PATHWAYS TO CARE AT CHILD-ADOLESCENT MENTAL HEALTH SPECIALIST SERVICES AND PATIENT-PROVIDER PERCEPTIONS ABOUT THE SERVICES IN DODOMA, TANZANIA

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DECLARATION

I hereby declare that this research project is my original work and has never been presented or submitted to any other University or institution towards an attainment of a master's degree.

Where other sources of information have been used, the authors were duly acknowledged and listed in the references.

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CERTIFICATION

I hereby certify that this research project was written by Gema Peter Simbee (Dr), a student of the University of Ibadan, Centre for Child and Adolescent Mental Health and has been reviewed and approved by us.

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This work is dedicated to Tanzanian children and young persons with mental health problems. It is my belief that through this work a step further towards your better mental health will be achieved. Together we can.

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ACRONYMS

ADHD - Attention Deficit Hyperactivity Disorder

ASD - Autism Spectrum Disorder

CAMH- Child and Adolescent Mental Health

CAMHS- Child and Adolescent Mental Health Services

CGAS - Children Global Assessment Scale

CI - Confidence Interval

DALYs- Disability Adjusted Life Years

DSM - Diagnostic and Statistical Manual

HICs - High Income Countries

ID - Intellectual Disability

K-SADS- Kiddie Schedule for Affective Disorders and Schizophrenia

LMICs - Low and Middle Income Countries

MMHH- Mirembe Mental Health Hospital

MoHCDGEC- Ministry of Health, Community Development, Gender, Elderly and Children

OPD - Out Patient Department

PI - Principal Investigator

PTSD - Post Traumatic Stress Disorder

UDOM- University of Dodoma

SES - Social Economic Status

SSA - Sub- Saharan Africa

SPSS - Statistical Package for Social Sciences

ABSTRACT

Background: The global burden of child and adolescent mental disorders is well established to be high, and affecting 1 in every 5 children and adolescents. However, there is paucity of data on the magnitude of child and adolescent mental health problems in Tanzania, particularly at Mirembe Mental Health Hospital (MMHH), which is the only referral tertiary mental health facility in the country, and receives patients from all over Tanzania mainland. There is also little or no information about the pathways utilized by people whose children may require mental health care in Tanzania. Therefore, the purpose of the present study was to determine the magnitude and pattern of neuropsychiatric morbidity among children and young persons at MMHH; pathways used to access CAMHS; factors influencing such choices; and caregivers' and health workers' perceptions to CAMHS offered in Tanzania.

Methodology: This was a descriptive, cross sectional, hospital based observational study, which was conducted at the CAMH clinic of MMHH, in Dodoma. It comprised of two groups of participants: a) 354 children/young persons aged 6-24 years as well as their caregivers attending the clinic, that were recruited consecutively; and b) 27 MMHH health workers, comprising of the CAMH clinic staff, and the hospital health management team, that were purposefully sampled. Tools used in data collection were: Researcher designed Socio-demographic Questionnaire, WHO Modified Encounter Form, the Kiddie Schedule for Affective Disorders and Schizophrenia Present and Lifetime version, DSM 5, 2016 (K-SADS-PL DSM 5, 2016), the Children Global Assessment Scale (C-GAS), Modified Patients Assessment Care for Chronic Conditions (PACIC) and Modified Assessment of Chronic Illness Care for Mental Illness (ACIC). Data were analyzed using the IBM SPSS software for Windows Version 23. Descriptive statistics such as frequency and proportions and inferential statistics including Chi square and Fisher's exact tests to test association between categorical variables; and t test to compare means were used. A significance level

was set at 5%. Logistic regression analysis model was employed to determine the independent predictors of both choice of care pathways and delay in care seeking.

Results: The children and young persons who participated in the study were aged 6 to 24 years, with a mean of 16.72 years (SD: ±5.584) years. Only 57 participants (16.1%) were aged 6-9 years. There were more males thans females 209 (59.0%). Three quarters were residents of Dodoma. The health workers comprised of 14 males and 13 females, with age range of 30 to 60 years, mean 43.19 years (SD ±9.564). They were of different health cadres.

Epilepsy was the most prevalent condition (56.5%), followed by Intellectual Disability [ID] (17.5%), schizophrenia (16.4%), psychosis due to general medical condition [GMC] (13.6%) and depression (10.2%) as the top 5, most common conditions. There was also a high comorbidity rate in this study partcipants, with 45% having comorbidities and majority (89.0%) having 2-3 conditions.

In addition, the disorders were found to have a specific age and gender distribution. It was shown that depression ($p=0.003$), bipolar disorders ($p=0.012$), schizophrenia ($p<0.000$), psychosis due to GMC ($p=0.000$), cerebral palsy [CP] ($p<0.000$), ID ($p<0.000$), Attention deficit hyperactivity disorder [ADHD] ($p<0.000$) and Autism spectrum disorder [ASD] ($p<0.000$) were age related. On the other hand, gender was associated with having schizophrenia ($p=0.049$), substance induced psychosis ($p=0.004$), epilepsy ($p=0.009$), CP ($p=0.027$), and cannabis use disorder ($p=0.006$). It was also found that schizophrenia ($p=0.001$), enuresis ($p<0.000$), encopresis ($p=0.006$), epilepsy ($p=0.000$), CP ($p<0.000$), ID ($p<0.000$), ADHD ($p<0.000$) and ASD ($p<0.000$) were associated with more functional impairment compared with other conditions.

Parents were the main care initiators (89.0%). Forty seven percent used the non-medical care pathways in their first contact of care whereas 15.0% went directly to MMHH.

Predictors of choice of a non-medical pathway were: father's and mother's education being primary (AOR=0.27, p=0.032) and (AOR=3.25, p=0.032) respectively, belief that the cause of illness was high fever or other (AOR=0.01, p<0.000), caregivers reporting not knowing the cause of the child's illness (AOR=0.01, p<0.000) and reporting worry/tension about the child's condition (AOR= 3.55, p=0.022).

Mean time for seeking care at MMHH since the onset of symptoms was 66.8 months, with 69.5% reporting having not sought care within a week of onset of symptoms. Factors that were independently associated with delay in care seeking were: being cared for by single parents (AOR=2.71, p=0.018), having normal functioning (AOR=2.59, p=0.010), belief that the cause of illness was high fever or other (AOR=0.50, p=0.031), and having epilepsy (AOR=0.24, p=0.000).

Stigma (50.0%), long distance (42.4%), and financial constraints (34.5%) were found to be common barriers to care. With regards to patients' and caregivers' perceptions of CAMHS in Tanzania, the overall mean score was 1.83 (median 1.9, interquartile range 1.55) indicating poor support. Health workers' perceptions about CAMHS offered at MMHH had an overall mean score of 1.9 with median of 1.8 and interquartile range of 0.3, indicating limited to basic support.

Conclusion: The primary initiators of care were parents, and the first choice of care pathway for a large proportion of the population continues to be through non-medical services. This study provided evidence that neuropschiatric morbidity is high; and that generally CAMH services in Tanzania are poor, the population is unaware about available services, and are further hampered by financial and distance constraints. Thus, there is a high unmet need and huge treatment gap for children and young persons with neuropsychiatric problems. Concerted efforts aiming to promote public awareness and

services utilization are urgently required; as well as effective integration of CAMHS into district and primary care clinics.

Key words: Children, young persons, caregivers, health workers, mental disorders, pattern, pathways to care, delay in care seeking, perceptions about care, Dodoma, Tanzania

CHAPTER ONE

INTRODUCTION

1.1 Background

The World Health Organization (WHO) views mental health as an integral part of health and defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1948). The WHO's Comprehensive Mental Health Action Plan 2013-2020 (World Health Organization, 2013) emphasizes that "Mental health is a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community". WHO comprehensive mental health package is comprised of services such as promotion, prevention, treatment, rehabilitation, care and recovery, research and training. Furthermore, in its Child and Adolescent Mental Health Policies and Plans document section, WHO defines child mental health as "Optimal psychological development and functioning, positive sense of self, ability to manage thoughts, emotions and build social relationships; aptitude to learn and acquire an education; and having an opportunity to ultimately be able to have full participation in society" (World Health Organization, 2005).

However, it well-established that the burden of mental, neurological and substance use disorders exists among different age groups globally; such estimates among children and adolescents are 20%, with estimates of 10-20% in Africa (Belfer, 2008). These figures are extrapolated from global studies including low and middle income countries (LMICs) in the world. There are few African studies on child mental disorders and even the few are geographically unevenly distributed and with variable findings (Cortina, Sodha, Fazel, & Ramchandani, 2012). In Tanzania, the estimated point prevalence of severe mental disorders among children is 0.5% (Schulsinger & Jablesnsky, 1991).

The impact of untreated child and adolescent mental disorders may be severe and lifelong such as undermining compliance with health regimens, and reducing the capacity of individuals to be productive. It is also known that disorders such as conduct disorder related behaviours may persist into adolescence and are associated with substance use, juvenile delinquency, adult crime, antisocial behaviour, unemployment, interpersonal problems, and poor physical health (WHO, 2003). Despite these well documented negative impacts; studies have shown that many children and adolescents with mental health problems do not receive the help they need (Verhulst & Der Ende, 1997; Sourander et al., 2001).

Tanzania is located in the eastern Africa region directly just south of the Equator. It has an area of 945 000 km² and a population of 44.9 million (although recent World Bank estimates is 50 million), with half of the population being under 18 (National Census Report, 2012) and about two thirds (63.96%) of the population being under 25 years. Life expectancy is 59 years; and the under-five child mortality rate is 68 per 1000 live births (Tanzania & NSSP, 2003).

According to the Word Bank classification, Tanzania is a low income country, with a per capita expenditure on health of 5.6% of GDP (World Bank, 2012). The individual person's income in Tanzania is low, 67.9 per cent of the population live below 1.25 US dollars per day (UNDP, 2013). Poverty in Tanzania mainly affects the rural population, and about 80 per cent of the poor reside in rural areas. The rural population consists of 75 per cent of the total population (World Bank, 2012). As noted above, more than half of the country's population is under 18 years. Statistics also show that most of the poor in Tanzania are children, who lack access to adequate health services, nutrition and education, all of which are necessary for their optimal mental, physical and psychological development.

Health services in Tanzania are organised in such a way that there are primary, secondary and tertiary levels of care. The referral process also follows that order from the lower level to the tertiary. Generally, the health care system has clear and sound strategic plans and policies

guides, however, there are great discrepancies in the actual implementation of services, particulary for CAMHS. The challenges faced by children in accessing mental health care in Tanzania are enormous and need to capture the attention of all stakeholders, in order to have a better nation.

In a report on 'Development of a Mental Health Policy and System in Tanzania', Mbatia and Jenkins in 2010, gave a picture of mental health system in Tanzania. They showed that at the tertiary level, mental health care was provided at the referral specialist neuropsychiatric hospital in the country, MMHH, in Dodoma; at Muhimbili National Hospital psychiatric unit, Dar es Salaam and at Mbeya Referral Hospital psychiatric unit, Mbeya (Mbatia & Jenkins, 2010). The authors further stated that mental health care service is provided at the 29 regional psychiatric units in the country, and district hospitals whereby at both levels there are about 20 inpatient beds reserved for mental health. At the primary care, services are provided at dispensaries and health centers which are mainly manned by nurses and clinical officers who received some training in mental health. The report further suggests that "Mental health appears as an integral component of health care at all levels, with defined interventions from primary care to tertiary hospitals" and that "mental health is integrated into primary care in most regions in mainland Tanzania".

Human resource in mental health is a challenge in Tanzania. According to the mental health atlas, 2014 it shows that in Tanzania there are 0.04 psychiatrists per 100,000 population. Furthermore, there is no child and adolescent psychiatrist in the country. Other cadres of mental health such as psychiatric nurses, psychologists and social workers are also in acute shortage. Therefore, based on the different challenges such as acute shortage of human resource, availability of skilled mental health professionals, availability of comprehensive mental health services, availability of psychotropic medication, accessibility factors, stigma,

poverty and lack of awareness of mental health/illnesses; the pathways to mental health care in general and those for child mental health care in Tanzania may be variable.

For years, scholars have looked into the role of traditional healing system in mental health. In Tanzania, it is reported that most people view psychiatric illness not as disease but as a curse, a product of both witchcraft and evil spirits of which the patients themselves were counted as the main contributor (Mbatia & Kilonzo, 1996; Njenga, 2002). It is known that the help seeking behaviour usually is determined by many factors, such as the local belief on the causes of the illness and the availability of health services within the locality. For example, more than two decades ago, Schulsinger and Jablesnsky found that 25.5% of patients with psychiatric complaints in a primary care setting had already consulted a traditional healer (Schulsinger & Jablesnsky, 1991**).** Over more than a decade later, (Ngoma, Prince, & Mann, 2003) found twice the number of people with mental disorders (48%) sought help from the traditional healers than those who went to the primary care clinics. Although this study did look at an adult population in a large urban primary care level setting, it still provides a useful framework for exploring pathways to mental health service use in a Tanzanian context and in particular at Mirembe Mental Health Hospital, where I did my study.

1.2: Operational definitions

Adolescent: Adolescence is defined as a period of transition between childhood to adulthood. The World Health Organisation defines it as a period between 10 to 19 years (WHO, 2005). In this study, children and adolescents will be defined as those aged 0 to 19 years of age. **Young person:** a young person is someone aged 10- 24 years (WHO, 2005), and that will be the definition in this study. **Caregiver:** a person who provides direct care (as for children, elderly people, or the chronically ill) [Merriam-Webster Dictionary]. The synonyms are carer, caretaker, and guardian. The Cambridge English Dictionary defines a caregiver as someone who takes care of a person who is young, old or sick). **Pathways to care** is defined

as the sequence of contacts with individuals and organizations prompted by the distressed person's efforts, and those of his or her significant others to seek help, as well as the help that is supplied in response to such efforts **(**Rogler, 1993).

1.3: Problem statement

Globally, the burden of child and adolescent mental disorders is estimated to be 10-20% (Belfer, 2008; Cortina et al, 2012). In Tanzania, a study conducted about 3 decades ago estimated the point prevalence of severe mental disorders to be 0.5% (Schulsinger & Jablesnsky, 1991), however; there is a paucity of recent data on the magnitude of CAMH problems. A few recent studies such as those by McCrann, Lalor and Katabaro, 2006; Messo, 2013; Manji and Hogan, 2013; Ngongi, 2013; Vagi *et al.*, 2016 and Lwidiko *et al.*, 2018 have been conducted, with variable findings on child mental health psychopathologies, and the studies are mainly on community samples, with almost non- existent data on clinical samples.

Mirembe Mental Health Hospital is the only referral tertiary mental health facility in the country, and receives patients from all over Tanzania mainland, with a population of about 50 million people. The hospital caters for all Tanzanians including the 64% of the 50 million Tanzanians who are under 24 years. The hospital lacks data on the pattern of psychiatric morbidity and pathways that people use when seeking mental health care although generally reports show that about 48.0% use traditional healing system for mental health care(Ngoma, Prince, & Mann, 2003) before later going to general hospitals or psychiatric facilities or access both systems of care concurrently.

1.4: Study justification

This study findings will generally throw light on CAMHS in Tanzania and pathways to care so that CAMH care needs are identified at MMHH as a mental health specialist facility, services are improved and scaled up, resources are better planned and prioritized, policies are

informed and CAMHS at lower levels are strengthened. In addition, the impact of this study will honor and put in practical terms the United Nation's Goal Number Three (SDG 3) of the Sustainable Development Goals in the 2030 Agenda for Sustainable Development, UN (2015) which stresses the importance of health in its totality, 'Ensuring healthy lives and promote well-being for all at all ages', children included. Furthermore, the global vision, as stipulated in the Mental Health Action Plan (2013 – 2020) "A world in which mental health is valued, promoted, and protected, mental disorders are prevented and persons affected by these disorders are able to exercise the full range of human rights and to access high-quality, culturally appropriate health and social care in a timely way to promote recovery, all in order to attain the highest possible level of health and participate fully in society and at work free from stigmatization and discrimination"

1.5: Research questions

1. What are the pathways patients take before they access CAMHS at MMHH and the factors influencing such choices?
2. What are the patterns of neuropsychiatric morbidity among children and adolescents attending a clinic at MMHH?
3. What are the factors limiting access to CAMHS at MMHH as reported by patients and caregivers?
4. What are the perceptions to CAMHS in Tanzania from patients, caregivers and health workers?

1.6: Aim

To determine pathways to child-adolescent mental health specialist services and patient-provider perceptions about the services in Dodoma, Tanzania.

1.7: Specific objectives

1. To determine the pathways to CAMH care, as well as factors influencing such choices.
2. To determine the pattern of neuropsychiatric disorders among children and young persons attending at MMHH.
3. To determine the barriers to care as reported by patients and caregivers as they access CAMHS at MMHH.
4. To determine the perceptions to CAMH services in Tanzania from patients, caregivers and health workers.

1.8: Outcome measures

Primary outcomes: Types of pathways to care (medical/non medical) for CAMHS

Secondary outcomes: Factors influencing choice of pathways to care (socio-demographic and clinical characteristics), pattern of neuropsychiatric disorders, barriers to care, perceptions of CAMH care received by patients and caregivers, and that offered by health workers at MMHH.

CHAPTER TWO

LITERATURE REVIEW

2.1: Burden of child and adolescent mental disorders globally

Globally, the burden of mental, neurological and substance use disorders among different age groups is well established, and mental health disorders are known to be one of the leading causes of disability worldwide (WHO, 2002). Three of the ten leading causes of disability in people between the ages of 15 and 44 are mental disorders, and the other causes are often associated with mental disorders (Merikangas et al., 2009). Furthermore, mental disorders have being found as the leading cause of disability in those aged 0-24 years, accounting for a quarter of all Years Lived with Disabilty (YLDs) [54.2 million] (Erskine et al., 2015). Another review paper reported a total number of incidents Disability Adjusted Life Years (DALYs) in those aged 10–24 years to be about 236 million, representing 15·5% of total DALYs for all age groups, with Africa having the highest rate of DALYs for the 10=24 age group, which was 2·5 times greater than in high-income countries (208 *vs* 82 DALYs per 1000 population). It was also found that worldwide, one of the three main causes of YLDs for this age group were neuropsychiatric disorders accounting for 45% of YLDs (Gore et al., 2011). However, a recent study by Vigo and colleagues estimated the global burden of mental illness to be 32·4% of YLDs and 13·0% of DALYs, instead of the earlier estimates suggesting 21·2% of YLDs and 7·1% of DALYs. They further argued that the currently used approaches underestimated the burden of mental illness, and based on their estimates they placed mental illness a distant first in global burden of disease in terms of YLDs, and leveled with cardiovascular and circulatory diseases in terms of DALYs (Vigo, Thornicroft, & Atun, 2016). This should be a wake up call to all involved in mental health from policy makes to clinicians.

2.2.1: Global pattern of psychiatric morbidity among children and young persons

Global estimates show that 1 in 5 adolescents has a recognizable and treatable mental disorders (Belfer, 2008). And from data of a nationally representative sample of 18 years and older in America, it is known that half of all lifetime cases of mental disorders start by age 14 years and three quarters by age 24 years (Kessler et al., 2005). It is also known that the global pattern of psychiatric morbidity among children and adolescents varies with region, in Australia for example, a study of 4-17 years revealed a 12 months' prevalence of 13.9%, with the commonest mental disorder being Attention Deficit Hyperactivity Disorder (ADHD) (7.4%), followed by anxiety disorders (6.9%), major depressive disorder (2.8%) and conduct disorder (2.1%). There was a variation of the prevalence with regard to gender where it was found that 16.3% of males and 11.5% of females, which was mainly accounted for by the higher prevalence of ADHD in males (10.4% compared with 4.3% for females). Conduct disorder was also more common in males (2.5%) than females (1.6%). However, the rate of depression was slightly higher in females (3.1% compared with 2.5% in males) (Merikangas et al., 2009).

In the US, in the 2001-2004 National Health and Nutrition Examination Survey which had a sample of 3042 children aged 8 to 15 years, the findings indicated that the twelve-month prevalence rates of DSM IV mental diagnoses were 8.6% for ADHD, 3.7% for mood disorders, 2.1% for conduct disorder, 0.7% for panic disorder or generalized anxiety disorder, and 0.1% for eating disorders. Boys had 2.1 times greater prevalence of ADHD than girls, girls had twofold higher rates of mood disorders than boys, and there were no gender differences in the rates of anxiety disorders or conduct disorder. Only approximately one half of those with one of the disorders assessed had sought treatment with a mental health professional (Merikangas et al., 2010).

In India, a meta-analysis involving sixteen community based studies on 14594 children and adolescents; and seven school based studies on 5687 children and adolescents, reporting prevalence of child and adolescent psychiatric disorder showed the prevalence of the disorders in community to be 6.46% and that in the school to be 23.33% (Malhotra & Patra, 2014).

2.2.2: Pattern of psychiatric morbidity among children and young persons in sub Saharan Africa (SSA)

In Africa, estimates for child mental disorders are approximately 10-20% (Belfer, 2008) although these figures are extrapolated from global studies or other low and middle income countries (LMICs) in the world. This is due to the fact that generally there are relatively few African studies on child mental disorders and that there is an uneven geographical distribution of those few studies that have been done and with variable findings (Cortina et al., 2012).

For example, in a systematic reviews of epidemiological data for mental disorders across all ages and countries, results showed that the mean global coverage of prevalence data for mental disorders in ages 5–17 years was 6.7% (Conduct disorder: 5.0%, ADHD: 5.5%, Autism Spectrum Disorder (ASD): 16.1%, Eating disorders: 4.4%, Depression: 6.2%, Anxiety: 3.2%). The collective mean coverage for all high income countries (HIC) was 26.4% and that for LMICs was 4.5%. It was also noted that of 187 countries, 124 had no data for any disorder and that many LMICs were poorly represented in the available prevalence data, for example, no region in SSA had more than 2% coverage for any disorder (Erskine et al., 2017).

In a meta-analysis involving community-based studies with a total of 9713 children from 6 SSA countries (South Africa, Kenya, Uganda, Ethiopia, Nigeria) that assessed the general psychopathology of children aged 0 to 16 years, the findings showed that 14.3% of children were identified as having psychopathology and that 9.5% had a specific psychiatric disorder. It also showed that the most common disorders were emotional problems such as depression, anxiety disorders, conduct, disruptive, and reactive behaviour disorders and PTSD; and that

boys tend to have higher rates of behavioural disorders, whereas girls tend to display more emotional disorders (Cortina et al., 2012).

Some other studies such as that in Ethiopia, among 1477 children in Butajira district in the southern part of the country, found that 3.5% of the children had one or more mental disorders, the most frequent disorders being anxiety (1.6%), ADHD (1.5%), disruptive behavior (1.5%), mood (1%) and elimination (0.8%) (Ashenafi et al., 2001). In South Africa, on the other hand, a systematic review for studies from 1985 to 2002 showed an overall prevalence of 25.0% for adults and 17.0% for children and adolescents. It further showed that the most common disorders among children and adolescents were generalised anxiety disorder (11.0%), followed by PTSD and major depressive disorder/dysthymia (both 8.0%) (Kleintjes et al., 2006).

Another study among 427 young persons aged 10-24 years attending psychiatric clinics in Benin city, Nigeria showed schizophrenia to be the commonest diagnosis 24.8% (n=106) while depression, mania and unspecified psychosis accounted for 74 (17.3%), 49 (11.5%) and 36 (8.4%) respectively (Ogboghodo et al., 2018).

2.2.3: Pattern of psychiatric morbidity among children and young persons in Tanzania

Child and adolescent mental health is a field in its early stage of practice in Tanzania. There is no recent major survey either community or hospital-based study in_Tanzania to capture the different specific mental disorders. A study conducted almost 3 decades ago estimated the point prevalence of severe mental disorders among children to be 0.5% (Schulsinger & Jablesnsky, 1991).

The few available studies have given a snapshot of the magnitude of such disorders in Tanzania. For example, in a 2009 unique experience of bomb blasts from a military base in Tanzania, at Mbagala area, Dar es Salaam, which involved 26 deaths, 600 casualties and

destruction of 9049 homes. A study was conducted among 520 bomb survivor children and found a 93% prevalence of PTSD symptoms (Messo, 2013).

Some studies have been done among children with neurodevelopmental disorders. For example, a survey of eight centers catering for children with special needs, which are mainly located in Dar es Salaam and the North-East part of the country, found the prevalence of 437 children (Manji & Hogan, 2013).

Furthermore, in the Ngongi study among 2193 primary school pupils in Kinondoni municipality, Dar es Salaam (54.6% females, and mean age of 8.81, SD=1.62) (Ngongi, 2013) found prevalence of ADHD symptoms to be 7.4% (n=162) with male to female ratio of 1:1 (82 and 80 children respectively). She also found that the most prevalent subtype was the combined (4.9%) followed by the inattentive (1.9%) and the hyperactive/ impulsive type (0.5%). Of interest, she found that children whose families had history of conflict were approximately 15 times more likely to have ADHD symptoms as compared to those with no family conflict (OR, 14.58, 95% CI: 9.74-21.83), and also being born prematurely (less than 37 weeks of gestational age) was approximately 3 times more likely to have ADHD symptoms.

Pertaining to the burden of other mental health problems among children in Tanzania, for example, in a 2009 household survey of a nationally representative sample of females and males aged 13-24 years, showed that about three in 10 females and one in eight males experience some form of childhood sexual violence before the age of 18 years, and that the health consequences were severe (Vagi et al., 2016). Yet another study in one of the universities in Tanzania which sampled 487 students and assessed for previous history of child sexual abuse found an overall prevalence of 27.7%, with higher rates for females than males. In addition, the average age of victims when abused was 13.8 years. It was also found that

generally perpetrators were unidentified by the respondents (McCrann, Lalor, & Katabaro, 2006).

Another study which was carried out in the Southern Highlands Zone of Tanzania among a cohort of 900 children and adolescents with HIV and non HIV found the overall prevalence of depressive symptoms to be 12.9%, with 27% of HIV-infected and 5.8% of HIV-uninfected participants respectively (Lwidiko, Kibusi, Nyundo, & Mpondo, 2018).

There has been a number of community-based studies on substance use disorders. Research indicates that as early as the 1970s and 80s an increased use of cannabis among youth in Tanzania was noted and as many as 5% of pupils in some primary and secondary schools had been exposed to drugs of abuse (Kilonzo & Maselle, 1986). More recent data from the Global Students Health Survey (Nyandindi, 2008), revealed that in Dar es Salaam, the prevalence of current alcohol use among students (i.e., drinking at least one drink containing alcohol on one or more of the past 30 days) was 5.1% (3.8-6.4) (MoHSW, 2008). Cigarette smoking has also been found to be a problem where a study among Injection Drug Users showed that they started smoking as early as 10 years of age by taking cigarettes (56.2%), followed by cannabis (34.8%); alcohol (8%) and poly-drug use (1%) (Msami, 2004). The overall prevalence of smoking for adolescents in schools aged 10-19 years in Tanzania was estimated at 5.5% (male 6.5% and female 4.4%). Following on that Mokiti (1999) reported that the prevalence of smoking in adolescence aged 11-15 years in Arusha municipality was 7.9% (male 11.2% and female 5.3%).

In Dodoma, Simbee (2012) found an overall prevalence of substance use among youth of 14.6%, with the commonest substances used being inhalants (7.6%), alcohol (6.8%), tobacco (3.7%) and cannabis (2.0%).

2.3: Pathways to Mental Health Care

Common pathways to mental health services have generally been described. However, the model pathway adapted may vary in the varied global sociocultural and health systems. For example, a pathway model outlined by Golberg and Huxley (1980) made an assumption that majority of patients seek help by first contacting their general practitioner. This assumption is supported by Harrison *e*t al., (1997) study in the United Kingdom which showed the majority of patients are more likely to go to their GP as a first contact and some (just under a quarter) access psychiatric services via the general hospital. However, in another part of the world, in China for example, a study showed that approximately three-quarters of the patients took an indirect pathway (74.8%) and on average, each patient consulted 3.4 caregivers. The vast majority of patients first visited local tertiary general hospitals (56.4%) or local secondary general hospitals (24.8%) (Zhang et al., 2013).

The pathways are influenced by factors such as socio-demographic, clinical and health system structure. The pathways taken may be influenced by conventions governing referral, relationships which exist between mental health services and other sources of help and by the availability/accessibility of mental health and other helping agencies (Gater et al., 1991).

In sub Saharan Africa (SSA), the picture of pathways to mental health care vary somewhat from other parts of the world. Model pathways are determined by shortage of mental health human resources, limited resources and perceived high cost of biomedical care. Hence a common pathway to mental health care is the traditional healing system (Ae-Ngibise et al., 2010). In Ghana, research shows that as high as 48% of patients contacted non-psychiatric treatment centres (faith-based, traditional healers and general medical practitioners) as their first point of contact for treatment of mental disorders (Ibrahim et al., 2016). Other SSA countries such as Uganda (Nsereko et al., 2011), Ethiopia (Bekele, Flisher, Alem, & Baheretebeb, 2009), Malawi (Kauye, Udedi, & Mafuta, 2014) and Tanzania (Ngoma, Prince

& Mann, 2003) and (Mwansisya, Outwater, & Liu, 2015) support the observation that a greater percentage of the population use traditional healing services as first contact of care.

2.3.1: Pathways to adult mental health services and factors influencing choice of such pathways: global studies

Different pathways to mental health services have generally been described and generally these pathways share common features, however the sociocultural and economic context determine how these pan out in reality. In two different multicentre studies conducted by Gater and colleagues, the first conducted about three decades ago, examined referral pathways taken by 1554 patients newly referred to the mental health services in 11 countries. It was found in centres that had relatively good psychiatric staff general practitioners were a key pathway and to a lesser extent hospital doctors, whereas their relatively less well-resourced centres showed a variety of pathways with native healers often playing an important part. Furthermore, it was shown that overall there were short delays in receiving services in all centres regardless of psychiatric resources, but in some centres longer delays to biomedical services were found on pathways involving native healers (Gater et al., 1991). In the second study, involving eight Western countries which was done more than a decade ago, findings revealed major pathways to be general practitioners, direct access and hospital doctors (Gater et al., 2005).

Similarly, in the United Kingdom (UK), a study among 286 patients, mean age 40.0 years (SD=13.4) showed that about two-thirds of the sample have had their first contact with a GP, whereas just under a quarter reached psychiatric services via the general hospital. (Harrison et al., 1997). Of factors associated with duration of pathways, the study found the distribution of the interval to care from being first seen by a health professional to reaching specialist psychiatric care ranged from less than one week to 10 years. The median was three weeks, and the mean was unexpectedly high at 12 weeks. Several factors were identified as contributory

to the delays in reaching specialist psychiatric care including younger age and presence of suicidal ideation being associated with shorter pathways. However, older age, married status, somatic symptoms, anxiety and depression were associated with slower pathways. It was also observed that being referred via accident and emergency departments of hospitals or general hospital wards were associated with reaching psychiatric services in less than three weeks. Moreover, the introduction of the community mental health team was associated with an average lengthening of time to specialist care (Harrison et al., 1997).

In another part of the world, in China for example, a study in an urban north area among 441 mentally ill patients at a tertiary level facility revealed that approximately three-quarters of the patients took an indirect pathway (74.8% vs 25.2%, $\chi 2 = 108.8$, $p < 0.0001$), and on average, each patient consulted 3.4 caregivers. The vast majority of patients first visited local tertiary general hospitals (56.4% vs 4.1%, $\chi 2 = 138.3$, $p < 0.0001$) or local secondary general hospitals (24.8% vs 4.1%, $\chi 2 = 40.96$, $p < 0.0001$). However, for the patients who first visited non-psychiatric hospitals, only 9.6% of patients were diagnosed with mental disorders whereas of those who first contacted psychiatry hospitals, 55.6% received a professional diagnosis and finally reached the tertiary level facility because of the poor treatment or high-cost medical care (Zhang et al., 2013).

2.3.2: Pathways to adult mental health services and factors influencing choice of such pathways: studies in Africa

In SSA, the picture of pathways to mental health care is a bit different from that of other parts of the world. The shortage of mental health human resources, limited resources and perceived high cost of care are deterrents. Hence these are likely among the factors that determine the traditional healing system as the pathway of choice. In Ghana for example, a study using a mixed method approach of semi structured interviews and focus group discussions aimed at exploring factors that support or obstruct collaboration between traditional healers and public

sector mental health services. Factors such as cultural perceptions of mental disorders, the psychosocial support afforded by such healers, as well as their availability, accessibility and affordability were found to be associated with more appealing use of traditional healing system (Ae-Ngibise et al., 2010).

In another study in Ghana, Ibrahim and colleagues conducted a cross-sectional study at Pantang psychiatric hospital in Accra, involving 107 patients of ages 18 and older and their family members. The findings showed that about 48% of patients contacted non-psychiatric treatment centres (faith-based, traditional healers and general medical practitioners) as their first point of contact for treatment of mental disorders. A little more than half of the patients went directly to the formal public psychiatric facility as their first point of contact for care of their mental disorders. Patients' occupation was significantly associated with their first point of contact for psychiatric care ($\chi 2 = 6.91$; $p < 0.033$). Interestingly, those with secondary education were less likely to initially seek care from the formal public psychiatric hospital compared to those with no formal education (uOR = 0.86; 95 % CI 0.18–4.08) (Ibrahim et al., 2016).

In Ethiopia, a study among 1044 patients at the commencement of new episodes of care at Amanuel Specialized Mental Hospital in Addis Ababa. The study showed 41% of patients had contacted the mental hospital directly. The remaining patients sought care from up to four different caregivers before arriving at the psychiatric hospital. Where the initial service was not received at the psychiatric hospital, 30.9% of patients sought care from priests/holy water/church. The median delay between onset of illness and arrival at the psychiatric hospital was 38 weeks. The longest delays before arriving at the mental hospital were associated with having no formal education, joblessness, and diagnoses of epilepsy and physical conditions (Bekele et al., 2009).

In Malawi almost a similar pathway to mental health care study is observed in that most patients went through a first carer before attending a psychiatric unit, with only 11.7% going straight to a psychiatric unit. All patients who went straight to a psychiatric unit did so to the private Christian Health Association of Malawi (CHAM) unit in the northern region of Malawi. About 22.7% of the patients had a native healer as a first carer. Only 23% of all patients seen went through a second carer, with none going through a third carer. Over 8% of those who had a paramedic as their first carer had a native healer as their second carer. Duration of stay at different carers varied a lot with about half (48.2%) of all patients who saw a native healer as the first carer spending more than 2 weeks before referral while about 67.0% of those who saw convectional health workers spent 3 days or less before referral (Kauye, Udedi & Mafuta, 2014).

In Uganda, interviews and focus group discussions were done to determine factors associated with help seeking behaviors among the mentally ill patients. The findings revealed that in some Ugandan communities, help is mostly sought from traditional healers initially, whereas western form of care is usually considered as a last resort. The factors found to influence help seeking behaviour within the community include: beliefs about the causes of mental illness, the nature of service delivery, accessibility, cost and stigma (Nsereko et al., 2011).

In Tanzania, a study also used a mixed method model to determine the perceived barriers to mental health services utilisation among adults in Dodoma and found that majority of respondents opted to use modern mental health facilities for mental illness treatment. They also used spiritual healing and other forms of traditional methods including herbal medicines. The most frequently identified causes of mental illness were: drug abuse, being cursed and witchcraft, demons or evil spirit possession. The reported significant perceived barriers were stigma, economic, lack of transport, witchcraft and lack of services (Mwansisya et al., 2015).

Even though this study is interested specifically in pathways to CAMH services, there are major lessons to be gleaned from the adult pathway reports, which have been studied more extensively; and is therefore included here in this review.

2.3.3: Pathways to CAMHS and factors influencing choice of pathways: global studies

Different referral pathways have been identified in seeking CAMHS, they include: family, social/legal agency, school and health/mental health referrals. Some studies found the family model whereby the family is involved in the initiation of the care process, to be the commonest sources of referral (Ivert et al., 2011) whereas other studies identified schools (36.0 %) and health professionals (32.0%) as the commonest sources of referral (Pedrini et al., 2015). It has also been argued that parental awareness that their child has a mental health problem is one of the key first steps in help seeking (Sayal, 2006). In addition Verhulst (1995), has argued that recognition of children's behaviour as being problematic by parents or other adults is dependent on the distress threshold of the behaviour; parental educational level, beliefs, and attitudes; as well as other cultural and environmental factors. Morgan et al., (2014) identify three important areas on understanding of differences in referrals to mental health care between individuals from different ethnic backgrounds, and they include: social networks, cultural contexts and beliefs about mental illness, and the range of available care options.

The analysis of a Swedish study at a tertiary child adolescents facility among 2054 children aged 11-19 years, identified four different sources of referrals: family 80.9%, n=1662, social/legal agency 7.9%, n=162, school 20.2%, n=414 and health/mental health 35.2, n=722 referrals. The findings revealed that the average age at first contact is 15 years (range 11 to 19) for both immigrant children and children with a Swedish background, but 16 years for the Asian and African groups. The most common source of referral was family/self-referrals, and the findings suggest that referrals by social/legal agencies were also significantly associated

with age at first contact (OR = 0.77), not living with both parents (OR = 2.92), and living in a neighbourhood with a high level of socioeconomic deprivation (OR = 1.29) (Ivert et al., 2011).

In a Northern Italian Region, a study among 399 patients at first contact with CAMHS, mean (SD) age was 10.5 (3.2) years, and found that most referrals were from school teachers (36.0 %) or health professionals (32.0 %), and 17.0 % were self-referrals. School issues (50.0 %) and emotional problems (17.0 %) were the most frequent reasons for contact. Patients with externalizing problems were more frequently referred by the parents themselves, while youth with internalizing problems were more often referred through health professionals. Families with non-traditional structures (adoptive, foster care, mono-parental) were more likely to consult CAMHS directly, while immigrant youth were more often referred by teachers. The study further revealed that 69.4 % of patients had received no previous treatment before their first CAMHS contact, while 17.1 % had been treated by private child specialists before CAMHS consultation (Pedrini et al., 2015).

2.3.4: Pathways to CAMHS and factors influencing choice of pathways: studies in Africa

Factors that may influence pathway to child and adolescent mental health care may not be very different from those to adult's mental health services since the challenges are shared. For instance, in their report, Belfer and Saxena (2006) showed that only 27% of SSA countries have designated child and adolescent mental health beds, and in most African countries there is approximately one child psychiatrist to 4 million people. The report goes on to describe the pattern which shows that usually the clinic may be the last resort after visiting other sources of care such as traditional healers, priests/imams, and the primary care. The factors identified as contributing to such situation include stigma, belief on spiritual causes of mental illnesses, lack/inadequate educational community programs, accessibility and affordability reasons,

dysfunctional referral system, lack/inadequate human resource and uneven distribution of child mental health services.

In West Africa, Abdulmalik and Sale (2012) describe the situation of mental health services in Nigeria. The situation is not any better from that most of other SSA countries in terms of human resource, beliefs in supernatural causes of mental illness, and stigma and ignorance on mental illnesses. In their study at a psychiatric facility in the northern part of Nigeria among 1-18 year olds, they found that about two thirds (64.5%) of the patients had been ill for longer than 6 months prior to presentation. One hundred and forty four subjects (59.5%) had received no care at all, while 36.4% had received treatment from traditional/religious healers prior to presentation. As regards their functional impairment, ADHD (80%) came out as the most disabling condition, followed by mental retardation (77.8%), epilepsy (64.1%) and psychotic disorders (50%).

In East Africa, Kamau and colleagues shows the significant child and adolescent psychiatric morbidity in a clinical sample in Kenya. The paper goes on to highlight the higher prevalence of substance use disorders in the study population (30.1%) compared to others, followed by depression (3.9%); the relatively longer duration (16.6 months) taken to access mental health care and the multitude of factors associated with that. The study found that 49.8% of the partcipants used medical pathways as their first contact of care. It also noted the role of teachers as one key referral agents to CAMH specialist services (26.5%) whereas referrals from the medical practitioners were 34%, and 11.5% were self-referrals (Kamau, Omigbodun, Bella-Awusah, & Adedokun, 2017). However, generally literature shows that in East Africa, approximately two-thirds of new patients presenting to the CAMHS have epilepsy; the majority of the remainder present with intellectual disability or neurodevelopmental disorders (often manifesting as disruptive behaviour). Symptoms of post-traumatic stress are often reported and psychosis starts to be seen in adolescence, but depression, anxiety, suicidality,

self-harm and emerging personality disorders rarely reach mental health services (Belfer & Saxena, 2006).

2.4 Patients' and health workers' perceptions about child and adolescent mental health care.

Health system research is a crucial aspect for service development and care delivery. Mental disorders being chronic in nature, and especially since about 75% of adult mental disorders have an onset before the age of 24 years, it is of paramount importance to know the patients/caregivers' and health workers' perception of the quality of child and adolescent mental health services rendered in Tanzania so that quality of services is improved. Studies on the perception of care have generally looked at both groups: health workers (Bonomi, Wagner, Glasgow, & VonKorff, 2002) and service users (Glasgow et al., 2005), in order to avoid possible report bias of health workers on the care they provide. The assessment is based on the Chronic Care Model (Bonomi et al., 2000) which focuses on six areas of system change that have been shown to influence the quality of care. This was a model invented for different general chronic conditions such as cardiovascular diseases, diabetes mellitus and mental disorders such as depression.

A study which consisted of 108 organizational teams in the United States of America which used the health workers version of the assessment namely Assessment of Chronic Illness Care (ACIC) to assess for care for congestive heart failure, diabetes mellitus, asthma and depression found an overall average baseline score across all teams, ranging from a score of 4.4 for information systems and 6.4 in the organization of care subscale, indicating basic to good support (Bonomi et al., 2002).

However, a recent WHO study under the Emerging Mental Health Systems in LMICs (EMERALD) project in the countries of Nepal, India, South Africa, Ethiopia, Nigeria and Uganda which assessed care for depression, alcohol misuse an schizophrenia among primary health care providers and health workers in the districts reported an overall little to basic

support of the services although there were variations in the individual scales, with some performing better for some countries than others (Petersen et al., 2017).

Regarding service users' perceptions of services, a study was done in German to validate the service users' version of the assessment tool namely Patients Assessment of Chronic Illness Care (PACIC) among patients aged 2-80 years with depression where they found the mean value of 3.5 with a range of 2.83 in follow up/coordination and 3.69 for problem solving subscales respectively (Gensichen et al., 2011). Although not in a children's population, these findings can be used to generally compare with the perceptions of service users on the care received at MMHH.

CHAPTER THREE

METHODOLOGY

3.1: Study location

The study was conducted at Mirembe Mental Health Hospital (MMHH), in Dodoma Municipality, Dodoma Region. The hospital was selected because it is the only tertiary referral mental health facility in the country, therefore has a larger patient's population serving patients from all over the country, more than other regional mental health units.

Dodoma Region is centrally positioned in Tanzania and is bordered by four regions namely: Manyara in the North, Morogoro in the East, Iringa in the South and Singida in the West. The region covers an area of 41,310 km² and has 2,083,588 inhabitants (National Census, 2012). The estimated total number of households is 74,914 with an average household size of 4.3 people. It is the 12th region in size, covers about 5% of Tanzania mainland. The region was established in 1963 consisting of three rural districts and one Township Authority. To date, Dodoma region has six rural districts and one urban district namely: Bahi, Chamwino, Kondoa, Chemba, Mpwapwa, Kongwa and Dodoma Urban.

Dodoma Urban District is the national capital of Tanzania, and the capital of the Dodoma region since 1973 although many government offices remained in the previous national capital, Dar es Salaam, which remains to be the commercial capital until 2015 when the elected President decided to officially move all the government offices to Dodoma. Since then, they have been moving in phases and that has further changed the city in many different ways including population wise and economic activities although the region was almost entirely dependent on agriculture and livestock production, which are locally practiced, largely at household level. Dodoma features a semi-arid climate with relatively warm temperatures throughout the year.

Furthermore, in the recent years, the city has been growing rapidly due to the opening of universities like the St. John's University of Tanzania and the University of Dodoma (UDOM) which has a capacity of 40,000 students. Both universities were officially opened in 2007. This has changed the composition of the population and services to meet the needs. Dodoma is now becoming an educational and commercial city.

3.2: Study setting

Mirembe Hospital was established in 1926 by the British Governor upon transfer of 50 mentally ill patients from Lutindi Institution, a private faith based facility in the north east part of the country. The reason for transferring the services to Dodoma was for easy access for all regions of the country considering the central position of Dodoma. In 1950, a forensic institution was established named 'Broadmoor' at Isanga grounds, about a kilometer away from MMHH to provide mental health services for criminal mental patients and subsequently 60 mentally ill offenders were moved from prisons to the institution.

The hospital continued to expand gradually and became a complex center despite the professional and economic hurdles. Eventually it developed into a complex comprising of the following departments: Mirembe Hospital Proper (for civil mental patients) with 350 bed capacity, Isanga Correction Centre (forensic mental patients) with 250 bed capacity, Mirembe Annex (half way home, which is non-functional for years) with 50 bed capacity, Hombolo Rehabilitation Village (which is 50 kilometers away from the city, also almost non- functional with condemned buildings, with recent renovation of a ward that has capacity of about 10 patients) with 50 bed capacity, Mirembe School of Nursing; and recenlty Itega Drug Dependence Treatment Centre which is a newly constructed unit and currently provides OPD services.

The hospital has also been providing services for physical ill patients since 1980. This was a move towards integration of mental health services and a stigma reduction strategy. Currently,

the hospital provides mental and physical health services, both OPD and IPD, for both adults and children. The hospital is at the tertiary level and receives referrals from all over the country, being the only tertiary psychiatric facility in the country. A three years trend of number of patients seen at the hospital is as follows: in 2014-63,319 patients of which 12,373 were psychiatric patients; in 2015-55,485 patients of which 15, 851 were psychiatric patients and 2016-65,857 patients of whom 14,749 were psychiatric patients.

Usually children/young persons are seen at the OPD and if require in-patient care are admitted in the adult wards whereby females are admitted in the ward for women with perinatal mental health issues and males to a ward either for physical problems or for weak/malnourished/elderly/adult patients with mental retardation.

In the year 2010, the Government of Tanzania through the Ministry of Health and Social Welfare announced in the Government Gazette No. 45 of 2010 the hospital to operate at the national level and provide mental health and substance use services at the super specialist level. As a way of streamlining and improving services, a special CAMH clinic was started towards the end of 2016 with two special clinic days: Child epilepsy clinic was held on Tuesdays and child mental health clinic on Thursdays. These clinics were run by general adult psychiatrists as there was no child adolescent psychiatrist or neurologist in the hospital. The children seen at these clinics were those perceived to need more special care but majority of children who attended the hospital were still seen by medical officers in the normal general OPD where both children and adults attend. Due to challenge of human resources, the clinic stopped operating from early 2018 and was re-opened in mid September, 2018. In total, the hospital has about 300 staff while the required number of staffing is over 700. There are 5 psychiatrists, 1 psychologist, 1 neurologist, 1 social worker, 5 occupational therapists and 20 psychiatric nurses (out of a total of about 87 nurses of all levels, and it is also important to

note that there are 75 medical attendants who basically function as key nursing staff in providing care).

In addition, the hospital serves as a clinical training area for psychiatry and mental health for different colleges and universities in the country.

3.3: Study design

This was a descriptive, cross sectional, hospital based study.

3.4: Study population

The study comprised of two groups of participants. The first group included children and young persons attending the hospital child and adolescent clinic and their caregivers and family members who accompanied them to the hospital.

The second category of participants were health care staff of MMHH specifically those providing mental health care at the child and adolescent clinic and included different cadres such as nurses, doctors and occupational therapists. This second category also included the health management team which consists of the hospital administration and the heads of all units/sections of the hospital. They oversee the day to day operations of the hospital.

3.4.1: Eligibility criteria

Study participants for Sample 1 included: -

1. Children/young persons aged between 6 and 24 years and their caregivers, attending the clinic at MMHH during the study period of January-March 2019
2. Children/young persons who assented
3. Caregivers of the patients and family members who accompanied the patients
4. Caregiver/family members who consented

Study participants for Sample 2 included: -

1. MMHH health care workers providing out-patient mental health services at the child and adolescent clinic who consented to participate in the study and

2. Members of the health management team (HMT) who consented to participate in the study.

3.4.2: Exclusion criteria

1. Those children and young persons who were severely ill were excluded from the study.

2. Participants who did not speak or understand Kiswahili were also excluded.

3.5: Sample size estimation

The estimated sample size N was computed using the formula below,

$$N = \frac{z^2pq}{d^2}$$

Where;

N = Estimated Sample Size

Z = is the standard normal deviate, which is 1.96 on using the 95% CI.

P= proportion of those who used medical pathway as first contact of care in a Kenyan study, which was 49.8% rounded off to 50% (Kamau et al., 2017)

q = (1-P) = proportion of people who used other care pathways as first contact which is 50

d= the desired level of precision set at 5% (0.05)

Therefore; $N=1.96^2 \times 0.5 \times 0.5 / (0.05)^2 = 384$

Estimating for a 10% nonresponse= 384/1-0.1=427

Sample size 2 for the Health Workers Population

To determine health workers' perception of child and adolescent mental health services at MMHH, an instrument called Assessment of Chronic Illness Care (ACIC) was used. ACIC is an instrument used to evaluate services provided by health workers for treatment of chronic illness like mental disorders. The tool requires the completion by consensus, of a representative group of staff between 4 and 10, and the study met this requirement whereby a total of 27 health workers were recruited (all 23 HMT members and all the 4 staff at the

CAMH clinic) of MMHH. Of the HMT members, two groups had 8 participants and one had 7 participants, whereas the CAMH clinic staff group had 4 participants.

3.6: Sampling technique/procedure

A consecutive sampling technique was used to get the patients/caregivers samples. All children/young persons and their caregivers that were attending the hospital CAMH clinic on week days, during official working hours (08:00am to 03:30 pm) were approached for the study. Those who were eligible were included in the study as they came, until the study sample was attained.

In addition, all the 4 staff working at the CAMH clinic and all the 23 HMT members were included in the study.

3.7: Study instruments

The following tools were used in data collection from study participants group sample 1: Socio-demographic Questionnaire, WHO Modified Encounter Form, the Kiddie Schedule for Affective Disorders and Schizophrenia Present and Lifetime version, DSM 5, 2016 (K-SADS-PL DSM 5, 2016), the Children Global Assessment Scale (C-GAS) and the Modified Patients Assessment Care for Chronic Conditions (PACIC). Data was collected from study participants group sample 2 by using the Modified Assessment of Chronic Illness Care for Mental Illness (ACIC).

3.7.1: Socio-demographic Questionnaire

The socio-demographic questionnaire designed by the principal investigator, [see Appendix A1 and A2] was used to elicit informations from both children/young persons and their caregivers on variables such as age, sex, education level, occupation and religion.

3.7.2 Modified WHO encounter form

This is a tool that has been designed by WHO (1987), for use in pathways to psychiatric care studies [see Appendix A3 and A4]. It has been used in a cross cultural study by Gater and colleagues (Gater et al., 1991) and in a large WHO collaborative multicenter study (Gater et

al., 2005). The tool has been modified for the purposes of this study and captures different aspects on pathways to care including basic information such as: date of first seeking help, first symptoms displayed, and the time of the first presentation of symptoms, diagnosis reported by caregiver and whether the client knows the diagnosis. The tool was adapted to include questions on whether it was the participant's first time to attend at MMHH for care and second, if not, when was their first attendance date. The aim of these questions were to determine the number of new cases at the CAMH clinic so that further interventions to raise awareness of the services be planned.

The second part covers the decision to first seek help which includes questions on who was first seen, when it was, whose advice was it to seek help and who was seen. The third and fourth parts focus on the first and second referrals and the questions seek to find out the timing of the referral, the person who initiated the referral, what the diagnosis was and where the patient was seen. The other parts include: questions on the current treatments and the perceived barriers and challenges (physical, psychological, social and other) in seeking the current CAMHS. In the latter part, I added a question on how the patients/caregivers think services can be improved.

3.7.3: The Kiddie Schedule for Affective Disorders and Schizophrenia Present and Lifetime version 2016 (K-SADS-PL 2016)

The Kiddie- schedule for affective disorders and schizophrenia present and lifetime (KSADS-PL 2016) (Kaufman et al., 1997), [see Appendix A9] is a semi structured tool used for diagnostic purposes. Its usage is freely permitted for research and clinical usage by non-profit organisations. It is designed for children and adolescents aged 6–18 years to assess current and past episodes of psychiatric morbidity according to Diagnostic and Statistical Manual of Mental Disorders-5th edition (DSM 5) criteria. In this sample, it was used for up to 24 years

since K-SADS was adapted from Schedule for Affective Disorders and Schizophrenia (SADS) which was the adult version (Endicott & Spitzer, 1987).

K-SADS PL 2016 covers most diagnoses in DSM 5 in children except Intellectual disability, Somatic symptom disorders and Epilepsy which were diagnosed clinically in this study. The tool has two parts; the diagnostic screening part which surveys and rates the primary symptoms of disorders and the diagnostic supplement part in which children who score above threshold during screening are assessed for the diagnosis of current and most severe past psychiatric episodes. It is administered to children, parents or teachers to generate summary ratings. In this study, it was administered to the parents and children/young persons and both the screening and supplement parts were used. The tool had not been used in Tanzania but it was used in a neighbouring country of Kenya (Kamau et al., 2017).

3.7.4: Children Global Assessment Scale (C-GAS)

Children Global Assessment Scale (C-GAS) [see Appendix A10] is a tool developed by Schaffer and colleagues (Shaffer et al., 1983) from the Department of Psychiatry, Columbia University, for assessing global functional impairment in children and adolescents aged 4-18 years. The tool is on a continuous scale of 0–100, with higher scores indicating a better functioning. It is usually used in tandem with the K-SADS PL in order to ascertain the impairment of functioning associated with the mental disorders. The level of functional impairment was re-categorised as normal functioning (71 and above), mild to moderate functional impairment (51-70) and severe functional impairment (50 and below).

3.7.5: Modified Version of the Patients Assessment of Care for Chronic Conditions (PACIC)

The PACIC is a self-rating instrument which assesses the patient's perspective on receipt of clinical services referring to the last six months [see Appendix A5 and A6]. Each item can be scored on a five point Likert scale ranging from 1 ('almost never') to 5 ('almost always'). The 20-item instrument has five subscales that refer to the major dimensions of the Chronic Care

Model (Glasgow et al., 2005), i.e. patient activation (three items), delivery system design/ decision support (three items), goal setting/ tailoring (five items), problem solving/ contextual (four items) and follow-up/ coordination (five items). Each subscale is obtained by calculating the arithmetic mean value of the items contained in it. The overall PACIC is scored by averaging scores across all 20 items.

In the introductory part of the tool, I added a question on level of facility attended for care in the last 6 months, with the aim of further understanding the distribution of levels of modern health care CAMH clinic attendees use. The levels included the least to the top in the organisation of health care systems in Tanzania, which were a) dispensary b) health centre c) district hospital d) regional hospital e) MMHH f) other tertiary level psychiatric hospitals. The last two are the same level but were meant to specifically identify those who attended MMHH from others.

3.7.6: Modified Assessment of Chronic Illness Care for Mental Illness (ACIC)

The ACIC [see Appendix A7 and A8] is a tool that can be filled in by an individual or completed as part of a focus group. It can be used in identifying areas for improvement in chronic illness care before beginning quality improvement work or to periodically evaluate the impact of the changes an organization is making to improve chronic illness care (Bonomi et al., 2000). It focuses on six areas of system change that is based on the Chronic Care Model (CCM) that have been shown to influence the quality of care. These areas are: organization of the healthcare system, linkages to community resources, self management support, decision support, delivery system design and clinical information systems.

The tool has 31 items that measure how well an organization is doing in terms of chronic illness care across six domains. The scale uses a 4 point Likert scoring system ranging from 1 = Little Support to 4 = Full Support. Questions such as “Does the facility health plans include chronic illness guidelines or resources at the clinic level?” aims to determine how well health

system components are organised to support effective delivery of chronic illness care while a question like “Are evidence-based guidelines or protocols e.g counselling guidelines available for nurses and doctors at the facility? “ aims to determine how well staff are trained and provided with the necessary skills and resources to enable them to provide optimum chronic care (Bonomi et al., 2002).

The tool has been used in a pilot WHO multicountry study for mental disorders in adult population. The countries include Nigeria, South Africa, Ethiopia, Uganda, Nepal and India (Petersen et al., 2017).

3.8: Study procedure

3.8.1: Adaptation of study instruments

All research tools which were self-administered were translated using the iterative back translation method into Kiswahili. This was performed with the help of linguistics experts as well as qualified persons working in the mental health field. However, for the KSADS and the C-GAS the English version was used as both were administered by the PI herself, who is a psychiatrist.

3.8.2: Recruiting and training of research assistants

Two medical doctors who worked at the child and adolescent clinic were recruited to serve as Research Assistants. They received a 2 days training on the research instruments and assessment protocols.

3.8.3: Pretesting the instruments

A pre-test of the study instruments was done 2 weeks before the study. The instruments were completed by patients attending the medical out-patient clinic at the hospital. This helped to assess the general feasibility of the study procedures, the validity and reliability of the instruments and identify any potential problems prior to starting the main study.

3.8.4: Administration of the instruments

The study was conducted at the child and adolescent clinic of MMHH. The Principal Investigator and the study assistants approached the participants for consent.

For the children/young persons and caregivers' sample: The participants were given the sociodemographic questionnaire, the WHO encounter form and the PACIC to fill. Upon completion, the research assistants administered the screening part of the K-SADS PL as part of usual clinical assessment. In addition, assessment for epilepsy, intellectual disability and somatic symptoms disorders were carried out (these 3 disorders not included in the screening part of the K-SADS PL). At the end of initial screening the reseachers–acknowledged the participants for their role in the research. Those who met the cut off were administered the diagnostic supplement part of the K-SADS PL. The principal investigator administered the specific diagnostic K-SADS PL to each participant who scored up to the cut off point of the screening section of K SADS PL. She also scored participants on the Children Global Assessment Scale. She also re-assessed the patients suspected of having epilepsy, intellectual disability and somatic symptoms disorders and confirmed their diagnoses. Epilepsy was diagnosed based on the history from caregivers and the following definition "*any suddent attack that was recurrent (at least two) and unprovoked i.e there has been no closely associated concurrent illness, fever or acute brain injury, occurring in a period of more than 24 hours, that manifests as motor, sensory, autonomic and psychic presentation"* (International League Against Epilepsy, 1993).

The American Association on Intellectual and Developmental Disabilities (AAIDD) describes ID as *characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills*; and usually originating before age 18. Therefore, ID diagnosis was made through interview with caregivers for developmental, family, social and educational history; coupled with comprehensive medical exam and testing of adaptive functioning. However, no formal psychological tests were administered to determine intelligent quotient (I.Q).

The PI together with the team, provided clinical management to all and showed their appreciation for participation in the study and directed them to the next care point in the clinic such as the occupational therapist, the social worker, the clinical pschologist or pharmacy. The whole assessment process up to the point of exit to other care point took an average of 90 minutes.

Participants Sample 2 (HMT and clinic staff): The administration of the instrument was done during the HMT's normal scheduled monthly meeting and as the first point on the agenda; and at that same time the child adolescent clinic group met at the clinic. All members of the HMT consented to participate and comprised three groups of eight participants for two and 7 participants for the third group. The child adolescent staff was one group of four people. The ACIC was then introduced simultaneoulsy to both groups and each item discussed and scored by consensus. It took approximately 60 minutes to complete the administration of the tool. The participants appreciated the opportunity to participate in the study.

3.9: Data management and analysis

All data obtained were stored by the PI in a secure environment. Data was entered, cleaned and analyzed using the IBM SPSS software for Windows Version 23. Both descriptive and inferential statistics were used, and significance level set at 5%. Continous variables were presented using mean, median and interquartile range while categorical variables were presented using frequency and proportions, with the Chi square and Fisher's exact tests used to test association between categorical variables; and t test to compare means. Pie and bar charts were also used for graphical presentation of the categorical variables. A logistic regression analysis model was employed to determine the factors that were independently associated with choice of pathways, medical/non-medical among child and young persons accessing mental health care services at MMHH. In addition, logistic regression model was used to assess the factors associated with delays in seeking care among child and young persons accessing mental health care services at MMHH. A subject was considered to delay in

seeking for care if he or she did not look for care within a week from the day of onset of symptoms (refer WHO encounter form, Appendix A3]. For both outcomes, a two stage approach was undertaken for the analysis. Firstly, bivariate model (unadjusted) was fitted for each independent variable and outcome variables to estimate the crude odds ratios (OR) and 95% confidence intervals (CI). Secondly, to obtain adjusted odds ratios (AOR) for the association between each of the proposed factor multiple logistic regression models were then fitted. The models included all predictors which were found to be significant in the bivariate analysis. The general multiple logistic regression model is given as:

$$\log it[\pi(x)] = \log\left(\frac{\pi(x)}{1-\pi(x)}\right) = \beta_0 + \beta_1 x_1 + ... + \beta_p x_p$$

Where, $\pi(x)$ is the likelihood of choosing non-medical pathways instead of medical for the first outcome variable or the chance of delay in seeking for care for the second outcome among subjects with x characteristics, $x_i's$ are covariates such as gender age, mother education, etc,, and $\beta_i's$ are their respective parameters. The results of the model were presented in the form of estimated odds ratios (OR). The estimated OR, determined by taking the exponent of the regression parameter estimates, shows the increase or decrease in the likelihood of using non-medical pathways or delay in looking for care for subjects at a given level of the independent variable as compared to those in the reference category. An estimate of OR > 1 indicates that the likelihood of using non-medical pathways or delay in looking for care is higher among subject in one level of exposure variable as compared to subjects in reference category. Similarly, an estimate of OR < 1 specifies that the chance selecting non-medical pathways or delay in looking for care for subjects at a given level of the independent variable is lower as compared to those in the reference category (Agresti, 2002).

3.10: Ethical considerations

3.10.1: Ethical issues and research clearance

Ethical approval to conduct the study was sought from the University of Dodoma Ethical Review Board. Permission to do the study was obtained from the Medical Superintendent, MMHH. Assent and consent to participate in the study was sought from both the eligible study candidates and their caregivers respectively. Patients were also encouraged and psychoeducated on the importance of continuing to attend the clinic for follow up care even after the study, in order to benefit more from the care they initially received.

3.10.2: Confidentiality

Information collected from participants was secured and kept confidential. The questionnaires were anonymously identified for the sake of matching the diagnostic results after analysis for record keeping in the file and better management for those who participated in research.

3.10.3: Informed consent

Written consent was sought from all the study candidates (young persons, caregivers and MMHH health care workers) while assent was obtained from the children and young perosns themselves. The participants were informed about the purpose of the study and requested to voluntary participate in the study. Kiswahili, which is the local language was used to translate all research protocols and consent forms to enable easy understanding by the participants. It was also made clear that, acceptance or refusal to participate in the study would have no untoward consequences and that participants were free not to participate or withdraw at any point in the study. They were also assured of confidentiality and the questionnaires did not have any participant's name, only numbers were used, therefore assuring them that information provided was kept confidential. Furthemore, they were informed of the benefits and risks of the study though no risks were expected from this study. In addition, candidates were informed that no financial gain would be obtained by participating in the study. They were given the address/contacts of the principal investigator as well as the contacts of the director for research and publication committee from UDOM.

3.10.4: Non- maleficence to participants

The participants were made to understand that they were not forced to respond to questions on the questionnaires, and that no invasive procedures were going to be carried out and maximum safety was ensured throughout the course of the study.

3.10.5: Voluntary participation

Participation in the study was completely voluntary and participants had the right to withdraw at any time during the course of the study without any penalty. Participants were not required to answer questions they were not comfortable with or did not want to answer.

3.10.6: Benefits

Since the participants had come to the hospital to seek mental health care, the PI ensured that all research participants received the necessary care. However, no financial gain was obtained from the study.

CHAPTER FOUR

RESULTS

A total of 354 children/young persons and their caregivers; and 27 MMHH health care workers who were in four groups were included into the study. All respondents agreed to participate in the study. However, 57 children were excluded from the children/young persons sample as they were ineligible due to age (below age 6 years). Due to the limitations of time the calculated sample size was not attained, but the attained sample size was adequate and with good power, therefore useful inferences can still be made from this study.

4.1 Socio-demographic profile of the children/young persons and their caregivers

The ages of the participants ranged from 6 to 24 years, with a mean of 16.7 years (SD: ±5.584) years. There were more males, 209 (59.0%) compared to females 149 (41.0%). Only fifty-seven participants (16.1%) were aged between 6 and 9 years.

One hundred and five respondents (29.7%) were currently attending school, 44 (41.9%) were in mainstream primary and 25 (23.8%) were in a special primary school, only 4 (3.8%) were in tertiary schools. Of those not attending school, 44 (7.7%) had either never gone to school, or dropped out of school 75 (30.1%), on account of their illness. The majority of study participants 293 (82.8%) were Christians (See Table 1).

Two hundred and sixty-nine (76.0%) caregivers were biological parents of the children/young persons, and 78 (22.0%) were adult relative caregivers. Of those who were being cared for by single parents, forty-nine (79.0%) were mothers. Two hundred and eighty-four of parents (80.2%) were both alive (See Table 2).

Three quarters (n=269) of the respondents were residents of Dodoma Region, followed by Singida 5.6%, Morogoro 4.5% and others as indicated in Figure 1. Of those who came from Dodoma, 54.3% came from Dodoma urban, 17.1% from Chamwino and 12.6% from Bahi district (Figure 2).

Table 1: Sociodemographic characteristics of the children/young persons

Variables	Frequency	Percentage
Age groups in years (N=354)		
6-9	57	16.1
10-13	41	11.6
14-17	60	17.0
18-20	109	30.8
21-24	87	24.6
Gender (N=354)		
Male	209	59.0
Female	145	41.0
School attendance status (N=354)		
Yes	105	29.7
No	249	70.3
Current school level (N=105)		
Primary	44	41.9
Secondary	32	30.5
Tertiary	4	3.8
Special school	25	23.8
Reasons for not being in school (N=249)		
Unspecified	118	47.4
Dropped out due to illness	75	30.1
Never attended school due to illness	44	17.7
Not yet of school age	12	4.8
Religion (N=354)		
Christian	293	82.8
Muslim	60	16.9
African traditional	1	0.3

Table 2: Socio-demographic profile of caregivers (N=354)

Variables	Frequency	Percentage
Type of caregiver		
Parent	269	76.0
Adult relative	78	22.0
Adult non relative	3	0.9
Other Self	4	1.1
Parental status		
Both parents alive	284	80.2
Single parent	62	17.5
Orphan	8	2.3
Father's educational level		
No formal education	45	12.7
Primary	269	76.0
Secondary and above	40	11.3
Mother's educational level		
No formal education	63	17.8
Primary	270	76.3
Secondary and above	21	6.0
Father's occupation		
Small scale farming	304	85.9
Professional	18	5.1
Non professional	32	9.0
Mother's occupation		
Small scale farming	328	92.7
Professional	11	3.1
Non professional	15	4.2

Figure 1: Map of Tanzania mainland showing the distribution of study participants' regions of residence (N=354).

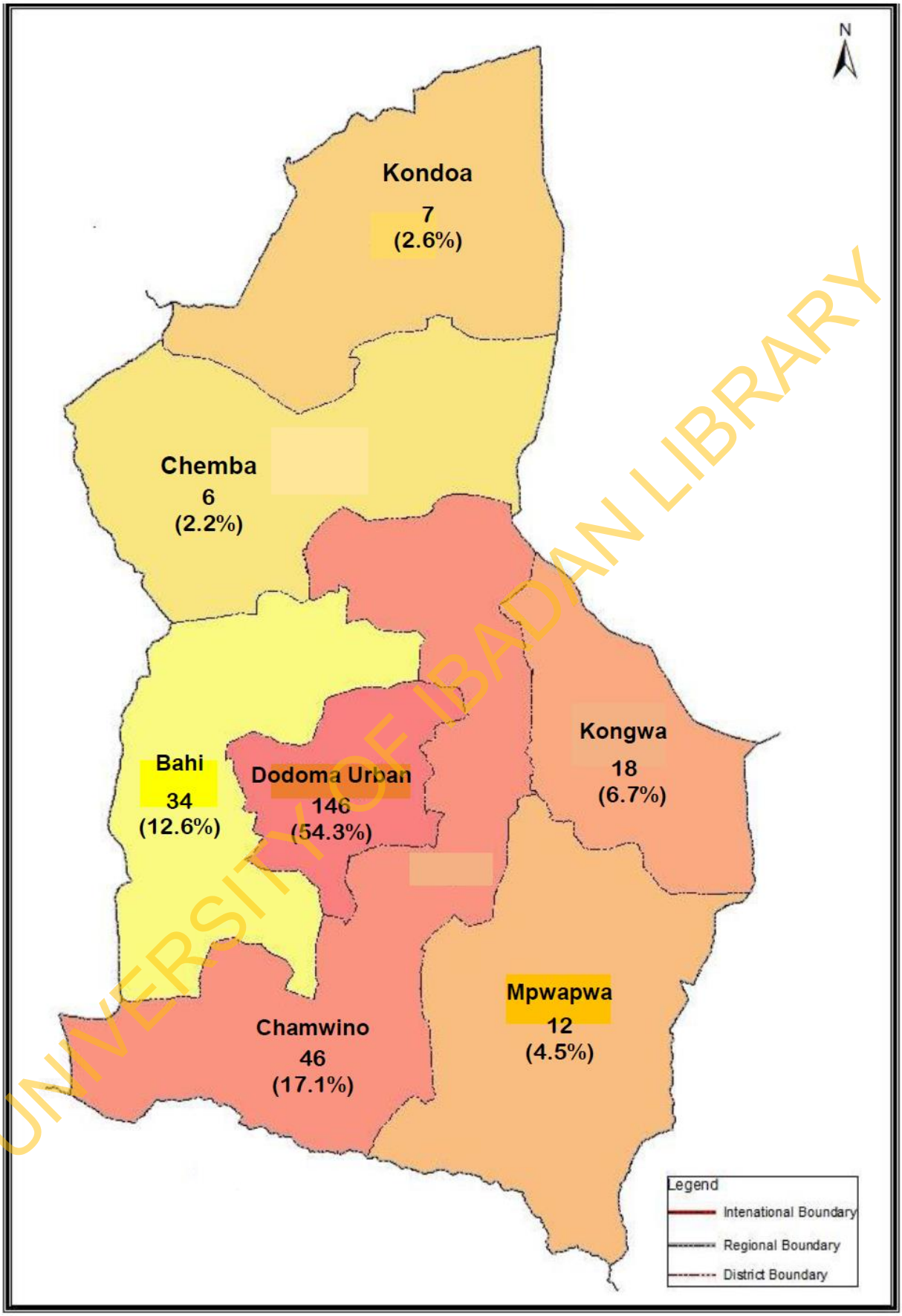

Figure 2: Map of Dodoma region showing the distribution of districts of residence of study participants (N=269).

4.2: Pattern of neuropsychiatric disorders among children and young persons attending MMHH for care

The 5 most common conditions among the respondents were Epilepsy 200 (56.5%), Intellectual disability 62 (17.5%), Schizophrenia 58 (16.4%), Psychosis due to general medical condition [GMC] 48 (13.6%), and Depression 36 (10.2%) (See Tables 3a and 3b).

In addition, when neuropsychiatric disorders were considered as groups, Epilepsy was still the commonest (56.5%), followed by Schizophrenia spectrum and other psychotic disorders (35.1%), Depressive and bipolar related disorders (18.4%), Intellectual disability (17.5%) and Neurodevelopmental, disruptive and conduct disorders (14.7%) (See Table 4).

Forty-five percent (n=159) of the respondents had co-morbidities, which ranged from 2 to 6 conditions. The majority of whom (89.0%) had 2-3 co-morbid diagnoses (Figure 3).

In addition, forty-nine of the children (13.8%) were having comorbid medical conditions: Typhoid fever (n=7), Malaria (n=5); Epistaxis, Down syndrome and specific learning disability (3 each).

Table 3: Frequency distribution of neuropsychiatric disorders among children and young persons at MMHH (N=354).

Diagnosis	Frequency	Percent
Depressive and bipolar related disorders (n=65)		
Major depressive disorder	36	10.2
Bipolar disorder	26	7.3
Disruptive mood dysregulation disorder	3	0.9
Schizophrenia spectrum and other psychotic disorders (n=124)		
Schizophrenia	58	16.4
Psychosis due to general medical condition	48	13.6
Substance induced psychosis	11	3.1
Schizophreniform disorder	6	1.7
Brief psychotic disorder	1	0.3
Anxiety, obsessive compulsive and trauma related (n=15)		
Specific phobia	10	2.8
Social anxiety/selective mutism	8	2.3
Separation anxiety	3	0.9
PTSD	2	0.6
Panic disorder	1	0.3
Elimination disorders (n=19)		
Enuresis	15	4.2
Encopresis	4	1.1
Neurodevelopmental, disruptive and conduct disorders (n=52)		
ADHD	21	5.9
Autism spectrum disorder	16	4.5
Conduct disorder	10	2.8
Tic disorder	3	0.9
Oppositional defiant disorder	2	0.6
Substance use disorders (n=28)		
Cannabis use disorder	15	4.2
Tobacco use disorder	9	2.5
Alcohol use disorder	4	1.1
Other (n=300)		
Epilepsy	200	56.5
Intellectual disability	62	17.5
Cerebral palsy	28	7.9
Somatic symptoms disorders	5	1.4

Note: No participant received a diagnosis of Eating disorders, Agoraphobia, Generalised anxiety disorder or Obsessive compulsive disorders (See Table 3 above).

Table 4: Frequency distribution of neuropsychiatric disorder groups among children and young persons at MMHH (N=354).

Diagnosis	Frequency	Percent
Epilepsy	200	56.5
Schizophrenia spectrum and other psychotic disorders	124	35.1
Depressive and bipolar related disorders	65	18.4
Intellectual disability	62	17.5
Neurodevelopmental, disruptive and conduct disorders	52	14.7
Cerebral palsy	28	7.9
Substance use disorders	28	7.9
Anxiety, obsessive compulsive and trauma related	24	6.8
Elimination disorders	19	5.4
Somatic symptoms disorder	5	1.4

NB: Due to presence of comorbidities, the total n (%) will be >100%

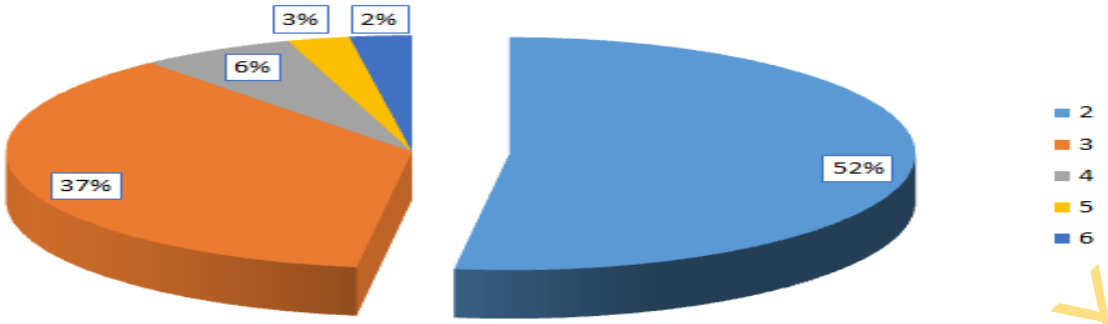

Figure 3: Pie chart showing distribution of patients according to number of co-morbid diagnoses (N=159).

4.3: Relationship between children's/young persons' neuropsychiatric disorders and their age and gender

Table 5a and 5b show that age was significantly associated with having certain neuropsychiatric disorders. The results showed that being 10-24 years was associated with having Depression (12.1%, p=0.003), Bipolar disorder (8.8%, p=0.012), Schizophrenia (19.5%, p<.000), and Psychosis due to GMC (16.2%, p=0.000) compared with their counterparts aged 6-9 years (0.0%) for all the above named disorders (See Table 5a).

In addition, being aged 6-9 years was associated with having CP (24.6%, p<0.000), ID (38.6%, p<0.000), ADHD (22.8%, p<0.000), and ASD (24.6%, p<0.000) when compared with their counterparts aged 10-24 years: 4.7%, 13.5%, 2.7%, and 0.7% respectively (See Table 5b).

The study also revealed a statistically significant association between gender and diagnosis as shown in Tables 6a and 6b. It was found that being male was associated with having Schizophrenia (19.6%, p=0.049), Substance induced psychosis (5.3%, p=0.004) (Table 6a) and Cannabis use disorder (6.7%, p=0.006) (Table 6b) compared with their female counterparts 11.7%, 0% and 0.7% respectively. In addition, being female was associated with having Epilepsy (64.8%, versus 50.7%, p=0.009), and CP (11.7% versus 5.3%, p<0.027) (See Table 6b).

Table 5a: Relationship between neuropsychiatric disorders and age (N=354).

Variable	Age (Years)		Fisher's Exact p-value
	6-9	10-24	
	n (%)	n (%)	
Depressive disorder			*0.003
No	57(100.0)	261(87.9)	
Yes	0(0.0)	36(12.1)	
Bipolar disorder			*0.012
No	57(100.0)	271(91.3)	
Yes	0(0.0)	26(8.8)	
Disruptive mood dysregulation			1.000
No	57(100.0)	294(99.0)	
Yes	0(0.0)	3(1.01)	
Schizophrenia			*<0.000
No	57(100.0)	239(80.5)	
Yes	0(0.0)	58(19.5)	
Schizophreniform disorder			0.595
No	57(100.0)	291(98.0)	
Yes	0(0.0)	6(2.0)	
Psychosis due to GMC			*0.000
No	57(100.0)	249(83.8)	
Yes	0(0.0)	48(16.2)	
Brief psychotic disorder			1.000
No	57(100.0)	296(99.7)	
Yes	0(0.0)	1(0.3)	
Substance induced psychosis			0.224
No	57(100.0)	286(96.3)	
Yes	0(0.0)	11(3.7)	
Panic disorder			1.000
No	57(100.0)	296(99.7)	
Yes	0(0.0)	1(0.3)	
Separation anxiety			0.410
No	56(98.3)	295(99.3)	
Yes	1(1.8)	2(0.7)	
Social anxiety			0.364
No	57(100.0)	289(97.3)	
Yes	0(0.0)	8(2.7)	
Specific phobia			1.000
No	56(98.3)	288(97.0)	
Yes	1(1.8)	9(3.0)	
PTSD			1.000
No	57(100.0)	295(99.3)	
Yes	0(0.0)	2(0.7)	
Enuresis			0.075
No	52(91.2)	287(96.6)	
Yes	5(8.8)	10(3.4)	
Encopresis			0.123
No	55(96.5)	295(99.3)	
Yes	2(3.5)	2(0.7)	
Fisher's exact test applied for all	*p<0.05		

Table 5b: Relationship between neuropsychiatric disorders and age (N=354).

Variable	Age (Years)		Chi square	p-value
	6-9	10-24		
	n (%)	n (%)		
Epilepsy			2.86	0.091
No	19(33.3)	135(45.5)		
Yes	38(66.7)	162(54.6)		
Cerebral palsy			25.86	*<.000
No	43(75.4)	283(95.3)		
Yes	14(24.6)	14(4.7)		
Intellectual disability			20.90	*<.000
No	35(61.4)	257(86.5)		
Yes	22(38.6)	40(13.5)		
Somatic symptoms disorder				‡1.000
No	57(100.0)	292(98.3)		
Yes	0(0.0)	5(1.7)		
ADHD			34.67	*<.000
No	44(77.2)	289(97.3)		
Yes	13(22.8)	8(2.7)		
ODD				‡1.000
No	57(100.0)	295(99.3)		
Yes	0(0.0)	2(0.7)		
Conduct disorder				‡1.000
No	56(98.3)	288(97.0)		
Yes	1(1.8)	9(3.0)		
Tic disorder				‡0.410
No	56(98.3)	295(99.3)		
Yes	1(1.8)	2(0.7)		
ASD				**<.000
No	43(75.4)	295(99.3)		
Yes	14(24.6)	2(0.7)		
Tobacco use disorder				‡0.365
No	57(100.0)	288(97.0)		
Yes	0(0.0)	9(3.0)		
Alcohol use disorder				‡1.000
No	57(100.0)	293(98.7)		
Yes	0(0.0)	4(1.4)		
Cannabis use disorder				‡0.143
No	57(100.0)	282(95.0)		
Yes	0(0.0)	15(5.1)		
Other substance use				‡1.000
No	57(100.0)	296(99.7)		
Yes	0(0.0)	1(0.3)		

‡Fisher's exact test applied *p<0.05

Table 6a: Relationship between neuropsychiatric disorders and gender (N=354)

Variable	Gender		Chi square	p-value
	Male n (%)	Female n (%)		
Depressive disorder			3.53	0.060
No	193(92.3)	125(86.2)		
Yes	16(7.7)	20(13.8)		
Bipolar disorder			0.07	0.788
No	193(92.3)	135(93.1)		
Yes	16(7.7)	10(6.9)		
Disruptive mood dysregulation				‡0.068
No	209(100.0)	142(97.9)		
Yes	0(0.0)	3(2.1)		
Schizophrenia			3.89	*0.049
No	168(80.4)	128(88.3)		
Yes	41(19.6)	17(11.7)		
Schizophreniform disorder				‡1.000
No	205(98.1)	143(98.6)		
Yes	4(1.9)	2(1.4)		
Psychosis due to GMC			0.04	0.835
No	180(86.1)	126(86.9)		
Yes	29(13.9)	19(13.1)		
Brief psychotic disorder				‡0.410
No	209(100.0)	144(99.3)		
Yes	0(0.0)	1(0.7)		
Substance induced psychosis				‡*0.004
No	198(94.7)	145(100.0)		
Yes	11(5.3)	0(0.0)		
Panic disorder				‡1.000
No	208(99.5)	145(100.0)		
Yes	1(0.5)	0(0.0)		
Separation anxiety				‡1.000
No	207(99.0)	144(99.3)		
Yes	2(1.0)	1(0.7)		
Social anxiety				‡1.000
No	204(97.6)	142(97.9)		
Yes	5(2.4)	3(2.1)		
Specific phobia				‡1.000
No	203(97.1)	141(97.2)		
Yes	6(2.9)	4(2.8)		
PTSD				‡0.092
No	207(99.0)	145(100.0)		
Yes	2(1.0)	0(0.0)		
Enuresis			2.85	0.092
No	197(94.3)	142(98.0)		
Yes	12(5.8)	3(2.01)		
Encopresis			0.14	0.712
No	207(99.0)	143(98.6)		
Yes	2(1.0)	2(1.4)		

‡Fisher's exact test applied *p<0.05

Table 6b: Relationship between neuropsychiatric disorders and gender (N=354)

Variable	Gender		Chi square	p-value
	Male n (%)	Female n (%)		
Epilepsy			6.93	*0.009
No	103(49.3)	51(35.2)		
Yes	106(50.7)	94(64.8)		
Cerebral palsy			4.91	*0.027
No	198(94.7)	128(88.3)		
Yes	11(5.3)	17(11.7)		
Intellectual disability			0.21	0.648
No	174(83.3)	118(81.4)		
Yes	35(16.8)	27(18.6)		
Somatic symptoms disorder				‡0.404
No	207(99.0)	142(98.0)		
Yes	2(1.0)	3(2.1)		
ADHD			1.42	0.234
No	194(92.8)	139(95.9)		
Yes	15(7.2)	6(4.1)		
ODD				‡0.515
No	207(99.0)	145(100.0)		
Yes	2(1.0)	0(0.0)		
Conduct disorder				‡1.000
No	203(97.1)	141(97.2)		
Yes	6(2.9)	4(2.8)		
Tic disorder				‡0.273
No	206(98.6)	145(100.0)		
Yes	3(1.4)	0(0.0)		
ASD			3.42	0.065
No	196(93.8)	142(97.9)		
Yes	13(6.2)	3(2.1)		
Tobacco use disorder				‡0.088
No	201(96.2)	144(99.3)		
Yes	8(3.8)	1(0.7)		
Alcohol use disorder				‡0.647
No	206(98.6)	144(99.1)		
Yes	3(1.4)	1(0.67)		
Cannabis use disorder			7.62	*0.006
No	195(93.3)	144(99.3)		
Yes	14(6.7)	1(0.7)		
Other substance use				‡0410
No	209(100.0)	144(99.3)		
Yes	0(0.0)	1(0.7)		
‡Fisher's exact test applied		*p<0.05		

4.4: Children's/ young persons' level of functioning as measured by Children Global Assessment Scale

Overall, 41.2% of the respondents had mild to moderate functional impairment, followed by 27.7% who had severe impairment (See Figure 4). With regards to individual scores, 29.9% had scores between 71-80 and 23.5% between 51-60 (See Table 7).

The results showed that there was a statistically significant relationship between certain diagnoses and level of functional impairment. It was found that having Schizophrenia was associated with having mild-moderate functional impairment (62.1% versus 37.2%, p=0.001). In addition, having Enuresis (86.7% versus 25.1%, p<0.000) and Encopresis (100.0% versus 26.9%, p=0.006) were both associated with having severe functional impairment (see Table 8a).

Furthermore, having Epilepsy was associated with having normal function (40.0% versus 19.5% p=0.000) whereas having CP (89.3% versus 22.4%, p<0.000), ID (89.3% versus 22.4%, p<0.000), ADHD (90.5% versus 23.7%, p<0.001), ASD (100.0% versus 24.3%, p<0.000) were all associated with having severe functional impairment (Table 8b).

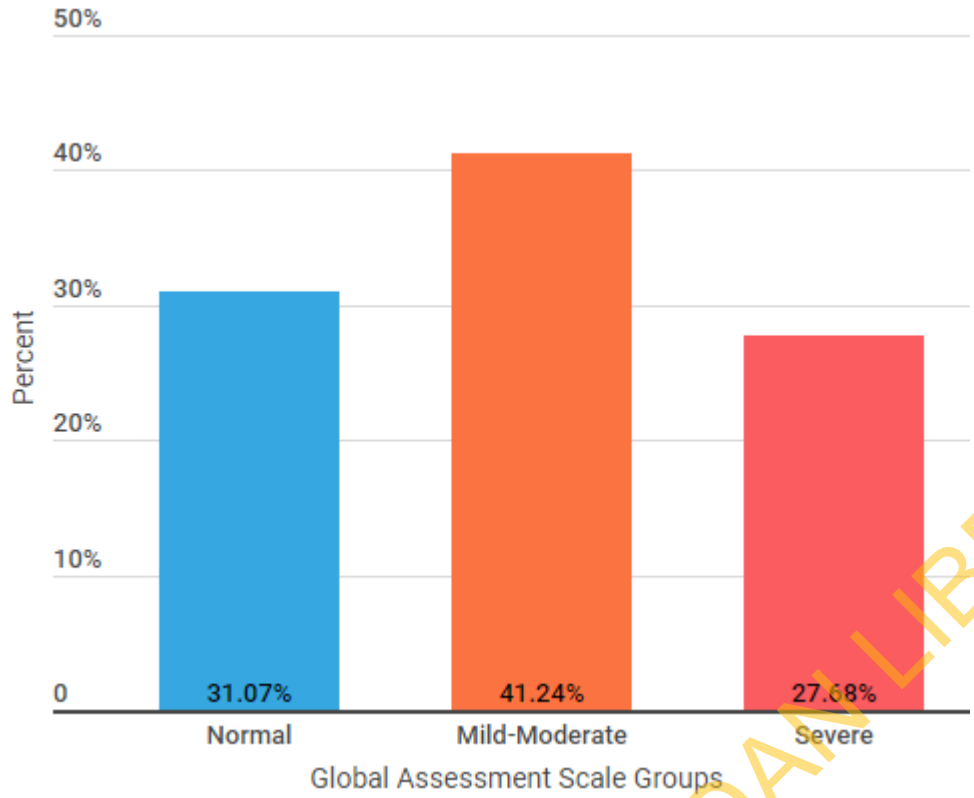

Figure 4: Bar chart showing severity of level of functional impairment as measured by C-GAS (N=354).

Table 7: Frequency distribution of Children Global Assessment Scale (N=354)

Variables	Frequency	Percentage
Categories of CGAS scores		
81-90	4	1.1
71-80	106	29.9
61-70	63	17.8
51-60	83	23.5
41-50	21	5.9
31-40	63	17.0
21-30	14	4.0
Total	**354**	**100.0**

Note: None of the participants scored above 90 or below 21.

Table 8a: Relationship between neuropsychiatric disorders and level of functional impairment (N=354)

Variable	Level of functional impairment			Chi square	p-value
	Normal n (%)	Mild-moderate n (%)	Severe n (%)		
Depressive disorder				3.43	0.180
No	102(32.1)	126(39.6)	90(28.3)		
Yes	8(22.2)	20(55.6)	8(22.2)		
Bipolar disorder				1.87	0.392
No	104(31.3)	132(40.7)	92(27.9)		
Yes	6(0.0)	14(100.0)	6(0.0)		
Disruptive mood dysregulation					‡0.120
No	110(31.3)	143(40.7)	98(27.9)		
Yes	0(0.0)	3(100.0)	0(0.0)		
Schizophrenia				13.39	*0.001
No	101(34.1)	110(37.2)	85(28.7)		
Yes	9(15.5)	36(62.1)	13(22.4)		
Schizophreniform disorder					‡0.885
No	108(31.0)	143(41.1)	97(27.9)		
Yes	2(33.3)	3(50.0)	1(16.7)		
Psychosis due to GMC				4.75	0.093
No	96(31.4)	120(39.2)	90(29.4)		
Yes	14(29.2)	26(54.2)	8(16.7)		
Brief psychotic disorder					‡1.000
No	110(31.2)	145(41.1)	98(27.8)		
Yes	0(0.0)	1(100.0)	0(0.0)		
Substance induced psychosis				2.36	0.308
No	108(31.5)	139(40.5)	96(28.0)		
Yes	2(18.2)	7(63.6)	2(18.2)		
Panic disorder					‡1.000
No	110(31.2)	145(41.1)	98(27.8)		
Yes	0(0.0)	1(100.0)	0(0.0)		
Separation anxiety				2.12	0.347
No	108(30.8)	145(41.3)	98(27.8)		
Yes	2(66.7)	1(33.3)	0(0.0)		
Social anxiety					‡0.090
No	110(31.7)	140(40.5)	96(27.8)		
Yes	0(10.0)	6(75.0)	2(25.0)		
Specific phobia					‡0.172
No	109(31.7)	139(40.4)	96(27.9)		
Yes	1(10.0)	7(0.0)	2(20.0)		
PTSD					‡1.000
No	109(31.0)	145(41.2)	98(27.8)		
Yes	1(50.0)	1(50.0)	0(0.0)		
Enuresis					‡*<.000
No	109(32.2)	145(42.8)	85(25.1)		
Yes	1(6.7)	1(6.7)	13(86.7)		
Encopresis					‡*0.006
No	110(31.4)	146(41.7)	94(26.9)		
Yes	0(0.0)	0(0.0)	4(100.0)		

‡Fisher's exact test applied *p<0.05

Table 8b: Relationship between neuropsychiatric disorders and level of functional impairment (N=354)

Variable	Level of functional impairment			Chi square	p-value
	Normal n (%)	Mild-moderate n (%)	Severe n (%)		
Epilepsy				17.6495	*0.000
No	30(19.5)	77(50.0)	47(30.5)		
Yes	80(40.0)	69(34.5)	51(25.5)		
Cerebral palsy					‡*<.000
No	110(33.7)	143(43.9)	73(22.4)		
Yes	0(0.0)	3(10.7)	25(89.3)		
Intellectual disability					‡<.000
No	110(37.7)	138(47.3)	44(22.4)		
Yes	0(0.0)	8(12.7)	54(89.3)		
Somatic symptoms disorder					‡1.000
No	108(31.0)	144(41.3)	97(27.8)		
Yes	2(40.0)	2(40.0)	1(20.0)		
ADHD					‡*<.000
No	110(33.0)	144(43.2)	79(23.7)		
Yes	0(0.0)	2(9.5)	19(90.5)		
ODD					‡0.743
Yes	110(31.3)	145(41.2)	97(27.6)		
No	0(0.0)	1(50.0)	1(50.0)		
Conduct disorder					‡0.283
No	109(31.7)	140(40.7)	95(27.6)		
Yes	1(10.0)	6(60.0)	3(30.0)		
Tic disorder					‡0.121
No	110(31.3)	146(41.6)	95(27.1)		
Yes	0(0.0)	0(0.0)	3(100.0)		
ASD					‡*<.000
No	110(32.5)	146(43.2)	82(24.3)		
Yes	0(0.0)	0(0.0)	16(100.0)		
Tobacco use disorder					‡0.327
No	108(31.3)	140(40.6)	97(28.1)		
Yes	2(22.2)	6(66.7)	1(11.1)		
Alcohol use disorder					‡1.000
No	109(31.1)	144(41.1)	97(27.7)		
Yes	1(25.0)	2(50.0)	1(25.0)		
Cannabis use disorder					‡0.134
No	108(31.9)	136(40.1)	95(28.0)		
Yes	2(13.3)	10(66.7)	3(20.0)		
Other substances use disorder					‡1.000
No	110(31.2)	145(41.1)	98(27.8)		
Yes	0(0.0)	1(10.0)	0(0.0)		

‡Fisher's exact test applied *p<0.05

4.5: Pathways to accessing child and adolescent mental health care services

4.5.1: General trend of patients flow in the different care pathways at the first three care points

Table 9 below shows the distribution of specific pathway taken by caregivers at the 3 care points. The results show that at the first point of care, majority (31.6%) visited traditional healers whereas majority (42.9%) and (96.0%) visited MMHH in their first and second referrals respectively (see Table 9).

In addition, Figure 5 further shows the general trend of patient's movements in those three care pints where the number of who visited the traditional healers, religious leaders and other health facilities at first contact kept decreasing in their second and third points of care while the number of those who first visited (15.8%) MMHH kept increasing in their second (43.2%) and third (96.0%) points of care respectively.

Table 9: **Frequency distribution of pathways taken by caregivers at the first three care points**

Variables	First care contact (N=354)	First referral (N=301)	Second referral (N=173)
Non-medical pathways:			
Traditional healer	112 (31.6%)	48 (16.0%)	1 (0.6%)
Religious leader	54 (15.2%)	24 (8.0%)	2 (1.2%)
Police	2 (0.6%)	0 (0.0%)	0 (0.0%)
Pharmacist	0 (0.0%)	1 (0.3%)	0 (0.0%)
Medical pathways:			
District hospital	58 (16.4%)	46 (15.3%)	0 (0.0%)
MMHH	53 (15.0%)	129 (42.9%)	166 (96.0%)
Regional hospital	45 (12.7%)	41 (13.6%)	2 (1.2%)
Health center	19 (5.6%)	3 (1.0%)	2 (1.2%)
Dispensary	11 (3.1%)	8 (2.7%)	0 (0.0%)
Other psychiatric hospitals	0 (0.0%)	1 (0.3%)	0 (0.0%)

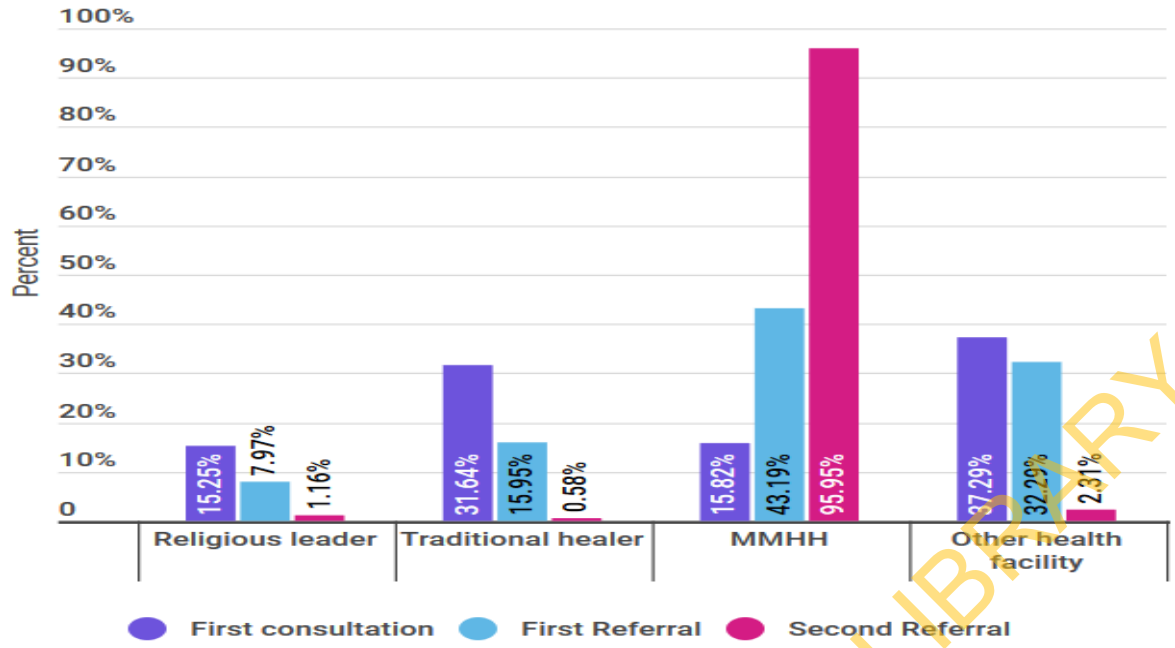

Figure 5: **Bar chart showing percentage distribution of patients at different care points as they access CAMH services.**

4.5.2: Description of the care initiators, presenting symptoms, awareness level on child mental disorders and medication use at the three care points

For one hundred and forty-one patients and caregivers (39.8%), it was their first time attending MMHH; of the remaining number, 90.6% visited the hospital within the last 6 years.

Only 13.8% of respondents were aware that children and young persons were vulnerable to mental health problems, prior to their child developing symptoms. Almost half (48.6%) of the caregivers reported that they did not know what the cause of the child's illness was, whereas 21.2% said it was bewitchment and other causes such as medical causes, respectively.

With regards to first consultation, almost all care seeking behavior was initiated by parents/caregivers (89.3%) and relative or friend initiated care in 9.0% of the cases, compared to 57.1% and 19.2% in the first referral and 23.5% and 13.3% at the second referral, respectively.

Fifty-two percent of the sample presented with seizures as their first symptom, followed by those who presented with confusion which was 20.1%. At all three care points, seizures and confusion were reported as the most common symptoms which necessitated care seeking whereby it was 53.7% and 23.5% at the first, 46.3% and 24.0% at the second, and 21.2% and 20.6 % at the third point of care, respectively.

Fifty-nine percent of the caregivers reported having already known the child's diagnosis at the first care contact, of which 75.2 % said it was "falling down". At the first care point, 34.8% were told of the child's diagnosis of which 50.4% reported it was epilepsy, compared to 55.1% and 55.4% at the first referral and 42.4 % and 52.0%, at the second referral, respectively.

Fifty-two percent received medications at the first contact of care compared with 64.9% at the first referral and 48.0% at the second referral, respectively (Table 10).

At the second referral, only 2.3% were using treatment offered at their previous point of care, and 85.3% of the respondents reported that the health care provider in the point of care before the current one did not know about their current care and treatment, of which 99.0% said it was due to lack of communication.

Table 10: Frequency distribution of care initiators, presenting symptoms, awareness level on CAMH disorders and medication use at the three care points

Variables	First contact of care	First referral	Second referral
Who initiated care seeking			
parent/guardian/self	316 (89.3)	202 (57.1)	83 (23.5)
relative/friend	32 (9.0)	68 (19.2)	47 (13.3)
Neighbor	1 (0.3)	1 (0.3)	3 (0.9)
child's teacher	3 (0.9)	5 (1.4)	17 (4.8)
health care worker	0 (0)	0 (0)	21 (5.9)
Other	2 (0.6)	4 (1.3)	1 (0.3)
Total	**354 (100)**	**301 (100)**	**173 (100)**
Symptoms necessitating care seeking			
Seizures	190 (53.7)	164 (46.3)	75 (21.2)
Confusion	83 (23.5)	85 (24.0)	73 (20.6)
Hyperactivity	7 (2.0)	13 (3.7)	0 (0)
delayed milestones	23 (6.5)	10 (2.8)	0 (0)
Other	51 (14.4)	29 (8.2)	21 (6.0)
not known	0 (0)	0 (0)	4 (1.1)
Total	**354 (100)**	**301 (100)**	**173 (100)**
Caregivers' reported child's diagnosis			
Epilepsy	62 (50.4)	108 (55.4)	78 (52)
Mental	30 (24.4)	79 (40.5)	72 (48)
Spiritual	20 (16.3)	0 (0)	0 (0)
Bewitched	9 (7.3)	0 (0)	0 (0)
Other	2 (1.6)	9 (4.6)	0 (0)
Total	**123 (100)**	**195 (100)**	**150 (100)**
Treatment offered			
Medications	184 (52.0)	230 (65.0)	170 (98.3)
herbs and rituals	104 (29.4)	47 (13.3)	0 (0)
Prayers	56 (15.8)	24 (8.0)	3 (1.7)
Total	**354 (100)**	**301 (100)**	**173 (100)**

4.6: Barriers to care as reported by patients and caregivers as they access CAMH care services at MMHH

The three commonest barriers reported during CAMH care seeking at MMHH were stigma (50.0%), long distance (42.4%) and financial problems (34.5%) (See Table 11).

Thirty-six percent (n=126) of the respondents had two types of barriers (Figure 7) and ninety-four (42.7%) had all three barrier categories (Figure 8).

Table 11: **Frequency distribution of barriers to care as reported by patients and caregivers as they access CAMH care services at MMHH**

Variable	Frequency	Percentage
Type of barriers		
Physical (N=354)		
No physical barrier	204	57.6
Long distance	150	42.4
Social (N=354)		
No social barrier	139	39.3
Financial problems	122	34.5
Lack of family support	93	26.3
Psychological (N=354)		
Stigma	177	50.0
No psychological barrier	75	21.2
Child needs constant support	53	15.0
Worry/tension about condition	49	13.8

NB: Due to the possibility of a participant having more than one challenge, the total n (%) will be >100%

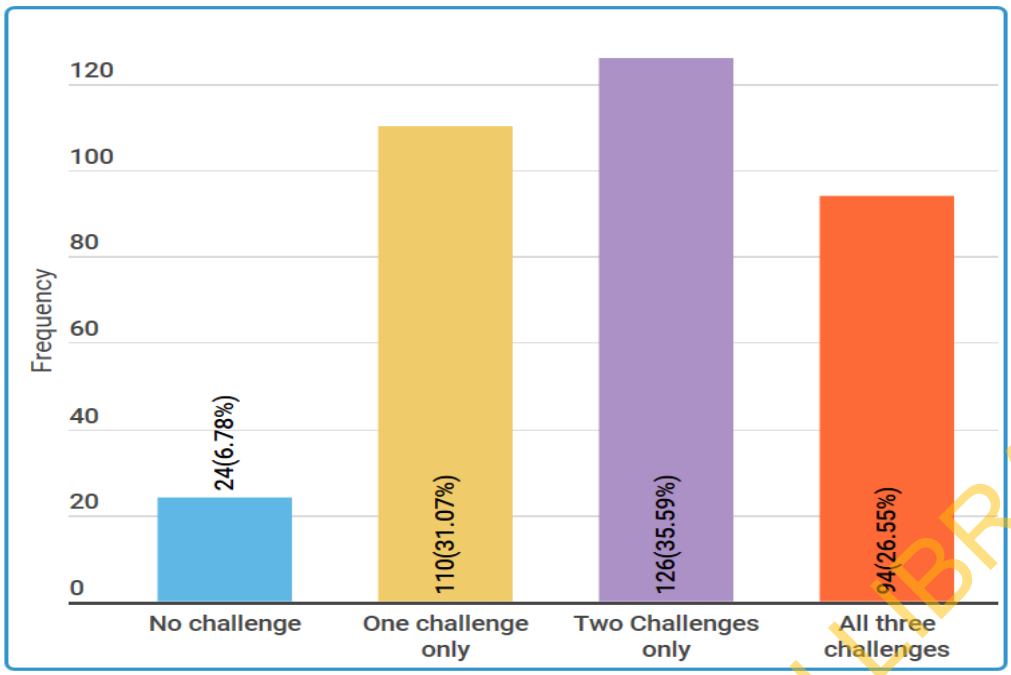

Figure 6: **Bar chart showing frequency distribution of patients by number of challenges (N=354).**

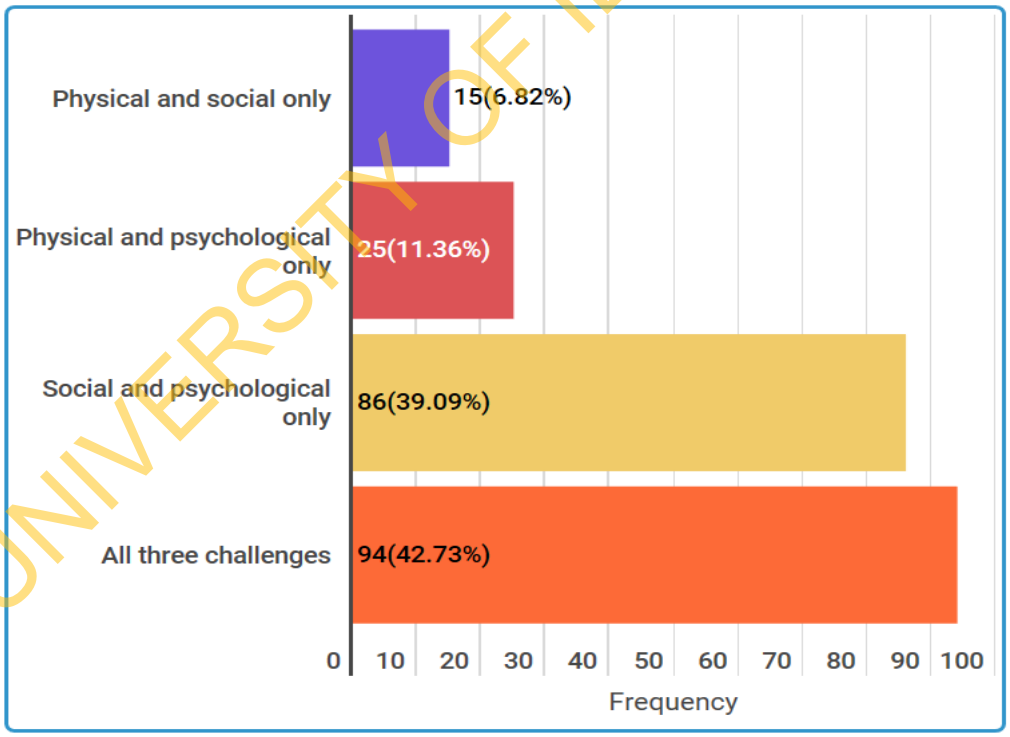

Figure 7: **Bar chart showing frequency distribution of challenges pattern among subjects with multiple challenges (N=220)**

4.7: Patients' and caregivers' opinion of care offered at MMHH

One hundred and sixty six (56.5%) of the patients and caregivers had an opinion that the care offered at MMHH was satisfactory.

Of those who were not satisfied with care (n=128) majority (55.5%) reported a problem with availability of drugs (See Table 12).

Table 12: Frequency distribution of patients' and caregivers' who were dissatisfied with CAMH care offered at MMHH (N=128)

Variable	Frequency	Percentage
Poor drugs availability	71	55.5
Poor availability of services	28	21.9
Poor accessibility of services	25	19.5
Other problems	4	3.1
Total	**128**	**100.0**

4.8: Factors associated with choice of type of first contact care pathways among children and young persons accessing care at MMHH.

4.8.1 Relationship between type of first contact care pathway chosen and socio-demographic characteristics

Table 13 shows that there is a statistically significant association between the specific type of first contact care pathway chosen and sociodemographic characteristics such as age of the child (p=0.002), school attendance status (p<0.000), parental status (p=0.042), and both education of father (p=0.025) and of mother (p=0.003).

The results show that being aged 6-9 years was associated with attending other health facilities (50.9%, p=0.002); and ages 10-19 years was associated with attending at MHH as their first care contact (22.0%); and being 20-24 years was associated with attending at religious leaders (20.3%) and traditional healers (39.1%) for care, respectively.

In addition, the child being currently in school was associated with attending at MMHH (21.9%) and other health facilities (55.2%) compared to their non-school attending counterparts (13.3%) and 29.7%) respectively. Furthermore, the child not currently attending school was associated with going to religious leaders (18.1%) and traditional healers (39%) compared with their school attending counterparts (8.6%) and (14.3%) respectively.

With regards to parental status, being cared for by a single parent was associated with visiting religious leaders for care (24.3% versus 13%) and being cared for by both parents was associated with attending at other health facilities (40.1% versus 25.7%).

As for parental educational level, fathers having no formal education was associated with using religious leaders' (22.2%) and traditional healers' (40%) services, and those fathers with primary education (15.6%, 36.4%) and secondary and above (25%, 52.5%) were more likely to use MMHH's and other health facilities' services, respectively.give values

Mother's education being primary was associated with seeking religious leaders' services (16.7%), and being primary (32.2%) and non-formal (38.1%) were associated with consultation for traditional healers' care. In addition, mother's education being non formal (17.5%) and primary (16%) was associated with attending at MMHH for care, while if it was secondary and above (81%) was associated with consulting other health facilities for care.

Table 13: Relationship between type of specific first contact pathways to care and socio-demographic characteristics (N=354).

Variables	Type of first contact pathway care					Chi square	p-value
	Religious leader n (%)	Traditional healer n (%)	MMHH n (%)	Other health facility n (%)	Total		
Age group (years)							
6-9	7 (12.3)	12(21.1)	9(15.8)	29(50.9)	57(100.0)	20.62	*0.002
10-19	20(12.2)	48(29.3)	36(22.0)	60(36.6)	164(100.0)		
20-24	27(20.3)	52(39.1)	11(8.3)	43(32.3)	133(100.0)		
Gender							
Male	33(15.8)	62(29.7)	33(15.8)	81(38.8)	209(100.0)	1.02	0.797
Female	21(14.5)	50(34.5)	23(15.9)	51(35.2)	145(100.0)		
School attendance status							
Yes	9(8.6)	15(14.3)	23(22.0)	58(55.2)	105(100.0)	34.97	*<.000
No	45(18.1)	97(39.0)	33(13.3)	74(29.7)	249(100.0)		
Type of caregiver							
Parent	45(16.7)	82(30.5)	40(14.9)	102(37.9)	269(100.0)	2.83	0.419
Others	9(10.6)	30(35.3)	16(18.8)	30(35.3)	85(100.0)		
Parental status							
Both parents	37(13.0)	90(31.7)	43(15.1)	114(40.1)	284(100.0)	8.22	*0.042
Single/orphan	17(24.3)	22(31.4)	13(18.6)	18(25.7)	70(100.0)		
Education of father							
No formal	10(22.2)	18(40.0)	4(8.9)	13(28.9)	45(100.0)	14.49	*0.025
Primary	41(15.2)	88(32.7)	42(15.6)	98(36.4)	269(100.0)		
Secondary and above	3(7.5)	6(15.0)	10(25.0)	21(52.5)	40(100.0)		
Education of mother							
No formal	8(12.7)	24(38.1)	11(17.5)	20(31.8)	63(100.0)	20.00	*0.003
Primary	45(16.7)	87(32.2)	43(16.0)	95(35.2)	270(100.0)		
Secondary and above	1(4.8)	1(4.8)	2(9.5)	17(81.0)	21(100.0)		

***** p value <0.05

4.8.2: Association between choice of type of first contact care pathways (non-medical/medical) and sociodemographic characteristics.

Tables 14 and Table 15 show the socio-demographic characteristics and other clinical factors associated with choice of type of first contact care pathways. The choice of pathway was significantly associated with age of the children (p=0.001), school attendance status (p<0.001), education level of the father (p=0.001), education level of the mother (p=0.002), belief on cause of illness (p<0.001), presenting first symptoms (p=0.014), social barriers (p=0.004) and psychological barriers (p=0.001).

Subjects aged 20-24 years were significantly more likely to use non-medical care as compared to children aged 6-9 years (OR=2.93, p=0.001). The choice of non-medical care was noted to be inversely related to education level of both the mothers and fathers of the children, in which the odds of using non-medical care among children and adolescents whose father's educational level was secondary and above was significantly lower as compared to those with nor formal education (OR=0.18, p=0.000). Likewise, children whose mother's educational level was secondary and above were less likely to use non-medical care in comparison with those with no formal education (OR=0.10, p=0.004).

With respect to belief on cause of illness, the results depicted that, the likelihood of using non-medical care among subjects who believed that the cause of illness was high fever or other (OR=0.01, p<0.000) and those who did not know the cause of the illness (OR=0.02, p<0.000) was significantly lower as compared to those who believed it was due to bewitched/spiritual causes. Patients with delayed milestones were significantly less likely to use non-medical care than those with seizures (OR=0.25, p=0.007). In addition, subjects who reported lack of family support (OR=2.16, p=0.005) and lack of financial support (OR=2.03, p=0.005) were having significant greater odds of using non- medical care in comparison to those who reported no social barriers. Regarding the effect of psychological barriers, it was noted that

compared to those who reported no barrier, patients with stigma were significantly more likely to use non-medical care than medical one compared to patients experiencing stigma (OR=3.00, p= 0.000).

Table 14: Socio-demographic factors associated with first contact choice of non-medical care pathway (N=354).

Variable	First contact care status			Unadjusted analysis	
	Medical n (%)	Non-medical n (%)	χ2 (p-value)	OR(95%CI)	p-value
Age group(in years)			14.50(*0.001)		*0.001
**6-9	38(66.7)	19(33.3)			
10-19	96(58.5)	68(41.5)		1.42(0.75, 2.67)	0.280
20-24	54(40.6)	79(59.4)		2.93(1.53, 5.61)	*0.001
Gender			0.42(0.515)		0.515
**Male	114(54.6)	95(45.5)			
Female	74(51.0)	71(49.0)		1.15(0.75, 1.76)	
School attendance status			34.78(*<.001)		0.172
Unspecified	51(43.2)	67(56.8)		1.48(0.68,3.25)	0.327
Currently in school	81(77.1)	24(22.9)		0.72(0.34,1.53)	0.393
Dropped out	31(41.3)	44(58.7)		0.89(0.40,2.00)	0.780
**Never attended school or other	25(44.6)	31(55.4)			
Type of caregiver			0.05(0.835)		0.831
**Parent	142(52.8)	127(47.2)			
Others	46(54.1)	39(45.9)		0.95(0.58, 1.55)	
Parental status			2.73(0.099)		0.100
**Both parents	157(55.23	127(44.7)			
Single parent	31(44.3)	39(55.7)		1.56(0.92, 2.63)	
Education of father			13.93(*0.001)		*0.002
**No formal education	17(37.8)	28(62.2)			
Primary	140(52.0)	129(48.0)		0.56(0.29, 1.07)	0.080
Secondary and above	31(77.5)	9(22.5)		0.18(0.07, 0.46)	*0.000
Education of mother			12.59(*0.002)		*0.012
**No formal education	31(49.2)	32(50.8)			
Primary	138(51.1)	132(48.9)		0.93(0.54, 1.60)	0.785
Secondary and above	19(90.5)	2(9.5)		0.10(0.02, 0.48)	*0.004
Who sought first care			0.00(0.950)		
Parent/caregiver	168(53.2)	148(46.8)		0.98[0.50,1.92]	0.950
**Others	20(52.6)	18(47.4)			
Region of residence			0.05(0.831)		
**Dodoma	142(52.8)	127(47.2)			
Other	46(54.1)	39(45.9)		0.95[0.58,1.55]	0.8306
* p value <0.05	**Reference variable			CI-confidence interval	

Table 15: Other social and clinical factors associated with first contact choice of non-medical care pathway (N=354).

Variable	First contact status			Unadjusted analysis	
	Medical care n (%)	Non-medical care n (%)	χ2 (p-value)	OR(95%CI)	p-value
Belief on cause of illness			141.43(*<0.001)		*<0.000
**Bewitched/spiritual	4(3.9)	99(96.1)			
High fever or other	59(74.7)	20(25.3)		0.01[0.00,0.04]	*<0.000
Do not know	125(72.7)	47(27.3)		0.02[0.00,0.04]	*<0.000
Presenting symptoms			12.44(*0.014)		*0.0253
**Seizures	96(52.2)	88(47.8)			
Confusion	30(42.3)	41(57.8)		1.49[0.86,2.59]	0.1566
Hyperactivity	4(50.0)	4(50.0)		1.09[0.27,4.49]	0.9041
Delayed milestones	22(81.5)	5(18.5)		0.25[0.09,0.68]	*0.0070
Other	36(56.3)	28(43.8)		0.85[0.48,1.50]	0.5737
Physical barriers			2.73(0.099)		
Long distance	72(48.0)	78(52.0)		1.43[0.94,2.18]	0.0992
**No physical barrier	116(56.9)	88(43.1)			
Social barriers			11.01(*0.004)		*0.004
Lack of family support	42(45.3)	51(54.8)		2.16[1.27,3.69]	*0.005
Financial problems	57(46.7)	65(53.3)		2.03[1.24,3.34]	*0.005
**No social barrier	89(64.0)	50(36.0)			
Psychological barriers			17.36(*0.001)		*0.001
Stigma	76(42.9)	101(57.1)		3.00[1.69,5.33]	*0.000
Needs constant support	29(54.7)	24(45.3)		1.87[0.90,3.88]	0.093
Worry/tension	31(63.3)	18(36.7)		1.31[0.61,2.81]	0.484
**No psychological barrier	52(69.3)	23(30.7)			
Functional impairment			1.98(0.372)		0.373
**Normal	52(53.1)	46(46.9)			
Mild-moderate	72(49.3)	74(50.7)		1.16[0.70,1.94]	0.566
Severe	64(58.2)	46(41.8)		0.81[0.47,1.41]	0.458
* p value <0.05	**Reference variable		CI-confidence interval		

The choice of pathways was also associated with symptoms profile. The results displayed in Table 16 show that the choice of pathways was associated with having a Schizophrenia spectrum and other psychotic disorder ($p<0.000$) and; anxiety and trauma related disorders ($p=0.000$). The odds of using non-medical care among subjects with schizophrenia spectrum and other psychotic disorders was almost 2.5 times that of patients with no schizophrenia spectrum and other psychotic disorders (OR=2.46, $p<0.0001$).

Table 16: Neuropsychiatric disorders associated with first contact choice of non-medical care pathway (N=354).

	First contact status			Unadjusted analysis	
Variables	**Medical n (%)**	**Non-medical n (%)**	**χ2 (p-value**	**OR(95%CI)**	**p-value**
Depressive and bipolar			1.98(0.159)		
Yes	34(61.8)	21(38.2)		0.66[0.36,1.18]	0.1609
** No	154(51.5)	145(48.5)			
Schizophrenia spectrum and other psychotic			15.89(*<0.001)		
Yes	48(38.7)	76(61.3)		2.46[1.57,3.86]	*<0.000
**No	140(60.9)	90(39.1)			
Anxiety and trauma related disorders			‡13.83(*0.000)		
Yes	15(100.0)	0(0.0)			
No	173(51.0)	166(49.0)			
Neurodevelopmental, disruptive, conduct disorders			1.60(0.206)		
Yes	25(62.5)	15(37.5)		0.65[0.33,1.28]	0.209
**No	163(51.9)	151(48.1)			
Substance use disorders			0.00(0.959)		
Yes	15(53.6)	13(46.4)		0.98[0.45,2.13]	0.959
** No	173(53.1)	153(46.9)			
Elimination disorders			0.30(0.585)		
Yes	9(60.0)	6(40.0)		0.75[0.26,2.14]	0.328
**No	179(52.8)	160(47.2)			
Epilepsy			0.00(0.963)		
Yes	106(53.0)	94(47.0)		1.01[0.66,1.54]	0.963
**No	82(53.3)	72(46.8)			
Cerebral palsy			2.66(0.103)		
Yes	19(67.9)	9(32.1)		0.51[0.22,1.16]	0.109
**No	169(51.8)	157(48.2)			
Intellectual disability			0.09(0.764)		
Yes	34(54.8)	28(45.2)		0.92[0.53,1.59]	0.764
**No	154(52.7)	136(47.3)			
Somatic symptoms			‡1.47(0.22)		
Yes	4(80.0)	1(20.0)		0.28[0.03,2.52]	0.255
**No	184(52.9)	165(47.3)			

***** p value <0.05 **Reference variable CI-confidence interval ‡Fisher's exact test applied

To determine independent factors associated with choice of pathways, variables which were significant in Tables 14, 15 and 16 were used in multiple logistic regression model. The results of the adjusted analysis are presented in Table 17. It is noted that age of the child (p=0.701), school attendance status (p=0.810), presenting first symptoms (p=0.346), having a schizophrenia spectrum and other psychotic disorders (p=0.278), reporting physical barriers (p=0.3630), and social barriers (p=0.799) were no longer significantly associated with choice of pathways.

It was shown that those fathers whose education level was primary (AOR=0.27, p=0.032) were less likely to use non-medical care in comparison to those with no formal education. It was also found that those mothers with education level of primary were at least 3 times more likely to use non-medical pathways (AOR=3.25, p=0.032) compared to their non-formal education counterparts.

Likewise, the likelihood of using non-medical care among subjects who believed that the cause of illness was high fever or other (AOR=0.01, p<0.000) and those who did not know the cause of the illness (OR=0.01, p<0.000) was significantly lower compared to those with bewitchment/spiritual cause belief.

Moreover, the adjusted odds of using non-medical care among patients reported worry/tension about the child's condition was at least 4 times higher compared to patients with no reported psychological barrier (AOR= 3.55, p=0.022).

Table 17: Multiple logistic regression for factors associated with first contact choice of non- medical care pathway (N=354).

Variables	Multivariate analysis AOR(95%CI)	p-value
Age group(in years)		0.701
**6-9	1	
10-19	0.81(0.27, 2.43)	0.755
20-24	1.10(0.30, 4.01)	0.867
School attendance status		0.810
Unspecified	0.80(0.27, 2.37)	
Currently in school	0.22(0.08,0.61)	
Dropped out due to illness	0.73(0.25, 2.16)	
**Never attended school due or other	1	
Education father		0.064
**No formal education	1	
Primary	0.27(0.08, 0.89)	*0.032
Secondary and above	0.91(0.09, 9.40)	0.933
Education mother		0.053
**No formal education	1	
Primary	3.25(1.11, 9.52)	*0.032
Secondary and above	0.91(0.09, 9.40)	0.933
Schizophrenia spectrum and other psychotic disorders		0.278
Yes	1.54(0.70, 3.38)	
**No	1	
Belief about cause of illness		*<.000
**Bewitched/spiritual	1	
High fever or other	0.01(0.00, 0.03)	*<.000
Do not know	0.01(0.00, 0.04)	*<.000
Presenting symptoms		0.346
**Seizures	1	
Confusion	0.89(0.33, 2.18)	0.678
Hyperactivity	5.86(0.72, 48.04)	0.093
Delayed milestones	0.51(0.12, 2.11)	0.359
Other	0.88(0.36, 2.14)	0.716
Physical barriers		0.630
Long distance	0.85(0.44,1.65)	
**No physical barrier	1	
Social barriers		0.799
Lack of family support	1.34(0.57, 3.13)	0.560
Financial problems	1.16(0.53, 2.53)	0.755
**No social barrier	1	
Psychological barriers		0.085
Stigma	2.72(1.15 ,6.43)	0.961
Needs constant support	2.79(0.87,8.95)	0.577
Worry/tension	3.55(1.17,10.71)	*0.022
**No psychological barrier	1	

* p value <0.05 **Reference variable CI-confidence interval

4.8.3: Time taken in care seeking

Seventy percent of the respondents reported not to have sought care within a week of onset of symptoms. Of those, 67.5% reported that it was due to lack of awareness of the problem and 30.9% said it was due to differences in beliefs about the cause of the illness among family members.

To access care at MMHH, on average it took 66.8 months since onset of symptoms, 71.1 months since their first contact of care, 56.1 months since their first referral and 40.5 months since their second referral (See Table 18).

To access care at MMHH, it took: 49 months or more for 170 (48.0%) of the respondents and 5 (1.4%) took a month or less since the onset of symptoms; 49 months or more for half the population since their first contact; 49 months or more for 40.5% of the population since their first referral; and 49 months or more for 24.6% (n=27) of the respondents, followed by 23.6% (n=26) who took between 13 and 24 months since their second referral (See Table 19).

Table 18: **Summary statistics of the time periods between onset of symptoms and getting to MMHH for care**

Time variable(months)	N	Mean(SE)	Median	IQR
Duration since onset of symptoms	354	66.82(3.35)	48	81
Duration since first contact of care	214	71.13(4.70)	48	93
Duration since first referral	195	56.13(4.16)	38	72
Duration since second referral	110	40.46(4.21)	24	38

Table 19: **Frequency distribution of time periods between onset of symptoms and getting to MMHH for care**

Variables	Event to care seeking at MMHH N (%)			
Time (in months)	**Onset of symptoms (n=354)**	**First contact of care (n=214)**	**First referral (n=195)**	**Second referral (n=110)**
<1	5 (1.4)	0 (0.0)	0(0.0)	0 (0.0)
1-6	38 (10.7)	22 (10.3)	32 (16.4)	17 (15.5)
7-12	31 (8.8)	27 (12.6)	26 (12.3)	11 (10.0)
13-24	45 (12.7)	20 (9.4)	20 (10.3)	26 (23.6)
25-36	43 (12.2)	26 (12.2)	20 (10.3)	17 (15.5)
37-48	22 (6.2)	23 (6.1)	18 (9.2)	12 (10.9)
49+	170 (48.0)	106 (49.5)	79 (40.5)	27 (24.6)

4.8.4: Factors associated with delay in care seeking

Delay in care seeking was significantly associated with school attendance status (p=0.032), type of caregiver (p=0.042), parental status (p=0.008), type of first contact care (p=0.013), belief on cause of illness (p=0.001), presenting symptoms (p=0.001), functional impairment (p=0.001); having a schizophrenia spectrum and other psychotic disorders (p=0.017); neurodevelopmental, disruptive and conduct disorder (p=0.012); substance use disorder (p=0.010) and epilepsy (p<0.001).

For socio-demographic characteristics, it was found that a child being taken care of by a non-parental caregiver, and single parents was significantly more likely to delay in care seeking (OR=1.95, p=0.045) and (OR=2.78, p=0.010) respectively than being taken care for by parents, or both parents, respectively. Also choosing the medical pathway in the first contact was associated with delay in care seeking (OR=1.90, p=0.013). In addition, believing the cause of the illness was high fever or other was more likely associated with delay in care seeking (OR=1.66, p=0.009) than if one reported not knowing the cause of the illness (See Table 20).

For clinical factors, the results showed that having a schizophrenia spectrum and other psychotic disorder (OR=1.96, p=0.018); neurodevelopmental, disruptive and conduct disorder (OR=4.22, p=0.019); substance use disorder (OR=9.07, p=0.032) were associated with more likelihood of delay in care seeking than not having the disorders. On the other hand, having epilepsy was associated with less likelihood of delay in care seeking (OR=0.21, p <0.000) than not having the condition.

With regards to level of functional impairment, it was shown that having normal functioning (OR=3.16, p=0.001) and mild to moderate functional impairment (OR=2.41, p=0.002) were more likely associated with delay in care seeking than having severe impairment (See Table 21).

Table 20a: Socio-demographic factors associated with delay in care seeking among children and young persons attending at MMHH for care

Variable	Care delay			Unadjusted analysis	
	No n (%)	Yes n (%)	χ2(p-value)	OR(95%CI)	p-value
Age groups (years)			1.54(0.464)		0.468
**6-9	10(17.5)	47(82.5)			
10-19	42(25.6)	122(74.4)		0.62[0.29,1.33]	0.219
20-24	31(23.3)	102(76.7)		0.70[0.32,1.55]	0.378
Gender			1.63(0.202)		
**Male	44(21.1)	165(79.0)			
Female	39(26.9)	106(73.1)		0.73[0.44,1.19]	0.203
School attendance status			5.09(*0.032)		0.166
Unspecified	20(16.95)	98(83.05)		1.82[0.90,3.67]	0.096
Currently in school	31(29.52)	74(70.48)		0.77[0.39,1.52]	0.450
Dropped out due to illness	19(25.33)	56(74.67)		1.37[0.63,2.79]	0.467
** Never attended school/other	13(23.21)	43(76.79)		0.68[0.31,1.48]	
Type of caregiver			4.14(*0.042)		
**Parent	70(26.0)	199(74.0)			
Others	13(15.3)	72(84.7)		1.95[1.02,3.73]	*0.045
Parental status			7.02(*0.008)		
**Both parents	75(26.4)	209(73.6)			
Single/orphan	8(11.4)	62(88.6)		2.78[1.27,6.08]	*0.010
Education father			0.52(0.769)		0.770
**No formal education	12(26.7)	33(73.3)			
Primary	63(23.4)	206(76.6)		1.19[0.59,2.44]	0.637
Secondary and above	8(20.0)	32(80.0)		1.46[0.53,4.03]	0.471
Education mother			2.60(0.272)		0.279
**No formal education	10(15.9)	53(84.1)			
Primary	67(24.8)	203(75.2)		0.57[0.28,1.19]	0.133
Secondary and above	6(28.6)	15(71.4)		0.47[0.15,1.51]	0.206
Region of residence			3.63(0.082)		
**Dodoma	69(25.7)	200(74.4)			
Other	14(16.5)	71(83.5)		1.75[0.93,3.30]	0.084

*p<0.05 **Reference variable CI-confidence interval

Table 20b: Social and other factors associated with delay in care seeking among children and young persons attending at MMHH for care

Variable	Care delay			Unadjusted analysis	
	No n (%)	Yes n (%)	χ2(p-value)	OR(95%CI)	p-value
Who sought first care			2.51(0.113)		
**Parent/caregiver	78(24.7)	238(75.3)			
Others	5(13.2)	33(86.8)		2.16[0.82,5.73]	0.121
Type of first contact of care			6.22(*0.013)		*0.013
**Non-medical	137(82.5)	29(17.5)			
Medical	134(71.3)	54(28.7)		1.90[1.14,3.17]	
Belief on cause of illness			13.99(*0.001)		*0.001
Bewitched/spiritual	15(14.7)	88(85.4)			0.128
High fever or other	30(38.0)	49(62.0)		1.66[0.86,3.20]	*0.009
**Do not know	38(22.1)	134(77.9)		0.46[0.26,0.83]	
Physical barriers			1.72(1.189)		
Long distance	30(20.00)	120(80.00)		1.40[0.85,2.33]	0.191
**No physical barrier	53(25.98)	151(74.02)			
Social barriers			1.71(0.701)		0.702
Lack of family support	19(20.4)	74(79.6)		1.31[0.70,2.47]	0.402
Financial problems	29(23.8)	93(79.2)		1.08[0.61,1.90]	0.792
**No social barrier	35(25.2)	104(74.8)			
Psychological barriers					0.060
Stigma	39(22.0)	138(78.0)		0.89[0.45,1.73]	
Needs constant support	10(18.9)	43(81.1)		1.08[0.44,2.62]	
Worry/tension	19(38.8)	30(61.2)		0.40[0.18,0.88]	
**No psychological barrier	15(20.0)	60(80.0)			

*p<0.05 **Reference variable CI-confidence interval

Table 21: Clinical factors associated with delay in care seeking among children and young persons accessing mental health care services at MMHH.

Variables	Care delay No n (%)	Yes n (%)	χ2(p-value)	Unadjusted analysis OR(95%CI)	p-value
Depressive and bipolar related			1.82(0.177)		
Yes	9(16.4)	46(83.6)		1.68[0.79,3.60]	0.181
**No	74(24.8)	225(75.3)			
Schizophrenia spectrum and other psychotic disorders			5.69(*0.017)		
Yes	20(16.1)	104(83.9)		1.96[1.12,3.43]	*0.018
**No	63(27.4)	167(72.6)			
Anxiety and trauma related			0.85(0.356)		
Yes	5(33.3)	10(66.7)		0.60[0.20,1.80]	0.360
**No	78(23.0)	261(77.0)			
Neurodevelopmental, disruptive and conduct			6.39(*0.012)		
Yes	3(7.5)	37(92.5)		4.22[1.27,14.05]	*0.019
**No	80(25.5)	234(74.5)			
Substance use disorders			6.69(*0.010)		
Yes	1(3.6)	27(96.4)		9.07[1.21,67.70]	*0.032
**No	82(25.2)	244(74.9)			
Elimination disorders			‡4.80(*0.029)		
Yes	0(0.0)	15(100.0)			
No	83(24.5)	256(75.5)			
Epilepsy			28.53(*<.001)		
Yes	68(34.0)	132(66.0)		0.21[0.11,0.39]	*<.000
**No	15(9.7)	139(90.3)			
Cerebral palsy			2.55(0.110)		
Yes	10(35.7)	18(64.3)		0.52[0.23,1.17]	0.298
**No	73(22.4)	253(77.6)			
Intellectual disability			0.26(0.612)		
Yes	13(21.0)	49(79.0)		1.19[0.61,2.32]	0.612
**No	70(24.0)	222(76.0)			
Somatic symptoms disorders			‡0.77(0.379)		
Yes	2(40.0)	3(60.0)		0.45[0.074,2.76]	0.235
**No	81(23.2)	268(76.8)			
Presenting symptoms			‡31.24(*<.001)		
Seizures	65(35.3)	119(64.7)			
Confusion	6(8.5)	65(91.6)			
Hyperactivity	0(0.0)	8(100.0)			
Delayed milestones	3(11.1)	24(88.9)			
Other	9(14.1)	55(85.9)			
Functional impairment			15.32(*0.001)		*0.001
Normal	15(15.3)	83(84.7)		3.16[1.61,6.20]	*0.001
Mild-moderate	28(19.2)	118(80.8)		2.41[1.37,4.24]	*0.002
**Severe	40(36.4)	70(63.6)			
* p value <0.05	**Reference variable			‡Fisher's exact test applied	

For independent factors associated with delay in care seeking, type of caregiver (p=0.525), region of residence (p=0.763), type of first contact care (p=0.374), having a schizophrenia spectrum and other psychotic disorder (p=0.670); neurodevelopmental, disruptive and conduct disorder (p=272) and substance use disorder (p=0.176) were no longer significantly associated with delay in care seeking at multiple logistic regression.

The adjusted odds of delay in care seeking among patients who were cared for by single parents were almost 3 times longer than those cared by both parents (AOR=2.71, p=0.018). Likewise, having normal functioning was more likely associated with delay care seeking at least 3 times longer (AOR=2.59, p=0.010) than having severe functional impairment.

On the other hand, the likelihood of delay in care seeking among those who believed that the cause of illness was high fever or other (AOR=0.50, p=0.031) was significantly lower compared to those who did not know the cause of the illness. Likewise, having epilepsy was significantly associated with lower likelihood of delay in care seeking (AOR=0.24, p=0.000) than not having epilepsy.

Table 22: **Multiple logistic regression for factors associated with delay in care seeking among children and young persons accessing mental health care services at MMHH.**

Variable	AOR(95%CI)	P-Value
Type of caregiver		
**Parent	1	
Others	1.27 (0.61, 2.66)	0.525
Parental status		
**Both parents	1	
Single parent	2.71 (1.19, 6.19)	*0.018
Region of residence		
**Dodoma	1	
Other	0.89 (0.43, 1.86)	0.763
Type of first contact of care		
**Non-Medical	1	
Medical	0.73 (0.36, 1.46)	0.374
Belief on cause of illness		*0.003
Bewitched/spiritual	1.82 (0.91, 3.64)	0.093
High fever or other	0.50 (0.27, 0.94)	*0.030
**Do not know	1	
Schizophrenia spectrum and other psychotic disorders		
Yes	1.16 (0.59, 2.26)	0.670
**No	1	
Neurodevelopmental, disruptive and conduct disorders		
Yes	2.13 (0.55, 8.22)	0.272
**No	1	
Substance use disorders		
Yes	4.39 (0.52, 37.48)	0.176
**No	1	
Epilepsy		
Yes	0.24 (0.13, 0.46)	*<0.000
** No	1	
Functional impairment		*0.024
Normal	2.59 (1.25, 5.34)	*0.010
Mild-moderate	1.82 (0.98, 3.36)	0.058
**Severe	1	
* p value <0.05 ** Reference variable	CI-confidence interval	

4.9: Patients' and caregivers' perceptions of the child and adolescent mental health services in Tanzania.

A total of 285 children and young persons had visited a health facility for care within six months equivalent to 80.5% of the study respondents. Of these, 74.0% visited MMHH while 22.8% visited district and regional hospitals.

Overall, 84% of the patients' and caregivers perceived CAMHS in Tanzania as "done a little of the time" (rated 2 out of a 5-point scale) whereas 15% reported "not done at all" (a rating of 1 out of a 5 points scale); (Figure 9 shows these findings).

Of the individual items, in 3 of the 20 items: being given a copy of the treatment plan, asked about whether the treatment/interventions recommended were in alignment with their values, beliefs and traditions; and whether contacted after their clinic visit to see how things were going were rated as being done none of the time in almost 100%.

Of the items that were rated as being done some of the time (a 3 out of 5 score) in at least 20-30% of the sample include: 31% asked questions about habits that negatively affect condition, 30% satisfied care was well organised, 27% asked about drugs problems and side effects, 26% given suggestions of things to do to improve health, 25% obtained skills that helped with better coping, 23% asked about how condition affects life and 22% given suggestions for possible interventions (See Table 24a and 24b).

Overall mean score 1.83 (median 1.9, interquartile range 1.55), with follow up scale being rated the lowest (mean 1.64) while the patient activation score being a little better. (See Table 23).

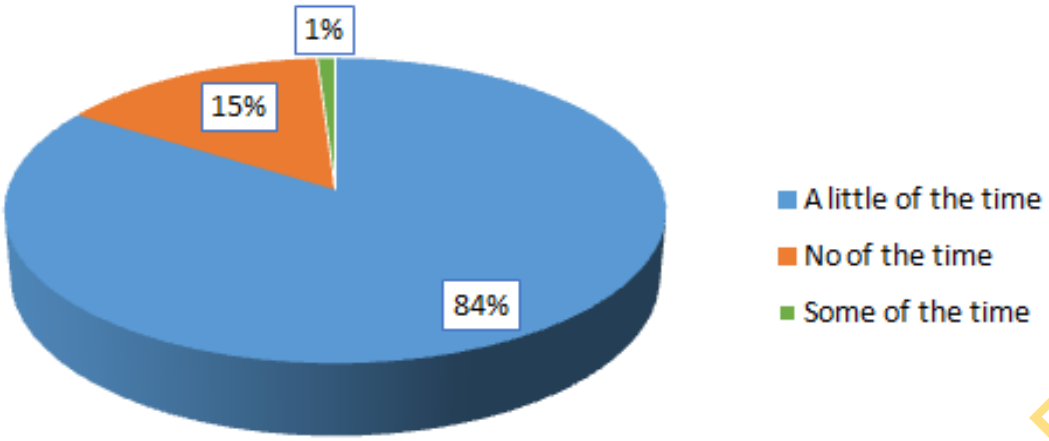

Figure 8: **Pie chart showing overall summary ratings of PACIC scores as rated by patients and caregivers (N=285)**

Table 23: Summary statistics of patients' and caregivers' perceptions of the child and adolescent mental health services in Tanzania (N=285)

Variables	Mean	Median	Lower quartile	Upper quartile
Scales				
Patient activation	2.18	2	1	4
Delivery system design/ decision support	2.08	2	1	5
Goal setting/ tailoring	1.78	1.8	1	3.4
Problem solving/ contextual	1.76	1.75	1	2.75
Follow-up/ coordination	1.64	1.8	1	2.4
The overall score	**1.83**	**1.9**	**1**	**2.55**

Table 24a: Distribution of PACIC scores as rated by patients and caregivers (N=285)

Variables	Rating				
	None of the time [1] n (%)	A little of the time [2] n (%)	Some of the times [3] n(%)	Most of the times [4] n(%)	Always [5] n (%)
Patient activation:					
Asked for ideas about an intervention plan that would work	36(12.6)	221(77.5)	25(8.8)	3(1.1)	0(0.0)
Given choices about possible interventions	37 (13.0)	182(63.9)	63(22.1)	3(1.01)	0(0.0)
Asked about problems with medicines/their effect	43(15.1)	156(54.7)	77(27.0)	9(3.2)	0(0.0)
Delivery system design/decision support: Given suggestions of things to do to improve health	55(19.7)	136(47.7)	73(25.6)	20(7.0)	1(0.4)
Satisfied care was well organized	56(19.7)	130(45.6)	86(30.2)	10(3.5)	3(1.1)
Been encouraged by providers to take more care of condition	115(40.4)	117(41.1)	48(16.8)	3(1.1)	2(0.7)
Goal setting/tailoring:					
Asked to talk about and set goals for caring for condition	88(30.9)	169(59.3)	25(8.8)	2(0.7)	1(0.4)
Helped to set specific goals to improve condition	90(31.6)	154(54.0)	39(13.7)	1(0.4)	1(0.4)
Given a copy of treatment plan	283(99.3)	1(0.4)	1(0.4)	0(0.0)	0(0.0)
Encouraged to go to a specific group to help cope	46(16.1)	205(72.0)	32(11.2)	1(0.4)	1(0.4)
Asked questions habits that negatively affect condition	22(7.7)	170(59.7)	87(30.5)	6(2.1)	0(0.0)

Table 24b: Distribution of PACIC scores as rated by patients and caregivers (N=285)

Variables	Rating				
	None of the time (1) n(%)	A little of the time (2) n(%)	Some of the times (3) n(%)	Most of the times (4) n(%)	Always (5) n(%)
Problem solving/contextual:					
Asked whether recommended interventions were in alignment with your values, beliefs, traditions	284(99.7)	1(0.4)	0(0.0)	0(0.0)	0(0.0)
Helped to make an intervention plan that could carry out in daily life	45(15.8)	212(74.4)	28(9.8)	0(0.0)	0(0.0)
Obtained skills to help deal with condition better	42(14.7)	170(59.7)	72(25.3)	1(0.4)	0(0.0)
Asked how condition affects your life	80(28.1)	137(48.1)	65(22.8)	2(0.7)	1(0.4)
Follow up/coordination:					
Contacted after clinic visit to see how things were going	283(99.3)	2(0.7)	0(0.0)	0(0.0)	0(0.0)
Encouraged to attend community programs that could help	78(27.4)	194(68.1)	13(4.7)	0(0.0)	0(0.0)
Referred to a counsellor/ equivalent who could help with psychosocial problems	51(17.9)	217(76.1)	17(6.0)	0(0.0)	0(0.0)
Told how visits with other type of providers could help in getting better	67(23.5)	218(76.5)	0(0.0)	0(0.0)	0(0.0)
Asked how visits with other providers were going	64(22.5)	221(77.5)	0(0.0)	0(0.0)	0(0.0)

4.10: Health workers' perceptions of the child and adolescent mental health services offered at MMHH.

A total of 27 MMHH health staff, 14 males and 13 females responded to the questions. Their age ranged from 30-60 years, with a mean of 43.19 years (SD ±9.564). There were 3 psychiatrists, 1 psychiatric nurse, 2 occupational therapists, 3 nursing officers, 2 assistant nursing officers, 3 medical officers, 2 health administrators, and 1 each of: social worker, pharmacist, radiographer, laboratory technician, ophthalmologist, dental surgeon, accountant, procurement officer, enrolled nurse, medical assistant, and clinical officer.

Generally, the frequency distribution of the individual items in the ACIC subscales show that majority were rated as 1 and 2 out of a 4, indicating limited to basic support (See Table 26a and 26b).

The overall mean score for the program was 1.9 with median of 1.8 and interquartile range of 0.3. The subscales that scored higher were organization of the health care system (mean 2.4) followed by patient's self-management support (mean 2.2) while linkages to community resources scored the least (mean=1.3) followed by decision support (mean=1.6) (Table 25).

Table 25: Summary statistics of health workers' perceptions of the child and adolescent mental health services offered at MMHH (N=27)

Variables	Mean scores	Median scores	Lower quartile	Upper quartile
Scales				
Health care organization subscale	2.4	2.4	2	2.8
Patient support for self-management	2.2	2	1.8	2.6
Clinical information system subscale	2.1	2.1	1.9	2.2
Community linkages subscale	1.8	1.9	1.6	2
Delivery system design subscale	1.8	1.8	1.7	2
Decision support subscale	1.6	1.5	1.3	2
Integration subscale	1.3	1.3	1.1	1.4
Overall program	1.9	1.8	1.7	2.0

Table 25a: Distribution of ACIC scores as rated by MMHH health workers (n=4 groups)

Variables	Rating			
	Little support [1] n(%)	Basic support [2] n(%)	Good support [3] n(%)	Full support [4] n(%)
Health care organization:				
Whether hospital health plans include CAMH guidelines/resources at the clinic level	0(0.0)	2(50.0)	1(25.0)	1(25.0)
Whether there is management of CAMI care at lower health care level	2(50.0)	1(25.0)	1(25.0)	0(0.0)
Extent health care goals and objectives include CAMI care	0(0.0)	1(25.0)	2(50.0)	1(25.0)
Whether there is an improvement strategy for CAMI care	2(50.0)	0(0.0)	2(50.0)	0(0.0)
Community linkages:				
How much child adolescent mental disorders linked to outside resources in the community	1(25.0)	3(75.0)	0(0.0)	0(0.0)
Whether community health workers are active and trained in CAMI care	1(25.0)	0(0.0)	3(75.0)	0(0.0)
Whether there is health promotion, awareness raising and population screening for CAMI	1(25.0)	3(75.0)	0(0.0)	0(0.0)
How patients are tracked down and provided with follow up medication in the community	3(75.0)	1(25.0)	0(0.0)	0(0.0)
Patient support for self-management:				
Whether patients are asked about their needs and help to set goals for managing their illness	0(0.0)	4(100.0)	0(0.0)	0(0.0)
Whether there is psychosocial support for managing the illnesses	0(0.0)	3(75.0)	1(25.0)	0(0.0)
Extent patients and families are helped to deal with concerns relating to the illness	0(0.0)	3(75.0)	1(25.0)	0(0.0)
Whether there are specific psychological interventions and peer support programmes for CAM disorders	2(50.0)	0(0.0)	1(25.0)	1(25.0)

Key: CAMI-child and adolescent mental illnesses

Table 26b: Distribution of ACIC scores as rated by MMHH health workers (n=4 groups)

Variables	Rating			
	Little support [1] n(%)	Basic support [2] n(%)	Good support [3] n(%)	Full support [4] n(%)
Decision support:				
Whether evidence based guidelines/protocols are available for nurses and doctors	3(75.0)	0(0.0)	1(25.0)	0(0.0)
Extent psychiatrists and psychologists involved in improving CAMI care	0(0.0)	4(100.0)	0(0.0)	0(0.0)
Whether there is training of facility staff in CAMI care	3(75.0)	0(0.0)	1(25.0)	0(0.0)
How accessible are essential supplies and technologies needed for CAMI care	3(75.0)	0(0.0)	1(25.0)	0(0.0)
Delivery system design:				
Whether there is a multidisciplinary team based approach for CAM disorders	2(50.0)	2(50.0)	0(0.0)	0(0.0)
How appointments for CAMI care managed	0(0.0)	4(100.0)	0(0.0)	0(0.0)
How follow up of CAMI patients managed	1(25.0)	2(50.0)	1(25.0)	0(0.0)
Referral systems available for CAMI care	1(25.0)	3(75.0)	0(0.0)	0(0.0)
Communication and coordination between service providers	0(0.0)	2(50.0)	2(50.0)	0(0.0)
Whether there is feedback from managers to staff about CAMI care	3(75.0)	1(25.0)	0(0.0)	0(0.0)
Clinical information system:				
Whether there is a registry for CAM disorders	0(0.0)	1(25.0)	3(75.0)	0(0.0)
Whether patient files include CAMH care forms	2(50.0)	2(50.0)	0(0.0)	0(0.0)
Whether patients treatment plans developed for CAM disorders	1(25.0)	2(50.0)	1(25.0)	0(0.0)
Whether there is available information about special subgroups of patients that need adapted treatment	0(0.0)	4(100.0)	0(0.0)	0(0.0)
Integration:				
Whether registries or information systems include patient self-management goals for CAM disorders	3(75.0)	1(25.0)	0(0.0)	0(0.0)
Whether community organizations give feedback about patient progress to facility staff	3(75.0)	1(25.0)	0(0.0)	0(0.0)
Whether plans for CAMI care are based on population data for the disorders	4(100.0)	0(0.0)	0(0.0)	0(0.0)
Whether there is routine follow up for appointments, patients assessments and treatment goal planning	2(50.0)	2(50.0)	0(0.0)	0(0.0)
Whether guidelines for CAMI care shared with patients	3(75.0)	1(25.0)	0(0.0)	0(0.0)

CHAPTER FIVE

DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

This was a hospital based, observational study which was carried out to determine the pathways to specialist child adolescent services in Dodoma, Tanzania and patient-provider perceptions on care. The study findings are discussed under 6 headings as follows: a) socio-demographic characteristics of the children/young persons and their caregivers, who participated in the study b) pattern of psychiatric disorders among children and young persons attending at MMHH for care c) pathways to accessing CAMH care services at MMHH and factors associated d) barriers to care as reported by patients and caregivers as they access CAMHS at MMHH e) patients' and caregivers' perceptions of the CAMH in Tanzania and f) health workers' perceptions of the CAMHS offered at MMHH.

5.1: Socio-demographic profile of children/young persons and their caregivers

In this study the higher male to female ratio among the children and young persons (59.0%) was comparable to Kamau and colleagues, who found males to be more than half of her study sample (54%) (Kamau et al., 2017). Children (6-9 years) being the minority of this sample is an important finding that gives an indication of the pattern of care seeking for child mental health problems in very young children in Tanzania. Lack of parental awareness was evident, as the majority (82.2%) of the caregivers reported that they did not think mental disorders could affect children, before their child got sick. This could be the reason behind low care seeking rate for this age group. However, in another East African country of Ethiopia, in Jimma city, a study on perceptions of CAMH problems and choice of treatment options, three quartetrs of caregivers identified genetic factors as causes and 20% of these further said it was due to neurochemical disturbances (Abera, Robbins, & Tesfaye, 2015) It is amazing how these two countries in the same geographical zone may have that different levels of literacy on

child mental health. Neverthless, it is known that multiple factors play part in such observations.

Those attending special school (approximately 7% of the sample) may not be a true representation of this group among those seeking mental health care at MMHH since they all came from one school which is located in Dodoma urban. They were brought by the school for a routine mental health assessment which is done for each new intake before commencement of studies. Only 1 child among this group had come from a different school, in another part of the country. It is also important to note here that there is a general lack of special school facilities and the majority of children with special needs, lack access to special schools.

The findings in this study sample regarding school attendance are alarming in that an overall 70% of the respondents are currently out of school; and a third of whom are out of school due to either never having been to school or dropping out on account of their mental health difficulties. This finding is supported by the robust research evidence which demonstrates that mental health problems are associated with school interference, and poor educational as well as occupational attainment (Esearch *et al.*, 2008; Gureje *et al.*, 2010; Esch *et al.*, 2014). The rates of out of school children and young persons in this study compare unfavourably to the 10.2% and 53.7% from studies in the SSA countries of Kenya and Nigeria respectively.

The caregivers' educational and occupational status show that the majority of participants' parents have either no formal education or primary level education and small scale farmers and are way lower compared to the 2012 census of the Tanzanian general population (National Census Report, 2012). This study sample may reflect a rather biased sample from lower socio economic and educational levels further pointing to the already established relationship between lower educational and socioeconomic status as risk factors for mental disorders.

The findings in this study with regard to religion practices reflect the country statistical profile of religions practices which show that majority of Tanzanians are Christians (National Census Report, 2012), although it varies from region to region, with more Muslims residing along coastal regions.

While MMHH is recognized as a National Referral centre offering specialist services, the reality as reflected in this study is that "MMHH serves the children and young people of Dodoma region mainly be due to accessibility factors". This is supported by the findings that three quarters of the sample are residents of Dodoma region and particularly Dodoma urban district where the hospital is located, and a small percentage from the adjacent districts Chamwino and then Bahi districts which are located 38.9km and 57.7 km respectively from Dodoma urban. Participants from other regions and districts illustrate the fact that the further the distance from Dodoma urban, the fewer the number of attendees.

The negative implication or conclusion is that children and young persons in other regions of the country do not receive specialist mental health services since there are no available. In neighbouring Kenya, Kamau et al (2017) also found majority of the study sample (62%) came from Nairobi, which was the study site. This is the reality for most SSA countries that many children and adolescents with mental disorders do not receive the help they need (Verhulst & Der Ende, 1997) (Sourander et al., 2001).

5.2: Pattern of neuropsychiatric disorders among children and young persons attending at MMHH for care

Epilepsy ranked as the most prevalent condition in this study, with more than half of the sample receiving the diagnosis. This is not a surprising finding, since epilepsy as a neurological disorder which is commonly treated at psychiatric clinics. In the case of Tanzania, the only other facility is the Muhimbili National Hospital, Dar es Salaam where there are specialized clinics for epilepsy. Tanzania has been cited as one of the countries with

high prevalence of epilepsy in SSA region (10.2 and 35.8 per 1000 population respectively (Preux & Druet-Cabanac, 2005). The main studies are the community studies by Rwiza and colleagues (Rwiza et al., 1992) but a recent study too (Mbando *et al.*, 2017) among the same Mahenge community which still showed a high prevalence of epilepsy (25 per 1000 population), which was associated with Onchocerca volvulus infection. Although the current study is on a clinical sample, it is still alarming that such a huge number attend a neuropsychiatric hospital for care, which could be due to the fact that they know the hospital provides such services or it could just be due to accessibility reasons as earlier explained, thereby highlighting a further unknown number who are attending other health facilities and other non-medical pathways for care. Further research may be required to unmask the true magnitude of the problem.

In their study, Abdulmalik and Sale (2012) found epilepsy to be the commonest presentation in a Northern Nigeria clinical sample but it was comparably lower (42.6%) than the 56.5% in our study, and also in a neighbouring country of Kenya, (Kamau et al., 2017) found the rate of epilepsy was only 10%. In Egypt, northern Africa, on the other hand, the rate was 22.5% among a clinical sample of ages 0-18 years (Kandil, Ahmed, Sayed, & Hamed, 2008).

The comparably lower rate of drugs use problems in this study, compared to that by Kamau et al (2017) who found the prevalence of substance use disorders to be 31.1% could partly be due to the fact that the Itega Drug Dependence Treatment Centre, which is one of the complexes of MMHH started operating a few weeks before the study, and majority of cases went direct to the Centre and did not pass through MMHH OPD. However, a few years back, a community study among secondary school students in Dodoma Municipality showed there was a drug use problem (overall prevalence of 14.6%). The common substances used were inhalants (7.6%), alcohol (6.8%), tobacco (3.7%) and cannabis (2.0%) (Simbee, 2012). It is surprising that in our study, inhalants did not feature as one of the common drugs used.

In this study, Intellectual disability (n=62) and Cerebral palsy (n=28) ranking second and fifth positions respectively is yet another striking finding. In the Tanzania community it is known that such cases are usually not taken to the hospital, but are more likely to be kept isolated at home. In this sample, it is possible that they were also brought to the hospital due to other comorbidities and not the recognized conditions per see though that would need to be clearly clarified by the caregivers themselves. Another possibility is that the majority of them that presented with these conditions might have been those who came from the special school as it was noted in their individual assessments that most of them had these conditions. Nevertheless, it could also be due to the high prevalence of Epilepsy since Epilepsy is one of the conditions associated with brain damage and common comorbid conditions are ID and cerebral palsy. Individually, these three conditions were also among those found to be significantly associated with functional impairment, others include schizophrenia ($p=0.001$), enuresis ($p<0.000$), encopresis ($p=0.006$), ADHD ($p<0.001$), and ASD ($p<0.000$).

Other common conditions that presented such as schizophrenia is not surprising since its common age of onset is late adolescence to early 20s (Sham, MacLean and Kendler, 1994). In addition, the general age and gender distribution of the study sample is in keeping with what is already known from other literature. However, what was surprising was the high prevalence of psychosis due to GMC found in this population, although the underlying medical conditions were common (malaria and typhoid fever) since these are endemic in Tanzania and can cause a lot of morbidity and mortality among all age groups, but especially among the children. Further study to explore this area may be warranted.

5.3: Pathways to accessing child and adolescent mental health care services at MMHH and factors associated with choice of such pathways

The findings indicate that the number of those who first visited the traditional healers, the spiritual healers and other health facilities decreased in the second care point and fell

significantly in the third care point whereas the trend for those who visited MMHH as their first care contact seemed to significantly increase in the first referral and peaked in the second referral. It is obvious that there are factors responsible for this picture, which would be interesting to know and they could be studied and used as intervention points to work towards medical pathways, particularly to specialised child mental health services, at MMHH.

Interestingly, the findings are comparable to that by Ngoma, Prince and Mann (2003) where about the same proportion (48% versus 47%) of patients with mental health problems in the commercial city of Dar es Salaam visited traditional healers for care as compared to only 24% who visited primary health care facilities. The results are also similar with a Ghanian study in a psychiatric hospital in Accra, those aged 18 and older where it was shown that about 48% of patients contacted non-psychiatric treatment centres as their first care point (Ibrahim et al., 2016). In the current study, the second side of the coin shows that the proportion of those who first sought care from health facilities at all levels was more than double that found by Ngoma and colleagues about 15 years ago. As indicated earlier even though Ngoma's study sample were adults it gave us a general picture of the trends in pathways to care in a Tanzanian context and this trend has not changed very much as reflected in this study with children and young persons.

With regards to care initiation, parents were found to be the main first care initiators (89.0%), which was almost comparable to a Swedish study by Ivert and colleagues who found family to be the main source of referral, which was 81% (Ivert et al., 2011). Nevertheless, in the current study the trend dramatically changed in the consecutive care points and it is not clear what might have changed this trend. It is possible that other family came in the picture after learning about the problem from parents. To access further specialized care may have involved planning, cost and travel and that without relatives support would have been impossible for the poor uneducated parent. In that way a relative or relatives may have

initiated the continued care. This is a rather typical pattern in an African setting where the extended family support each other in points of need. This is a point of strength in child mental health that needs to be fully harnessed and strengthened in order to provide respite and support for caregivers.

In this study the media is not recognized as initiating care at any of the three care points, and hospital records indicate that no mass sensitization had been done prior to or during the study. This can serve as an important intervention point since the media is one of effective ways for mass health education. Without media intervention in terms of mass health education 40% of the sample were new cases at MMHH and strengthened by the media this percentage may be strikingly higher. The clinic was formerly reopened in September 2018 and number of new cases have been on the increase. It is possible that word of mouth among Dodoma attendees regarding the study may have prompted some to bring their children.

Furthermore, the alarmingly low level of awareness about child mental health and its causes in this population as evidenced by only 13.8% reporting that it never occurred to them that children could suffer from mental disorders and 48.6% reporting not knowing the cause of their child's illness. Another 29.1% thought it was due to witchcraft and spiritual causes. The implications of this evidence of widespread ignorance about child mental health problems is clearly the urgent need for public awareness campaigns to promote awareness and service utilization. It is certainly noteworthy that traditional beliefs (e.g. witchcraft) continue to be influential in how parents interpret a child's mental health problem and determines their choice of care pathway. It is a long established fact that the Tanzanian community believes in witchcraft as a causal factor in mental illness (Kilonzo & Mbatia, 1996; Njenga, 2002). This belief continues to be held by a large portion of the population despite all of the socio-cultural and political changes over the past few decades as reflected in this study and a recent study by Mwansisya and colleagues (Mwansisya et al., 2015). What is interesting however is that

despite their beliefs some study participants were ready to forgo traditional treatment in favour of biomedical treatment (as their second and third referral). This may not be unrelated with their lack of satisfaction with treatment outcomes in those settings.

In this study, the role of teachers was also not clear since all the 25 students whose care was initiated by their teachers were those 25 students who had come from a special school for routine assessment before commencing their school year, and that cannot possibly serve as a true reflection of role of teachers in care seeking in Tanzania. None of the other children among the sample was referred by a teacher. This was not in keeping with studies such as that by Kamau and colleagues in Kenya and in Italy (Pedrini et al., 2015) where teachers/schools were found to be among the key players in the referral process with 26.5% and 36% respectively. Thus, in order to change this situation, there may be a need for school mental health awareness campaigns including teacher training. So that school teachers can be effective partners in promoting early identification and prompt referrals in Tanzania.

The role of health care workers was also blurry and it somehow points to a non-functional referral system. Results indicate that teachers/schools did not initiate care and only 6.0% in each care point initiated care in the first and second referrals. Again, this was contrary to the findings in the same Kenyan and Italian studies where health care workers referred 34.0% and 36.0% of the sample, respectively.

Independent predictors of choice of pathways to care in this study include: father's education level being primary was in favor of medical pathways (AOR=0.27, p=0.032) whereas mother's education level being primary was in favor of non-medical pathway choice (AOR=3.25, p=0.032). Other predictors include: believing the cause of the illness was high fever or other (AOR=0.01, p<0.000) and caregivers reporting not knowing the cause of the child's illness (OR=0.01, p<0.000) were associated with less likelihood of choosing a non-medical pathway. In addition, caregivers reporting worry/tension about the child's condition

was at least 4 times higher (AOR= 3.55, p=0.022) compared to patients with no reported psychological barriers. Some of these factors such as parental education level, beliefs on cause, and attitudes were rightly pointed out by other scholars as guiding choice of pathway to care (Verhulst & Der Ende, 1997; Nsereko et al., 2011). However, reporting worry/tension about the child's condition as a guiding factor in choosing care was peculiar for our study and it may need further exploration to understand the reasons for being so.

5.4: Delays in care seeking

Regarding time taken to care seeking, the study found that only 30% of the sample sought care within a week of onset of symptoms. Of those who did not, 68% reported lack of awareness of the problem and 31% due to differences in beliefs about the cause of the illness among family members. On average it took 66.8 months since onset of symptoms, 71.1 months since their first care contact, and 56.1 months since their first referral and 40.5 months since their second referral for clients to access care at MMHH. These time periods are significantly higher compared to the Kenyan study in a similar setting where it was found that on average it took 16.6 months to access CAMH services after the onset of symptoms (Kamau et al., 2017).

Regarding factors associated with delay in care seeking, our study showed that factors such as being cared for by single parents (AOR=2.71, p=0.018) and having normal functioning (AOR=2.59, p=0.010) were found to independently associated with delay in care seeking. On the other hand, the likelihood of delay in care seeking among those who believed that the cause of illness was high fever or other (AOR=0.50, p=0.030) and having epilepsy (AOR=0.24, p=0.000) were significantly lower compared to those whose belief was witchcraft/spiritual causes or did not have epilepsy, respectively. A point worth noting is that epilepsy seems to be the most recognized condition in this study population, as evidenced by 60% reporting knowing what the child's diagnosis was at the first point and three quarters of them mentioning it was epilepsy. It was also the condition that necessitated care seeking in more than half the study population. The question to ponder is whether people with epilepsy

came to the hospital because they thought it was a mental disorder, which is usually the case, or they thought it was a medical condition (further supported by those who, for example believed the cause of the child's illness to be fever or "other" which mainly comprised of medical causes) and that is why they did not delay in care seeking.

On the contrary, in an Ethiopian study among attendees of a psychiatric hospital, with age range 2-85 years, having epilepsy and physical conditions was found to be associated with delay in care seeking. Other factors that delayed care in their study were having no formal education and being jobless, which were not the case in the current study (Bekele et al., 2009).

5.5: Barriers to care as reported by patients and caregivers as they access child and adolescent mental health services at MMHH.

It is not surprising that stigma featured as the commonest single barrier to accessing care, with 50% of the sample reporting it, closely followed by 42% who reported long distance as a problem, and 34% financial problems. Stigma and financial challenges were also among the factors found in another Dodoma study among an adult population as perceived barriers to mental health care (Mwansisya et al., 2015). In the current study, stigma was also found to be associated with choice of a non-medical pathway (p=0.000).

The majority of the respondents had multiple challenges, and about a quarter of them sample viewed availability of medications as a problem, which was particularly true for patients with epilepsy where regular supply of antiepileptic drugs at the hospital has been problematic; and resulting in frequent drug switching - which seems to affect patients' compliance. It is however noteworthy that more than half of the sample reported being satisfied with the CAMH services offered at MMHH and did not think there was anything to improve. This is contradicted by their objective assessment using PACIC where generally it is indicated that the performance of child mental health system in Tanzania, with MMHH included is very poor. The subjective endorsement on patient satisfaction items is in keeping with previous

reports that patients often endorse positive satisfaction with hospital services. However, when asked specific questions about aspects of service delivery, it becomes apparent that they were not altogether, very satisfied – as was the case here with the PACIC scores. This again raises the issue of mass education on patients' rights and what quality services should be so that together the community can advocate for better child mental health for Tanzanian children and their families.

5.6: Patients' and caregivers' perceptions of the child and adolescent mental health services in Tanzania.

It not surprising that patients' and caregivers' perceptions of the CAMHS care they receive in Tanzania is low. This is not comparable to the German study which was done to validate PACIC among patients aged 2-80 years with depression where they found the mean value of 3.5 (versus 1.83 in our study), with a range of 2.83 in follow up/coordination and 3.69 for problem solving subscale respectively (Gensichen et al., 2011). It is however important to note that Germany is a high income country and if compared to Tanzania, the disparity could be huge for obvious reasons such lack of infrastructure, financial resources, quality services and a paucity of human resources. Nevertheless, the German study was done in a community sample while the majority (74.0%) of our respondents assessed the MMHH services they received in the last 6 months. It is our opinion that since MMHH is a tertiary level facility it should have served as a gold standard and hence provided better, and more comprehensive services.

It is also not very surprising that patients were not asked about whether the interventions were in alignment with their values, beliefs and traditions; were not given a copy of their treatment plan, and were not contacted after clinic visits. It is opined that these are some aspects of care that require extra resources such as time and funds, since one has to produce a printed treatment plan; and calling requires having mobile phones and airtime which are not usually

within normal hospital budgets. As for asking about interventions being in keeping with patients' beliefs/values/traditions, it is not the culture for medical personnel since the old paternalistic model still holds sway, and patients feel whatever the health provider decides for them is right and they may not even ask questions. This however, can be an area of improvement so that patients take greater ownership of their care.

5.7: Health care workers' perceptions of the child and adolescent mental health services offered at MMHH.

With regards to health care workers' perceptions of the CAMHS, this study found that generally, in Tanzania, there is limited support for CAMHS (mean score of 1.9, median of 1.8, and interquartile range of 0.3). In spite of the general limited support observed, some subscales performed scored on the higher side, that is the organization of the health care system (mean 2.4) and patients self-management support (mean 2.2) while linkages to community resources (mean=1.3) and decision support (mean=1.6) scored on lower side. It is also interesting that the findings from the patients and caregivers sample on perceptions of care are comparable to this, with an overall mean score of 1.83. It seems the findings are contradictory to what was reported by Mbatia and Jenkins (2010) several years ago in their report on mental health services in Tanzania. It is possible that there has been a deterioration of the situation or it may be a true reflection of the situation of CAMHS, which is still in its infancy stage in Tanzania.

Comparably, a study among 6 Emerald countries of South Africa, Ethiopia, Nigeria, Uganda, Nepal and India, although not specifically assessing for CAMHS, reported an overall little to basic support of the services. However, there were variations in the individual scales, with some performing better for some countries (Petersen et al., 2017).

Conclusion:

In conclusion the study findings indicate that the primary initiators of care are parents and their first choice of the care pathway for a large proportion of the population continues to be non-medical services. The choice is based primarily it seems on lack of awareness/education and cultural beliefs. The fact that health care workers were unrecognizable in identifying and initiating CAMHS indicates that health education and public health policy has not kept pace with advances in the field of child psychopathology especially the awareness of the benefit of early screening and intervention and the negative implication of long delays in accessing medical care leading to poorer prognosis, and interfering with education, which in this study was alarmingly high when compared to other SSA. It can also be concluded that the gap in CAMHS is enormous an awareness of the benefit of early screening and intervention and lack of accessible and affordable CAMHS.

The high prevalence of epilepsy in this study, suggests that significant investment and priority attention should be dedicated towards research and services for epilepsy and other neuropsychiatric conditions among Tanzanian children and young persons. These conditions have also been found to be associated with significant comorbidities and functional impairments, including interference with educational attainment.

Furthermore, the minimal role of healthcare workers and teachers as care initiators, identifies another potential gap that needs to be explored more fully. However, in Western countries teachers are important sources of referral for child mental health conditions. Interestingly, the health education in the media currently has minimal content on CAMH conditions. Thus, we can conclude that the health professionals and media are not playing their expected roles. Other areas for potential interventions include parent education programs at prenatal and post-natal clinics; which may encourage the parents to seek the most appropriate care for their child early, and appreciating the importance of early intervention. This should be supported by

public awareness campaigns to promote awareness of mental health and discourage the persistent beliefs in witchcraft/spiritual causes for CAMH conditions.

This study provided evidence that generally, CAMHS in Tanzania, are poor and with limited support, and it can also be concluded that MMHH, as the only neuropsychiatric hospital in the country, only serves the population of Dodoma. CAHMS is not accessible to the general population, especially rural dwellers. This clearly shows the unmet needs and the huge treatment gap among children and young persons with neuropsychiatric problems in Tanzania.

Limitations:

The following are some limitations from this study:

The patients and caregivers were required for example to provide historical sequence in terms of pathways to care and this covered relatively long time intervals. Thus, this may have introduced recall bias and information obtained may not be totally reliable or accurate. However, the researcher made sure interview methods were sensitive and utilized prompts to obtain as accurate as possible information.

Sample size bias is another possibility since as shown in the results that three quarters of the sample are residents of Dodoma region of low socioeconomic status and educational level, therefore the findings might not be generalizable for the whole country.

This study was among children and young persons as a group, however, most other studies are among children and adolescents as a group, hence challenges in comparing with other studies may be present since different populations were sampled.

The clinical diagnosis of Intellectual disability did not involve psychological testing of the children's Intelligence Quotient (I.Q) and was only based on adaptive functional assessment.

This study was cross sectional in nature, it could therefore not show the cause-effect relationship of the factors studied.

Recommendations:

1. **Provision of comprehensive and integrated mental and neurological care packages:** In order to improve the CAMHS in Tanzania, the government and other key stakeholders should ensure that comprehensive and integrated care is established within gerenal medical services from primary level to tertiary facilities.
2. **Promotional and prevention programs**: The high prevalence of mental and neurological disorders in this study, calls for more work on promotion and prevention areas too; in order to ensure optimal mental well-being in this population. For instance better antenatal care services can significantly prevent and reduce the high prevalence of Epilepsy in this population.
3. **Public educational programs**: These are necessary to raise awareness levels about common CAMH conditions and to encourage health seeking behavior from medical facilities; thereby avoiding unnecessary delays in seeking care.
4. **Training programs:** Primary care health workers, teachers and traditional/religious healers should be empowered by appropriate professional training to identify, intervene and institute early referrals for treatment.
5. **Effective implementation of laws, regulations and policies on CAMH in Tanzania:** Interesectoral collaboration is mandatory so that the laws, policies and regulations are effectively implemented especially based on equity and equality principles. It is clearly indicated that SDGs number 3 and 4 have not beeen well operationalized in this study population.

6. **Research**: Further studies (clinical as well as community based), should be conducted to clearly delineate the magnitude of epilepsy and other neuropsychiatric conditions in Tanzania, to aid in proper planning of care and resources allocation.

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APPENDICES

APPENDICES A: RESEARCH TOOLS

APPENDIX A1: RESEARCHER DESIGNED SOCIODEMOGRAPHIC QUESTIONNAIRE- ENGLISH VERSION.

Date: …….

Reseach allocated identification number: ……..

1. Region of residence: please mention …….
2. If from Dodoma Region, please circle the district: a) Dodoma Urban b) Bahi c) Chamwino d) Kondoa e) Chemba f) Mpwapwa g) Kongwa
3. Age of child, please mention the date of birth: (day, month, year): ……..
4. Gender: a) male b) female
5. Is the child attending school? a) Yes b) No
6. If no, please give reasons: …….
7. If he/she stopped school, circle the grade he/she stopped at: a) 1 b) 2 c) 3 d) 4 e) 5 f) 6 g) 7 h) Form I i) Form II j) Form III k) Form IV l) Form V m) Form VI
8. If in school, circle the grade: a) 1 b) 2 c)3 d) 4 e) 5 f) 6 g) 7 h) Form I i) Form II j) Form III k) Form IV l) Form V m) Form VI
9. Primary caregiver: a) biological parent b) adult relative: specify relationship…… c) Non-relative adult: specify …… d) self e) other: specify……
10. Parental status:

a) Both parents alive b) single parent: specify if mother…….father…… c) orphan

11. Level of father's/male caregiver's education:

a) no formal education b) primary school c)secondary school d)post-secondary school (not university) e) university degree and above

12. Level of mother's/female caregiver's education:

a) no formal education b) primary school c) secondary school d) post-secondary school (not university) e) university degree and above

13. Father's/ primary male caregiver's occupation: ……..
14. Mother's/ primary female caregiver's occupation: …….
15. Do you practice any religion? a) Yes b) No
16. If yes to number 15 above, please specify: …….

APPENDIX A2: RESEARCHER DESIGNED SOCIODEMOGRAPHIC QUESTIONNAIRE- KISWAHILI VERSION.

Tarehe: ……..

Namba maalum ya utafiti: …….

1. Makazi (mkoa): …….
2. Kama unaishi mkoa wa Dodoma, tafadhali zungushia wilaya utokako a) Dodoma mjini b) Bahi c) Chamwino d) Kondoa e) Chemba f) Mpwapwa g) Kongwa
3. Umri wa mtoto, taja tarehe ya kuzaliwa: (siku, mwezi, mwaka) …….
4. Jinsi a) me b) ke
5. Je, mtoto anasoma shule? a) Ndiyo b) Hapana
6. Kama sivyo, tafadhali taja sababu: …….
7. Kama aliacha shule, tafadhali zungushia darasa aliloachia a) la kwanza b) la pili c)la tatu d) la nne e) la tano f) la sita g) la saba h) Kidato cha kwanza i) Kidato cha pili j) Kidato cha tatu k) Kidato cha nne l) Kidato cha tano m) Kidato cha sita
8. Kama anasoma shule, tafadhali zungushia darasa analosoma a) la kwanza b) la pili c)la tatu d) la nne e) la tano f) la sita g) la saba h) Kidato cha kwanza i) Kidato cha pili j) Kidato cha tatu k) Kidato cha nne l) Kidato cha tano m) Kidato cha sita
9. Mlezi wa mtoto: a) mzazi b) ndugu aliye mtu mzima: taja uhusiano: ……. c) mtu mzima asiye ndugu: taja …… d) yeye mwenyewe e) wengine: taja…….
10. Hali ya wazazi: tafadhali zungushia a) wazazi wote wapo hai b) malezi ya mzazi mmoja: taja kama ni mama……baba…… c) yatima
11. Elimu ya baba/mlezi wa kiume: a) hajasoma shule b) msingi c) sekondari d) chuo ngazi ya chini ya chuo kikuu e) chuo kikuu
12. Elimu ya mama/mlezi wa kike: a) hajasoma shule b) msingi c)sekondari d) chuo ngazi ya chini ya chuo kikuu e) chuo kikuu
13. Kazi ya baba/mlezi wa kiume: …….
14. Kazi ya mama/mlezi wa kike: ……..
15. Je, una dini yeyote? ……
16. Kama ndiyo, tafadhali taja ……

APPENDIX A3: MODIFIED WHO ENCOUNTER FORM-ENGLISH VERSION.
Pathways to child and adolescent mental health care services in Tanzania: a service user's perspective

1. Basic information

Date: ……

Research allocated identification number: …….

i. Is this your first time attending at this hospital? a) Yes b) No
ii. If no, when were you first seen at the MMHH OPD? Please mention date (date/month/year)…….
iii. Before your child got unwell, did you think mental health problems could affect children and adolescents? a) Yes b) No.
iv. What was the first symptom developed by your child? .....
v. How long ago? (in months) …….
vi. State your child's diagnosis (if known): …….
vii. If diagnosis unknown by caregiver, why? ……

2. Decision to first seek help

viii. When your child got unwell, what did you believe was the cause of the illness? ……
ix. Who was first seen? a) pastor b) traditional healer c) MMHH d) Other hospital/clinic: mention……e) special school f) pediatrician g) chemist h) psychiatrist i) police j) other: mention ……
x. How long ago? (In months)……
xi. Who initiated first contact? /who advised you on where to go? a) Self b) relative/friend c) patient's neighbors d) child's teacher e) medical practitioner f) workmate/colleague g) media (TV, radio, newspaper, internet) h) spiritual leader i) traditional healer j) other……..
xii. What symptom caused decision to seek care .....
xiii. If did not seek help immediately (within a week), why? .....
xiv. What were you told was the child's diagnosis? ……
xv. What treatment(s) were offered? ……...

3. The first referral

xvi. Who was next seen? a) pastor b) traditional healer c) MMHH d) Other hospital/clinic: mention……e) special school f) pediatrician g) chemist h) psychiatrist i) police j) other: mention ……

xvii. How long ago? (In months)……..

xvii. Who made the decision? Who decided/advised you to see this person/go to that facility?

a) Self b) relative/friend c) patient's neighbors d) child's teacher e) medical practitioner f) workmate/colleague g) media (TV, radio, newspaper, internet) h) spiritual leader i) traditional healer j) other……..

xvii. What symptom caused you to seek first referral? .....

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

xx. What treatment(s) were offered? ……

4. Second referral

xxi. Who was next seen? a) pastor b) traditional healer c) MMHH d) Other hospital/clinic: mention……e) special school f) pediatrician g) chemist h) psychiatrist i) police j) other: mention ……

xxii. How long ago? (In months)……..

xxxiii. Who made the decision? Who decided/advised you to see this person/go to that facility?

a) Self b) relative/friend c) patient's neighbors d) child's teacher e) medical practitioner f) workmate/colleague g) media (TV, radio, newspaper, internet) h) spiritual leader i) traditional healer j) other……..

xxiv. What symptom caused you to seek first referral? .....

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

xxvi. What treatment(s) were offered? …….

5. Concurrent treatments

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

xxviii. If yes, which ones? ……..

xxix. Is your child being treated for another/other conditions? a) Yes b) No

xxx. If yes, which ones? ……...

xxxi. Does your other doctor/ healer/ care provider knows you attend this clinic? a) Yes b) No

xxxii. If no, why? .....

6. Patients' ad caregivers' perceived barriers and challenges to the current CAMHS

xxxiii. What are the main problems that you have encountered while seeking help for your child?

a) Physical: …….

b) Social: ……..

c) Psychological: ……

d) Other: ……

xxxvi. How do you think we can improve the services?
……
……

APPENDIX A4: MODIFIED WHO ENCOUNTER FORM-KISWAHILI VERSION.
Njia za kufikia huduma za afya ya akili ya watoto na vijana, Dodoma, Tanzania.

1. **Taarifa za awali:**

Tarehe: ……

Namba ya utafiti: …….

i. Je, hii ni mara yako ya kwanza kuonwa katika hopsitali hii a) Ndiyo b) Hapana
ii. Kama sivyo, je, ni lini ilikuwa mara yako ya kwanza kuonwa katika kitengo cha huduma za wagonjwa wa nje za Hospitali ya Mirembe? Tafadhali taja tarehe: ……..
iii. Je, kabla mwanao hajaugua, uliwahi kufikiri matatizo ya afya ya akili yaweza kuwapata watoto? a) Ndiyo b) Hapana
iv. Je, ni dalili ipi ya mwanzo aliyoonesha mtoto wako? ……..
v. Ni muda gani sasa umepita? (katika miaka) ……
vi. Tafadhali taja jina la aina ya ugonjwa wa mwanao (kama unafahamu) ……
vii. Kama aina ya ugonjwa wa mtoto haiujulikani na mlezi, kwanini? Taja sababu……

2. **Uamuzi wa kutafuta msaada/huduma kwa mara ya kwanza**

viii. Je, mwanao alipougua, uliamini nini kilikuwa chanzo cha ugonjwa wake? ……
ix. Je, ni nani alionwa kwa msaada kwanza? a) mchungaji/padre b) mganga wa jadi c) Hospitali ya Mirembe d) hospitali nyingine/kliniki: taja……e) shule ya watoto wenye mahitaji maalum f) daktari bingwa wa magonjwa ya watoto g) mhudumu wa duka la dawa h) daktari bingwa wa magonjwa ya akili i) polisi j) wengineo: taja ……
x. Ni muda gani sasa umepita? (katika miaka) …….
xi. Je, ni nani aliyetafuta huduma ya kwanza/ aliyeshauri mahali pa kwenda kwa huduma? a) mzazi/mlezi/mtoto mwenyewe b) ndugu/rafiki c) jirani ya mtoto d) mwalimu wa mtoto e) mtaalam wa afya f) mtumishi mwezie mzazi/ mlezi g) vyombo vya habari (runinga, redio, gazeti, mtandaoni) h) kiongozi wa kiimani i) mganga wa jadi j) wengineo:……..
xii. Dalili ipi ilifanya mfanye uamuzi wa kutafuta huduma? ……..
xiii. Kama hamkutafuta msaada mara baada ya dalili kuanza (ndani ya wiki), kwanini? tafadhali taja sababu ……
xiv. Je, mliambiwa mtoto ana ugonjwa gani? tafadhali taja ……..
xv. Je, ni matibabu gani yalitolewa? …….

3. **Rufaa ya kwanza**

xvi. Je, ni nani aliyeonwa baada ya hapo? a) mchungaji/padre b) mganga wa jadi c) Hospitali ya Mirembe d) hospitali nyingine/kliniki: taja……e) shule ya watoto wenye mahitaji maalum f) daktari bingwa wa magonjwa ya watoto g) mhudumu wa duka la dawa h) daktari bingwa wa magonjwa ya akili i) polisi j) wengineo: taja ……

xvii. Ni muda gani sasa umepita? (katika miaka) …….

xvii. Je, ni nani aliyefanya uamuzi huo/ aliyeshauri mtu wa kwenda kumwona/ mahali pa kwenda kwa huduma? a) mzazi/mlezi/mtoto mwenyewe b) ndugu/rafiki c) jirani ya mtoto d) mwalimu wa mtoto e) mtaalam wa afya f) mtumishi mwenzie mzazi/ mlezi g) vyombo vya habari (runinga, redio, gazeti, mtandaoni) h) kiongozi wa kiimani i) mganga wa jadi j) wengineo:……..

xviii. Dalili ipi ilifanya mfanye uamuzi wa kutafuta huduma? ……

xix. Je, mliambiwa mtoto ana ugojwa gani? tafadhali taja ……

xx. Je, ni matibabu gani yalitolewa? …….

4. **Rufaa ya pili**

xxi. Je, ni nani aliyeonwa baada ya hapo? a) mchungaji/padre b) mganga wa jadi c) Hospitali ya Mirembe d) hospitali nyingine/kliniki: taja……e) shule ya watoto wenye mahitaji maalum f) daktari bingwa wa magonjwa ya watoto g) mhudumu wa duka la dawa h) daktari bingwa wa magonjwa ya akili i) polisi j) wengineo: taja ……

xxii. Ni muda gani sasa umepita? (katika miaka) …….

xxxiii. Je, ni nani aliyefanya uamuzi huo/ aliyeshauri mtu wa kwenda kumwona/ mahali pa kwenda kwa huduma? a) mzazi/mlezi/mtoto mwenyewe b) ndugu/rafiki c) jirani ya mtoto d) mwalimu wa mtoto e) mtaalam wa afya f) mtumishi mwenzie mzazi/ mlezi g) vyombo vya habari (runinga, redio, gazeti, mtandaoni) h) kiongozi wa kiimani i) mganga wa jadi j) wengineo:……..

xxiv. Dalili ipi ilifanya mfanye uamuzi wa kutafuta huduma? …….

xxv. Je, mliambiwa mtoto ana ugojwa gani? tafadhali taja ……...

xxvi. Je, ni matibabu gani yalitolewa?

5. **Matibabu mengineyo**

xxvii. Je, bado unaendelea kufuatilia matibabu uliyokuwa ukipata awali? a) Ndiyo b) Hapana

xxviii. Kama ndivyo, ni yapi? Tafadhali taja ……..

xxix. Je, kwa sasa, mwanao anatibiwa kwa tatizo/ugonjwa mwingine/mengine? a) Ndiyo b) Hapana

xxx. Kama ndivyo, ni yapi? Tafadhali taja ……....

xxxi. Je, daktari/mtaalamu wa afya/mganga wako wa jadi anafahamu kuwa unapata huduma hapa? a) Ndiyo b) Hapana

xxxii. Kama sivyo, kwanini? ……

6. Mtazamo wa wagonjwa na ndugu wanaowahudumia juu ya matatizo na changamoto kufikia huduma za afya na magonjwa ya akili ya watoto

xxxiii. Je, ni matatizo na changamoto gani kubwa ulizokumbana nazo katika kutafuta huduma kwa ajili ya mtoto wako?

a. Kimazingira:
   …….

b. Kijamii:
   …….

c. Kisaikolojia:
   …….

d. Nyingine:
   …….

xxxiv. Je, unafikiri mambo gani yanaweza kufanyika kuboresha huduma?
……
……

APPENDIX A5: THE MODIFIED PATIENT ASSESSMENT OF CARE FOR CHRONIC CONDITIONS (PACIC)- ENGLISH VERSION.

i. **Date: …….**

ii. **Allocated research allocated number: …….**

iii. **Instructions:**

Please fill ONLY if you attended medical care services in the last 6 months.

Please tick the level of care you attended in the last 6 month

(a) Dispensary (b) health centre (c) district hospital (d) regional hospital (e) Mirembe Mental Health Hospital (f) Another Psychiatric tertiary level hospital

iv. **Introduction:** Staying healthy can be difficult when you/your child has a chronic condition. We would like to learn about the type of help that you/your child gets for your/his/her condition from your health care team. This might include your nurses at the clinic, doctors, psychologists, counsellors and community health workers. Your answers will be kept confidential and will not be shared with your doctors/nurses/ or clinic.

v. **Questions: Over the past 6 months, when you received care for your/your child's mental health condition (child and adolescent mental health disorder) were you**:

	None of the time (1)	A little of the time (2)	Some of the time (3)	Most of the time (4)	Always (5)
Asked for your/your child's ideas about a treatment/intervention plan that would work for you/them?					
Given choices about possible interventions/treatments to think about?					
Asked about any problems that you/your child may have with the medicines or their effects?					
Given suggestions of things that you could do to improve your/your child's health?					
Satisfied that your/your child's care was well organized, for example, that there was good coordination between different providers involved with the care?					
Been encouraged by providers to take more care of your/your child's condition, for example, shown how any actions that you have taken to take care of yourself/your child has improved your/their condition?					
Asked to talk about and set goals for caring for your own/your child's condition?					
Helped to set specific goals to improve your condition, e.g., getting active, acting on a problem, joining a support group?					
Given a copy of your/your child's treatment plan?					

Encouraged to go to a specific group to help you cope with your/your child's condition?					
Asked questions about the habits that may negatively affect your/your child's condition?					
Asked about whether the treatment/interventions recommended were in alignment with your values, beliefs and traditions?					
Helped to make a treatment/intervention plan that you could carry out in your/your child's daily life?					
Obtained skills to help you to deal with your/your child's condition better even when under great stress or hard times?					
Asked how your/your child's condition affects your/their life?					
Contacted after your visit to the clinic to see how things are going?					
Encouraged to attend programs in the community that could help you/your child?					
Referred to a counsellor or equivalent who could help you with your psychosocial problems?					
Told how your visits with other type of providers, like a counsellor could help you/your child get better?					
Asked how your visits with other providers were going?					

APPENDIX A6: MODIFIED PATIENT ASSESSMENT OF CARE FOR CHRONIC CONDITIONS (PACIC) - KISWAHILI VERSION.

TATHIMINI YA WAGONJWA ILIYOBORESHWA YA HUDUMA YA MAGONJWA YA MUDA MREFU

i. **Tarehe: …….**

ii. **Namba ya mshiriki: …….**

iii. **Maelekezo:**

Tafadhali jaza tu kama umeshawahi kuhudhuria huduma za afya katika miezi 6 iliyopita.

Tafadhali weka alama katika ngazi uliyohudhuria katika kipindi cha miezi sita iliyopita**.**

(a) zahanati (b) kituo cha afya (c) hospitali ya wilaya (d) hospital ya mkoa (e) hospitali ya magonjwa ya afya ya akili Mirembe (f) hospitali nyingine ya magonjwa ya afya ya akili ya ngazi ya juu.

iv. Utangulizi: Kuwa na afya njema kunaweza kuwa kugumu kama wewe/mwanao ana ugonjwa wa muda mrefu. Tungependa kujifunza kuhusu aina ya msaada unaopata au mwanao anaopata kwa ajili ya tatizo lake kutoka kwa watoa huduma wa afya. Hii inajumuisha wauguzi, madaktari, wanasaikolojia, washauri nasaha na watoa huduma katika jamii. Majibu yako yatakuwa siri na wala watao huduma wako (madaktari, wauguzi, au kliniki) hawatashirikishwa majibu yako.

Maswali: Katika kipindi cha miezi sita iliyopita, wakati ulipopata huduma wewe mwenyewe au mwanao kwa ajili ya tatizo la afya ya akili (mtoto na kijana mwenye shida ya afya ya akili) je:-

	Sijawahi (1)	**Mara chache (2)**	**Wakati mwingine (3)**	**Mara nyingi (4)**	**Mara zote (5)**
Uliulizwa kuhusu mawazo yako au ya mwanao juu ya utaratibu wa matibabu ambao unafaa kwako au kwao?					
Ulipewa machaguzi kuhusu matibabu unayo fikiria.					
Uliulizwa kuhusu matatizo na dawa au madhara yatokanayo na dawa ambayo wewe au mwanao anayo?					
Ulipewa mapendekezo ya vitu ambavyo unaweza kuvifanya ili kuboresha afya yako au ya mwanao?					
Uliridhika kuwa huduma uliyopewa wewe au mwanao ilikuwa katika utaratibu mzuri, kwa mfano kwamba kulikuwa na uhusiano mzuri kati ya watoa huduma tofauti wanaohusika katika kukupatia huduma?					
Ulitiwa moyo na watoahuduma kuangalia zaidi hali yako au ya mwanao, kwa mfano ulioneshwa kwa namna gani tendo lolote unalofanya kuangalia afya yako au ya mwanao imeboresha hali yako au ya mwanao?					
Uliulizwa kuzungumzia kuhusu na kuweka malengo ya kupata huduma kwa ajili ya hali yako au ya mwanao?					
Ulisaidiwa kuweka malengo ya kuboresha hali yako. (mfano. kuwa mkakamavu, kushugulikia matatizo, kujiunga na kundi la msaada.)					
Ulipewa nakala ya mpango wa matibabu yako au ya mwanao?					
Kukutia moyo kwenda kwenye kundi maalumu la kukusaidia kukubaliana na hali yako au ya mwanao?					
Uliulizwa maswali kuhusu tabia ambazo zinaweza kuwa na madhara hasi kwa hali yako au ya mwanao?					
Uliulizwa kuhusu endapo matibabu yaliyo pendekezwa yanaendana na hadhi yako, imani yako na mila yako?					
Ulisaidiwa kutengeneza mpango wa					

watibabu ambao unaweza kuutumia kwako mwenyewe au kwa mwanao katika maisha ya kila siku?					
Ulipata maarifa ya kukusaidia wewe kukabiliana na hali yako au ya mwanao kwa namna bora zaidi hata wakati ambao upo katika shida au wakati mgumu?					
Uliulizwa kwa namna gani hali yako au mwanao iliathiri maisha yako au ya mwanao?					
Waliwasiliana na wewe baada ya kuhudhuria kliniki kujua unavyoendelea?					
Ulishawishiwakuhudhuria programu katika jamii ambazo zinaweza kukusaidia wewe au mwanao?					
Ulipewa rufaa kwenda kwa mshauri nasaha au mtu sawia ambaye anaweza kukusaidia katika matatizo yako ya kiafya?					
Uliambiwa namna gani mahudhurio yako kwa watohuduma wengine kama washauri nasaha yanaweza kukusaidia wewe au mwanao kupata nafuu.					
Uliulizwa namna gani madhudhurio yako kwa watoa huduma wengine yalivyo kwenda?					

APPENDIX A7: MODIFIED ASSESSMENT OF CHRONIC ILLNESS CARE FOR MENTAL ILLNESS (ACIC)-ENGLISH VERSION.

The Modified Assessment of Chronic Care for Mental Illness (ACIC)

Please complete the following information about Mirembe Mental Health Hospital (MMHH) - Child and Adolescent Mental Health services. This information will not be disclosed to anyone besides the researchers of this study

Date: _____/_____/_____(Day Month Year)

Research allocated number: …….

Sociodemographic profile of the research participant:

Age: ……..

Gender: a) male b) female

Carder: a) nurse b) doctor c) other

Directions for Completing the Survey

This survey is designed to help improve the system for managing children and adolescents with mental health conditions. The results can be used to help your team identify areas for improvement. Instructions are as follows:

Answer each question from the perspective of Mirembe Mental Health Hospital.

Answer each question bearing in mind how Mirembe Mental Health Hospital is doing with respect to the provision of care for child and adolescent mental health conditions.

ADMINISTRATION INSTRUCTIONS: **For each row**, **circle the number** that best describes what currently happens. The rows in this form show what is needed for the best level of care for chronic mental illness. The higher numbers indicate that the actions described in that box are more fully implemented. For example 0 means that the action is not implemented at all, 11 means that it is implemented in the best or most complete way.

SCORING INSTRUCTIONS FOR INTERVIEWER: Add up the points in each section (e.g., total score for Part 1), then calculate the average score (e.g., the total score from Part 1 divided by the number of questions in Part 1), and enter these scores in the space provided at the end of each section. Then add up all of the section scores and calculate the average score for the whole programme by dividing this by the total number of questions asked.

The Modified Assessment of Chronic Care for Mental Illness

Part 1: Organisation of the Healthcare Delivery System

This section looks at those health system components that, if organised effectively, can support chronic care for child mental illnesses at the (MMHH) facility level.

	Questions	Little support (1)	Basic support (2)	Good support (3)	Full support (4)
1	**Do the hospital health plans include child and adolescent mental illness guidelines or resources at the clinic level?**	No, the plans hardly mention child and adolescent mental illness care.	Yes they are included in hospital plans but have not been implemented yet.	They are included and they also include guidelines and resources for one or two child and adolescent mental disorders.	They are included and also include guidelines and resources for **most** child adolescent mental illnesses.
2	**Is there management of child and adolescent mental illness care at lower health care levels (i.e below the tertiary facility level)?**	It does not exist or there is little interest in child and adolescent mental illness care.	Management is covered in health plans and policies but no resources are set aside for the work.	There is senior level management of child and adolescent mental chronic care, and human and financial resources are allocated for it.	Management of **child and adolescent mental** care is part of the health system's long term strategy. It has sufficient resources and there is staff accountability.
3	**To what extent do the hospital health care goals and objectives include child and adolescent mental illness care?**	Goals for **child and adolescent mental** care do not exist or are limited to one condition.	They exist but are not actively reviewed.	Goals for **child and adolescent mental** care are measurable and reviewed.	They are measurable, reviewed routinely, and incorporated into plans for improvement.

	Questions	Little support (1)	Basic support (2)	Good support (3)	Full support (4)
4	**Is there an improvement strategy for child and adolescent mental illness care?**	There is little that is done to improve **child and adolescent mental** illness care.	It only addresses specific problems **as they occur.**	There is an evidence-based improvement strategy for **specific problems.**	There is an evidence-based improvement strategy for **all problems** which is used proactively.

Part 2: Community Linkages

This section looks at community-level resources for children and adolescents with mental illness and how they can best be coordinated to provide optimal care.

	Questions	Little support (1)	Basic support (2)	Good support (3)	Full support (4)
1	**For the child and adolescent mental disorders, how much are patients linked to outside resources in the community (e.g. social workers)?**	Hardly at all.	They are linked to a few **easily accessible** community resources (e.g. social workers).	Links are made by a **designated staff member** who refers and tracks patients and ensures that service providers and patients make the best use of community resources.	Links are made through an **active network of health service providers and community services** that are known by clinic staff and work together with patients for optimal care.
2	**Are community health workers active and trained in child and adolescent mental illness care?**	Not at all.	Only when specific cases arise.	This is an important part of **child and adolescent mental** care at our facility but there are few resources to ensure it is consistently done.	This is an integral part of a team-based approach to chronic care at our facility and is coordinated with the training of other facility staff.
3	**Is there health promotion, awareness raising and**	It is hardly done.	It is done in an uncoordinated way by groups outside of our	It is done independently by community health workers, who	It is done by community health workers as part of our facility's

	Questions	Little support (1)	Basic support (2)	Good support (3)	Full support (4)
	population screening for child and adolescent mental illnesses?		facility.	sometimes give feedback to facility staff.	coordinated strategy for increasing awareness, prevention and management of child and adolescent mental illness among the community.
4	**How are patients tracked and provided with follow-up medication in the community?**	This is not really done.	It is done in an **uncoordinated** way by individual community health workers.	It is done in a **coordinated** way by a **team** of community health workers.	It is routinely done by community health workers as part a **child and adolescent mental** care team at our facility who work together for optimal patient management.

Part 3a: Patient Support for Self-Management

This section looks at how patients and their caregivers can be assisted to have control over their illness and live with their condition through implementing self-management and adopting healthy behaviours.

	Questions	Little support (1)	Basic support (2)	Good support (3)	Full support (4)
1	**For the child and adolescent mental disorders, are patients asked about their needs and helped to set goals for managing their illness?**	This is not really done.	This is done but not in a consistent or standardised way.	This is consistently done in a standardised way by staff at our facility.	This is done routinely by all staff and these goals are recorded in standardised form that is linked to the patient's treatment plan.
2	**Is there psychosocial support**	There is no psychosocial support.	It is limited to nurses giving patients psycho-education only.	There is both psycho-education by nurses as well as	There is psycho-education **and supportive counselling** given by

	(psycho-education & supportive counselling) for managing the illnesses?			take-home self help support material (e.g. pamphlets) available.	nurses, as well as take-home self help support material (e.g. pamphlets).
3	**To what extent are patients and their families helped to deal with concerns relating to the illness? (e.g. managing stigma, income generation)**	This is not really done.	It is done for specific patients and families when they request it.	This is encouraged, and staff are trained to do this.	This is an integral part of **child and adolescent mental health** care and is done for all patients.
4	**Are there specific psychological interventions (dedicated counselling) and peer support programmes for child and adolescent mental disorders?**	These are not really available at our facility.	Yes but this is limited to giving out pamphlets, booklets or other written information.	This happens through referral of non-adherent patients to specialised centres with staff who are trained in giving these interventions.	These are readily available at our facility and are an integral part of routine care for all chronic care patients.

Part 3b: Decision Support for Service Providers

This section looks at optimising service providers' expertise and skills to enable them to provide the best possible care.

	Questions	Little support (1)	Basic support (2)	Good support (3)	Full support (4)
1	**Are evidence-based guidelines or protocols (e.g. counselling guidelines or psychosocial rehabilitation guidelines) available for nurses and doctors at the facility?**	These are not available.	They are available but are not used all the time.	They are available and used by staff who have been trained in their use.	They are available, and used consistently by all staff as part of routine care.
2	**To what extent are psychiatrists and psychologists involved in improving child and adolescent mental illness care?**	It does not really happen.	They are involved through the usual referral systems.	They are involved as a referral resource as well as in training facility staff in **child and adolescent mental** illness care.	They are involved in providing training, support and supervision of facility staff in the use of mental health guidelines.
3	**Is there training of facility staff** (nurses, counsellors, community health workers, doctors) **in child and adolescent mental illness**	This training is not provided.	There is occasionally training like this.	This training is provided as and when needed for some facility staff through traditional training methods (e.g. once-off workshops/courses).	This training is provided routinely for all facility staff through traditional training methods, as well as on the job training and supportive supervision.

	Questions	Little support (1)	Basic support (2)	Good support (3)	Full support (4)
	care?				
4	**How accessible are the essential supplies** (e.g. drugs) **and technologies that are needed for child and adolescent mental illness care?**	The availability of these essential supplies is unpredictable and inconsistent.	They are only available as needed through unregulated supply systems.	They are available only when needed through regulated supply systems.	They are routinely available to all staff through well-managed and regulated supply systems.

Part 3c: Delivery System Design

This section looks at ways that team-based child and adolescent mental health care can be promoted through identifying the roles and responsibilities of the different members of the healthcare team so that they can work optimally together.

	Questions	Little support (1)	Basic support (2)	Good support (3)	Full support (4)
1	**Is there a multi-disciplinary team-based approach to child and adolescent mental disorders?** (Including nurses, doctors, counsellors, community health workers, specialists).	This does not exist.	This sometimes happens in response to specific problems.	This happens every now and then through team meetings to discuss guidelines, roles and accountability of different team members, and any problems that arise.	This happens through regular team meetings, with clearly defined roles for team members including providing proactive follow-up, patient education, and linking with resources in the community.
2	**How are appointments for child and adolescent mental illness care managed?**	Appointments are not made specifically for **child and adolescent mental** illness care.	There are scheduled appointments for **child and adolescent mental** mental illness care.	Scheduled appointments allow for flexibility to respond to unique patient needs (e.g. longer appointments, or family sessions).	Scheduled appointments enable the patient to see multiple service providers (e.g. nurse, doctor, psychologist) in a single visit.
3	**How is follow-up of child and adolescent mentally ill patients managed?** **Scores**	Follow-up is not scheduled.	Follow up is scheduled by the staff or patient as and when needed.	There is regular follow up through scheduled visits.	There is regular follow up through scheduled appointments and by staff who actively follow up those who miss appointments (e.g. phone, in person).
4	**What referral systems are available for child and adolescent mental illness care?**	There aren't really referral systems for chronic mental illness care.	Referrals are made as and when needed **within** the facility.	Referrals are made as and when needed within **and outside** of the facility.	There is a well-established referral system that is used consistently by all staff for optimal integrated care.

	Questions	Little support (1)	Basic support (2)	Good support (3)	Full support (4)
5	**How much communication and coordination is there between service providers regarding patients receiving child and adolescent mental illness care?**	This is not a priority.	There is sometimes written communication between facility staff and specialists (e.g. psychiatrist, psychologist).	Communication between facility staff, specialists and other relevant service providers (e.g. community organisations) is important but it **does not happen routinely**.	This is high priority at our facility and involves active coordination between all those involved in patient care (e.g. facility staff, counsellors, community health workers, specialists and other relevant service provider organisations).
6	**Is there feedback from managers to staff about child and adolescent mental illness care?**	This is not available.	This is provided occasionally and is delivered through written reports.	This happens often enough to monitor and improve the team's performance.	This happens routinely and is given to the team through discussion with a respected leader to improve team performance.

Part 3d: Clinical Information Systems

This section looks at how information can best be captured to facilitate clinical care and follow up.

	Questions	Little support (1)	Basic support (2)	Good support (3)	Full support (4)
1	**Is there a registry (list) of patients with child and adolescent mental disorders?**	No, this is not available.	Yes but this limited to a list of patients with **any** mental illness (type of disorder is not specified).	Yes, and this includes the specific diagnosis.	Yes, and this includes the specific diagnosis, as well as patient details (name, contact details) and information about the treatment process and outcomes.

	Questions	Little support (1)	Basic support (2)	Good support (3)	Full support (4)
2	**Do patient files include child and adolescent mental health care forms?**	They don't include **child and adolescent mental health** care forms.	They include **child and adolescent mental health** care forms but mental illness is not recorded on the form.	They include **child and adolescent mental care** forms but don't specify the type of mental illness.	They have **child and adolescent mental health** care forms which include the specific mental illnesses, and are routinely completed at each patient visit.
3	**Are patient treatment plans developed for the child and adolescent mental disorders?**	This does not really happen.	These are developed by individual facility staff.	These are developed by facility staff together with patients and patient self management plans.	These are developed collaboratively by a chronic care team and include patient self management plans as well as plans for regular follow-up.
4	**Is information available about special subgroups of patients that need adapted treatment? (e.g. treatment resistant mental illness)**	This information is not available.	This information can only be obtained with special effort.	This information can be obtained upon request but it is not routinely available.	This information is routinely available to staff to help them deliver optimal care.

Part 4: Integration of Chronic Care Model Components

This section looks at how all the elements of the chronic care model can be integrated for optimal care.

	Questions	Little support (1)	Basic support (2)	Good support (3)	Full support (4)
1	**Do registries or information systems include patient self-management goals for child and adolescent mental disorders?**	Registries do not include patient self-management goals.	Registries include results of clinical patient assessments but not patient self-management goals.	Registries include results of clinical patient assessments, as well as patient self-management goals.	Registries include results of clinical patient assessments, patient self-management goals and reminders to the facility staff or patient about follow-up and re-evaluation of goals.
2	**Do community organisations give feedback about patient progress to facility staff?**	They do not provide this feedback.	They provide occasional feedback about patients' progress in their programmes.	They provide regular feedback to facility staff using formal mechanisms (e.g., written report) about patients' progress.	They provide regular feedback about patients' progress which includes patient input that is then used to better meet the needs of patients.
3	**Are plans for child and adolescent mental illness care at the facility based on population data for the disorders?**	The plans are not based on population data.	The plans use data from facility information systems to plan care.	The plans use data from information systems to plan care, including patient self-management programmes and partnerships with community organisations.	The plans uses **data and input from teams to proactively plan and evaluate care**, including patient self-management programmes and community partnerships.
4	**Is there routine follow-up for appointments, patient assessments and treatment goal planning?**	This is hardly done.	There is occasional follow up, usually for appointments only.	There is follow up routinely by assigning these responsibilities to specific staff.	There is routine follow up by specific staff who uses the registry and other information to coordinate treatment planning with patients and the entire clinic team.
5	**Are guidelines for child and adolescent mental illness care shared with patients?**	They are not shared with patients.	They are given to patients who express a specific interest in self-management of their condition.	They are given to all patients to help them develop effective self-management, and identify when they should see a service provider.	They are given to patients as part of a discussion to devise a self-management programme that takes into account both the guidelines and patient goals.

Briefly describe the process you used to fill out the form (e.g., reached consensus in a face-to-face team meeting; filled out with the team leader in consultation with other team members as needed; the team leader filled out the form themselves with consultation with other team members as needed; each team member filled out a separate form and the responses were averaged).

Description: _____

_____

	Section	**Score**
1	**Total Health Care Organisation Score**	
	Average Score (Total Health Care Organisation Score / 4)	
2	**Total Community Linkages Score**	
	Average Score (Total Community Linkages Score / 4)	
3a	**Total Patient Support for Self-Management Score**	
	Average Score (Total Patient Support for Self-Management Score / 4	
3b	**Total Decision Support Score**	
	Average Score (Total Decision Support Score / 4)	
3c	**Total Delivery System Design Score**	
	Average Score (Total Delivery System Design Score / 6)	
3d	**Total Clinical Information System Score**	
	Average Score (Total Clinical Information System Score / 4)	
4	**Total Integration Score**	
	Average Integration Score (Total Integration Score/ 5)	
	Overall Programme Total (add up all total scores above)	
	Average Score (Overall Programme Score / 7)	

What do the scores mean?

The ACIC is organised so that the highest score (=11) on any individual item, subscale, or the overall score (an average of the seven ACIC subscale scores) indicates optimal support for chronic illness. The lowest possible score on any given item or subscale is a "0", which

corresponds to limited support for chronic illness care. The guidelines for interpretation are as follows:

Between 0 and 2 = limited support for chronic illness care

Between 3 and 5 = basic support for chronic illness care

Between 6 and 8 = reasonably good support for chronic illness care

Between 9 and 11 = fully developed chronic illness care

It is fairly typical for teams to begin a collaborative with average scores below "5" on some (or all) areas the ACIC. After all, if everyone was providing optimal care for chronic illness, there would be no need for a chronic illness collaborative or other quality improvement programmes. It is also common for teams to initially believe they are providing better care for chronic illness than they actually are. As you progress in the collaborative, you will become more familiar with what an effective system of care involves. You may even notice your ACIC scores "declining" even though you have made improvements; this is most likely the result of your better understanding of what a good system of care looks like. Over time, as your understanding of good care increases and you continue to implement effective practice changes, you should see overall improvement on your ACIC scores.

APPENDIX A8: MODIFIED ASSESSMENT OF CHRONIC ILLNESS CARE FOR MENTAL ILLNESS (ACIC)-KISWAHILI VERSION.

Tathmini iliyoboreshwa ya huduma ya magonjwa ya akili ya muda mrefu

Tafadhali jaza taarifa zifuatazo kuhusu Hospitali ya afya ya akili Mirembe juu ya huduma ya afya ya akili kwa watoto na vijana. Taarifa hizi zitakuwa siri, hakuna mtu yeyote atakeyeweza kuziona isipokuwa watafiti wa utafiti huu tu.

Tarehe: _____/_____/_____(siku, mwezi , mwaka)

Namba ya uandikishwaji ya mshiriki: …….

Taarifa binafisi za mshiriki wa utafiti:

Umri: ……..

Jinsia : a) mwanamume b) mwanamke

Idara : a) muuguzi b) daktari c) nyingine

Maelekezo ya kujaza dodoso

Utafiti huu umebuniwa ili kusaidia uboreshwaji wa mfumo wa matibabu ya watoto na vijana wenye matatizo ya afya ya akili. Matokeo yanaweza kutumika kusaidia kutambua aneo linalo hitaji maboresho. Maelekezo ni kama ifuatavyo:

Jibu kila swali kwa mtazamo wa Hospitali ya magonjwa ya afya ya akili Mirembe.

Jibu kila swali kwa kuzingatia namna ambavyo Hospitali ya magonjwa ya afya ya akili Mirembe inavyo -fanya kuhusu utoaji wa huduma kwa watoto na vijana wenye matatizo ya afya ya akili.

MAELEKEZO YA NAMNA YA KUJAZA: Kwa kila mstari, zungushia numba ambayo inaelezea vizuri inavyofanyika kwa sasa. Mistari katika fomu hii inaonesha nini kinahitajika ili kuwa na huduma bora za magonjwa ya akili ya muda mrefu. Namba kubwa zaidi inaonesha kwamba vitendo vilivyo elezwa katika kisanduku vina tekelezwa kikamilifu, kwa mfano 0 inamaana kwamba kitendo hakitekelezwi kabisa, 11 inamaanisha kwamba kinatekelezwa vizuri au kikamilifu.

MAELEKEZO YA KUTOA ALAMA: Jumlisha pointi katika kila sehemu (mf. jumla ya alama katika sehemu ya kwanza) kasha tafuta wastani (mf. Jumla ya alama katika sehemu ya kwanza gawia kwa idadi ya maswali katika sehemu ya kwanza) na ingiza hizi alama katika sehemu iliyowekwa mwisho wa kila sehemu. kisha jumlisha alama za sehemu zote na tafuta wastani wa alama kwa programu nzima kwa kugawa jumla hii na jumla ya idadi ya maswali yaliyo ulizwa

Sehemu ya 1: Muundo wa mfumo wa utoaji wa huduma za afya.

Sehemu hii ina inaangalia zile sehemu za mfumo wa afya ambazo, kama zikiundwa kwa ufanisi zitasaidia huduma za muda mrefu kwa mtoto mwenye ugonjwa wa akili katika hospitali ya magonjwa ya afya ya akili mirembe katika ngazi ya kituo.

	maswali	**Msaada kidogo (1)**	**Msaada wa kawaida (2)**	**Msaada mzuri (3)**	**Msaada kamili (4)**
1	**Je mpango wa afya wa hospitali umejumuisha miongozo ya magonjwa ya akili kwa watoto na vijana au rasilimali katika ngazi ya kliniki.**	Hapana, mpango mara chache hutaja huduma za magonjwa ya akili kwa watoto na vijana	Ndiyo, imejumuishwa katika mipango ya hospitali lakini haijatekelezwa.	Imejumuishwa kwenye mipango na pia imejumuisha miongozo na rasilimali kwa ajili ya watoto au vijana mmmoja au wawili.	Imejumuishwa pia imejumuisha miongozo na rasilimali kwa ajili ya watoto na vijana wengi wenye magonjwa ya akili.
2	**Katika ngazi ya chini ya huduma ya afya je, kuna matibabu ya magonjwa ya afya ya akili kwa watoto na vijana**	Haipo au kuna shauku ndogo katika huduma ya magonjwa ya akili kwa watoto na vijana.	Matibabu yamo kwenye mipango na sera lakini hakuna rasilimali zilizotengwa kwa kazi hii.	Kuna matibabu ya juu ya watoto na vijana wenye magonjwa ya akili ya muda mrefu, na rasilimali watu na pesa zimetengwa.	Matibabu ya watoto na vijana wenye matatizo ya akili ni sehemu ya mfumo wa afya.in rasilimari za kutosha na uwajibikaji wa wafanyakazi.
3	**Ni kwa kiasi gani malengo ya huduma za afya ya hospitali yamejumuisha huduma za magonjwa ya akili ya watoto na vijana?**	Malengo kwa ajili ya huduma za magonjwa ya akili kwa watoto na vijana hayapo au yanazuwiwa na sababu flani.	Yapo ila huwa hayafanyiwi mapitio.	Malengo ya huduma za magonjwa ya akili kwa watoto na vijana yapo na yanafanyiwa mapitio.	Yanapimika, hufanyiwa mapitio mara kwa mara na huingizwa kwnye mpango kwa ajili ya maboresho.
4	**Je kuna mkakati wa kuboresha huduma za magonjwa ya akili kwa watoto na vijana?**	Upo juhudi kidogo inayofanywa kuboresha huduma za magonjwa ya akili kwa watoto na vijana.	Zimejielekeza kwenye matatizo maalimu jinsi yanavyotokea**.**	Kuna mikakati ya kuboresha matatizo maalumu. iliyo thibitishwa kitaalamu	Kuna mikakati ya uboreshaji iliyo thibitishwa kitaalamukwa matatizo yote ambayo inatumika.

Sehemu ya 2: Kuunganishwa na jamii

Sehemu hii inaangalia rasilimali kwa ajili ya watoto na vijana wenye magonjwa ya akili katika ngazi ya jamii na namna gani zinaratibiwa ili kutoa huduma stahiki.

	Maswali	Msaada kidogo(1)	Msaada wa kawaida (2)	Msaada mzuri (3)	Msaada kamili (4)
1	**Kwa watoto na vijana wenye matatizo ya afya ya akili ni kwa kiasi gani wagonjwa wameunganishwa na rasilimali zilizopo katika jamii?mf ustawi wa jamii)**	Ngumu sana	Wameunganishwa na rasilimali chache zinazopatikana katika jamii (mf. ustawi wa jamii).	Kuunganishwa hufanya na mafanyakazi maalumu ambaye hutoa rufaa na kufuatilia wagonjwa na kuhakikisha watoa huduma na wagonjwa wanatumia vizuri rasilimali zilizo katika jamii.	Kuunganishwa hufanywa kwa kutumia mtandao wa watoa huduma za afya na huduma za kijamii ambazo zinafahamika na wafanyakazi na wanafanya kazi pamoja kwa ajili ya huduma bora. .
2	**Je watoa huduma za afya katika jamii wamepewa mafunzo na wanatoa huduma kwa sasa kwa watoto na Vijana wenye magonjwa ya akili?**	Hapana kabisa	Wakati ikitokea kasi maalumu.	Hii ni sehemu muhimu ya huduma ya afya ya akili kwa watoto na vijana katika kituo chetu, lakini kuna rasilimali kidogo kuhakikisha inafanyika.	Hii ni sehemu ya huduma ya magonjwa ya muda mrefu katika kituo chetu na huwa inaratibu mafunzo kwa wafanyakazi wa vituo vingine.
3	**Je kuna shuguli za kukuza afya, kuongeza uelewa au kufanya uchunguzi wa magonjwa ya akili kwa watoto na vijana?**	Huwa inafanyika marachache	Hufanyika bila kuratibiwa nje ya kituo chetu.	Inafanywa kwa kujitegemea na wafanyakazi wa afya ngazi ya jamii ambao muda mwingine hutoa mrejesho kwa wafanyakazi wa kituo.	Inafanywa na wafanyakazi wa afya ngazi ya jamii kama sehemu ya mkakati ulioratibiwa katika kituo chetu ili kuongeza uelewa, kinga na matibabu ya watoto na vijana wenye magonjwa ya akili katika jamiii.
4	**Ni kwa namna gani wagonjwa wanatafutwa na kupatiwa ufuatiliaji wa dawa katika jamii?**	Huwa haifanyiki	Inafanywa na mfanyakazi mmoja mmoja katika ngazi jamii bila kuratibiwa.	Inafanyika na kuratibiwa na timu ya wafanyakazi ngazi ya jamii.	Inafanywa mara kwa mara na wafanyakazi wa afya ngazi ya jamii kama sehemu ya timu ya huduma kwa watoto na vijana katika kituo chetu kwa ajili ya matibabu bora kwa wagonjwa .

Sehemu ya 3a. Msaada wa kujisimamia matibabu mwenyewe kwa wangonjwa.

Sehemu hii inanagalia namna wagonjwa na watoa huduma wao wanavyoweza kusaidiwa kuweza kuhimili magonjwa yao na kuishi na matatizo yao kwa kutekeleza mpango wa kujihudumia mwenyewe na kufuata tabia nzuri za afya.

	Maswali	Msaada kidogo (1)	Msaada wa kawaida (2)	Msaada mzuri (3)	Msaada kamili (4)
1	**Je watoto na vijana wenye magonjwa ya akili huwa wanaulizwa na kusaidiwa kuweka malengo ya kusimamia magonjwa yao?**	Huwa haifanyiki kabisa	Inafanyika lakini sio endelevu au kwa viwango stahiki	Hii huwa inafanyika katika viwango stahiki na wafanyakazi katika kituo chetu	Hii huwa inafanywa mara kwa mara na wafanyakazi wote na malengo hayo yamenakiliwa katika fomu maalumu ambazo zimeunganishwa na mpango wa matibabu wa mgonjwa.
2	**Je, kuna msaada wa kisaikolojia na kijamii (elimu ya tiba ya kisaikolojia au msaada wa ushauri) kwa ajili ya matibabu ya magonjwa?**	Hakuna msaada wa kisaikolojia na kijamii	Inafanywa na wauguzi tu kuwapa wagonjwa elimu tiba ya kisaikolojia.	Kuna vyote elimu tiba ya kisaikolojia inayotolewa na wauguzi na vitu vya kujisomea vya kwenda navyo nyumbani mf. vitini au vipeperushi. .	Kuna elimu tiba ya kisaikolojia na massada wa ushauri nasaha unaotolewa na wauguzi pia na vitu vya kujisomea vya kwendanavyo nyumbani .mf. vitini au vipeperushi.
3	**Kwa kiasi gani wagonjwa na familia zao wanasaidiwa kukabiliana na mambo yanayo weza kusababishwa tokanayo na magonjwa (mf unyanyapaa, kutengeneza mapato**	Hii huwa haifanyiki kabisa	Huwa inafanyika kwa wagonjwa na familia maalumu pale wanapo omba.	Hii inapewa kipaumbele na wafanyakazi wamepewa mafunzo ya kufanya	Hii ni sehemu muhimu ya huduma ya afya ya akili kwa watoto na vijana na hufanywa kwa wagonjwa wote.
4	**Je kuna matibabu ya kisaikologia (ushauri thabiti) na program ya msaada rika kwa watoto na vijana wenye magonjwa ya akili?**	Haipatikani kabisa katika kituo chetu.	Ndio lakini hii inaishia kuwapa vitini, vijitabu au taarifa nyngine zilizo kimaandishi,	Hii inafanyika kupitia rufaa ya wagonjwa wasiozingatia dawa katika vituo vilivyobobea na hufanywa na wafanyakazi watiopata mafunzo kwa ajili ya kutoa huduma hii	Hizi zinapatikana tayari katika kitup chetu na imekuwa ni sehemu muhimu ya matibabu ya kawaida ya wagonjwa wa muda mrefu.

Sehemu ya 3b: Msaada wa kufanya maamuzi kwa watoa huduma

Sehemu hii inaangalia uboreshwaji wa utaalamu na ujuzi wa watoa huduma ili kuwawezesha kutoa huduma bora iwezekanavyo.

	Maswali	**Msaada kidogo (1)**	**Msaada wa kawaida (2)**	**Msaada mzuri (3)**	**Msaada kamili (4)**
1	**Je kuna miongozo iliyo thibitishwa (mf. Muongozo wakutoa ushauri au huduma za kurejesha uwezo wa kisaikolojia na kijamii) kwa wauguzi na madaktari katika kituo?**	Hizi hazipatikani	Zinapatikana lakini hazitumiki wakati wote	Zinapatikana na kutumiwa na wafanyakazi walipo patiwa mafunzo ya kutumua.	. Zinapatikana na zinatumiwa na wafanyakazi kama sehemu ya huduma za kila siku.
2	**Nikwa kiasi gani madakitari bingwa wa magonjwa ya akili na wanasaikolojia wanahusika kuboresha huduma za watoto na vijana wenye magonjwa ya akili?**	Huwa hawahusiki kabisa	Wanahusisika kwa kupitia mfumo wa kawaida wa rufaa	Wanahusika kutoa huduma za rufaa pia kutoa mafunzo kwa wafanyakazi wa kituo juu ya utoaji huduma kwa watoto na vijana wenye magonjwa ya akili.	Wanahusika kutoa mafunzo, msaada na usimamizi wa wafanyakazi wa kituo juu ya matumizi ya miongozo ya afya ya akili.
3	**Je kunamafunzo ya wafanyakazi wa kituo (wauguzi, washauri, wafanyakazi wa afya ngazi ya jamii, madaktari) kuhusu huduma kwa watoto na vijana**	Mafunzo kama haya huwa hayatolewi	Mafunzo huwa yanatolewa marachache	Mafunzo hutolewa kama na wakati yahitajikapo kwa baadhi ya wafanyakazi wa vituo kwa njia ya mafunzo ya kawaida (mfano warsha ,kozi fupi)	Mafunzo haya hufanyika mara kwa mara kwa wafanyakazi wote wa kituo kwa njyia za kawaida za mafunzo pamoja na mafunzo kazini na usimamizi shirikishi.

	Maswali	Msaada kidogo (1)	Msaada wa kawaida (2)	Msaada mzuri (3)	Msaada kamili (4)
	magonjwa ya akili?				
4	**Ni kwa kiasi gani mahitaji muhimu (mf dawa) na teknolojia wanayohitaji yanaweza kupatikana kwa ajili ya huduma kwa watoto na vijana wenye magonjwa ya akili?**	Upatikanaji wa haya mahitaji muhimu hautabiriki na sio endelevu.	Yanapatikana tu yakihitajika kupitia mfumo wa usambazaji usio dhibitiwa.	Yanapatikana yakihiytajika tu kwa kupitia mfumo wa usambazaji unao dhibitiwa	Yanapatikana mara kwa mara kwa wafanyakazi wote kwa kupitia mfumo unao simamiwa vizuri na kudhibitiwa

Sehemu 3c: Muuundo wa mfumo wa utoaji huduma

Sehemu hii inaangalia namna ushirikiano wa watoa huduma kwa watoto na vijana wenye magonjwa ya akili unavyoweza kukuzwa kwa kutambua majukumu na wajibu wa kila mtu katika timu ya watoa huduma za afya ili wawezekufanya kazi vizuri pamoja.

	Maswali	Msaada kidogo (1)	Msaada wa kawaida (2)	Msaada mzuri (3)	Msaada kamili (4)
1	Je kuna huduma zinazo husisha timu kutoka kada tofauti (kama wauguzi, madaktari, watoa huduma ngazi ya jamii, madaktari bingwa) katika kuwa hudumia watoto na vijana wenye magonjwa ya akili.	Hii haipo	Mara chache hutokea kwa ajili ya tatizo maalumu.	Hii hutokea mara kwa mara kwa vikao vya timu kujadili miongozo, wajibu na uwajibikaji wa wajumbe tofauti na kama kunatatizo lolote lililo jitokeza /	Hii hutokea kwa kupitia mikutano ya timu, ambayo imeweka wazi wajibu wa kila mjumbe, hii inajumuisha kuwafuatilia wagonjwa, kuwapa elimu na kuunganishwa na rasilimali katika jamii/
2	**Namna gani uwekaji ratiba ya kuonana na mtoa huduma (appointment) kwa huduma za watoto na vijana wenye magonjwa ya**	Kuweka ratiba ya kuonana na muhudumu hawa haifanyiki kwa ajili ya watoto na vijana wenye magonjwa ya akili.	Kuna ahadi za kuonano na mhudumu ambazo zinapangwa kwa ajili ya huduma za watoto na vijana wenye magonjwa ya akili.	Ratiba ya kuonana na mtoa huduma iliyopanga, inayo ruhusu mabadiliko ili kukidhi mahitaji ya wagonjwa (mf. ahadi ya muda mrefu au vipindi vya familia)	Ratiba ya kuonana na mtoa huduma inayo muwezesha kuonana na watoa huduma wengi (mf muuguzi, msaikolojia na daktari) katika hudhurio moja

	Maswali	Msaada kidogo (1)	Msaada wa kawaida (2)	Msaada mzuri (3)	Msaada kamili (4)
	akili unasimamiwa?				
3	**Ni kwa namna gani ufuatiliwaji wa watoto na vijana wenye magonjwa ya akili unasimamiwa**	Ufuatiliwaji hauja pangwa kiratiba	Ufuatiliaji unapangwa mfanyakazi au mgonjwa pale unapohitajika.	Kuna ufuatiliaji wa mara kwa mara kwa kufuata ratiba ya mahudhurio	Kuna ufuatiliaji wa mara kwa mara kwa mujibu wa ratiba ya kuonana na wahudumu iliyo pangwa.na kwa wafanyakazi ambao wanafuatilia wale ambao hawakuja (mf. Simu, usokwa uso)
4	**Ni mfumo gani wa rufaa unapatikana kwa mtoto na kijana mwenye ugonjwa wa akili**	Hakuna mfumo wa rufaa kwa magonjwa ya akili ya muda mrefu.	Rufaa zinafanyika kama na wakati zinahitajika katika kituo.	Rufaa zinafanyika kama na wakati zikihitajika ndani na nje ya kituo.	Kuna mfumo mzuri ulio imarishwa ambao unatumiwa na wafanyakazi wote kwa huduma nzuri.
5	**Ni kwa kiasi gani upatikanaji wa mawasiliano na uratibu kati ya watoa huduma kuhusu wagonjwa wanao pata huduma za magonjwa ya akili ya watoto na vijana?**	Sio kipaumbele	Mara chache huwa kuna mawasiliana ya kimaandishi kati ya wafanyakzi wa kituo na mabingwa (daktari wa magonjwa ya akili, mtu wa saikolojia	Mawasiliano kati ya wafanyakazi, mabingwa na watoa huduma wengine wanao husika (mf taasisi za kijamii) ni muhimu lakini haifanyiki mara kwa mara.	Hii ina pewa kipaumbele sana katika kituo chetu na inausisha uratibu kati ya watu wote wanao husika kutoa huduna kwa wagonjwa
6	**Je kuna mrejesho kutoka kwa meneja kwenda kwa wafanyakazi kuhusu huduma za watoto na vijana wenye magonjwa ya akili?**	Hii haipo	Hii hutolewa mara chache na huwasilishwa kwa njia ya ripoti	Hii inafanyika vya kutosha kwa ajili ya ufuatiliaji na uboreshaji wa utendaji kazi wa timu.	Hii hufanyika mara kwa mara na inatolewa kwa majidiliano na viongozi ili kuimarisha utendaji kazi wa timu.

	Maswali	Msaada kidogo (1)	Msaada wa kawaida (2)	Msaada mzuri (3)	Msaada kamili (4)
	Alama				

Sehemu ya 3d. Mfumo wa taarifa za kimatibabu.

Sehemu hii inaangalia kwa namna gani taarifa zinaweza kunaswa ili kurahisisha huduma za matibabu na ufuatiliaji wa wagonjwa

	maswali	Msaada kidogo (1)	Msaada wa kawaida (2)	Msaada mzuri (3)	Msaada kamili (4)
1	**Je kuna orodha ya wagonjwa ambao ni watoto na vijana wenye matatizo ya akili?**	Hapana, hii hipo	Ndiyo, lakini hii imeishia kwenye orodha ya wagonjwa winye magonjwa ya akili (aina ya magonjwa haija ainishwa)	Ndiyo, hii inajumuisha aina ya ugonjwa.	Ndiyo nah ii inajumuisha aina ya ugonjwa pia taarifa za mgonjwa (jina na mawasiliano) na taarifa kuhusu mchakato wa matibabu na matokeo yake.
2	**Je mafaili ya mgonjwa yamejumuisha fomu za huduma ya afya ya akili kwa watoto na vijana?** **Alama**	Hayajumuishi fomu za huduma ya afya ya akili kwa watoto na vijana	Yanajumuisha fomu za huduma ya huduma ya afya ya akili kwa watoto na vijana lakini ugonjwa wa akili hauku nakiliwa kwenye fomu.	They include **child and adolescent mental car**e forms but don't specify the type of mental illness yanajumuisha fomu za huduma ya afya ya akili kwa watoto na vijana lakini haija weka wazi aina ya ugonjwa wa akili	Yana fomu za huduma ya afya ya akili kwa watoto na vijana ambayo imejumuisha aina ya ugonjwa wa akili, na huwa inajazwa mara kwa mara kwa kila mhudurio la magonjwa.
3	**Je mipango ya matibabu ya wagonjwa huwa inatengenezwa kwa ajili ya watoto na vijana wenye matatizo ya akili?**	Hii huwa haifanyiki kabisa	Hii huwa inaetengenezwa na mfanyakazi binafsi wa kituo	Hii huwa inatengenezwa na mfanyakazi wa kituo pamoja na mgonjwa na mpango wa kujisimamia matibabu mwenyewe	Hii hutengenezwa kwa ushirikiana na timu ya watoa huduma ya magonjwa ya muda mrefu na inajumuisha mpango wa mgonjwa wa kujisimamia matibabu mwemyewe pia mpango wa ufuatiliaji wa mara kwa mara.

4	**Taarifa kuhusu makundi maalumu ya wagonjwa ambao wanahitaji matibabu maalumu (mf. matibabu ya magonjwa ya akili sugu) je zinapatikana?**	Hii taarifa haipatikani	Hii taarifa inaweza kupatikana tu kwa juhudi maalumu.	Hii taarifa inaweza kupatikana kwa maombi lakini kwa kawaida huwa haipatikani.	Hii taarifa huwa inapatikana mara kwa mara kwa wafanyakazi kuwasaidia kutoa huduma nzuri.

Part sehemu ya 4: Muunganiko wa sehemu za huduma ya muda mrefu

Sehemu hii inaangalia ni kwa namna gani vipengele ya mfumo wa huduma ya muda mrefu vinaweza kuunganishwa kwa ajili ya uboreshaji wa huduma.

	Maswali	**Msaada kidogo (1)**	**Msaada wa kawaida (2)**	**Msaada mzuri (3)**	**Msaada kamili (4)**
1	**Je kitabu la usajili au mfumo wa taarifa unajumuisha malengo ya mpango wa kujisimamia mwenyewe matibabu kwa watoto na vijana wenye matatizo ya afya ya akili**	Kitabu cha usajili hakijajumuishi malengo ya mgonjwa kujisimamia mwenyewe matibabu.	Kitabu cha usajili kinajumuisha matokeo ya uchunguzi wa kitababu wa mgonjwa lakini sio malengo ya kujisimamia mwenyewe matibabu.	Kitabu cha usajili kimejumuisha matokeo ya uchunguzi wa kitabibu wa mgonjwa pia na malengo ya mgonjwa kujisimamia mwenyewe matibabu.	Kitabu cha usajili kimejumuisha matokeo ya uchunguzi wa kitabibu, malengo ya mgonjwa kujisimamie mwenyewe na kukumbusha wafanyakazi na mgonjwa kuhusu ufuatiliaji na kutathimini malengo.
2	**Je taasisi za kijamii zinatoa mrejesho kuhusu maendeleo ya mgonjwa kwa wafanyakazi wa kituo?**	Huwa hawatoi mrejesho	Wanatoa mrejesho mara chache kuhusu maendeleo ya wagonjwa katika programu zao	Wanatoa mara kwa mara mrejesho kwa wafanyakazi wa kituo kwa kutumia njia ya kawaida. (Ripoti za maandishi kuhusu maendeleo ya wagonjwa.	Wanatoa mara kwa mara mrejesho kuhusu maendeleo ya wagonjwa ambayo inajumuisha michango ya wagonjwa ambayo hutumika ili kukidhi mahitaji ya wagonjwa
3	**Je mipango ya huduma kwa watoto na vijana wenye magonjwa ya akili katika kituo yanatokana na data za**	The plans are not based on population data. Mipango haitegegemi data kutoka wenye jamii.	Mipango inatumia data kutoka kwenye mfumo wa taarifa wa kituo kupanga mipango ya huduma.	Mipango hutumia data kutoka kwenye mfumo wa taarifa kupanga kuhusu huduma, inajumuisha mpango wa	Mipango hutumia data na michango kutoka kwa timu kupanga na kufanya tathimini ya huduma, inajumuisha mpango wa kujisimamia mwenyewe

	Maswali	Msaada kidogo (1)	Msaada wa kawaida (2)	Msaada mzuri (3)	Msaada kamili (4)
	matatizo kutoka katika jamii?			kujisimamia mwenyewe matibabu na ushirikiano za taasisi za kijamii.	matibabu na ushirikiano na taasisi za kijamii.
4	**Je kuna ufuatiliaji wa mara kwa mara wa ahratiba ya kuonana na mtoa huduma, uchunguzi wa mgonjwa na kupanga malengo ya matibabu.**	Huwa ni ngumu kufanyika	Hufanyika mara chache, huwa ni kwa kufuata ratiba ya kuonana na mtoa huduma	Huwa kunaufuatiliaji wa mara kwa mara kwa kuwapa hili jukumu watu maalumu.	Kuna ufuatiliaji wa mara kwa mara unafanywa na wafanyakazi maalumu ambao hudumia kitanu cha usajili na taarifa nyingine kuratibu upangaji wa matibabu na wagonjwa na timu nzima ya kliniki.
5	**Je miongozo ya huduma kwa watoto na vinjana wenye magonjwa ya akili mgonjwa anapatiwa?** **Alama**	Mgonjwa hapatiwi	Anapewa mgonjwa ambaye ameonesha shauku ya kujisimamia mwenyewe matibabu ya tatizo lake.	Wanapatiwa wagonjwa wote ili kuwasaidia kutengeneza mpango wakujisimamia mwenyewe matibabu wenye ufanisi na kutambua lini wanatakiwa kwenda. kupata huduma	Wanapatiwa wagonjwa kama sehemu ya majadiliano ili kupanga programu ya kujisimamia mwenyewe matibabu ambayo inatumia vyote miongozo na malengo ya mgonjwa.

Kwa kifupi elezea utaratibu ulio utumia kujaz fomu hii,(mf.ulifikia makubaliano katika kikao cha uso kwa uso,ilijazwa na kiongozi wa timu kwa kuwasiliana na wajumbe wengine kama ilivyo hitajika ,kiongozi wa timu aliijaza yeye mwenyewe kwa kushirikisha wajumbe wengine , kila mjumbe wa timu alijaza fomu tofauti na majibu yalipatiwa wastani .

Maelezo: _____

_____

	Sehemu	**Alama**
1	**Jumla ya alama za muundo wa mfumo wa utoaji wa huduma za afya**	
	Wastani wa alama (Jumla ya alama za muundo wa mfumo wa utoaji wa huduma za afya / 4)	
2	**Jumla ya alama za kuunganishwa na jamii**	
	Wastani wa alama (Jumla ya alama za kuunganishwa na jamii / 4)	
3a	**Jumla ya alama za msaada wa kujisimamia matibabu mwenyewe kwa wangonjwa**	
	Wastani wa alama (Jumla ya alama za msaada wa kujisimamia matibabu mwenyewe / 4	
3b	**Jumla ya alama za msaada wa kufanya maamuzi kwa watoa huduma**	
	Wastani wa alama (Jumla ya alama za msaada wa kufanya maamuzi / 4)	
3c	**Jumla ya alama za muuundo wa mfumo wa utoaji huduma**	
	Wastani wa alama (Jumla ya alama za muuundo wa mfumo wa utoaji huduma / 6)	
3d	**Jumla ya alama za mfumo wa taarifa za kimatibabu**	
	Wastani wa alama (Jumla ya alama za mfumo wa taarifa za kimatibabu / 4)	
4	**Jumla ya alama za muunganiko**	
	Wastani wa alama (Jumla ya alama za muunganiko / 5)	
	Jumla kuu ya programu (Jumlisha jumla ya alama zote hapo juu)	
	wastani wa alama (Jumla kuu ya programu / 7)	

Alama zina maana gani?

Hii ACIC imetengenezwa ili alama ya juu kabisa (=11) kwa kila sehemu, sehemu ndogo au jumla ya alama (wastani wa alama katika sehemu zote saba) inamaanisha msaada mzuri kwa magonjwa ya muda mrefu. Alama ndogo iwezekanavyo kwa kila sehemu ndogo ni 0 ambayo inamaanisha hakuna msaada wa huduma za magonjwa ya muda mrefu. Muongozo wa tafsiri ni kama ifuatavyo:

Kati ya 0 na 2 = msaada hafifu wa huduma za magonjwa ya muda mrefu

Kati ya 3 na 5 = msaada wa wastani wa huduma za magonjwa ya muda mrefu

Kati ya 6 na 8 = msaada mzuri wa huduma za magonjwa ya muda mrefu

Kati ya 9 na 11 = msaada ulio kamili wa huduma za magonjwa ya muda mrefu

APPENDIX A9 K-SADS-PL, DSM 5, 2016

KSADS-PL DSM-5 SCREENING PART				
SN.	**ITEM**	**SCORES** **Codes:** **0=No information 1=Not present** **2=Subthreshold 3=Threshold**		
		Parent	**Child**	**Summary**
	Depression			
1.	Depressed mood (past)			
	Duration of depressed mood (current)			
	Duration of depressed mood (most severe past)			
2.	Irritability and anger (past)			
	Duration of irritable mood (current)			
	Duration of irritable mood (most severe past)			
3.	Anhedonia, lack of interest, apathy, low motivation, or boredom (past)			
	Duration of anhedonia (current)			
	Duration of anhedonia (past)			
4a.	Recurrent thoughts of death (past)			
4b.	Suicidal ideation (past)			
4c.	Suicidal acts-intent (past)			
4d.	Suicidal acts-medical lethality (past)			
4e.	Non- suicidal, self-injurious behaviour (past)			
	Mania/hypomania			
1.	Elevated, elated or expansive mood (past)			
2.	Explosive irritability or anger (past)			
3.	Increased energy or activity (past)			
4.	Decreased need for sleep (past)			
5.	Hyper sexuality (past)			
	Disruptive mood dysregulation disorder			
1.	Irritability (past)			
2.	Recurrent temper outbursts (past)			
	Psychosis			
1.	Hallucinations (past)			
2.	Delusions (past)			
	Panic disorder			
1.	Panic attacks (past)			
	Agoraphobia			
1.	Agoraphobia (past)			
2.	Distress/avoidance (past)			
	Separation anxiety			
1.	Fears calamitous event that will cause separation (past)			
2.	Fears harm befalling attachment figure (past)			
3.	School reluctance/refusal (past)			
4.	Fears sleeping away from home/sleeping alone (past)			
5.	Fears being alone at home(past)			

	Social anxiety/selective mutism disorder						
1.	Fear of social situations (past)						
2.	Failure to speak in specific social situations (past)						
	Specific phobias						
1.	Specific phobias (past)						
2.	Distress/avoidance (past)						
	Specify most intense phobia						
	Specify other phobias						
	Generalised anxiety disorder						
1.	Excessive worries (past)						
2.	Somatic complaints (past)						
	Obsessive compulsive disorder						
1.	Obsessions (past)						
2.	Compulsions (past)						
	Enuresis						
1.	Repeated voiding						
a.	Night time (past)						
b.	Daytime (past)						
c.	Total (past)						
	Distress Impairment: (home, school, peers) Duration: (specify)						
2.	Evidence of enuresis (current) Evidence of enuresis (past) Specify if nocturnal only, diurnal only ,or nocturnal and diurnal						
	Encopresis						
1.	Repeated passage of faeces						
a.	Night time						
b.	Daytime						
c.	Total						
	Distress Impairment: (home, school, peers) Duration: (specify)						
2.	Evidence of encopresis (current) Evidence of encopresis (past) Specify if nocturnal only, diurnal only ,or nocturnal and diurnal						
	Eating disorders						
1.	Fear of becoming obese (past)						
2.	Emaciation (past)						
3.	Weight loss methods	**Parent**		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
a.	Using diet pills						

b.	Taking laxatives						
c.	Taking water pills						
d.	Throwing up						
e.	Exercising a lot						
f.	Taking only non-caloric fluids for a week or more; restricting energy intake						
g.	Combined frequency weight loss methods						
4.	Eating binges or attacks (past)						
	Attention deficit hyperactivity						
1.	Difficulty in sustaining attention on tasks or play activities (past)						
2.	Easily distracted (past)						
3.	Difficulty remaining seated (past)						
4.	Impulsivity (past)						
	Oppositional defiant disorder						
1.	Loses temper (past)						
2.	Argues a lot with adults/ authority figures (past)						
3.	Disobeys rules a lot/defies or refuses to comply with adult requests (past)						
	Conduct disorder						
1.	Lies (past)						
2.	Truant (past)						
3.	Initiates physical fights (past)						
4.	Bullies, threatens, or intimidates others (past)						
5.	Non aggressive stealing (past)						
	Tic disorders						
1.	Motor tics (past)						
2.	Phonic tics (past)						
	Autism spectrum disorders						
1.	Stereotyped or repetitive speech, motor movements or use of objectives (past)						
2.	Insistence on sameness, inflexible adherence to routines, ritualised patterns of verbal or non-verbal behaviour (past)						
3.	Highly restricted, fixated interests that are abnormal in intensity or focus (past)						
4.	Deficits in non-verbal communicative behaviours used for social interaction (past)						
	Item	**Codes:** **0=no information 1=No 2=Yes**					
	Tobacco use						
1.	Use						
a.	Ever smoked						
b.	Ever chewed tobacco						
c.	Ever smoked (or chewed) tobacco daily for 1 month or more						
2.	Quantity of tobacco use						

a.	Current use (cigarettes/day or “dips” of chew/day)			
b.	Greatest amount of use (cigarettes/day or “dips” of chew/day)			
	Age years			
3.	Have you ever smoked or “dipped” chew at least once a day for a month or more?(1 cigarette or 1 “dip” of chew/day or more for at least 30 days)			
	Age of first regular use (in months)			
4.	Ever attempt to quit			
5.	Ever quit			
	If yes, report longest number of months			
	Alcohol use			
1.	Use			
a.	Drank two drinks in one week four or more times			
b.	Age above (at first regular use-years)			
c.	Current frequency of use (days per month)			
d.	Have you ever had three or more drinks in a single day?			
2.	Problems related to alcohol			
3.	Received treatment for alcohol problems?			
	Alcohol use disorders			
1.	Quantity (past)			
a.	How many drinks do you usually have when you sit down to drink? (past)			
b.	What’s the most that you ever drank in a single day? When was that? How about in the last 6 months? What’s the most you drank in a day? (past)			
2.	Frequency (past)			
	What’s the most number of days in a given week that you had something to drink? (report longest number of months)……. Do you usually drink Friday and Saturday night? Midweek too?			
3.	Concerns from others about drinking (past)			
	Has anyone ever complained about your drinking? Friends? Parents? Teachers? Have you ever been worried about it at all?			
	Substance use			
1.	Drug use: Let me know if you have used any of the drugs on this list before, even if you have only tried them once. Which have you used?	**Parent ever**	**Child ever**	**Summary ever**
a.	Cannabis			
b.	Stimulants			
c.	Sedatives/hypnotics/anxiolytics			
d.	Cocaine			
e.	Opioids			
f.	PCP			
g.	Hallucinogens			

h.	Solvents/inhalants						
i.	Others: prescription drugs, nitrous oxide, ecstasy, MDA, etc.; specify: …….						
j.	Polysubstance (assess for combined use of all listed substances)						
	Substance use disorders						
1.	Frequency: In the past six months, what is the most you have used……? Every day or almost every day for at least one week? Less? More? Was there a time when you used ……more?	**Parent**		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
a.	Cannabis						
b.	Stimulants						
c.	Sedatives/hypnotics/anxiolytics						
d.	Cocaine						
e.	Opioids						
f.	PCP						
g.	Hallucinogens						
h.	Solvents/inhalants						
i.	Others: prescription drugs, nitrous oxide, ecstasy, MDA, etc.; specify: …….						
j.	Polysubstance (assess for combined use of all listed substances)						
2.	Problems related to substance use/abuse Has your use of …….ever caused you any problems at home? With your parents? With your schools work? With teachers? With friends? With the police?						
	Post-traumatic stress disorder						
1.	Traumatic events						
a.	Car accident						
b.	Other accident						
c.	Fire						
d.	Witness of a disaster						
e.	Witness of a violent crime						
f.	Victim of a violent crime						
g.	Confronted with traumatic news						
h.	Terrorism related trauma						
i.	War zone trauma						
j.	Witness to domestic violence						
k.	Physical abuse						
l.	Sexual abuse						
m.	Other:						
	Mention the incident						
	Evidence of Post-Traumatic Stress Disorder	**Parent**		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
1.	Recurrent memories, thoughts or images						
2.	Feelings of detachment						
3.	Efforts to avoid activities or situations that remind you of the trauma						

4.	Nightmares						
5.	Hypervigilance						

SUPPLEMENT #1: DEPRESSIVE AND BIPOLAR RELATED DISORDERS SUPPLEMENTS

SN	ITEM	SCORES Codes: 0=No information 1=Not present 2=Subthreshold 3=Threshold		
		Parent	**Child**	**Summary**
	Depression:			
1a.	Reassessment of depressed and irritable mood (past)			
	Duration of (current) depressed/irritable mood (weeks)…….			
	Duration of (most severe past) depressed/irritable mood (weeks)…….			
1b.	Depression and/or irritable mood is present in more days than not for at least one year (past)			
2.	Insomnia (past)			
	a. Initial insomnia			
	b. Middle insomnia			
	c. terminal insomnia			
3.	Hypersomnia (past)			
4.	Fatigue, lack of energy and tiredness (past)			
5.	Cognitive disturbance (past) a. decreased concentration or slowed thinking			
	b. indecision			
6.	Appetite/weight (past) a. Decreased appetite			
	b. weight loss			
	c. Increased appetite			
	d. Weight gain			
7.	Psychomotor disturbances (past) a. Agitation			
	b. Psychomotor retardation			
8.	Self-perceptions			

	a. Worthlessness/negative self-image						
	b. Excessive or inappropriate guilt						
		Codes: **0=No information 1=No 2=Yes**					
	Other criteria:	**Parent**		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
1.	Evidence of a precipitant (specify)……..						
2.	Symptoms occur or worsen with monthly menstruation						
3.	Impairment a. Socially (with peers)						
	b. With family						
	c. In school						
		Summary CE		**Summary MSP**			
4.	Evidence of major depressive disorder						
5.	Evidence of MDD with psychotic features						
6.	Evidence of Schizoaffective disorder with depressed type (SA-D)						
7.	Evidence of Unspecified depressive disorder						
8.	Evidence of adjustment disorder with depressed mood						
	Optional subtype questions for Major depressive disorder	**SCORES** **Codes:** **0=No information 1=Not present** **2=Subthreshold 3=Threshold**					
		Parent		**Child**		**Summary**	
9.	Lack of reactivity of depressed mood or irritable mood to positive stimuli (past)						
10.	Quality of dysphoric mood different than grief (past)						
11.	Diurnal mood variation (past)						
12.	Rejection sensitivity (past)						
		Summary CE		**Summary MSP**			
13.	Meets diagnostic criteria for major depression with melancholic features						
14.	Evidence of seasonal pattern						
15.	Evidence of atypical depression						

SN	ITEM	SCORES Codes: 0=No information 1=Not present 2=Subthreshold 3=Threshold		
		Parent	**Child**	**Summary**
	Dysthymia/persistent depression supplement:			
1.	Poor appetite or overeating more days than not (past)			
2.	Sleep disturbance (past)			
3.	Feels tired or without energy more days than not (past)			

4.	Feels inadequate or doesn't like self, has low self-esteem more days than not (past)			
4.	Fatigue, lack of energy and tiredness (past)			
5.	Poor concentration, limited attention span, or slower thinking, or has difficulties making decisions more days than not (past)			
6.	Hopelessness			
		Codes: **0=No information 1=No 2=Yes**		
		Summary CE	**Summary MSP**	
7.	Evidence of persistent depressive disorder (Dysthymia) specify: With anxious distress……. With mixed features…….. With melancholic features……. With atypical features……. With mood congruent psychotic features…….. with mood incongruent psychotic features With peripartum onset ……..			
8.	Persistent depression-Primary type			
9.	Persistent depression-Secondary type			

SN	**ITEM**	**SCORES** **Codes:** **0=No information 1=Not present** **2=Subthreshold 3=Threshold**		
		Parent	**Child**	**Summary**
	Mania/hypomania:			
1.	Reassessment of duration of distinct period of elated/elevated and/or irritable mood (with potential associated manic symptomatology) (past)			
2.	Grandiosity/inflated self-esteem (past)			
3.	More talkative or pressured speech (past)			
4.	Racing thoughts (past)			
5.	Flight of ideas (observational or reported by informant) (past)			
6.	Increased goal directed activity/sociability (past)			
7.	Psychomotor agitation (past)			
8.	Excessive involvement in high risk pleasurable activities (past)			
9.	Distractibility (past)			
10.	Influence of drugs or alcohol (past)			
11.	**Patterning of manic symptoms**	**Codes:** **0=no information 1=1 day(>4 hours)** **2=2-3 days 3=4-6 days 4=7-14 days** **5=multiple weeks 6=2-6 months 7=>6 months**		
	a. Longest duration of (Hypo) manic periods			
		Codes: **0=no information 1=1 day(>4 hours)**		

		2=2-3 days 3=4-6 days 4=7-14 days 5=multiple weeks 6=2 or more months					
	b. Typical duration of (Hypo) manic periods						
		Codes: 0=no information 1=not present in the past year 2=1-3 discreet episodes per year 3= 4 or more episodes per year					
	c. Number of episodes per year Number per year…….. Number per month…….						
		Codes: 0=no information 1=no significant periods of euthymic mood 2=euthymic mood lasts 3-6 days 3= euthymic mood has lasted 1-2 weeks 4= euthymic mood has lasted 2- 8 weeks 5=euthymic mood has lasted > 2 months					
	d. Longest duration of euthymic mood						
		Codes: 0=no information 1=1-3 days 2=4-10 days 3= 10-20 days 4= > 20 days					
	e. Total lifetime duration of mania/hypomania						
	f. Age of onset (in years)……						
		Codes: 0=No information 1=No 2=Yes					
		Parent		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
10.	Impairment a. Socially (with peers)						
	b. With family						
	c. In school						
	d. Hospitalization (for mania)						
	e. Other (e.g. police, other adults, etc.): …….						
		Summary CE			**Summary MSP**		
11.	Evidence of Manic episode						
12.	Evidence of hypomanic episode						
13.	Criteria of Mixed episodes						
14.	Bipolar I disorder, most recent episode hypomanic						
15.	Bipolar I disorder, most recent episode manic						
16.	Bipolar I disorder, most recent episode depressed						
17.	Bipolar I disorder, most recent episode mixed						
18.	Bipolar I disorder with psychosis						
19.	Bipolar II disorder						
20.	Bipolar II disorder with psychosis						
21.	Unspecified bipolar disorder						
22.	Cyclothymia						
23.	Schizoaffective disorder, bipolar type (the disturbance includes a manic or mixed						

	episodes or a Manic or mixed episode and major depressive episodes)		
24.	Mood disorder due to a general medical condition		
25.	Substance induced mood disorder		
	Disruptive mood dysregulation disorder:		
1.	Symptoms have been present for 12 months or more, no period of 3 or more consecutive months without symptoms		
2.	Symptoms are present in at least two of the three settings: Home……., school….. peers…….		
3.	Onset of symptoms before age 10		
4.	Evidence of disruptive mood dysregulation disorder		

SUPPLEMENT #2: SCHIZOPHRENIA SPECTRUM AND OTHER PSYCHOTIC DISORDERS SUPPLEMENT

SN	**ITEM**	**SCORES** **Codes:** **0=No information 1=Not present** **2=Subthreshold 3=Threshold**					
		Parent		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
	Hallucinations						
1.	**Auditory hallucinations** a. Non-verbal sounds (e.g. music)						
	b. Command hallucinations						
	Specify if content always related to depression or mania	**1=yes 2=no**	**yes no**	**yes no**	**yes no**	**yes no**	**yes no**
	c. Running commentary (commenting voice)						
	Specify if content always related to depression or mania	**1=yes 2=no**	**yes no**	**yes no**	**yes no**	**yes no**	**yes no**
	d. Conversing voices						
	Specify if content always related to depression or mania	**1=yes 2=no**	**yes no**	**yes no**	**yes no**	**yes no**	**yes no**
	e. Thoughts aloud						
	f. Other verbal hallucinations						
	Specify if content always related to depression or mania	**1=yes 2=no**	**yes no**	**yes no**	**yes no**	**yes no**	**yes no**
2.	Location of voices/noises Inside head only						
	Outside head only						
	Combination						
3.	Visual hallucinations						
	Specify if content always related to depression or	**1=yes**	**yes**	**yes**	**yes**	**yes**	**yes**

	mania	**2=no**	**no**	**no**	**no**	**no**	**no**
4.	Tactile hallucinations						
	Specify if content always related to depression or mania	**1=yes 2=no**	**yes no**	**yes no**	**yes no**	**yes no**	**yes no**
5.	Olfactory hallucinations						
	Specify if content always related to depression or mania	**1=yes 2=no**	**yes no**	**yes no**	**yes no**	**yes no**	**yes no**
6.	Illusions						
7.	Interviewer rating	**Summary CE**			**Summary MSP**		
		Parent		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
8.	Cultural acceptance of hallucinations						
9.	Duration of hallucinations						
10.	Association with affective illness						
	Specify: with MDD, Mania or both						
11.	Association with trauma						
	Specify:…….						
12.	Association with substance use or medical condition (high fever, seizures, medication)						
	Specify:						
13.	Evidence of a precipitant						
	Specify: ……..						
14.	Duration of symptoms one week or greater						
	Specify duration in weeks: …….						
	Delusions:						
1.	Grandiosity						
2.	Guilty/sin						
3.	Delusions of control						
4.	Somatic delusions						
	4a. Only during affective episode						
5.	Nihilism						
6.	Thought broadcasting						
7.	Thought insertion						
8.	Thought withdrawal						
9.	Message from TV/radio						
10.	Delusions of persecution						
11.	Delusions that others can read his/her mind						
12.	Delusions of reference						
13.	Other bizarre delusions						
		Summary CE		**Summary MSP**			
14.	Interviewer rating						
		Parent		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
15.	Subcultural or family delusions						
16.	Multiple delusions						
17.	Delusions always occurred within 2 weeks of an affective illness						
	Specify: MDD, Mania or both						
18.	Delusions always occurred in the context of substance use or during the course of a medical						

	illness						
19.	Content of delusions always related to depressed or elated mood						
20.	Evidence of a precipitant						
21.	Duration of symptoms one week or more						
	Specify duration in weeks:……..						
	Other psychotic symptoms **Rate based on observation during interview**						
1a.	Flat affect						
1b.	Inappropriate affect/grossly disorganised						
2a.	Disorganised speech/incoherence						
2b.	Loosening of association						
3.	Catatonic behaviour						
	Impaired functioning during active illness						
1.	Impaired school functioning						
2.	Impaired peer relations						
3.	Impaired family relations						
4.	Impaired self-care						

	Diagnostic tree: Psychosis	**Parent**	**Child**	**Summary**
	Ever had psychotic symptoms not associated with depression or mania? (If psychosis is better accounted for by depression or mania rate as 1)			

		Summary CE	**Summary MSP**
1.	**Evidence of Schizophrenia**		
	If meets criteria for schizophrenia, specify:		
1.	First episode, currently in acute episode		
2.	First episode, currently in partial remission		
3.	First episode, currently in full remission		
4.	Multiple episodes, currently in acute episode		
5.	Multiple episodes, currently in partial remission		
6.	Multiple episodes, currently in full remission		
	Unspecified: describe……		
2.	**Evidence of schizophrenic disorder**		
	If meets criteria for Schizophreniform disorder, specify if:		
	a. with good prognostic features		
	b. without good prognostic features		
3.	**Brief psychotic disorder**		
	If meets criteria for brief psychotic disorder, specify if: With marked stressors		
	Without marked stressors		
	Post-partum onset		
4.	**Psychotic disorder due to general medical condition**		
5.	**Substance induced psychotic disorder**		
6.	**Psychotic disorder not elsewhere classified**		

SUPPLEMENT #3: ANXIETY, OBSESSIVE-COMPULSIVE, AND TRAUMA-RELATED DISORDERS

SN	ITEM	SCORES Codes: 0=No information 1=Not present 2=occasionally occurs during an attack 3=always or almost always occurs during an attack					
	Panic disorder	**Parent**		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
	When you have those nervous/scary feelings, do you have?						
1.	Shortness of breath (dyspnoea)						
2.	Dizziness (vertigo)/faintness						
3.	Palpitations						
4.	Trembling or shaking						
5.	Sweating						
6.	Choking						
7.	Nausea or abdominal distress						
8.	Depersonalization/derealisation						
9.	Numbness/tingling						
10.	Heat or chills						
11.	Chest pains						
12.	Fear of dying						
13.	Fear of losing control						
		Codes: **0=No information 1=No 2=Yes**					
14.	Circumscribed stimuli						
15.	Attack unanticipated						
16.	Minimum symptom (at least one attack with 4 symptoms)						
17.	a. Record the maximum number of attacks in a given month						
	b. Record number of attacks in past week						
18.	Fear of having another attack						
19.	Onset of attacks (During at least 1 attack, 4 symptoms developed and intensified within 10 minutes)						
20.	Agoraphobia						
21.	Impairment Socially (with peers)						
	With family						
	In school						
		Summary CE		**Summary MSP**			
22.	Evidence of panic disorder						
		Codes: **0=No information 1=Not present** **2=Subthreshold 3=Threshold**					
	Agoraphobia	**Parent**		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
1.	**Phobic stimuli/situations** buses						
	trains						

	subways						
	open spaces						
	shops						
	theatres						
	malls						
	cinemas						
	being outside the home alone (after 10 years old)						
	crowds						
	standing in lines						
	other (specify)						
	Marked fear/anxiety about at least one situation from two or more of the group situations						
		Codes: **0=No information 1=No 2=Yes**					
2.	Fear of situation is due to thoughts that escape might be difficult, help may be unavailable or other incapacitating symptoms (incontinence)						
3.	Agoraphobic situation almost always provokes anxiety						
4.	Situations avoided or require the presence of companion or endured with marked distress						
5.	The fear/anxiety is out of proportion to the danger posed by the situation						
6.	Significant distress or impairment with family, in school or with peers						
7.	Duration 6 months or longer						
8.	Evidence of a precipitant (specify)						
		Summary CE			**Summary MSP**		
9.	Evidence of Agoraphobia						

SN	**ITEM**	**SCORES** **Codes:** **0=No information 1=Not present** **2=Subthreshold 3=Threshold**					
	Separation anxiety disorder	**Parent**		**Child**		**Summary**	
1.	Nightmares						
2.	Physical symptoms on school/separation days						
3.	Excessive distress in anticipation of separations						
4.	Excessive distress upon separation						
		Codes: **0=No information 1=No 2=Yes**					
		Parent		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
5.	Duration of disturbance						
	Record approximate duration of symptoms in weeks						
6.	Impairment a. Socially (with peers)						
	b. With family						

	c. In school						
7.	Evidence of a precipitant (specify): ……						
		Summary CE		**Summary MSP**			
8.	Evidence of Separation anxiety disorder						

SN	**ITEM**	**SCORES** **Codes:** **0=No information 1=No 2=Yes**					
	Social anxiety disorder/Selective mutism	**Parent**		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
1.	Review situations that elicit distress Talking in class…… Writing on the chalkboard ……. Going to parties/social events…… Performance situations…… Eating in front of others…… Using public restrooms…….. Changing in front of others…….. Talking in any social situation…… Other (specify)…….						
2.	Exposure almost always elicits anxiety						
3.	Avoidance or endures with intense anxiety						
4.	Fears humiliation, embarrassment or rejection						
		Codes: **0=No information 1=No 2=Yes**					
5.	Impairment Socially (with peers)						
	With family						
	In school						
6.	Fear out of proportion to actual threat						
7.	Duration in months (record) Social anxiety disorder: 6 or more months Selective mutism: (1 month or more)						
8.	Language limitations						
7.	Evidence of a precipitant (specify): ……						
		Summary CE		**Summary MSP**			
8.	Evidence of social anxiety disorder						
	Specify if: Performance only…….if the fear is restricted to speaking or performing in public						
9.	Evidence of selective mutism						

SN	**ITEM**	**SCORES** **Codes:** **0=No information 1=Not present** **2=Subthreshold 3= Threshold**		
		Parent	**Child**	**Summary**

	Phobic disorders						
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
	Current episode						
1.	Phobic stimuli/situations						
	Heights						
	Dark						
	Blood						
	Dogs						
	Other animals						
	Insects						
	Being outside the home alone						
	Crowds						
	Open spaces (going out alone after 10 years)						
	Travelling (buses, subways)						
	Elevators						
	Stores or other closed spaces except elevators						
	Going over bridges or through tunnels						
	Other (specify e.g. fear of going to school) NB: **g** to **n** are agoraphobic fears.						
	Are agoraphobic fears associated with concern of having an unexpected or situationally predisposed panic attack or panic like symptoms?						
2.	Recognises fear as excessive						
3.	Duration (specify)……6 months or more						
4.	Impairment Socially (with peers)						
	With family						
	In school						
5.	Evidence of a precipitant						
		Summary CE		**Summary MSP**			
6.	Evidence of Specific phobia						
	Specify (Current, Past) Animal e.g. spider, dogs…….. Natural environments e.g. heights, storms…… Situational e.g. airplanes, elevators……. Blood…… Other ……						
7.	Subtypes						
	Animal type (e.g. bugs, spiders, snakes)						
	Natural environment type (e.g. heights, storms, water)						
	Blood, injection, injury type						
	Situational type (planes, elevators, enclosed places)						
	Other type (e.g. fear of chocking, vomiting, or contracting an illness; in children fear of loud sounds or costumed characters)						

SN	**ITEM**	**SCORES** **Codes:** **0=No information 1=Not present**

		2=Subthreshold 3=Threshold					
	Generalised anxiety disorder	**Parent**		**Child**		**Summary**	
1.	Preoccupation with appropriateness of past behaviour (past)						
2.	Marked self-consciousness (past)						
3.	Over-concern about competence (past)						
4.	Worries about the future (past)						
		Codes: **0=No information 1=No 2=Yes**					
		Parent		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
5.	Inability to control worries						
6.	Other symptoms of Generalised Anxiety disorder 1.Restlessness or feeling keyed up or on edge						
	2.Being easily fatigued						
	3.Difficulty concentration or mind going blank						
	4.Sleep disturbance (e.g. difficulty falling asleep, staying asleep, or restless, unsatisfying sleep)						
	5.Muscle tension, aches or soreness						
	6. Irritability						
7.	Duration (specify):……3 months or longer						
8.	Evidence of impairment or distress a. Socially (with peers)						
	b. With family						
	c. In school						
9.	Evidence of a precipitant (specify): ……						
		Summary CE		**Summary MSP**			
10.	Evidence of Generalised anxiety disorder						
SN	**ITEM**	**SCORES** **Codes:** **0=No information 1=Not present 2=Obsessions of questionable clinical significance 3= Definite obsessions**					
	Obsessive-compulsive disorder	**Parent**		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
	Obsessions						
1.	Content of obsessions						
	Contamination (e.g. cleanliness/germs, safety etc.)						
	Need for symmetry or exactness (certainty/precision, order)						
	Aggressive thoughts (concerning self or others)						
	Nihilistic or morbid thoughts						
	Sexual obsessions						
	Meaningless phrases/sounds/images						
	Religious						
	Somatic/illness						
	Hoarding/saving						
	Other (specify): …….						
		Codes: **0=No information 1=No 2=Yes**					
2.	Thoughts intrusive/senseless						
3.	Suppression						
4.	Level of insight Origin of thoughts						
	Discomfort with thoughts						

5.	Time consuming						
6.	Obsessional thoughts Related to disgust						
	Related to fear						
	Related to both						
7.	Impairment Socially (with peers)						
	With family						
	In school/work						
	Severe distress						
	Compulsions	**Codes:** **0=No information 1=Not present 2=Compulsions of questionable clinical significance 3= Definite compulsions**					
	Types of compulsions Cleaning/washing						
	Ordering/arranging objects						
	Checking (e.g. did not harm others, nothing bad happened, did not make mistakes)						
	Touching						
	Counting						
	Repeating/re-doing (e.g. assignment, activity like going through door or up/down from chair etc.)						
	Scheduling activities						
	Collecting/hoarding						
	Other (specify): ……..						
		Codes: **0=No information 1=No 2=Yes**					
2.	Purpose of compulsions						
3.	Perception of compulsion						
4.	Time consuming						
5.	Impairment Socially (with peers)						
	With family						
	In school/work						
	Severe distress						
		Summary CE		**Summary MSP**			
6.	Evidence of Obsessive-compulsive disorder						
	Specify if: With good or fair insight……. With poor insight …… With absent insight/delusional beliefs ……						
	Specify if: Tic related…….						

SN	**ITEM**	**SCORES** **Codes:** **0=No information 1=No 2= Yes**					
	Post-traumatic stress disorder	**Parent**		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
1.	Dissociative episodes						
2.	Flashbacks						
3.	Negative emotions						

4.	Sleep disturbance						
5.	Irritability or outburst of anger						
6.	Psychological distress when exposure to stimuli that resemble or symbolise event						
7.	Inability to recall an important aspect of the trauma						
8.	Anhedonia/diminished interest in activities						
9.	Efforts to avoid memories, thoughts of feelings of traumatic event						
10.	Restricted affect						
11.	Sense of fore-shortened future						
12.	Difficulty concentrating						
13.	Negative beliefs and expectation						
14.	exaggerated startle response						
15.	Psychological reactivity upon exposure to events that symbolise traumatic event						
16.	Reckless/self-destructive						
17.	No positive emotions						
18.	Impairment Socially (with peers)						
	With family						
	In school /work						
19.	Duration (in weeks)						
		Summary CE		**Summary MSP**			
20.	Evidence of Post-traumatic stress disorder						
21.	Evidence of Acute stress disorder						
22.	Unspecified Anxiety Disorder						

SUPPLEMENT #4: NEURODEVELOPMENTAL, DISRUPTIVE AND CONDUCT DISORDERS SUPPLEMENT

SN	**ITEM**	**SCORES** **Codes:** **0=No information 1=Not present** **2=Subthreshold 3=Threshold**		
		Parent	**Child**	**Summary**
	Attention deficit hyperactivity disorder:			
1.	Makes a lot of careless mistakes (past)			
2.	Doesn't listen (past)			
3.	Difficulty following instructions (past)			
4.	Difficulty organising tasks (past)			
5.	Dislikes/avoids tasks requiring attention (past)			
6.	Loses things (past)			
7.	Forgetful in daily activities (past)			
8.	Fidgets (past)			
9.	Runs or climbs excessively (past)			
10.	On the go/acts like driven by a motor (past)			
11.	Difficulty playing quietly (past)			
12.	Blurts out answers (past)			
13.	Difficulty waiting turns (past)			

14.	Interrupts or intrudes (past)						
15.	Talks excessively (past)						
		Codes: **0=No information 1=No 2=Yes**					
		Parent		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
16.	Duration …….(6 months or more)						
17.	Age of onset: specify ……(some symptoms present before age 12 years)						
18.	Impairment (must be present in **two** settings) a. Socially (with peers)						
	b. With family						
	c. In school						
		Summary CE		**Summary MSP**			
19.	Evidence of ADHD						
20.	Predominantly inattentive presentation						
21.	Predominantly hyperactive-impulsive type						
22.	Combined type						
23.	Other specified attention deficit hyperactivity disorder						

SN	**ITEM**	**SCORES** **Codes:** **0=No information 1=Not present** **2=Subthreshold 3=Threshold**					
		Parent		**Child**		**Summary**	
	Oppositional defiant disorder:						
1.	Easily annoyed (past)						
2.	Angry or resentful (past)						
3.	Spiteful and vindictive (past)						
4.	Annoys people on purpose (past)						
5.	Blames others for own mistakes (past)						
		Codes: **0=No information 1=No 2=Yes**					
		Parent		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
6.	Duration …….(6 months or more)						
7.	Impairment a. Socially (with peers)						
	b. With family						
	c. In school						
8.	Evidence of precipitant (specify)						
9.	Are ODD symptoms present in the following environments: a. with parents						
	b. with other adult family members (e.g. grandparents, aunts, uncles, etc.)						
	c. in school						
	d. in community settings (e.g. coaches, police,						

	healthcare providers, etc.)						
	e. with peers						
		Summary CE		**Summary MSP**			
10.	Evidence of Oppositional defiant disorder						
	Specify: (current) mild……(one setting) moderate…….(two settings) severe…….. (three+ settings)						
	Specify: (past) mild……(one setting) moderate…….(two settings) severe…….. (three+ settings)						
11.	Evidence of unspecified disruptive behaviour disorder						
12.	Evidence of parent-child relational problems						

SN	**ITEM**	**SCORES** **Codes:** **0=No information 1=Not present** **2=Subthreshold 3=Threshold**					
		Parent		**Child**		**Summary**	
	Conduct disorder						
1.	Vandalism, destroyed others' property (past)						
2.	Breaking and entering (past)						
3.	Aggressive stealing (past)						
4.	Fire setting (past)						
5.	Often stays out at night (past)						
6.	Ran away overnight (past)						
7.	Use of a weapon (past)						
8.	Physical cruelty to persons (past)						
9.	Forced sexual activity (past)						
10.	Cruelty to animals (past)						
		Codes: **0=No information 1=No 2=Yes**					
		Parent		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
11.	Impairment a. Socially (with peers)						
	b. With family						
	c. In school						
12.	Duration …….(6 months or more)						
13.	Childhood onset type…… (onset of at least on conduct problem prior to age 10)						
14.	Adolescent onset type (no conduct problem prior to age 10)						
		Summary CE		**Summary MSP**			
15.	Evidence of Conduct disorder						
	Specify (current):with limited prosocial emotion Specify (past):with limited prosocial emotion						
	Specify severity(current):						

	Mild…….moderate…….severe……. Specify severity (past): Mild…….moderate…….severe……..		
16.	Group type		
17.	Solitary aggressive type		
18.	Undifferentiated type		
19.	Callous and unemotional		
20.	Severity (code): 0=mild, 1=moderate, 2=severe		

SN	**ITEM**	**SCORES** **Codes:** **0=No information 1=No 2=Yes**					
	Simple and complex motor disorders	**Parent**		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
	Simple motor						
1.	Eye blinking						
2.	Other facial ticks						
3.	Head jerks						
4.	Shoulder jerks						
5.	Arm movements						
6.	Stomach twitches						
7.	Leg movements						
8.	Other						
9.	Summation of all above (simple motor tics occur many times a day or have occurred intermittently for 1 year or longer)						
	Complex motor						
1.	Touching/tapping things						
2.	Hopping/spinning						
3.	Echokinesis						
4.	Hurts self						
5.	Other						
6.	Summation of all above(complex motor tics occur many times a day or have occurred intermittently for 1 year or longer)						
	Simple and complex vocal disorders						
	Simple vocal phonic						
1.	Sniffing/ coughing, throat clearing						
2.	Snorting/ grunting						
3.	Other						
4.	Summation of all above (simple vocal tics occur many times a day or have occurred intermittently for 1 year or longer)						
	Complex vocal phonic						
1.	Repeat own words/sentences						
2.	Repeat others' speech						
3.	Corprolalia (obscene words)						
4.	Insults/racial slurs						
5.	Other						

6.	Summation of all above (vocal tics occur many times a day or have occurred intermittently for 1 year or longer)						
7.	Impairment a. Socially (with peers)						
	b. With family						
	c. In school						
		Summary CE		**Summary MSP**			
8.	Criteria for Tourette's disorder						
	Tic disorders						
9.	Evidence of persistent (Chronic) motor or vocal tic disorders						
	Specify (current): With motor tics only…… With vocal tics only……. Specify (past): With motor tics only…… With vocal tics only…….						
10.	Evidence of provisional tic disorder						
	Specify (current): With motor tics only…… With vocal tics only……. Specify (past): With motor tics only…… With vocal tics only…….						
11.	Tic disorder not otherwise specified						

SN	**ITEM**	**SCORES** **Codes:** **0=No information 1=Not present** **2=Subthreshold 3=Threshold**					
		Parent		**Child**		**Summary**	
	Autism spectrum						
1.	Deficits in social-emotional reciprocity (past)						
2.	Deficits in developing and maintaining relationships appropriate to developmental level (past)						
3.	Hyper or hypo reactivity to sensory input or unusual interest in sensory aspects of environment (past)						
4.	Motor deficits in performance of skilled movement not limited to social communication (past)						
		Codes: **0=No information 1=No 2=Yes**					
		Parent		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
5.	Communication and social deficits common among patients with autism spectrum disorder a. One sided verbosity						
	b. Speech pragmatic deficits						
	c. Abnormalities in voice modulation/prosody						

	d. Incessant and insensitive pursuit of others						
6.	Features of patients with high functioning autism a. Social isolation						
	b. Echolalic speech						
7.	Developmental history a. Symptoms present in early childhood						
	b. Speech pragmatic deficits						
8.	Impairment a. Socially (with peers)						
	b. With family						
	c. In school						
		Summary CE		**Summary MSP**			
9.	Evidence of Evidence of autism spectrum disorders						
	Specify: with accompanying intellectual impairment without accompanying intellectual impairment with accompanying language impairment without accompanying language impairment associated with a known medical or genetic condition or environmental factor associated with another neurodevelopmental, mental or behavioural disorder						
	Specify severity: level 1: requiring support level2: requiring substantial support level 3: requiring very substantial support						

SUPPLEMENT #5: EATING AND SUBSTANCE RELATED DISORDERS SUPPLEMENT

NB: Take weight and height of child/adolescent and calculate BMI

SN	**ITEM**	**SCORES** **Codes:** **0=No information 1=Not present** **2=Subthreshold 3=Threshold**					
		Parent		**Child**		**Summary**	
	Eating disorders:						
1.	Disturbance of body image (past)						
2.	Lack of control (past)						
		Codes: **0=No information 1=No 2=Yes**					
		Parent		**Child**		**Summary**	
		CE	**MSP**	**CE**	**MSP**	**CE**	**MSP**
3.	Self-evaluation influenced by weight (past						
		Summary CE		**Summary MSP**			
4.	Duration (in weeks) of eating disturbance: current…….. past…….						

5.	Evidence of anorexia nervosa		
	A. Restricting type		
	B. Binge-eating/Purging type Specify severity: mild, moderate, severe, extreme Partial remission Full remission		
6.	Evidence of binge- eating disorder		
7.	Evidence of bulimia nervosa		
8.	Specify type Purging type		
	Non purging type		
	Specify severity (present):mild, moderate, severe, extreme (past): mild, moderate, severe, extreme		

Substance related disorders:

Instructions: Ask the same questions such as those in the alcohol use disorder table for each of the substances listed below that the child/adolescent uses/has ever used:

Sn	Type of substance	Yes/No
1	Alcohol	
2	Cannabis	
3	Stimulants	
4	Sedatives/hypnotics/anxiolytics	
5	Cocaine	
6	Opioids	
7	Solvents/inhalants	
8	PCP	
9	Hallucinogens	
10	Other: specify	
11	Polysubstance	

Alcohol use disorders

Sn.	Criteria	Codes: 0=no information 1=not present 2= subthreshold 3=threshold					
		Parent CE	Parent MSP	Child CE	Child MSP	Summary CE	Summary MSP
1	Drinks/uses more than planned						
2	Failure to fulfil major role responsibilities						
3	Use in physically hazardous situations						

4	Negative consequences-legal						
5	Use despite social problems						
6	Tolerance						
7	Withdrawal symptoms						
8	Tried to quit or reduce use						
9	A lot of time spent in associated activities						
10	Important occupational, social, or recreational activities given up or reduced due to abuse						
		Codes: 0=no information, 1=yes 2=no					
		Parent CE	**Parent MSP**	**Child CE**	**Child MSP**	**Summary CE**	**Summary MSP**
11	Negative consequences-physical						
12	Negative consequences-psychological						
13	Craving						
14	Impairment Socially (with peers)						
	With family						
	School or work						
	Legal consequences						
15	Distress						
16	Duration (in weeks)						
17	Evidence of alcohol use disorder						
18	In remission, specify: Specify severity (current) (past)						

APPENDIX A10: CHILDREN GLOBAL ASSESSMENT SCALE (C-GAS)

Instructions: rate the child's/adolescent's level of functioning and record the score.

Score	**Corresponding functional level**
100-91	Superior functioning
90-81	Good functioning
80-71	No more than slight impairment of functioning
70-61	Some difficulty in a single area of functioning but generally functioning pretty well
60-51	Variable functioning with sporadic difficulties
50-41	Moderate degree of interference in functioning
40-31	Major impairment to functioning in several areas
30-21	Unable to function in almost all areas
20-11	Needs considerable supervision
10-1	Needs constant supervision

APPENDIX B: CONSENT FORM

APPENDIX B1: WRITTEN INFORMED CONSENT-ENGLISH VERSION.
Consent to participate in a study titled "Pathways to care at child-adolescent mental health specialist services and patient-provider perceptions about the services in Dodoma, Tanzania.

I am a Master of Science student from the Centre for Child and Adolescent Mental Health (CCAMH), University of Ibadan, conducting a research titled as above. The aim of the study is to determine the pathways and factors influencing choice of such pathways to child and adolescent mental health specialist services; and patient-provider perceptions about the services in order to improve the quality of services and care of the patients.

If you agree to join the study, you will be required to answer some questions that will be distributed to you although other questions will be asked directly. It is approximated that 45 to 60 minutes will be used to do that activity. Participation in this study will be completely voluntary. Information obtained from you or your child will be kept confidential and anonymous. No client name will be written on any questionnaire. The information collected will be entered into computers with only the participant's identification number. The results of the study will be reported as group results.

We do not expect that any harm will happen to you or your child because of joining in this study. You may refuse to participate or withdraw from the study at any time. Refusal to participate or withdrawal from the study will not involve penalty or loss of any benefit to which you are otherwise entitled. There will be no specific financial benefits to you; the results of the study will contribute to the present body of knowledge on child mental health and pathways to care.

If you ever have questions about your rights as a participant, you may contact Professor F. Fabian, Director of Research and Publications Committee, University of Dodoma, Dodoma.

If you agree please sign or thumb print below; and if you do not agree then you do not have to sign/put your thumb print.

I have read the contents in this form and understood. I agree to participate in this study.

Signature of research participant: ……

Signature of researcher: ……

Date of signed consent: ……

APPENDIX B2: WRITTEN INFORMED CONSENT- KISWAHILI VERSION:
Ridhaa ya kushiriki kwenye utafiti kuhusu "Njia za kufikia matibabu ya kitaalam ya afya ya akili ya watoto na mtazamo wa wagonjwa na watumishi wa afya juu ya huduma hizo Dodoma".

Mimi ni mwanafunzi kutoka Chuo Kikuu cha Ibadan, Nigeria; nasoma kozi ya Shahada ya Uzamili katika Afya na Magonjwa ya Akili ya Watoto na Vijana. Nafanya utafiti juu ya mada tajwa hapo juu, lengo likiwa ni kujua njia hizo za kufikia huduma, sababu zinazochangia uchaguzi wa njia hizo na mtazamo wa wagonjwa na watumishi wa afya juu ya huduma hizo ili kuweza kuboresha huduma hizo kwa ujumla wake.

Nitafurahi iwapo utashiriki katika utafiti huu, ushiriki wako ni wa hiyari kabisa na madodoso yatatunzwa kwa usiri na hayatakuwa na majina ya wahusika bali ni namba tu zitatumika. Pia, taarifa za utafiti zitaingizwa kwenye kompyuta kwa kutumia namba tu, na majibu ya utafiti yatatolewa kwa ujumla wake. Iwapo unakubali kushiriki, utahitaji kujibu maswali kwenye madodoso, japo kuna maswali utakayoulizwa moja kwa moja, na kwa ujumla tunategemea kutumia takriban dakika 45-60 hivi.

Kutokana na aina ya utafiti huu hatutegemei madhara yoyote kwa kushiriki kwako. Pia unaweza kukataa au kujitoa katika ushiriki huu wakati wowote bila kukuletea madhara yoyote. Hakutakuwa na mafao yoyote kwako binafsi kama mshiriki bali ushiriki wako utasaidia kuongeza ujuzi kuhusiana na mada tajwa na hivyo kupanga njia za maboresho ya huduma kwa ujumla.

Iwapo utakuwa na swali lolote kuhusiana na utafiti huu unaweza kuwasiliana na mimi kwa namba 0755254758, ambaye ni mtafiti mkuu wa utafiti huu. Na iwapo utakuwa na swali lolote juu ya haki zako kama mshiriki unaweza kuwasiliana na Mkurugenzi wa Kamati ya Tafiti na Machapisho, Profesa F. Fabian, UDOM, Dodoma.

Kama unakubali kushiriki katika utafiti huu tafadhali weka sahihi yako/dole gumba hapa chini na iwapo hauko tayari kushiriki basi huhitaji kuweka sahihi/dole gumba.

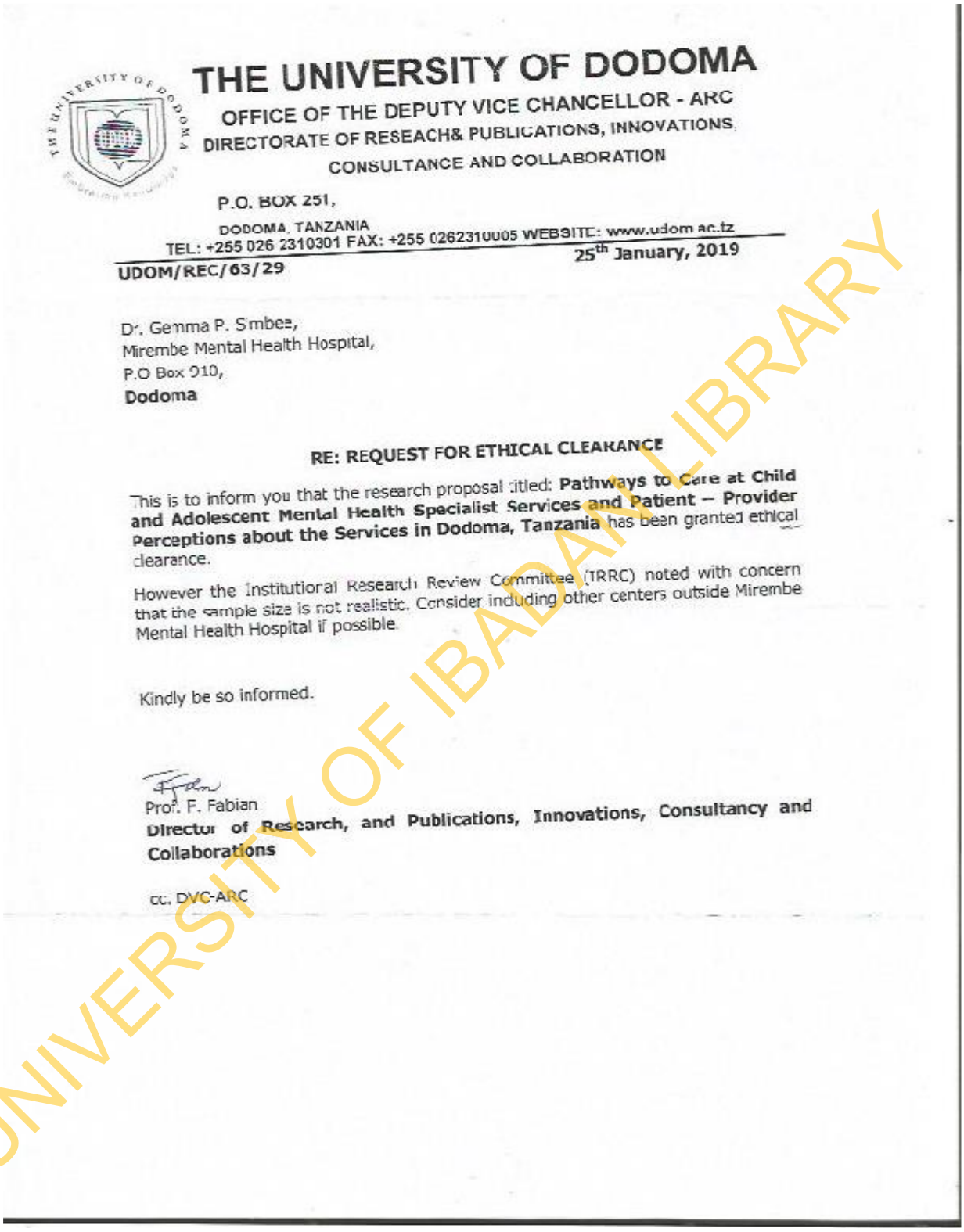
Mimi……..nimesoma maelezo haya na nimeyaelewa vyema; nakubali kushiriki katika utafiti huu.

Sahihi ya mshiriki wa utafiti: ……..

Sahihi ya mtafiti: ……

Tarehe ya kutia saini: …….

APPENDIX C: Ethical approval



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UDOM/REC/63/29

25th January, 2019

Dr. Gemma P. Simbea,
Mirembe Mental Health Hospital,
P.O Box 910,
Dodoma

RE: REQUEST FOR ETHICAL CLEARANCE

This is to inform you that the research proposal titled: **Pathways to Care at Child and Adolescent Mental Health Specialist Services and Patient – Provider Perceptions about the Services in Dodoma, Tanzania** has been granted ethical clearance.

However the Institutional Research Review Committee (IRRC) noted with concern that the sample size is not realistic. Consider including other centers outside Mirembe Mental Health Hospital if possible.

Kindly be so informed.

Prof. F. Fabian
Director of Research, and Publications, Innovations, Consultancy and Collaborations

cc. DVC-ARC