had psychiatry disorders had their primary caregiver as the initiator of first intervention to seek help. There was a statistical significant difference between the groups on who initiated the first intervention at (P=0.004) and who initiated the second intervention (P=0.010). See Table 6 below.

Table 6: Comparison of Initiators of contact for the various care sought after the onset of symptoms of Epilepsy and Psychiatry disorders

N=57

Variable	Epilepsy n (%)	Psychiatry Disorder n (%)	X^2 (P-value)
Who initiated the first intervention			
Primary Caregiver	38 (71.7)	25 (48.1)	15.337 (0.004)
Relative/friend	12 (22.6)	11 (21.2)	
Neighbours	0 (0.0)	2 (3.8)	
Medical practitioner	2 (3.8)	1 (1.9)	
Others	1 (1.9)	13 (25.0)	
Total	53 (100.0)	52 (100.0)	
Who initiated the second intervention			
Parent/Guardian	18 (39.1)	29 (59.2)	15.033 (0.010)
Relative/friend	12 (26.1)	7 (14.3)	
Neighbours	1 (2.2)	2 (4.1)	
Child's teacher	0 (0.0)	5 (10.2)	
Medical practitioner	14 (30.4)	4 (8.2)	
Others	1 (2.2)	2 (4.1)	
Total	46 (100.0)	49 (100.0)	
Who initiated the third intervention			
Parent/Guardian	10 (41.7)	15 (68.2)	8.218 (0.145)
Relative/friend	6 (25.0)	2 (9.1)	
Neighbours	1 (4.2)	2 (9.1)	
Child's teacher	0 (0.0)	1 (4.6)	
Medical practitioner	6 (25.0)	2 (9.1)	
Others	1 (4.2)	0 (0.0)	
Total	24 (100.0)	22 (100.0)	

*Others – Pastor & NGO

4.2 Time taken between interventions by caregiver after onset of symptoms

4.2.1 Time between onset of symptoms and the first intervention of the study sample

Table 7a shows the summary statistics of the time taken to seek help at each stage of intervention.

It took less than a week (0.14) for most of the caregivers of epilepsy group to seek any form of care while it was a month (4 weeks) for most of the caregivers of the childhood psychiatry disorder group to seek care after the onset of symptoms.

The median time (in weeks) between onset of the symptoms and seeking the first intervention was 2 weeks (IQR=30.86) for caregivers of epilepsy group while for psychiatry disorders the median time was 6 weeks (IQR= 96.50) at p=0.06.

At second intervention, it took within 4 weeks for caregivers of the epilepsy group to seek any form of care while it took within a week (0.14) for most caregivers of the childhood psychiatry disorders to seek care after the onset of symptoms.

The median time (in weeks) between the onset of the symptoms and seeking help at the second intervention was 22 weeks (IQR of 51.76) for caregivers with children or adolescent with epilepsy while for psychiatry disorders the median time (weeks) was 12 weeks with IQR of 100.50 weeks at p=0.61.

There was no statistical significant difference between the times taken at different interventions by caregiver after onset of symptoms to seek care. See Table 7a below.

Table 7

Summary Statistics of time taken (weeks) by caregivers after onset of illness symptoms to seek care

Event	Illness	Mean	Median	Mode	Range	Interquartile range	Chi-square	P-value
First intervention	Epilepsy	29.40	2.00	0.14	311.86	30.86	3.53	0.06
	Mental Health	94.82	6.00	4.00	779.86	96.50		
Second intervention	Epilepsy	45.43	22.00	4.00	207.86	51.76	0.26	0.61
	Mental Health	48.21	12.00	0.14	623.86	100.50		
Third intervention	Epilepsy	102.96	40.00	12.00	336.00	147.00	0.13	0.72
	Mental Health	53.04	24.00	4.00	332.00	40.00		

4.2.2 Time between onset of symptoms and the time taken to seek medical intervention at a tertiary facility

The median time taken between onset of symptoms and finally reaching the tertiary/specialist facility for childhood epilepsy was 52 weeks while it was 48 weeks for childhood psychiatry disorders. There was no significant difference in the median time (weeks) taken by caregivers of childhood epilepsy and childhood psychiatry disorders p=0.073. See Table 7b below.

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Table 7b: Test of equality of the survival distribution of the time taken (weeks) by caregivers after onset of illness symptoms to seek healthcare at tertiary facility

Illness	Median Survival Time (weeks)	Interquartile Range	Chi-square	P-value
Epilepsy	52.00	124.00	3.224	0.073
Psychiatry	48.00	91.00		

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4.2.3 Cox regression analysis of socio demographic independently associated with the time taken to seek care at the tertiary facility

Socio demographic factors were not significantly associated with the time taken to seek help after the detection of symptoms on survival analysis were taken through Cox regression analysis. Hazards ratio and 95% intervals from Cox regression for these factors are shown in table 8.

Fathers with primary level of education were more likely than those with post-secondary education (HR 20.5 95% CI=1.678-251.48) to delay taking a child to tertiary hospital after controlling for all other variables. Other variables such as age in years, present class, fathers' occupation, mothers' level of education, parental status, primary guardian, and religion were not independently significantly associated with time to tertiary hospital. See Table 8.

Table 8: Cox Regression model of the time taken to seek care at a tertiary hospital childhood Epilepsy & childhood psychiatric disorder

Variable	OR	95% CI	P-value
Age (years)	0.989	0.888-1.101	0.838
Gender			
Male	1.070	0.495-2.313	0.864
Female (ref)			
Present Class			
Pre-primary/primary	2.790	0.814-9.564	0.103
Secondary & above	1.924	0.520-7.118	0.327
Others (ref)			
Father's level of Education			
No formal education	0.349	0.0-2.223	0.895
Primary school	20.540	1.678-251.48	0.018
Secondary school	0.841	0.310-2.279	0.733
Post-secondary (ref)			
Father's Occupation			
Professional	0.196	0.014-2.697	0.223
Non-professional	0.137	0.009-2.079	0.152
Not Employed (ref)			
Mother's level of Education			
No formal education	0.049	0.02-5.787	0.673
Primary school	0.028	0.0-53.764	0.354
Secondary school	0.853	0.347-2.096	0.729
Post-secondary (ref)			
Mother's Occupation			
Professional	0.344	0.055-2.133	0.252
Non-professional	0.633	0.101-3.985	0.626
Not Employed (ref)			
Parental Status			
Both parent alive	0.061	0.002-2.226	0.128
Single parent	0.037	0.001-1.258	0.067
Orphan (ref)			
Primary Guardian			
Biological parent	182.907	0.0-2.744	0.960
Relative adult	83.149	0.0-1.250	0.966
Non-relative adult (ref)			
Religion			
Christianity	0.883	0.434-1.795	0.731
Islam (ref)			

4.3.1 Association of diagnosis of children with Epilepsy and pathway of care

Forty (87.0%) of children with generalized epilepsy were taken through medical pathways by their caregivers while 6(13.0%) were taken through non-medical pathway of care.

There was a significant association between generalized epilepsy and medical pathway taken by the caregivers of children with childhood epilepsy disorder at first intervention (P<0.01). See Table 9a below

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Table 9a: Association of diagnosis of children with Epilepsy and pathway of care

N=57

| Diagnosis | First Seen | | |
	Non-Medical [n(%)]	Medical [n(%)]	X^2 (P-value)
Generalized Epilepsy			
Yes	6(13.0)	40(87.0)	15.352(<0.01)
No	33 (48.5)	35 (51.5)	
Partial Epilepsy			
Yes	1 (9.1)	10 (90.9)	3.413(0.065)
No	38 (36.9)	65 (63.1)	

Significant at (p<0.05)

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4.3.2 Relationship between the type of childhood psychiatry disorder and pathway of care

Eleven (64.7%) of children with psychotics and bipolar disorders were taken through non-medical pathways by their caregivers while 6(35.3%) were taken through non-medical pathway of care.

There was a significant association between psychotics and bipolar disorders and medical pathway taken by the caregivers of children with childhood psychiatry disorder at first intervention (P=0.004). See Table 9b below.

There was a significant association between disruptive disorder and medical pathway taken by the caregivers of children with childhood psychiatry disorder at first intervention (P=0.015). See Table 9b below.

There was a significant association between neuro-developmental disorder and medical pathway taken by the caregivers of children with childhood psychiatry disorder at first intervention (P=0.034). See Table 9b below

Table 9b: Relationship between type of Psychiatry Disorder and pathway of care

N=57

Diagnosis	First Seen Non-Medical [n(%)]	First Seen Medical [n(%)]	x^2 (P-value)
Psychotic & Bipolar disorders			
Yes	11 (64.7)	6 (35.3)	8.255(0.004)
No	28 (28.9)	69 (71.1)	
Depression & Anxiety disorders			
Yes	2 (40.0)	3 (60.0)	0.078(0.780)
No	37 (36.7)	72 (63.3)	
Disruptive disorders			
Yes	3 (100.0)	0 (0.0)	5.925(0.015)
No	36 (35.1)	75 (64.9)	
Neuro-developmental disorders			
Yes	15 (50.0)	15 (50.0)	4.510(0.034)
No	24 (28.6)	60 (71.4)	
Others			
Yes	1 (50.0)	1 (50.0)	0.226(0.635)
No	38 (33.9)	74 (66.1)	

Others- Substance use disorder, Organic mental disorder, Urinary Retention

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4.3.3 Association between socio-demographic factors of the study participants in the paediatrics neurology group and the first intervention

For the purpose of analysis, the first intervention points were divided into medical (involving hospital settings) and non-medical interventions (involving non-hospital settings such as seeking an intervention from a religious leader or the traditional healer).

Age was not associated with pathway to care (P=0.230).

Males patients 31(93.9%) in the paediatrics neurology group sought help at the medical pathway than females participants 5(79.2) at first intervention. There was no statistical significant difference between both groups (P=0.094).

None of the personal socio-demographic characteristics were significantly associated with the pathways taken to care at first intervention.

See Table 10a below

Table 10a: Association between Personal Socio-demographic characteristics of patients with childhood Epilepsy and pathway of care

N=57

	First seen		
Variable	Non-Medical [n(%)]	Medical [n(%)]	X^2 (P-value)
Age (years)			
0-10	3 (9.3)	24 (90.7)	1.442(0.230)
11-18	1 (21.4)	15 (78.6)	
Gender			
Male	2 (6.1)	31 (93.9)	2.810 (0.094)
Female	5 (20.8)	19 (79.2)	
Attending School			
Yes	4 (10.8)	33 (89.2)	0.438 (0.508)
No	1 (5.6)	17 (94.4)	
Present Class			
Pre-Primary/Primary	1 (4)	24 (96)	4.286 (0.117)
Secondary & above	3 (27.3)	8 (72.7)	
Others*	0 (0.0)	2 (100)	

*Others – Special school

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4.3.4: Association between socio-demographic factors of the study participants in the childhood psychiatry disorders group and the first intervention

Ten (62.5%) children in the 0-10 years age group were taken through non-medical pathway by their caregivers as their first pathway to care, while 21(67.7%) older children aged 11-18 years (p=0.496) visited non-medical pathway by their caregivers. There was no significant association between age of the patient and pathway to care. See Table 10b below.

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Table 10b: Association between personal socio-demographic characteristics of patients with childhood psychiatry disorders and pathway of care

N=57

Variable	First seen		
	Non-Medical n(%)	**Medical n(%)**	X^2 **(P-value)**
Age (years)			
0-10	10 (62.5)	6 (37.5)	0.462 (0.496)
11-18	21 (67.7)	19(76.0)	
Gender			
Male	17 (56.7)	13 (43.3)	0.045 (0.832)
Female	14 (53.8)	12 (46.2)	
Attending School			
Yes	25 (56.8)	19 (43.2)	0.177 (0.674)
No	6 (50)	6 (50)	
Present Class			
Pre-Primary/Primary	6 (75)	2 (25)	1.397 (0.497)
Secondary & above	17 (53.1)	15 (46.9)	
Others*	2 (50)	2 (50)	

*Others – Special school

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4.3.5 Association between family socio-demographic characteristics of patients with childhood epilepsy disorders and pathway of care

There was no significant association between family socio-demographics and taking a medical or non-medical pathway to care.

See Table11a below.

Table 11a: Association between family socio-demographic characteristics of patients with childhood epilepsy disorders and pathway of care

N=57

Variable	First seen		
	Non-Medical	**Medical**	X^2 **(P-value)**
Primary Guardian			
Biological parent	7 (13.5)	45 (86.5)	1.376 (0.241)
Relative adult	0 (0.0)	5 (100.0)	
Non-Relative adult	0 (0.0)	0 (0.0)	
Parental status			
Both Parent Alive	6 (11.5)	46 (88.5)	0.506 (0.477)
Single Parent	1 (25)	3 (75)	
Father's Level of Education			
Primary School	0 (0.0)	1 (100)	4.985 (0.083)
Secondary School	0 (0.0)	15 (100)	
Post-secondary & University	7 (17.1)	34 (82.9)	
Father's Occupation			
Professional	2 (28.6)	24 (48.0)	0.969 (0.325)
Non-professional	5 (71.4)	26 (52.0)	
Mother's Level of Education			
Primary School	0 (0.0)	2 (100)	2.187 (0.335)
Secondary School	1 (5.3)	18 (94.7)	
Post-secondary & University	6 (16.7)	30 (83.3)	
Mother's Occupation			
Professional	4 (19.0)	17 (33.3)	2.300 (0.317)
Non-professional	3 (9.7)	28 (90.3)	
Not Employed	0 (0.0)	5 (100)	
Religion			
Christianity	4 (80)	1 (20)	0.439 (0.803)
Islam	3 (8.6)	32 (91.4)	

Relative adult – Aunt, Grandma, Uncle

Professional – Up to University degree; Job specification Non-Professional – Requires little or no formal education

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4.3.7 Association between family socio-demographic characteristics of patients with childhood psychiatry disorders and pathway of care

Mother's with secondary school level of education 9 (64.3%) sought help from non-medical pathway for childhood psychiatry disorders while 19 (55.9 %) of mothers with post-secondary & University degree level of education sought help from medical pathways. The more educated the caregivers were the more likely they would come to a medical facility. There is a statistically significant difference between mother's level of education and the pathways taken (P=0.015).

22(66.7%) of non-professional mother's sought help from non-medical pathways while 11(33.3%) of professional mothers sought help from medical pathways. There is a statistically significant difference between mother's highest level of education and the pathways to care taken (P=0.036). See Table 11b below.

Table 11b: Association between family socio-demographic characteristics of patients with childhood psychiatry disorders and pathway of care

N=57

	First seen		
Variable	**Non-Medical n(%)**	**Medical n(%)**	**X² (P-value)**
Primary Guardian			
Biological parent	28 (59.6)	21 (40.4)	5.565 (0.062)
Relative adult	3 (75.0)	1 (25)	
Non-Relative adult	0 (0.0)	3 (100)	
Parental status			
Both Parent Alive	21 (53.8)	18 (46.2)	3.567 (0.312)
Single Parent	10 (71.4)	4 (28.6)	
Orphan	0 (0.0)	1 (100)	
Father's Level of Education			
No Formal Education	1 (100)	0 (0.0)	6.740 (0.081)
Primary School	3 (100)	0 (0.0)	
Secondary School	8 (72.7)	3 (27.3)	
Post-secondary & University	19 (48.7)	20 (51.3)	
Father's Occupation			
Professional	11 (50.0)	11 (50.0)	2.022 (0.364)
Non-professional	16 (64.0)	9 (36.0)	
Not Employed	3 (37.5)	5 (62.5)	
Mother's Level of Education			
No Formal Education	2 (100)	0 (0.0)	10.441 (0.015)
Primary School	5 (100)	0 (0.0)	
Secondary School	9 (64.3)	5 (35.7)	
Post-secondary & University	15 (44.1)	19 (55.9)	
Mother's Occupation			
Professional	5 (29.4)	12 (70.6)	6.649 (0.036)
Non-professional	22 (66.7)	11 (33.3)	
Not Employed	4 (66.7)	2 (33.3)	
Religion			
Christianity	22 (91.70)	2 (8.3)	2.934 (0.231)
Islam	9 (33.3)	18 (66.7)	

Relative adult – Aunt, Grandma, Uncle, Significant at p<0.05

Professional – Up to University degree; Job specification Non-Professional – Requires little or no formal education

4.4 Barriers to accessing medical health care services

4.4.1 Perceived challenges experienced while seeking help for childhood Epilepsy

Table 12a reveals some perceived challenges experienced by caregivers in seeking help for childhood epilepsy. These challenges were classified as personal, hospital facilities and staff related.

Slightly over a third of participants 16 (37.2%) of caregivers interviewed revealed that they faced financial constraints while seeking help for their children with epilepsy. Also 16 (37.2%) mentioned the work and had to suspend or miss some working days in order to seek help for their wards.

Another challenge pointed out by the caregivers 7(16.3%) was hospital facilities related. They complained that there are bottlenecks in the system leading to unnecessary delays in getting help for their wards 1(2.3%). Poor health care facilities and the unwelcoming attitudes of staff in hospitals was another challenge faced by few caregivers 2(4.7%) while seeking help for children and adolescents with epilepsy. See Table 12a below

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Table 12a: Perceived challenges experienced while seeking help for childhood Epilepsy

		N=43	
	Theme	Number of mentions n (%)	Examples
Personal	Family issues	2 (4.7)	*"No family support"* *"Family issues"*
	Financial issues	16 (37.2)	*"Financial challenges"* *"Financial issues"* *"Stress & financial issue"*
	Work issues	16 (37.2)	*"Work, I have to suspend the day work,* *"it is like cancelling the whole day "*
Hospital Facilities	Distance	2 (4.7)	*"Distance"* *"Stress due to long distance to the clinic"*
	Delays	1 (2.3)	*"Delay at the hospital"*
	Stress of navigating the facility	4 (9.3)	*"UCH stress is too much, stress of navigating from one point to the other"*
Staff	Poor attitude/service	2 (4.7)	*"Doctors are not giving me satisfactory care"* *"Staffs are not accommodating"*

Table 12b: shows the perceived challenges experienced while seeking help for childhood psychiatry disorders.

From the information presented in the table below, financial constraint was the most commonly mentioned issue by caregivers 22(59.5%).

Others 4(10.8%) mentioned the distance to where clinics and hospitals are located for treatment of this disorder is quite far.

Some caregivers 4(10.8%) also complained of having to skip work in order to seek help for their wards. Other challenges witnessed while seeking help also included unnecessary delays due to bottlenecks within the hospital system 4(10.8%). See Table 12b below

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Table 12b: Perceived challenges experienced while seeking help for childhood Psychiatry Disorder

<div align="center">N=38</div>

	Theme	Number of mention n (%)	Examples
Personal	Family issue	1 (2.7)	*"Family issues*
	Financial issue	22 (59.5)	*"Financial constraints"* *"Financial crisis, we had to trek a bit before we took a cab to clinic"* *"Financial issues,* *"Lack of funds"*
	Time issue	1 (2.7)	*"Time is not on our side"*
	Parent availability	1 (2.7)	*"Parent availability"*
	Care giver's health	1(2.7)	*"caregivers health condition"*
	Work issue	4 (10.8)	*"Work"*
Hospital Facility	Distance	4 (10.8)	*"Journey is quite stressful,* *"Distance to clinic is quite stressful"*
	Stress of navigating the hospital protocol	4 (10.8)	*"Stressful"* *"UCH stress is too much, they can take ones' time unnecessarily"*

4.4.1b Caregivers' suggestions of ways to improve access to care at the paediatric neurology clinic

Of all 57 people who responded 33(57.9%) felt access to health care for childhood epilepsy will improve if the waiting time to getting health care is adjusted.

Other suggestions were reducing the consultation fee (19.3%), employing more doctors (1.8%), and also increasing public awareness about childhood epilepsy (3.5%).

See table 13a below

Table 13a: Caregiver's perception towards possible measures to improve access to care for childhood Epilepsy

<div align="center">N=57</div>

Theme	Number of mention n (%)	Example
Awareness	2 (3.5)	*"By creating awareness on how to seek proper help"* *"By creating public awareness"*
Get more staff	1 (1.8)	*"Employ more doctors "*
Time of the clinic	33 (57.9)	*"If the time can't be adjusted to be more favourable"* *"If the timing can be adjusted"* *"If the timing can be better.* *"The timing is poor"* *"Time issue"*
Time spent in the hospital	8(14.0)	"The time issue has to change, I spend a lot of time here"
Subsidize service	11 (19.3)	*"Subsidized fees"*
Okay service	2(3.5)	*"It is ok to some extent"* *"Things are getting better"*

4.4.1b Caregivers' perception towards possible measures to improve access to care for childhood Psychiatry disorders

Thirty (53.6%) of study participants felt the service currently rendered was good to some extent while others advised the clinic management to continue the good work (16.1%).

However, 20.0% of study participants talked about more awareness and health advocacy.

Also few participants (1.8%) felt the waiting room is small and hence, the ventilation need to be improved.

See Table 13b below

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Table 13b: Caregiver's perception towards possible measures to improve access to care for childhood psychiatry Disorder

		N=56
Theme	Number of mention n (%)	Examples
Awareness	9 (16.1)	*"If there could be awareness about this illness"* *"More advocacy"* *"More health education"* *"More health talk"*
Home Follow-up	1 (1.8)	*"We will appreciate if someone is assigned to keep up with patients' parent to encourage and follow-up on them when defaulted from clinic"*
Satisfactory Service	30 (53.6)	*"Everything is fine"* *"okay"* *"Service is good"* *"The service is ok to some extent"* *"The setting is okay"*
More staff	8(14.3)	*"Provision of more child psychiatrist"* *"Nearby speech therapist"* *"provision of special service for children with mental retardation"*
Subsidized service	3(5.4)	*"Subsidized services"*
Improve infrastructure	1 (1.8)	*"waiting room is small & poor ventilation"*
Others	4 (7.1)	*"Can't really say"* *"First time in clinic"* *"Need to put more effort"*

DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Discussion

This study was a comparative cross-sectional study carried out to examine and compare the various pathways to care taken by caregivers offer children and adolescents presenting at a paediatrics neurology clinic and child psychiatry clinic with epilepsy and psychiatry disorders respectively. There were a total of 114 children who took part in the study, 57 study participants in each group.

5.1.1 Sociodemographic Characteristics

The study participants in the paediatrics neurology group were aged 8 months 18 years with the mean age of 9.87(SD=5.52). A similar study in the same clinic had the mean age of 10.6 (SD=3.2) years (Lagunju et al. 2012) with male participants predominating in each study groups, the sample for the epilepsy group with (57.9%) male as well as (54.4%) male predominating the sample for psychiatry group.

The gender pattern observed among participants with childhood epilepsy in this study are similar to what has been reported in an epilepsy study in a tertiary facility (University College Hospital) with a total of 84 children and a higher proportion of male participants (54.8%) in an epilepsy study (Lagunju et al. 2012) and also a study conducted in Indiana University School of Nursing. reported same gender pattern among participants with childhood epilepsy. The sample consisted of 115 subjects with more males participants (51.3%) in an epilepsy study (Austin et al. 2000). This might suggest that epilepsy occurs more commonly in males. About two-third of the children in the epilepsy group were of school-going-age in this study; with a similar result of a study with 68.4% of all participants of school -age in an epilepsy study were attending school (Lagunju et al. 2012).

This study found out that of 127children and adolescents referred to a tertiary facility care in Ibadan, South west Nigeria had a mean age of 12.7 years, and a higher proportion of males (62%) presenting at the child and adolescent mental health clinic(Omigbodun 2004). This same study in 2004 in the Southwest of Nigeria also found over a quarter (27.6%) children not

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enrolled in school due to some psychiatry disorders (Omigbodun 2004). For comparison, a study from Kenya showed that about one tenth (10.2%) of children and adolescents who presented for similar reasons at tertiary health facility were not attending school. A reason for this differences maybe that users presenting to the tertiary health facility in the Southwest of Nigeria had more disabling disorders than in Kenya.

This study showed a failure to attend school among 18(32.7%) children with epilepsy and 12(21.1%) children with psychiatry disorders. This is in keeping with the observation by Kessler and colleagues that other individuals suffering from psychiatry and neurological disorders are more likely to have a truncated education due to the disability from the disorder(Kessler et al. 1995).

In this study, Generalized epilepsy (80.7%) were the most common type of epilepsy presenting at the paediatrics neurology clinic followed by partial epilepsy (19.3%) in keeping with Eriksson (Eriksson et al. 1997) Generalized seizure and epilepsy/syndrome types were more prevalent in children 0-6 years of age and partial/ localization-related in children 6-15 years of age (Eriksson et al. 1997).

Neuro-developmental disorders was the most common disorders (52.6%) then followed by Psychotic and bipolar disorders (29.8%) for childhood psychiatry disorders. A study conducted in an out-patient clinic in the Aminu Kano Teaching hospital in the Northern part of Nigeria revealed that the most disabling conditions were attention deficit hyperactivity disorder (80%), mental retardation (77.8%), epilepsy (64.1%) and psychotic disorders (50%) (Abdulmalik et al. 2012). A survey of 106 cases of children and adolescents patients attending a Teaching Hospital Psychiatric Clinic in Lagos, Nigeria revealed that about half of the children (49.1%) seen had a diagnosis of either a seizure disorder or mental retardation (Oshodi et al. 2010). In this study, psychiatry disorder in the epilepsy group was the only diagnosis that was statistically significantly associated with the pathway been taken. Two-thirds of children with psychiatry disorder were more likely to be taken through medical pathways by their caregivers.

In this study, over 60% of children and adolescent (<10 years) study participants in epilepsy group were attending school while over 70% of middle and late adolescents (>10 years) for psychiatry group were attending school. Despite the nature of their illness, this study affirms

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that children and adolescents with childhood epilepsy and childhood psychiatry disorders can still have their educational needs met and they shouldn't be discriminated from this right. People with epilepsy have many unmet needs in the areas of education, employment, residential and community services, and access to appropriate health care (de Boer 2010). Discrimination in access to education is not unusual for people affected by this conditions (de Boer 2010).

All other family sociodemographic factors (parental status and religion) were not found to be significantly related to service use in the current study for childhood epilepsy.

In this study, there was also significant association between mother's level of education and the pathway of care. The more educated they are the more likely they come to medical facility. There was an association between father's occupation, father been unemployed and presence of a psychiatry illness. In the child psychiatry group (14.3%) were significantly more likely to be unemployed than fathers in the epilepsy group. A reason for this could be that the stress of fathers' unemployment for psychiatry group is contributing to the child's mental health due to the stress encountered at home. This study observed that most of study participants came with their mothers to the clinic which revealed the association gotten from mothers occupation at P=0.036. However, a study revealed that children from poor family, experience a greater psychological distress compared to children who are not from a poor family background (McLeod et al. 1993). In this study, there was also significant association between mother's level of education and the pathway of care. The more educated they are the more likely they come to medical facility at P=0.015.

5.1.3 Factors in Pathways to care

This study identified medical pathway as the most used first point of care sought out by caregivers of children with epilepsy after the detection of the child's symptoms. In scrutinizing the "medical pathway" of care for childhood epilepsy, it was observed that almost all of the caregivers in the study sought for help at the University College Hospital, a tertiary facility as a last resort for Epilepsy only after having tried other hospitals/clinics (private, public and primary health care centres). A study carried to compare the pathways followed by Malay patients with psychoses and Malay patients with epilepsy to a tertiary health center in the northeastern area of peninsular Malaysia shows that the most popular pathway for both groups was first contact with traditional or alternative healers (Razali et al. 2008). This would appear to indicate a better understanding

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of epilepsy as a medical/neurological condition in Nigeria compared to Malaysia but a similar understanding of psychiatry illness as non-medical in both settings. Cockerell and colleagues revealed that patients with epilepsy may be subject to an increased risk of premature death from the underlying cause, or from the epilepsy in itself. This could be the understanding caregivers had that made them choose medical pathways as their first point of contact. Moreover, cultural belief could also be associated to this because African tends to belief the disorder is contagious compared to childhood psychiatry disorders so they tend to seek help from medical intervention to keep other relatives safe from contacting the disorder.

It appears to be the other way round for childhood psychiatry disorder, where 42.1% caregivers sought help at non-medical pathways first before reporting to the hospital. A Pathway to care study among a similar population conducted in Maiduguri in Northeast Nigeria, revealed that 34% of the participants with psychiatry disorders had been taken for care to traditional and religious leaders before presenting at the tertiary facility (Abdulmalik et al. 2012). A Similar study done in Kenya, which showed that half of the caregivers sought for help at Kenyatta National hospital, a tertiary facility as a first intervention for children with childhood psychiatrydisorders (Kamau et al. 2017). These surprising differences among caregivers towards pathways to care for psychiatrydisorders may reflect difference in attitude of caregivers in Kenya and Nigeria, possibly due to better awareness of the medical basis of mental disorders in Kenya than Nigeria. Approximately similar observations in an adult survey by The World Health Organization revealed that half of individuals seeking formal health care for mental disorders in Africa choose traditional and religious healers as their first care provider (Leonardi et al. 2002). This picture extends to the wider circle of low and middle income (LAMICs) in other parts of the world (Mkize et al. 2004). Caregivers appear to patronize these alternative form of care by traditional and religious healers is high particularly for psychiatrydisorders because African clients interpret psychiatryillness as bewitchment (Mkize et al. 2004) explaining why the caregivers seek help from non-medical pathways for childhood psychiatrydisorders. Study participants socio demogrraphic factors(age, gender, attending school, present class) were not found to be statistically associated to the pathways taken at first intervention for both disorders. Abdulmalik and colleague (Abdulmalik et al. 2012) children and adolescents are particularly vulnerable as they do not partake in the decision making

process, but can only seek care, at the discretion and through the pathways that the parents may choose.

In this study, over 90% of parents in the epilepsy group had both parents alive but only 74.1% in the child psychiatry group had their parent alive. However, it makes it more interesting because most information and the steps taken to seek care for their children is going to be a genuine one and not that the responsibility is been placed on majority of non-biological adults. There was a significant association between mother's level of education and the pathway taken for childhood psychiatry disorders, in this current study, it shows that the more educated their mothers are the more likely they come to a medical facility. Previous studies of selected groups in Nigeria have suggested that negative attitude to mental illness may be less pervasive among the well-educated (Odejide et al. 1979).

In this study, for childhood epilepsy, both male and female were more likely to be taken for medical intervention (93.9% males, 79.2% females). However the findings from this study is consistent with the study conducted earlier by Lagunju which found that more help was sought for males than females (Lagunju et al. 2012)

However, for the child psychiatry group, both male and female sought help from non-medical intervention (56.7% males, 53.8% females).The finding from a similar study by Kamau et al (Kamau et al. 2017) is consistent with this study, which found that more help was sought for males than females. In a study conducted in psychiatry hospital in Lagos revealed there were male preponderance in the gender of children brought to the clinic (Oshodi et al. 2010). The males in this study were more likely to be taken for intervention after the onset of symptoms compared to their female counterparts for both disorders. These studies though have not found reasons why more males than females are more likely to receive more attention health wise.

In a study carried out by Kamau and colleagues in Kenya (Kamau et al. 2017), the primary guardian was the key initiator to any first intervention after detection of symptoms and this was significantly associated with the shortened duration to help seeking behavior. However, medical practitioners were the main referral agents to child and adolescent mental health service. In the current study, the primary guardian was the key initiator of care at first intervention in either non-medical or medical intervention after detection of symptoms. Primary guardian been the key

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initiator is more likely because most participants in this study had their biological parents both alive. A finding in this study was that Medical practitioners played an important role in the 2nd and 3rd referral of more than a quarter of the study participants for childhood epilepsy. This demonstrates some epilepsy literacy and increased involvement of medical practitioners in pathways to care. In a study conducted in sub-Saharan Africa, particularly in rural region revealed that close family ties, communal living situation, and traditional belief systems undoubtedly influence the expression of stigmatization (Baskind et al. 2005). Baskind and colleague had proved that children and adolescents with epilepsy actually experience stigma, but the rate at which they are stigmatized is dependent on some factors associated with the individual. Relatives/friends 14.3% played an important role in the referral of childhood psychiatry disorders. Moreover, childhood psychiatry disorder is an illness that gets a lot of stigmatization which could make caregivers keep information about their children's illness strictly within the family setting. Many people with serious psychiatry disorders therefore face a double challenge. According to a study on stigma at the individual psychological level, it was discovered that while patients with psychiatry illness struggle with the symptoms and disabilities that result from the disease they are also challenged by the stereotypes and prejudice that result from misconceptions about mental illness (Corrigan 2002). Although religious leaders had been visited more by caregivers of study participants with childhood psychiatry disorders, they were hardly involved in the referral process with 4.1%, which is similar to a finding by Kauma (Kamau et al. 2017) in Kenya where it was found that with 166 study participants for psychiatry group, only 6% religious leaders referred caregivers, despite about 10% of the participants visiting them.

4.1.4 Time taken to seek care

The mean time taken by the caregiver to seek any type of intervention for childhood epilepsy was 29 weeks while the longest mean time was 102 weeks. For childhood psychiatrydisorders was 95 weeks median duration which was also the longest mean time in the current study. This finding is likely to be as a result of parents' social and cultural beliefs. One cause frequently mentioned in the literature is the influence of cultural beliefs on diagnosis and proper treatment (Leonardi et al. 2002). Many people with epilepsy believe that their seizures are due to supernatural forces and consequently spend considerable personal time and financial resources

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seeking remedies from traditional healers (Chin 2012). Even in one of the Sub-saharan countries (Ethiopia), people with epilepsy often feel stigmatized and may avoid seeking treatment (Shibre et al. 2006). Indeed, in the local setting, treatment is usually unavailable at the community level and patients frequently need to travel long distances for proper diagnosis and treatment as shown in North-eastern Nigeria. (Abdulmalik et al. 2012). Even where resources are available services are also often under-utilized because of widespread ignorance and supernatural beliefs about the etiology of mental illnesses (Abdulmalik et al. 2012). The consequence, therefore, is a long and tedious pathway to care for patients with psychiatry illness, especially children and adolescents. Kamau and colleagues were of the opinion that it could be as a result parents not been able to recognise the salient prodromal symptoms of mental health disorders as abnormal and only presented in crises (Kamau et al. 2017).

In the current study, the median survival time to seek care at the tertiary facility, (University college Hospital) for childhood epilepsy at the paediatrics neurology clinic was 52 weeks while for childhood psychiatrydisorders it took 48 weeks to present at the Center for child and adolescent mental health UCH. In contrast to the findings obtained in Kenya, caregivers of childhood psychiatry disorders sought help within a month which was as a result of school teachers involvement (Kamau et al. 2017). In line with Kamau study, if Nigeria school teachers are involved in these disorders (childhood epilepsy and childhood psychiatrydisorders) there's more likelihood that cases will be presented ealier. In keeping with a study done in department of psychiatry among children and adolescents in Aminu Kano Teaching Hospital revealed that, two thirds (64.5%) of the patients had been ill for longer than 6 months prior to presentation. 144 subjects (59.5%) had received no care at all, while 36.4% had received treatment from traditional/religious healers prior to presentation out of 242 patients diagnosed of childhood psychiatrydisorders (Abdulmalik et al. 2012). In this current study caregivers of children and adolescents with childhood epilepsy had medical pathways in all their stages of intervention , and yet they still ended up coming to the University College hospital, a tertiary facilty to access care may suggest that they are not getting proper improvement from all the medical hospitals/ services they had been incontact with. The delay in accessing proper care in which children and adeolescents with childhood epilepsy disorder is likely to be as result of inadequate management from the peripheral centres.

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4.1.5 Percevied barriers and measures to improve access to care for childhood epilepsy and childhood psychiatrydisorders

In this study, the delay in seeking care for childhood psychiatry disorder may be associated with the caregiver's cultural belief about the illness (with non-medical pathway as their first intervention at 42.1%), stigma (keeping child's illness within the family, which probably might have been the cause of relatives/friends been the second in percentage after primary guardian as the initiator of contact at first referral) and lack of caregivers knowledge about the illness. (Gureje et al. 2005) found that most people in the community would be afraid to have a conversation with someone known to have a mental illness and only a few would consider such a person for friendship (Being able to and sustain friendship is part of a child's normal social development). The closer the intimacy required for the interaction, the stronger the community's desire to keep a distance. Thus, less than 4% would consider marrying anyone with mental illness.

The first intervention for childhood epilepsy and childhood psychiatry disorder has a direct bearing upon child's wellbeing later in the next few years. Kamau found that the first step in help seeking for childand adolescent mental problem is the abilityof caregiver to recognise that the child has a problem (Kamau et al. 2017). In the current study, barriers to seeking can be influenced by various reasons like caregiversbeliefs, caregivers financialstatus, caregivers knowledge .e.t.c. Osungbade and colleagues found that in (Osungbade et al. 2011) face-to-face interviews were conducted with 365 adults without epilepsy. 12% attributed epilepsy to brain disorder, witchcraft (81.4%), destiny (49.8%), heredity (27.8%), and demonic possession (26.8%). (Kamau et al. 2017) also had same same pattern of caregivers thinking and their line of action with 12% of the caregivers thinking that the child's problem was spiritual in nature, and yet still brining their children for care in medical settings.

In this current study, personal barriers such as financial issues (37.2%) and work related issues (37.2%) were the major barriers to accessing care for caregivers of study participants with childhood epilepsy. While for childhood psychiatry disorders, personal barriers such as financial (59.5%) was the major barrier to care. A study revealed how Culture-influenced personal beliefs (knowledge about mental illness and stigma) were found to play a substantial role in shaping individuals' attitudes toward mental health services. negative attitudes towards

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seeking help generally (Jang et al. 2007), as well as concerns about cost, transportation or inconvenience, confidentiality, other people finding out, feeling like they can handle the problem on their own, and the belief that the treatment will not help (Gulliver et al. 2010).

Caregivers70.2% seeking care at neurology clinic at UCH, were of the opinon that the ease of access to care was problematic because of unfavourability of time in clinic and would have preferred a suitable time, where they get to go back home on time. 66.7% of care givers seeking care at child and adolescent mental and new world clinic spoke favourably about the quality of the services and they encouraged the training of more child psychiatrists. 20.0% of caregivers made mention of "more advocacy"and "awareness"as one of the possible measures to improve access to care for children and adolescent with childhood psychiatrydisorders. (Gulliver et al. 2010) who opined that strategies for improving help-seeking by adolescents and young adults should focus on improving mental health literacy, reducing stigma, and taking into account the desire of young people for self-reliance.

Conclusion

This study revealed that for childhood epilepsy, the most frequently used intervention was to access care in a hospital setting while for childhood psychiatrydisorder, was to access care in a non-medical pathway. At somepoint, some of the children might ended up not going through the medical pathway, which simply means that some children aand adolescents with childhood epilepsy and childhood psychiatrydisorders may not be exposed to the medical practitioners at all, but it's likely to experienced more for children and adolescents with psychiatrydisorders than epilepsy.

The caregivers in the study identified various interventions to address the barriers that are perceived, and if implemented, they would improve service delivery and encourage more service users to acess care through the proper pathways.

Study Limitations

This study was a comparative cross sectional descriptive study that relied on information on events that had already happened; recall of guardian may have been affected.

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This study was a purposive sampling technique, the sample may not be representative of all the children with epilepsy and psychiatry disorders.

Case note diagnosis was used.

Recommendations

Based on the study finding, the folowing recommendations are made:

1. **Increased community awareness**

   Increased knowledge and beliefs about these disorders will aid their recognition, management and Prevention of these disorders. This can also be done by adopting enlisted summarized strategy suggestions for improvement of mental health literacy in developing countries by Ganasen and colleagues for both disorders (Ganasen K A et al. 2008)

2. **Linkage of primary care centres with tertiary hospitals**: Omigbodun (Omigbodun 2001) highlighted some models on how to incorporate a cost effective model for increasing access to mental health care at the primary care level in Nigeria.

3. **Collaboration with alternative care system**: Collaboration between modern and traditional health care systems may also improve treatment accessibility. It is not a new idea to try to use traditional medicine as a way of maximizing epilepsy and psychiatry services for the community (Jilek 1971) and various models exist for working together with traditional healers (Freeman et al. 1992).

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4. **Further research**: The Clinics (Pediatrics Neurology Clinic, Centre for Child and Adolescent Mental Health and New World Clinic), should be looked caregivers' perception towards possible measures to increasing access to care for a better service to the society. More so, in line with this, suggestions were made by Omigbodun and colleague (Olayinka Omigbodun et al. 2003) on some simple measures mentioned that can be carried out for an immediate improvement in the service delivery within our institutions and primary health care centres.

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REFERENCES

Abdulmalik, J. O. and S. Sale 2012. "Pathways to psychiatric care for children and adolescents at a tertiary facility in northern Nigeria." Journal of Public Health in Africa 3(1): 4.

Adewuya, A. and R. Makanjuola 2009. "Preferred treatment for mental illness among Southwestern Nigerians." Psychiatr Serv 60(1): 121-124.

75

Aghukwa, C. N. 2012. "Care seeking and beliefs about the cause of mental illness among Nigerian psychiatric patients and their families." Psychiatr Serv 63(6): 616-618.

Alhazzani, A. A., et al. 2016. "Public awareness, knowledge, and attitudes toward epilepsy in the Aseer region, Saudi Arabia - A community-based cross-sectional study." Epilepsy Behav 63: 63-66.

Ambikile, J. S. and A. Outwater 2012. "Challenges of caring for children with mental disorders: Experiences and views of caregivers attending the outpatient clinic at Muhimbili National Hospital, Dar es Salaam-Tanzania." Child and Adolescent Psychiatry and Mental Health 6(1): 16.

Austin, J. K. and D. W. Dunn 2002. "Progressive behavioral changes in children with epilepsy." Progress in brain research 135: 419-427.

Austin, J. K., D. W. Dunn and G. A. Huster 2000. "Childhood epilepsy and asthma: changes in behavior problems related to gender and change in condition severity." Epilepsia 41(5): 615-623.

Baskind, R. and G. L. Birbeck 2005. "Epilepsy-associated stigma in sub-Saharan Africa: the social landscape of a disease." Epilepsy & Behavior 7(1): 68-73.

Berzins, K. M., A. Petch and J. M. Atkinson 2003. "Prevalence and experience of harassment of people with mental health problems living in the community." The British Journal of Psychiatry 183(6): 526-533.

Boydell, K. M., et al. 2006. "Family perspectives on pathways to mental health care for children and youth in rural communities." The Journal of Rural Health 22(2): 182-188.

Burns, J. K. and A. Tomita 2015. "Traditional and religious healers in the pathway to care for people with mental disorders in Africa: a systematic review and meta-analysis." Soc Psychiatry Psychiatr Epidemiol 50(6): 867-877.

Campbell-Hall, V., et al. 2010. "Collaboration between traditional practitioners and primary health care staff in South Africa: developing a workable partnership for community mental health services." Transcult Psychiatry 47(4): 610-628.

Chin, J. 2012. "Epilepsy treatment in sub-Saharan Africa: closing the gap." Afr Health Sci 12(2): 186-192.

Corrigan, P. W. 2002. "Understanding the impact of stigma on people with mental illness." 1(1): 16-20.

Cortina, M. A., et al. 2012. "Prevalence of child mental health problems in sub-Saharan Africa: a systematic review." Archives of Pediatrics & Adolescent Medicine 166(3): 276-281.

Davies, S., I. Heyman and R. Goodman 2003. "A population survey of mental health problems in children with epilepsy." Developmental Medicine & Child Neurology 45(5): 292-295.

De Bleser, L., et al. 2006. "Defining pathways." Journal of nursing management 14(7): 553-563.

De Boer, H. M. 2002. ""Out of the shadows": a global campaign against epilepsy." Epilepsia 43(s6): 7-8.

de Boer, H. M. 2010. "Epilepsy stigma: moving from a global problem to global solutions." Seizure 19(10): 630-636.

De Boer, H. M., et al. 2013. "ILAE/IBE/WHO Global Campaign Against Epilepsy: a partnership that works." Current opinion in neurology 26(2): 219-225.

de Menil, V., et al. 2015. "Cost-effectiveness of the Mental Health and Development model for schizophrenia-spectrum and bipolar disorders in rural Kenya." Psychological medicine 45(13): 2747-2756.

DeWalt, D. A., et al. 2004. "Literacy and health outcomes." Journal of general internal medicine 19(12): 1228-1239.

Eriksson, K. and M. Koivikko 1997. "Prevalence, classification, and severity of epilepsy and epileptic syndromes in children." Epilepsia 38(12): 1275-1282.

Evidence, W. H. O. M. H., R. Team and D. C. P. Project 2006. Disease control priorities related to mental, neurological, developmental and substance abuse disorders, World Health Organization.

Freeman, M. and M. Motsei 1992. "Planning health care in South Africa—is there a role for traditional healers?" Social Science & Medicine 34(11): 1183-1190.

Ganasen K A, P. S., S. D. J. Hugo C J and S. S. Emsley R A 2008. "Mental Health Literacy: focus on developing countries".

GATER, R., et al. 2005. "Pathways to psychiatric care in Eastern Europe." The British Journal of Psychiatry 186(6): 529-535.

Gater, R., et al. 1991. "The pathways to psychiatric care: a cross-cultural study." Psychological medicine 21(03): 761-774.

Gulliver, A., K. M. Griffiths and H. Christensen 2010. "Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review." BMC Psychiatry 10(1): 1.

Gureje, O. and A. Alem 2000. "Mental health policy development in Africa." Bull World Health Organ 78(4): 475-482.

Gureje, O., et al. 2005. "Community study of knowledge of and attitude to mental illness in Nigeria." The British Journal of Psychiatry 186(5): 436-441.

Hale, E. D., G. Treharne and G. Kitas 2007. "The Common-Sense Model of self-regulation of health and illness: how can we use it to understand and respond to our patients' needs?" Rheumatology 46(6): 904-906.

Ikwuka, U., et al. 2016. "Pathways to mental healthcare in south-eastern Nigeria." Transcult Psychiatry 53(5): 574-594.

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Jang, Y., et al. 2007. "Attitudes of older Korean Americans toward mental health services." Journal of the American Geriatrics Society 55(4): 616-620.

Jilek, W. G. 1971. "From crazy witch doctor to auxiliary psychotherapist–the changing image of the medicine man." Psychopathology 4(4): 200-220.

Johnson, E. K., et al. 2004. "The relative impact of anxiety, depression, and clinical seizure features on health-related quality of life in epilepsy." Epilepsia 45(5): 544-550.

Kamau, J. W., et al. 2017. "Who seeks child and adolescent mental health care in Kenya? A descriptive clinic profile at a tertiary referral facility." Child and Adolescent Psychiatry and Mental Health 11(1): 14.

Kessler, C., C. Foster and W. Saunders 1995. "Social consequences of psychiatric disorders, I: educational attainment." Am J Psychiatry 152.

Kieling, C., et al. 2011. "Child and adolescent mental health worldwide: evidence for action." Lancet 378(9801): 1515-1525.

Kisa, R., et al. 2016. "Pathways and access to mental health care services by persons living with severe mental disorders and epilepsy in Uganda, Liberia and Nepal: a qualitative study." BMC Psychiatry 16: 305.

Kohn, R., et al. 2004. "The treatment gap in mental health care." Bull World Health Organ 82(11): 858-866.

Kreyenbuhl, J., et al. 2010. "The schizophrenia patient outcomes research team (PORT): updated treatment recommendations 2009." Schizophrenia bulletin 36(1): 94-103.

Lagunju, B. and O. Takon 2012. "Mental health problems in Nigerian children with epilepsy: Associations and risk factors." Epilepsy & Behavior 25(2): 214-218.

Lagunju, I. B. A. 2013. "Complementary and alternative medicines use in children with epilepsy in Ibadan, Nigeria." African journal of medicine and medical sciences 42(1): 15-23.

Lau, R. R. and K. A. Hartman 1983. "Common sense representations of common illnesses." Health psychology 2(2): 167.

Leonardi, M. and T. B. Ustun 2002. "The global burden of epilepsy." Epilepsia 43(s6): 21-25.

Lewis-Fernández, R. and N. Díaz 2002. "The cultural formulation: a method for assessing cultural factors affecting the clinical encounter." Psychiatric Quarterly 73(4): 271-295.

Lwanga SK, L. S. 1991. "Sample size determination in Health Studies: A practical Manual. Geneva: World Health Organization."

McAndrew, L. M., et al. 2008. "Using the common sense model to design interventions for the prevention and management of chronic illness threats: from description to process." British journal of health psychology 13(2): 195-204.

78

McLeod, J. D. and M. J. Shanahan 1993. "Poverty, parenting, and children's mental health." American sociological review: 351-366.

Meinardi, H., et al. 2001. "The treatment gap in epilepsy: the current situation and ways forward." Epilepsia 42(1): 136-149.

Mkize, L. and L. Uys 2004. "Pathways to mental health care in KwaZulu-Natal." Curationis 27(3): 62-71.

Morgan, C., et al. 2006. "Clinical and social determinants of duration of untreated psychosis in the AESOP first-episode psychosis study." Br J Psychiatry 189: 446-452.

O'Callaghan, E., et al. 2010. "First episode psychosis and the trail to secondary care: help-seeking and health-system delays." Soc Psychiatry Psychiatr Epidemiol 45(3): 381-391.

Odejide, A. and M. Olatawura 1979. "A survey of community attitudes to the concept and treatment of mental illness in Ibadan, Nigeria." Nigerian medical journal: journal of the Nigeria Medical Association 9(3): 343.

Odejide, A. O., L. K. Oyewunmi and J. U. Ohaeri 1989. "Psychiatry in Africa: an overview." Am J Psychiatry 146(6): 708-716.

Olayinka Omigbodun and O. Esan 2003. "Reasons for consultation in the psychiatric out-patient clinic of a university teaching hospital in Nigeria: is this optimal use of psychiatrists' time and expertise?".

Omigbodun, O., et al. 2008. "Prevalence and correlates of suicidal behaviour among adolescents in southwest Nigeria." Int J Soc Psychiatry 54(1): 34-46.

Omigbodun, O. O. 2001. "A cost-effective model for increasing access to mental health care at the primary care level in Nigeria." Journal of Mental Health Policy and Economics 4(3): 133-140.

Omigbodun, O. O. 2004. "Psychosocial issues in a child and adolescent psychiatric clinic population in Nigeria." Social Psychiatry and Psychiatric Epidemiology 39(8): 667-672.

Oshodi, Y. and A. Erinfolami 2010. "Presentation and follow-up patterns of child and adolescent patients attending a teaching hospital psychiatric clinic in Lagos, Nigeria." Niger J Psychiatry 8.

Osungbade, K. O. and S. L. Siyanbade 2011. "Myths, misconceptions, and misunderstandings about epilepsy in a Nigerian rural community: implications for community health interventions." Epilepsy Behav 21(4): 425-429.

Oye Gureje, et al. 2015. "The role of global traditional and complementary systems of medicine in treating mental health problems."

Paasche-Orlow, M. K. and M. S. Wolf 2001. "The causal pathways linking health literacy to health outcomes." American journal of health behavior 31(Supplement 1): S19-S26.

Patel, V., et al. 2007. "Mental health of young people: a global public-health challenge." Lancet 369(9569): 1302-1313.

Razali, S., U. Khan and C. Hasanah 1996. "Belief in supernatural causes of mental illness among Malay patients: impact on treatment." Acta Psychiatrica Scandinavica 94(4): 229-233.

Razali, S. and M. M. Yasin 2008. "The pathway followed by psychotic patients to a tertiary health center in a developing country: a comparison with patients with epilepsy." Epilepsy & Behavior 13(2): 343-349.

Rickwood, D., K. Thomas and S. Bradford 2012. Help-seeking measures in mental health: A rapid review, Retrieved from saxinstitute: https://www. saxinstitute. org. au/wp-content/uploads/02_Help-seeking-measures-inmental-health. pdf.

Rickwood, D. J., F. P. Deane and C. J. Wilson 200. "When and how do young people seek professional help for mental health problems." Med J Aust 187(7 Suppl): S35-S39.

Russ, S. A., K. Larson and N. Halfon 2012. "A national profile of childhood epilepsy and seizure disorder." Pediatrics 129(2): 256-264.

Sayal, K. 2006. "Annotation: Pathways to care for children with mental health problems." Journal of Child Psychology and Psychiatry 47(7): 649-659.

Scott, R. A., S. D. Lhatoo and J. W. Sander 2001. "The treatment of epilepsy in developing countries: where do we go from here?" Bull World Health Organ 79(4): 344-351.

Shibre, T., et al. 2006. "Perception of stigma in people with epilepsy and their relatives in Butajira, Ethiopia." Ethiopian Journal of Health Development 20(3).

Shorvon, S. D. and P. J. Farmer 1988. "Epilepsy in developing countries: a review of epidemiological, sociocultural, and treatment aspects." Epilepsia 29 Suppl 1: S36-5

Sillanpää, M., et al. 1998. "Long-term prognosis of seizures with onset in childhood." New England Journal of Medicine 338(24): 1715-1722.

Sorketti, E. A. 2013. "Pathways to mental healthcare in high-income and low-income countries." International Psychiatry 10(2): 45-47.

Tanywe, A., C. Matchawe and R. Fernandez 2016. "The experiences of people living with epilepsy in developing countries: a systematic review of qualitative evidence." JBI Database System Rev Implement Rep 14(5): 136-192.

Tarun Dua, A. J., Anna Muscetta 2006. Nerological Disorders: Public Health Challenges.

Thornicroft, G., et al. 2007. "Stigma: ignorance, prejudice or discrimination?" Br J Psychiatry 190: 192-193.

Tongco, M. D. C. 2007. "Purposive sampling as a tool for informant selection." Ethnobotany Research and Applications 5: 147-158.

Ustün, T. 1999. "The global burden of mental disorders." American journal of public health 89(9): 1315-1318.

APPENDIX A

INFORMED CONSENT FORM (PARENT/GUARDIAN)

Title of research: Pathways to care among Children and Adolescents in Ibadan, Nigeria: Comparison between childhood epilepsy and childhood psychiatric disorders.

My name is Adebayo Adeola Oluwanifemi, a Nigerian psychologist in training, currently a student of Master of Science in Child and Adolescent Mental Health at the University of Ibadan, Nigeria. The purpose of this study is to find out and compare the pathways between childhood epilepsy and childhood psychiatric disorders in three study sites which are; University College

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Hospital (Ibadan), Ade-Oyo Maternity Hospital (Ring-road, Ibadan), New-world Clinic (Challenge, Ibadan).

I am asking for your permission as the caregiver to permit me to ask questions mainly regarding where did you sought for help in the course of the search for treatment(s)? How long did it take to pass the various modes in the path? What sign(s) or symptom(s) caused you to seek help from the hospital? This will be done using questionnaire as a guide to answering the questions and it will take about 45 to 50 minutes of your time to administer. Other than the questions been asked, there will be no procedure carried out on your child and more so, I however need to check the doctors note to see what he or she is being treated for specifically.

All information obtained from you in this study will be given code number and no name nor your identity will be recorded anywhere.

Participation in this research is entirely voluntary. It is your choice whether to participate or not and you may also choose to withdraw from participating in the study. If you choose to participate, please do answer the questions to your best ability. And if not, it would not cost you anything neither would it hinder you fair hospital services. There will be neither financial gain nor gift in the course of this study.

CONSENT FORM

As a caregiver of the child attending this clinic, I hereby give my consent to participate in this study and I fully understand the nature and purpose of this study.

Signature of the participant:_____   Date_____

Name:_____

FÓÒMÙ ÌGBÀYÀNDA LÓWÓ ÀWỌN ÒBÍ.

Àkólé iṣé ìwádìí: Ipa Ọ̀nà ìtójú láàárín àwọn ọmọdé àti ọ̀dọ́ ní Ìbàdàn, Nàìjíríà: Àfiwé láàárín àrùn wárápá nígbà ewe àti àìpé-ọpọlọ nígbà èwe.

Orúkọ mi ni Adébáyọ̀ Adéọlá Olúwanífẹ́mi, ọmọ bíbí orílẹ̀-èdè Nàìjíríà tí ń kẹ́kọ̀ọ́ nípa ìhùwà èdá ènìyàn. Ní báyìí mò ń kàwé lọ́wọ́ láti gba oyè kejì ìmọ̀ Sáyẹ́nsì lórí ètò ìlera ajẹmọ́pọlọ àwọn èwe àti ọ̀dọ́ ní Yunifásitì Ìbàdàn, Nàìjíríà.

Èròngbà iṣẹ́ yìí ni láti ṣe àfiwé àti ìwàdìí lórí ipa ọ̀nà ìtọ́jú àrùn wárápá ìgbà èwe àti àìpé ọpọlọ nígbà èwe láàárín agbègbè mẹ́ta ọtọ̀ọ̀tọ̀ ní ìlí Ìbàdàn, Nàìjíríà tí a ti yàn fún iṣẹ́ ìwádìí yìí, àwọn náà ni: Ilé-ìwòsàn gbogbonìṣe ti Yunifásitì Ìbàdàn (UCH), Ilé ìwòsàn ti aláboyún tí ń bẹ ní Adé-Ọ̀yọ́ Ring-road, Ìbàdàn, àti Ilé ìwòsàn New-word tó wà ní Challenge.

Mò ń bèrè fún ìyànda àti ìfàyègbà yín láti bẹ̀rẹ̀ àwọn ìbéérè tó ní i ṣe pẹ̀lú níbo, kín ni ìdí àti nígbà wo ni olùtọ́jú/alábọ́jútó gbọdọ̀ máa wá ìrànlọ́wọ́ nípa wíwá ìtọ́jú? Yóò tó bí i ìgbà wo láti la oníríuurú ipa ọ̀nà náà kọjá. Kín ni àwọn àmìn tí ó mú ọ wá ìrànlọ́wọ́ wá sí ilé ìwòsàn?

A ó ṣe èyí nípa lílo àwọn àtòjọ ìbéérè èyí tí yóà gbà tó bí iṣẹ́jú márùndínláàdọ́ta sí àádọ́ta nínú àkókò yín. Yàtọ̀ sí àwọn ìbèèrè wọ̀nyí tí a bèrè, kò sí àyẹ̀wò kankan tí a ó ṣe fún yín tàbí ọmọ yín.

Ẹ ni láti mọ̀ pé gbogbo ìdáhùn ni a ó pa mọ́ dáradára. A ó ṣe àwọn àtòjọ ìbéérè náà ní ọ̀nà tí ẹ ò fi nílò àti kọ orúkọ yín sí i lórí.

Àkíyèsí: o lè yàn láti má kópa nínú iṣẹ́ ìwádìí yìí, ó ní ẹ̀tọ́ láti yọwọ́ nígbàkúgbà tí ó bá wù ọ́. Bákan náà, ìdáhùn òtítọ́ tọkàntọkàn sí àwọn àtòjọ ìbéére yìí yóó ṣe ìrànlọ́wọ́ púpọ̀ fún ìgbérúsókè ààyé sí iṣẹ́ ìtọ́jú àti ìwòsàn àrùn ọpọlọ fún àwọn ènìyàn, tí yóó sì tún dín iye àwọn ènìyàn tí kò rí ààyè àti ànfàní sí iṣẹ́ ìtọ́jú ajẹmọ́pọlọ tí ó jẹ ojúlówó kù.

Ẹ jọ̀wọ́ ẹ ní láti mọ̀ pé ipinu yín láti ma kópa nínú iṣẹ́ ìwádìí yìí kò ní dí yín lọ́wọ́ láti ní ààyè sí iṣẹ́ ìwòsàn tó péye àtipé kò sí èrè tàbí ẹ̀bùn tí ó rọ̀ mọ́ kíkópa yín.

ÌJẸ́RÍSÍ: Ní báyìí tí a ti ṣe àlàyé lórí iṣẹ́ ìwádìí yìí fún mi lẹ́kùn-únrẹ́rẹ́, tí ohun tí iṣẹ́ náà dá lé sì yé mi pẹ̀lú, gẹ́gẹ́ bí i alábọ́jútó ọmọ tí ń wá sí ilé ìwòsàn yìí, mo gbà láti kọpa nínú iṣẹ́ ìwádìí yìí.

_____   _____

Ìbuwọ́lù Akópa   **Déétì Ọjọ́ Ìfọ̀rọ̀wánilẹ́nwò**

Letter of Assent

I have had the description of this research explained to me thoroughly in the presence and with the aid of…………………………………………………………………………………………

The purpose, methods, risks and benefit have also been explained in such manner that I understood and I am satisfied with the explanation.

I have been made to understand that my participation is voluntary and I may choose to withdraw from the research any time.

If at any time during the course of the study, I need further explanation or clarification, I have been told that I can freely enquire from the researcher.

During the study, my………………………………………………………………………..may also make enquires or seek clarification on my behalf.

Hence, I willingly give assent to the researcher to proceed with study.

DATE………………………………………………………………………………………….

NAME……………………………………………………………………………………………

THUMBPRINT…………………………………………………………………………………

STATEMENT OF PERSON BEARING WITNESS:

I bear witness that………………………………………………………………………………….fully understands the description of the research as explained by the researcher.

WITNESS' SIGNATURE……………………………………………………………….

WITNESS' NAME……………………………………………………………………………………

APPENDIX B:
B1: RESEARCHER DESIGNED SOCIO-DEMOGRAPHIC QUESTIONNAIRE

Socio demographic questionnaire

Date……………………

Client number……………………..

Date of Birth of child (day/month/year)………………………….

1. Age of child………….

2. Gender   a) Male   b) Female

3. Attending school?   a) Yes   b) No

4. If No, why?...

5. Grade in school……………………………………………………………………

6. Age appropriate   a) Yes   b) No

7. If No, why?..

8. Primary Guardian

   a) Biological parent
   b) Relative adult specify relationship…………………………
   c) Non-relative adult specify……………………………………
   d) Self
   e) Other (specify)

9. Parental status

   a) Both parents alive b) Single parent c) Mother d) Father e) Orphan

10. Level of Father's education

a) No formal education b) Primary school c) Secondary school   d) Post-Secondary (Not University) e)University degree and above f) others……….

11. Father's occupation……………………………………………………………

12. Father's average monthly income in naira ………………………………..

13. Level of Mother's education

a) No formal education b) Primary school c) Secondary school d) Post-Secondary (Not University) e)University degree and above f) others……….

14. Mother's occupation………………………………………………………………

15. Mother's average monthly income in naira………………………………………

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16. Do you practice any religion? a) Yes   b) No

17. If Yes, please specify
which…………………………………………………………………………………

B2: MODIFIED WHO ENCOUNTER FORM

Pathways Encounter Form

1. Basic Information

Date…………………………………..

Patient Number…………………………………

1.1 Date first seen at the Patient Support Centre/Adolescent Clinic at UCH/Ade-Oyo/ New World Clinic…………………………………………

1.2 Before your child got unwell, did you think mental health problems could affect children and adolescent?..

1.3 What was the first symptom developed by the patient?..............………………… long ago?(Months)………………………………

1.4 State your child's Diagnosis (if known)…………………………………………..…... If Diagnosis is unknown by guardian, why?……………………………………………………………………………………

2. The decision to first seek help

2.1 When your child first got unwell, what did you believe was the cause of the illness?
……………………………………………………………………………………………

2.2. Who was first seen?

a) Pastor   b) Traditional healer   c) UCH   d) Ade-oyo Hospital
e) Other hospital/clinic……………… f) Special school   g) Pediatrician
h) Chemist   i) Medical laboratory   j) Psychiatrist   k) Police l) others……………

2.3 How long ago (Months)……………………………………………………………

2.4 Who initiated first contact? (Who advised you on where to go?)
a) Self   b) Relative/Friends   c) Patient   d) Neighbors   e) Child's teacher
f) Medical practitioner   g) Workmates/Colleagues   h) Police
i) Media (TV, Radio, Newspaper, Internet)   j) Other…………………………………….

2.5 What symptom caused the decision to seek care………………………………….

2.6 If you did not seek help immediately (within a week),
why?...
   2.7 What were you told was the child's diagnosis?.............................……………………
   2.8 What treatment(s) was offered?

   ……………………………………………………………………………………………

3. The first Referral

3.1 Who was next seen?

a) Pastor b) Traditional healer c) UCH   d) Ade-oyo Hospital e) other
    hospital/clinic……………………….. f) Special school   g) Pediatrician
h) Chemist   i) Medical laboratory   j) Psychiatrist
k) Police   l) Other……………………………………...

3.2 How long ago? Months)……………………………………………………………

3.3 Decision taken by whom? (Who decided/advised you to see this person?)

a) Parent/Guardian   b) Relative/Family   c) Patient   d) Neighbors
 e).   Child's teacher   f) Medical practitioner   g) Workmates/Colleagues

 h).   Media (TV, Radio, Newspaper, Internet) i) Police   j) Other…………………….

3.4 What symptoms caused you to see the first referral?.....………………………………
3.5 What were you told was the child's diagnosis………………………………………

3.6 What treatment(s) was offered?...……………

4. Second Referral

4.1 Who was next seen?

a) Pastor b) Traditional healer c) UCH   d) Ade-oyo Hospital e) other
    hospital/clinic……………………….. f) Special school   g)
    Pediatrician
h) Chemist   i) Medical laboratory   j) Psychiatrist
k) Police   l) Other…………………………………….

4.2 How long ago? (Months)……………………………………………………..
4.3 Decision taken by whom? (Who decided/advised you to seek this person?)

a) Parent/Guardian   b) Relative/Family   c) Patient   d) Neighbors
 e).   Child's teacher   f) Medical practitioner   g) Workmates/Colleagues
h).   Media (TV, Radio, Newspaper, Internet)   i) Police   j) Other…………………

4.4 What symptoms caused the decision to seek second referral?…………………………

4.5 What were you told was the child's diagnosis? ……………………………………

4.6 What treatment (s) was offered?……………………………………………………

5. Concurrent Treatments

5.1 Are you still seeking other previous treatments?   a) Yes   b) No

5.2 If Yes, which
ones?..

5.3 Is your child being treated for another condition?   a) Yes   b) No

5.4 If Yes,
what?...

5.5 Does the other doctor know that your child attends this clinic?

    a) Yes   b) No

    If No,
why?...

Perceived barriers and challenges to the current child mental health services

5.1 What are the main problems you have encountered while seeking help for your child?
6.1.1: Personal

………………………………………………………………………………………………
………………………………………………………………………………………………
………………………………………………………………………………………………
…………………………………………………………………………………………

6.1.2: Hospital facilities

………………………………………………………………………………………………
………………………………………………………………………………………………
………………………………………………………………………………………………
…………………………………………………………………………………………

6.1.3: Staff

………………………………………………………………………………………………
………………………………………………………………………………………………
………………………………………………………………………………………………
…………………………………………………………………………………………

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6.1.4: Others

………………………………………………………………………………………………………
………………………………………………………………………………………………………
………………………………………………………………………………………………………
………………………………………………………………………………………………………

7. How do you think we can improve the provision of medical care to children with mental disorders?

a) ……………………………………………………………………………………
   ………………………………………………………………………………………..

b) ……………………………………………………………………………………
   …………………………………………………………………,…………………………..

c) ……………………………………………………………………………………
   …………………………………………………………………………………………..

8. Are you satisfied with the treatment(s) you are being offered?   YES   NO

If YES, how satisfied ?

………………………………………………………………………………………………………
………………………………………………………………………………………………………
………………………………………………………………………………………………………
………………………………………………………………………………………………………
………………………………

If NO, Why?

………………………………………………………………………………………………………
………………………………………………………………………………………………………
………………………………………………………………………………………………………
………………………………………………………………………………………………………
………………………………

QUESTIONNAIRES

B1: RESEARCHER DESIGNED SOCIO-DEMOGRAPHIC QUESTIONNAIRE

Socio demographic questionnaire

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Date……………………

Client number……………………..

Date of Birth of child (day/month/year)…………………………….

    1. Age of child in months ……….………….

    Age at diagnosis of epilepsy ………………….. months

    For how long has the child had epilepsy? ……………………… months

    For how long has child attended neurology clinic?............................. months

    2. Gender   a) Male   b) Female

    2. Attending school?   a) Yes   b) No
If yes, state present class …………………………………

3. If No,
    why?...

4. Grade in
    school………………………………………………………………………..

5. Age appropriate   a) Yes   b) No

6. If No, why?...

7. Primary Guardian
    f) Biological parent
    g) Relative adult specify relationship……………………………
    h) Non-relative adult specify……………………………………
    i) Self
    j) Other (specify)

8. Parental status

    b) Both parents alive b) Single parent   c) Mother d) Father e) Orphan

9. Level of Father's education

    a) No formal education b) Primary school c) Secondary school
    d) Post-Secondary (Not University)   e)University degree and above f) others……….
10. Father's occupation……………………………………………………

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11. Father's average monthly income in naira ……………………………………..

12. Level of Mother's education

a) No formal education b) Primary school c) Secondary school   d) Post-Secondary (Not University)   e)University degree and above f) others……….

13. Mother's occupation…………………………………………………………………

14. Mother's average monthly income in naira……………………………………………

15. Do you practice any religion? a) Yes   b) No

16. If Yes, please specify which…………………………………………………………

B2: MODIFIED WHO ENCOUNTER FORM

Pathways Encounter Form

1. Basic Information

Date…………………………………..

Patient Number…………………………………

1.1 Date first seen at the Patient Support Centre/Adolescent Clinic at UCH/ Ade-Oyo/New World Clinic ……………………………………

1.2 Before your child got unwell, did you think epilepsy could affect children and adolescent? YES NO

1.3 What was the first symptom developed by the patient?..

1.4 How long ago? (Months)……………………………….

1.5 State your child's Diagnosis (if known)…………………………………………………

1.6 Type of epilepsy……………………………………………………………………………….

1.7 Does the disease cause child any pain?...............(YES) (NO)

1.8 If Diagnosis is unknown by guardian, why?...

2 The decision to first seek help

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2.1 When your child first got unwell, what did you believe was the cause of the illness?..

2.2. Who was first seen?

    a) Pastor   b) Traditional healer   c) UCH   d) Ade-oyo Hospital
        e) Other hospital/clinic…………………………………………………….

    f) Special school   g) Pediatrician   h) Chemist   i) Medical laboratory
       j) Psychiatrist   k) Police   l) other

  2.3 How long ago (Months)…………………………………………………………………….

  2.4 Who initiated first contact? (Who advised you on where to go?)

    a) Self   b) Relative/Friends   c) Patient   d) Neighbors   e) Child's teacher
    f) Medical practitioner   g) Workmates/Colleagues   h) Police
        i) Media (TV, Radio, Newspaper, Internet)   j) Other………………….

  2.5 What symptom caused the decision to seek care…………………………………………….

  2.6 If you did not seek help immediately (within a week), why?..……………………………………………………………………

  2.7 What were you told was the child's diagnosis?…………………………………………………

 2.8 What treatment(s) was offered? …………………………………………………………………

3   The first Referral

  3.1 Who was next seen?   a) Pastor   b) Traditional healer   c) UCH   d) Ade-oyo Hospital   e) other hospital/clinic…………..   f) Special school   g) Pediatrician   h) Chemist   i) Medical laboratory   j) Psychiatrist   k) Police   l) Others…………………….

  3.2 How long ago? (Months)………………………………………………

  3.3 Decision taken by whom? (Who decided/advised you to see this person?)

  b) Parent/Guardian   b) Relative/Family   c) Patient   d) Neighbors

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e). Child's teacher   f) Medical practitioner   g) Workmates/Colleagues

h). Media (TV, Radio, Newspaper, Internet)   i) Police   j) Other………………………..

3.4 What symptoms caused you to see the first referral?…………………………………………

3.5 What were you told was the child's diagnosis…………………………………………………..

3.6 What treatment(s) was offered?..

4   Second Referral

4.1 Who was next seen?

a) Pastor   b) Traditional healer   c) UCH   d) Ade-oyo Hospital
   e) other hospital/clinic…………………….. f) Special school   g) Pediatrician
h) Chemist   i) Medical laboratory j) Psychiatrist   k) Police
      l) Other…………………………………………………….

4.2 How long ago? (Months)………………………………..

4.3 Decision taken by whom? (Who decided/advised you to seek this person?)

b) Parent/Guardian   b) Relative/Family   c) Patient   d) Neighbors

e). Child's teacher   f) Medical practitioner   g) Workmates/Colleagues

h). Media (TV, Radio, Newspaper, Internet) i) Police   j) Other…………………………

4.4 What symptoms caused the decision to seek second referral?……………………………

4.5 What were you told was the child's diagnosis?…………………………………………………

4.6 What treatment (s) was offered?……………………………………………………………

5   Concurrent Treatments

5.1 Are you still seeking other previous treatments?   a) Yes   b) No

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5.2 If Yes, which ones?..

5.3 Is your child being treated for another condition?　　a) Yes　　　　　　b) No

5.4 If Yes, what?...

5.5 Does the other doctor know that your child attends this clinic?

　　a) Yes　　　　　　　　b) No

　　If No, why?...

5.6 How controlled is the epilepsy?

………………………………………………………………………………………………………
…..
......

6　Perceived barriers and challenges to the current child mental health services

6.1 What are the main problems you have encountered while seeking help for your child?

6.1.1: Personal

……
……
……
………………………………

6.1.2: Hospital facilities

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…………

6.1.3: Staff

AFRICAN DIGITAL HEALTH REPOSITORY PROJECT

………
………
………
……………

6.1.4: Others

………
………
………
………

6. How do you think we can improve the provision of medical care to children with mental disorders?

d) ………
    ………………………………………………………………………………………..

e) ………
    ……………………………………………………………,…………………………..

f) ………
    ………………………………………………………………………………………..

7. Are you satisfied with the treatment(s) you are being offered?   YES   NO

If YES, how satisfied?

………
………
………
………
…………………………………

If NO, Why?