ASSESSMENT OF KNOWLEDGE AND PRACTICE ABOUT CHILDHOOD AUTISM AMONG HEALTH CARE WORKERS AT KENYATTA NATIONAL HOSPITAL

BY

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STUDENT'S DECLARATION

This dissertation is my original work and has not been presented for the award of a degree in any other university.

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DEDICATION

I dedicate this work to all children with autism seen at Kenyatta National Hospital.

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I am grateful to the following for their contribution to this project:
Almighty God, for giving me good health to carry out this project
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ABBREVIATIONS

AAP	American Association of Psychiatry
ABA	Applied Behavior Analysis
ADHD	Attention Deficit Hyperactivity Disorder
ANPPCAN	African Network for the Prevention & Protection against Child Abuse & Neglect
ASD	Autism Spectrum Disorder
AQ	Autism spectrum Quotient
CARD	Centre for Autism Related Disabilities
CAST	Childhood Asperger Syndrome Test
DALY	Disability Adjusted Life Years
DSM	Diagnostic & Statistical Manual of Mental Disorders
FDA	Food & Drug Administration
FGD	Focused Group Discussion
GI	Gastro-Intestinal
GP	General Practitioner
HCP	Health Care Professional
HCW	Health Care Worker
ICD	International Classification of Diseases
IQ	Intelligence Quotient
KCAHW	Knowledge about Childhood Autism among Health Care Workers
KNH	Kenyatta National Hospital
M-CHAT	Modified Checklist for Autism in Toddlers
PI	Principal Investigator
UK	United Kingdom
UON	University Of Nairobi
USA	United States of America

OPERATIONAL DEFINITION OF TERMS

Autism-a biologically based neurodevelopmental disorder characterized by persistent deficits in social communication and social interaction and restricted, repetitive patterns of behaviour, interests, and activities.

Knowledge-facts, information, skills, awareness or familiarity acquired through experience or education.

Practice: Application of knowledge in the management of a condition.

Health care workers-nurses, medical officers, clinical officers, Occupational therapists, Residents (paediatrics, paediatric surgery & psychiatry), Consultant paediatricians.

Childhood- the state or period of being a child, who is a young human being below the age of puberty or below the legal age of majority.

ABSTRACT

Background

Autism spectrum disorder (ASD) is a recognised worldwide public health concern and represents some of the greatest burdens of disease in children and adolescents. Limited knowledge among health care providers, is among the issues daunting autism in Africa. A significant gap in recognition and availability of health and social services for autism exists in Kenya. Knowledge on autism leads to early diagnosis and timely intervention, leading to independent & productive lives.

Assessing the HCWs knowledge, practice & challenges, to detect areas of knowledge gap is essential as it facilitates bridging the gaps identified .

Paucity of studies on practice of HCWs on childhood autism both globally and locally, informs the need for this study.

Objectives

The primary objective was to determine the level of knowledge of health care workers in Kenyatta National Hospital on childhood autism.

The Secondary objectives were to determine the practice of health care workers in Kenyatta National Hospital on childhood autism & to describe the challenges HCWs face in diagnosis, management & follow up of children with autism**.**

Study Methods

Mixed methods study at KNH. Multi-stage sampling technique to select 230 HCWs.

Data was collected through a structured validated questionnaire, focused group discussions and key informant interviews. Data was entered and cleaned in Microsoft Excel and analysed using SPSS Version 23.

Descriptive data analysis was done using means for contionous variables and frequencies and percentages for categorical variables. A p-value of < 0.05 was regarded as significant.

Results

Out of 230 participants in the study, 120 (52.2%) had good knowledge on childhood autism. The highest knowledge gap was associated with impaired communication. There was good practice that included a multidisciplinary approach with appropriate referral however some bad practice such as lack of autism specific screening existed. Major Challenges encountered in autism management were inadequate training , lack of local management guidelines on autism, lack of awareness among parents/caregivers, cultural beliefs and practices & limited number of normal schools with instituted special needs.

Conclusion

Only 54% of the HCWs had good knowledge on childhood autism. There was generally good practice among the HCWs. Major challenges in autism management do exist.

CHAPTER 1: INTRODUCTION

Definition / terminology

Autism spectrum disorder (ASD) is a composite neurodevelopmental disorder that involves persistent and constant challenges in speech and nonverbal communication, social interaction and skills and a limited range of repetitive/restricted behaviours(1).

The Definition and diagnostic criteria for ASD vary geographically. In the United States, the Diagnostic and Statistical Manual of Mental Disorders (DSM) is used predominantly and was updated in 2013 (DSM-5). In other countries throughout the world, the World Health Organization International Classification of Diseases, 10^{th} revision (ICD-10) is used(2,3).

DSM-5 — The DSM-5 diagnosis of ASD is characterized by:

Persistent deficits in social communication and social interaction (e.g. Nonverbal communicative behaviours; deficits in social reciprocity; and skills in developing, understanding and maintaining relationships), and Restricted, stereotyped, repetitive and monotonous patterns of behaviour, activities or interests.

ICD — In contrast to DSM-5, which uses ASD as a single diagnostic label, the ICD-10 classifies ASD as "pervasive developmental disorders" and includes several subtypes, including childhood autism, pervasive developmental disorder not otherwise specified (which includes atypical autism), Asperger syndrome, childhood disintegrative disorder and Rett syndrome.

It is an inveterate neurodevelopmental condition that begins in childhood. However Many children with autism go on to live independent and productive lives(4).

Burden and Epidemiology

The median prevalence of ASD globally is 62/10000(4). In the united states, it is estimated to affect up to 3% of children and the estimated prevalence among 4 year old children is 17/1000 children(5).In Arab Gulf countries, the prevalence of ASD ranges between 1.4-29/10,000(6).

A progressive increase in the prevalence of ASD globally has been observed over time with the reasons being multifactorial, and the main factor being increased awareness. Other explanations include changes in case definition and true increase in prevalence(5). ASD is one of the fastest-growing serious neurodevelopmental disabilities in children, it is as a worldwide public health

concern and represents some of the eminent burdens of disorders in children and adolescents(7,8). The global burden of autism is not known currently but it is estimated that its annual societal cost exceeds several billions in the US and in the UK(4).

In Singapore, ASD accounts for the greatest disability-adjusted life years (DALY) in children under 15 years of age(8).

There is no data on the prevalence of ASD in sub-Saharan Africa, despite non-communicable diseases, especially neurodevelopmental disorders becoming a greater health burden in these countries(9). Prevalence studies of general neuropsychiatric disorders in underdeveloped and developing countries propose that mental disorders are as prevalent as in developed countries(10). In Africa, the prevalence of autism is approximated to range from 0.7% to 33.6% and this is majorly from reports in neurology and psychiatry clinics(11).

ASD occurs more commonly in males Up to three times the rate in females with the male-to-female ratio being approximately 3:1(12).

Aetiology & Pathogenesis

The aetiology of ASD is complex and multifactorial, entailing genetic predisposition, immunopathogenic mechanisms and environmental factors(13). It is a highly heritable disorder associated with more than 100 genetic polymorphisms(9). These genetic polymorphisms interfere with the normal development of the brain, explicitly the neuronal connections, consequently affecting the development of social communication and hence the repetitive behaviours and restricted interests(14). Given the complexity of ASD, it is likely that an interplay between various several genes accounts for ASD and that environmental exposures and epigenetic factors contribute to variable expressions(15).

Environmental factors can be divided into: pre-natal, peri-natal and post-natal factors(16).

1. Pre-natal factors include congenital infections such as congenital rubella syndrome, &/or exposure to teratogens or pesticides.
2. Peri-natal factors include obstetric conditions like hypoxic-ischemic encephalopathy, pre-term delivery and low birth weight.
3. Post-natal factors include autoimmune diseases, viral infections, heavy metal toxicity e.g. mercury and vitamin D deficiency among others.

Its pathogenesis is quite uncertain and the mechanisms promoting autism are poorly known but several theories suggest an alteration in the normal development of the brain and its

consequences on the functional unit of the brain. Some of these theories include neural migration, dendritic morphology, neural connectivity, neural activity both excitatory and inhibitory, neuroimmune; dysregulation of calcium signalling pathways and mirror neurone theories(16). Advanced parental age (both maternal and paternal) has been shown to increase the risk of getting a child with ASD. The link between increased risk of getting a child with ASD and advanced parental age is alterations in genetic imprinting and/or spontaneous mutations(17).

Clinical presentation

Autism is characterized by a wide range of clinical manifestations of atypical or impaired social interaction, social communication, restricted interests and repetitive or stereotyped patterns of behaviours(18). According to American psychiatry association 2013, sustained and pervasive impairment in social interaction and social communication is the first core symptom of ASD. The second core symptom of ASD is restricted and repetitive pattern of behaviours, activities, and interests. About two-thirds of ASD patients fail to achieve communication skills before two years of age and a quarter to a third achieve early language milestones but have regression of social skills, language and communication between 15-24 months of age(19). Stereotypes and repetitive motor mannerisms for example hand twisting or flapping, toe walking and rocking are a core symptom of ASD(20). Children with ASD also have restricted interests, marked resistance to change during preschool years, and lack of interest in others and lack of empathy (19, 20).

Diagnosis

The diagnosis can be made clinically from the history taken and/or the observations made clinically on the behaviours. Different diagnostic criteria exist: the Diagnostic and Statistical Manual of Mental Disorders (DSM) criteria is the criteria most widely used worldwide.

DSM, Fifth edition criteria – based on the DSM, Fifth Edition (DSM-5) criteria, a diagnosis of ASD requires all of the following:

1•Persistent deficits in social communication and social interaction in multiple settings; demonstrated by deficits in all three of the following (either currently or by history):

-Social-emotional reciprocity (e.g., failure to produce mutually enjoyable and agreeable conversations or interactions because of a lack of mutual sharing of interests, lack of awareness or understanding of the thoughts and/or feelings of others)

-Nonverbal communicative behaviours used for social interaction (e.g., difficulty coordinating verbal communication with its nonverbal aspects [eye contact, facial expressions, gestures, body language, and/or tone of voice])
-Developing, maintaining, and understanding relationships (e.g., difficulty adjusting behaviour to social settings, lack of ability to show expected social behaviours, lack of interest in socializing, difficulty making friends even when interested in having friendships)

2•Restricted, repetitive patterns of behaviour, interests, or activities; demonstrated by ≥2 of the following (either currently or by history):
-Repetitive or stereotyped movements, use of objects, or speech (e.g. rocking, flapping, or spinning); echolalia (repeating parts of speech; repeating scripts from movies or prior conversations)
-Insistence on sameness, excessive and unwavering adherence to routines, or ritualized patterns of verbal or nonverbal behaviour (e.g., ordering toys into a line) or excessive resistance to change
-Highly restricted, fixated interests that are abnormal in strength or focus (e.g., preoccupation with certain objects [trains, vacuum cleaners, or parts of trains or vacuum cleaners]); perseverative interests (e.g., excessive focus on a topic such as dinosaurs or natural disasters)
-hyper or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., adverse response to particular sounds; apparent indifference to temperature; excessive touching/smelling of objects)

3• the symptoms must limit and impair everyday functioning (e.g., social, academic, completing daily routines).

4• the symptoms must be present in early childhood and early developmental period. However, they may not become fully apparent until social demands exceed limited capacities; in later life, symptoms may be masked by learned strategies.
5•the symptoms are not better explained by intellectual disability (formerly referred to as mental retardation) or global developmental delay.

ASD may or may not co-occur with medical, mental, neurodevelopmental, genetic, or behavioural disorders (e.g. Language impairment, intellectual disability). The presence or absence of such disorders is defined as part of ASD DSM-5 diagnosis (e.g., ASD without accompanying language impairment or ASD with accompanying intellectual impairment)

Screening

Identifying children with ASD has been quite a lengthy process for the past few years since some children with ASD exhibit outstanding and exceptional skills in areas such as mathematics, arts, and music among others(21). Evidence supports the benefits of early developmental screening for ASD as part of the routine and standard paediatric care. Nevertheless inadequate or lack of training and lack of time have been identified as barriers to implementation of routine and regular screening(22).

In 2006, the American Academy of Paediatrics (AAP) released a policy statement recommending that paediatricians:

(1)Use a formal developmental screening tool if risks are present.

(2) Incorporate developmental monitoring and surveillance into every well-child visit.

(3) Administer autism-specific screening at 18 and 30months of age(23).

Many pre-diagnosis screening methods for autism have been identified to help diagnose it early, ensure early and prompt referral and improve and enhance the understanding of ASD for the various stakeholders involved, such as parents, caregivers, family members and teachers. These include: Modified Checklist for Autism in Toddlers (M-CHAT), the Autism Spectrum Quotient (AQ) and Childhood Asperger Syndrome Test (CAST). M-CHAT is one of the most widely studied and most widely used ASD screening tools. It is a checklist for the parents, with 23 items and a recommendation for staff follow-up for clarification and explanation of failed items. No specific screening tool or method has been adopted as a standardised one but the general consensus is that, screening questionnaires filled by parents are more cost and time-efficient (21,22).

Early intervention

In the 1960s and 1970s, very poor outcomes for children with ASD were observed, this was due to the unavailability of numerous comprehensive interventions(24). Evidence suggests that

the earlier the intervention the greater the probability of improved and favourable developmental trajectory and better long term outcomes. Early intervention is more time and cost-effective. Although there is no known cure for ASD, early intervention and intensive and thorough behavioural therapy are associated with better outcomes(25). Better prognosis and improved outcomes in communication, developmental skills, social skills, language and communication have been seen in children who received interventions at younger ages in their childhood(26).

Medical co-morbidities

ASD can be associated with other conditions which form part of the spectrum of the diagnosis(1). Some of the conditions associated with ASD include: sleep disorders, seizures, psychiatric disorders and gastrointestinal disorders. Co-occurrence of gastrointestinal disturbances, seizures and sleep disorders predict more severe behavioural symptoms in children with ASD(27). Given that the general paediatric population experiences GI problems quite frequently, gastrointestinal disorders occur even more frequently in ASD(28).

ASD frequently co-occurs with other neurodevelopmental conditions such as depression, anxiety, ADHD and oppositional defiant disorders(29–31). intellectual disability is a very common co-occurrence in ASD affecting approximately 50-80% of ASD cases, 30% have epilepsy and 20-85% have ADHD(30,32). Tuberous sclerosis, Fragile X and Rett syndrome have also been reported as co-occurrences(30). Intellectual disability, epilepsy and ADHD are poor prognosticating factors(33).

These co-morbidities delay diagnosis and maybe the indication for admission to hospital or contribute to the child's plan of care(34,35).

Treatment

Treatment options are classified into three broad categories: behavioural, psychopharmacological and alternative and complementary models.

Behavioural- various psychosocial interventions exist targeting both the core and the related or associated symptoms of ASD. One of the behavioural models is Applied behaviour analysis (ABA) which is a form of therapy that focuses on specific targeted interventions along with practical and positive reinforcements such as edible rewards or verbal praises. Early intensive

ABA may lead to appealing and remarkable outcomes with nearly half of the children on this treatment being mainstreamed into regular classes and attaining significant IQ points.

Pharmacology- Pharmacological therapy is primarily used for treating the associated symptoms of ASD (aggression, insomnia, irritability and self-injury) because its efficacy in the treatment of the core symptoms has not been reported or established. Atypical antipsychotics such as Risperidone and Aripiprazole, have been approved by the Food and drug administration (FDA) for the management of irritability associated with ASD. Risperidone is approved for children at least 5 years and above while Aripiprazole is approved for 6 year old children and older. Typical antipsychotics such haloperidol has benefits in symptoms such as hyperactivity and stereotypical behaviours. Antidepressants have been considered for use in ASD owing to certain symptoms such as insistence on restricted patterns of routines.

Complementary-The complementary/alternative treatment in ASD that has been best studied is the efficacy of melatonin for sleep disturbance. Other complementary treatments though still under studies include omega 3 fatty acid supplementation, methyl B12, intravenous immunoglobulin and N acetylcysteine. Digestive enzymes and special diets are potential treatments in ASD due to the higher rate of GI symptoms in patients with ASD, though evidence does not support any improvement in neither core nor associated symptoms of ASD with these treatments. The current evidence limits therapy options for the main clinical manifestations of autism to psychosocial therapies, such as behavioural therapy(36).

CHAPTER 2: LITERATURE REVIEW

2.1 knowledge about childhood autism among health care workers

ASD is rising at an alarming rate and therefore health care workers need to be empowered and equipped with adequate knowledge and to be adequately prepared to interact with and provide care for these special children(37). A large number of studies across various nations have reported varying results regarding knowledge of autism among health care professionals. A survey done by Stone et al, clearly demonstrated that many health care professionals in different disciplines lack precise knowledge regarding autism and how it manifests in children and adolescents(38).

Varying levels of knowledge on childhood autism have been evident all over the world. A survey of autism knowledge in a health care setting in the United States, among 3 different groups of health professionals, CARD personnel (i.e., professional with the Centre for Autism Related Disabilities), specialists (child psychiatrist, psychologist and speech therapists) and primary care providers (paediatricians, family physicians and neurologists), found varying levels of knowledge between primary care providers and specialists. Despite all the three groups having precise affirmation of the DSM-IV criteria, Primary health care providers and specialists differentially endorsed various statements regarding the course, prognosis, and treatment compared to CARD personnel. Overall, primary providers had the greatest number of dissimilarities(39).

Similarly, Paediatric residents in the USA were noted to have poor knowledge and low self-competency in care of children with ASD and therefore more education of the residents on how to care for children with autism is needed(40). School-based speech and language pathologists in the USA had precise knowledge about the characteristics of autism in children. However, they had varied perceptions of the criteria for diagnosing autism and would therefore still have benefitted from extra training on autism(41).

A cross-sectional study done in Istanbul Turkey on the Pharmacists' knowledge and attitude about childhood autism indicated that majority of the pharmacists lacked accurate knowledge about the aetiology and social characteristics of childhood ASD. Only one third knew that children with autism have difficulties playing with children of the same age group. They

believed in outdated theories and thereby their knowledge about ASD needed to be enhanced to help them direct the families of children with ASD to the right health personnel(42).

Healthcare Professionals in Saudi Arabia had moderately low levels of knowledge about childhood ASD with psychiatrists followed by paediatricians having the highest knowledge. Scarcity of knowledge among HCPs regarding ASD proposes that focused strategies need to be put in place in order to bridge these knowledge gaps so as to ensure early detection, appropriate diagnosis, timely referral, and evidence-based interventions(43). Similarly in a cross-sectional study in nine teaching primary health care centres in Riyadh Saudi Arabia, only 10.5% of family medicine residents correctly answered more than or equal to 50% of the questions on knowledge about childhood autism. Poorest knowledge was on Recognition of the signs and symptoms of autism in individuals with good language and no apparent intellectual disabilities. Low awareness level and moderately low level of confidence in the residents with regards to ASD led to the recommendation of Integration of lectures and clinical exposure of ASD to the residency training program curriculum(44).

Sixth-year medical students in a medical college in Saudi Arabia had significantly much better knowledge (about the aetiology, diagnosis, characteristic features and management of ASD) and positive attitudes in comparison to students in their second year of medical college. This was due to their prior awareness about ASD in their paediatric curriculum and the positive attitudes were attributed to their better knowledge. This study recommended the provision of adequate clinical experience in the training of the medical students to allow them to get confronted with ASD cases as this will be a helpful tool for better screening upon qualification. This will ensure early diagnosis, early intervention, early management of ASD and better prognosis (45).

In Lahore Pakistan, (a low income developing country), the same trend of poor knowledge has been observed. Unbalanced understanding of Autism was found among health care professionals both Physicians (paediatricians, psychiatrists, family physicians neurologists) and non-physicians (speech therapists and psychologists). The observation made was accurate acquaintance with diagnosing autism as per the DSM 4 criteria, and this was more likely among the non-physicians. Nonetheless, significant misconceptions of some of the key characteristics of autism were found in both groups. These gaps called for continued and additional education of health care professionals across various disciplines with regards to Autism(46). Another

survey done by Rahbar et al regarding knowledge and attitude of autism among GPs in Karachi Pakistan showed that young GPs approximately 30 years old and those who recently qualified for their degrees had a more likelihood of having good knowledge on childhood Autism(47).

A preliminary survey in Tehran Iran on knowledge and attitude of HCWs and paediatricians on autism showed that HCWs with higher working experience had a higher rate of knowledge about autism. The difference between the two study groups in rating DSM-IV criteria for ASD as necessary for diagnosis was not statistically significant. Other Socio-demographic factors such as age, gender and marital status did not influence the HCWs answers on diagnostic criteria of autism (48).

An earlier survey conducted in south-east Nigeria by the African Network for the Prevention and Protection against Child Abuse and Neglect (ANPPCAN) and world bank looking at the level awareness and knowledge of HCWs on autism, showed a moderate to low level of knowledge in all the different categories of HCWs and the highest level of awareness being in healthcare workers working in psychiatric centres(46). Many studies on autism done in Nigeria conclude poor knowledge of HCWs on Autism. In North-West Nigeria, specialised medical doctors particularly psychiatrists and paediatricians have good knowledge of autism. Limited knowledge is seen in GPs with the biggest knowledge gap being about the onset and co-morbidities of Autism, therefore, making it necessary to improve the knowledge about ASD among the GPs(49).

Owalabi Bakari et al conducted a cross-sectional questionnaire-based survey on 134 HCWs in tertiary health care facilities in Nigeria. The questionnaire used in the study was the Knowledge about Childhood Autism among Health Workers (KCAHW) questionnaire. The total mean score of the participants on the questionnaire was 12.35 +/- 4.40 out of a total score of 19. The highest Knowledge gap was regarding symptoms of repetitive and obsessive patterns of behaviour, followed by symptoms of impairments in social interaction, the subtype of autism disorder and its co-morbidities and symptoms of impaired communication. There was a significant relationship between the Knowledge about childhood autism (KCA) and the age and previous experience of the healthcare workers, with those approximately 40 years old and those with previous experience in the management of childhood ASD having a higher mean score. A near significant association between the level of knowledge and area of speciality, and with the duration of working experience of the healthcare workers was also found. Those HCWs

working in psychiatry compared to paediatrics had a higher mean score. The study concluded that it is important to update the knowledge gaps of the HCWs(50).

A study done on paediatric and psychiatry nurses in Nigeria, using the KCAHW questionnaire and evaluating their knowledge about childhood autism showed inadequate knowledge which may interfere with adequate counselling they give to the families of these children. There was a notable relationship between the total mean score of the two groups on the questionnaire and the field of specialisation and previous experience in managing children with childhood autism. The scores of the KCAHW questionnaire were poor and reflected pitfalls in knowledge about childhood autism. Nurses' knowledge about childhood autism is very crucial for them as members of multidisciplinary teams in the provision of proper counselling and holistic care to the families or caregivers of these children (51). In another study that involved 134 HCWs in Nigeria, 27% had a wrong belief on the aetiology of ASD to be supernatural, for example, devil's actions, lineage curses, and being under a curse by ancestral spirits.54.5% and 32.1% believed childhood autism to be treatable and preventable respectively(52).

Joseph K Gona et al did a cross-sectional survey in a multicultural context in Kenya, on the parents of children with ASD, and the professional (clinicians, social workers and special needs teachers) assessing their Perceptions on the aetiology and management Options for Autism Spectrum Disorders (ASD). The study found that HCWs poor knowledge of the presentation, treatment and prognosis of ASD could lead to underestimation of the caregivers' distress and their need for essential information. These gaps in knowledge among the HCWs affects decisions regarding treatment taken by the caregivers as they seemed to make decisions based on their beliefs on the cause of the disorder(53).

As noted by Rhoades et al, HCWs' knowledge, as well as lack of knowledge about ASD, significantly influences the mean age of diagnosis and whether or not the HCW provides the necessary information to the caregivers about autism both of which significantly affect the prognosis of ASD. And such knowledge or lack of it is a reflection of the training such physicians received(54). By increasing the awareness and knowledge about ASD among HCWs, early referral and early interventions can result in better prognosis(55).

Table 2. 1: Summary of studies on knowledge of autism among health care workers.

Study title, author, country & year of study	**Study design**	**Study population and sample size**	**Outcome**
A survey of autism knowledge in a health care setting in the USA Heidgerken AD et al. 2005	Cross-sectional	111 professional with the Centre for Autism Related Disabilities, specialists and primary health care providers	varying levels of knowledge among primary care providers and specialists
The pharmacists' awareness, knowledge and attitude about childhood autism in Istanbul. Luleci NE et al. 2016	Cross-sectional descriptive study	141 pharmacists	knowledge about causative factors of childhood ASD was lacking Belief in outdated theories.
Assessment of knowledge about childhood autism spectrum disorder among healthcare workers in Makkah-Saudi Arabia. Hayat AA et al. 2019	Cross-sectional survey	147 healthcare professionals across various specialities.Pediatricians, psychiatrists, psychologists, physiotherapists, occupational therapists, general physicians, surgeons, medical specialists and few medical trainees.	Mean score - 9.80(S.E.M ±0.32). Mean percent score - 51.60%. Moderately low knowledge.

Study title, author, country & year of study	**Study design**	**Study population and sample size**	**outcome**
Knowledge about childhood autism among health workers (KCAHW) questionnaire: description, reliability and internal Consistency Muideen O Bakare et al. **2008**	Cross-sectional study	50 Psychiatry nurses	showed good test-retest reliability, internal consistency & is a reliable tool for assessing knowledge of HCWs about childhood autism. It would be a useful tool in improving early recognition of autism.
A survey of Autism knowledge and attitudes among the healthcare professionals in Lahore, Pakistan Imran N et al. **2011**	Cross-sectional survey	247 Physicians (psychiatrists, paediatricians, neurologists and family physicians) and non-physicians (psychologists and speech therapists)	unbalanced understanding of autism several significant misconceptions on the salient features of autism in both groups.
Knowledge of Childhood Autism and Challenges of Management among Medical Doctors in Kaduna State, Northwest Nigeria E.E Eseigbe et al 2013	Cross-sectional	175 medical doctors	Mean score 13.5± 3.7, median 15 Good knowledge was significantly associated with being a paediatrician or psychiatrist and practising in a tertiary health facility Poor knowledge was significant among general practitioners.

Study title, author, country & year of study	**Study design**	**Study population and sample size**	**Outcome**
Assessment of knowledge about childhood autism among paediatric and psychiatric nurses in Ebonyi state, Nigeria Monday N et al. 2011	Cross-sectional survey	80 paediatric and psychiatric nurses	A significant relationship between the total mean score on the KCAHW questionnaire for the two groups and the area of specialisation of the nurses. Deficits in knowledge.
Parents' and Professionals' Perceptions on the Causes and Treatment Options for Autism Spectrum Disorders (ASD) in a Multicultural Context on the Kenyan Coast Gona JK et al. 2015	Cross-sectional study	103 participants (parents of children with ASD, special needs teachers, clinicians, and social workers)	HCWs poor knowledge of ASD could lead to underestimation of the caregivers' distress and need for information. This knowledge gap among the HCWs affects treatment decisions taken by the caregivers.

2.2 Challenges HCWs face in diagnosis, management & follow up of children with autism.

Assessing challenges encountered by HCWs in the management of autism helps in addressing issues confronting the disorder. This has been shown to improve the standards of care and outcomes in autism(49).

Varying perceptions regarding the criteria used for the diagnosis autism was found to be a challenge among speech-language pathologist in the USA and a majority of the participants acknowledged that minimal time was spent on addressing during their training. Furthermore, some speech-language pathologists had lack of confidence in their skills and capabilities in providing services to children with autism(41). On the other hand in Pennsylvania, unavailability of resources for the poor families and those in the rural areas was a challenge leading to delay in diagnosis compared to urban children and those with higher incomes(56).

Reluctance and fear among HCWs in labelling a child with autism at an early age were noted to be challenges in HCWs in Pakistan. Most of the health care workers in Pakistan have minimal or no formal training in childhood and adolescent psychiatry (46,57).

Scarcity of specialist services, poor perspectives of caregivers and cost of accessing care were major challenges noted in the management of childhood autism in North-West Nigeria. A need to address the challenges impeding management of autism in order to achieve desirable outcomes was found to be of key importance(49). Another study on 134 HCWs in Nigeria, indicated that laws and facilities for the rights and needs of children with autism were not available in Nigeria. Other challenges included; lack of availability of interventional facilities for the medical needs as well as the social needs of children with autism. 66.4% of the HCWs had the opinion that these facilities are lacking, 83.6% thought that training facilities for HCWs are unavailable and 53% of the HCWs communicated and conveyed the opinion that laws protecting the rights/interests of children autism do not exist(50).

Poor knowledge among nurses in Nigeria who are important members of multidisciplinary teams involved in the care of children with autism was thought to be a challenge to early intervention. This may also interfere with the counselling services given to families of these children(51).

In Ethiopia, severe scarcity of services for children with autism is a challenge. Services for diagnosis of autism children are unavailable to the rural population who are the majority. In

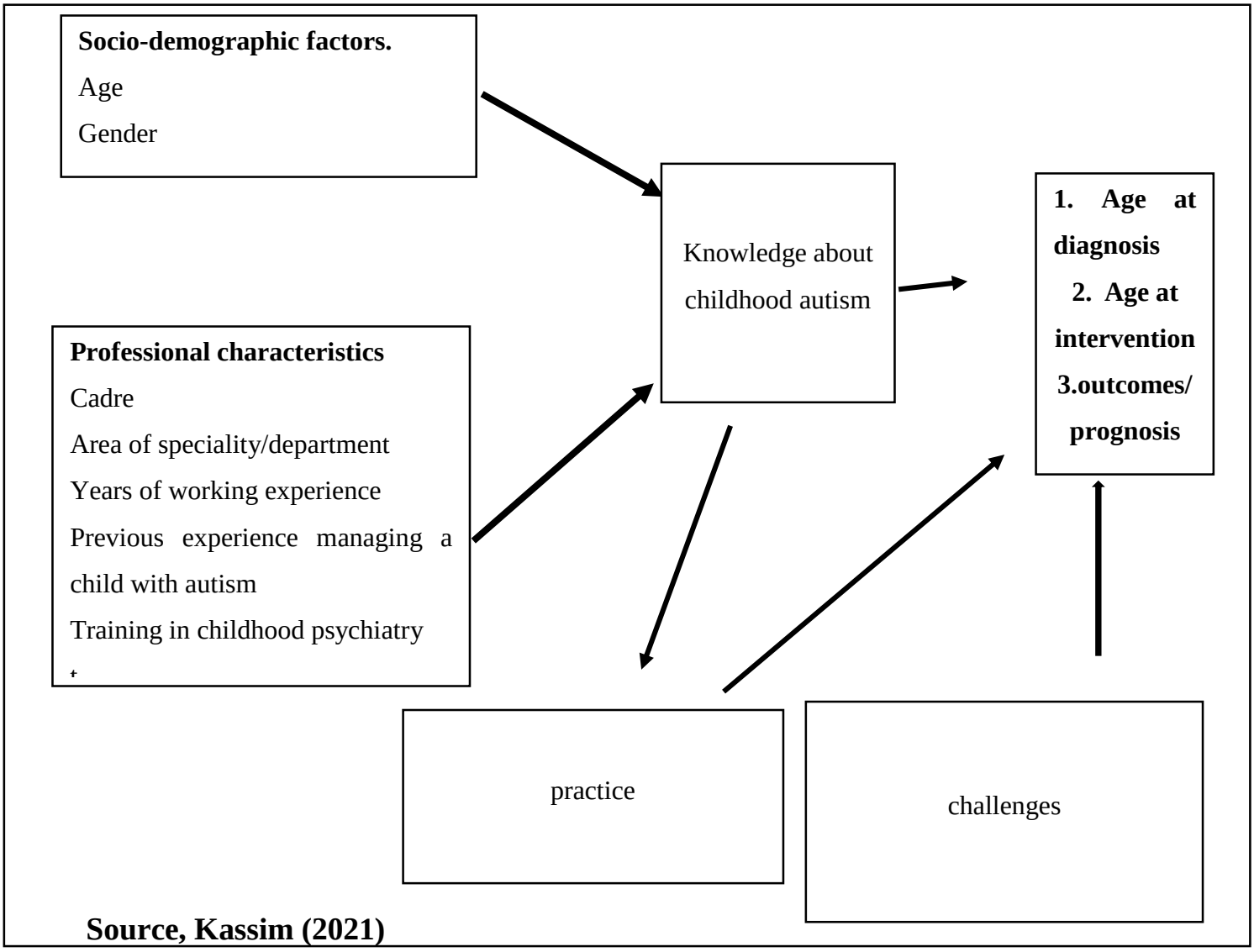
addition, there are few child psychiatrists(58). Treatment and care of children with autism are hampered by parents' misconceptions about its causes, stigma and negative stereotypes. (59,60). Standardised and well-established tools for ASD have contributed to knowledge about autism in high-income countries nonetheless a scarcity of validated tools and barriers associated with access to diagnostic tools remains a ma
or challenge to management of autism in Africa (9,61).

In a study done by Joseph K Gona et al on the coastal regions of Kenya, Mombasa and Kilifi, lack of psychologists or speech and language therapists was found to be a challenge (53).

The above studies highlight the following challenges in diagnosis, management and follow up of children with autism:

1. Mixed perceptions of diagnostic criteria for autism.
2. Lack of resources leads to a delay in diagnosis.
3. Reluctance and fear among HCWs in labelling a child with autism at an early age.
4. Minimal or no formal training among HCWs in childhood psychiatry.
5. A dearth of specialist services, poor perspectives of caregivers and cost of accessing care.
6. Unavailability of facilities for intervention that caters for the health care needs as well as social concerns of children with autism.
7. Poor knowledge among multidisciplinary team members involved in the care of children with autism.

CONCEPTUAL FRAMEWORK



Source, Kassim (2021)

CHAPTER 3: STUDY JUSTIFICATION, UTILITY, RESEARCH QUESTIONS AND RESEARCH OBJECTIVES

3.1 Justification and utility

A rise in the prevalence of ASD has been noted globally over the past few decades. ASD is a global public health concern and represents some of the greatest burdens of disease in children and adolescents. Among the major issues confronting autism in Africa is poor knowledge among health care workers.

Although ASD is usually diagnosed in childhood, it is a lifelong condition that persists into adolescence and adulthood. It is for this reason that Health care workers need to be armed with adequate knowledge about this condition so as to be adequately prepared in managing & providing care to children with ASD.

Having knowledge on autism leads to early diagnosis both at community and hospital level and early intervention; this improves communication, social function, and other cognitive abilities (8).

Health care workers (HCWs) being the first point of contact with children with autism, need to have good and adequate knowledge of childhood autism. Their knowledge has a great impact on the average age of diagnosis and provision of further necessary information to caregivers, both of which greatly affect the overall prognosis.

Early intervention such as intensive and thorough behavioural therapy is concomitant with better outcomes(25).

There is paucity of studies on practice of HCWs on childhood autism both globally and locally. This informs the need for this study.

Assessing the HCWs knowledge, practice & challenges, to detect areas of knowledge gap is essential as it could facilitate bridging the gaps identified and provide necessary information to the HCWs.

3.2: Research Question and Research Objectives

3.2.1 Research questions

What is the level of knowledge & practice of healthcare workers in Kenyatta National hospital on childhood autism?

3.2.2 Hypothesis

Null Hypothesis - There is no difference in level of knowledge among different cadres of HCWs.

Alternative Hypothesis - There is a difference in level of knowledge among different cadres of HCWs

3.2.3. Research Objectives

3.2.3.1 Primary Objective

1) To determine the level of knowledge of health care workers in Kenyatta National Hospital on childhood autism.

3.2.3.2 Secondary objectives

1) To determine the practice of health care workers in Kenyatta National Hospital on childhood autism.

2) To describe the challenges HCWs face in diagnosis, management & follow up of children with autism.

CHAPTER 4: METHODOLOGY

4.1 Study Design

We conducted a mixed methods study with both qualitative and quantitative components. Quantitative data collection was employed using a validated prestuctured questionnaire wheresas qualitative data collection was through FGDs and in-depth interviews with key informant interviews (KII).

4.2 Study Location

It was a hospital-based study conducted in Kenyatta National Hospital, the largest teaching and referral hospital in East and Central Africa.

It is a level 6 hospital located in Nairobi, Kenya with a large number of HCWs that attend to children.

The study included a majority of the departments that deal with children. These included mental health department, child welfare clinic, paediatric emergency unit, paediatric general wards, paediatric surgical wards , paediatric specialized wards including renal, intensive care and oncology units (PRU, PICU, 1E), paediatric outpatient unit- clinic 23 and occupational therapy department.

4.3 Study Population

The study population were Health care workers in Kenyatta National Hospital. They included nurses (paediatrics,paediatric specialised units, psychiatry,&paediatric surgery), Medical officers, Clinical officers, Occupational therapists, Residents (paediatrics, psychiatry, paediatric surgery) and Consultant paediatricians.

Study Population for the Qualitative arm of the study

The key informant interviewed was the head of department of paediatrics KNH. He was purposefully selected because he is the highest in the hierarchy, and is more likely to handle majority of the issues in the department therefore more likely to know more about the facility than other healthcare workers. His views were then be of value to the study.

4.3.1 Inclusion Criteria

- HCWs who give informed consent to take part in the study.

4.3.2 Exclusion Criteria:

- Interns
- HCWs on annual leave during the study period.
- HCWs who have worked less than a month in their specific working areas.

4.4 Study Period
The study was conducted over a 3 month period in the years 2020 and 2021.

4.5 Sample Size Calculation
Based on statistics from the hospital's medical records, there was an average of 572 HCWs in the departments relevant to this study.

The sample size was calculated using Fisher's Formulae;

$$n = \frac{Z^2 p (1-p)}{d^2}$$

$$n = \frac{(1.96)^2 0.505 (1-0.505)}{(0.05)^2}$$

n=384

Correction factor

$$n' = \frac{1}{1/n + 1/N}$$

$$n' = \frac{1}{1/384 + 1/572}$$

n' =230

Where:

- n = estimated sample size
- Z =the normal deviate correlating with a confidence interval of 95% = 1.96
- p =estimated percentage of level of knowledge on autism= 50.5% (Bakare et al, 2008)
- d = 5% degree of precision/accuracy
- N = estimated target population
- n' = corrected sample size using finite population

The estimated percentage of the level of knowledge was determined from percentage level of knowledge at 50.5% in a study done by Bakare et al. in Nigeria assessing the description, reliability and internal consistency of the Knowledge about childhood autism among health workers(KCAHW) questionnaire(62).

4.6 Sampling Method

4.6.1 Quantitative sampling method

- The sample size of HCWs was determined using Multistage stratified sampling technique. Stratification of HCWs by cadre and calculation of proportional allocation of HCWs sampled in each cadre was done.
- Convenient sampling of HCWs until the desired number of respondents per cadre is achieved.

Table 4. 1: Sample frame

Strata	Population	Percentage	Sample
Nurses	315	49.1	113
Residents	178	27.8	64
Clinical Officers	44	6.9	16
Medical Officers	23	3.5	8
Consultants	45	7.0	16
Occupational Therapists	36	5.7	13

Table 4. 2: **Stratified tabulation for nurses in their respective areas**

Work Station	Percentage	Sample
Paediatric wards	**33%**	**37**
Specialised units	**44%**	**49**
Outpatient	**17%**	**19**
Surgical wards	**6%**	**8**

Table 4. 3: Stratified tabulation for residents in their respective areas

Work Station	Percentage	Sample
Paediatrics	53%	34
Paediatric surgery	6%	4
psychiatry	41%	26

4.6.2 Qualitative sampling method

1. **Focused Group Discussion**

FGDs were conducted with different HCWs from different departments. Purposive sampling was done so as to have a diverse group of HCWs with varying years of working experience .The participants were informed briefly about the discussion and verbal consent taken from them. The discussions were conducted post completion of ward activities at a time convenient for each participant.

Data was collected by the principal investigator and research assistants. Each FGD had 5 to 8 participants and lasted approximately one hour. The discussions were done online so as to facilitate easier discussion. A voice recorder was used during the FGDs and confidentiality was maintained throughout.

2. Key Informant Interviews

In-depth interview was with the key opinion leader. The KII was selected based on his position as the head of department of paediatrics department. Since he is the in-charge, he is more likely to handle majority of the issues in the department therefore more likely to know more about the facility than other healthcare workers.

4.7 Study Tools

1) Informed consent

2) Questionnaire- a 19 item validated and self-administered questionnaire (appendix

3) FGD topic guide: since there is no validated tool for assessment of practice and challenges healthcare workers face in management of childhood autism, FGDs & in-depth interviews with KOLs were used to assess these.There was an interview guide for the questions to be asked on practice and challenges HCWs face in management of childhood autism

4) In-depth interviews for KOLs: interview guide for the KII

4.8 Study Procedures

Quantitative Arm

Selected participants were approached by the principal investigator at their respective work departments for recruitment into the study after obtaining verbal clearance from the in-charges. Participants were informed of the study and informed consent obtained from them

prior to their enrolment into the study. Research assistants introduced the questionnaires to the participants. Questionnaires on knowledge about childhood autism were administered to the sampled participants. Instructions on how to fill the questionnaires were printed on the questionnaires as part of it.

Qualitative Arm

Qualitative data was collected by way of FGD and in-depth interviews with KOLs by the principal investigator. There was an interview guide for the questions to be asked on practice and challenges HCWs face in the management of childhood autism. We conducted four FGDs with five to eight HCWs. One with residents, a second one with medical and clinical officers, a third one with nurses and the fouth one with occupational therapists.They were purposively sampled so as to have a heterogeneous group comprising of HCWs with varying years of experience and different genders.The FGDs were done online on Google meet platform. A link was availed and consent for recording sought. The key informant was the head of department paediatrics KNH. Health care workers were made aware that the survey was only for academic purposes and that the results were confidential.The Key informant interview was conducted in the office of the interviewee at a time that was convenient for each.

4.9 Data Collection Procedures

4.9.1 Socio-demographic questionnaire

A socio-demographic questionnaire was used to get information like age, sex, area of speciality/department, cadre, duration/years of working experience and prior experience in the management of childhood autism.

4.9.2 Knowledge about childhood autism among health care workers Questionnaire

The knowledge about childhood autism among health care workers (KCAHW) questionnaire was used. It assesses basic knowledge of autism and was designed by a group of psychiatrists and psychologists (Bakare et al.) in 2008 in Nigeria. It can be used for comparing knowledge among different categories and classes of HCWs. It is a useful tool in low and middle income or developing countries where the knowledge and awareness about childhood autism are low and varies.

Since knowledge about childhood autism may differ from one geographical region to the other, the mean score on the KCAHW questionnaire among a specific study population is a measure of the level of knowledge about childhood autism among that particular sample population.
It is a validated 19 item self-administered questionnaire that is divided into four domains.

Table 4. 4: **Knowledge about childhood autism among health care workers Questionnaire**

KCAHW Domain	Knowledge Assessed	Number of items	Total score
1	Impairments in social interaction	8	8
2	Impaired communication	1	1
3	Obsessive stereotyped and repetitive pattern of behaviour	4	4
4	Type of autism disorder and related comorbidity	6	6

KCAHW= Knowledge about Childhood Autism among Health Care Workers.

The possible total score after summing up of the four domain scores is a minimum of 0 and a maximum of 19. The average score on the KCAHW questionnaire is identified as the benchmark of knowledge about childhood among participants in that specific population. A score below the median score is regarded as poor knowledge whereas a score above the median score is considered good knowledge. Knowledge gaps are identified if a participant's total score in a domain is suboptimal.

4.9.3 Focused group discussions

The FGDs was conducted by the principal investigator. Each FGD consisted of 5-8 HCWs and lasted approximately an hour. The discussions were done online on Google meet platform so as to facilitate easier discussion and the sessions were recorded. Notes were taken verbatim.
The FDG was conducted in four stages:

Stage 1: Scene setting and ground rules

The principal investigator welcomed the participants as they logged into the meeting. Once the group was complete, the principal investigator formally started the FGD by introducing herself, stating the research topic and the reason of the study. The PI informed the participants that they

were all invited to give their own opinions and that there are no right or wrong responses. Respondents were requested to respect each other's opinions and to allow one individual to speak at a time. The PI requested the respondents for permission to record the discussion and assured them of confidentiality.

Stage 2: The opening topic

The PI engaged the participants by introducing the topic and enquired about the participant's views and opinions on childhood autism.

Stage 3: Discussion

The participants were involved in a detailed discussion of the study topic using questions availed in the FDG topic guide. The PI further probed the responses given by the participants.

Stage 4: Ending the discussion: The PI concluded the discussion by thanking the group for their participation.

4.9.4 Key informant interviews

An In-depth interview was conducted with the head of paediatrics department.

This was scheduled based on the interviewees' availability and was conducted in his office so as to maintain privacy.

4.10 Quality assurance procedures

The research proposal was reviewed by the department of Paediatric and Child Health (UON) and KNH and UON Ethics and Research Committee before being allowed to carry out the study

A validated questionnaire was used

The questionnaires were completed by participants and immediately taken back from them at the survey point so as to minimise and prevent consultation of study materials or discussions among colleagues.

Study identification numbers were used in the questionnaires.

Each questionnaire was individually checked daily, to ensure that they do not contain personal identifiers in order to protect the confidentiality of the participants and any personal identifiers identified were removed.

The Principal Investigator assessed the collected data on a daily basis to oversee data entry.

The questionnaires were safely locked in a cabinet that was only accessible to the principal investigator and the research assistants.

The audio- recorded FGDs were saved on a password-protected laptop and protected external hard drive that were safely locked in a cabinet. These recordings and transcripts were only accessible to the principal investigator and research assistants.

Voice recorders were used in the FGDs so as not to miss any important information.

4.11 Ethical considerations

Ethical approval was sought from the KNH/UON research and ethics committee. Data collection and analysis was commenced only after ethical approval.

Consent was sought and only consenting health care workers were enrolled in the study.

Confidentiality was assured throughout the study by use of study identification numbers without recording personal identification details.

Necessary information was provided to the HCWs during the FGDs.

4.12 Data Management and Analysis

4.12.1 Quantitative data

Completed Questionnaires were coded by the PI to reduce errors prior to analysis.Data was cleaned & entered into Microsoft Excel

Data was then transferred to SPSS Version 23 for analysis.

Demographic and other characteristics were summarized into frequencies & percentages

Means, mean percent, medians and interquartile ranges were used to summarise the HCWs knowledge scores from the questionnaires.

The average performance and the total mean was calculated for the different categories of HCWs.

A p-value of < 0.05 was regarded as significant.

4.12.2 Qualitative data

The audio recorded FGDs and interviews were transcribed verbatim and cleaned for analysis Transcribed Data was put in atlas.ti version for thematic analysis.

Analysis was based on the conceptual framework with apriori themes informed by literature review.

Emerging Quotes were identified & used to represent and illustrate the practice & challenges.

For the practices , each question was analysed separately to indicate the practice and the correctness of the practices employed by healthcare workers in the management of childhood autism.

4.13 Dissemination of study findings

The study findings were presented to the UON Department of Paediatrics and Child Health as part of the requirements of the MMed Program in both hard and soft copies. Hard copies of the results shall be sent to the University of Nairobi repository for storage and the head of department paediatrics in KNH with a view of dissemination of the new knowledge that has been generated to improve patient care. The findings shall also be submitted for publication in peer-reviewed scientific journals.

4.14 Control of Errors & Biases

Selection bias was reduced by the use of the sampling frame and stratification. Information bias was reduced by assessment of the responses given to the questionnaires daily during data entry to ensure validity of collected data. All FGDs and KIIs were conducted by the principle investigator to ensure consistency of responses and the data was transcribed daily to ensure accuracy.

CHAPTER 5: RESULTS

5.1. Quantitative Data

5.1.1 Socio-demographic Characteristics of Participants

There were 230 participants in the study. There was a female preponderance 146 (63.5%) were female, and 84 (36.5%) were male. The median age was 32.0 (IQR 29.0-35.0) years, where majority of the respondents were between the age 25-34 years (165, 71.7%). Nurses formed majority of the respondents with 113 (49.1%) of them. On years of experience, the median number of years was 5.0 (IQR 3.0-8.0) years. Majority 41.7% had 5-9 years of working experience.In terms of current work station, 97(42.2%) of the respondents were from paediatrics, 29(12.6%) from the NBU, 26 (11.3%) from psychiatry, 21 (9.1%) from outpatient,18 (7.8%) from the specialized units, 13(5.7%) where from occupational therapy,and 12(5.2%) were from the paediatric surgical ward. One hundred and one (43.9%) participants had no previous experience managing a child with autism.

Table 5. 1 A: Sociodemographic characteristics

Age	**Frequency**	**Percent**
<25	1	0.4
25-34	165	71.7
35-44	53	23.0
≥ 45	11	4.8
Gender		
Male	84	36.5
Female	146	63.5
Cadre		
Clinical officer	16	7.0
Occupational therapist	13	5.7
Nurse	113	49.1
Medical officer	8	3.5
Resident	64	27.8
Consultant	16	7.0

Table 5. 2 B: Sociodemographic characteristics

Speciality	Frequency	Percent
General Paediatrics	37	16.1
New Born Unit	29	12.6
Occupation Therapy	13	5.7
Outpatient	21	9.1
Paediatrics	74	32.2
Paediatric Surgery	12	5.2
Psychiatry	26	11.3
Specialized Unit	18	7.8
Experience (years)		
< 5	87	38.7
5-9	98	42.6
10-14	27	11.7
15-19	8	3.5
≥ 20	10	4.3
Experience		
Yes	133	57.8
No	97	42.2

5.1.2 Knowledge about Childhood Autism among Health Care Workers

The total mean score on the knowledge about childhood autism among health care workers questionnaire was 14.4 out of a possible maximum score of 19. The mean KCAHW score was identified as the benchmark of knowledge among participants. 120 (52.2%) of the particiants had good knowledge whereas 110 (46%) had poor knowledge on childhood autism.

Table 5. 3: **Performance on Knowledge about Childhood Autism**

	Frequency	Percent
Good (≥ 14.4)	120	52.2
Poor (< 14.4)	110	48

Domain 1 which assesses impairements in social interaction had the highest mean score (6.4), followed by domain 4 (characteristics of autism as a disorder and its comorbidities (4.1), then domain 3 (Obsessive stereotyped and repetitive pattern of behaviour) (3.1), and the least performance in domain 2 (Impaired communication) (0.9).

Table 5. 4: Performance on Knowledge about Childhood Autism by domain

	Mean (SD)	Median (IQR)	Minimum	Maximum
Overal Score	14.4 (2.4)	15.0 (13.0 – 16.0)	6	19
Domain 1	6.4 (1.3)	7.0 (6.0 – 7.0)	3	8
Domain 2	0.9 (0.3)	1.0 (1.0 – 1.0)	0	1
Domain 3	3.1 (0.9)	3.0 (3.0 – 4.0)	0	4
Domain 4	4.1 (1.2)	4.0 (3.0 – 5.0)	1	6

Table 5.3.1: Domain 1 – impairements in social interaction

N= 230	Correct	Percent Correct
D1Q1	220	95.7%
D1Q2	201	87.4%
D1Q3	176	76.5%
D1Q4	187	81.3%
D1Q5	166	72.2%
D1Q6	204	88.7%
D1Q7	166	72.2%
D1Q8	145	63.0%

Table 5.3.2: Domain 2 - Impaired communication

N= 230	Correct	Percent
D2Q1	204	88.7%

Table 5.3.3: Domain 3 - Obsessive stereotyped and repetitive pattern of behaviour

N= 230	Correct	Percent
D3Q2	144	62.6%
D3Q3	189	82.2%
D3Q4	167	72.6%

Table 5.3.4: Domain 4 - Characteristics of autism as a disorder and its comorbidities

N= 230	Correct	Percent Correct
D4Q2	181	78.7%
D4Q3	180	78.3%
D4Q4	164	71.3%
D4Q5	114	49.6%
D4Q6	113	49.1%

Best knowledge as identified by the mean performance score of the KCAHW questionnaire was by psychiatry residents (16.4) whereas least performance was by clinical officers (11.4).

Table 5. 5: **Mean Scores by cadre**

Cadre	Frequency	Mean (SD)
Psychiatry residents	26	16.4 (2.5)
Consultants	16	15.8 (1.8)
Paediatrics surgery residents	4	15.8 (0.5)
Medical officers	8	15.6 (1.3)
Occupational therapists	13	15.1 (1.2)
Paediatric residents	34	14.3 (2.3)
Nurses	113	14.0 (2.1)
Clinical officers	16	11.4 (1.9)

A one-way ANOVA was conducted to determine if the knowledge of the healthcare workers was different amongst the cadres. Data is presented as mean ± standard deviation. The scores differences was statistically significantly different between different cadres, with a p value of < .001.

Table 5. 6: ANOVA of the mean differences

	Sum of squares	**df**	**Mean square**	**F**	**p-value**
Between groups	320.1	7	45.7	10.4	<0.001
Within groups	977.1	222	4.4		
Total	1297.2	229			

An independent samples t-test was conducted to determine the significance of the difference in consultant's knowledge against the other cadres. Data is presented as mean (SD). The difference of the mean score of 4.4 with clinical officers and 1.8 with nurses were statistically significant as shown below.

Table 5. 7: T-test for the mean differences in knowledge amongst different cadres

Cadre	n	Frequency	Mean (SD)	Mean Difference	p-value
Consultants	16		15.8 (1.8)	-	-
	26	Psychiatry residents	16.4 (2.5)	-0.4	0.426
	4	Paediatrics surgery residents	15.7 (0.5)	0.1	0.947
	13	Occupational therapists	15.1 (1.2)	0.7	0.216
	16	Clinical officers	11.4 (1.9)	4.4	**<0.001**
	34	Paediatrics residents	14.3 (2.3)	1.5	0.026
	8	Medical officers	15.6 (1.3)	0.2	0.796
	113	Nurses	14.0 (2.1)	1.8	**0.001**

5.2 Qualitative Data

5.2.1 Practice of health care workers on childhood autism

Participation in management

A minority of the health care workers had participated in the management of a child with autism However, some had been involved in either one or all of the following aspects of management, diagnosis, management, counselling and referral.

R: I have once been involved in the diagnosis of a child and the management of that patient included occupational therapy, speech therapy and we involved the neurologist and gave anti-convulsions as part of the management

R:I participated in the diagnosis and evaluation of a patient when I was in the psychiatry department during my internship and that patient had been referred from another facility

R: I have seen a child diagnosed with autism but I have never diagnosed one myself or counsel

R: there was a case I suspected to be autism but wasn't sure and comfortable making the diagnosis so I referred to a paediatrician

Referral

All participants referred children with autism and for those who had never seen one before still stated that they would refer. The referrals were to either paediatricians, psychiatrist, neurologist, psychologist, speech therapist, physiotherapist and occupational therapist.

R: Management of autism needs a multidisciplinary approach depending on the needs of the specific child.

R: Autism is a multi- disciplinary disease so the referrals should be geared to like people who deal with oral-therapy if they cannot communicate

R: Even if the patient does not have the associated symptoms I would still refer that patient to a psychologist, psychiatrist or psychologist because maybe there is something I have missed and maybe these guys will be able to pick it or rule out if I have made the wrong diagnosis

R: I would also refer to a physiotherapist to enhance their motor skills and to an occupational therapist to improve their fine motor skills

Screening

All of the participants apart from psychiatry residents, were unaware of the universal recommendation on screening for autism and noted that they did not practice any form of screening for autism. The psychiatry residents though aware of the screening tools, do not practice routine screening.

R: We don't, we usually diagnose basically from clinical symptoms

R: Might be through normal routine clinical screening but not specific to autism

R: I have actually never thought of screening as a matter of routine

Interventions

Majority of the participants stated a range of treatment options including multidisciplinary approach, use of medications, Behavioral therapy, Speech therapy, Occupational therapy and dietary intervention.

R: Medical intervention is not for all children but only for specific children. We usually do ENT reviews because hearing loss is common in autism, we also send them to occupational therapists to enhance sensory integrations and physiotherapists to enhance gross motor skills.

R: Intervention will be multidisciplinary so the intervention can include behavioral therapy or occupational therapy. so basically address every issue the patient presents with.

R: I think minimising sugars for those with hyperactivity is important.

R: I think because autism is an all-round issue so we need to initiate medication or speech therapy for those who have speech challenges so you need an intervention which will enable the kid to live well in the society.

Role of medication in autism

Participants stated that medication has a role in management of autism.

R: you can give them some form of sedation

R: Use medication only when the child is very aggressive

Type of school Recommendation in autism

There were mixed responses, some recommended normal schools, some special schools and some normal schools with special units.

R: I recommend Special school because when they are giving information they might have challenges so they need well trained teachers in special education who understand them and can guide them so they need specific special schools.

R: I think these children need to go to a normal school because being 'autistic' is not special so to say so in normal schools they can mingle with other normal children during break time hence will be able to learn other behaviors from other children who are not autistic.

Counselling in childhood autism

All Participants practice parental counselling and emphasised on it as an important aspect because there are a lot of myths around autism to the caregivers and parents so they need proper information and Counseling ensures cooperation with the caregivers and parents.

R: with counseling the parents will help in the management and therefore intervention will be better.

R:counselling enhances understanding of the disorder and without the cooperation of the parents it will be difficult to achieve the goals of management.

R: Having an autistic child is not easy because you spend most of your time to stay with the child so counseling usually helps because they are usually very stressed.

R: Also the stigma related to autism really affects the parents so they really need a lot of counseling so usually we do counsel and also refer them to the counsellors.

Information given to parents

Participants educate the parents that autism is a lifelong condition and by learning about the child they will know how to live with the child. They also provide the parents with information on the etiology and the prognosis of the condition.

R: It is important for the parents to have the right information since they are the primary caregivers because they stay with the children most of the time and they are the main decision makers and the ones to decide on the best treatment for their children.

R: Okay for etiology we usually tell them about the genetics because genetics play a major role in the etiology of autism and that it is a lifelong condition.

R: It is important to give the parents and caregives the psychological support and let them know that it is not their own doing that their child has autism and also explain to them how the condition comes about about and how they can manage and support the child to atleast to live near normal.

R: Important information to parents is that autism is a life long condition and that behavioral therapy, occupational and speech therapy improve on their normal behaviors.

Stem cell therapy as an option for autism

Majority felt that stem-cell therapy is not a good therapy for autism.

R: I don't, I don't think stem-cell therapy is good.

R: I have heard about it that it is being practiced in some countries but in Kenya we don't do it because it doesn't provide 100% cure rate.

R: In Kenya I don't think it is possible although I think the world is headed into that direction of stem-cell therapy.

5.2.2 Challenges HCWs face in the diagnosis and management of childhood autism

The main themes identified from the focused group discussions were:

Theme 1: Inadequate training and deficient knowledge

Theme 2: Lack of guidelines for management of childhood autism

Theme 3: Unavailability of intensive behavioral therapy

Theme 4: Lack of awareness among parents and caregivers

Theme 5: Cultural believes and practices

Theme 6: Limited number of normal schools with instituted special needs

Theme 1: Inadequate training and deficient knowledge

All participants reiterated that they have inadequate training and do not get much experience.

R: Our curriculum does not have enough content on autism
R: We don't have enough exposure and i don't feel that we have been well trained in diagnosis and management of childhood autism.
R: I was not trained to deal with autistic cases maybe with advanced training one can learn on the diagnoses and management.

Theme 2: Lack of guidelines for management of childhood autism

All the participants noted that there are no protocol and guidelines for the management of childhood autism.

R: I have not heard of any protocol or guidelines of treating children with autism
R: I have not come across any treatment protocol for childhood autism for our instituition and I believe its important we have one that is conversant with our children and resources.

Theme 3:unavailability of intensive behavioral therapy

Lack of intensive behavioural behavioural therapy was mentioned as a challenge as it is very important and may lead to appealling and remarkable outcomes.

R: intensive behavioural therapy is key in the management of autism though im not too sure sure if it is available

Theme 4: lack of awareness among parents and caregivers

From the discussions, it was identified that lack of awareness among parents &/or caregivers posed as a challenge in early and proper intervention.

R: Lack of awareness among parents makes management and follow up difficult because if the parent doesnot understand the condition he or she will not understand why their child needs follow up and its importance.
R: The parents have the main role in the management of childhood autism so if the parents are not cooperative it will delay the intervention and management

R: The parents cooperation is key because they are part of the team in terms of management. They have the child at home and they are the ones who have to bring the child to the clinic so if they are not aware which occurs in majority of the cases they will not seek treatment leading to poor outcomes.

Theme 5: cultural beliefs and practices

All participants noted that cultural beliefs and practices were a great challenge and led to a delay in diagnosis, delay in intervention and eventually poor prognosis.

R:There are many myths about autism.Our African tradition affects the management because people believe that these things are caused by other forces in our cultures.
R:I think most of the cultures in our country usually believe that the child has been bewitched or attacked by demons so they turn to traditional management first and this affect the medical management like early diagnosis and this can lead to late treatment so this affects the child's quality of life

R: Some religion like the [Akorino] believe that people are not supposed to go to hospital but they are supposed to pray until they get healed so I think that delays the treatment and the management of these children

Theme 6: Limited number of normal schools with instituted special needs

Some of the participants stated the recommended type of school for children with autism which is normal schools with special units are very few.

R: I will say there are no enough schools with special needs and for the slow learner they experience a lot of challenges specially in our school setting where competition is key so I don't think in Kenya there are enough schools with special unit to facilitate the management of these children

CHAPTER 6: DISCUSSION

6.1 Discussion

Autism spectrum disorder (ASD) is a global public health concern, and represents some of the greatest burden of disease in children and adolescents. The knowledge , attitudes, patterns of practice of childhood autism among HCWs and identifying challenges associated with its diagnosis and management could facilitate bridging the gaps,and ensuring better outcomes and help design relevant educational trainings in future.

Majority (52.2%) of the HCWs displayed Good knowledge of autism, with a mean knowledge score of 14.4 out of 19. This could be attributed to the study being conducted in a tertiary hospital with almost all cases of autism being referred here.Studies indicative of good knowledge of autism among HCWs have also been reported from other parts of the world. Eseigbe et al in their study in north west Nigeria noted good knowledge with a mean score of 13.5 ± 3.7 & median score of 15 (49). Contrary to these, poor knowledge with a Mean score of 9.80 out of 19 was found in a study done in Saudi Arabia(43).

Varying levels of knowledge was identified amongst the different cadres of the healthcare workers. Best performance was among the psychiatry residents and least performance among the clinical officers. This finding could be due to the differences in years of working experience and different areas of speciality. Higher knowledge has been noted in cadres working in paediatrics and psychiatry. This pattern of knowledge distribution among the participants is consistent with previous findings that indicate a better knowledge of autism among those in the specialties and practice of paediatrics and psychiatry. In a study done in the USA, varying levels of knowledge among primary care providers and specialists was found(39). Similarly in Nigeria, good knowledge was found among paediatricians and poor knowledge among general practitioners(49). Psychiatry nurses were noted to have a higher total mean score than paediatric nurses in a state in Nigeria(51).

The highest knowledge gap was regarding communication impairements in childhood autism (KCAHW Domain 2) while the least was concerning impairements in social interaction (KCAHW Domain 1). Different studies in different parts of the world demonstrated variable performances in different domains of the KCAHW questionnaire. Best knowledge was found in KCAHW Domain 2 ,while Domain 4 which assesses characteristics of autism as a disorder and its comorbidities had the least performance in a study done in Nigeria (49). Igwe et al also

found consistent findings in their study among psychiatry and paediatric nurses in nigeria where best performance was in KCAHW Domain 1 and the least performance in KCAHW Domain 2 (51). Knowledge gaps identified in the KCAHW domains in this study and other related studies could suggest a deficient autism education in the professional formative years of the HCWs.

In this study, practice of HCWs on ASD was generally good, however some poor practices also existed. This finding is similar to the practice of paediatricians in Nepal(63). All HCWs did not practice any form of autism specific screening and were not aware of its recommendation which is contrary to a study done by Elizabeth et al where health care providers showed awareness and reported need for research to support early ASD screening. They also demonstrated preferences about screening tool characteristics and processes.(64) The American Academy of paediatrics recommends that all children should be screened for ASD at ages 18 and 24 months, along with regular developmental surveillance. Early Screening is associated with early identification and thus early management and better outcomes Despite significant advances in the ability of screening tools to detect autism spectrum disorders in young children, previous research has found that most children are not identified until they are in school, and past the age at which early intervention services are most beneficial.(65)

All HCWs identified that multidisciplinary approach in management of autism is crucial. Julie et al in her study, found that interprofessional collaboration between disciplines does not always take place resulting in practitioners working independently of each other and also indicated that there are a limited number of disciplines collaborating using a multidisciplinary approach and working with children with autism. This emphasizes the need for improved interprofessional collaboration using a multidisciplinary approach as it increases the effectiveness of health care services offered to children ASD(66). The role of medication in childhood autism was unclear to the HCWs with some stating no need of medication while others mentioning role of sedation. This is contrary to literature and recommendations from trials which have shown pharmacological management to be efficacious in treating associated symptoms of autism and target symptoms that have been demonstrated to respond to medication(67).

HCW's recommendation for school placement included normal, special & normal school with instituted special unit. Studies have demonstrated that children with ASD in normal schools exhibit more pro-social and that these social skills are generalised best in integrated

settings(68).among the interventions identified by the HCWs in this study is behavioural therapy. Although there is no known cure for ASD, early interventions such as intensive and thorough behavioural therapy is concomitant with appealing and remarkable outcomes(25).HCWs indicated that they do not practice or recommend stem cell therapy and this is in accordance to current literature recommendation. Few studies have been done on stem cell therapy in autism which show encouraging positive effects in relief of ASD symptoms . However, to date, only five clinical trials have been performed with several differences among them (study design, subjects enrolled, cellular types, route of administration, outcome measures), which will require further examinations. Taken together the limitation considerations and the promising ameliorative effects of cellular therapies in ASD treatment, more complete and exhaustive investigations and large trials will be needed in order to claim definitive results and recommendations(69).

A good practice of counselling and providing information to the parents/caregivers of children with autism emerged from this study. Provision of further necessary information to caregivers greatly affects the overall prognosis. parents are instrumental in the management of ASD symptoms, Parents/care givers of children with Autism Spectrum Disorder (ASD) often have increased levels of stress, depression, and anxiety. Educating and informing the parents/care givers will enhance the health-related quality of life of the parent carers, their families and their child with ASD. Whereas not addressing these issues poses a significant risk to the psychological, physical, and social well-being of the parents of the child affected by ASD and jeopardizes the adaptive functioning of the family as well as the potential of the child affected by ASD(70)(71).

The challenges identified by the participants in the management of autism are typical of challenges encountered in the care of children with autism in similar studies done in Africa. Issues that have been identified as confronting diagnosis and management of autism include Poor knowledge and awareness among caregivers, strong traditional beliefs & practices,inadequate training and deficient knowledge amongst healthcare workers, lack of guidelines for management of childhood autism, unavailability of intensive behavioral therapy, limited number of normal schools with instituted special needs. Eseigbe et al found similar challenges such as poor knowledge and poor perspective of caregivers on the disorder and their lack of awareness and traditional beliefs. Lack of institutionalized social support was also a

challenge consistent in our study and one done in Nigeria(49). Inadequate training and unavailability of training facilities for healthcare workers who are likely to be involved in the multidisciplinary management of autism was a challenge found both in our study and a study done in Nigeria(50). Minimal or no formal training of HCWs in autism and childhood psychiatry in general was a challenge demonstrated in our study and in pakistan(46,58). Attenuating these challenges has the potential of improving autism outcomes even in resource limited settings like ours.

The implications of gaps in autism knowledge among health care workers and the burdensome management challenges include misdiagnosis, delayed diagnosis and intervention, caregiver use of multiple and sometimes detrimental health care options, increased cost of care whilst shopping for remedies, increased family burden and disharmony, and ultimately poorer autism outcomes. Bridging the knowledge gap and attenuating management challenges have the potential of improving autism outcomes even in resource limited settings like ours.

Participants in this were receptive to new information and updates on autism. They further expressed that continuous medical educations or trainings on childhood autism would be of great benefit to them and subsequently the care they provide to children with autism and their families.

6.2 Study Strengths

Study strengths include the use of a validated tool to assess knowledge. Multi-disciplinary collaboration from paediatrics, paediatric surgery, psychiatry and occupational therapy. This study will create more awareness and propose ways of bettering care & management of childhood autism. No studies done on practice of HCWs on childhood autism.

6.3 Study Limitations

The KCAHW questionnaire is designed to be self- administered and immediately taken upon completion at the point of the survey. Thus this questionnaire only gives a point assessment of knowledge.

Lack of a validated tool to assess practice.

This study was limited to HCWs working in a tertiary public facility and the findings may not be transferrable to the primary, secondary and private facilities in Kenya.

6.4 Conclusions

Good knowledge on childhood autism amongst the HCWs was 52.2%

There is generally good practice among the HCWs that includes a multidisciplinary approach with appropriate referral however some bad practice exist

Lack of autism specific screening among all the HCWs

Major challenges encountered in autism management were deficient knowledge, inadequate training, lack of guidelines for management of childhood autism, unavailability of intensive behavioral therapy, lack of awareness/poor perspective among parents and caregivers, cultural beliefs and practices and limited number of normal schools with instituted special needs.

6.5 Recommendations

Continuous medical education and training on childhood autism for all HCWs

Need for treatment protocols / guidelines for the management of childhood autism in our Setup.

Screening all children for ASD at all visits through a combination of developmental surveillance and standardized autism- specific screening.

Need to have integrated and coordinated services Since autism needs a multidisciplinary approach.

Need to address the challenges hampering management of childhood autism so as to facilitate the achievement of better outcomes.

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APPENDICES

Appendix 1: Healthcare Workers Consent Form

Principal Investigator: Dr Fatma Kassim 0734069566

Dear Participant: I would like to ask your voluntary participation in this scientific study in the form of a survey. A questionnaire is provided for you to answer.

TITLE OF THE STUDY: Assessment of Knowledge, Attitude and Practice about childhood autism among Healthcare workers

PURPOSE OF THE STUDY: This study aims to assess the knowledge, attitude and pattern of practice on childhood autism and describe the challenges in its diagnosis and management. This will help in identifying the knowledge gaps and areas in autism management that need improvement thus forming the basis for quality interventions.

STUDY PROCEDURE: Each healthcare worker who consents to participation will be given a self-administered questionnaire by the investigator to fill. Each participant will be given a time of 15 to 30 minutes to complete.

RISK OF THE STUDY: There is no risk in participating in the study.

POSSIBLE BENEFITS: By participating in the study, you will aid in providing information on what is known about autism and the knowledge gaps, and identification of any challenges in its diagnosis and management.

COMPENSATION: There will be no compensation given.

RIGHT TO WITHDRAW: Your participation in this study is completely voluntary. You are free to decline it. You have the right to change your mind anytime without giving explanations.

CONFIDENTIALITY: All answers obtained from you will be considered privileged information. These will be documented and analyzed anonymously. Only researchers have access to personal information. Your identity will remain absolutely confidential. The

researchers aim to publish this paper purely for academic and scientific purpose. You will be given a copy of consent form

DATA DISSEMINATION: Results of this study will be availed to the University of Nairobi (UON) Department of Paediatrics and Child Health Academic Staff and Students in fulfilment of the requirements of the M.Med Program. The findings shall also be shared with the office of the head of department paediatrics in KNH

If you have any questions regarding the study, feel free to contact me or any of my supervisors or the Chairman of the KNH/UON Ethics and Research committee

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PART II: CERTIFICATE OF CONSENT

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate in this research.

_____ Signature of participant

_____ Signature of Investigator

_____ Date.

Appendix 2: Key Opinion Leaders Consent Form

Principal Investigator: Dr Fatma Kassim 0734069566

TITLE OF THE STUDY: Assessment of Knowledge, Attitude and Practice about childhood autism among Healthcare workers at KNH.

PURPOSE OF THE STUDY: This study aims to assess the knowledge, attitude and practice on childhood autism and describe the challenges in its diagnosis and management. This will help in identifying the knowledge gaps and areas in autism management that need improvement thus forming the basis for quality interventions.

STUDY PROCEDURE: Information shall be sought by interviewing selected key opinion leaders i.e. head of departments. Each healthcare worker who consents to participation will be involved in an in-depth interview pertaining the attitudes, patterns of practice and challenges HCWs face in management of childhood autism. Consent for audio recording will be sought be sought prior to the start of the interview. The interview shall last approximately 20- 30 minutes.

The interviews will be done in a conducive and friendly environment. Notes will be taken by the interviewer during the interview. : I will be interviewing you in a private area where you feel comfortable answering questions.

RISK OF THE STUDY: There is no anticipated risk in participating in the study.

POSSIBLE BENEFITS: By participating in the study, you will aid in providing information on what is known about autism, any negative attitudes, any incorrect practices and identification of any challenges in its diagnosis and management.

COMPENSATION: There will be no compensation given.

RIGHT TO WITHDRAW: Your participation in this study is completely voluntary. You are free to decline it. You have the right to change your mind anytime without giving explanations.

CONFIDENTIALITY: All answers obtained from you will be considered privileged information. These will be documented and analyzed anonymously. Only researchers have

access to personal information. Your identity will remain absolutely confidential. The researchers aim to publish this paper purely for academic and scientific purpose. You will be given a copy of consent form

DATA DISSEMINATION: Results of this study will be availed to the University of Nairobi (UON) Department of Paediatrics and Child Health Academic Staff and Students in fulfilment of the requirements of the M.Med Program. The findings shall also be shared with the office of the head of department paediatrics in KNH

If you have any questions regarding the study, feel free to contact me or any of my supervisors or the Chairman of the KNH/UON Ethics and Research committee

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PART II: CERTIFICATE OF CONSENT

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate in this research.

_____ Signature of participant

_____ Signature of Investigator

_____ Date.

Appendix 3: Socio-demographic questionnaire

Age

Gender

Cadre

Area of speciality/department

Years of working experience

Previous experience managing a child with autism- Yes/No

Knowledge about Childhood Autism among Health Workers (KCAHW) Questionnaire

Please do not consult formal textbooks to answer these questions.

Thank you for your co-operation.

The following behaviours best describe a child with childhood autism:

Domain 1

i. Marked impairment in the use of multiple non-verbal behaviours such as eye to eye contact, facial expression, body postures and gestures during social interaction?

(A) Don't Know, (B) Yes, (C) No

ii. Failure to develop peer relationship appropriate for developmental age?

(A) Don't Know, (B) Yes, (C) No

iii. Lack of spontaneous will to share enjoyment, interest or activities with other people? (A) Don't Know, (B) Yes (C) No

iv. Lack of social or emotional reciprocity? (A) Don't Know (B) Yes, (C) No

v. Staring into open space and not focusing on anything specific? (A)Don't Know, (B) Yes, (C) No

vi. The child can appear as if deaf or dumb? (A) Don't Know (B) Yes, (C) No

vii. Loss of interest in the environment and surroundings?

(A) Don't Know, (B) Yes, (C) No

viii. Social smile is usually absent in a child with Autism?

(A)Don't Know, (B) Yes (C) No

Domain 2

i. Delay or total lack of development of spoken language?

(A) Don't Know (B) Yes (C) No

Domain 3

i. Stereotyped and repetitive movement (e.g. Hand or finger flapping or twisting)?

(A) Don't Know (B) Yes, (C) No

ii. May be associated with abnormal eating habit?

(A) Don't Know, (B) Yes, (C) No

iii. Persistent preoccupation with parts of objects?

(A) Don't Know (B) Yes, (C) No

iv. Love for regimented routine activities? (A) Don't Know (B) Yes, (C) No

Domain 4

i. Autism is Childhood Schizophrenia? (A) Don't Know (B) Yes (C) No

ii. Autism is an auto-immune condition? (A) Don't Know (B) Yes (C) No

iii. Autism is a neurodevelopmental disorder? (A) Don't Know (B) Yes (C) No

iv. Autism could be associated with Mental Retardation? (A) Don't Know (B) Yes (C) No

v. Autism could be associated with Epilepsy? (A) Don't Know (B) Yes (C) No

vi. The onset of Autism is usually in, (A) Neonatal age, (B) Infancy, (C) Childhood

Scoring of Knowledge about Childhood Autism among Health Workers (KCAHW questionnaire

Domain 1

i Marked impairment in the use of multiple non-verbal behaviours such as eye to eye contact, facial expression, body postures and gestures during social interaction?

(A) 0 (B) 1 (C) 0

ii Failure to develop peer relationship appropriate for developmental age? (A) 0 (B) 1 (C) 0

iii. Lack of spontaneous will to share enjoyment, interest or activities with other people?

(A) 0 (B) 1 (C) 0

iv Lack of social or emotional reciprocity? (A) 0 (B) 1 (C)

v Starring into open space and not focusing on anything specific?

(A) 0 (B) 1 (C) 0

vi. The child can appear as if deaf or dumb? (A) 0 (B) 1 (C) 0

vii. Loss of interest in the environment and surroundings? (A) 0 (B) 1 (C) 0

viii. Social smile is usually absent in a child with Autism? (A) 0 (B) 1 (C) 0

Domain 2

i. Delay or total lack of development of spoken language? (A) 0 (B) 1 (C) 0

Domain 3

i. Stereotyped and repetitive movement (e.g. Hand or finger flapping or twisting)?

(A) 0 (B) 1 (C) 0

ii. May be associated with abnormal eating habit? (A) 0 (B) 1 (C) 0

iii. Persistent preoccupation with parts of objects? (A) 0 (B) 1 (C) 0

iv. Love for regimented routine activities? (A) 0 (B) 1 (C) 0

Domain 4

i. Autism is Childhood Schizophrenia? (A) 0 (B) 0 (C) 1

ii. Autism is an auto-immune condition? (A) 0 (B) 0 (C) 1

iii Autism is a neuro-developmental disorder? (A) 0 (B) 1 (C) 0

iv. Autism could be associated with Mental Retardation? (A) 0 (B) 1 (C) 0

v. Autism could be associated with Epilepsy? (A) 0 (B) 1 (C) 0

vi Onset of Autism is usually in, (A) 0 (B) 0 (C) 1

A total maximum score of 19 and a minimum score of 0 are possible. The average score on the KCAHW questionnaire among a particular sample population gives an index level of knowledge about childhood autism in that particular population.

Appendix 4: Focus Group Discussion Interview guide for Health Care Workers

Welcome and thank you for volunteering to take part in this focus group. You have been asked to participate in this group as your point of view is important to us.

Introduction

The aim of this discussion will be to explore your experiences,practices and challenges you encounter in managementof childhood autism, so as to bridge any gaps identified. The information from this study will be used to create awareness and propose ways of improving care and management of children with autism and possibly plan future trainings. The FDG will take about an hour.

Anonymity

Despite being voice recorded, I would like to assure you that the discussion will be anonymous. The voice records will be kept safely in a locked facility and they are transcribed word for word, then they will be destroyed. The notes taken during the FGD will not record individuals' names. Try to answer and comment accurately and truthfully as possible. Kindly refrain from discussing the comments of other group members outside the focus group. If there are any questions or discussions that you do not wish to answer or participate in, you do not have to do so; however please try to answer and be as involved as much as possible.

Ground rules

Only one person speaks at a time. If someone is talking please wait until they have finished before you start.

There are no wrong or right answers.

You do not have to speak in any particular order.

When you do have something to say, please do so, regardless of the other group members' opinions.

You do not have to agree with the views of other people in the group.

Does anyone have any questions? (Answers).

Okay let's begin

Part 1: Practice of health care workers on childhood autism

1. In your practice since graduation, have you participated in the management of a child with autism? (Management entails participation in diagnosis, treatment, counselling & referral)

2. In which of the following aspects of management of childhood autism have you participated in?

a) Diagnosis

b) Management

c) Counselling

d) Referral

3. Do you practice any form of autism-specific screening at every child visit/ encounter ?

4. For those diagnosed with autism what interventions do you think are helpful?

a) Medications: Antipsychotics, antidepressants, mood stabilizers, psychostimulants, hypnotics, others.

b) Speech therapy

c) Dietary intervention

d) Behavioural therapy

5. In case of need for referral, whom do you refer to?

a) Psychiatrist

b) Psychologist

c) Paediatrician

d) Others

6. What kind of school do you recommend to parents or teachers?

a) Normal school

b) Special school

c) Normal school with a specialised unit

d) No school

7. Do you practice parental counselling? And what kind of information do you give to the parents/ caregivers with regards to the aetiology, treatment options and the prognosis of childhood autism

8. Do you think stem cell transplant therapy is a good option for autism?

Part 2: Challenges health care workers face in childhood autism.

What challenges do you encounter with diagnosis, care and management of children with autism?

Conclusion

Thank you for participating. This has been a very informative discussion. Your opinions are a valuable asset to this study. We hope the discussion was interesting. I would like to remind any comments featured in this research will be anonymous.

Appendix 5: Key Informant Interview Guide

Key Informant Interview Guide

Initial..... Age..... Gender..... Date.....

My name is Fatma Kassim. I am a graduate student at the University of Nairobi. As a requirement for partial fulfilment of a Masters in Paediatric and Child Health, I am Assessing Knowledge, Practice and Challenges about childhood autism among HCWs at KNH. This study aims to explore your experiences & opinions about Childhood autism so as to bridge any gaps identified which will be fundamental for creating awareness and help propose ways of improving diagnosis, care & management of childhood autism. The research is purely for academic purposes and the responses provided will be treated with the utmost confidentiality. The findings will be fundamental in identifying existing gaps and help plan future training and continued education of HCWs on childhood autism.

I am requesting your permission to record this interview. This will help me remember everything accurately and avoid unnecessary mistakes during data analysis and results presentation. Please be comfortable and if you are uncomfortable with any question treat it as optional and do not answer it. If need be, I shall arrange to give you a copy of my research once it is completed.

Thank you for your time.

Questions

1**.** How long have you worked in your current position/department?

2. What are the services available in KNH for children with autism?

3. What are the policies that have been put in place to ensure optimal care & services are offered to children with autism?

4. Is there an integrated and coordinated system of care for children with autism in KNH?

5. Do you practice any form of autism-specific screening?

6. Do you refer children with autism? If yes, whom do you refer to?

7. From your experience, what treatment options do parents seek for their child with autism? And what are the treatment options that you advice?

8. What are the challenges that you face in the diagnosis and management of childhood autism?

9. Are there any opportunities for HCWs to have training or continuing education in Childhood autism?

10. What are the resources/partner(s) available to support the above programs?

11. Any other comments or additional concerns?

Thank you very much for your valuable time. Hope you will be willing to co-operate with me should need arise.

Appendix 6: Study Budget

NAME OF THE ITEM	COST OF EACH ITEM	NUMBER OF ITEMS NEEDED	TOTAL COST
Pens	Kshs 10	5	Kshs 50
Printing of questionnaires and consent forms	Kshs 10 per page	20 x 230 20 x 230	Kshs 9200
Airtime			Kshs 1,000
Statistician			Kshs 15,000
Ethics Committee KNH			Kshs 5,000
Poster presentation			Kshs 1,500
GRAND TOTAL			Kshs 31,750

Source of funds: Personal savings

Appendix 7: Timelines
(April 2020- April 2021)

	1	2	3	4	5	6	7	8	9	10	11	12
Proposal writing	■	■	■									
Submission to ethics				■	■							
Data collection						■	■	■				
Data analysis									■	■		
Report writing											■	
Presentation of results												■