THE BURDEN OF CARE IN CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER(ASD) ATTENDING OUTPATIENT CLINICS AT KENYATTA NATIONAL AND REFERRAL HOSPITAL.

By

DR. MERCY NDINDI MUSA

H58/12001/2018

A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT FOR THE AWARD OF DEGREE OF MASTER OF MEDICINE IN PSYCHIATRY

15 th AUGUST 2022

Declaration of Originality Form

I, Dr. Mercy Ndindi Musa, do hereby declare that this is my original work carried out in partial fulfillment of the award of master's degree of medicine in psychiatry, Department of Psychiatry, the University of Nairobi. I further declare that this has not been presented to any other degree or another higher institution for any award.

Signed Date: 15 TH AUGUST 2022

Dr. Mercy Ndindi Musa

Masters of Medicine in Psychiatry

Department of Psychiatry, University of Nairobi

Merciemusa77@gmail.com

0715553453

Approval of Supervisors

This dissertation has been submitted with our full approval as supervisors:

1. **Dr. Kangethe Rachael N.**

Kangethe

Department of Psychiatry, University of Nairobi

Email: rkangethe@uonbi.ac.ke

2. **Dr. Teresia Ndilu Mutavi**

Teresia

BA (CUEA), MA (Nairobi), HND Counselling (KIPC), PhD, Cl Psy (Nairobi)
P.O. Box 74-00519, Mlolongo, Kenya
Tel: +254-722-391236/ + 245-720963920
Department of Psychiatry, University of Nairobi
Email: terrymutavi254@gmail.com/mutavi.teresia@uonbi.ac.ke

Acknowledgment

I would like to thank my supervisors Dr. Kangethe Rachael N and Dr. Teresia N. Mutavi for the guidance, immerse inputs and support they have given me in my academic progress during the development of this research thesis. Your effort, sacrifice, and hard work towards this work are truly much appreciated. I thank God above all for his grace and strength to complete this dissertation, may all the glory and honor return to the Lord Jesus Christ.

Dedication

I dedicate my thesis to my family, colleagues, and friends. Special appreciation to my dear husband Dr. Charles Mulwa for being very supportive and a strong pillar in my life. My dear children; Esther Mulwa and Josiah Mulwa, thank you so much for your support during this work, hopefully, this work will benefit autistic children and their parents out there.

Thank you to Emma Wamucii for the immerse support too during this work.

Table of Content

Contents

List of Figures

List of Abbreviations

ASD- Autism Spectrum Disorder

ASK- Autism Society of Kenya

ADDM- Autism and Developmental Disabilities Monitoring (ADDM) Network

CDCP- Centers for Disease Control and Prevention

CNS- Central Nervous System

DSM 5 – Diagnostic and Statistical Manual of Mental Disorders 5th edition

DSM IV- Diagnostic and Statistical Manual of Mental Disorders 4th edition

DS- Down Syndrome

GHQ- General Health Questionnaire

ICD-10- International Classification of Diseases 10th Revision

ID- Intellectual Disability

KNH- Kenyatta National Referral Hospital

OT- Occupational Therapy

TORCHES- Toxoplasmosis Gondii, Others (Syphilis, Parvovirus B19) Rubella, Cytomegalovirus, Herpes Simplex Virus

ZBI - Zarit Burden Interview

Operational Definition of Terms and Phrases

Burden of care- refers to problems, difficulties or adverse events in a psychiatric patient that affects other family members.

Comorbidity- the presence of more than one disorder co-occurring with a primary condition

Inpatients – those admitted in a psychiatric unit for treatment.

Mental disorder- refers to a syndrome characterized in significant disturbances in an individual's cognition, emotional regulation or behavior that reflects a dysfunction in biological, psychological or developmental process underlying mental functioning.

Outpatients– those who attend a clinic in hospitals/units for treatment but do not stay there overnight (get admitted).

Abstract

Introduction: Autism spectrum disorder (ASD) is one of the demanding neurodevelopmental disorders that presents with deficits in social interactions, communication, and disruptive behaviors which necessitate consistent, long-term attention by the caregiver. Most research on autism and caregiver burden has been done in high-income countries with paucity of data in the middle and low-income. Caregiver burden has previously been identified as a key theme during management of autistic children in the Country, Kenya. There are challenges that affect their emotional state, psychological well -being, financial status and cause psychiatric morbidity (anxiety and depression) therefore assessment, immense support and psychoeducation are needed.

Objectives of the study: This study aims to assess the caregiver burden in caregivers attending to children diagnosed with ASD, to determine factors in the autistic children and caregiver's factors associated with caregiver burden. The study aims to screen caregivers for psychiatric morbidity and investigate the lived experiences of caregivers attending to children with ASD.

Method: This is a descriptive cross-sectional study, using mixed methods (embedded) study design, that was conducted in Kenyatta National Referral Hospital (KNH)- outpatient clinics attending to ASD patients. The study population using purposive sampling included all caregivers of children diagnosed with ASD. A socio-demographic questionnaire with two domains capturing the child and caregiver's information was administered, the caregiver burden was assessed using the Zarit Burden Interview (ZBI) 22- questionnaire and a General Health Questionnaire (GHQ)-12 item tool to screen for psychiatric morbidity in the caregivers were administered. Qualitative data was collected using a sociodemographic questionnaire and face-to-face interview, following semi-structured open- ended questions conducted by the researcher.

Data analysis: SPSS Version 25.0 was used for data analysis. Univariate analysis was done to show the socio-demographic characteristics of caregivers and the children with ASD. Bivariate analysis was done comparing exposure factors to the outcome variable. Multivariate analysis was conducted for variables with P value < 0.05 on bivariate analysis. The qualitative data was analyzed through line-by-line coding then transcribing done and NVivo software used for thematic analysis. Codes were clustered into categories and subcategories then labelled into descriptive phrases reducing into one theme

Results: There were 91 participants for the quantitative study and 7(seven) participants for the qualitative study. Mean age of caregivers was 34.9 (SD 6.7) years, majority aged between 30 years and 39 years (52, 57.1%). Male to female ratio for the children was 3;1. 46 (50.5%) who are the majority had mild to moderate burden. The burden score was statistically significant in relation to gender (p value < 0.042) and employment status (p value < 0.022) at the bivariate analysis. Child factors; mean age (p value < 0.020) and age at the time of diagnosis (p value < 0.020) was found to be statistically significant at the bivariate analysis. The average score of the GHQ-12 was 22.91 ±10.56, which was much higher than 12 which is the cut-off point. The respondents had symptoms of anxiety, depression and social dysfunction. The key findings from the 7 caregivers were distress and devastation following diagnosis of ASD on their children. Participants expressed caring for their children was challenging with immerse difficulty to cope.

Conclusion: This study adds to the current knowledge about ASD and its associated caregiver burden, psychiatric morbidity and lived experiences of caregivers in the Country. Caregiver burden in this study is found to be significant and is associated with emotional status of the caregivers and child’s age at the time of diagnosis. This will guide the policymaker, health professionals, and caregivers of children diagnosed with ASD on the need to screen, diagnose, and manage stress-related disorders.

CHAPTER ONE

Introduction and Background Information

1.1 Introduction

1.1.1 Outline of ASD

Autism Spectrum Disorder (ASD) is of childhood onset that remain to be a public health problem according to World Health Organization (WHO) 2013. It's cure is unknown though early intervention treatment, improves child's development (CDCP, 2020). ASD starts in infancy, presenting at or before the first three years of life with failure to use words to communicate becoming the first concern most often, with social and behavioral challenges. According to a 2012 review of prevalence estimates from around the world, 1 in 161 people (0.62%) in the world have ASD (Elsabbagh et al., 2012).

Extensive information that is widely known is from high-income countries, currently the prevalence of ASD children in United States was 18.5 per 1,000 i.e. (one in 54 children) as stated by the Autism and Developmental Disabilities Monitoring (ADDM) network and more among boys than girls (Centre for Disease Control, 2020). Studies done in high-income countries such as Europe and middle East Asia have shown a prevalence in the middle of 1% and 2 % (Baio J., 2018). In Africa, similar presentation as that of high-income countries of ASD has been shown (Bakare, 2011). ASD studies have shown males are more affected than females at a ratio of 4.3:1, similar results were found in a study done in a private hospital in Nairobi, Kenya among 1,711 medical records of ASD children (Samia et al., 2020).

Autism spectrum disorder (ASD) according to DSM-5 presents with several challenges faced by affected children. It is also known as childhood autism according to ICD-10. ASD is characterized by diagnostic categories in DSM -5; persistent, pervasive, and sustained impairment in corresponding communication and social interaction (Criterion A), and repetitive patterns of behavior, interests, or activities (Criterion B). Children are mostly diagnosed during early developmental period thus restrict their daily social and occupational functioning which meets Criteria C and D (Diagnostic and Statistical Manual of Mental Disorders, 2013). The word 'autism' was first invented by Leo Kanner in 1943, where childhood autism is also named as Kanner's syndrome (B.K. Puri, A. Hall, 2014).

The deficit in social interactions becomes obvious as they grow up, they don't seek peers when happy, point or show objects of interest to them with repetitive behaviors (odd behaviors) developing in pre-schooling years. Around half of ASD children have average to above-average intelligence (IQ of 85 or above), ability to communicate verbally, and few disruptive behaviors are described as ‘high functioning autistics. Some with ASD have lower intellectual functioning (IQ below 70), difficulty with verbal communication, and significant disruptive behaviors are described as ‘low functioning autistics. Epidemiological studies have defined ASD as a range of disorders, including Disintegrative Disorder, Asperger’s Disorder, Rett Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) which all vary according to their onset, severity, and pervasiveness.

Several studies have been done to establish the cause of ASD with difficulty to explain the cause though with connection to heredity (Miles, 2011), older age in parents (Ronald & Hoekstra, 2011), and environmental factors (Landrigan, 2010). In the African continent, various aspects ASD are unknown (Bakare, 2011). ASD is poorly diagnosed, managed with few studies on ASD and even caregiver burden, yet it has a great psychological, economic, and social impact on the family. In Africa, Kenya included few studies have been done on screening and treatment of ASD this has hampered the need to establish the cause and services needed by ASD patients and even their caregivers.

The services needed while handling the ASD children are quite vast ranging from psychopharmacology, psychotherapy, occupational therapy, and schooling starting from elementary school to adulthood. There is scarce information on the etiologies and biology of autism. Treatment modalities are focused mainly on psychoeducation and behavior modification with several psychoactive drugs such as risperidone being of benefit in reducing maladaptive behaviors (Lord et al., 2000).

1.1.2 Burden of care

The burden of care has been defined as “the presence of difficulty which impacts on the life (lives) of the psychiatric patient’s significant other(s)” e.g., members of the family (Platt, 1985). This is a topic of great interest over the years with several studies being conducted on caregivers' burden due to having a child with a disorder. Caregiver burden which is of interest in this study is described as a parental perception on the stressors and caregiving responsibilities of being a parent/ caregiver (Khanna et al., 2015). Research has shown that the type of disorder determines the stress and burden experienced by family members.

ASD being a chronic illness of a childhood-onset leads to a great burden to the caregivers from the onset of diagnosis, treatment, rehabilitation care (S.Hartley, M.Seltezer, Lara. H, 2013), education, and even support throughout adulthood. This has an impact on the family, family’s routine, finances, the health of the family members in addition to caring for other children in the family. Caregivers thus suffer from physical problems, psychological or emotional problems, social and financial challenges. A study done in the United States found out, fathers caring for children with ASD had depressive symptoms (S.Hartley, M.Seltezer, Lara. H, 2013) and parents with children with ASD had more stress compared to parents of normally growing children (Hastings et al., 2005).

All family members living with an autistic child and down syndrome are affected including siblings having less social relations, less disagreements , and tend to compete less than in normal children (Kaminsky & Dewey, 2001).The caregiver who mainly attends to the patient may be neglected, with the main focus directed to the autistic child knowing the family setting in an African context, parents have other responsibilities. The caregiver has other responsibilities such as taking care of the spouse, other siblings, household activities, professional works, or community activities.

Many caregivers lack knowledge about diagnosis, available rehabilitation care, this includes health care workers who are also less knowledgeable on ASD, which makes the level of care to be poor (L. Z. Kamau, 2017). The number of children diagnosed with ASD is increasing based on; more awareness of the disorder, mobilization of resources, and more demand for specialized care thus a clear need to also focus on the caregivers. Autistic children have difficulty in social interaction, completely atypical patterns of activities and behaviors, impaired communication, focus on details, and present with unusual body sensations. ASD is a laborious childhood disorder as regards to caregiver’s role (Ardhanaari et al., 2020).

Caregivers of mentally ill patients experience both subjective and objective burdens (Platt, 1985). Subjective burden refers to psychological consequences while objective refers to demands placed on the family members for example reduced or no leisure time at all, cutting working hours, and even quitting their work. Some challenges occur due to caring for the ASD patient because they affect their families adversely. A study done in Kenya showed that relatives of mentally ill patients caused economic constraints and disturbing behaviors such as verbal, hostility, and refusal to take medicines which affected them in many ways (D M Ndetei et al., 2009). Most prior studies of caregiver burden have been done in other countries largely focusing on caregivers of young children with other mental disorders. There is paucity of data on studies that have investigated caregiver burden among children with autism spectrum disorder in our local context.

A scope of interventions, from early childhood and across lifespan can improve development, well- being and different aspects of life in the autistic individual and caregivers (WHO, 2021).

ASD is of childhood-onset and poses significant challenges on clinical management and also psychological consequences. The diagnosis of autism affects family members personal independence, psychological support, and economic cost which affects the child's development and management (Aida et al., 2019). The caregiver role comes with a multidimensional range of problems and it becomes important to identify these areas of burden and provide support. Worldwide research on experiences of caregivers is increasing and thus important to look at caregiver burden in ASD.

Caregivers always work towards relating with the child to improve their language and social self-help, assist the child with sensory stimulation, control their object use, to avoid harming themselves. There several implications both direct and indirect cost on the psychiatric patient, caregivers and society at large (Awad & Voruganti, 2008). Direct implications include; cost of hospitalization, life-long psychiatric and medical care, cost of medication, and social-economic support then indirect cost includes loss of productivity (Awad & Voruganti, 2008).

It's critical after diagnosis of autism, children together with their caregivers, a wholistic approach includes being given relevant information, services, support based on their individual needs and preferences (Cloete et al., 2019). It is critical to identify through conducting studies on caregiver burden, this will contribute to not only their psychological well-being also to the good prognosis of the children's growth and development. This information will guide on how to improve services while attending to ASD children and incorporate caregivers in the service delivery and thus reduce caregivers' stress-related disorders.

1.2 Background Information

Autism Spectrum Disorder does not only affect social communication and interaction with restrictive and repetitive behavior but also stagnation and regression in language. The other aspects of functioning such as sensory responsiveness, play motor activities, are affected and not all autistic children have mental retardation but all have disturbances in social behavior. It's approximated that 30% of autistic patients have comorbidities such as seizure disorder (Lord et al., 2000). Autistic children also struggle with the cognitive task with the inability to understand the context of a given situation, inability to connect to their past experiences with present situations thus impairing the ability to recall relevant information and planning future actions. ASD children are highly impulsive affecting their executive functioning.

Autistic children also have additional health concerns such as epilepsy, gastrointestinal problems (McElhanon et al., 2014), markedly reduced sleep duration (Humphreys et al., 2014), impaired immunity, odd behaviors such as aggression and self – an injury which may indicate pain associated with other medical condition (Seong et al., 2015). They are also affected by other mental health issues (depression, anxiety, phobias, schizophrenia), poor motor skills with heightened sensitivity to sounds and texture. Studies have shown that severe disruptive behaviors, and severe autistic symptoms is linked to poorer quality of life in caregivers this includes socializing, work, and relationships (Kheir et al., 2012). Autistic children are less intimate and so hurt their relationship with siblings, have prosocial behavior, and nurturance compared to the down syndrome and normally developing group of children (Kaminsky & Dewey, 2001).

Burden of care occurs in caregivers as a result of taking care of mentally ill patient. Care given is invariable continuous (Dada et al., 2011) and demanding based on; the unusual behaviors, they have to be taught how to interact, they have to be taught basic life skills, they have impulsiveness and are at risk of dangers and thus need protection. They have to be assisted to transition to adulthood and live with the community. ASD children exhibit challenging behaviors such as self-injury, hostility, non-compliance to drugs which are physically dangerous to caregivers and thus affect these children by impeding their learning and access to normal activities (Matson & Nebel-schwalm, 2007).

Children's mental illness act as a source of distress on caregivers yet burden resulting from caring for children and adolescents with psychiatric disorders has been abandoned and not studied extensively (Angold et al., 1998) . High -income countries have data on caregiver burden with serious dearth of information in the developing countries such as Kenya. The present situation in Africa on various aspects of ASD is unclear (Bakare, 2011). The physical, psychological, financial, occupational strain of caregivers of children with ASD affects other aspects of their lives. Families of autistic children have heavier burden than families of normal children and need help from many aspects from economic, social and emotional support (Xiong et al., 2011).

Research studies on perceived burden of care among caregivers with autistic children have been conducted more in the high- income and middle- income countries this includes Arab countries (Pandey & Sharma, 2018) (Alnazly, 2019). Parents with children who are autistic undergo more challenges compared to parents of normally developing children with certain degree in social impairment and the severity of the ASD in the child has been shown to lead to caregiver's burden (Lin, 2011). Marital status, education level, religious and economic status affect the care of children with disabilities and thus this study will show the effect of these caregiver factors on caregiving. Autistic children lead to financial burden such that the cost of living on their parents is more than that of children with physical disabilities and three times as much as their typical peers (Xiong et al., 2011).

This study will screen for any psychiatric morbidity in the caregivers because research has shown that psychiatric disorders in children and adolescents are less-reported and under-treated, with depressive disorder being a common mental disorder in the caregivers according to a study in Ethiopia, Africa (Minichil et al., 2019). The parents/ caregiver's physical health and the mentally ill's child education level is the best predictors of caregiver burden and also the best predictor of the way of coping in a study done in China, Middle East (Liu et al., 2007). Previous research findings are that caregivers of children with ASD, suffer significant stressors e.g., physical, social etc. and different levels of caregiver burden. Caregivers also have other roles in the family and with paucity of data on the caregiver burden in developing countries this affects negatively on the quality of care offered to caregivers and the children (Dada et al., 2011).

The findings will increase pool of information in mental health on caregiver burden in caregivers caring for children diagnosed ASD and determine psychiatric morbidity in these caregivers. The study will determine the caregiver and child sociodemographic factors that influence caregiver's burden. The lived experiences of caregivers, their challenges and how caregivers cope while attending to children with ASD will be investigated. The results of this study will which enable the development of strategies by the clinician and policy makers, aimed at screening for effects of caregiving to children diagnosed with ASD on caregivers.

1.3 Problem statement

Kenya is categorized as one among middle to low income earning countries having several challenges ranging from low resource allocation for mental health to scares human resource for mental health including psychologists, psychiatrists and occupational therapists. Kenya has few psychiatrists (David M. Ndetei et al., 2007) who are mainly based in the regional referral hospitals ,in the cities, others teach in the universities with few in the county hospitals. This poses a challenge on caregivers because of inadequate, inaccessible services on diagnosis and follow for ASD children. Caregiving of ASD children causes emotional stress and strain, this leads to exhaustion, fatigue and could lead to psychiatric morbidity.

Caregivers have changes in family life e.g., abandoned careers, unavailable and inaccessible services and support, economic burdens of receiving treatment. There is dissatisfaction among family members on the inappropriate share of each family member's time, energy and money for the mentally ill child leads to a stressful life. Family members also suffer negative attitudes expressed to them by other family members and neighbors who are less informed about ASD. Caregiver burden and psychological distress among caregivers (those tasked with care) go unnoticed because more attention is on the autistic child. Low- income countries have paucity of information and even intervention on caregiver distress from caring for children and adolescents with psychiatric disorders (Angold et al., 1997).

In Kenya, there is dearth of information on the difficulty incurred by caregivers while accessing earlier detection in addition to other important supportive services (Obaigwa & Cloete, 2019). Research studies done previously have focused on depression and anxiety among caregivers of ASD with paucity of data on caregiving burden among ASD children in a local context. Literature shows paucity of data on ASD in Africa about screening, diagnosis and effectiveness of intervention (Elsabbagh et al., 2012). It is against this background that this research study intends to access the scale of burden perceived by caregivers attending to children diagnosed with Autism Spectrum Disorder attending outpatient clinics at KNH, Nairobi.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter will discuss available information by reviewing literature in the same field of study, give a theoretical framework, and finally a conceptual framework with diagrammatic representation of the same. The literature review will have three main parts with the first part discussing the disease background for ASD showing the unique distressing features. In the second part, the concept of caregiver burden will be discussed and specifically, caregiving in children diagnosed with ASD will be discussed. The main focus of this study is on caregivers and children diagnosed with ASD. The caregiver's socio-demographics factors and also, child factors that are associated with caregiver burden from diverse literature will be discussed. This chapter will also discuss the psychiatric morbidity that could be associated with being a caregiver caring for an ASD child, the experiences and challenges faced by caregivers then the third part includes theoretical framework explained with one model and finally the conceptual framework.

2.1.1 Disease background

Autism or ASD is one of the neurodevelopmental disorders of childhood-onset. It is a life-long disorder whose symptoms are in three main domains; social interactions, communication/ language, and repetitive, restrictive patterns of behavior, interest, or activities (Pandey & Sharma, 2018). ASD is also characterized by several diagnostic categories in addition to the three core domains, there is impairment in communication, academic and typically manifests early in development(Diagnostic and Statistical Manual of Mental Disorders, 2013). These symptoms often manifest before a child is school-going and change with development and many times concealed by compensatory mechanisms as they grow.

Autism Spectrum Disorder was first studied in early 1940 by Dr. Leo Kanner, after examining 11 children that expressed severe behavioral and developmental problems, thus Kanner coined the term " infantile autism"(Baron-Cohen, 2015). Another scientist who was an Austrian pediatrician, Hans Aspergers explained about children and adolescents who had deficits in communication, social skills and with restrictive, repetitive patterns of behaviors.

2.1.2 The etiology of ASD

The etiology of ASD is still unknown with possible causative theories being first described as; genetics- the heritability is over 90% and neurodevelopmental theory (B.K. Puri, A. Hall, 2014).

Genetics studies have shown that concordance in twins is higher, with 70 % concordance in monozygotic pairs, and generally reported recurrence risk is 4% in the first affected female and 7% if it's a male child (Schaefer & Mendelsohn, 2008). Autism Spectrum Disorder is associated with a family history of psychosis or affective disorders and with genetic family loading for ASD with phenotypic overlap with ADHD, with the two conditions having the same genetic liability.

The neurodevelopmental theory includes antenatal infection e.g., (TORCHES) Toxoplasmosis Gondii, Others (Syphilis, Parvovirus B19) Rubella, Cytomegalovirus, Herpes Simplex Virus, perinatal injuries, sodium valproate use in pregnancy, Central Nervous System malformations (CNS), and a gestational age of less than 35 weeks among other factors. There is no specific cause for autism, but its etiology is genetic predisposition and several environmental factors. It suggested that genetic predisposition is necessary, environmental factors also act as risk factors to cause Autism Spectrum Disorder (Grabrucker, 2013).

2.1.3 Prevalence of ASD

Epidemiological survey of Autistic Spectrum Disorder and Pervasive Development Disorders (PDDs) worldwide, shows prevalence estimate of ASD to have a medium of Sixty two (62) cases per 10,000 people with a lack of literature from low and middle-income countries (Elsabbagh et al., 2012). Epidemiological data estimates autistic children to be 52 million worldwide, affects around 1-2 % of children around the globe (Hahler & Elsabbagh, 2015). A study recently done in Italy done on caregiver burden in school-aged children with neurodevelopmental disorders among 105 caregivers showed primary diagnosis were ASD (32.4%), Attention Deficit and Hyperactivity Disorder (ADHD) (14.3 %), Learning Disorder (27.6%) and Developmental Coordination Disorder (DCD) (11.4%) (Purpura et al., 2021).

The prevalence of autism has been on the rise in the high-income countries and this could be related to increased awareness, case finding, and community mobilization about autism. Reported cases of autism per 1000 children grew in the U.S. from the year 1996 to 2007 (Hessian, 2017). According to estimates from Autism and Developmental Disabilities Monitoring (ADDM) network about 1 in 68 children were diagnosed with ASD (CDC, 2020). A study done in the middle East- Dubai found autism to be a challenging public health issue, with 84.9% of the cases were males, 51.9% were females and the diagnostic test showed an estimate of 1 in every 146 births were autistic (Hessian, 2017).

On the contrary to high-income countries, the contribution of sub-Saharan Africa is unknown due to the paucity of population-based research, with data being available in countries like Nigeria and South Africa. Another health facility-based study in Bamako, Mali found the prevalence of ASD to be 4.5% (105 per 2,343) (Modibo & Boubacar, 2019). A survey of 1,169 children in Uganda, aged 2 and 9 years had prevalence for ASD of 6.8/1000 children (Kakooza-mwesige et al., 2014). Research evidence shows male predilection. In Kenya, the Autism society of Kenya (ASK) gives an estimate of 800,000 people, to be living with ASD in the country (L. Z. Kamau, 2017).

2.1.4 Clinical features of ASD

The DSM 5 outlines categories of clinical features of ASD. Category A defines deficits in social, emotional expression, non-verbal communicative behaviors and sustain social relationship (Diagnostic and Statistical Manual of Mental Disorders, 2013). Autistic children present with non-verbal ways to communicate and lack facial expression. They tend to use their hands to point to what they need or using items that express their internal need mostly those who are not school-going. Manifestation of Category A tends to vary among different children with autism. This makes these children be dependent throughout their lives.

Category B describes their ritualistic, repetitive behaviors with high sensitivity to certain textures and stimuli e.g., hitting their head/ mouth with an object, hand flapping, headbanging, etc. (Diagnostic and Statistical Manual of Mental Disorders, 2013). Autistic children express ritualistic, repetitive behaviors distressing to caregivers which include but are not limited to obsession, compulsions, echolalia and self-injurious behaviors. Most tend to insist on sameness on routine every day with even insistence to use the same route to their household. A thoroughly detailed history of their daily functioning behaviors is needed while interacting with the child and caregiver.

Category C describes autism as a childhood-onset disorder usually manifest with deficits in social interaction, repetitive and disruptive behavior, doesn’t maintain eye contact, at around three years, before they start schooling(Diagnostic and Statistical Manual of Mental Disorders, 2013). They present with stagnation or regression in developmental milestones. Diagnostic category D, autistic children have deficits in their social interaction, occupational functioning, and other areas of their lives (Diagnostic and Statistical Manual of Mental Disorders, 2013). The symptoms persist even in autistic adults who remain reliant on their family for support often result to caregiver burden on their parents who are the caregivers (Vogan et al., 2014).

2.1.5 Diagnosis and treatment of ASD

ASD is mainly diagnosed using clinical presentation i.e., proper history taking and clinical examination (Schaefer & Mendelsohn, 2008). UK (United Kingdom) Nice clinical guidelines are important in recognition, referral, and diagnosis of children and young people with features suggestive of ASD. A variety of screening tools to study mental illness in children aged approximately 18 months and older have been used in population-based studies and high-risk populations e.g. SRS, CCC, etc.(M. Leboyer, 2015). The Social Responsive Scale(SRS) measures social deficits, Children's Communication Checklist (CCC) measures language and communication deficits, Repetitive Behavior Scale (RBS) measures routine behavior and Autism Spectrum Quotient scale measures the overall presence of autistic symptoms (M. Leboyer, 2015).

Autism spectrum disorder therapy uses a multimodal intervention from pharmacological to non-pharmacological treatment which includes rehabilitative, behavioral, and educative intervention. ASD treatment is mainly behavioral; pharmacological treatment reduce comorbid symptoms but does not treat core ASD symptoms (M. Leboyer, 2015). Drugs such as psychostimulants, antipsychotics, anxiolytics have been used based on individual presentation targeting specific symptoms. Stimulants increase attentiveness, antipsychotics are used where the children present with irritability, psychotic features, and tranquilizers are used where the patients present with extreme obsessive and compulsive symptoms (NIH, 2021). No single drug has been used for the cure or complete treatment of ASD core symptoms (CDCP, 2019). Dietary treatments have been developed but little has been evidenced to support its use in ASD symptoms (Sathe et al., 2017).

Occupational therapy is the cornerstone and great tool for addressing ASD. Occupational therapists work to address the child's developmental milestone and enhance sensory processing and sensory- motor performance thus enables the child's self-care (Cloete et al., 2019). These interventions improve the child's emotional expression, communication, activities of daily functioning, adaptation, and life skills are acquired to try and make them live independently. There are many frames of reference that occupational therapy uses such as sensory integration, environmental enrichment-based therapy, auditory integration- based therapy, music therapy-based and other intervention that target sensory challenges (Weitlauf et al., 2017).

A study done in KNH among 300 caregivers, which utilized focused group discussion (FGDs) showed that caregivers experienced emotional burden and difficulty in accessing services while caring for ASD children, through attending occupational therapy they learned other parents go through the same challenges and difficulties (Cloete et al., 2019). Another study done in Nairobi, Kenya on barriers encountered during diagnosis, treatment, and management among 39 participants and 11 professionals found out that there was no awareness, little to no research on intervention, lack of treatment procedures, with minimal government support (L. Z. Kamau, 2017). The same study identified several challenges in a local setting that affect both the caregiver and child including financial constrain, social stigma, and broken families.

2.2 Caregiver and Caregiving

A caregiver according to Cobuild advanced English dictionary, is someone in charge of looking after another person, e.g., a person who has a disability or is ill or very young. Caregiving refers to assistance provided by one or more members of the family to another ailing member that is more than the aid required as a part of regular everyday life (Walker et al., 2015). Aid cannot be easily distinguished because this responsibility of looking for the ill or disabled in the family is part of the normal exchange in family relationships.

2.2.1 Caregiver burden definition

Stephen Platt in 1985 defined burden as " the presence of problems, difficulties, or adverse events which affect the life (lives) of the psychiatric patient's significant other(s) (Angold et al., 1997). 'Burden of care' is a complex concept emerging in literature as physical, emotional, social, and financial difficulty that can be encountered by family caregivers. Many definitions have been proposed but the emphasis is on the effect the patient has on the family, daily routine even their well -being. The family already has its high-level hardship which caregiving of ill or patients with a disability adds its burden. Studies on caregivers' burden have found that caregivers' experience can have both objective burden (this includes aid i.e. daily tasks given to the patient) and subjective burden (e.g. what would negatively affect caregiver's well-being, worry) (Angold et al., 1997).

Hoenig and Hamilton in the late 1960s defined objective and subjective aspects of burden. 'Objective burden' is used to identify anything that occurs as a disturbance of the norms in the family life owing to the patient's illnesses. 'Subjective burden' is the feeling that a burden is being carried 'in a subjective sense' (Platt, 1985). The two scientists described objective burden dividing it into type 1; financial effects, effects of health on any family member, effects on children, and effects of the family routine. Objective burden refers to patient's strange behaviors and harm that causes distress to family members.

Normally there are challenges associated with taking care of a child, and most definitely there must be associated burdens with taking care of an ailing child. Parents are held responsible for causing their child's mental illness while siblings and spouses are held liable for not ensuring that relatives with mental illness adhere to treatments plans (Corrigan & Miller, 2004). There are several emotional distresses that have been observed such as; helplessness, feeling of being a failure, guilt, anger, shock because of the unfamiliar diagnosis, frustration while attending to the ASD child, and resentment from a health system and community that is not supportive.

Literature shows objective burden is classified into four tasks; the tasks related directly to the provision of care, chores related indirectly to the provision of care, dealing with patient's distress lastly, impacts of caregiving on other family life roles (Sales, 2003). Chores related directly to the provision of care include; the time spent by the caregiver to help and or oversee the patient. Subjective burden refers to the emotional consequences of the provision of care on the caregivers i.e. worry, distress, stigma, shame, and guilt (Sales, 2003).

2.2.2 Caregiver burden in ASD

Autism affects both the patient and the caregiver due to their deficits in social interactions, communication, and odd behaviors which all need keen monitoring, and behavioral teaching. Thus, taking care of an autistic child leads to a high level of stress in addition to other roles played by family members. There is emotional, physical, and mental (psychological strain) effects, the concept of ‘burden of care’ involves concepts such as shame, guilt and self- blame (Awad & Voruganti, 2008). Understanding how family members interact with the disease, allows the professionals to realize that family caregivers also need care, guidelines, and strategies for stress relief (Baptista & Junior, 2015).

Caregivers have to cope with demands of the ASD child resulting from disruptive behavior, throwing tantrums, self-injury behavior, insistence on daily routines, and great dependency. Caregivers of ASD children sacrifice their sleep, leisure time to ensure they are comfortable thus at a high risk of self-isolation. Caring for an ASD child has been found to be a consistent distress sufficient to disarrange various areas of adult life and cause mental illnesses (Ardhanaari et al., 2020). The stress related to taking care of autistic children is related to the course of disorder being chronic, permanent with little that is known about its cause, and thus family members, the community at large tend to fail to accept the bizarre behaviors. A study conducted in Taiwan, East Asia found mothers of adolescents with ASD indicate that functional independence, disruptive behaviors, and severity of autistic features to be predictive of maternal caregiving burden (Lin, 2011).

A study done in Toronto, Canada conducted among 297 adolescents and young adults with ASD parents, findings were; ASD severity, externalizing behaviors, medical comorbidity and parents age were predictors of burden of care (Vogan et al., 2014). Another study in United States conducted among 172 families raising ASD children reported more caregiver burden exacerbated by pervasive symptoms than parents of normal children (Roper et al., 2014). A study done in Italy on caregiver burden in 105 caregivers found majority of the caregivers showed moderate to high levels of stress. The same study found out parents of children with ASD and Intellectual Disability had greater difficulties than parents of children with Attention- Deficit and Hyperactivity Disorder, Language/ Learning Disorder, Developmental Coordination Disorder (Purpura et al., 2021)

A study done in India among 60 parents showed that the impact of ASD on caregivers well- being was scaled to be moderate to severe in 59 % of the caregivers and perceived severity of ASD symptoms was impacted on 53 % of the study population (Ardhanaari et al., 2020). Similar to another study on perceived burden in caregivers of children with ASD in Nepal, conducted among 61 caregivers, range of burden was moderate to severe with average burden score of 41.49 ± 12.25 (Pandey & Sharma, 2018). Findings of a state wide study in Malaysia on perceived stress using Perceived Stress Scale (PSS-10) among 227 caregivers of children with ASD, found to have high level of stress, with a total mean score was 20.84 higher than average score of 12-15 (Aida et al., 2019).

A study in Al- Najaf province among 152 caregivers of ASD children, found 50 % had moderate burden level of psychosocial burden (Al-Dujaili & Al-Mossawy, 2017). The findings of a descriptive cross-sectional study in Lagos, Nigeria among 155 caregivers of children with mental disorders attending a psychiatric clinic found 33.5% had mild to moderate burden while a scale of moderate to severe burden, was among 25.2% of caregivers (Dada et al., 2011).

In Kenya, the lived experience in 300 caregivers attending to children with ASD, 'One theme' i.e., the burden of care was identified, lack of information on the cause of ASD and isolation by family circles due to difficult behaviors expressed by these children were among the findings (Cloete et al., 2014). This is similar to another study done among 170 participants at Garissa County, the caregivers felt anxious, stressed, sad with challenges such as social stigma and isolation after ASD diagnosis (L. Kamau et al., 2020) thus a great need to look further into the topic. WHO made resolutions on ASD to strengthen the ability of caregivers and the expertise of the health workforce to provide appropriate and effective care (WHO, 2014). Caregivers of families affected by ASD need social and psychological support and care this, includes persons with autism spectrum disorders. This initiative by WHO has been hard to achieve due to lack of resources, poor advocacy, and inadequate collaborative effort among other factors (WHO, 2017).

The caregivers attending to children with autism undergo many distressing situations and studies show increased psychological distress, this includes both in the ASD child and their siblings. A study conducted among 50 caregivers and special providers of children diagnosed and treated for ASD children in Kenya experienced; lack of awareness, cultural issues and financial constraints (Kamau, 2017) thus a need to explore even more on caregiver burden among ASD patients. In

Kenya, there is a great need to establish support systems for childhood mental disorders such as ASD with emotional, economic, and social burdens being unknown because of several challenges.

2.3 Caregiver factors associated with the burden of care

Caregiver's burden has been associated with certain sociodemographic factors which are of great interest in this study which directly or indirectly influence the burden of care which are discussed below with the literature review. The socio-demographic variables that are of interest in this study include caregiver's age, sex, religion, ethnicity, monthly income, employment status, marital status, education status, and relation to the child.

2.3.1 Caregiver gender, age, and the burden of care

A review of literature shows that most caregivers are females (Aida et al., 2019), (Al-Dujaili & Al-Mossawy, 2017) who are mainly mothers (Ardhanaari et al., 2020). Another study showed mothers to be more than twice the number of fathers (Kheir et al., 2012), showing mothers bear more responsibility for autistic children. Another study found out that mothers experienced higher levels of caregiver burden than fathers and similarly parents taking care of autistic children reported caregiver burden than parents of normally developing children (Roper et al., 2014).

The demographic characteristics of 155 caregivers of mentally ill children attending a psychiatric clinic in Lagos, Nigeria showed females to be the majority at 80.5% of the caregivers with mothers accounting 78%, others included fathers, siblings, aunties, uncles, and grandparents (Dada et al., 2011). Fathers are not spared of the child-related difficulties while taking care of ASD children (S. Hartley, M. Seltezer, Lara. H, 2013). A study done in Nepal on the perceived caregiver burden showed an average age of the 61 caregivers was between 33.6±5.1 years and that of the children was 7.9 ±3.5 (Pandey & Sharma, 2018) which is consistent with a Kenyan study on insights on childhood ASD, where the children presented at a median age of 3 years (Samia et al., 2020).

Mothers of autistic children are at risk of not pursuing their professional careers, leisure time is taken away and even other psychosocial morbidities due to excessive time demand for caring for the child. Mothers feeling is a contributing factor to the physical, psychological aspect of the life in caregivers of children with autism (Shu, 2009)

There are different findings on gender and age of the caregivers in association to caregiver burden. Several studies have found no association between caregivers age and caregivers burden this hints that caring for a ASD child is difficult to all age groups(Pandey & Sharma, 2018)(Greeen, 2007). Contrary to these other studies have found an association between age of caregivers of ASD children with ID (Intellectual disability) and caregiver burden among with an older age reporting caregiver burden.

2.3.2 Level of education and burden of care

Most studies show the majority of ASD children caregivers to be educated most up to high school (Ardhanaari et al., 2020), a study in Southeast Asia, most of caregivers education level attained was at college/ University and above (Aida et al., 2019)(Al-Dujaili & Al-Mossawy, 2017). Caregiver burden in 61 caregivers with ASD showed a greater percentage (69%) of the caregivers had attained education of secondary level thou those who were unemployed were 59% thus working as homemakers (Pandey & Sharma, 2018). The same study showed an association between caregiver burden and education level, those who achieved higher level of education expressed less burden. The level of education is an important factor to study because generally, more education leads to more potential earning. Another study found no link between parental education and caregiver burden (Vogan et al., 2014). There are mixed findings from literature about the association of level of education with caregiver burden thus more studies are needed.

2.3.3 Economic status and burden of care

Kenya is a developing country with economic challenges especially to the middle- and lower-class citizens. Mental disorders has been shown to have negative effects to the economic level of family members (D M Ndetei et al., 2009). The mentally ill patients became financially dependent, resources are used during their care even relatives reduce working hours. There is a risk of parents experiencing caregiver burden when they cannot afford to pay rendered for their children (Vogan et al., 2014). The perspective of clinical experience in India about autism shows quite significant financial implications with no insurance system to be used, few centers that offer subsidized care, and social stigma because ASD is poorly understood (Krishnamurthy, 2008).

Financial status is a factor that contributes to caregiver burden especially when parents have to spend their resources taking care of the sick child. This study will be conducted during the Covid-19 pandemic which has had economic effects and psychological effects on the whole population in the country. Economic distress is expected to be more even among caregivers who are taking care of chronically ill family members.

The economic status matters a lot when it comes to caregiving more so for an autistic child that needs frequent psychiatric reviews, occupational therapy services, medication, and proper nutrition. Another study in Iraq showed the household monthly income of caregivers was sufficient (Al-Dujaili & Al-Mossawy, 2017). COVID-19 pandemic, has effects on the economic status of caregivers and reduced patient turnover in outpatient controlling overcrowding so as to observe public Covid- 19 protocols thus most patients don't attend their clinics. The health workers are also affected by the pandemic with many have to self-isolate thus few workers attend to such patients when they attend outpatient services.

There other caregiver factors that are associated with burden of care; A study done in Jordan showed that sociodemographic factors of caregivers; marital status, employment, age, and the number of family members were associated with the level of parental burden and caregiving outcomes (Alnazly, 2019). A study done in Australia showed caregivers had healthy self-esteem but thou had lower marital happiness and family cohesion than had the norm (Higgins et al., 2005). A study done in the Middle Eastern region showed that caregivers religious background helped them to accept a child with ASD though quality of life didn't differ significantly in caregivers of children with or without ASD (Kheir et al., 2012). A study conducted in KNH, Kenya found that caregivers faced isolation by family circles, strained marriage relation and several cultural myths were used to explain the cause of ASD (Cloete et al., 2019).

2.4 Child factors associated with the burden of care

Literature shows several child-related factors associated closely to caregiver burden in severity of symptoms, psychiatric comorbidities, and intellectual disability disorder (Al-Dujaili & Al-Mossawy, 2017), (Roper et al., 2014)(Vogan et al., 2014). Previous research has shown that the severity of ASD symptoms is one of the parental predictors of caregiver burden (Al-Dujaili & Al-Mossawy, 2017) (Ardhanaari et al., 2020). A study in Lagos, Nigeria on 155 caregiver burden in child and adolescent facility found more than half the patients [56.4%] had seizure disorder, 16.2% had attention deficit/ hyperactivity disorder, 6.8 % had autism among other diagnoses (Dada et al., 2011).

There are other child-related factors which include the presence of externalizing behaviors such as self-injury, aggression, and internalizing factors such as the child's history of depression and anxiety. A study found ASD severity, internalizing and externalizing behaviors, medical comorbidity to be child factors that were associated with caregivers' burden (Vogan et al., 2014). Other factors associated with caregiver burden include child's level of impairment and functioning as assessed by the caregivers. An autistic child has severe impairment and a lower level of functioning then this poses greater burden on the caregiver (Dada et al., 2011). The adaptive functioning, cognitive abilities, academic performance, grade level are among child factors that can be studied as predictors of caregiver burden.

2.4.1 Age and caregiver burden

Age of the child is a factor considered in this study to determine if it's a predictor of caregiver burden. As the child grows more demands are placed on the parents. These children need autism accredited schools for efficient learning. As they grow out of the pediatric clinics and high school education caregivers need to find their daily activities, meaning full jobs and volunteer activities in the community. A study done in Nepal showed no association between caregiver burden and age and sex of the ASD child(Pandey & Sharma, 2018). Similarly, another study found no association between caregiver burden and age of the child (Vogan et al., 2014). Literature is mixed whether it's a predictor or not, thus age as a factor needs to be studied more.

2.4.2 Gender and caregiver burden

The gender of the child is of great interest to determine any caregiver burden association so that intervention can be targeted specifically to specific genders. ASD is known to be more common in male child even up to four times more common than females. Literature has shown different findings with others showing no association between gender and caregiver burden(Pandey & Sharma, 2018).

2.4.3 Age at the time of diagnosis and caregiver burden

An early diagnosis means, early onset of treatment, occupational therapy, family adjustment about the new diagnosis. There is an expected better developmental outcome on behavioral change, early and better choice of autism accredited schools, and possible good prognosis. Treatment is started sooner and keen follow up thus parents understanding the disease early and starts to meet the demands of the autistic child at an early age

A study done in Nepal found out age of diagnosis ranges from 1 year to 13 years of age (Pandey & Sharma, 2018) yet another study done in Kenya showed children with ASD, had a median age to be around 3 years (at presentation) with an age range of 1 years to 23 years of age (Samia et al., 2020). A study done in Al- Najaf province in Iraq among 152 caregivers showed that the approximate age at diagnosis (67.1 %) was not more than 3 years (Al-Dujaili & Al-Mossawy, 2017). Few studies have been done to check for a relationship between caregiver burden and age at diagnosis showing the need to study this child factor.

The relationship between caregiver burden and early age at diagnosis shows a great need for mobilization and community case identification for early detection of ASD. The period of psychiatric illness and diagnosis of the child is not associated with caregiver burden in certain studies that have been done (Pandey & Sharma, 2018)(Dada et al., 2011). Parents don't feel strain, worried, or even stressed based on the duration of the diagnosis. Similarly, the presence or otherwise of psychosis in the child is not associated with caregiver burden (Dada et al., 2011).

2.5 Psychiatric disorders and burden of care

Several psychological disorders have been evidenced among caregivers of ASD; a study conducted in India among 60 parents of ASD children, 84% had depression and anxiety that are related to caregiver burden (Ardhanaari et al., 2020). There is a need to screen, diagnose and treat stress related disorders in caregivers because this affects the prognosis of the child too. Mental illness is a silent 'epidemic' in caregivers of children and adolescents with mental disorders because all is always focused on the care of the child. Depressed and anxious caregivers are at risk of suicide ideation and even attempt, medical complications due to poor appetite, and sleep disturbances.

There is a great need for caregivers to be in support groups or even parent support groups thus exchange experiences among themselves and reduce social isolation. Self-confidence, gaining more knowledge and courage to handle such hard task is critical for caregivers. Caregiving in ASD has marital implications with several studies showing effects such as increased divorce rate, less marital satisfaction while others show no effects, a study done in Australia showed lower marital happiness, family bond, and family flexibility compared to a norm group (Higgins et al., 2005).

A Study in an Arab country showed significant relationship between psychosocial burdens in caregivers caring for children diagnosed with ASD and caregiver's general mental health (Al-Dujaili & Al-Mossawy, 2017). In Nepal, Asia among 61 caregiver using Hopkin's Symptom Checklist-25, found that 33.0% of caregivers had symptoms of anxiety while 24.6% had symptoms of depression. A study done in Jordan using hospital anxiety and depression scale in 123 parents of children with ASD showed they had caregiver burden that lead to psychological distress especially anxiety and depression (Alnazly, 2019).

Studies that have been done among children with mental disorder have shown under- diagnosed and under- treated mental health problem, depression in caregivers being one of them. A study in Addis, Ethiopia on prevalence of depression among 416 caregivers caring for children with mental illness, showed overall prevalence of depression to be 57.6%, with ASD and ADHD diagnoses of children being associated with depressive disorder at a p value < 0.05 (Minichil et al., 2019). Ardhanaari et.al in India conducted a study on caregiver burden among 60 ASD caregivers found that 84% of the caregivers attending to ASD children reported the feeling of depression and anxiety (Ardhanaari et al., 2020). A study in Lagos, Nigeria among 155 caregivers using General

Health Questionnaire (GHQ) found psychiatric morbidity was significantly associated with caregiver burden [r=0.709, p < 0.001] (Dada et al., 2011).

The caregivers take up the physical, emotional, medical, and financial demands of these children yet with little experience, preparation, and support from health workers and the community. There are other risk factors such as time spent caring for the autistic children, the marital status, and also caregivers' quality of life which all lead to problems associated with being caregivers. A previous history of a psychiatric morbidity could be an additional stressor unto caring for a demanding ASD child similarly caring for an ASD child could lead to psychological distress(Dada et al., 2011). Thus, this study to screen for psychiatric morbidity is of great importance because little attention is being paid to caregivers yet they play a critical role to ensure well-being of a child with ASD.

2.6 Lived experiences and challenges of caregivers of ASD children

Caring for a child with ASD is challenging, stressful and demanding work that affects all aspects of the caregiver's life and also family members especially in a resource limited setting. Caregivers experience psychological, emotional and social distress due to the prolonged periods of interacting with an autistic child. A study done in Western Australia from 1983 to 2005, found mothers caring for autistic children were in distress with increased vulnerability to severe medical diseases such as cancer thus increased risk for early death (Fairthorne et al., 2015).

Research studies done in high-income countries have showed several parental concerns and challenges that have assisted improve services offered to ASD children in the Western Countries. A study in United Kingdom (UK) among 1047 parents who filled an online survey about their experiences during attainment of ASD diagnosis on their children and indicated a delay of 3.5 years for the diagnosis of ASD to be made, with most of the parents expressing dissatisfaction with the medical services (Crane et al., 2016). The same study found parents overall level of satisfactions was predicted by the time taken for a diagnosis to be made, information given after diagnosis, and post- diagnosis support. A qualitative study done among 9 mothers in Europe, Greece found a sense of burden (emotional, family and social), distress and vulnerability as the maternal lived experiences and challenges (Papadopoulos, 2021).

There is paucity of data on the experiences in caregivers caring for children with ASD in middle-income countries and low-income countries compared to high-income countries. A qualitative study done in Egypt among 14 mothers of ASD children aged between 5-14 years found ASD to have impacted negatively on the social life, emotional well-being of these caregivers (Gobrial, 2018). The same study also found the main themes as; inadequate education, inaccessible healthcare services and stigma as the conccerns by the mothers. There several challenges that have been identified ranging from delayed diagnosis, lack of information after the diagnosis of ASD, minimal support from the clinicians, family, community and institutional or government (L. Z. Kamau, 2017).

Several qualitative studies have been done in Kenya with similar themes, reported such as delayed diagnosis, despair and confusion about the problem and prognosis (L. Kamau et al., 2020) (Cloete et al., 2019). Similar findings in literature are; lack of social support, social stigma, isolation by the community as challenges faces by the parents/ caregivers of children with ASD (Papadopoulos, 2021) (L. Z. Kamau, 2017). Previous research shows caregivers challenges to be little support from the community due to cultural reasons being used to explain the cause of ASD in their children. Myths such as the woman being the cause of ASD, marrying from the wrong tribe, and supernatural causes being the community views of the causes of ASD (Cloete et al., 2019).

A study in Kenya on the experiences of caregivers of children with ASD, found ways of coping included; accepting their children’s disorder, receiving support and initiating the role of advocacy as a learning process of caring for children with ASD (Cloete et al., 2019). Research findings have suggested, provision of support throughout the process reduces negative impacts the diagnosis of ASD has on the family (Keenan et al., 2010).

Therefore, this qualitative study will investigate the in- depth lived experiences and challenges in caregivers of children with ASD. The aims in this study is to give insight into caregiving experience, and also provide knowledge that can be used to develop family focused interventions in Kenya. Several studies have been done making emphasis on the maternal experiences but this study will look at both paternal and maternal experiences.

Theoretical Framework

This study uses the stress process model that is particularly important in understanding caregiver burden and even in particular to this study, caregiver burden in caregivers of children diagnosed with Autism Spectrum Disorder. Pearlin et al. explains the stress process model as a combination of three major conceptual domains; the sources of stress, the mediator of stress, and the manifestation/outcomes of stress (Pearlin et al., 2011). Literature has put considerable interest to life events and chronic life strain. Coping and social support have been used as conditions capable of mediating the impacts of stressful circumstances and stress manifestation ranges from emotional, behavioral, and physical expressions.

The first domain which is sources of stressful life events and chronic stressors has been postulated to be a cause of burnout, burden, and even mental health problems. Autism spectrum disorder is of childhood-onset and lifelong (Hahler & Elsabbagh, 2015), has a chronic course with challenges from screening, diagnosis, and management which directly affect caregivers of such children. This study takes a child diagnosed with autism as the source of stress. These child characteristics includes; gender, current age, age at the time of diagnosis, and diagnosis of ASD with or without other comorbidities i.e., other mental or medical problems.

The stress process model's second domain is mediators; thus, with this concept it’s important to identify variables that impact the caregiving role. It is critical to identify mediators that play a role in caregiver burden that lessen the effects of the stressors (Raina et al., 2004) which include coping mechanisms and social support. Theses includes family empowerment and family coping mechanism that includes lifestyle changes, financial adjustments etc., to support the ASD child.

The stress process model’s third domain is outcomes. Pearlin’s stress process model suggest that there are stressors that affect the caregivers’ physical and mental health (Raina et al., 2004). When the theory is applied, caregiver burden and psychiatric morbidity in this study is an outcome that is affected by the caregivers' background and primary stressors are those factors that directly link to the individual and the disorder (Raina et al., 2004). The background/ context variables are considered caregivers factors such as gender, age, level of education, relationship to the child, economic status (monthly income) employment status, and marital status.

Conceptual framework

A conceptual framework explains the relationship between study variables. The diagram shows an adopted model of Pearlin’s stress process model and its relationship in this study.

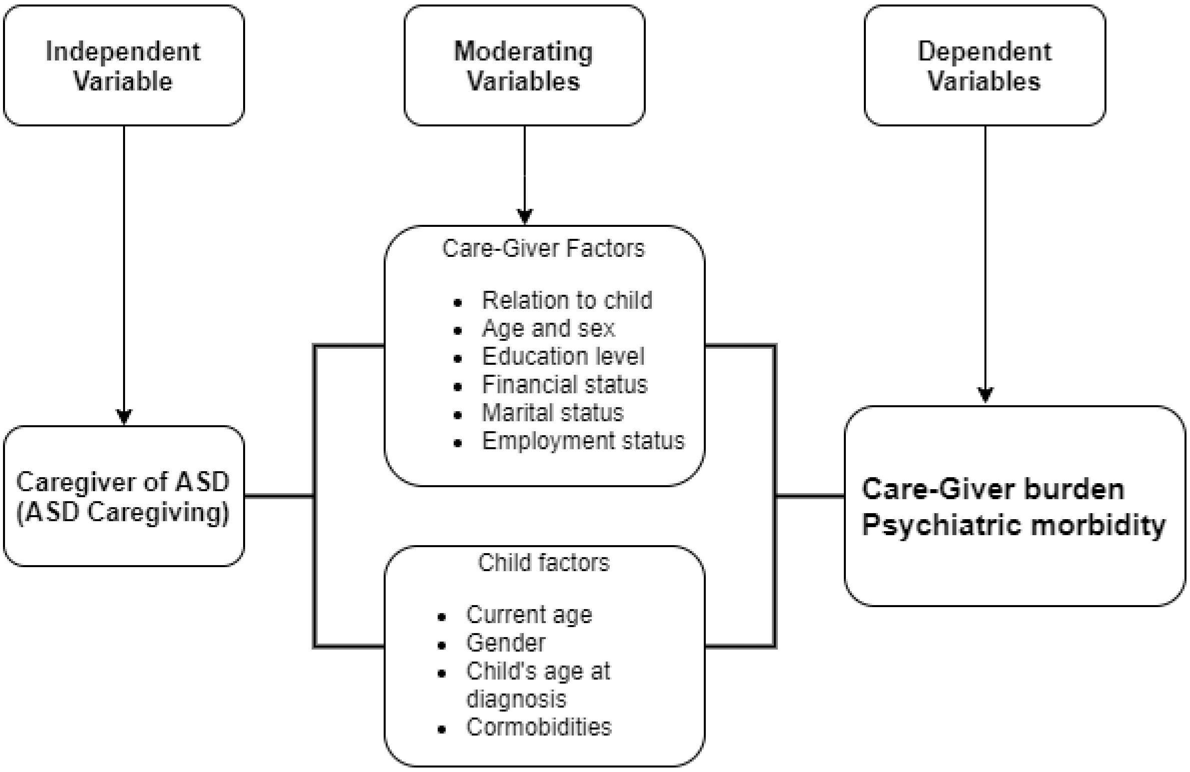


Figure 1; Conceptual framework

Study Justification

The long term effects include stress and could in the long run lead to psychiatric illness that would have otherwise not have occurred. Caregivers are most times neglected and not given priority, even when they bring their children to hospital, much focus being on the child. The caregiver role is life long and most of them may not even take care of their lives ensuring all needs of the child are met alongside other family related demands. This study will characterize the caregivers of the ASD children accessing KNH outpatient clinics. The study is important because it will find out more about the caregiver burden, mental well- being and experiences of these caregivers. Currently there is no recent documentation on the same in the country. The study will help inform on the importance of screening caregivers of ASD children and thus reduce psychiatric morbidity among this population and family setting at large. The information from this study will impress the head of departments and other stakeholders to develop tools for caregiver burden assessment. This will improve care given to ASD children and affect their prognosis positively.

Rationale/Significance

This results from the analysis of this study will contribute to the informational pool as to the mental well -being and challenges of caregivers attending to with ASD children. This study aims to provide great information to health professionals and also show the need to screen all caregivers of children with ASD. The screening will assist to lower mental health illnesses among this study population by early detection, treatment and provide supportive programs for the caregivers. Depending on the results, it can assist with specific intervention that are tailored to assisting the caregivers and improving their psychological, emotional and social state. The results will assist the ministry of health and the departments that are attending to ASD children with their caregivers, on planning, policy making and coming up with supportive methods that will assist the caregivers.

Research question

1. What is the level of caregiver burden among caregivers of children diagnosed with ASD attending outpatient clinics at KNH?

2. What is the caregiver characteristics and child characteristics associated with caregiver burden of children diagnosed with ASD (diagnosed with ASD), attending outpatient clinics at KNH?

3. What is the psychological well-being of caregivers of children with autism spectrum disorder?

4. What is the lived experience of caregivers of children with autism spectrum disorder?

Research objectives

Broad objective

To determine the burden of care in caregivers of children with Autism Spectrum Disorder attending outpatient clinics at Kenyatta National Hospital.

Specific objective

1. To assess sociodemographic factors in caregivers and the child diagnosed with ASD attending the outpatient clinics at Kenyatta National Hospital.

2. To identify caregiver characteristics and child characteristics associated with caregiver burden of children diagnosed with ASD attending out-patient clinics at Kenyatta National Hospital.

3. To screen for psychiatric morbidity of caregivers attending to children diagnosed with ASD attending outpatient clinics at Kenyatta National Hospital.

4. To investigate the lived experience of caregivers of children with ASD attending outpatient clinics at Kenyatta National Hospital.

Hypothesis statements of the study

Null hypothesis (H_0)

There is no caregiver burden among caregivers attending to children with autism spectrum disorder attending outpatient clinics at Kenyatta National and Referral Hospital.

Alternative hypothesis(H_1)

There is caregiver burden among caregivers attending to children with autism spectrum disorder attending outpatient clinics at Kenyatta National and Referral Hospital.

CHAPTER THREE

Methodology

3.1 Introduction

This chapter explains the methodology followed during this study with sections that include study design, area of study description, study population, sample size, sampling technique, recruitment and consenting procedure, data collection, data management, data analysis, and ethical issues.

3.2 Study design

This was a descriptive cross-sectional study using mixed methods (embedded) study design. The study sought to test the association between exposure factors and outcome of interest (caregiver burden) at a time-point.

3.3 Area of study description

This study was conducted at two outpatient clinics in Kenyatta National Hospital, Nairobi Kenya: child and adolescent psychiatry clinic, and occupational therapy clinic. KNH is a State Corporation established through Legal Notice No. 109 of 6th April 1987 with the mandate to receive patients on referral for specialized services from all over the country and neighboring countries and participates in national health planning. It is also a site for the training of medical students-undergraduate, graduate students and is a research institution for the University College of Health Sciences and other medical training institutions in Kenya (KNH, n.d.). KNH has a total of 22 outpatient clinics with child and adolescent psychiatry clinics and occupational therapy clinics being some of these clinics.

The child psychiatry clinic runs once every week in the Mental health department and attends to approximately 20 ASD children per month. They are attended to by different mental health workers this includes, consultant psychiatrists and psychologists. The management of ASD includes sensory integration thus all ASD children are also attended to in occupational therapy clinics.

The occupational therapy clinic is divided into three units including the sensory integration unit, the general pediatric unit, and the physical dysfunction unit. Children diagnosed with Autism Spectrum Disorder are followed in the sensory integration unit and speech therapy. On average 120 ASD children are attended to at the sensory integration clinic, on monthly basis.

3.4 Study Population

This study targeted caregivers of children (both male and female) diagnosed with ASD being attended to at KNH outpatient clinics- child and adolescent psychiatry clinic and occupational therapy clinic during the study period. This study selected the caregivers based on the method established in a study on the role of sleep problems in the decision of families to institutionalize elderly relatives (Pollak & Perlick, 1991). According to this method which was adopted by a study on caregiver burden in India (Ardhanaari et al., 2020), a primary caregiver met 3 or more of the following criteria;

1. Parent or guardian of the child with ASD
2. Most frequent contact with the patient
3. Supports patient financially
4. Most frequent collateral participant in the patient's treatment.

Inclusion criteria for this study;

1. Primary caregiver who were defined by the criteria above.
2. Caregivers who gave informed consent.
3. Caregivers whose age was between 18 years- 60 years of age.
4. Caregiver who attended to ASD children more than a year (one).
5. All children who had been diagnosed with ASD (both male and female).

Exclusion criteria for this study;

1. Caregivers who have been attending to the ASD child for a period of less than 1 year.
2. Caregivers who could not speak in English or Kiswahili.

3.5 Sample size

Cochran's (1977) sampling formula is applied to estimate the sample size. The formula;

$$\mathbf{n = \frac{z^2\, p\, (1-p)}{d^2}}$$

Where: **n** – Estimated sample size

d – The level of precision

p - Proportion of those with the condition of interest

z – Confidence level

Using a confidence interval of 95%, expected prevalence (p) of 79% (Mbugua et al., 2011) and a level of significance of 5% (0.05),

$$n = \frac{1.96^2 \times 0.79\,(1-0.79)}{0.05^2}$$

n = 255

Corrected sample size for finite population

$$n` = \frac{n}{1 + \frac{(n-1)}{N}}$$

Where, **n`** =adjusted sample size

n=sample size

N=population size

The population size of child psychiatry and occupational therapy clinics at KNH is estimated to be 140. Thus:

N= 140

Therefore n`=91

Allowing 10% non-response rate, sample size =100 caregivers of 100 children diagnosed with ASD.

3.5 Study recruitment and consenting procedure

-Purposive sampling method was used on the caregivers who accompanied the children booked for child psychiatry clinic on Mondays and Occupational clinic at KNH

-The investigator explained the nature of the study and what it entailed

-Participants were evaluated for those who met the inclusion criteria

-Those who consented signed an informed consent

-Questionnaire were administered and filled by the researcher

- In-depth qualitative interviews for qualitative data collection was conducted by the researcher.

3.7 Data collection procedure

Quantitative data collection procedure

Once the eligible participants had been identified and consented, the researcher allowed caregiver and the child to comfortably sit in a private room ensuring a distance of 2 meters between the researcher and participants as part of covid 19 safety guidelines.

The researcher ensured use of masks and always sanitization before and after every contact with a participant to observe Covid-19 protocols. Routine body temperature was measured before each consultation / therapy.

-The self-developed sociodemographic questionnaire was administered to the participant, Zarit Burden Interview and General Health Questionnaire were also administered by the researcher using the caregiver's preferred language (English/ Kiswahili). The 2 tools (ZBI and GHQ tools) had been translated to Kiswahili, which is the national language in Kenya.

-The data collection tools were administered by the principal investigator.

Qualitative interview procedure

-Once the eligible participant through purposive sampling was identified. Participants were selected those who can communicate effectively in English or Kiswahili.

-Informed consent was obtained for administering a questionnaire and the interview guide questions then the researcher allowed the caregiver and the child to a private room at the clinics observing all Covid- 19 safety guidelines.

- Semi-structured qualitative interview, was done using five open-ended questions were conducted by the principal investigator on 7 (Seven) study participants from the sample size. Audio recording was done during the interview.

-The data collected from the study was stored in a secure place awaiting analysis. Data stored on a computer was secured with a password to which only the researcher is privy.

3.8 Data collection instruments

Quantitative study

The data collection tools were composed of 3 parts;

The first part; A closed-ended questionnaire of socio-demographic profile of the caregivers raising a child with ASD was be administered. The variable of interest being the caregivers' age, gender, relationship to the child, marital status, educational background, employment status, income and religion. The study was to determine child factors i.e., as age, gender, age at diagnosis, and diagnosis of the child with or without psychiatric/ medical comorbidity have an association with caregiver burden.

The second part; Zarit Burden Interview ZBI (22 questions) was administered to the caregiver, it’s an assessment tool for caregiver burden that is widely used in the whole world (many studies). It’s a caregiver self-report measure that was developed to measure strain associated with the caregiving in adults with Alzheimer's disease (Zarit et al., 1980). Originally the tool was developed as the Burden Interview, a 29- item self-report inventory, which included questions in areas described by caregivers as problems in their life that is caregivers’ health, psychological well-being, finances, social life etc. The Zarit Burden Interview had a 4- point Likert-type response scale, with a possible total burden score of 84 (Zarit et al., 1980). The ZBI was later reduced to 22- items, with a 5- point Likert type response scale, is a widely used instrument to assess caregiving burden both in clinical and research settings (Amirkhanyan & Wolf, 2003) (Dada et al., 2011) (Pandey & Sharma, 2018).

This tool includes total score ranges from 0-88 with the total score calculated by addition of all the item scores and high scores indicate a higher level of burden. ZBI has been diversly used on different population of caregivers and translated into several languages such as; German, Hebrew, Japanese, Korean, Chinese and used in diverse range of patient populations (e.g. cancer, developmental disorders, psychiatric illness and stroke) (Bachner & O’Rourke, 2007). In Kenya, ZBI it has been widely in several studies in the country and standardized tool that has been validated. A previous study on the assessment of needs, care in the homes and clinical trends among the elderly in Kenya, ZBI was used as a tool for assessment (D. Ndetei et al., 2010).

The ZBI was administered to parents to fill out assessing both subjective and objective burdens associated with their parenting role, taking approximately 10 to 15 minutes to fill out. The interpretation of the score was as; 0-20 points mean little or no burden, 21-40 points mean mild to moderate burden, 41-60 points mean moderate to severe burden, 61-88 points mean severe burden.

This tool included factors described by caregivers such as their physical, psychological health, finances, social life and relationship with the patient (Dada et al., 2011). The ZBI items are sorted into three scales:

-Personal Strain Scale (items 1, 4, 5, 6, 9, 13, 14, 16, 18, and 19)

-Role Strain Scale (items 2, 3, 7, 8, 10, 11, 12, 15, 17, and 22)

-Guilty Scale (items 20, 21)

Third part; a General Health Questionnaire lastly was administered to the caregivers. It's a 12 item- version which was used to screen psychiatric morbidity in the caregivers. It is was designed as a self-administered tool sensitive to detect any psychiatric disorder even in this study, among caregivers of children with ASD. It's a validated tool that has been used in several studies in the country that evaluates 3 factors; anxiety and depression, social dysfunctions, and loss of confidence (Graetz, 1991). GHQ has also been used by authors in the local context (D. Ndetei et al., 2010).

Qualitative study

First, study participants will complete a sociodemographic questionnaire before the interview. Qualitative interviews elicited in-depth perspective of 7 (Seven) study participants throughout the course of the child's disorder from past to present. During the interview the participant described, in their own words, feelings they had when the diagnosis of ASD was made, how raising an autistic child has affected their personal, family life, social life, challenges they have faced and lastly ways of coping. The questions from the interview guide include; 'How has it been like caring for a child with autism spectrum disorder?' 'How do you cope with the challenges identified?' The questions were short, open ended, to the point and were meant to make the participant comfortable.

During the interview, based on responses of the participants, extra probes added information regarding the themes study participants perceive as most relevant. The researcher took notes as well as audio recordings during the interviews.

3.9 Data collection flow chart

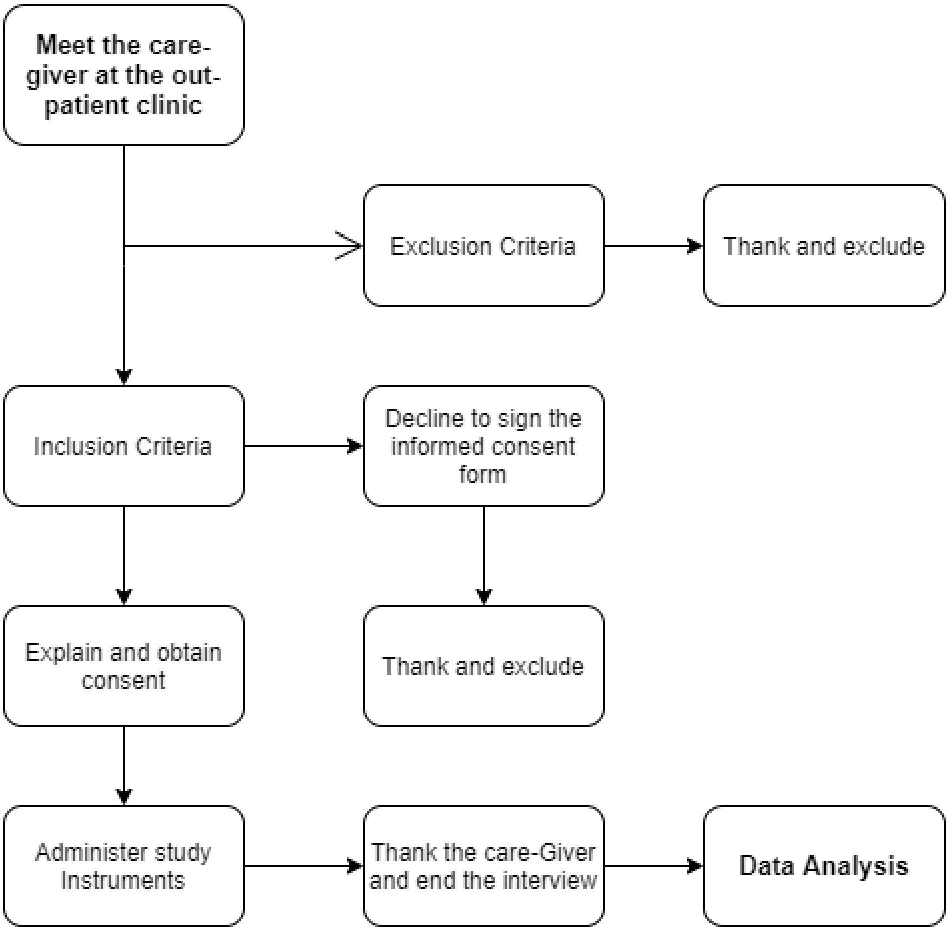


Figure 3.1 Data collection flow chart.

3.10 Quality assurance

The questionnaire was be pre-tested to avoid pitfalls after administering data collection tool. Pretesting allowed the researcher to administer the questionnaire on a smaller group (10 participants) to get feedback and corrections from Kenyatta National Referral Hospital. The questions if they are relevant, clear, and understandable.

Quality and accuracy of data during qualitative interview was achieved through audio recordings then subsequently transcribed verbatim by the researcher was done.

3.11 Ethical Consideration

1. This study was conducted under the supervision of two lecturers at the University of Nairobi's Department of Psychiatry.
2. Approval to perform this study was sought and given from the Scientific Ethics and Research Committee of the University of Nairobi, Kenyatta National Hospital (KNH-UON ERC).

3. Department of research at the Kenyatta National Hospital was informed of the intention to carry out the study at their departments and the purpose of the study was explained and documented, consent was sort to collect data from children and adolescents' psychiatry clinic and occupational therapy clinic.
4. Study participants' names were not recorded but unique study identification numbers were used to protect the confidentiality and anonymity of respondents.
5. Informed consent form was filled for each study participant, filling in the questionnaire and writing notes as well as recorded interview session.
6. Completed data collection forms was stored in cabinets that are lockable with controlled access by the principal investigator.
7. Data was handled with confidentiality and no external intrusion data stored on the device was secured with a password that only the principal investigator is privy to.
8. Double entry and checking procedures were done in the entry of data to minimize errors.
9. The results obtained from the data collected was presented at the University of Nairobi department of psychiatry
10. Publishing of the study results will then be done in a peer-reviewed journal.

3.12 Data management

Data coding and data entry

After data enumeration, the researcher ensured proper and complete data entry. Collected data was transported to a central place where it will be stored under lock and key. At the central place, data was coded.

In a Microsoft Access application, a prototype was developed. The template will specified the name (name of the field), the form (character or numeric) and the length of each variable, and the number of decimal places for the numeric variables and then data entry was made**.**

Data cleaning

Quantitative data cleaning was done using Microsoft Excel. Once any errors were detected, they were corrected. A clean dataset was stored in a computer hard disk ready for analysis. Cleaning and validation were done when the data has been entered, checked, and corrected. The qualitative data was organized and data cleaned using Microsoft Word so as to develop a thematic framework.

Statistical analysis

Quantitative data was analyzed using Microsoft Excel software (Microsoft Office, Santa Rosa, California, USA) and SPSS® Version 23 software (IBM, New Orchard Road Armonk, New York, USA). Means and medians were calculated in continuous variables and frequencies and proportions in categorical variables.

Univariate analysis was done to show the socio-demographic characteristics the caregivers who are the study subjects and also their children diagnosed with ASD. Bivariate analysis was done comparing exposure factors to the outcome variable (Little to moderate burden/moderate to severe burden). The primary exposure factors in each group were socio-demographic factors of the caregivers, and child factors. Multivariate analysis was conducted for variables with <0.05 P value in bivariate analysis. T-test, Pearson's correlation, were conducted to examine factors related to caregiver burden by setting statistical significance at p<0.05.

Qualitative data was analyzed to state the participants' unique perspectives in regard to raising a child with autism, through a detailed examination of their perceptions and life experiences. More focus was on subjective point of view of the participants than on factual data during text review. Then the researcher read and reread each participant's transcript separately in order to familiarize with the data and obtain a holistic participants' thoughts and feelings then record each observation and comments.

In the next phase, the researcher performed line- by -line coding of each interview transcript. Transcribing was done in Microsoft Word the data run through NVivo software for thematic analysis approach. Codes were clustered into subcategories, then labelled with descriptive phrases, reducing into themes.

CHAPTER 4

4.0 DATA RESULTS

4.1 Introduction

This chapter presents data analysis, interpretation and presentation of the data analyzed. The first part outlines caregiver's socio-demographics factors and also, child factors, second part: covers the main focus, which was to assess caregivers' burden in caregivers of children diagnosed with ASD. Third part shows caregivers factors associated with caregiver burden according to the objectives. Fourth part gives a descriptive analysis of the psychiatric morbidity among the caregivers and lastly their lived experiences and challenges they face while caring for autistic children.

Ninety-one (91) caregivers of children diagnosed with Autism Spectrum Disorder attending out-patient clinics in KNH were recruited into the quantitative study with 100% response rate. 7 caregivers caring for children diagnosed with Autism Spectrum Disorder, whose children were attended to in KNH were also recruited into the qualitative study. All data collected was analyzed to respond to each study objective.

The results were as presented below.

4.2 Socio-demographic Characteristics of the caregivers

Results of the socio-demographic characteristics as shown in Table 1 indicate that the mean age of caregivers was 34.9 (SD 6.7) years, where minimum age was 22.0 years, and the maximum was 53.0 years. The median age was 34.0 (Inter Quarter Ratio 31.0 – 39.0) years.

The majority of the caregivers were aged 30 years and 39 years (52, 57.1%). The females formed the largest group of caregivers, 89% (n=81). Most of caregivers were mothers, 83.5%(n=76). Among all caregivers 92. 3% were Christians (n=84), 7.7% (n=7) Muslims, 56% (n=51) had attained tertiary level of education, 80.3% (n= 70) were employed/self-employed while 19.8% (n=18) were unemployed, while majority of the caregivers were married at 84.6% (n=77). 41.8% (n=38) earned less than 20,000 Kenya Shillings, while 20.9% (n=19) had no income at all and thus dependent on their spouses or other sources of income. 20. 67 % (n=61) of the caregivers indicated their monthly income was insufficient to meet their basic needs while 13.2% (N=12) has sufficient amount of money.

Table 1; Socio- demographic characteristics of participants (91).

	Frequency (91)	**Percent**
Age		
20 – 29	19	20.9
30 – 39	52	57.1
40 – 49	17	18.7
≥50	3	3.3
Gender		
Male	10	11.0
Female	81	89.0
Relation to patient		
Father	9	9.9
Mother	76	83.5
Other relative	6	6.6
Religion		
Christian	84	92.3
Muslim	7	7.7
Education		
Primary	12	13.2
Secondary	28	30.8
Tertiary	51	56.0
Employment		
Employed/Self-employed	73	80.2
No employment	18	19.8
Marital status		
Single	9	9.9
Married	77	84.6
Separated/Divorced	5	5.5
Residence		
Urban	79	86.8
Rural	12	13.2
Monthly net income		
Less than 20000	38	41.8
20001 – 35000	19	20.9
35001 – 50000	12	13.2
Above 50000	3	3.3
No income	19	20.9
Income sufficiency		
Insufficient	61	67.0
Barely sufficient	18	19.8
Sufficient	12	13.2

Clinical and other characteristics of study participants (n=91).

Majority of the caregivers at 92.3% (n= 84) had no training about ASD. 95.6 % (n= 87) didn't report any psychiatric illness while 4.4 % (n=4) reported to have suffered depression and anxiety disorders.

Table 2; Clinical and other characteristics of study participants (91).

Training on Autism		
Not once	84	92.3
Once	4	4.4
Twice	2	2.2
Three and more	1	1.1
Psychiatric illness		
Yes	4	4.4
No	87	95.6
Psychiatric illness type		
Anxiety	1	1.1
Depression	3	3.3
NA	87	95.6

4.3 Socio-demographic Characteristics of the ASD children

For children, the male (n=69) and female (n=22), giving a ratio of 3 males to 1 female (3:1). Mean age of the children was 4.8 (SD 2.6) years, where the minimum age was 2.0 years, and the maximum was 12.0 years. The median age was 4.0 (Inter-Quarter Ratio 3.0 – 5.0) years. The mean age of the children at ASD diagnosis was 3.2 (SD 1.4) years, minimum age was 2.0 years while maximum was 10.0 years. The median age was 3.0 (IQR 2.0 – 4.0) years.

Majority 62.6% (n=58) of the children had ASD, 27.5% (n=25) diagnosed with ASD and Attention Deficit Hyperactivity Disorder and, while 9.9% (n=9) had a working diagnosis of ASD with another medical condition; 4 had convulsive disorder, 2 cerebral palsy, 1 delayed milestone, 1 hearing loss with rickets, 1 rickets**.**

Table 3; Sociodemographic characteristics of the ASD children

Child's sex	**Frequency**	percentage
Male	69	75.8
Female	22	24.2
Child's age		
2	10	11.0
3	25	27.5
4	19	20.9
5	15	16.5
≥6	22	24.1
Child's age at diagnosis		
2	32	35.2
3	32	35.2
4	15	26.5
5	6	6.6
≥6	6	6.6
Family children with ASD		
Yes	13	14.3
No	78	85.7
Working diagnosis		
ASD	58	62.6
ASD with another psychiatric diagnosis	25	27.5
ASD with another medical condition	9	9.9

4.4 Caregivers' burden

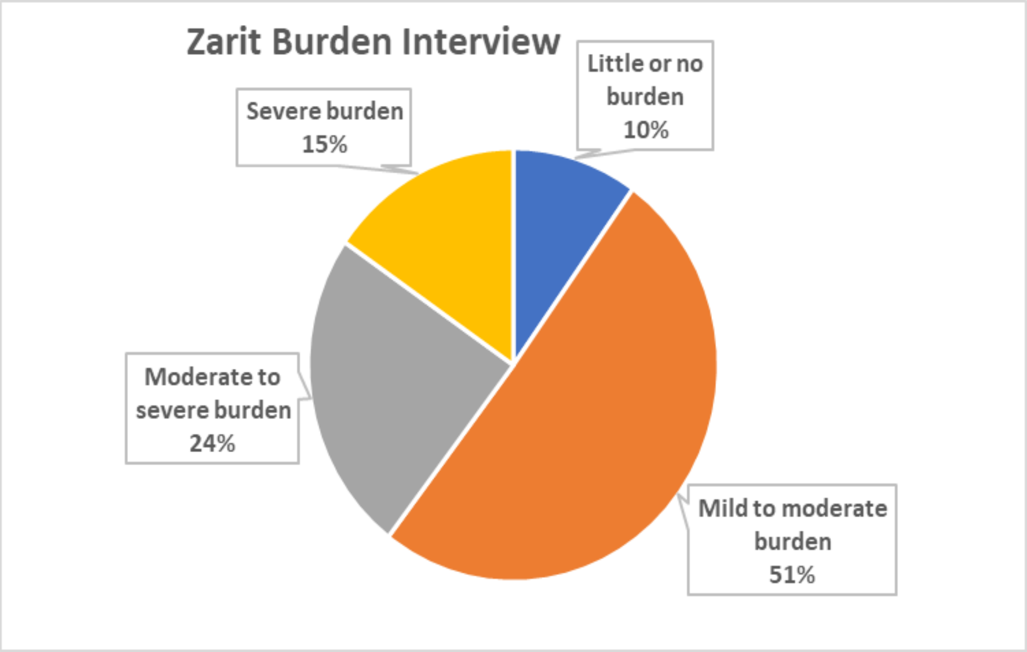
This is presented in Table 4 and figure 3. 9 study participants (9.9%) didn't experience burden, 46 (50.5%) participants had mild to moderate caregiver burden, 22 (24.2%) has moderate to severe, 14 (15.4%) had severe burden.

Table 4; Caregiver burden

Majority of the caregivers (50.5%, n= 46) in this study experienced mild to moderate burden (scores ZBI 21-40), while 24.2% (n= 22) had moderate to severe burden (ZBI 41- 60), 15.4% n=14 had severe burden (61-88) and the least of the caregivers 9.9% n=9 experienced no/little burden

	Frequency	**Percent**
Little or no burden (0-21)	9	9.9
Mild to moderate burden (21-40)	46	50.5
Moderate to severe burden (41-60)	22	24.2
Severe burden (61-88)	14	15.4

Figure 3; The Burden of care (pie chart)



4.5 Association between caregiver characteristics and caregiver burden

Table 4 shows the burden score was statistically significant in relation to gender (p value of less than 0.042) while employment status (p value was less than 0.022). This study found no significant association between burden scores and age, relationship to the patient, religion, education level, marital status, residence, monthly net income and income sufficiency.

Table 4; The association between caregiver's characteristics and caregiver burden

	Little or no burden	Mild to moderate burden	Moderate to severe burden	Severe burden	p-value
Age					
20 – 29	3 (33.3)	10 (21.7)	3 (13.6)	3 (21.4)	0.841
30 – 39	6 (66.7)	25 (54.3)	12 (54.5)	9 (64.3)	
40 – 49	0 (0.0)	9 (19.6)	6 (27.3)	2 (14.3)	
≥50	0 (0.0)	2 (4.3)	1 (4.5)	0 (0.0)	
Gender					
Male	1 (11.1)	3 (6.5)	6 (27.3)	0 (0.0)	**0.042**
Female	8 (88.9)	43 (93.5)	16 (72.7)	14 (100.0)	
Relation to patient					
Father	1 (11.1)	3 (6.5)	5 (22.7)	0 (0.0)	0.188
Mother	8 (88.9)	38 (82.6)	17 (77.3)	13 (92.9)	
Other relative	0 (0.0)	5 (10.9)	0 (0.0)	1 (7.1)	
Religion					
Christian	9 (100.0)	44 (95.7)	18 (81.8)	13 (92.9)	0.189
Muslim	0 (0.0)	2 (4.3)	4 (18.2)	1 (7.1)	
Education					
Primary	2 (22.2)	3 (6.5)	2 (9.1)	5 (35.7)	0.057
Secondary	1 (11.1)	13 (28.3)	10 (45.5)	4 (28.6)	
Tertiary	6 (66.7)	30 (65.2)	10 (45.5)	5 (35.7)	
Employment					
Employed/Self-employed	5 (55.6)	42 (91.3)	16 (72.7)	10 (71.4)	**0.022**
No employment	4 (44.4)	4 (8.7)	6 (27.3)	4 (28.6)	
Marital status					
Single	0 (0.0)	4 (8.7)	1 (4.5)	4 (28.6)	0.235
Married	9 (100.0)	40 (87)	19 (86.4)	9 (64.3)	
Separated/Divorced	0 (0.0)	2 (4.3)	2 (9.1)	1 (7.1)	
Residence					
Urban	8 (88.9)	41 (89.1)	19 (86.4)	11 (78.6)	0.728
Rural	1 (11.1)	5 (10.9)	3 (13.6)	3 (21.4)	
Monthly net income					
Less than 20000	1 (11.1)	22 (47.8)	8 (36.4)	7 (50)	0.121
20001 – 35000	2 (22.2)	9 (19.6)	6 (27.3)	2 (14.3)	
35001 – 50000	2 (22.2)	8 (17.4)	1 (4.5)	1 (7.1)	
Above 50000	0 (0.0)	3 (6.5)	0 (0.0)	0 (0.0)	
No income	4 (44.4)	4 (8.7)	7 (31.8)	4 (28.6)	
Income sufficiency					
Insufficient	5 (55.6)	27 (58.7)	17 (77.3)	12 (85.7)	0.150
Barely sufficient	1 (11.1)	13 (28.3)	2 (9.1)	2 (14.3)	
Sufficient	3 (33.3)	6 (13.0)	3 (13.6)	0 (0.0)	

4.5.1 The predictors of burden (caregiver factors)

Multivariate analysis using the ordinal regression model was done, neither gender or employment status was a predictor to burden severity as shown in table 5 below.

Table 5; Multivariate analysis of caregivers factors associated with burden

Variable	**Cumulative logit (95% CI)**	**p-value**
Gender		
Male	Reference	
Female	0.7 (0.2 – 2.2)	0.561
Employment		
Employed/Self-employed	0.7 (0.3 – 1.9)	0.476
No employment	Reference	

4.6 Characteristics of the children in association with caregiver's burden

Table 6 indicate the findings of this study. Mean age and age of the children at the time of diagnosis was found to be statistically significant at the bivariate analysis while child factors were not statistically significant.

Table 6; Characteristics of the children in association with caregiver's burden

	Little or no burden	**Mild to moderate burden**	**Moderate to severe burden**	**Severe burden**	**p-value**
	(n=9)	**(n=46)**	**(n=22)**	**(n=14)**	
Age, *Mean (SD)*	3.2 (1.0)	4.4 (2.4)	5.8 (3.0)	5.7 (2.9)	**0.020**
Gender of child, *n (%)*					
Male	8 (88.9)	31 (67.4)	19 (86.4)	11 (78.6)	0.260
Female	1 (11.1)	15 (32.6)	3 (13.6)	3 (21.4)	
Age at diagnosis, *Mean (SD)*	2.4 (0.5)	3.0 (1.4)	3.4 (1.4)	4.1 (1.6)	**0.020**
Family children with ASD, *n (%)*					
Yes	0 (0.0)	11 (23.9)	1 (4.5)	1 (7.1)	0.064
No	9 (100.0)	35 (76.1)	21 (95.5)	13 (92.9)	
Working diagnosis, *n (%)*					
ASD	7 (77.8)	31 (67.4)	14 (63.6)	5 (35.7)	0.081
ASD with another psychiatric diagnosis	1 (11.1)	14 (30.4)	4 (18.2)	6 (42.9)	
ASD with another medical condition	1 (11.1)	1 (2.2)	4 (18.2)	3 (21.4)	

4.6.1 Predictors of burden (child factors)

The children age and age at the time of diagnosis are the predictors of burden. This study found each unit increase of child's age increases the odds of a higher burden by 1.2 times but this was not statistically significant (p <0.055), but the age of diagnosis results indicate that each unit increase of the child's age increases the odds by 1.4 times and this was statistically significant (p <0.035) at the multivariate analysis.

Table 7; The multivariate analysis of factors associated with burden

Variable	Cumulative logit (95% CI)	p-value
Age	1.2 (1.0 – 1.4)	0.055
Age at diagnosis	1.4 (1.1 – 2.0)	**0.035**

4.7 Psychiatric morbidity among caregivers caring for ASD children

The mean score of the GHQ-12 was 22.91 (SD =10.56), which was above the cut-off points of 12. This indicated that the mental health of the respondents was in very poor condition. In particular, the highest scores were for items 1, 2, 5,7 which were equal and more than 2.10. The average score of items 7 was 2.55 (SD = 0.78), as the highest, indicating the participants who didn't enjoy their daily activities where 52.8% thus enjoyed their activities less than usual (score of 2) and much less than usual (score of 3). The average score for item 1 was 2.53 (SD=0.87) meaning 62.6% they could not concentrate on doing things. Scores for item 2 was 2.10 (SD=1.01) meaning 59.4% had not lost sleep over worry. Item 5 had a mean of 2.41(SD=1.08), 55% of the participants felt they were constantly under strain.

Table 8; Descriptive statistics for GHQ-12 items among the caregivers (N=91)

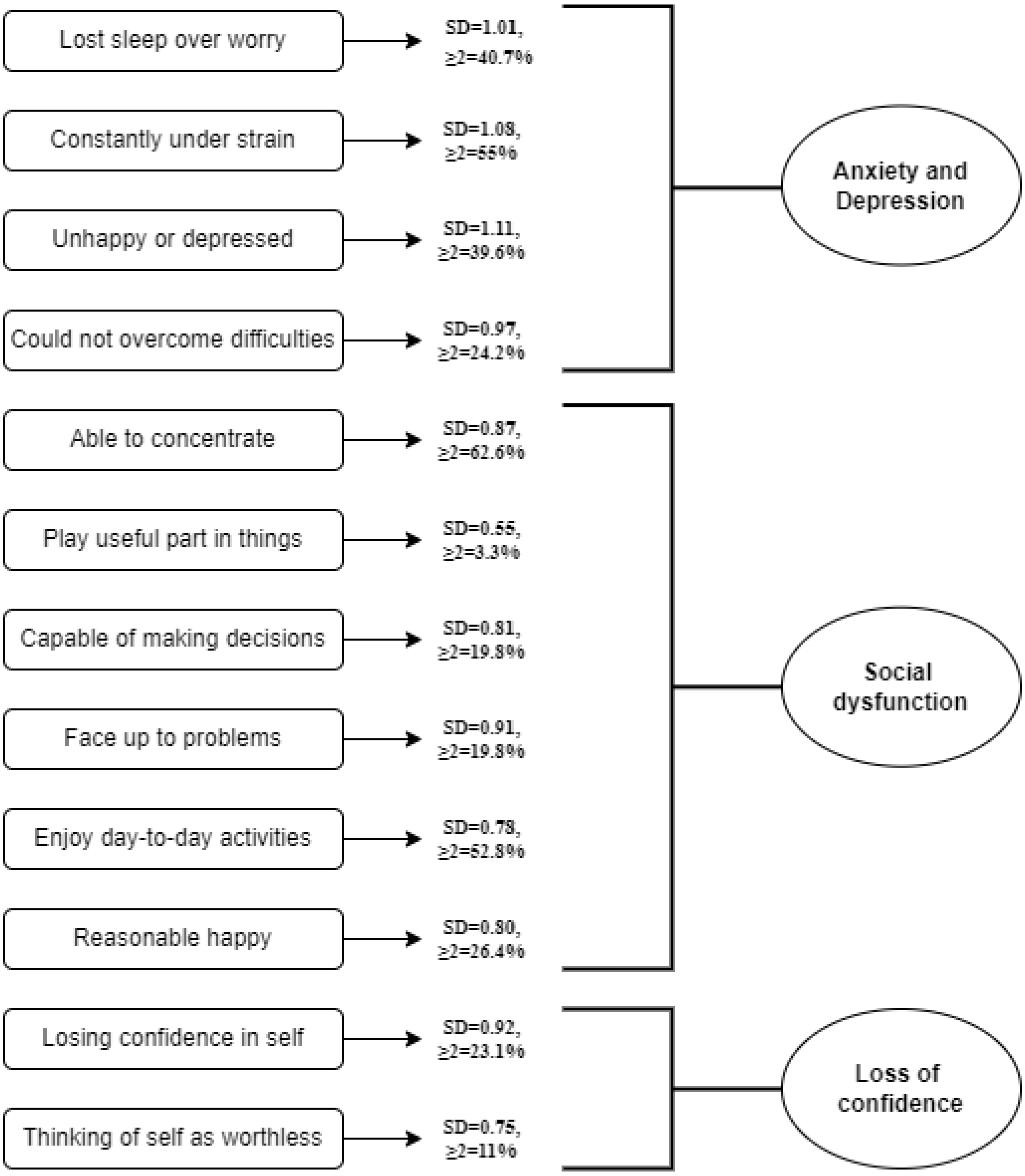
	Mean	**Standard deviation**	**Response Frequencies in percentage**			
			0	**1**	**2**	**3**
1. Concentrate on doing things	2.53	0.87	17.6	19.8	54.9	7.7
2. Lost much sleep over worry	2.10	1.01	38.5	20.9	33.0	7.7
3. Playing a useful part in things	1.25	0.55	79.1	17.6	2.2	1.1
4. Capable of making a decision	1.71	0.81	49.5	30.8	18.7	1.1
5. Constantly under strain	2.41	1.08	29.7	15.4	39.6	15.4
6. Couldn't overcome difficulties	1.67	0.97	62.6	13.2	18.7	5.5
7. Enjoy daily activities	2.55	0.78	7.7	39.6	42.9	9.9
8. Face-up your problems	1.80	0.91	46.2	34.1	13.2	6.6
9. Unhappy and depressed	2.02	1.11	48.4	12.1	28.6	11.0
10. Losing confidence in self	1.58	0.92	68.1	8.8	19.8	3.3
11. Worthless person	1.27	0.75	86.8	2.2	7.7	3.3
12. Reasonably happy	2.02	0.80	27.5	46.2	23.1	3.3
Mean GHQ Score	22.91	10.56				

SD- standard deviation

A higher score indicates a worse situation

Item 1, the caregivers reported not to concentrate on what they were doing, 62.6 % (n=91) of the caregivers had less than usual (scores of 2) and much less than usual (scores of 3) on the GHQ-12 tool. On Item 7, 52.8% (n=91) of the participnats reported not to enjoy their day to day activities less than usual (score of 2) and much less than usual (score of 3). Item 1 and 7 are symptom of social dysfuction. The study found 55% (n=91) of the caregivers felt constantly under strain scoring 2 and 3 on the GHQ-12 tool on item 5. Item 5 is indicative that the caregivers had symptoms of anxiety and depression. Item 2, where the majourity of caregivers reported not to have lost sleep over worry 59.4 % (n= 91) of the caregivers i.e not at all (scores of 1) and no more than usual (scores of 2) on the GHQ-12 tool.

Figure 4; Shows item scores (percentage and SD) of > 2 in the GHQ-12 tool



4.7.1 Comparison of the GHQ mean score

The difference in the average mean score between male and female scores were not statistically significance which is shown in table 8. An independent samples t-test was done to determine if there were differences in the mean scores between male and female participants, the results indicated there were no statistical differences (p=0.786).

Table 9; Comparison of the GHQ mean score

	n	**Mean**	**Standard Deviation**	**p-value**
Male	10	23.4	5.3	0.786
Female	81	22.9	5.9	

4.8 A Correlation between GHQ and ZBI

A correlation between GHQ and ZBI was tested with the use of Pearson Correlation, of which the results reveal that the relation was moderate and statistically significant (r=0.580, p<0.001).

Table 10; A Correlation between GHQ and ZBI

		ZBI
GHQ	Pearson Correlation	0.580
	p-value	**<0.001**
	N	91

4.9 Results of the qualitative narratives

A qualitative study using individual interview of the caregivers was done to investigate the lived experience of the caregiver and below are the results. The study interviewed 7 participants, of which 6 of them were females and 1 was male, and their mean age was 36.6 (SD 8.8) years, where the youngest of them was 28.0 years and the oldest being 53.0 years. Five of them were mothers to the children, while 1 was a father, and the other a grandmother to a child. They were all Christians. For marital status, 4 of them were married while the other 2 had separated from their spouse. All lived in urban area. There were 6 male children and 1 female child.

Table 10; Participants Characteristics

	1	2	3	4	5	6	7
Participant	Grandmother	Mother	Father	Mother	Mother	Mother	Mother
Age	58	37	28	41	30	29	38
Religion	Christian	Christian	Christian	Christian	Christian	Christian	Christian
Level of education	Secondary	College	Secondary	College	College	College	College
Employment status	No Employment	Employed	Employed	Employed	No employment	Employed	Employed
Marital status	Separated	Married	Married	Married	Married	Separated	Married
Residence	Urban	Urban	Urban	Urban	Urban	Urban	Urban
Age of the child	4 years 6 months	3 years	3 years	5 years	3 years	2 years 6 months	12 years
Gender	Male	Male	Male	Male	Male	Female	Male

4.9.1 Caregivers feelings at the diagnosis of their child

The participants were asked about how they felt when they heard their child was diagnosed with ASD and the overall effect of raising their children. Some mothers were tearful during the interview when describing their feelings of overwhelming emotions about their child's diagnosis, daily struggles related to caring for their children and they also raised concerns about their child's future in comparison to a normal child.

4.9.1.The emotional reaction to the child's diagnosis

The responses were similar across board of which they mentioned shock, devastation, surprise, and being stressed out. The responses from some of the participants is as below:

"I felt so bad, I was wondering what is this unfortunate thing that is following us as a family."

(Client 1)

"I was devastated, I was in denial, and I didn't want to believe that my child had Autism. I was sure it was developmental delay, but as time went by and through a lot of research, talking with relatives I was able to accept that he had Autism, and I knew if I don't accept, I will not be helping him, but once I accepted, I was able to do more research, especially on early intervention."

(Client 2)

"I was stressed out. You know I had stayed in this marriage for a long time without a kid. Now, that I got the boy it was my expectation that he will be like a normal child, and I didn't know he was going to get another problem, and he is the only one I have as per right now."

(Client 4)

"It broke my heart, because it's something I didn't expect, as in nobody likes things like these."

(Client 6)

"It was devastating, and I was shocked."

(Client 7)

Most of the participants expressed their feelings about the diagnosis but one mother went ahead to express her concern with the child's future

"It was just a confirmation, I had already queried autism, so when they confirmed I just expected it. I felt really bad, I got worried, especially about our future, I understood he was not like normal kids."

(Client 5)

4.9.2 How it had been like raising a child with ASD

The second item of the interview guide for the participants were to determine how their experience was raising children with Autism Spectrum Disorder. All the participants expressed challenges and difficultly while raising their children. Some participant raised concerns with the child's behavior which were worrisome and difficult to handle.

"He appears not to be aware of any danger, he doesn't even know if a car on the road can be a danger and hit someone, he doesn't know if he climbs something that he can easily fall. He doesn't know anything dangerous."

(Client 1)

"It has been difficult, though there are things I can say he can do by himself like going to the toilet, he can do it. The challenges I face are like moving around, the boy can't just settle, like he can leave me in the house and go far away, and that has really been disturbing me."

(Client 4)

A mother expressed difficulty with raising the child because of the child's lack of communication.

"Am really trying, plus the help am getting from the doctors, especially the Psychiatrist, but with the help from everyone, we are trying. The challenge I get is being able to calming her down, and her inability to communicate is the biggest problem, as you know communication is the key to everything, because if you can't communicate then it's hard to know what does she want.

(Client 6)

This mother expressed distress of not knowing who they could rely on, to help their child. The theme was a sense of frustration and uncertainty.

"It's always a new experience, and it's very challenging, because the younger one also had symptoms, but with time so I had already learnt one or two things, so I was able to know what to do. Getting house helps to assist has been a little bit challenging."

(Client 7)

4.9.2 Relationship with other children in the family (siblings)

All the participants across board expressed optimism about handling the child with ASD and other children in the family.

"It has not really affected, I do still do normal routine with the other two children, I take them to school, and still pick them up, because it appears that my daughter will not be able to do it. Even for the girls we hire to assist in the house, they are only here for house chores, because the girls would not know what the needs of the kid are, and since I am always with the children, I would always know what they need."

(Client 1)

"They are well, they normally understand him"

(Client 3)

"According to the teacher, she doesn't have a problem playing with other kids"

(Client 5)

"The siblings have been ok, since we have explained to them that it's normal for someone to be born with a disability, so they should be able to understand their brother, plus also they have their own activities."

(Client 7)

One mother had no any other child and thus had a different response

"I don't have other children, so it has not affected me."

(Client 4)

Relationship with spouse

All the participants expressed mixed feelings but most reported their spouse to be supportive but challenging to care for an autistic child, though there was a single participant who expressed disagreement and strife with her spouse.

"He is taking it positively, and that is one thing I am happy about him, and if there is any support system for myself, it's my spouse. He tells me it's going to be ok, and he's very active on anything that the baby needs unless he's not able to do, he's very active. He provides, and spends time with him."

(Client 2)

Client 3, a father expressed the concerns of the wife (mother to the child) being at work and also as the sole provider of the family, his less hours with the child during the day because of his work made caregiving challenging because the child has to be under the care of some else whom they may not fully trust.

"It has been challenging, because for one, she's working, so most of her time she spends at work rather than spending it with the child. So, you might not be able to know the kind of relationship he might have with the house help, and how they relate in the course of the day from morning till evening."

(Client 3)

"He's ok, I have not seen him change his day-to-day routine"

(Client 4)

Client 5, a mother separated with her spouse after continuous disagreement with how to handle their child with ASD.

"I used to complain a lot. I used to say, "This kid has a problem, why is she not talking at all, she's one and a half?" He used to say, your work is only to overthink, and this could bring arguments. When he left, it was not because of her, but when you think about it, I guess it was about her. Yeah, it was about her, because I became protective of her, and the father wanted to go with her where I didn't know, and I wasn't for the idea because I was afraid how she might be treated in my absence, so when I stopped him from taking her anywhere, he would get angry, and this brought a lot of issues, and I think, that's the reason he left, after that argument."

(Client 5)

Relationship with relatives

All the most common response was that their relatives were supportive to them while caring for their children with ASD.

"My own relatives have been giving great support."

(Client 1)

"They are very accommodating of him on both sides."

(Client 2)

"The relatives are ok, but also you cannot know what is in one's mind. You see it is our kid, and it is our responsibility, and we cannot leave that to our relatives or anyone else."

(Client 3)

"My mom and my aunt are very supportive because we already have another autistic kid, but for my mom, this stuff really affects her since she is the one who takes care of the two. You can imagine how tough it is to take care of two autistic kids. It really affects her, you find most times she's not happy, because she's wondering, my sister has this one, and then my daughter has this one again."

(Client 5)

Relationship with neighbors

The participants gave varied responses but most common theme coming out was lack of understanding. The neighbors talk about their autistic child whose behaviors are different from other children.

"Now like where we had moved from, the neighbors had started talking about him in terms of, they inquired how we bore a child that is not normal, his age mates have gone to school, and they are speaking, so we just kept to ourselves."

(Client 1)

"They don't understand him, and yet we don't have the time to explain."

(Client 2)

"As I said you can't tell what's in someone's mind about your kids. Maybe they talk behind your back, and you will never know anything about that. But like I said, it's our kid and we have to take full responsibility regardless of what people might talk positively or negatively about it."

(Client 3)

This mother reported about her child's behavior following the diagnosis of ASD.

"The boy normally stays alone; he can't play with many children. He can play with them at times but within few minutes, he leaves."

(Client 4)

This mother expressed minimal interaction with her children and neighbors.

"We don't take them outside, but they go to school"

(Client 5)

Relationship with employer

The participants responses were varied, for those employed some of them mentioned their employers were understanding and supportive. Those self-employed, some mentioned taking the child wherever they go. While others just mentioned it had been tough.

"They are very understanding and they know about the spectrum, and they are very cooperative and supportive too."

(Client 2)

A mother expressed overwhelming feeling because of lack for time spent alone. Following a tedious time at work, when she reaches at home, she needs to take care of an autistic child who needs her attention.

"With the kind of work I do, it's tough, and there are times you just want to have time to yourself."

(Client 3)

"*Since I do my own business, I normally go with him"*

(Client 4)

4.9.2 Financial challenges

Financial challenges and strain were a common theme expressing their financial state as being difficult. Families had to make changes to accommodate the expenditure of their child. Several issues could explain the financial strain such as poor insurance coverage for needed services and higher costs for intense interventions (i.e., speech and occupational therapy). The parents expressed the challenge time of attending to their work to raise finances to take care of their families and also their time being consumed while attending to their child's health in the hospital. None reported stopping to access hospital services due to lack of finances.

"It has been challenging and difficult, everything you do is about money, bus fare, one of the reasons we decided to move as a family from Narok to Nairobi to come live here."

(Client 1)

"Financial challenges are there, especially for therapy, it has been quite a challenge."

(Client 2)

"I can say mostly financial. For example, now that I have to bring him here every week, I have to find that amount, and sometimes my business is not doing well, and I have to bring the boy here."

(Client 4)

A mother expressed her hope in God who provided despite the financial demands in their family and while caring for an Autistic child.

"Yeah, but God has blessed us. We have never lacked even despite all these issues."

(Client 5)

Accessing healthcare services

The responses had a common theme that health care was available and accessible.

"They are accessible, it's just that the finances are not there"

(Client 2)

"Accessing here has been good, I have no problem."

(Client 4)

"We come here, and there has been no problem, it's slightly far from here, and sometimes we take a matatu, and sometimes we take a cab."

(Client 5)

"It has not been a problem."

(Client 7)

Accessing education services

The participant's responses were varied, but some indicated they got little education, and some went through self-education and had gained experience through raising a child with ASD

"*Mostly it has been self-initiative and a lot of it has been from the health workers."*

(Client 2)

"I have not been taught how to deal with it."

(Client 4)

"*For education purposes, I google, and am also in a support group, and also on Instagram I follow mothers who have autistic kids."*

(Client 5)

4.9.3 Social Life

Participants expressed a significantly limited time to spend socially, and an inability to bring children to social gatherings due to behavioral concerns and some expressed guilt of leaving their child at home in their absence.

"It's like I don't have a social life, for example if it's a weekend you have to release the house girl, and even if I was to go for an occasion, I would not be able to even enjoy that occasion. Even if you were to go with the baby, it would be more of taking care of the baby than enjoying the occasion.

(Client 2)

"Everywhere I go, I go with him, unless he's sleeping, I go everywhere with him."

(Client 4)

"Sometimes you feel guilty, sometimes you go to a place, and then start thinking about your kid, as in you are not comfortable because you find yourself always thinking about her. For relationship wise, it is not easy to get into one, because it will not be easy to get someone to understand the condition of the kid, even with friends it is tough, in short, it affects."

(Client 6)

Coping with the challenge

The participants were interviewed to determine how they coped with the challenges they had identified; the responses varied but the common subordinate themes emerging were that it was challenging, difficult and straining to cope with all the different challenge.

"On finances, we are straining but trying, and on cope with social challenges, family occasion I don't miss, and I always introduce him to the other kids and tell them to even play with him, and when of course when it comes to relatives, they are very understanding."

(Client 2)

"It's a bit hard, trust me, it's very hard. I lost my job during COVID-19 pandemic including my wife who lost hers too, and so we had to spend the little we had. We have had to sacrifice by digging deeper into our pockets and also getting financial assistance from friends"

(Client 3)

"Sometimes I try and reach out to some friends when am to bring him to hospital, in case I do not have some money then I return later. Coping socially, is difficult like I mentioned earlier, the boy can't settle down, and thus unless I travel to the rural area, here in Nairobi, we spend most time in the house."

(Client 4)

"*I try and work extra hard, i look for other extra source of income. I try to balance my social life, I try to separate these issues, her life and my life. I have time for her, by making sure she gets the best, and try to get some little time friends, but I also know that too has a limiting."*

(Client 6)

CHAPTER 5

5.0 DISCUSSION

5.1 Socio-demographic Characteristics of the caregivers

This study found out that caregivers were aged 30 years to 39 years (52, 57.1%), where mean age of caregivers was 34.9 years (SD 6.7). This is comparable with other studies that show an age between 30 to 42 years. A study done in Italy among 105 Italian parents found the mean age of caregivers was 41.93 years (SD = 5.17), with most of them having ages of 31 to 57 years (Purpura et al., 2021). A cross-sectional study done in Najaf Province, Iraq showed caregiver's age was 32 years to 38 years (42.1%) (Al-Dujaili & Al-Mossawy, 2017). A cross-sectional study conducted in a child and adolescent mental health clinic in Lagos, Nigeria showed mean age of caregivers was 41.5 years (SD 8.9)(Dada et al., 2011).These studies clearly indicate the most affected age group is within the child bearing age because the diagnosis of Autism Spectrum Disorder is confirmed mainly in childhood.

Most of the study participants were females at 89.0 % (n=91) and mothers at 83.5 % (n= 91). This is similar to other studies that showed females/ mothers to be the majority (Ardhanaari et al., 2020). A study in Najaf province, Iraq with 152 caregivers majority were females at 74.3% (Al-Dujaili & Al-Mossawy, 2017) which comes along with a study, 406 whose respondents 280 (68.6%) were females (Minichil et al., 2019). A study in Lagos, Nigeria showed females to be 80.5% (N=155) with mothers accounting 78%, (Dada et al.,2011). This shows that mothers as caregivers compared to fathers and other family members bear more responsibility for autistic children and highlights challenges faced by the mothers /female caregivers. In our culture, women perform more home responsibilities whereas fathers spend more time working to financially support their families (Alnazly, 2019). A study in Qatar which had more fathers than mothers, showing cultural differences where a male is considered the leader of the home who speaks on behalf of the family and also found in public places. All these differences in findings could be explained by the diversity in cultural responsibilities.

This study found majority of the participants to be Christians at 92.3%. This can be explained by the fact that most recent national census in Kenya done in 2019 showed that 85.5% of the population are Christians, and among them ,33.4% are Protestant, 20.4% affiliated to the evangelical churches and 20.6% are Catholics (Population census). The results of this data analysis showed out of 91 participants 30.8% had completed secondary school (high school) and 56.0% had completed tertiary education (college and university). This is similar to a cross sectional study done in India which showed out of 63 caregivers their education status, 31.75 % were educated up to high school, 26.98 % to the university level (Ardhanaari et al., 2020). These results did not correspond with a parental survey conducted among 146 caregivers in Virginia, USA found 64 % of caregivers had attained college education (Rhoades et al.,2007). The difference in findings is because Rhoades et al conducted his study in a developed country.

This study found 80.2% of the participants were employed/self -employed while 19.8% were unemployed comparable to a cross sectional study in Italy where out of 105 caregivers 61.1% of caregivers had their jobs, while the 38.9% didn't have a job that gave them earnings and thus stayed at home to take care of their families (Purpura et al., 2021). Of those who in this study were employed or in business, the majority (41.8%) were earning below 20,000 Kenya shilling as net income per month, 67% reporting their monthly income was insufficient. This indicates that despite the majority caregivers being employed the income was little and could not meet their daily demands. This is could be explained by, majority lived in the urban area where the cost of living is high compared to the rural areas, high demands of special care and medical follow up for their children. The result of this study is inconsistent with other studies; In India a study found monthly earnings of caregivers to be enough to meet their daily needs (Ardhanaari et al., 2020), while findings from Najaf province, Iraq reported 50 % of the participants were of a high level of household of monthly income (Al-Dujaili & Al-Mossawy, 2017). This could be difference in socio-economic status.

This study results show 86.8% of the study participants were from the urban areas similar to 94% of caregivers whose housing was from the urban area (Nikmat et al., 2008). This is because cities and urban areas are populated with such families considering to live in the urban area because of the available and accessible health care of their children and more job opportunities to support their families financially. This findings are inconsistent from a study done in India that showed 74.60 % participants lived rural area, 15.87% were living in towns and 9.52 % in the cities (Ardhanaari et al., 2020). The results of this study found 84.6% (n=91) were married (Mbugua et al., 2011) which shows the culture practices of marriage where both sexes tend to marry early in life. Other studies have shown majority caregivers of autistic children to be married (Ardhanaari et al., 2020) (Al-Dujaili & Al-Mossawy, 2017). These findings are explained by similarity in culture where the normal structure of a home.

This study found 92.3% of the caregivers in this study had not gone through any training on Autism Spectrum Disorder caregiving with only 4% having gone through one training and 1% had been trained four or more times. This findings are different from a study done in Nepal among 61 caregivers where more than 78.7% (n=61) caregivers had no training about raising a child with

ASD (Pandey & Sharma, 2018). A study among Jordanian parents found 55.3% (n=123) had not previously trained about ASD while 44.7% (n=123) had been trained despite having 56.9% of study participants having college training (Alnazly, 2019). The lack of training in this study could be explained by few medical professionals that handle children who are autistic, more medical attention to the autistic child and lack of national policies that could support educative services to such caregivers in the country. This study found that majority (95.6%) had not suffered any psychiatric illness with 3 reporting of depression and 1 of anxiety disorder.

5.2 Socio-demographic Characteristics of the ASD children

This study found males to be 75.8% (n=69) while females to be 24.2% (n=22) with a male: female ratio of 3;1. This study found higher prevalence of ASD in male children compared with females. The findings of this study are consistent with other previous studies; a study in Lagos, Nigeria found of the patients (159 children) attending a psychiatry clinic ,had 52.8% (n=81) males while 48% (n=74) were females (Dada et al., 2011). Most of the autistic children in India were males 82.5% (n=52) (Ardhanaari et al., 2020), 77% (n=46) males 23 % (n=14) females in Nepal (Pandey & Sharma, 2018), most of the autistic children ; 80.3% (n=122) are males while 19.7% (n=29) are females in Najaf Province (Al-Dujaili & Al-Mossawy, 2017). A study in Kenya found boys (94, 81.1%) were more than girls (22, 18.9%) at a ratio of 4.3:1 (Samia et al., 2020). A study in Nepal found the male: female ratio was found to be 3.4:1 (Pandey & Sharma, 2018).

This study found mean age of the children to be 4.8 (SD 2.6) years, minimum age was 2.0 years, maximum was 12.0 years while median age, 4.0 years and a mean age of the children at ASD diagnosis was 3.2 (SD 1.4) years. These findings are similar to study done in children with ASD conducted in Kenya where the median age at presentation was 3 years (Samia et al., 2020). A similar study done in Nepal found mean age of diagnosis extend from 1 year to 13 years which covers part of the school going age group (Pandey & Sharma, 2018).

The findings of this study found children had a median age of four years at diagnosis significantly lower than other African groups where median age is eight years (Africa et al., 2016). These results of a young age at diagnosis could be explained by the socio-economic and educational status and more awareness about ASD of the families that sought services at KNH. The availability of a specialist consultant child psychiatrist and other health experts providing diagnostic services at this hospital might have eased early diagnosis.

This study found the 62.6% (n=58) of the children had ASD, 27.5% (n=25) had ADHD 9.9% (n= 9) others having medical diagnosis (convulsive disorder, delayed milestones and rickets). Hyperactivity, aggressive behavior, communication difficulties are a great concern to the caregivers. Clinical teams should also take into regard that ADHD is a common co-morbidity (Lerthattasilp et al., 2015). This is comparable to a study done in Italy among different neurodevelopmental disorders that showed ASD (32.4%) with comorbidity of ,ID (14.3%), ADHD (14.3%) (Purpura et al., 2021). A study in Lagos, Nigeria done among all children attending a mental health clinic showed 56.4% had seizure disorder, 16.2% had ADHD, 7.7% mood disorder 6.8% autism, 6.8% had unspecified psychosis and 1.7% organic psychosis, 1.7% schizophrenia and mental retardation were 2.6% (Dada et al., 2011) .

5.3 Caregivers' burden

Majority of caregivers (50.5%, n= 46) in this study experienced mild to moderate burden (scores ZBI 21- 40), while 24.2% (n= 22) had moderate to severe burden (ZBI 41-60), 15.4% n=14 had severe burden (61-88) and 9.9% n=9 experienced no/little burden. These findings are similar to a study done in Nepal among 61 caregivers of autistic children using ZBI where (47.5% (n=29) had mild to moderate scores, 42.6% (26) had moderate to severe with a Mean Burden Score of 41.49 showing the caregivers fell between moderate to severe burden range of scores (Pandey & Sharma, 2018). The finding in this study is compatible with a study which found parents of individuals with ASD were under profound distress (Aida et al., 2019). A study in Thailand using ZBI as a tool found 45.1% of participants had little or no burden, 45.1% reported mild to moderate burden level, 7.8% had moderate to severe burden level, and only 2.0% had severe burden (Lerthattasilp et al., 2015).

A cross-sectional study in Lagos, Nigeria among 155 caregivers using ZBI found 33.5% had scores of mild to moderate burden, while 22% had scores of moderate to severe burden, 41.3% had little or no burden (Dada et al., 2011). The high scores could be explained by difference in study population this study where the study was among all children with mental disorders. A study in India among 60 caregivers used Burden Assessment Schedule, reported higher scores of moderate to severe scores in 59 % of these caregivers (Ardhanaari et al., 2020) . The findings in this study had lower scores from those found in a cross-sectional study in Italy where 105 caregivers children in the school going age group found, half of caregivers had moderate scores (mean ZBI-total mean score: 24.96, SD = 17.48) (Purpura et al., 2021).

A study done in Najaf province using ZBI to measure perceived stress found 50% (n=152) moderate burden, 30.3% (n=46) had mild burden, 15.1% (n=23) has severe burden while 4.6 (n=7) has no/little burden (Al-Dujaili & Al-Mossawy, 2017) . 123 Jordanian parents were studied using Oberst caregiving outcomes scale which found most of the caregivers had moderate level of burden (M= 3.14, SD = 0.95) (Alnazly, 2019). This same study found out excess time spent on caregiving, the worse the caregiving end results, leading to increased levels of burden. Parents had difficulty balancing caring for themselves and their children with ASD and also other family members and responsibilities. This study comparable to a study on caregiver burden in Malaysia among 51 parents using ZBI, where 45.1% reported little or no burden, 45.1% had mild to moderate burden level only 7.8% had moderate to severe burden level, and only 2.0% had severe burden (Lerthattasilp et al., 2015).

The findings of this study support other studies that have studied burden of care which all indicate the caregivers have remarkable burden and stress. A study in Qatar on the concerns and consideration of caregivers found lack of social and community acknowledgement of the nature of autism and indicate stigma attached with this condition and thus preferred keeping their children indoors (Kheir et al., 2012). This further adds to the psychological burden of their parents. A study in Malaysia among 52 parents using Parenting stress index found 90.4% of parents with autistic children have remarkable stress (Nikmat et al., 2008).

5.4 Association between caregiver characteristics and caregiver burden

This study found gender (P= 0.042) is associated with caregiver burden at bivariate analysis. A study in Najaf found notable relation between the caregiver gender with caregiver burden of caregiver (Al-Dujaili & Al-Mossawy, 2017). This is comparable to a study in Italy which found out that gender and relationship of the caregivers to the child to be a determinant of burden but were not notably associated with burden (Dada et al., 2011). A study done in Malaysia found no notable association between gender and with caregivers stress (Nikmat et al., 2008). At the multivariate level gender was not associated with caregiver burden (P=0.561). This may indicate cultural transfer of responsibility where fathers now take more duties of caring and nurturing their children. Caring for a child with mental disorder is burdensome regardless of gender of the caregiver. The nature of ASD and the caregiving demands have a larger impact on female caregivers because they disturb the sequence of the female caregiver's life cycle.

This study found employment status to be associated with caregiver burden at $p< 0.022$ shown by 80.2% (n=73) of the caregivers were either employed or self-employed with similar findings in a study done in Jordan (Alnazly, 2019). This shows that despite their efforts to take care of a demanding child they also have to meet financial demands to their families too and this is explained by social norms of the County which is assumed to be a working nation. The findings of this study are similar to another study which found mothers who were employed had more burden due to the demands of the child and job responsibilities (Greeen, 2007). Employment status is not be associated with burden of care due to the fact that most of the caregivers were either home keepers or would leave their children at day care centers (Pandey & Sharma, 2018). Another study in Malaysia found occupational status doesn't affect the perceptivity of burden (Bahry et al., 2019). These differences in findings could be explained by socio-economic variations in different nations.

This study found age, the relationship to the patient, religion, education level, marital status, residence, monthly and income sufficiency not linked with burden of care. Age is not linked with burden of care thus caring for a child with ASD is difficult for caregivers of any age. Literature reviewed previously has shown that parental age has no association with burden of care (Pandey & Sharma, 2018). A study in Jordan found age to correlate with the level of care burden as well as with anxiety and depression (Alnazly, 2019). The finding of this study are different from a study in Canada which revealed that parents age was related with burden at the multiple regression analysis with older parents reporting pronounced burden (Vogan et al., 2014). This difference in this finding could be related to difference in number of participants and social norms in Kenya and Canada. The duty of caring for an ASD person is a long-lasting duty yet the intensity of care increases over time. Studies have found caregivers of a young age reduce their social life to do their caregiving role.

This study found religion not be related with caregiver burden where 92.3% (n=91) were found to be Christians. The religious belief of caregivers could be the reason for these caregivers to cope with caring for an autistic child. Christianity teaches about resilience even in difficulty, acceptance that an autistic child is God given and such happenings are meant to test one's faith. This finding are similar to a study in Qatar where Islamic teachings helped parents cope and used other emotional focused strategies thus reducing burden of care (Kheir et al., 2012).

This study found education level not to be related to burden of care which is different findings from a study in Nepal that found the level of education to be associated with overall burden, finances challenges and control of life where caregivers with higher level of education were found to have less burden than those with lower level (Pandey & Sharma, 2018).This study found marital status was not linked with burden of care which is of a similar findings in a study in Jordan which found marital status did not correlate with the level of parents' burden and caregiving outcome (Alnazly, 2019)

5.5 Association between child characteristics and caregiver burden

This study found age of the children is associated with caregiver burden at the univariate analysis and thus a predictor of burden. At the multivariate analysis, each unit increase of child's age increases the odds of a higher burden by 1.2 times but this was not statistically significant (p <

0.055). A similar study in Nepal found that age of the caregivers had no relation with burden of care(Pandey & Sharma, 2018). Caring for child with ASD there are some unique challenges associated with caregiving which are similar for either a male or a female child (Pandey & Sharma, 2018). The results of this study are similar to the findings obtained from other studies which have found, age of the child had no relation to caregiver burden (Dada et al., 2011) (Vogan et al., 2014).

The age of the child at the time of diagnosis is associated with caregiver burden at the univariate analysis and thus a predictor of burden. Multivariate analysis showed that each unit increase of the child's age increases the odds by 1.4 times and this was statistically significant (P value < 0.035). Therefore, early diagnosis will enable treatments to be implemented to change the course of early maladaptive behavior. Contrary to the results of this study, child's age at diagnosis had no relation uniting the caregiver burden and child's age at diagnosis (Al-Dujaili & Al-Mossawy, 2017).

4.4 Psychiatric morbidity among caregivers caring for ASD children

Several studies on caregiver burden have shown the importance of psychological disorders therefore this study used 12-item GHQ to detect psychological morbidity as a cause of disease burden among caregivers caring for children with ASD. The GHQ-12 items are used to screens for a mental problem over few weeks using a 4-point scale (from 0-3). This study used Model IIIB which is the 3-factor model that screens for: Anxiety and Depression, Social dysfunction, and Loss of Confidence (Graetz, 1991). This study found caregivers to have psychological distress; anxiety, depression and social dysfunction which could be due caregiving of children with ASD. Majority of the caregivers 62.6 % (n=91) could not concentrate on what they were doing (on item 1) and 52.8% (n=91) of the participants reported not to enjoy their day-to-day activities (item 7) which are symptom of social dysfunction. 55% (n=91) felt constantly under strain (item 5) which is a symptom of anxiety and depression.

A study in Nepal that used Hopkin's Symptom Checklist-25, 33.0% of caregivers had traits of anxiety while 24.6% had symptoms of depression (Pandey & Sharma, 2018). A study of 123 caregivers of children with ASD parents reported high anxiety and depression levels while burden often leads to psychological distress (Alnazly, 2019). However, Similarly, a study carried out in Thailand found 5.9% of all participating caregivers had depression, thus within the morbidity of depression of 2-7% in the general population (Lerthattasilp et al., 2015). Caregivers might be engulfed by their own life events and adjustments to the needs of children with ASD this could lead to psychiatry morbidity.

This study found the correlation between GHQ and ZBI was tested with the use of Pearson Correlation, of which the results reveal that the relation was moderate and statistically significant ($r=0.580$, $p<0.001$). This finding shows relation between caregiver burdens among caregivers of ASD children with respect to general mental health psychological distress. A study done in Najaf found the same findings of caregivers with autistic children have association between psychosocial burden and psychological wellbeing (Al-Dujaili & Al-Mossawy, 2017).

4.5 Lived experiences of the caregivers caring for children diagnosed with ASD

Semi-structed discussion were conducted to investigate the experiences of caregivers on raising children diagnosed with Autism Spectrum Disorder attending Kenyatta National Hospital outpatient clinics.

Studies have reported increased caregiver burden associated with raising a child with autism, including increased levels of worry, anxiety and guilt. A qualitative study done among 9 mothers in Europe, Greece found a feeling of emotional distress and vulnerability as maternal lived experiences and challenges (Papadopoulos, 2021). A study of parents of children with a range of mental health disorders reported they commonly sought for the answer to a question, namely "why did this happen to us?"(Armitage et al., 2020). This study found a similar question, namely "what is this unfortunate thing that is following us" in a family where children (siblings /cousins) coming from the same family had been diagnosed with Autism Spectrum Disorder.

Qualitative work that searched databases for relevant articles found out, parents of children with ASD experience distress in relation to their child's potentially disruptive, maladaptive behavior and functional lifetime dependency (Depape & Lindsay, 2015).This study found caring for an ASD child to be challenging and difficult due to the child's behaviors that range from lack of verbal and non-verbal socio-communicative abilities of the child. The lack of interest and repetitive behaviors that caregivers to have difficulty calming them down. This study found that many lacked experiences on how to care for their ASD children and this has negative impact on the care given to the child. Parents of disabled children may lack enough knowledge and understanding of their child's needs and behaviors while others may not use positive expertise to grow the parent-child interactions and reward the child when they express appropriate behavior (Papadopoulos, 2021).This study outlines the caregivers' experiences, in relation to caring to their children and sibling relationships, spouses, relatives, neighbors and employer. Caregivers in this study expressed optimism among their children with great support given to the child diagnosed with ASD.

Majority of the caregivers in this study reported immerse support from their spouses despite the burden of caring. This study had a participant whose marital relationship ended in divorce while insufficient time and energy to commit to their spouse or siblings of the child with ASD were also reported. Higher rate of divorce among parents of children with ASD than in families of children without mental disorder have been reported (Brobst et al., 2009). A Quantitative study found out parents who abide in marital relationship and were raising a child with autism, they had lower marital contentment compared to that of married parents of typically developing children (Gau et al., 2012). This leads to expression of negative emotions that affects care given to the ASD child. A similar study in Kenya found caring for a child with ASD wear down caregivers, particularly in terms of intimacy between married couples (Cloete et al., 2019).

This study found several difficulties encountered by caregivers of children with ASD such as financial, accessibility of health care services and accessing education services. This study found majority of the caregivers had financial constraints ranging from affordability of therapy sessions (speech and occupational therapy) and accessing the hospital. A comparable qualitative study done in Egypt among 14 mothers of ASD children found financial constrain from the economic cost of care, due to therapy expenses (Gobrial, 2018). In Kenya, due to the presence of National Health Insurance Services but therapy (speech and occupational therapy) is not included in the services for children with ASD, and disabilities in general, parents pay out of the pocket for the services. This is study found associated reduction in family income, with some parents working for additional hours or changing jobs to handle their child’s special education and medication.

This study found lack of common source for accessing education services with most caregivers using social media as the main source of information to educate themselves about ASD. A similar study found inadequate provision of adequate education, health care and other resources constitute the main issue in relation to ASD in Egypt (Gobrial, 2018). A qualitative study in Kenya found the lack of awareness, limited research, cultural factors, the lack of treatment protocols as themes among eight other themes as barriers found in treatment of ASD (L. Z. Kamau, 2017). The most commonly used methods of intervention in Kenya were diet-based interventions, sensory integration and drug therapies used to treat hyperactivity, reduce repetitive behaviors and improve social interaction(L. Z. Kamau, 2017).

This study found out that parents had limited time to spend alone (socially), and an inability to bring children to public gatherings due to disruptive behaviors. This was similar to a study in Kenya where social isolation was expressed as a method of protecting their children from the negative reactions of the community (Cloete et al., 2019). A study in Egypt mothers reported predominantly feelings of stigma, to prevent disgrace, these mothers kept their children at home (Papadopoulos, 2021). This, in turn, affects the mothers where they became socially isolated which is a similar finding in this study.

This study found varied responses on how they coped with different challenges but the common theme emerging was that coping was challenging, difficult and straining. The challenges included financial, accessing health care services and education services. A similar study done in Kenya at KNH found acceptance of their children's disorder, receiving support and initiating the role of advocacy were important ways to cope with the actuality of having a child with ASD (Cloete et al., 2019). This study found out that participants saw the importance of creating time in which caregivers of children with ASD could interact informally before, during or after therapy sessions.

CHAPTER 6

Recommendation

Clinical care should focus child's specific diagnosis but caregivers' stress should be assessed. Treating caregivers with mental illness as well as screening those due to stress may develop anxiety, depression and social dysfunction in the process of caregiving should be included in hospital services.

Caregivers based on the findings should be part of caregiver support group despite COVID-19 pandemic.

Training of the caregivers caring for children with ASD may positively impact caregiver-perceived stress.

A comparable study can be done looking at perceived burden and lived experience among caregivers caring for adolescence and adults with ASD.

Further qualitative research where other family members are interviewed may be helpful in assessing challenges and ways of coping among family members and also a multicenter study will be helpful.

Strengths and limitation

This study gives important findings on the burden of care in caregivers of ASD children in a resource constrained country. This study had qualitative and quantitative aspects with both genders included as participants which gives in-depth information on the caregiver burden. This study was carried out in a child and adolescent child psychiatry clinic (mental health center) and Occupational therapy clinic, thereby providing adequate ecological validity.

However, the findings are limited in that it was not a multicenter but in a national and referral hospital in the county. The findings do not reflect the views of caregivers of children with ASD who have never accessed child psychiatry clinic and occupational therapy services in the public health sector. The study used an out-patient setup as the study population whose results may not represent the state of in-patients who are very sickly and with comorbidities. There were low numbers of caregivers and their children with ASD being attended to in these clinics because of financial constraints due to Covid-19 pandemic. The qualitative data was collected among a small number of the participants' and thus caution must be placed while generalizing the findings of the study. Despite these limitations, a clear picture of vulnerable caregivers of ASD children who also need proper attention while attending to their ill children was elaborately described.

Conclusion

This study clearly indicated caregiver burden among those caring for children with ASD ranging from mild to moderate. Caregiver burden in this study is found to be significant and is associated with emotional status of the caregivers and child’s age at the time of diagnosis. This will guide the policymaker, health professionals, and caregivers of children diagnosed with ASD on the need to screen, diagnose, and manage stress-related disorders.

References

Africa, A. S. D., Ruparelia, K., Abubakar, A., Badoe, E., Bakare, M., Visser, K., Chugani, D. C., Chugani, H. T., Donald, K. A., Wilmshurst, J. M., Shih, A., Skuse, D., & Newton, C. R. (2016). *Autism Spectrum Disorders in Africa : Current Challenges in Identification , Assessment , and Treatment : A Report on the International Child Neurology Association Meeting on*. https://doi.org/10.1177/0883073816635748

Aida, N., Adib, N., Ibrahim, M. I., Rahman, A. A., & Bakar, R. S. (2019). *Perceived Stress among Caregivers of Children with Autism Spectrum Disorder : A State-Wide Study*. 1–11.

Al-Dujaili, A. H., & Al-Mossawy, D. A. J. (2017). Psychosocial burden among caregivers of children with autism spectrum disorder in Najaf province. *Current Pediatric Research*, *21*(2), 272–282. https://doi.org/10.20546/ijcrar.2017.504.018

Alnazly, E. K. (2019). *Psychological distress and perceived burden in caregivers of persons with autism spectrum disorder*. *August 2018*. https://doi.org/10.1111/ppc.12356

Amirkhanyan, A. A., & Wolf, D. A. (2003). *Caregiver Stress and Noncaregiver Stress : Exploring the Pathways of Psychiatric Morbidity*. *43*(6), 817–827.

Angold, A., Messer, S. C., Stangl, D., Farmer, E. M. Z., Costello, E. J., & Burns, B. J. (1997). *Perceived Parental Burden and Service Use for Child and Adolescent Psychiatric Disorders*. 75–80.

Ardhanaari, M., Ashweeja, N., Jain, P., Priya, K., & Nappinnai, N. R. (2020). *A Study to Assess Caregiver Burden in Parents of Children with Autism Spectrum Disorder*. *7*(46). https://doi.org/10.18410/jebmh/2020/555

Armitage, S., Parkinson, M., Halligan, S., & Reynolds, S. (2020). Mothers' Experiences of Having an Adolescent Child with Depression: An Interpretative Phenomenological Analysis. *Journal of Child and Family Studies*, *29*(6), 1617–1629. https://doi.org/10.1007/s10826-020-01705-5

Awad, A. G., & Voruganti, L. N. P. (2008). *The Burden of Schizophrenia A Review*. *26*(2), 149–162.

B.K. Puri, A. Hall, R. H. (2014). *Revision Notes in Psychiatry* (Third Edit). CRC Press.

Bachner, Y. G., & O'Rourke, N. (2007). Reliability generalization of responses by care providers to the Zarit Burden Interview. *Aging and Mental Health*, *11*(6), 678–685. https://doi.org/10.1080/13607860701529965

Bahry, N. S., Mat, A., Kori, N. L., Ali, A. M., Abdul, Z., Zaim, M., & Salleh, M. (2019). *Challenges Faced by*

Malaysian Parents in Caregiving of a Child with Disabilities. *7*(2), 118–124.

Baio J., et al. (2018). Centers for Disease Control and Prevention MMWR. *Surveillance Summaries*, *67*(6).

Bakare, D. M. (2011). *Autism spectrum disorders (ASD) in Africa : a perspective*. *July*, 208–210.

Baptista, F., & Junior, A. (2015). *Family burden and children with Autism Spectrum Disorders: Sobrecarga familiar e crianças com transtornos do espectro*. *17*(2), 192–200.

Baron-Cohen, S. (2015). Leo Kanner, Hans Asperger, and the discovery of autism. In *The Lancet* (Vol. 386, Issue 10001, pp. 1329–1330). Elsevier Ltd. https://doi.org/10.1016/S0140-6736(15)00337-2

Brobst, J. B., Clopton, J. R., & Hendrick, S. S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities*, *24*(1), 38–49. https://doi.org/10.1177/1088357608323699

CDCP. (2019). *Treatment and Intervention Services for Autism Spectrum Disorder*. https://www.cdc.gov/ncbddd/autism/treatment.html

CDCP. (2020). *What is Autism Spectrum Disorder?* https://www.cdc.gov/ncbddd/autism/facts.html

Cloete, L. G., Obaigwa, E. O., Health, I., & Cloete, L. (2019). *Lived experiences of caregivers of children with autism spectrum disorder in Kenya*. 1–9.

Corrigan, P. W., & Miller, F. E. (2004). *Shame , blame , and contamination : A review of the impact of mental illness stigma on family members*. *13*(December), 537–548. https://doi.org/10.1080/09638230400017004

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, *20*(2), 153–162. https://doi.org/10.1177/1362361315573636

Dada, M. U., Okewole, N. O., Ogun, O. C., & Bello-mojeed, M. A. (2011). *Factors associated with caregiver burden in a child and adolescent psychiatric facility in Lagos , Nigeria : a descriptive cross sectional study*.

Depape, A. M., & Lindsay, S. (2015). Parents' experiences of caring for a child with autism spectrum disorder. *Qualitative Health Research*, *25*(4), 569–583. https://doi.org/10.1177/1049732314552455

Diagnostic and Statistical Manual of Mental Disorders, 2000. (2013). *DSM-5* (Fifth Edit). American Psychiatric Association.

Elsabbagh, M., Divan, G., Koh, Y. J., Kim, Y. S., Kauchali, S., Marcín, C., Montiel-Nava, C., Patel, V., Paula, C. S., Wang, C., Yasamy, M. T., & Fombonne, E. (2012). Global Prevalence of Autism and Other

Pervasive Developmental Disorders. *Autism Research*, *5*(3), 160–179. https://doi.org/10.1002/aur.239

Fairthorne, J., De Klerk, N., & Leonard, H. (2015). Health of mothers of children with intellectual disability or autism spectrum disorder: a review of the literature. *Medical Research Archives*, *3*, 1–21. https://doi.org/10.18103/mra.v0i3.204

Gau, S. S. F., Chou, M. C., Chiang, H. L., Lee, J. C., Wong, C. C., Chou, W. J., & Wu, Y. Y. (2012). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders*, *6*(1), 263–270. https://doi.org/10.1016/j.rasd.2011.05.007

Gobrial, E. (2018). The lived experiences of mothers of children with the autism spectrum disorders in Egypt. *Social Sciences*, *7*(8). https://doi.org/10.3390/socsci7080133

Grabrucker, A. M. (2013). Environmental factors in autism. *Frontiers in Psychiatry*, *3*(JAN), 1–13. https://doi.org/10.3389/fpsyt.2012.00118

Graetz, B. (1991). Multidimensional properties of the General Health Questionnaire. *Social Psychiatry and Psychiatric Epidemiology*, *26*(3), 132–138. https://doi.org/10.1007/BF00782952

Greeen, S. E. (2007). *'" We " re tired , not sad '': Benefits and burdens of mothering a child with a disability*. *64*, 150–163. https://doi.org/10.1016/j.socscimed.2006.08.025

Hahler, E., & Elsabbagh, M. (2015). *Autism : A Global Perspective*. 58–64. https://doi.org/10.1007/s40474-014-0033-3

Hastings, R. P., Kovshoff, H., Ward, N. J., Espinosa, F., Brown, T., & Remington, B. (2005). *Systems Analysis of Stress and Positive Perceptions in Mothers and Fathers of Pre-School Children with Autism*. *35*(5). https://doi.org/10.1007/s10803-005-0007-8

Kakooza-mwesige, A., Ssebyala, K., Karamagi, C., Kiguli, S., Smith, K., Anderson, M. C., Croen, L. A., Trevathan, E., Hansen, R., Smith, D., & Grether, J. K. (2014). *Adaptation of the " ten questions " to screen for autism and other neurodevelopmental disorders in Uganda*. https://doi.org/10.1177/1362361313475848

Kamau, L., Kamau, L. Z., & Author, C. (2020). Autism Spectrum Disorders (ASD) in Kenya: The Diagnostic Experience of Parents of Persons with Autism in Garissa County, and its Policy Implications Cultural Competency for Behavior Analysis Practitioners View project Autism Spectrum Disorders (ASD) in Ke. *Quest Journals Journal of Research in Pharmaceutical Science*, *6*(1), 2347–2995. www.questjournals.org

Kamau, L. Z. (2017). *Autism Spectrum Disorders (ASD) in Kenya : Barriers Encountered in Diagnosis ,* *Treatment and Management . 3*(7), 1–11.

Kaminsky, L., & Dewey, D. (2001). *Siblings Relationships of Children with Autism*. *31*(4).

Khanna, R., Smith, M. J., Patrick, J. H., & Becker-cottrill, B. (2015). *Psychometric properties of the Caregiver Strain Questionnaire (CGSQ) among caregivers of children with autism*. https://doi.org/10.1177/1362361311406143

Kheir, N. M., Ghoneim, O. M., Sandridge, A. L., Hayder, S. A., Al-ismail, M. S., & Al-rawi, F. (2012). *Concerns and considerations among caregivers of a child with autism in Qatar*. 1–7.

KNH. (n.d.). KNH annual report and financial statements. In *Paper Knowledge . Toward a Media History of Documents*.

Landrigan, P. J. (2010). *What causes autism ? Exploring the environmental contribution*. https://doi.org/10.1097/MOP.0b013e328336eb9a

Lerthattasilp, T., Charernboon, T., Chunsuwan, I., & Siriumpunkul, P. (2015). Depression and burden among caregivers of children with autistic spectrum disorder. *Journal of the Medical Association of Thailand*, *98*, S45–S52.

M. Leboyer, P. C. (2015). Autism Spectrum Diosders Phenotypes, Mechanisms, and Treatments. In *Angewandte Chemie International Edition, 6(11), 951–952.*

Matson, J. L., & Nebel-schwalm, M. (2007). *Assessing challenging behaviors in children with autism spectrum disorders : A review*. *28*, 567–579. https://doi.org/10.1016/j.ridd.2006.08.001

Mbugua, M. N., Kuria, M. W., & Ndetei, D. M. (2011). The Prevalence of Depression among Family Caregivers of Children with Intellectual Disability in a Rural Setting in Kenya. *International Journal of Family Medicine*, *2011*, 1–5. https://doi.org/10.1155/2011/534513

Miles, J. H. (2011). *Genetics in Medicine Autism spectrum disorders — A genetics review*. *13*(4). https://doi.org/10.1097/GIM.0b013e3181ff67ba

Minichil, W., Getinet, W., Derajew, H., & Seid, S. (2019). *Depression and associated factors among primary caregivers of children and adolescents with mental illness in Addis*. 1–9.

Modibo, S., & Boubacar, M. (2019). *African Journal of Neurological Sciences African Journal of Neurological Sciences*. *38*(1), 91–101.

Ndetei, D., Khasakhala, L., Kuria, M. W., Mutiso, V., & Muriungi, S. (2010). A study on assessment of needs, care in the homes and clinical trends among the elderly in Kenya. *University of Nairobi*, 1–4. http://erepository.uonbi.ac.ke/bitstream/handle/11295/29233/Prof. Ndetei - Study on assessment of needs%2C care in the homes and clinical trends among the elderly in Kenya.pdf?sequence=1&isAllowed=y

Ndetei, D M, Pizzo, M., Khasakhala, L. I., Maru, H. M., Mutiso, V. N., Ongecha-owuor, F. A., & Kokonya, D. A. (2009). *Perceived economic and behavioural effects of the mentally ill on their relatives in Kenya : a case study of the*. 293–299.

Ndetei, David M., Ongecha, F. A., Mutiso, V., Kuria, M., Khasakhala, L. I., & Kokonya, D. A. (2007). The challenges of human resources in mental health in Kenya. *African Journal of Psychiatry (South Africa)*, *10*(1), 33–36. https://doi.org/10.4314/ajpsy.v10i1.30231

NIH. (2021). *Medication Treatment for Autism*. https://www.nichd.nih.gov/health/topics/autism/conditioninfo/treatments/medication-treatment

Nikmat, A. W., Ahmad, M., Oon, N. G. L. A. I., & Razali, S. (2008). *Stress and psychological wellbeing among parents of children with autism spectrum disorder*. *9*(2), 64–72.

Pandey, S., & Sharma, C. (2018). *Perceived Burden in Caregivers of Children with Autism Spectrum Disorder*. *16*(2), 184–189.

Papadopoulos, D. (2021). Mothers' experiences and challenges raising a child with autism spectrum disorder: A qualitative study. *Brain Sciences*, *11*(3), 1–16. https://doi.org/10.3390/brainsci11030309

Pearlin, L. I., Menaghan, E. G., Lieberman, M. a, & Mullan, J. T. (2011). Process The Stress. *Journal of Health and Social Behavior*, *22*(4), 337–356.

Platt, S. (1985). Measuring the burden of psychiatric illness on the family: An evaluation of some rating scales. *Psychological Medicine*, *15*(2), 383–393. https://doi.org/10.1017/S0033291700023680

Pollak, C. P., & Perlick, D. (1991). *Problems and Institutionalization of the Sleep Elderly I nstitutionalization*.

Purpura, G., Tagliabue, L., Petri, S., Cerroni, F., Mazzarini, A., & Nacinovich, R. (2021). Caregivers' burden of school-aged children with neurodevelopmental disorders: Implications for family-centred care. *Brain Sciences*, *11*(7). https://doi.org/10.3390/brainsci11070875

Raina, P., Donnell, M. O., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., Russell, D., Swinton, M., King, S., Wong, M., Walter, S. D., & Wood, E. (2004). <Caregiving process and caregiver burden.pdf>. *BMC Pediatrics*, *13*, 1–13. https://bmcpediatr.biomedcentral.com/articles/10.1186/1471-2431-4-1

RhoaRhoades, R. A., Scarpa, A., & Salley, B. (2007). (2007). The importance of physician knowledge of autism spectrum disorder: Results of a parent survey. *BMC Pediatrics*, *7*, 1–10. https://doi.org/10.1186/1471-2431-7-37

Ronald, A., & Hoekstra, R. A. (2011). *Autism Spectrum Disorders and Autistic Traits : A Decade of New Twin Studies*. *January*. https://doi.org/10.1002/ajmg.b.31159

Roper, S. O., Allred, D. W., Mandleco, B., Freeborn, D., & Dyches, T. (2014). *Caregiver Burden and Sibling Relationships in Families Raising Children With Disabilities and Typically Developing Children*. *32*(2), 241–246.

S.Hartley, M.Seltezer, Lara.H, A. L. (2013). *Psychological Well-being in Fathers of Adolescents and Young Adults with Down Syndrome, Fragile X Syndrome, and Autism*. *61*(2), 327–342. https://doi.org/10.1111/j.1741-3729.2011.00693.x.Psychological

Sales, E. (2003). Family burden and quality of life. *Quality of Life Research*, *12*(SUPPL. 1), 33–41. https://doi.org/10.1023/A:1023513218433

Samia, P., Kanana, M., King, J., Donald, K. A., Newton, C. R., & Denckla, C. (2020). *Childhood Autism Spectrum Disorder : Insights From A Tertiary Hospital Cohort In Kenya Material and Methodology Study Design Measures Anthropometric data was documented using*. *33*(2), 12–21.

Sathe, N., Andrews, J. C., McPheeters, M. L., & Warren, Z. E. (2017). Nutritional and dietary interventions for autism spectrum disorder: A systematic review. *Pediatrics*, *139*(6). https://doi.org/10.1542/peds.2017-0346

Schaefer, G. B., & Mendelsohn, N. J. (2008). Genetics evaluation for the etiologic diagnosis of autism spectrum disorders. *Genetics in Medicine*, *10*(1), 4–12. https://doi.org/10.1097/GIM.0b013e31815efdd7

Vogan, V., Lake, J. K., Weiss, J. A., Robinson, S., Tint, A., & Lunsky, Y. (2014). Factors associated with caregiver burden among parents of individuals with ASD: Differences across intellectual functioning. *Family Relations*, *63*(4), 554–567. https://doi.org/10.1111/fare.12081

Walker, A. J., Pratt, C. C., Eddy, L., Walker, A., Pratt, C. C., & Eddy, L. (2015). *INFORMAL CAREGIVING TO AGING FAMILY MEMBERS A CRITICAL REVIEW **. *44*(4), 402–411.

Weitlauf, A. S., Sathe, N. A., McPheeters, M. L., & Warren, Z. (2017). Interventions Targeting Sensory Challenges in Children With Autism Spectrum Disorder? An Update. *Comparative Effectiveness Review Number 186*, *AHRQ Publication No. 17-EHC004-EF*, 657. https://www.effectivehealthcare.ahrq.gov/ehc/products/660/2439/ASD-interventions-report-170523.pdf%5Cnhttp://www.effectivehealthcare.ahrq.gov/index.cfm/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productid=2439

WHO. (2021). *Autism spectrum disorders*. Home/Newsroom/Fact Sheets/Detail/Autism Spectrum

Disorders. https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders

Xiong, N., Yang, L., Yu, Y., Hou, J., Li, J., Li, Y., Liu, H., Zhang, Y., & Jiao, Z. (2011). Investigation of raising burden of children with autism, physical disability and mental disability in China. *Research in Developmental Disabilities*, *32*(1), 306–311. https://doi.org/10.1016/j.ridd.2010.10.003

Zarit, S., Reever, K., & Bahc-Peterson, J. (1980). Relatives of the impaired Elderly: Correlates of Feelings of Burden. *The Gerontologist*, *20*(6), 649–655.

Appendices

Appendix 1 CONSCENT EXPLANATION

Title: The burden of care among caregivers of Autism Spectrum Disorder children attending outpatient clinics in Kenyatta National Referral Hospital.

Participant Study Identification Number ……………………………………

Date ………………………………………….

Dear Sir/Madam,

Introduction

My name is Dr. Mercy Ndindi, a postgraduate student in the department of Psychiatry at the University of Nairobi. In collaboration with the University of Nairobi, we are doing a study on the burden of care among caregivers of Autism Spectrum Disorder children attending outpatient clinics in Kenyatta National Referral Hospital.

To this end, we kindly request for your participation in the study and this includes information about the child being attended to at KNH.

Procedure

If you agree to participate in the study, you will sign below as an informed consent expressing your voluntary participation. This will be in form of a questionnaire that will take about 30 minutes to complete.

Benefits: There are no direct benefits for participating in this study.

However, results from this study can help improve mental health of caregivers who take care of ASD children and also improve the management of ASD patients.

Risks: It is possible that you might feel embarrassed or uncomfortable as you give personal information about caregiving for an autistic child and psychiatric illness, which are sensitive topics. In case there is psychological disturbance, you will be offered psychological support.

Voluntary Participation:

Your participation in this research is entirely voluntary and if you decide to participate, you are free to withdraw at any time. You may also choose not to answer specific questions or withdraw from the study at any time. Your choice not to participate or choice to withdraw will not affect any treatment needs that the ASD child has sought at KNH.

Confidentiality:

Your identity will be kept confidential. Your name or any other personal identifier will not be used in any reports or publications arising from this study. Instead, you will be assigned a unique study number to protect your identity.

Compensation: You will not be paid to participate in this study.

Participant statement

The above statements regarding my participation in the study is clear to me. I have been given a chance to answer questions and also answered to my satisfaction. My participation in this study is entirely voluntary. I understand my record has been kept private and that I can leave the study at any time. I understand I will not be victimized for leaving the study.

Signature of the participant………………………date……………………………..

Investigator's Statement

I, the undersigned have explained to the volunteer in a language she/ he understands the procedures to be followed in the study and the risks and benefits involved.

Interviewers Signature………………………….. date…………………………………….

Viambatisho

Kiambatisho 1 MAELEZO YA HUSIKA

Kichwa: Mzigo wa utunzaji kati ya walezi wa Ugonjwa wa Autism Spectrum Disorder watoto wanaohudhuria kliniki za wagonjwa wa nje katika Hospitali ya Rufaa ya Kitaifa ya Kenyatta.

Nambari ya Kitambulisho cha Mshiriki ……………………………………
Tarehe ………………………………………….

Mheshimiwa wapenzi / Madam,

Utangulizi
Jina langu ni Dk Mercy Ndindi, mwanafunzi wa uzamili katika idara ya Saikolojia katika Chuo Kikuu cha Nairobi. Kwa kushirikiana na Chuo Kikuu cha Nairobi, tunafanya utafiti juu ya **mzigo wa matunzo kati ya walezi wa watoto wenye Ugonjwa wa Autism Spectrum Disorder wanaohudhuria kliniki za wagonjwa wa nje katika Hospitali ya Rufaa ya Kitaifa ya Kenyatta**.
Ili kufikia mwisho huu, tunaomba kwa ushiriki wako katika utafiti na hii ni pamoja na habari kuhusu mtoto anayehudumiwa katika KNH.

Utaratibu
Ikiwa unakubali kushiriki kwenye utafiti, utasaini hapa chini kama idhini inayofahamika inayoonyesha ushiriki wako wa hiari. Hii itakuwa katika fomu ya dodoso ambayo itachukua kama dakika 30 kukamilisha.

Faida: Hakuna faida za moja kwa moja za kushiriki katika utafiti huu.
Walakini, matokeo kutoka kwa utafiti huu yanaweza kusaidia kuboresha afya ya akili ya walezi ambao hutunza watoto wa ASD na pia kuboresha usimamizi wa wagonjwa wa ASD.

Hatari: Inawezekana unaweza kuhisi aibu au wasiwasi wakati unatoa habari ya kibinafsi juu ya utunzaji wa mtoto mwenye akili na ugonjwa wa akili, ambayo ni mada nyeti. Ikiwa kuna shida ya kisaikolojia, utapewa msaada wa kisaikolojia.

Ushiriki wa Hiari:
Ushiriki wako katika utafiti huu ni wa hiari kabisa na ukiamua kushiriki, una uhuru wa kujiondoa wakati wowote. Unaweza pia kuchagua kutojibu maswali maalum au kujiondoa kwenye utafiti wakati wowote. Chaguo lako la kutoshiriki au uchaguzi wa kujiondoa hautaathiri mahitaji yoyote ya matibabu ambayo mtoto wa ASD ametafuta katika KNH.

Usiri:
Kitambulisho chako kitahifadhiwa kwa siri. Jina lako au kitambulisho kingine chochote cha kibinafsi hakitatumika katika ripoti zozote au machapisho yanayotokana na utafiti huu. Badala yake, utapewa nambari ya kipekee ya masomo ili kulinda kitambulisho chako.

Fidia: Hautalipwa kushiriki katika utafiti huu.

Taarifa ya mshiriki
Maneno hapo juu kuhusu ushiriki wangu katika utafiti ni wazi kwangu. Nimepewa nafasi ya kujibu maswali na pia nikajibiwa kuridhika. Kushiriki kwangu katika utafiti huu ni kwa hiari kabisa. Ninaelewa rekodi yangu imehifadhiwa kwa faragha na kwamba ninaweza kuondoka kwenye masomo wakati wowote. Ninaelewa sitadhulumiwa kwa kuacha masomo.

Saini ya mshiriki
……………………………………………………………………………………… ..

Taarifa ya Mchunguzi
Mimi, aliyesajiliwa chini nimemuelezea kujitolea kwa lugha ambayo anaelewa taratibu zinazopaswa kufuatwa katika utafiti na hatari na faida zinazohusika.

Saini ya wanaohoji ………………………… .. tarehe ……………………………………….

Appendix 2 Questionnaire to be Filled by the Caregiver

Part 1: To be filled by caregiver

1. Which year were you born
2. What is your age in years…………..
3. What gender are you:
   - ○ Male
   - ○ Female
4. How are you related to the patient;
   - ○ Father
   - ○ Mother
   - ○ Sibling
   - ○ Other relative

5. What religion do you practice………………………….

6. What is the highest level of education you have achieved?

- ○ None
- ○ Primary
- ○ Secondary
- ○ Some University
- ○ Bachelor degree
- ○ More than Bachelor degree

7. What is your current employment status?

- ○ Employed/Self employed
- ○ No Employment

8. What is your marital status?

- ○ Single
- ○ Married
- ○ Separated
- ○ Divorced
- ○ Widow/ widower

9. What is your place of residence?
    - Urban
    - Rural

10. What is your monthly net income?
    - Less than 20,000 kshs
    - 20,001 – 35,000 kshs
    - 35,001 – 50,000 kshs
    - Above 50,000 kshs
    - Other (Specify)……………………

11. Do you earn enough monthly income to meet your needs?
    - Insufficient
    - Barely insufficient
    - Sufficient

12. Have you ever participated in any training(s) about autism spectrum disorder?
    - Not once
    - Once
    - Twice
    - Three and more

13. Have you suffered from any psychiatric illness before?
    - Yes if yes which illness?............................
    - No

Sociodemographic of the child

Part 2; To be filled by the caregiver about the child

14 What is the sex of your child?
  - Male
  - Female

15 Date of birth of your child?.....................

16 What is the current age of your child?...................

17 At what age was your child when the diagnosis of ASD was made?

18 Is there a child or children in your nuclear family with a diagnosis of ASD?

General Information on ASD

Part 3: To be filled with information from interviewee's file

19 What is the working diagnosis?

- ○ ASD
- ○ ASD with another psychiatric diagnosis. Which one………………
- ○ ASD with another medical condition

20 What was the age of the child at diagnosis?...

Hojaji ya kujazwa na Mlezi

Jamii ya Jamii ya Mlezi

Sehemu ya 1: Kujazwa na mlezi

1. Umri wako ni nini katika miaka ……………

2. Wewe ni jinsia gani:
o Mwanaume
o Mwanamke

3. Una uhusiano gani na mgonjwa;
o Baba
o Mama
o Ndugu
o Jamaa mwingine

4. Unafanya dini gani ……………………………

5. Je! Umepata kiwango gani cha juu cha elimu?
o Hakuna
o Msingi
o Sekondari
o Chuo Kikuu fulani
o Shahada ya kwanza
o Zaidi ya Shahada ya kwanza

6. Je! Una hali gani ya ajira sasa?
o Kuajiriwa / Kujiajiri
o Hakuna Ajira

7. hali yako ya ndoa ikoje?
o Mseja
o Kuolewa
Kutengwa
o Talaka
o Mjane / mjane

8. Unakaa wapi?
o Mjini
o Vijijini

10. Je! Mapato yako ya kila mwezi ni nini?
o Chini ya kshs 20,000
o 20,001 - 35,000 ksh
o 35,001 - 50,000 kshs
o Zaidi ya kshs 50,000
o Nyingine (Taja) ……………………

11. Je! Unapata mapato ya kutosha kila mwezi kukidhi mahitaji yako?
o haitoshi
o haitoshi kabisa
o Inatosha

12. Je! Umewahi kushiriki katika mafunzo yoyote kuhusu ugonjwa wa wigo wa tawahudi?
o Sio mara moja
o Mara moja
o Mara mbili
o Tatu na Zaidi

13. Je! Umewahi kuugua ugonjwa wowote wa akili kabla?
o Ndio ikiwa ndio ugonjwa gani?
o Hapana
Jamii ya kijamii ya mtoto

Sehemu ya 2; Kujazwa na mlezi kuhusu mtoto

Je! Jinsia ya mtoto wako ni nini?
o Mwanaume
o Mwanamke

Tarehe ya kuzaliwa kwa mtoto wako? ....

Je! Mtoto wako ana umri gani sasa? ....

17 Mtoto wako alikuwa na umri gani wakati uchunguzi wa ASD ulifanywa?

18 Je! Kuna mtoto au watoto katika familia yako ya nyuklia aliye na utambuzi wa ASD?

Maelezo ya jumla juu ya ASD

Sehemu ya 3: Kujazwa na habari kutoka faili ya mhojiwa

19 Je! Ni utambuzi gani wa kazi?
o ASD
o ASD na utambuzi mwingine wa akili. Gani………………
o ASD na hali nyingine ya kiafya

20 Je! Mtoto alikuwa na umri gani wakati wa kugunduliwa? ....

Appendix 3: The Zarit Burden Interview

0 : NEVER
1 : RARELY
2 : SOMETIMES
3 : QUITE FREQUENTLY
4 : NEARLY ALWAYS

Please circle the response the best describes how you feel.

Question	**Score**
1 Do you feel that your relative asks for more help than he/she needs?	0 1 2 3 4
2 Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0 1 2 3 4
3 Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0 1 2 3 4
4 Do you feel embarrassed over your relative's behaviour?	0 1 2 3 4
5 Do you feel angry when you are around your relative?	0 1 2 3 4
6 Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0 1 2 3 4
7 Are you afraid what the future holds for your relative?	0 1 2 3 4
8 Do you feel your relative is dependent on you?	0 1 2 3 4
9 Do you feel strained when you are around your relative?	0 1 2 3 4
10 Do you feel your health has suffered because of your involvement with your relative?	0 1 2 3 4
11 Do you feel that you don't have as much privacy as you would like because of your relative?	0 1 2 3 4
12 Do you feel that your social life has suffered because you are caring for your relative?	0 1 2 3 4

Question	**Score**
13 Do you feel uncomfortable about having friends over because of your relative?	0 1 2 3 4
14 Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0 1 2 3 4
15 Do you feel that you don’t have enough money to take care of your relative in addition to the rest of your expenses?	0 1 2 3 4
16 Do you feel that you will be unable to take care of your relative much longer?	0 1 2 3 4
17 Do you feel you have lost control of your life since your relative’s illness?	0 1 2 3 4
18 Do you wish you could leave the care of your relative to someone else?	0 1 2 3 4
19 Do you feel uncertain about what to do about your relative?	0 1 2 3 4
20 Do you feel you should be doing more for your relative?	0 1 2 3 4
21 Do you feel you could do a better job in caring for your relative?	0 1 2 3 4
22 Overall, how burdened do you feel in caring for your relative?	0 1 2 3 4

Interpretation of Score:

0 - 21 little or no burden
21 - 40 mild to moderate burden
41 - 60 moderate to severe burden
61 - 88 severe burden

Patient last name: . . . . Date of birth: . . . . / . . . . / . . . .
Patient first name: . . . . .Date: . . . . / . . . . / . . . .

Kiswahili- ZBI

0: KAMWE

1: NADRA

2: MARA NYINGINE

3: MARA KWA MARA

4: KARIBU DAIMA

Wekea mduara majibu yanayoelezea vizuri jinsi unavyohisi.

Swali	**Alama**
1 Je! Unahisi jamaa yako anauliza msaada zaidi ya anavyohitaji?	0 1 2 3 4
2 Je! Unahisi kuwa kwa sababu ya muda unaotumia na jamaa yako kuwa hauna wakati wa kutosha kwako?	0 1 2 3 4
3 Je! Unajisikia mkazo kati ya kumtunza jamaa yako na kujaribu kufikia majukumu mengine kwa familia yako au kazini?	0 1 2 3 4
4 Je! Unahisi aibu juu ya tabia ya jamaa yako?	0 1 2 3 4
5 Je! Unahisi hasira wakati uko karibu na jamaa yako?	0 1 2 3 4
6 Je! Unahisi kuwa jamaa yako kwa sasa anaathiri uhusiano wetu na wanafamilia wengine au marafiki kwa njia mbaya?	0 1 2 3 4
7 Je! Unaogopa hali ya baadaye kwa jamaa yako?	0 1 2 3 4
8 Je! Unahisi jamaa yako anakutegemea?	0 1 2 3 4
9 Je! Unahisi shida wakati uko karibu na jamaa yako?	0 1 2 3 4
10 Je! Unahisi afya yako imeumia kwa sababu ya ushiriki wako na jamaa yako?	0 1 2 3 4
11 Je! Unahisi kuwa hauna faragha kama vile ungependa kwa sababu ya jamaa yako?	0 1 2 3 4
12 Je! Unahisi kuwa maisha yako ya kijamii yameteseka kwa sababu unamjali jamaa yako?	0 1 2 3 4

Swali	**Alama**
13 Je! Hujisikii wasiwasi juu ya kuwa na marafiki kwa sababu ya jamaa yako?	0 1 2 3 4
14 Je! Unahisi jamaa yako anaonekana anatarajia umtunze kana kwamba wewe ndiye wewe tu ambaye angemtegemea?	0 1 2 3 4
15 Je! Unahisi kuwa hauna pesa za kutosha kumtunza jamaa yako pamoja na matumizi yako yote?	0 1 2 3 4
16 Je! Unahisi kuwa utashindwa kumtunza jamaa yako kwa muda mrefu zaidi?	0 1 2 3 4
17 Je! Unahisi umepoteza udhibiti wa maisha yako tangu ugonjwa wa jamaa yako?	0 1 2 3 4
18 Je! Unatamani ungemwachia mtu mwingine matunzo ya jamaa yako?	0 1 2 3 4
19 Je! Unahisi hauna uhakika juu ya nini cha kufanya juu ya jamaa yako?	0 1 2 3 4
20 Je! Unahisi unapaswa kufanya zaidi kwa jamaa yako?	0 1 2 3 4
21 Je! Unahisi unaweza kufanya kazi bora katika kumtunza jamaa yako?	0 1 2 3 4
22 Kwa jumla, unajisikia mzigo gani katika kumtunza jamaa yako?	0 1 2 3 4

Tafsiri ya Alama:

0 - 21 mzigo mdogo au hakuna;

22 - 40 mzigo mdogo hadi wastani;

41 – 60 wastani hadi mzigo mzito;

61- 88 mzigo mzito

Mgonjwa jina la mwisho:. . . . . Tarehe ya kuzaliwa: . . . . /. . . . /. . . . .
Jina la kwanza la mgonjwa:. . . . . Tarehe: . . . . /. . . . /. . . . .

Appendix 4: Short General Health Questionnaire (GHQ 12)

Have you recently?

1. Been able to concentrate on what you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
2. Lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
3. Felt you were playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
4. Felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
5. Felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
6. Felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
7. Been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
8. Been able to face up to your problems?	More so than usual	Same as usual	Less so than usual	Much less able
9. Been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
10. Been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
11. Been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
12. Been feeling reasonably happy, all things considered	More so than usual	About same as usual	Less so than usual	Much less than usual;

Hoja dogo la Afya kwa Jumla (GHQ 12)

Je! Wewe hivi karibuni?

1. Umeweza kuzingatia kile unachofanya?	Bora kuliko kawaida	Sawa na kawaida	Badala ya zaidi ya kawaida	Kiasi kidogo kuliko kawaida
2. Kupoteza usingizi mwingi juu ya wasiwasi?	Sio kabisa	Hakuna zaidi ya kawaida	Badala ya zaidi ya kawaida	Zaidi ya kawaida
3. Ulihisi ulikuwa unacheza sehemu muhimu katika vitu?	Zaidi kuliko kawaida	Sawa na kawaida	Chini ya muhimu kuliko kawaida	Haifai sana
4. Alihisi kuwa na uwezo wa kufanya maamuzi juu ya vitu?	Zaidi kuliko kawaida	Sawa na kawaida	Chini ya kawaida	Uwezo mdogo sana
5. Alijisikia kila wakati chini ya shida?	Sio kabisa	Hakuna zaidi ya kawaida	Badala ya zaidi ya kawaida	Zaidi ya kawaida
6. Ulihisi haukuweza kushinda shida zako?	Sio kabisa	Hakuna zaidi ya kawaida	Badala ya zaidi ya kawaida	Zaidi ya kawaida
7. Umeweza kufurahiya shughuli zako za kawaida za kila siku?	Zaidi kuliko kawaida	Sawa na kawaida	Chini kuliko kawaida	Kiasi kidogo kuliko kawaida
8. Umeweza kukabiliana na shida zako?	Zaidi kuliko kawaida	Sawa na kawaida	Chini ya kawaida	Uwezo mdogo sana
9. Umekuwa ukisikia furaha na unyogovu?	Sio kabisa	Hakuna zaidi ya kawaida	Badala ya zaidi ya kawaida	Zaidi ya kawaida
10. Je! Umepoteza kujiamini kwako?	Sio kabisa	Hakuna zaidi ya kawaida	Badala ya zaidi ya kawaida	Zaidi ya kawaida
11. Je! Umejifikiria kama mtu asiye na thamani?	Sio kabisa	Hakuna zaidi ya kawaida	Badala ya zaidi ya kawaida	Zaidi ya kawaida
12. Umejisikia mwenye furaha ya kutosha, vitu vyote vimezingatiwa	Zaidi ya kawaida	Karibu sawa na kawaida	Chini ya kawaida	Kiasi kidogo kuliko kawaida;

Appendix 5: Interview Consent Explanation Form

Title: The burden of care among caregivers of Autism Spectrum Disorder children attending outpatient clinics in Kenyatta National Referral Hospital.

Participant Study Identification Number ……………………………………

Date …………………………………………

Dear Sir/Madam,

Introduction

My name is Dr. Mercy Ndindi, a postgraduate student in the department of Psychiatry at the University of Nairobi. In collaboration with the University of Nairobi, we are doing a study on the burden of care among caregivers of Autism Spectrum Disorder children attending outpatient clinics in Kenyatta National Referral Hospital.

To this end, we kindly request for your participation in the study and this includes information about the child being attended to at KNH.

Procedure

If you agree to participate in the study, you will sign below as an informed consent expressing your voluntary participation. This will be an interview where you will express your experience on taking care of an autistic child. Feel free to express yourself freely. There will audio recording of our discussion and I will write down your feeling on the topic which will take about 40 minutes to complete.

Benefits: There are no direct benefits for participating in this study.

However, results from this study can help improve mental health of caregivers who take care of ASD children and also improve the management of ASD patients.

Risks: It is possible that you might feel embarrassed or uncomfortable as you give personal information about caregiving for an autistic child and psychiatric illness, which are sensitive topics. In case there is psychological disturbance, you will be offered psychological support.

Voluntary Participation:

Your participation in this research is entirely voluntary and if you decide to participate, you are free to withdraw at any time. You may also choose not to answer specific questions or withdraw from the study at any time. Your choice not to participate or choice to withdraw will not affect any treatment needs that the ASD child has sought at KNH.

Confidentiality:

Your identity will be kept confidential. Your name or any other personal identifier will not be used in any reports or publications arising from this study. Instead, you will be assigned a unique study number to protect your identity.

Compensation: You will not be paid to participate in this study

Participant statement

The above statements regarding my participation in the study is clear to me. I have been given a chance to answer questions and also answered to my satisfaction. My participation in this study is entirely voluntary. I understand my audio recording will be kept private and that I can leave the study at any time. I understand I will not be victimized for leaving the study.

Signature of the participant………………………date……………………………..

Investigator's Statement

I, the undersigned have explained to the volunteer in a language she/ he understands the procedures to be followed in the study and the risks and benefits involved.

Interviewers Signature………………………….. date……………………………………

Fomu ya Maelezo ya Dhahiri ya Mahojiano

Kichwa: Mzigo wa utunzaji miongoni mwa walezi wa watoto wa Autism Spectrum Disorder wanaohudhuria kliniki za wagonjwa wa nje katika Hospitali ya Rufaa ya Kitaifa ya Kenyatta.

Nambari ya Utambulisho wa Utafiti wa Mshiriki …………………………………………
Tarehe …………………………………………….
Mpendwa Mheshimiwa/Madam,

Utangulizi

Jina langu ni Dkt. Mercy Ndindi, mwanafunzi wa shahada ya uzamili katika idara ya Saikolojia katika Chuo Kikuu cha Nairobi. Kwa ushirikiano na Chuo Kikuu cha Nairobi, tunafanya utafiti kuhusu mzigo wa matunzo miongoni mwa walezi wa watoto wa Autism Spectrum Disorder wanaohudhuria kliniki za wagonjwa wa nje katika Hospitali ya Rufaa ya Kitaifa ya Kenyatta.

Kwa hili, tunaomba ushiriki wako katika utafiti na hii inajumuisha maelezo kuhusu mtoto anayehudumiwa katika KNH.

Utaratibu

Ukikubali kushiriki katika utafiti, utatia saini hapa chini kama kibali cha taarifa kinachoonyesha ushiriki wako wa hiari. Haya yatakuwa mahojiano ambapo utaeleza uzoefu wako kuhusu kumtunza mtoto mwenye tawahudi. Jisikie huru kujieleza kwa uhuru. Kutakuwa na rekodi ya sauti ya mjadala wetu na nitaandika hisia zako juu ya mada ambayo itachukua kama dakika 40 kukamilika.

Faida: Hakuna faida za moja kwa moja za kushiriki katika utafiti huu.
Hata hivyo, matokeo ya utafiti huu yanaweza kusaidia kuboresha afya ya akili ya walezi wanaowatunza watoto wa ASD na pia kuboresha usimamizi wa wagonjwa wa ASD.

Hatari: Inawezekana kwamba unaweza kujisikia aibu au kukosa raha unapotoa taarifa za kibinafsi kuhusu matunzo ya mtoto mwenye tawahudi na ugonjwa wa akili, ambazo ni mada nyeti. Ikiwa kuna usumbufu wa kisaikolojia, utapewa msaada wa kisaikolojia.

Ushiriki wa Hiari:

Ushiriki wako katika utafiti huu ni wa hiari kabisa na ukiamua kushiriki, uko huru kujiondoa wakati wowote. Unaweza pia kuchagua kutojibu maswali mahususi au kujiondoa kwenye utafiti wakati wowote. Chaguo lako la kutoshiriki au chaguo la kujiondoa halitaathiri mahitaji yoyote ya matibabu ambayo mtoto wa ASD ametafuta katika KNH.

Usiri:

Utambulisho wako utawekwa siri. Jina lako au kitambulisho kingine chochote cha kibinafsi hakitatumika katika ripoti au machapisho yoyote yanayotokana na utafiti huu. Badala yake, utapewa nambari ya kipekee ya utafiti ili kulinda utambulisho wako.

Fidia: Hutalipwa kushiriki katika utafiti huu

Taarifa ya mshiriki

Taarifa zilizo hapo juu kuhusu ushiriki wangu katika utafiti ziko wazi kwangu. Nimepewa nafasi ya kujibu maswali na pia kujibiwa kwa kuridhika kwangu. Kushiriki kwangu katika utafiti huu ni kwa hiari kabisa. Ninaelewa kuwa rekodi yangu ya sauti itawekwa faragha na kwamba ninaweza kuondoka kwenye utafiti wakati wowote. Ninaelewa kuwa sitadhulumiwa kwa kuacha utafiti.

Saini ya mshiriki ……………………………………………………………

Taarifa ya Mpelelezi

Mimi, aliyetia sahihi hapa chini, nimemweleza mfanyakazi wa kujitolea katika lugha anayoelewa taratibu zinazopaswa kufuatwa katika utafiti na hatari na manufaa yanayohusika.

Sahihi ya Wahoji…………………………….. tarehe…………………………..................

Appendix 6: Interview Question Guide

Thank you very much for agreeing to participate in this interview. Before I start, I would like to remind you that there are no right or wrong answers in this discussion. My interest is to understand what you think, please feel free to be frank and share your point of view, it is very important that I hear all your views about this topic. What you say during this discussion will be kept confidential.

Sociodemographic of the Caregiver of a child with ASD

Part 1: To be filled by caregiver

1.What is your age in years………………

2.What gender are you;

o Male

o Female

3. How are you related to the patient;

o Father

o Mother

o Sibling

o Other relative

4. What religion do you practice…………………………

5. What is the highest level of education you have achieved?

o None

o Primary

o Secondary

o Some University

o Bachelor degree

o More than Bachelor degree

6. What is your current employment status?

o Employed/Self employed

o No Employment

7. What is your marital status?

o Single

o Married

o Separated

o Divorced

o Widow/ widower

8. What is your place of residence?

o Urban

o Rural

9. What is the current age your child with ASD?.........................

10. What is the gender of your child?.....................

Part 2.

QN 1. How did you feel when you were told that your child has autism spectrum disorder

QN 2. How has it been like raising a child with autism spectrum disorder?

QN 3 How has having a child with autism spectrum disorder affected your relationship with:

- your other children

- your spouse

- your relatives

- your neighbors

- your employer?

QN 4 What challenges have you faced in taking care of a child with autism spectrum disorder? (Probe: Financial challenges? Accessing health care services? Accessing education services? Social challenges?)

QN 5 How do you cope with the challenges identified above?

Thank you very much for taking your time to participate in this discussion.

Mwongozo Wa Maswali Ya Mahojiano

Asante sana kwa kukubali kushiriki katika mahojiano haya. Kabla sijaanza, ningependa kuwakumbusha kuwa hakuna majibu sahihi au yasiyo sahihi katika mjadala huu. Nia yangu ni kuelewa unachofikiria, tafadhali jisikie huru kuwa mkweli na kushiriki maoni yako, ni muhimu sana nisikie maoni yako yote kuhusu mada hii. Utakachosema wakati wa mjadala huu kitawekwa siri.

Demografia ya kijamii ya Mlezi wa mtoto mwenye ASD

Sehemu ya 1: Kujazwa na mlezi

1.Una umri gani wa miaka …………………

2.Wewe ni jinsia gani;

- o Mwanaume
- o Mwanamke

3. Una uhusiano gani na mgonjwa;

- o Baba
- o Mama
- o Ndugu
- o Jamaa mwingine

4. Unafuata dini gani ………………………………

5. Ni kiwango gani cha juu cha elimu ulichopata?

- o Hakuna
- o Msingi
- o Sekondari
- o Baadhi ya Chuo Kikuu
- o Shahada ya kwanza
- o Zaidi ya Shahada ya Kwanza

6. Hali yako ya ajira kwa sasa ikoje?

- o Kuajiriwa/Kujiajiri
- o Hakuna Ajira

7. Hali yako ya ndoa ikoje?

o Mtu mmoja

o Ndoa

o Imetenganishwa

o Wameachwa

o Mjane/mjane

8. Unaishi wapi?

o Mjini

o Vijijini

9. Mtoto wako mwenye ASD ana umri gani kwa sasa?.........................

10. Mtoto wako ana jinsia gani?................................

Sehemu ya 2.

QN 1. Ulijisikiaje ulipoambiwa kuwa mtoto wako ana ugonjwa wa tawahudi?

QN 2. Je, imekuwaje kama kulea mtoto mwenye ugonjwa wa tawahudi?

Swali la 3 Je, kuwa na mtoto mwenye ugonjwa wa tawahudi kumeathiri vipi uhusiano wako na:

- watoto wako wengine
- mwenzi wako
- jamaa zako
- majirani zako
- mwajiri wako?

QN 4 Je, umekumbana na changamoto gani katika kumtunza mtoto aliye na ugonjwa wa tawahudi? (Uchunguzi: Changamoto za kifedha? Kupata huduma za afya? Kupata huduma za elimu? Changamoto za kijamii?)

Swali la 5 Je, unakabiliana vipi na changamoto zilizoainishwa hapo juu?

Asante sana kwa kuchukua muda wako kushiriki katika mjadala huu.

Dummy Table

Dummy table 1: Socio-demographic characteristics of the caregiver

Characteristic	**Frequency**	**Percentage**
Age-groups		
Sex		
Male		
Female		
Relation to patient		
Father		
Mother		
Sibling		
Other relative		
Religion		
Christian		
Muslim		
Others		
Education level		
None		
Primary		
Secondary		
Some University		
Bachelor degree		
More than Bachelors		
Employment status		
Employed/self employed		
No employment		
Marital status		
Single		
Married		
Separated		
Divorced		
Widow/ widower		
Residence		
Urban		
Rural		

Dummy table 2: Socio-demographic characteristics of the ASD patients

Characteristic	**Frequency**	**Percentage**
Age-groups		
Sex Male Female		
Age of ASD diagnosis Age-groups		

Dummy table 3: Caregiver income status and psychiatric illness suffered

Characteristic	**Frequency**	**Percentage**
Monthly net income Less than 20,000 kshs 20,001 – 35,000 kshs 35,001 – 50,000 kshs Above 50,000 kshs Other (Specify)…………		
Income able to meet needs Insufficient Barely insufficient Sufficient		
Psychiatric illnesses		

Dummy table 4: Caregiver burden Zarit score

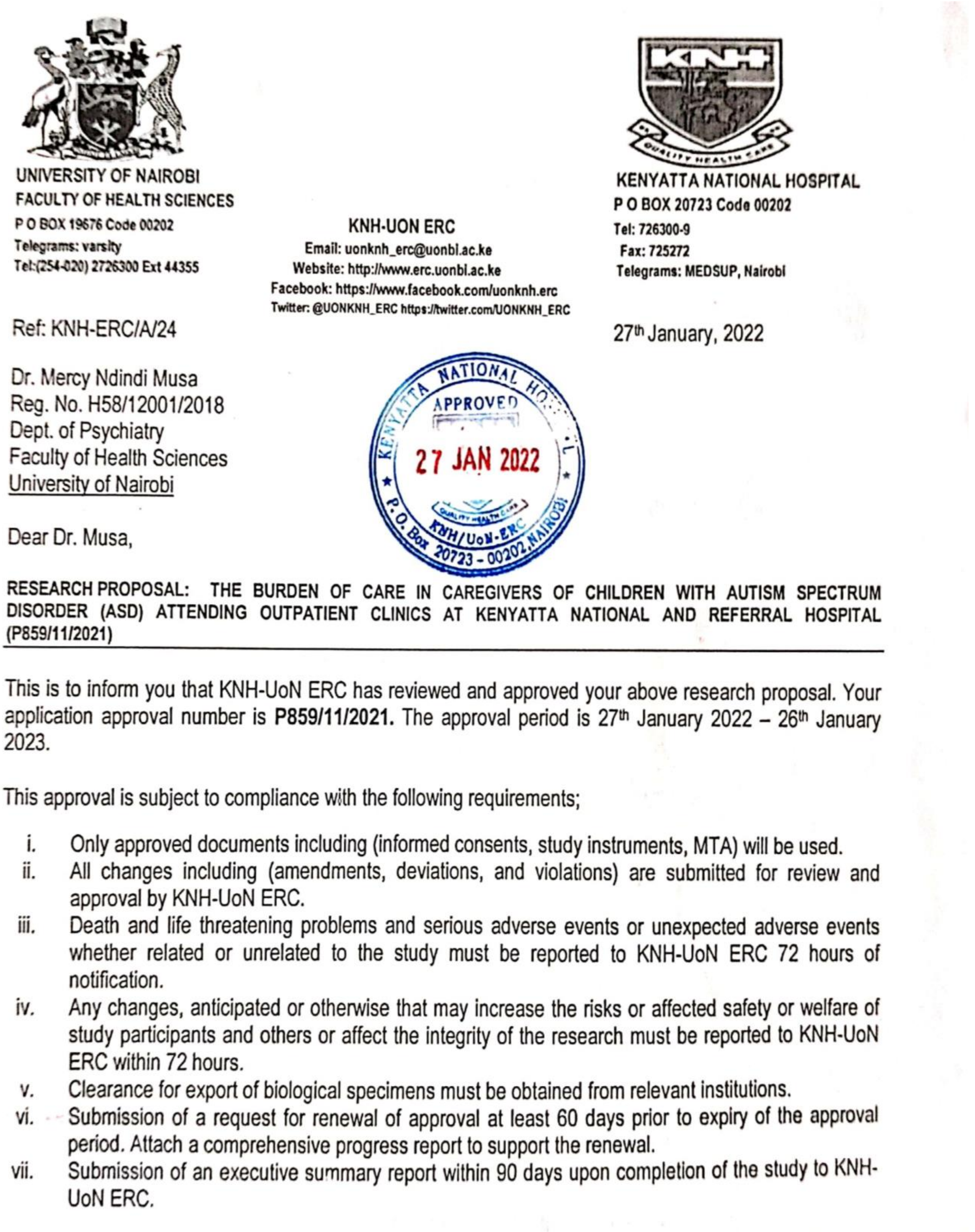
Characteristic	**Frequency**	**Percentage**
Little to No burden (0-20)		
Mild to Moderate (21-40)		
Moderate to severe (41-60)		
Severe burden (61-88)		

Dummy table 5: Caregiver GHQ score

Characteristic	**Frequency**	**Percentage**

Dummy table 6: Comparison of caregiver burden with caregiver and child socio-demographic factors

Caregiver factors	**Little/No**	**Mild to Moderate**	**Moderate to severe**	**Severe**
Mean age				
Gender				
Relationship				
Marital status				
Employment status				
Child mean age				
Sex of child				



UNIVERSITY OF NAIROBI
FACULTY OF HEALTH SCIENCES
P O BOX 19676 Code 00202
Telegrams: varsity
Tel:(254-020) 2726300 Ext 44355

KNH-UON ERC
Email: uonknh_erc@uonbi.ac.ke
Website: http://www.erc.uonbi.ac.ke
Facebook: https://www.facebook.com/uonknh.erc
Twitter: @UONKNH_ERC https://twitter.com/UONKNH_ERC

KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726300-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/24

27th January, 2022

Dr. Mercy Ndindi Musa
Reg. No. H58/12001/2018
Dept. of Psychiatry
Faculty of Health Sciences
University of Nairobi

KENYATTA NATIONAL HOSPITAL
APPROVED
27 JAN 2022
KNH/UoN-ERC
P.O. Box 20723 - 00202 NAIROBI

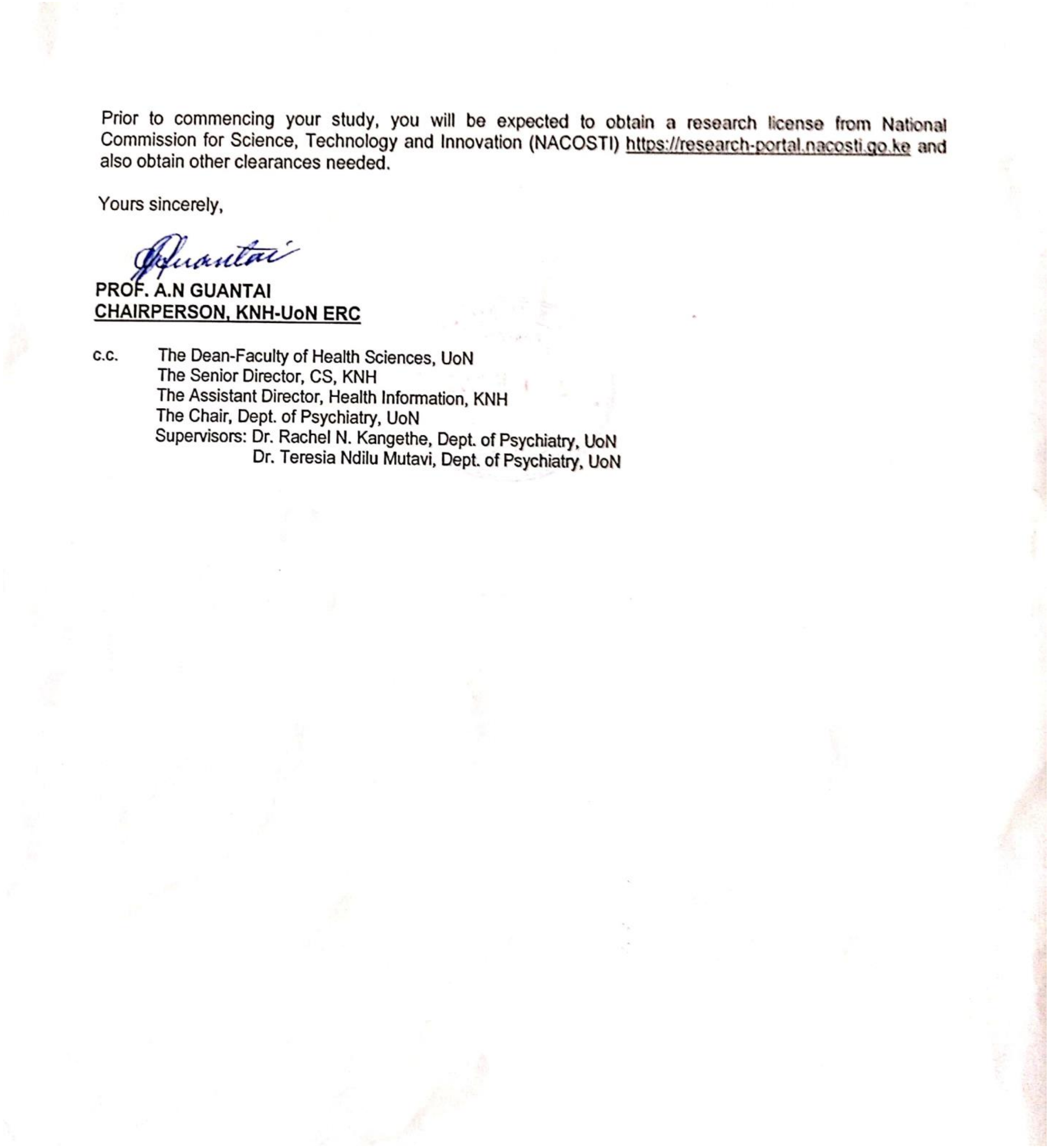
Dear Dr. Musa,

RESEARCH PROPOSAL: THE BURDEN OF CARE IN CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER (ASD) ATTENDING OUTPATIENT CLINICS AT KENYATTA NATIONAL AND REFERRAL HOSPITAL (P859/11/2021)

This is to inform you that KNH-UoN ERC has reviewed and approved your above research proposal. Your application approval number is **P859/11/2021.** The approval period is 27th January 2022 – 26th January 2023.

This approval is subject to compliance with the following requirements;

i. Only approved documents including (informed consents, study instruments, MTA) will be used.
ii. All changes including (amendments, deviations, and violations) are submitted for review and approval by KNH-UoN ERC.
iii. Death and life threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to KNH-UoN ERC 72 hours of notification.
iv. Any changes, anticipated or otherwise that may increase the risks or affected safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH-UoN ERC within 72 hours.
v. Clearance for export of biological specimens must be obtained from relevant institutions.
vi. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. Attach a comprehensive progress report to support the renewal.
vii. Submission of an executive summary report within 90 days upon completion of the study to KNH-UoN ERC.



Prior to commencing your study, you will be expected to obtain a research license from National Commission for Science, Technology and Innovation (NACOSTI) https://research-portal.nacosti.go.ke and also obtain other clearances needed.

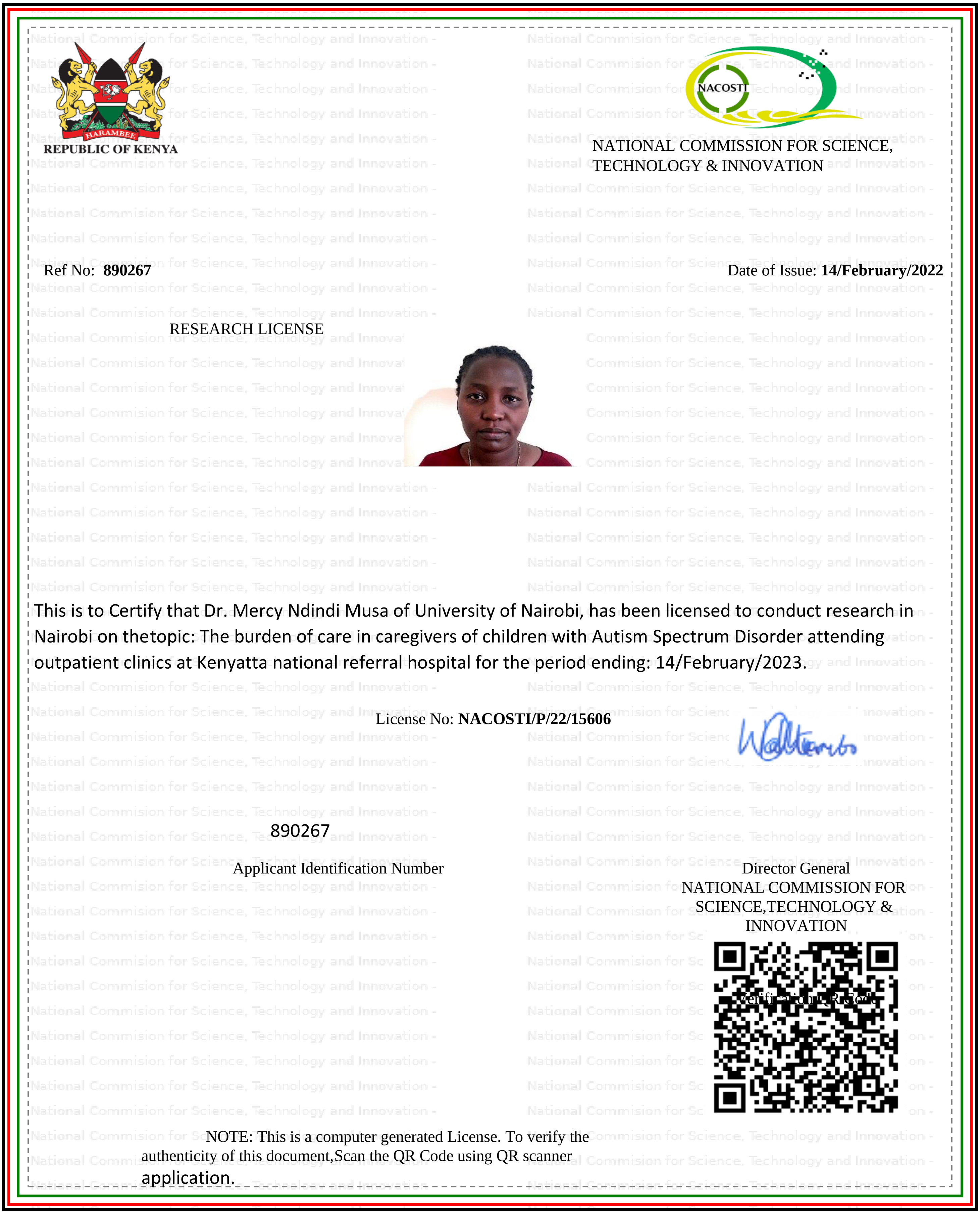
Yours sincerely,

Guantai

PROF. A.N GUANTAI
CHAIRPERSON, KNH-UoN ERC

c.c. The Dean-Faculty of Health Sciences, UoN
The Senior Director, CS, KNH
The Assistant Director, Health Information, KNH
The Chair, Dept. of Psychiatry, UoN
Supervisors: Dr. Rachel N. Kangethe, Dept. of Psychiatry, UoN
Dr. Teresia Ndilu Mutavi, Dept. of Psychiatry, UoN

NACOSTI Approval



REPUBLIC OF KENYA

NATIONAL COMMISSION FOR SCIENCE,
TECHNOLOGY & INNOVATION

Ref No: **890267**

Date of Issue: **14/February/2022**

RESEARCH LICENSE

This is to Certify that Dr. Mercy Ndindi Musa of University of Nairobi, has been licensed to conduct research in Nairobi on thetopic: The burden of care in caregivers of children with Autism Spectrum Disorder attending outpatient clinics at Kenyatta national referral hospital for the period ending: 14/February/2023.

License No: **NACOSTI/P/22/15606**

890267

Applicant Identification Number

Director General
NATIONAL COMMISSION FOR
SCIENCE,TECHNOLOGY &
INNOVATION

Verification QR Code

NOTE: This is a computer generated License. To verify the authenticity of this document,Scan the QR Code using QR scanner application.

THE SCIENCE, TECHNOLOGY AND INNOVATION ACT, 2013

The Grant of Research Licenses is Guided by the Science, Technology and Innovation (Research Licensing)

Regulations, 2014CONDITIONS

1. The License is valid for the proposed research, location and specified period
2. The License any rights thereunder are non-transferable
3. The Licensee shall inform the relevant County Director of Education, County Commissioner and County Governor beforecommencement of the research
4. Excavation, filming and collection of specimens are subject to further necessary clearence from relevant Government Agencies
5. The License does not give authority to tranfer research materials
6. NACOSTI may monitor and evaluate the licensed research project
7. The Licensee shall submit one hard copy and upload a soft copy of their final report (thesis) within one year of completion of theresearch
8. NACOSTI reserves the right to modify the conditions of the License including cancellation without prior notice

National Commission for Science, Technology
and Innovationoff Waiyaki
Way, Upper Kabete,
P. O. Box 30623, 00100 Nairobi, KENYA
Land line: 020 4007000, 020 2241349, 020 3310571, 020 8001077
Mobile: 0713 788 787 / 0735 404 245
E-mail: dg@nacosti.go.ke /
registry@nacosti.go.keWebsite:
www.nacosti.go.ke

Plagiarism Report - Dr. Mercy Ndindi Musa H58/12001/2018

The Burden Of Care In Caregivers Of Children With Autism Spectrum Disorder (ASD) Attending Outpatient Clinics At Kenyatta National And Referral Hospital.

ORIGINALITY REPORT

13%	10%	8%	4%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	www.ncbi.nlm.nih.gov Internet Source	1%
2	cdr.lib.unc.edu Internet Source	1%
3	Shrijana Pandey, Chandrakala Sharma. "Perceived Burden in Caregivers of Children with Autism Spectrum Disorder in Kathmandu Valley", Journal of Nepal Health Research Council, 2018 Publication	1%
4	www.mdpi.com Internet Source	1%
5	www.biomedcentral.com Internet Source	1%
6	Eman Khamis Alnazly, Amjed Abojedi. "Psychological distress and perceived burden in caregivers of persons with autism spectrum	1%

First Supervisor
Dr. Kangethe Rachael N.
Kangethe

Prof. Anne Obondo
Chairman department of psychiatry
15/08/2022