PSYCHIATRIC MORBIDITY AND BURDEN AMONG CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN SELECTED HOSPITALS IN GHANA

BY

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DECLARATION

I, Peggy Asiedu Ekremet, declare that this dissertation is being submitted in partial fulfilment of the award of Master of Science in Child and Adolescent Mental Health (MSc. CAMH) at the University of Ibadan, Nigeria. It has not been submitted for the award of any other degree at this or another University.

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CERTIFICATION BY SUPERVISORS

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DEDICATION

This is dedicated to all caregivers of children with Autism Spectrum disorder. Together, we can find a spectrum of solutions to every challenge.

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KEY TO ABBREVIATIONS

ADHD	ATTENTION DEFICIT HYPERACTIVITY DISORDER
ANOVA	ANALYSIS OF VARIANCE
APA	AMERICAN PSYCHIATRIC ASSOCIATION
ASD	AUTISM SPECTRUM DISORDER
GHQ	GENERAL HEALTH QUESTIONNAIRE
ISCO	INTERNATIONAL STANDARD CLASSIFICATION OF OCCUPATION
OCD	OBSESSIVE COMPULSIVE DISORDER
OPD	OUTPATIENT DEPARTMENT
SD	STANDARD DEVIATION
WHO	WORLD HEALTH ORGANISATION
ZBI	ZARIT BURDEN INSTRUMENT

ABSTRACT

Background: Caring for children with autism spectrum disorder (ASD) can be a very challenging task for carers and other family members especially in a resource restricted country like Ghana. In the past, Autism was considered to be a rare condition especially among Black populations. However, epidemiological studies have documented a gradual but consistent increase in the global prevalence of autism. Consequently, there have been reports of increased burden and psychiatric morbidity among caregivers of these children. Limited research in this area has been done in Africa and more specifically Ghana. This study seeks to fill this knowledge gap and serve as basis for intervention to support caregivers.

Methodology: The study was a cross sectional one, using a mixed method (quantitative and qualitative) approach, that determined the prevalence of psychiatric morbidity and the level of burden of care among informal caregivers of children with autism spectrum disorder (ASD) attending the outpatient clinics of selected hospitals in Ghana. It was carried out at the Komfo Anokye Teaching Hospital Psychiatry clinic, Accra Psychiatric Hospital and Pantang Psychiatric Hospital. The instruments used were a sociodemographic questionnaire, the 12-Item General Health Questionnaire (GHQ-12) and the Zarit Burden Interview (ZBI). Three focus group discussions were held to explore burden of care experienced by caregivers.

Results: Sixty one caregivers participated in the study. The mean age of children was 10.64 (SD 5.15) years, 73.8% were males, 54.1% were first born children, lived in predominantly monogamous home settings (98.4%), with a quarter of their parents separated, divorced, or widowed. The mean age of caregivers was found to be 43.53 years (SD 8.97). Females were the predominant gender (82%) with mothers forming 73.8% and 18% of caregivers were unemployed. The prevalence of psychiatric morbidity among caregivers was 45.9% and 36.1%

of all caregivers had a high level of burden of care. Factors significantly associated with psychiatric morbidity and a high burden were the child's birth order and employment status of the caregiver, respectively. Following multiple linear regression with adjustment for age, a predictor of high burden was found to be the employment status of the caregiver. And unemployed caregivers were found to be 8 times more likely to be burdened as compared to the employed (adjusted OR=7.69, 95% CI 1.71-34.68, p = 0.008). Also, it was found that caring for a child who was either a second or third born, was associated with a caregiver being 4 more times at risk of having psychiatric morbidity, as compared to caring for a first born child (unadjusted OR= 4.03, 95% CI 1.28-12. 62, p = 0.017). Caregivers perceived that autism was caused by spiritual and biomedical causes. Challenges experienced by the caregivers included dealing with the disorder and caregiving, stigma and social exclusion, financial problems, relationship problems, coping with the challenges and the need for support. Unmet needs included acceptance from family and the society, special schools, support systems (social, financial, skills training), advocacy and education.

Conclusion: Psychiatric morbidity among caregivers of children with autism is common with a prevalence of 45.9%, implying that about 5 in 10 caregivers is affected. Also, 36.1% of all caregivers had a high level of burden of care. These results are in keeping with literature about the fact that caregivers of children with autism experience a higher level of psychosocial burden, compared to typically developing children and children with other neurodevelopmental disorders. There is, therefore, the need to incorporate mental health screening of caregivers of children with ASD into routine care of their children. Furthermore, there is a need to develop policies, interventions, and support systems to mitigate the psychosocial burden they face.

Keywords: Psychiatric morbidity; Burden; Caregiver; Children; Autism Spectrum Disorder

Word count = 599

CHAPTER 1 – INTRODUCTION

1.1 Background

Caring for children with chronic disorders can be a very challenging task for carers and other family members. Autism Spectrum Disorders (ASD) is a term used to describe a range of neurodevelopmental disorders that affect children early in their lives, usually before the age of 3 years. (APA, 2013). The term "autism" comes from the Latin root 'autismus' and was described by Eugene Bleuler as part of primary symptoms of schizophrenia. He described it as 'the phenomenon of a patient's getting lost in personal ideas, emotions, and intentions without being able to adapt to the external reality, resulting in a reduction of communication' (Maatz et al., 2015). Autism is characterised by a persistent deficit in reciprocal social interaction and communication in multiple contexts and repetitive and restricted pattern of one's interests, activities, or behaviours (APA, 2013)

In the past, Autism was a rare condition especially among Black populations; however, epidemiological studies have documented a gradual but consistent increase in the global prevalence of autism (Bello-Mojeed et al., 2013a; Bauman and Kemper, 2005). Global prevalence rates for autism over the years have been found in the Western world with a limited report on the continent of Africa. Though prevalence studies on ASD among African children were mostly conducted among Africans living abroad, studies on the continent have documented occurrences and increase in the prevalence of ASD in Africa (Lotter, 1978; Barnevik-olsson et al., 2010; Bakare et al., 2012; Seif Elden et al., 2008; Bello-Mojeed et al., 2013a).

According to the Centre for Disease Control and Prevention (CDC), Autism and Developmental Disabilities Monitoring (ADDM) network, the current prevalence of ASD is 16.8 per 1000 (Baoi et al., 2018). It was also found that the prevalence of autism among Black and Hispanic children was approaching that of white children (Baoi et al., 2018), with a dire implication of increased caregiving responsibilities especially on families of affected children on the continent of Africa (Bello-Mojeed et al., 2013b). Children with autism spectrum disorder, also have many disabling and debilitating impairments associated with the disorder (APA, 2103; WHO,1992; Mody and Belliveau, 2013; Bello-Mojeed et al., 2017) which tend to make caregiving very challenging as they may need care and support for most of their lives.

The presence of problems, difficulties or adverse events that affect the life of an individual taking care of another can be referred to as burden (Platt, 1985). Informal caregivers who are mostly family members, friends, or neighbours form the majority of caregivers for many people with chronic illnesses (Day, 2018). Caring for a child with autism is more burdensome as compared to typically developing children or children with other disabilities such as Down's Syndrome, intellectual disability, and cerebral palsy (Hayes and Watson, 2013). This can be attributed to the core symptoms of autism itself (Hayes and Watson, 2013; Bello-Mojeed et al., 2013b; Bello-Mojeed et al., 2017), other variable confounding characteristics (Mody and Belliveau, 2013), as well as the presence of other comorbidities such as epilepsy, attention deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), anxiety, depression, among others (Hayes and Watson, 2013; Bello-Mojeed and Bakare, 2013; Bello-Mojeed et al., 2013a)

Across studies, significant levels of psychiatric morbidity among informal caregivers of children with ASD have been documented, with higher reports of psychological distress in ASD group than the controls (Picardi *et al.*, 2018Bello-Mojeed et al., 2010;). A study done in Iraq found 25% of caregivers of children with autism to be psychologically distressed (Al-Dujaili and Al-Mossawy, 2017) while another research from Nepal reported 30% and 25% of caregivers had anxiety and depression symptoms respectively (Pandey and Sharma, 2018). Similarly, studies on the burden of caregiving in ASD have documented a moderate to severe level of burden in the studied population. In a study conducted in Nigeria, Bello-Mojeed et al. (2013b) examined rates of psychological morbidity and burden among mothers of children with autism. The study reported 65% for psychiatric morbidity and 70% for psychosocial burden of care (Bello – Mojeed et al., 2013b). Al-Dujaili and Al-Mossawy (2017) found 50% of caregivers reported moderate burden of care, 42% endorsed moderate to severe levels of burden (Pandey and Sharma, 2018) and 47.2% reported severe burden (Ezzat et al., 2017,) which has serious implications on the quality of caregiving.

Psychological morbidity among caregivers has been related to the burden of caregiving. Some studies have found predictors of psychological morbidity and distress among caregivers of children with a neurodevelopmental disorder to be the actual burden of caregiving itself (Gallagher *et al.*, 2008; Shanthi et al., 2015). Similarly, the burden of care has been found to be a predictor of psychological distress and vice versa in studies involving caregivers of children with autism (Dada et al., 2011; Bello-Mojeed et al., 2013b; Al-Dujaili and Al-Mossawy, 2017; Pandey and Sharma, 2018).

Many factors have been associated with the development of psychiatric morbidity and increase the burden of care among informal caregivers. Some of these factors include the patient's level of functioning, severity of ASD symptoms, patient's level of education, younger age of child, low income, younger parents, maladaptive coping mechanisms, psychiatric morbidity in the caregiver and level of impairment as assessed by the caregiver (Picardi et al., 2018; Pandey and Sharma, 2018; Dada et al., 2011; Al-Dujaili and Al-Mossawy, 2017; Bello-Mojeed et al. 2013b, 2017; Dardas and Ahmad, 2014). The dearth of information on psychiatric morbidity and burden of care among caregivers of children with ASD in Ghana indicates a dire need for this study.

1.2 Problem statement

Autism spectrum disorder is a disabling neurodevelopmental disorder that demands much attention and care from a caregiver, and it is a disorder with growing global health concern (Bello-Mojeed and Bakare, 2013; Abubakar et al., 2016), increasing prevalence and its associated burden of care. Despite this, ASD is still poorly recognised, under-diagnosed and less researched in Sub-Saharan Africa (SSA). Studies on ASD from literature show that majority of the studies are from developed countries in the West with little representation from the African continent, despite reports that Africa has most of the World's children living within its borders (Bakare et al., 2014; Bello -Mojeed et al., 2013a).

Very few studies have been done on Autism Spectrum Disorder in Africa (Bello-Mojeed et al.; 2013a; Bakare et al., 2014; Thomas et al., 2015) and the burden of ASD in SSA is not well known (Abubakar et al., 2016; Bello-Mojeed and Bakare , 2013;). A systematic review of published work on ASD found that over 70% of studies were conducted in 2 African countries, (Nigeria and South Africa), with over 80% being done in the last decade. Areas covered in these studies included the development of measurement tools of ASD, prevalence of ASD, identification of risk factors and risk markers, and examining psychosocial issues (Abubakar et al., 2016). This leaves a gap in knowledge in the area of psychiatric morbidity and burden among caregivers of children with ASD in many African countries, including Ghana.

A summarised report from 14 African Countries (including Kenya, Nigeria, Ghana, and South Africa) found that there was an inadequate provision of services and a scarcity of service providers for the assessment and management of Autism in many of the countries (Ruparelia et al., 2016). There were also few support organisations, training programs and research work on autism due to lack of funding and concentration on communicable diseases (Bello-Mojeed et al.; 2013a; Bello-Mojeed and Bakare, 2013; Bakare et al., 2014; Ruparelia et al., 2016). This further compounds the problem and necessitates research in ASD.

1.3 Justification

The dearth of studies on autism poses a huge dilemma for many African countries including Ghana, as such regions lag behind the developed nations in the identification, assessment, and management of children with ASD in Africa. It is therefore essential that research on ASD among affected children as well as those involved in their care be done to influence clinicians and other mental health professionals to be better able to manage these children together with their caregivers. Without a culturally relevant research database to inform interventions, policies and plans, Africa will be underequipped and may rely on findings from the West which may not be entirely appropriate for affected children and their caregivers in African settings.

The topic 'autism' is a grey area in terms of research in Ghana, and few studies have been done although there are unpublished works mostly done by Non-Governmental Organisations (NGOs). The previous studies on the topic in Ghana were mainly on treatment and education of children with disabilities such as ASD (Thomas et al., 2015) and challenges and coping by parents of children with ASD (Agyekum, 2018a; Agyekum 2018b). Thus, there is a considerable lack of knowledge in Ghana concerning psychiatric morbidity and burden among caregivers in autism research in Ghana.

Caregiver burden is either undetected or neglected in the management of the affected children (Ezzat et al., 2017) and unmet mental health needs of a caregiver pose a significant risk to the psychological, physical, and social well-being of both the affected child and carer. Mental health issues in caregivers may threaten the adaptive functioning of the affected family as well have a harmful effect on the development of the child's potential (Bello-Mojeed et al., 2013b, 2017; Catalano et al., 2018). Thus, it is important to study the mental health of caregivers to provide evidence base to support caregivers and also to enable Ghana to attain Sustainable Development Goal (SDG) 3, through the promotion of mental health and wellbeing.

This study sought to assess psychiatric morbidity and burden of care among caregivers of children with autism. The findings of this study would provide the information required to fill the knowledge gap in autism research on the African continent and particularly in Ghana. Reports from this study should serve as a basis for a framework to provide services and interventions targeted at meeting the needs of both the child and caregiver.

1.4 Aim and objectives

1.4.1 Aim

To determine the prevalence of psychiatric morbidity and the level of burden of care among informal caregivers of children with autism spectrum disorder (ASD) attending the outpatient clinics of selected hospitals in Ghana.

1.4.2 Objectives

1. To determine the prevalence of psychiatric morbidity among caregivers of children with Autism spectrum disorder in selected hospitals in Ghana
2. To assess the level of burden among caregivers of children with ASD at the selected study locations
3. To determine the sociodemographic and other associated factors of psychiatric morbidity among caregivers
4. To determine the sociodemographic and other associated factors of burden of care among caregivers

1.5 Research Questions

1. What is the prevalence of psychiatric morbidity among caregivers of children with ASD?

2. What is the level of burden of care among caregivers of the selected children with ASD?
3. What are the sociodemographic and other associated factors of psychiatric morbidity among the informal caregivers of children with ASD?
4. What are the sociodemographic and other associated factors of burden among the informal caregivers of children with ASD?

1.6 Outcome Measures

The primary outcome is psychological distress among caregivers of children with ASD.

The secondary outcomes will be the burden of care among informal caregivers.

Word count = 1872

CHAPTER 2 – LITERATURE REVIEW

2.1 Autism Spectrum Disorder

2.1.1 Definition

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder with onset in early childhood, usually before the age of 3 years. ASD is characterised by a persistent deficit in reciprocal social interaction and communication in multiple contexts and repetitive and restricted pattern of interests, activities, or behaviours (APA, 2013). Autism spectrum disorder encompasses the previous diagnosis referred to as childhood autism, Kanner's autism, infantile autism, Asperger's syndrome among others (APA, 2013), however some of these disorders are still maintained and all classified under pervasive developmental disorders in the International Classification of Diseases, 10th Edition (ICD -10) by the World Health Organisation (WHO, 1992).

Most symptoms of ASD are often recognisable in the second year of life, between 12 to 24 months and it is possible to recognise them earlier than at 12 months if the developmental delays are severe or later than 24 months if the presentation is subtle. Core diagnostic features are apparent during the developmental period of a child (Bello-Mojeed et al, 2017), yet intervention, compensation, and current supports may guise difficulties in some contexts. Clinical presentation of the disorder also differs greatly depending on the severity of the range of the disorder, developmental level, and chronological age; hence, the term spectrum (APA, 2013).

2.1.2. Historical Perspectives

The history of autism is a fascinating one which has undergone a great deal of revolution spanning from descriptions and result of individual clinical reports to well-organised research studies. In the book ‘Autism in History’, written by Rab Houston, there is a description of a 39-year-old Hugh Blair, the son of a Scottish landowner who appeared in an Edinburg court for a legal decision on his mental capacity to contract marriage. He was described to have had problems with social relationships including being tactless and having an abnormal gaze, severe impairments with his language such as repetition of phrases and both questions and answers, as well as having odd and repetitive behaviours such as collecting feathers and sticks, having seat preferences and retaining objects in one place. He was said to have lacked common sense at that time and was said to have a ‘silent madness’ (Wolff, 2004).

Another account is given of a boy of about seven years in an 1809 publication ‘Observations on Madness and Melancholy’ by John Haslam, describe as having convulsions, measles and a smallpox inoculation who was restless, inattentive and had delayed speech and walking. At an older age, he referred to himself in the third person and had obsessive preoccupations. At that time, those symptoms were, however, attributed to a post-encephalitic syndrome. A description of a 13-year-old boy who may have had Asperger syndrome was mentioned by Henry Maudsley in the 1897 edition of ‘Pathology of Mind’. There have been earlier speculations of the possible disabilities of ‘wolf children’ whom when found in the wild were mute with other peculiarities, believed to be reared by wolves or other animals.

A popular one was a 12-year-old Victor, “the wild boy of Aveyron”, who was found in the woods naked with multiple scars in 1798. He had a sensitivity to pleasant or loud noise, indifference to odours and expressionless and shifting gaze. Also, he made guttural sounds and had repetitive behaviours such as rocking to and fro, object preferences, inappropriate laughter, and gluttony. Through a behavioural modification by French Physician Jean Itard, his symptoms improved, and he was able to distinguish emotional responses of others, match alphabets and make requests for things via writing. His speech, however, remained monosyllabic and incoherent (Wolff, 2004).

It was earlier thought that autism might be a form of childhood schizophrenia (Wolff, 2004), as Emil Kraepelin's description of dementia praecox (now schizophrenia)s was extended to children making the terms childhood schizophrenia and childhood psychosis synonyms as it was assumed that many severe childhood disturbances must be a form of schizophrenia (Martin and Volkmar, 2007). In 1943 however, the American Psychiatrist Leo Kanner, gave a description of a syndrome of 'autistic disturbances' among 11 children aged 2 to 8 years who shared distinct and unique behaviours such as social isolation, obsession, delayed speech, difficult social imagination, echolalia, pronoun reversal, intolerance of change and repetitive purposeless activities (Rutter, 1978; Rutter et al., 2008; Martin and Volkmar, 2007). The use of the term 'autism' in Leo Kanner's context was meant to describe the unusual self-centred quality observed but it was confused with Eugene Bleuler's use of the same word 'autism', to describe the active withdrawal into fantasy associated with schizophrenia (Rutter, 1978; Martin and Volkmar, 2007).

The Diagnostic and Statistical Manual for Mental Disorders (DSM), first edition classified autism as a type of childhood schizophrenia. With the advent of the third edition, DSM-III, the group of disorders were described under Pervasive Developmental Disorders (PDD) which included conditions such as infantile autism and childhood-onset PDD. Diagnostic and Statistical Manual for Mental Disorders (DSM-IV) saw the introduction of Asperger Syndrome (Rutter et al., 2008), while DSM-V now groups those disorders as Autism Spectrum Disorder (APA, 2013).

2.1.3. Prevalence of Autism

Epidemiologic surveys of autism started in the mid-1960s in England, and ever since then, several other surveys have been done in other countries. Those studies used a categorical diagnostic approach based on different sets of criteria but relied on a definition of autism comprising of impairments in language and communication, reciprocity of social interactions and behaviour and play. Earlier studies, however, did not include other pervasive developmental disorders which fell short of a diagnosis of autism (for example, pervasive developmental disorder – not otherwise specified and Asperger Syndrome), unlike more recent studies (Bauman and Kemper, 2005).

Autism was thought to be a rare condition in the past but after epidemiological surveys, a great wealth of data has now become available, and it has been found out that the prevalence rates are higher than speculated over time. Currently, the global burden of autism is unknown. However, high-income countries such as the United States and the United Kingdom spend several billion every year on the condition (Elsabbagh *et al.*, 2012). Global prevalence rates for autism over the years have been found in the Western world with dearth of epidemiological data on prevalence of ASD in Africa on the continent of Africa (Bello-Mojeed et al., 2013a; Abubakar et al., 2016); most epidemiological studies on the prevalence of ASD among African children were done in Africans living abroad (Barnevik-olsson et al., 2010; Bello-Mojeed et al., 2013a)

From selected epidemiologic studies from 1966 to 2003 it was found that the median prevalence rate for 18 surveys published from 1966–1992 was 4.6/10,000, and the median rate for the 16 surveys published in the period 1993–2003 was 12.7/10,000. According to the Centre for Disease Control and Prevention (CDC) Autism and Developmental Disabilities Monitoring (ADDM) network, the current prevalence of ASD is 16.8 per 1000. It was also found that the prevalence of autism among Black and Hispanic children was approaching that of white children (Baoi et al., 2018).

2.2. Impairments in Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) typically presents early in life. The spectrum of the disorder is characterised by developmental deficits that cause impairments in personal, social, academic, or occupational functions (APA, 2013). Children with autism have deficits in their social communication and social interaction in more than one context. For example, they may have problems with social-emotional reciprocity such as holding back and forth conversations and being able to share one's feelings with others (APA, 2013; WHO, 1992).

Language abilities may range from being nonverbal to highly distinctive language with repetition of words, phrases (echolalia) and unusual stress in tone and inflexion in speech (prosody) (Mody and Belliveau, 2013). They may also have problems with non-verbal communication such as maintaining eye contact, lack of facial expression, poor use and understanding of gestures. They also may have problems making and keeping relationships and often may lack imaginative play or fail to mingle and play with peers (APA, 2013; WHO, 1992).

Children with autism also have impairments with their pattern of interests, behaviour or activities which often are restricted or repetitive. For example, a child may dislike it when his usual routine is changed and may be distressed at this and insist on taking the same road to school, eating a particular food. A child with autism may engage in repetitive activities such as lining up toys in one particular order, moving parts of his body repeatedly such as rocking to and fro, flapping the arms or repeatedly saying the same word after he hears it. Also, children with autism may have unusual preoccupation to specific objects and have restricted interest in a particular subject, object, among others (APA, 2013; WHO, 1992).

Impairments in ASD affect the day to day functioning of the affected individual. In addition to core deficits, other variable characteristics such as sensory processing and attention are associated and interact with the core features of ASD, adding to the heterogeneity of the disorder and its clinical presentation (Mody and Belliveau, 2013). Impairments in ASD can be a significant source of stress for both the child and the caregiver. Researchers have proposed that it is the core deficits in ASD such as restrictive and repetitive behaviours and social communication impairments that are stressful to most parents (Hayes and Watson, 2013; Bello-Mojeed et al., 2013b).

2.3. Caregiving

Caregiving refers to a process of providing assistance and support to others who are not able to engage in certain activities by themselves because of limitations such as chronic illness, physical disability, or cognitive impairment. Caregiving may be formal or informal. Formal caregivers are usually paid for their services or are volunteers associated with a service system. Informal caregivers are unpaid and could be family members, friends, church members or neighbours, who out of obligation, love or friendship offer care to an individual (Day, 2018).

Caregiving may involve time-consuming, stressful, and demanding activities. Some activities that a caregiver may render include household chores such as washing, sweeping, maintaining personal health care such as bathing, brushing one’s teeth, cleaning up after toilet, among others. Caregivers may also be involved in the management of the care recipient and would be involved in medication administration and bringing the recipient for hospital review. Caregiving activities can run for 24hours in a day and leave the caregiver with little or no time to attend to his or her own needs.

2.4. Caring for Children with Mental Illness and Developmental Disorders

Taking care of children, in general, can be an arduous task, let alone taking care of children with special needs. Having a child with a mental illness or developmental disorder would demand that extra attention and effort are put in to ensure that the various needs of the child are met. These needs may be present and endure because some of those disorders run a long course. As a result, this may tend to make caring for such children very challenging as they tend to need care and support for most of their lives.

Research on caregiver burden in severe mental illnesses such as schizophrenia and bipolar affective disorder has shown that some factors affecting the burden of care among caregivers included the patient's behaviour, frequent hospitalisations, length of illness and the severity of the illness. Carers of patients with bipolar disorder commonly had depression or somatic complaints as well, with a higher burden among those whose relatives had recurrent depressive episodes (Pramita and Jena, 2011). Similar studies have reported some of the common challenges caregivers encountered as stress and emotional problems, financial problems, lack of adequate information about patient's condition by health workers, lack of social support and physical strain in the form of illnesses such as hypertension and migraines (Shamsaei et al., 2015).

A Nigerian based study set out to determine the prevalence of psychiatric morbidity among caregivers of children attending a Child and Adolescent Mental Health Clinic in Lagos found that majority of the caregivers were females while the majority of the patients were males. Also, about 40% of caregivers screened had psychiatry morbidity and factors associated with this morbidity included the high level of impairment, low-level functioning of the child, low educational level of the child as well as a high perceived burden of care (Okewole et al., 2011).

In addition to the impairments associated with autism spectrum disorder and other developmental disorders, children may have other co-morbidities. At least, about 50% of all children with ASD have intellectual disabilities, and even those with normal Intelligence Quotient (IQ) may have problems with language and communication (Mody and Belliveau, 2013). Research shows that about 70% of people with autism spectrum disorder study qualify for at least one more comorbid disorder (Hayes and Watson, 2013) such as tic disorders, epilepsy, attention deficit hyperactivity disorder (ADHD), Obsessive Compulsive disorder (OCD), anxiety, depression, oppositional defiance disorder (ODD), intellectual disabilities, epilepsy, tuberous sclerosis and emotional disorders (Hayes and Watson, 2013; Bello-Mojeed and Bakare, 2013, Bello-Mojeed et al., 2011, 2013a).

Children with autism and other developmental disorders tend to have atypical behaviours, which may influence caregiving and add to the stress. Some documented behaviours include unusual eating habits such as excessive food selectivity, ritualistic eating patterns and food refusal. Others such as abnormal sleep pattern, aggression, temper tantrums and self-injurious behaviours may be present (Dominick *et al.*, 2007; Bello-Mojeed et al, 2011, 2013b, 2016). All these, together with possible comorbidities may contribute directly or indirectly to affect the caregiving process and add on more challenges.

As compared to children having no disabilities or disorders, parents, and caregivers of children with developmental disorders are more likely to have high levels of stress and many other challenges. Parents of children with intellectual disability reported high levels of anxiety and depression as compared to children of typically developing children due to their increased burden in caregiving (Gallagher *et al.*, 2008) and it has been found that as burden increases, psychiatric morbidity also increases (Shanthi, Sireesha and Kuna, 2015; Bello-Mojeed et al., 2013b)

2.5. Psychological Distress and Burden Among Informal/Family Caregivers of Children with Autism

Caregiving is often seen as part of normal duties. However, it has been shown that giving care to a child with an enduring problem takes a toll on both the physical and psychological health of a caregiver and is often burdensome (Pandey and Sharma, 2018). Even though caring for children with special needs is more demanding than for normally developing children, meta-analysis research shows that caring for children with autism is more stressful as compared to caring for children with typical development or with disabilities such as intellectual disability, Down's syndrome and cerebral palsy (Hayes and Watson, 2013).

Caregiving for children with autism has been associated with family stress, and an increase in emotional and physical problems, especially among mothers. Caregivers have been noted to manage and cope with the various forms of impairments found in the child and often bear the social, psychological, and financial aspect of the child rearing. This makes them prone to 'burn out syndrome' and social isolation and places them at an increased risk of developing disorders such as depression and anxiety (Bello – Mojeed et al., 2013).

It is therefore vital that both the physical and mental health of caregivers be assessed, and the necessary support given them. There have been recommendations to give psychological support especially, and empowerment to families who have children with autism in terms of general education about clinical behaviour to aid early detection, and help with the addition of programs to strengthen community mental health (Al-Dujaili and Al-Mossawy, 2017; Bello-Mojeed et al., 2016, 2017). Also, early intervention to reduce parental stress may help restore balance in family functioning and equipping caregivers with skills to overcome challenging behaviour may decrease the effect of these behaviours on caregiver stress (Hayes and Watson, 2013; Bello-Mojeed and Bakare, 2013; Bello-Mojeed et al., 2016)

Anyone can be affected by stress, which can lead to both psychological and physical health issues. Stress refers to an emotional experience, which is uncomfortable and is accompanied by predictable changes in physiology, biochemical and behaviour of an individual. It can also be described as a feeling of worry, being overwhelmed, or run-down. Extreme levels of stress can affect the cardiovascular, neuroendocrine, immune, and central nervous system, of an individual (American Psychological Association, 2018).

Psychological stress is thus an adaptation of the fight-or-flight system caused by stressful life events which could induce psychological and physiological changes, which may include activation of the hypothalamic-pituitary-adrenal (HPA) axis and sympathetic nervous system. It may be classified as acute or chronic psychological stress depending on the time duration of the stress. Acute psychological stress may be present before an examination or a surgical operation while chronic psychological stress (subdivided into disconnected and persistent) includes anxiety about things, financial difficulties and headaches (Yang *et al.*, 2015).

According to Platt (1985), burden “refers to the presence of problems, difficulties or adverse events which affect the life (lives) of psychiatric patient’s significant other(s), e.g. members of the household and the family” (Platt, 1985). These problems can be found in many areas of a caregiver’s life, and from literature, the burden is often described as subjective or objective. Subjective burden refers to psychological reactions a caregiver may experience such as feeling embarrassed in social settings, having a low mood, anxiety, and feelings of loss of hopes and dreams. The objective burden, on the other hand, describe practical problems such as disruptions in social activities, occupation, recreation, family difficulties as well as financial problems (Picardi *et al.*, 2018).

Many studies have been done around the world which documents various levels of psychological distress and burden of care among caregivers of children with developmental disorders such as intellectual disability and autism spectrum disorder. In a study done in Nepal to describe perceived burden among caregivers of children with autism, caregivers were found to averagely fall within the moderate to severe category of burden (42.6%). The presence of psychological distress among the same group showed over 30% of the caregivers having symptoms of anxiety and about 25% having depressive symptoms (Pandey and Sharma, 2018).

Another study in Iraq found 25% of caregivers of children with autism to be psychologically distressed and 50% of the same population as having a moderate burden of care (Al-Dujaili and Al-Mossawy, 2017). A study among Nigerian mothers of children with autism found 65% of mothers having psychological distress and 70% being rated as having a high burden of care (Bello – Mojeed et al., 2013b).

Research shows that as compared to controls, parents of children with ASD reported having more burden, more frequent psychological distress and a lower social support as compared to controls (Picardi *et al.*, 2018). In another study, almost half (47.2%) of all caregivers with children having autism, had a severe burden, and over 30% had moderate burden as compared to 2% and 6% in the control group, respectively. None of the caregivers with children having autism reported having no burden as against 48% of control group caregivers who reported having no burden (Ezzat et al., 2017).

2.6. Factors associated with Psychiatric Morbidity and Burden Among Informal Caregivers of Children with Autism

Various factors have been purported to contribute to the development of psychiatric morbidity and burden among caregivers of children with autism and other neurodevelopmental disorders such as intellectual disability. Some studies have found predictors of psychological morbidity and distress among caregivers of children with intellectual disability to be the actual burden of caregiving (Gallagher *et al.*, 2008; Shanthi et al., 2015). Similarly, the burden of care is a predictor of psychological distress and vice versa in studies involving caregivers of children with autism (Pandey and Sharma, 2018; Dada et al., 2011; Bello-Mojeed et al., 2013b; Al-Dujaili and Al-Mossawy, 2017).

Other factors that contribute to psychiatric morbidity and burden include personal characteristics of the child or the caregiver, such as their sociodemographic profile. The number and type of impairment present in the child with autism (Bello-Mojeed *et al.*, 2013) and the caregiver's appraisal and perception of the caregiving can also predispose a caregiver to be burdened (Pandey and Sharma, 2018).

In a study conducted among parents of children with ASD in Nepal, the caregiver burden was high in areas such as perceived burden in a relationship, emotional wellbeing, social and family life, loss of control over one’s life, but not in the financial domain, and these were significantly associated with psychological distress. The overall burden was also seen to be comparatively higher among those who either had anxiety or depression as against those who did not have (Pandey and Sharma, 2018).

Dada et al. in 2011 in a study to identify factors associated with caregiver burden among children and adolescents with mental health problems in Nigeria found no significant association between child and caregiver sociodemographic variables and caregiver burden. They, however, found that the patient's level of functioning, patient's level of education, psychiatric morbidity in the caregiver and level of impairment as assessed by the caregiver, had a significant association with caregiver burden (Dada *et al.*, 2011).

Similarly, a study in the Middle East Country of Iraq found no statistically significant association between the overall psychosocial burden of caregivers with their socio-demographic features and clinical characteristics for the child. However, factors such as the severity of ASD, caregiver's monthly income and psychological distress of the caregiver, were seen to have a strong correlation with a caregiver's burden of care (Al-Dujaili and Al-Mossawy, 2017).

Picardi et al. (2018), in a study in Italy, found that the younger age of the child, a deficiency in the child's adaptive functioning and skills were associated with psychological distress. Also, the severity of ASD symptoms, intellectual disability, emotion-focused coping strategies such as distraction and disengagement coping and problem-focused coping strategy such as engagement coping, were positive predictors of burden. Social support was found to be protective against psychological distress and perceived burden of care.

Other studies show that factors such as having a high income, excellent and varied problem-solving skills and exhibiting less responsibility acceptance behaviour were associated with lower reports of distress and a higher quality of life. Similarly, being an older parent, knowing child's diagnosis for a long time, employing more distance coping and using less escape – avoidance coping made individuals less stressed and improved quality of life as well as the relationship between caregiver and the child (Dardas and Ahmad, 2014)

2.7. Relevance of this Study to Child and Adolescent Mental Health Practice in Ghana

It has been shown that the global prevalence of autism has been increasing over time (Bauman and Kemper, 2005; Baio et al., 2018; Bello-Mojeed et al, 2013a), meaning that more and more children are likely to be diagnosed with autism in many countries including Ghana. Thus, more children are likely to be seen in the clinics seeking help, and many caregivers are likely to bear the brunt of providing care for them. Families having children with ASD experience significant stress that warrants attention and intervention (Bello-Mojeed and Bakare, 2013). Finding ways to lessen this stress among family members may be able to improve a family's structure and functioning (Hayes and Watson, 2013; Bello-Mojeed and Bakare, 2013; Bello-Mojeed et al, 2016).

Over past decades, little attention was paid to the burden of care among caregivers of children with psychiatric disorders, even in high-income countries. However, this phenomenon is changing, and studies on caregiving have arisen, though more focus has been on caregivers of adult patients (Dada *et al.*, 2011). Coupled with the fact that child mortality has improved over the years, it is vital that more studies in this area are done (Bello-Mojeed et al, 2013a; Bakare et al, 2014). Research in Ghana on autism is almost non-existent, so there is a great avenue to explore various aspects of the autism research terrain.

This study is essential to add to baseline knowledge on the presence of psychiatric morbidity and level of burden of care among informal caregivers of children with autism spectrum disorder, considering the paucity of information available in Ghana. This will inform clinicians and go a long way to influence interventions and future policies to ensure the health of children who have autism and that of their caregivers in Ghana.

Word count = 4027

CHAPTER 3 – METHODOLOGY

3.1. Study Location

3.1.1 Ghana – An overview

The study was conducted in 2 hospitals in Accra, the capital city of the Greater Accra Region (shaded red and numbered 16 in Fig. 3.1) and one hospital in Kumasi, the capital city of the Ashanti Region (shaded ocean blue and numbered 3 in Fig. 3.1) of the Republic of Ghana.

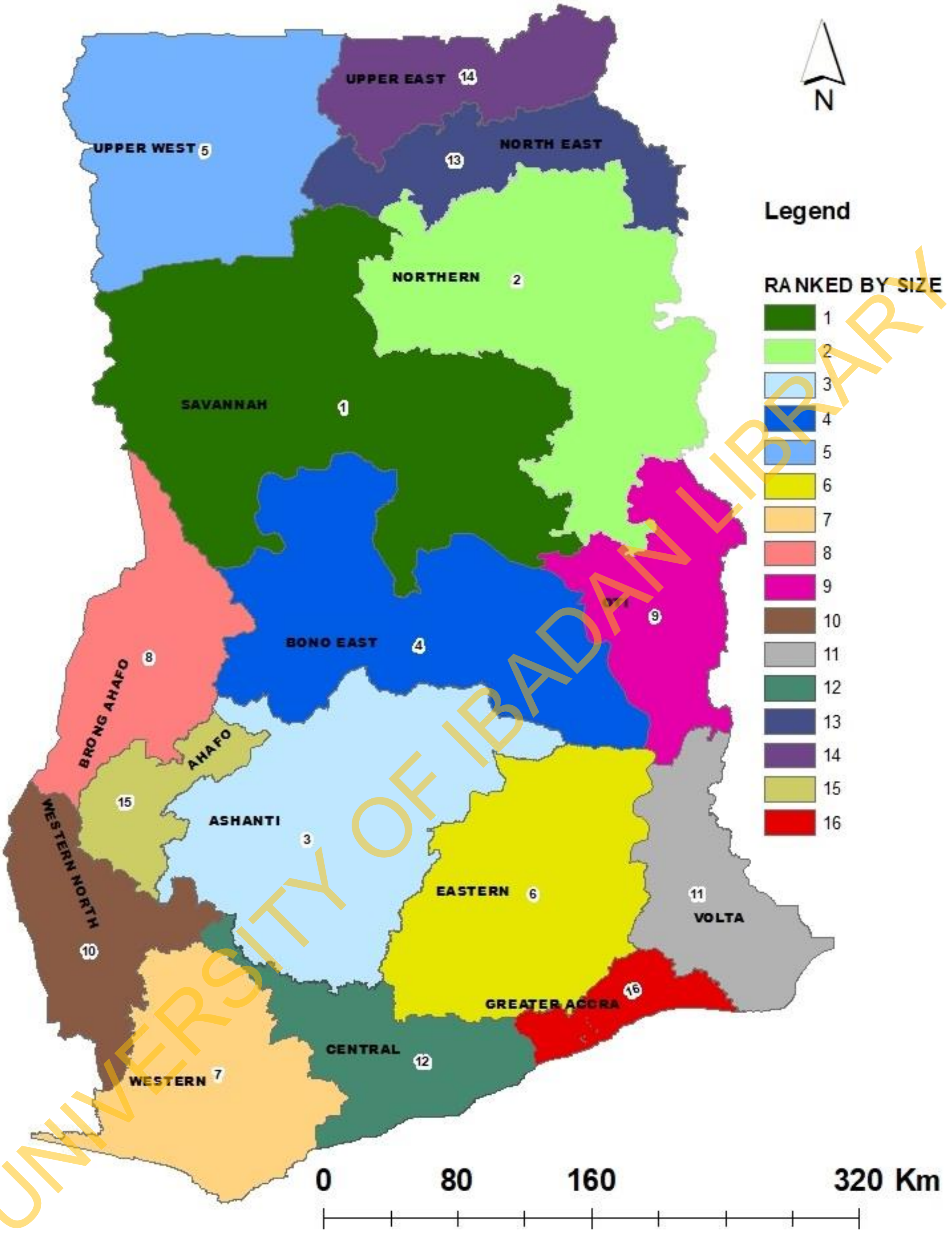

Figure 0-1: Map of Ghana

The Republic of Ghana, formerly known as The Gold Coast, gained independence on the 6th of March 1957 from British Colonial rule and became a republic the British Commonwealth of Nations on July 1st, 1960. Ghana is a West African country with a total land area of 238,537 square kilometres. It is bordered by three French-speaking countries, namely, Côte d'Ivoire on the west, Togo on the east and Burkina Faso on the North and northwest. On the southern part of Ghana lies the Gulf of Guinea which covers a total coastline of about 560 kilometres.

Ghana has a tropical climate, is mainly a lowland country with a range of highlands on the eastern border and has three ecological zones; low sandy coastal plains, a dense canopy of semideciduous rainforest in the middle and western parts and a northern savannah with interspersed rivers and streams across the country. The Volta Lake, one of the largest artificial lakes in the world can be found in the eastern part of the country and has a dam which supplies hydroelectric power to the nation (GSS et al., 2015).

According to the Population and Housing Census (PHC), Ghana recorded a population of 24,658,823 (with more than half of its population living in urban areas) in 2010 and projected population for 2014 was estimated at 27 million. Ghana's population has a youthful structure (Figure 3.2), with a broad base consisting of large numbers of children and a conical top of a small number of elderly persons. The proportion of the population aged less than 15 years was estimated at 38.3% in 2010 while the old adolescent (15-19 years) and young adults (20-24 years) population has increased steadily from 1.1 million in 1960 to 4.9 million in 2010 (GSS, 2013)

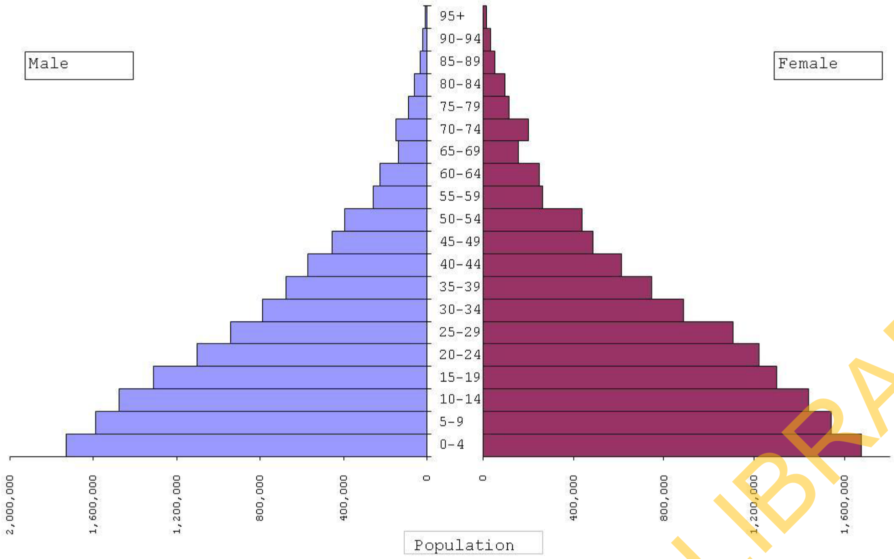

Figure 0-2: 2010 Population Pyramid of Ghana

Source: Derived from the 2010 Population and Housing Census

Ghana had 10 administrative regions until last year when 6 other regions were added: the regions are now Upper East, Upper West, North East, Northern, Savannah, Bono East, Ahafo, Brong Ahafo, Ashanti, Western North, Western, Central, Greater Accra, Oti, Volta and Eastern. The capital city, Accra, is located in the Greater Accra Region (red portion of Figure 3.1). About 50% of Ghana's population can be found in the Ashanti, Eastern, and Greater Accra regions. The regions are subdivided into 216 districts to ensure equitable resource allocation and efficient, effective administration at the local level (GSS 2013b). Within the country, the Northern region has the largest land area, almost a third of the total land area of Ghana (29.5%) while the Greater Accra occupies the least land area of 1.4%. The Greater Accra Region is the second most populated region (4,010,054) after the Ashanti Region (4,780,380). The largest Ethnic group in the Country is Akan (47.3%), followed by Mole Dagbani (16.6%), Ewe (13.9%), Ga-Dangme (7.4%), Gurma (5.7%) and Guan (3.7%) according to GSS et al., 2015.

3.1.2 Hospitals

The study was carried out in the following Hospitals located in Accra and Kumasi; Komfo Anokye Teaching Hospital Child Psychiatry Clinics, Accra Psychiatric Hospital and Pantang Psychiatric Hospital. These hospitals are major Public Facilities which receives referrals for children with neurodevelopmental conditions, apart from a few private clinics in Accra. Komfo Anokye Teaching Hospital (KATH) serves the middle and upper regions of Ghana while the other 2 serve the southern part of Ghana. This makes the hospitals representative of the country population

3.1.3. Komfo Anokye Teaching Hospital, Kumasi

It is the second largest Hospital in Ghana after Korle Bu Teaching Hospital in Accra. It has a capacity of 1200 beds and receives referrals from within the Ashanti Region as well as the three northern Regions (Northern, Upper East and Upper West, Savannah, North East), Brong Ahafo, Ahafo, Bono East, Central, Western, Eastern and parts of the Volta Region. In the 1940s a hospital was located on the hill over-looking the Bantama Township designated African and European Hospital to treat Africans and Europeans respectively. By 1952, there was a need to construct a new hospital to cater for the fast increasing population in Kumasi, so the European Hospital was transferred to the Kwadaso Military Quarters. The new hospital was completed in 1954/55 and named the Kumasi Central Hospital. The name was later changed to the Komfo Anokye Hospital in honour and memory of the powerful and legendary fetish priest, Komfo Anokye. The hospital became a Teaching hospital in 1975 for the training of Medical Student in collaboration with the School of Medical Sciences of the Kwame Nkrumah University of Science and Technology, Kumasi. The Psychiatry Department runs a child clinic every Tuesdays and runs a joint clinic with the Paediatric Neurology Team on the first Tuesdays of every month. The number of children seen at the clinic with ASD is 87 (Medical records).

3.1.4. Accra Psychiatric Hospital, Accra

In 1888, the old High Court of Victoria Borg (a prison) in Gold Coast was converted into Lunatic Asylum for the mentally ill. However, there were issues of overcrowding, lack of medical care and the same treatment for mentally ill and criminals. Accra Psychiatric Hospital (still known as the lunatic asylum) was thus established in 1904 to address these issues and commissioned in 1906 to accommodate 200 patients. Over time, there were modifications and extensions to the hospital to give it a total of 600 beds to run both 24hr in-patient and outpatient services. Clinics are formally on Mondays to Thursdays, with Wednesday being reserved for Child and Adolescent Psychiatry clinic. The number of children seen at the clinic with ASD currently is 32 (Medical records).

3.1.5. Pantang Psychiatric Hospital, Accra

Pantang Psychiatric Hospital is the second public psychiatric hospital in Accra commissioned in 1975 to offer both inpatient and outpatient services. The hospital offers Primary Health Care, Reproductive and Child Health services, HIV counselling, screening and treatment services, general Outpatient Department (OPD), X-ray and Electro convulsive Therapy (ECT) to over 15 villages in its catchments area of about 10km. Pantang is noted for its drug treatment and rehabilitation unit opened in 2009 to cater for substance use disorders. The hospital also runs a newly established Child and Adolescent Psychiatric clinic on Mondays which started six months ago. This clinic is run by a Specialist Psychiatrist who is also a Child and Adolescent Mental Health professional. The number of children seen at the clinic with ASD is 4 (Medical records).

3.2. Study Design

The study was a cross-sectional one, which used a mixed methods approach, in which both quantitative and qualitative data were collected to meet the aim of the study. It determined the prevalence of psychological distress and assessed the burden of care among caregivers of children with autism spectrum disorder in selected hospitals in Ghana.

3.3. Study Population

The study was conducted among caregivers of children with autism spectrum disorder attending OPD clinics at the selected hospitals in Ghana.

3.4. Inclusion and Exclusion Criteria

3.4.3. Inclusion Criteria

- Caregivers of children with a diagnosis (existing or new) of Autism.
- Individual is the primary caregiver and in charge of child's management
- Caregiver is 18 years and above

3.4.4. Exclusion Criteria

- Individual refuses to participate by not giving informed consent
- Caregiver less than 18 years

3.5. Sample Size Determination

The sample size for this study was calculated using the following formula

$n = Z\alpha^2 \, pq/d^2$

where

n = estimated minimum sample size

$Z\alpha = 1.96$ at 95% confidence level

p = prevalence of psychological distress among caregivers of children with ASD found in literature

$q = 1 – p$

d = absolute level of sampling error, taken as 5% (0.05)

Bello – Mojeed et al., 2013 found the prevalence of psychological distress among mothers of children and adolescents with autism attending a neuropsychiatric hospital in Lagos to be 65%.

Therefore, p in this case was 0.65 and q = 0. 35

$n = 1.96^2 \, pq/d^2$

$n = 1.96^2 \times 0.65 \times 0.35 / 0.05^2$

$n = 349.58 \quad = 350$

Total number of children with ASD at the study locations = 123

Finite Population Correction

$$n = \frac{no}{1 + \frac{(no - 1)}{N}} .$$

c

no = sample size = 350

N= children and adolescents with ASD at the study location = 123

$$n = \frac{350}{1 + \frac{(350 - 1)}{123}} .$$

n = 91.2

10% (9.1) attrition rate was added,

Therefore, n = 100.3

n = 100

The total sample size for the study was 100

3.6. Sampling Technique

Purposive sampling of caregivers of consecutive patients with a pre-existing or new diagnosis of ASD attending the various OPD clinics was done. This was based on the caregivers meeting the inclusion criteria and giving consent. Participants (5 – 10) for the focused group discussion were also conveniently sampled.

3.7. Study Instruments for Data Collection

Questionnaire and instruments used in this study were pre-tested at the Accra Psychiatric Hospital Child clinic, using caregivers of children with intellectual disability and necessary changes and adjustments made to the questionnaire, based on feedback obtained. The questionnaires and instruments were translated into the primary local language in Ghana, Twi. This translation was used to assist caregivers give appropriate answers in the case where they could not read or write English. The following questionnaires and instruments were used.

3.7.3. Sociodemographic Questionnaire

This was a modified version of the Sociodemographic questionnaire by Omigbodun et al., (2008) used in a study of adolescents in Ibadan. The adapted questionnaire was semi-structured and used to collect sociodemographic information about the child and caregiver. Some of this information included the age, sex, marital status, education, past and present mental health conditions, among others.

3.7.4. General Health Questionnaire – 12 (GHQ-12)

This is a 12-item self-administered questionnaire that is used to screen for psychological distress or minor psychiatric morbidity in the general population, within the community or non-psychiatric clinical settings such as primary care or general medical out-patients. The scale was developed by Goldberg in the 1970s and has 12 questions which enquire whether the respondent has experienced a particular symptom or behaviour recently. Rating is on a four-point scale with answers 'less than usual', 'no more than usual,' 'rather more than usual', or 'much more than usual'. The GHQ-12 gives a total score of 36 or 12 based on the selected scoring method, the most prevalent being bi-modal (0-0-1-1) and the Likert scoring styles (0-1-2-3). It is suitable for all ages from adolescent upwards, but not children. Gureje and Obikoya, 1990, have validated this instrument for use in Nigeria with good psychometric properties and suggested a cut-off score of 3 points. This would result in categorisation of having Psychological distress or psychiatric morbidity with scores 3 or more and no distress with scores 2 or below.

3.7.5. Burden Interview

It is a 22-item questionnaire administered to caregivers to find out the extent of burden while taking care of another person. It is self-administered and assesses how one feels while giving care. Some Modification was made on some content of the Burden Interview Instrument; for example: “your relative” was changed to “your child”. Responses ranged on a 5-point Likert Scale from ‘0 – never’, ‘1 – rarely’, ‘2 – sometimes’, ‘3 – quite frequently’ to ‘4 – severely’. Severity of the burden was categorised based on the total score into Little Burden (0 – 20), mild to moderate (21 – 40), moderate to severe (41 – 60) and Severe burden (61 – 88) (Zarit et al., 1980). The items were obtained from clinical and research experience with dementia caregivers. It encompassed common areas of concern of an individual caregiver such as health, finances, social life, and interpersonal relations (Zarit and Zarit, 1990).

3.7.6. Interview Guide

This interview guide was designed by the investigator and used to collect qualitative data that explored the perception of caregivers about caregiving, the challenges they faced, support and interventions available to them, as well as interventions they wished they had. Qualitative data was from focused group discussions composed of 5 to 10 caregivers with or without key informant interview at each study location site.

3.8. Ethical Consideration

Permission was obtained from the various Heads of the Hospitals, through the Research and Development Units. Ethical approval was obtained from the Committee on Human Research, Publication and Ethics, of the Kwame Nkrumah University of Science and Technology and Komfo Anokye Teaching Hospital. Informed consent was sought and obtained from all participants. The forms were translated into Twi for those who were unable to speak English. Participants confirmed their participation by signing or thumbprinting on the consent form in the presence of a witness who also countersigned.

Voluntariness: The purpose and main objective of the study was explained to participants before recruitment. Participants were free to either give or refuse consent at their own will after obtaining adequate information, without duress or undue inducements. Those who gave consent were also free to withdraw from the study at any time they wished to.

Beneficence: Patients who screened positive for depression or anxiety during the study were referred appropriately for expert psychiatric management at the Accra Psychiatric Hospital and the Pantang Hospital. Results and subsequent knowledge derived from this study will also go a long way to be useful in managing caregivers of these children and would inform interventions and policies in the management of children and their care givers

Non- maleficence: This study posed only minimal risk to study participants as no invasive procedures was performed on them.

Confidentiality: Information obtained from the study was kept strictly confidential and was inaccessible to others, except the Researcher, and Supervisors of the study. Study participants were not identified by names on the forms. Initials, individual identification numbers and codes were used as unique identifiers for each participant.

3.9. Procedure

Permission to conduct the study, was obtained from the Heads of the various Hospitals before data was collected. This was done first verbally then through written letters and submission of proposal to the Accra Psychiatric Hospital and Pantang Psychiatric Hospitals. Official approval letters were sent from the Hospitals. A copy of the proposal, together with a filled form was submitted to the Research and Development Unit of the Komfo Anokye Teaching Hospital. After approval from KATH, an application was sent to the Committee on Human Research, Publication and Ethics, of the Kwame Nkrumah University of Science and Technology. Ethical approval was obtained in early March 2019, by which time pretesting of questionnaires had been done and data collection started.

Caregivers of children attending the OPD clinics of the hospitals were screened as per the inclusion criteria and informed consent obtained after adequate information was given to them. Questionnaire and other instruments were then given. The instruments were self-administered by participants who were literate while questions were read out in Twi from a translated version of the instruments and illiterate participants assisted to complete them by the help of the Researcher or trained Research assistants at the various hospitals. Five to ten caregivers at each study site were selected conveniently to form a focus group to discuss their perception and challenges of their caregiving experience, based on their availability after giving consent.

Due to an observed high default rate on follow up treatment, folder numbers were retrieved so from medical booking records and CAMH registry at KATH, and phone numbers for parents and other caregivers extracted. Calls were made to these numbers and the purpose of the study explained to them. Appointments were scheduled for both interviews and focus group discussion. Those who could not be reached were sent a message. Those who were able to come for the interview and/or focus group discussion were compensated for their travel with a transportation allowance and some refreshment. For others who were interested but could not find time to come, information leaflet and questionnaire were sent via WhatsApp and email and calls were made for the interviews.

Some of the caregivers were contacted also via a school, Autism Awareness Care and training Centre located in Accra. Permission was sought officially from the Head of the School and letters explaining the purpose of the study, were written to parents seeking their participation. An Information leaflet about the study was also added and questionnaires made available for those interested in taking part of the study.

In all, three focus group discussions (2 in Accra and 1 in Kumasi) were held with a total of 19 participants. Study participants who had psychological distress according to the cut off used in the GHQ were interviewed and given a referral for expert psychiatric care.

3.10. Expected Outcome

The primary outcome of this study was the psychiatric morbidity among caregivers of children with ASD.

The secondary outcome was the burden of care among informal/family caregivers.

3.11. Data Analysis and Management

Data from this study was entered, cleaned and analysed by the Researcher using Statistical Package for Social Sciences (SPSS) Version 23. Results such as sociodemographic characteristics was summarised in the form of tables, and frequency and proportions calculated. Mean and standard deviations were obtained for quantitative variables such as age, GHQ scores and Zarit burden interview scores. Associations and correlates of psychological distress and burden of care among caregivers were found using Chi-squared test, correlation and logistic regression analysis. Statistical significance for all testing was p-value < 0.05. Qualitative data from the focused group discussions were transcribed and translated to English where applicable and analysed using a thematic approach.

Word count = 2895

CHAPTER 4 – RESULTS

4.1. Sociodemographic characteristics of children with autism

A total of 61 caregivers of children with autism spectrum disorder participated in the study. The initial sample size of 100 was not attained due to challenges such as default and loss to follow up by some families, coupled with unreachable contact phone numbers found in folders.

Table 4.1 shows the sociodemographic characteristics of the children. Their ages range from 2 to 21 years with a mean age of 10.64 (SD 5.15). More than 60% of the children were below the age of 12 years with 42.6% of them aged 7 to 12 years. Male children formed 73.8% while more than a third of children were out of school (36.1%). About a quarter of parents of the children with autism were separated, divorced or widowed. Family type was mainly of the monogamous setting (98.4%) and more than 50% of the children were first born children.

4.2. Clinical Characteristics of Children with Autism

Table 2 shows the clinical characteristics of the children. On average, children had their first contact with a health facility at a mean age of 3.62 ± 2.19 years with 57.4 % of them having contact between the ages of 2 and 4 years. The age range at first contact was 6 months to 10 years. Children had their diagnosis made from ages 1 to 17 years with about three quarter (75.4%) receiving diagnosis between ages 0 to 5 years with a mean age of 4.90 (SD 3.38).

Caregivers reported that about a quarter (26.2%) of the children had previously diagnosed co-morbid medical and mental health conditions. The co-morbid conditions included seizure disorder (18.8%), intellectual disability (37.5%), ADHD (18.8%) and others included asthma, hydrocephalus and visual impairment as shown in Figure 4.1.

Table 4.1: Sociodemographic characteristics of children with autism

N= 61

Variable	**n (%)**
Age Range (in years)	
≤ 6	14 (23.0)
7 – 12	26 (42.6)
≥13	21 (34.4)
Gender	
Male	45 (73.8)
Female	16 (26.2)
Educational level	
None	22 (36.1)
Nursery/ Primary	31 (50.8)
JHS/ SSS	8 (13.1)
Marital status of parents	
Married	47 (77.0)
Separated/ Divorced/ Widowed	14 (23.0)
Family Type	
Monogamous	60 (98.4)
Polygamous	1 (1.6)
Child's birth order	
1st	33 (54.1)
2nd - 3rd	22 (36.1)
4th – 5th	6 (9.8)

Table 4.2 Clinical characteristics of children with autism

N = 61

Variable	**n (%)**
Age at first contact with health facility	
Less than 2	8 (13.1)
2 – 4	35 (57.4)
Above 4	18 (29.5)
Age at first diagnosis with autism	
0 – 5	46 (75.4)
6 – 10	10 (16.4)
Above 10	5 (8.2)
Comorbidities	
Present	16 (26.2)
Absent	45 (73.8)

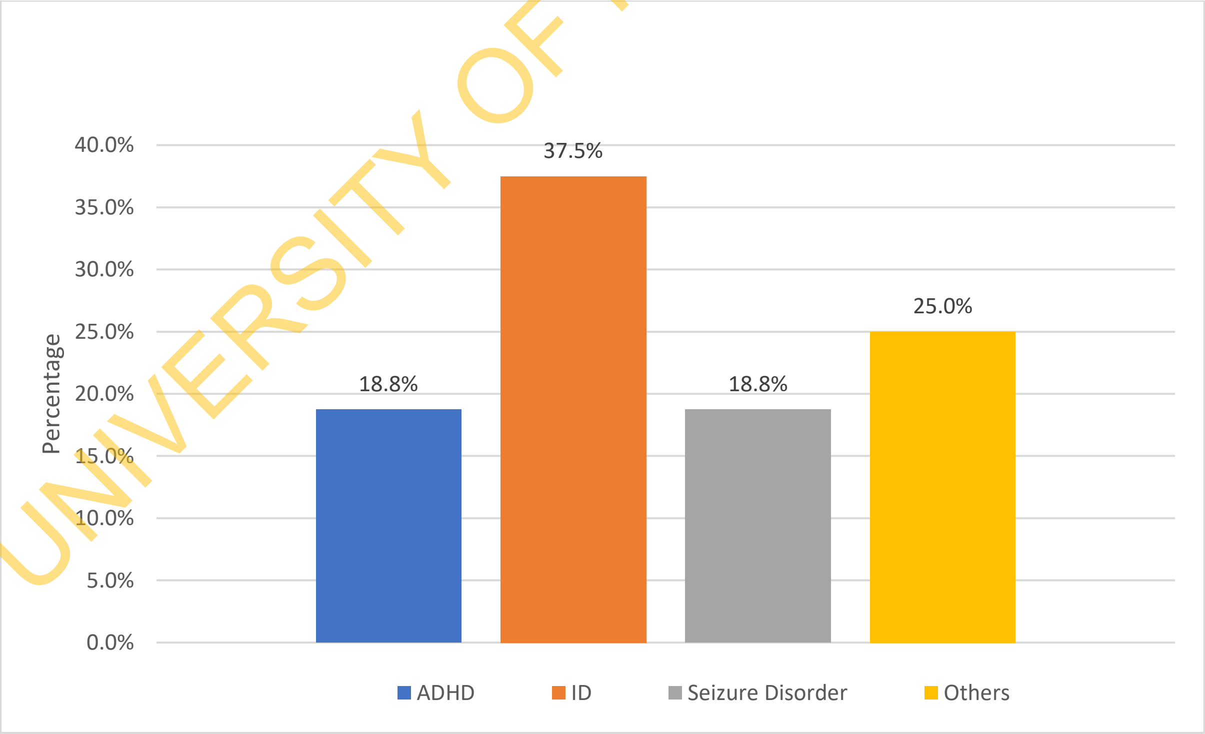

Fig 4.1: Types of comorbidities mentioned to be present in children with autism N = 16

4.3. Sociodemographic characteristics of caregivers of children with autism

Tables 4.3 show the sociodemographic characteristics of the caregivers. Their age was 24 to 65 years with a mean age of 43.53 (SD 8.97). Females constituted 82% of the caregiver population of which majority were mothers (73.8%). Majority (75.4%) of caregivers of the children with autism were married and 57.4% had basic to secondary education. More than half of caregivers belonged to ISCO class 4 to 6 occupations comprising Clerical support worker, service and sale workers and skilled agricultures worker such as traders, office clerks, secretaries, customer service workers and hairdressers. A proportion of 18.0% of caregivers were unemployed. Mean monthly income of caregivers (n = 22) was (Ghana Cedis) GHc 1642.27 ($304) with SD of 1925.77($357). The Akan ethnic group formed the majority (80.3), majority (88.5) of caregivers lived in urban areas and were Christians (95.1%).

Table 4.3: Sociodemographic characteristics of caregivers

N= 61

Variable	n (%)
Age Range	
40 and below	24 (39.3)
41 – 50	24 (39.3)
51 and above	13 (21.3)
Gender	
Male	11 (18.0)
Female	50 (82.0)
Marital status	
Single	3 (4.9)
Married	46 (75.4)
Separated/Divorced/widowed	12 (19.7)
Educational level	
Primary school or less	18 (29.5)
Secondary School	17 (27.9)
Tertiary/Post-secondary	26 (42.6)
Occupational class of caregiver (n=59)	
ISCO Class 1 – 3	21 (34.4)
ISCO Class 4 – 6	33 (55.9)
ISCO Class 7 – 9	5 (8.5)
Employment status of caregiver (n=59)	
Unemployed	11 (18.0)
Employed	50 (82.0)
Ethnicity	
Akan	49 (80.3)
Others (e.g. Ga, Ewe, Dagbani)	12(19.7)
Residence	
Rural	7 (11.5)
Urban	54 (88.5)
Religion	
Islam	3 (4.9)
Christian	58 (95.1)
Relationship to child	
Mother	45 (73.8)
Father	10 (16.4)
Others (e.g. Aunt, Uncle, grandmother)	6 (9.8)

ISCO = International Standard Classification of Occupation

4.4. Prevalence of Psychiatric morbidity among caregivers

Table 4.4 represents the GHQ – 12 score frequency of caregivers. It was found that the prevalence of psychiatric morbidity (scores ≥3) among caregivers was 45.9%.

The scores ranged from 0 to 9 with a mean score of 3.08 (SD 2.82).

Table 4.4: Psychiatric morbidity among Caregivers

N=61

GHQ – 12 Score	**n (%)**
No Psychiatric morbidity (<3)	33 (54.1)
Psychiatric morbidity (≥3)	28 (45.9)

< = less than

≥ = greater than or equal to

GHQ – General Health Questionnaire

4.5. Zarit Burden Interview (ZBI) scores of caregivers

The ZBI scores for the caregivers was within the range of 7 to 69 with a mean score of 37.00 (SD 13.82) as illustrated in Table 4.5. About half (50.8%) of all caregivers had mild to moderate burden, followed by 31.2% being moderately to severely burdened.

The ZBI scores were further categorised into low and high burden (Table 4.5) with scores of less than/or equal to 40 and greater than 40 respectively. About a third of caregivers (36.1%) were found to have high burden

Table 4.5a: Zarit Burden Interview Scores of Caregivers. N= 61

Burden severity Grade	Score range	n (%)
Little or no burden	0 – 20	8 (13.1)
Mild to moderate burden	21 – 40	31 (50.8)
Moderate to severe burden	41 – 60	19 (31.2)
Severe burden	61 - 88	3 (4.9)

Table 4.5b: Degree of burden of Caregivers N= 61

Burden severity Grade	Score range	n (%)
Low burden	0 – 40	39 (63.9)
High burden	41 – 88	**(36.1)**

4.6. Sociodemographic and clinical factors associated with psychiatric morbidity in caregivers of children with autism

Tables 4.6a, 4.6b and 4.6c show association between psychiatric morbidity in caregivers and sociodemographic characteristic of the children and caregivers respectively.

Table 4.5a shows the association between sociodemographic characteristics of children with autism and psychiatric morbidity in caregivers. A comparatively higher proportion of psychiatric morbidity was found with caring for a female child (50%) compared to a male (44.4%) as well as being a married caregiver (48.8%) as compared to being separated/divorced/widowed (35.7%). However, the differences were not statistically significant (p= 0.702, p = 0.384 respectively).

The presence of psychiatric morbidity was found to be associated with an increasing birth order of the child. It was seen that caring for a child with birth order 2nd to 5th was associated with more psychiatric morbidity in the caregiver, as compared to caring for a first born child (p = 0.029).

Table 4.6a: Association between sociodemographic characteristics of children with autism and psychiatric morbidity in caregivers.

N = 61

	No psychiatric morbidity	**Psychiatric morbidity**		
	n (%)	**n (%)**	**x^2**	**p**
Age Range (years)				
≤ 6	8 (57.1)	6 (42.9)	0.307	0.858
7 - 12	13 (50.0)	13 (50.0)		
≥13	12 (57.1)	9 (42.9)		
Gender				
Male	25 (55.6)	20 (44.4)	0.147	0.702
Female	8 (50.0)	8 (50.0)		
Educational level				
None	12 (54.5)	10 (45.5)	0.354^f	0.937^f
Nursery/ Primary	16 (51.6)	15 (48.4)		
JHS/ SSS	5 (62.5)	3 (37.5)		
Marital status of parents				
Married	24 (51.1)	23 (48.9)	0.759	0.384
Separated/Divorced/ Widowed	9 (64.3)	5 (35.7)		
Family Type				
Monogamous	33 (55.0)	27 (45.0)	1.198	0.459^f
Polygamous	0 (0.0)	1 (100.0)		
Child's birth order				
1st	23 (69.7)	10 (30.3)	6.978^f	**0.029^f****
2nd - 3rd	8 (36.4)	14 (63.6)		
4th – 5th	2 (33.3)	4 (66.7)		

^{f} = Fisher's exact test, ** Significant p value

Table 4.6b: Association between sociodemographic characteristics of caregivers and psychiatric morbidity in caregivers

N = 61

	No psychiatric morbidity	**Psychiatric morbidity**		
	n (%)	**n (%)**	**x^2**	**p**
Age Range				
40 and below	14 (58.3)	10 (41.7)	0.556	0.759
41 - 50	13 (54.2)	11 (45.8)		
51 and above	6 (46.2)	7 (53.8)		
Gender				
Male	4 (36.4)	7 (63.6)	1.700	0.317
Female	29 (58.0)	21(42.0)		
Marital status				
Single	3 (100)	0 (0.0)	3.596^f	0.155^f
Married	22 (47.8)	24 (52.2)		
Separated/Divorced/widowed	8(66.7)	4 (33.3)		
Educational level				
Basic school or less	9 (50.0)	9 (50.0)	5.999	0.273
Senior Secondary School	7 (41.2)	10 (58.8)		
Tertiary/Post-secondary	17(65.4)	9 (34.6)		
Occupational class of Caregiver (n=59)				
ISCO Class 1 – 3	11 (52.4)	10 (47.6)	0.203	1.000^f
ISCO Class 4 – 6	18 (54.5)	15 (45.5)		
ISCO Class 7 – 9	3 (60.0)	2 (40.0)		
Employment Status				
Unemployed	5 (45.5)	6 (54.5)	0.404	0.525
Employed	28 (56.0)	22 (44.0)		

ISCO = International Standard Classification of Occupation, ^{f} = Fisher's exact test

Table 4.6c: Association between sociodemographic characteristics of caregivers and psychiatric morbidity in caregivers

N = 61

	No psychiatric morbidity	**Psychiatric morbidity**		
	n (%)	**n (%)**	**x^2**	**p**
Ethnicity				
Akan	27 (55.1)	22 (44.9)	0.101	1.000
Other Ethnic Groups	6 (50.0)	6 (50.0)		
Residence				
Rural	3 (42.9)	4 (57.1)	0.402	0.693
Urban	30 (55.6)	24 (44.4)		
Religion				
Islam	1 (33.3)	2 (66.7)	0.551^f	0.589^f
Christian	32 (55.2)	26 (44.8)		
Relationship to child				
Mother	26 (57.8)	19 (42.2)	2.874^f	0.248^f
father	3 (30.0)	7 (70.0)		
Others	4 (66.7)	2 (33.3)		

^{f} = Fisher's exact test

4.7. Sociodemographic and clinical characteristics associated with burden among caregivers

Tables 4.7a and 4.7b and 4.7c show the association between psychiatric morbidity in the caregivers and the respective sociodemographic and clinical characteristic of both the children and caregivers. No statistically significant association was found between child's factors and burden in the caregivers. Caregivers who were unemployed had a higher burden (72.7%) as compared to those who were employed (28.8%). It was found that this association was statistically significant (p = 0.012). Caregiver burden was higher in rural dwellers than urban. Similarly, fathers expressed greater burden than mothers. However, these differences were not statistically significant (p = 0.495 and p = 0.106 respectively).

Table 4.7a: Association between sociodemographic characteristics of children with autism and burden in caregivers.

N = 61

	Low Burden	**High burden**		
	n (%)	**n (%)**	**x^2**	**p**
Age Range (years)				
≤ 6	9 (64.3)	5 (35.7)	0.133	0.935
7 – 12	16 (61.5)	10 (38.5)		
≥13	14 (66.7)	7 (33.3)		
Gender				
Male	28 (62.2)	17 (37.8)	0.218	0.640
Female	11 (68.8)	5 (31.3)		
Educational level				
None	12 (54.5)	10 (45.5)	5.448	0.066
Nursery/ Primary	19 (61.3)	12 (38.7)		
secondary	8 (100)	0 (0.00)		
Marital status of parents				
Married	29 (61.7)	18 (38.3)	0.443	0.506
Separated/Divorced/ Widowed	10 (71.4)	4 (28.6)		
Family Type				
Monogamous	38 (63.3)	22 (36.7)	0.574	1.000^f
Polygamous	1 (100.)	0 (0.0)		
Child's birth order				
1st	24 (72.7)	9 (27. 3)	2.977^f	0.266^f
2nd - 3rd	11 (50.0)	11 (50.0)		
4th – 5th	4 (66.7)	2 (33.3)		

^{f} = Fisher's exact test

Table 4.7b: Association between sociodemographic characteristics of caregivers and burden in caregivers

N = 61

	Low Burden	**High burden**		
	n (%)	**n (%)**	**x^2**	**p**
Age Range				
40 and below	15 (62.5)	9 (37.5)	1.263	0.549
41 - 50	14 (58.3)	10 (41.7)		
51 and above	10 (76.9)	3 (23.1)		
Gender				
Male	6 (54.5)	5 (45.5)	0.513	0.505
Female	33 (66.0)	17 (34.0)		
Marital status				
Single	3 (100)	0 (0.0)	1.486^f	0.562^f
Married	28 (60.9)	18 (39.1)		
Separated/Divorced/widowed	8 (66.7)	4 (33.3)		
Educational level				
Basic school or less	12 (66.7)	6 (33.3)	1.266	0.531
Senior Secondary School	9 (52.9)	8 (47.7)		
Tertiary/Post-secondary	18 (69.2)	8 (30.8)		
Occupational class of Caregiver (n=59)				
ISCO Class 1 – 3	16 (76.2)	5 (23.8)	2.788	0.294^f
ISCO Class 4 – 6	20 (60.6)	13 (39.4)		
ISCO Class 7 – 9	2 (40.0)	3 (60.0)		
Employment status				
Unemployed	3 (27.3)	8 (72.7)	7.823	0.012^{**f}
Employed	36 (72.0)	14 (28.0)		

^{f} = Fisher's exact test, ISCO = International Standard Classification of Occupation,

** Significant p value

Table 4.7c: Association between sociodemographic characteristics of caregivers and burden in caregivers

N = 61

	Low Burden	**High burden**		
	n (%)	**n (%)**	**x^2**	**P**
Ethnicity				
Akan	33 (67.3)	16 (32.7)	1.258	0.322
Other Ethnic Group	6 (50.0)	6 (50.0)		
Residence				
Rural	4 (57.1)	3 (42.9)	0.158	0.495
Urban	35 (64.8)	19 (35.2)		
Religion				
Islam	3 (100)	0 (0.0)	1.780	0.547^f
Christian	36 (62.1)	22 (37.9)		
Relationship to child				
Mother	28 (62.2)	17 (37.8)	4.224^f	0.106^f
father	5 (50.0)	5 (50.0)		
Others	6 (100)	0 (0.0)		

^{f} = Fisher's exact test,

4.8. Correlation between GHQ – 12 scores and ZBI scores

The Zarit Burden Interview Score of caregivers significantly correlates positively with the General Health Questionnaire Score (r=0.430) with p value of 0.001 (Table 4.10). This positive relationship between psychiatric morbidity and burden among caregivers is graphically illustrated in figure 4.2.

Table 4.8: Table showing Correlation between psychiatric morbidity and burden among caregivers

N = 61

		The Zarit Burden Interview Score
The Zarit Burden Interview Score	Pearson Correction	1
	Sig. (2-tailed)	
	N	61
General Health Questionnaire 12	Pearson Correction	.430**
	Sig. (2-tailed)	.001
	N	61

**. Correlation is significant at the 0.01 level (2-tailed).

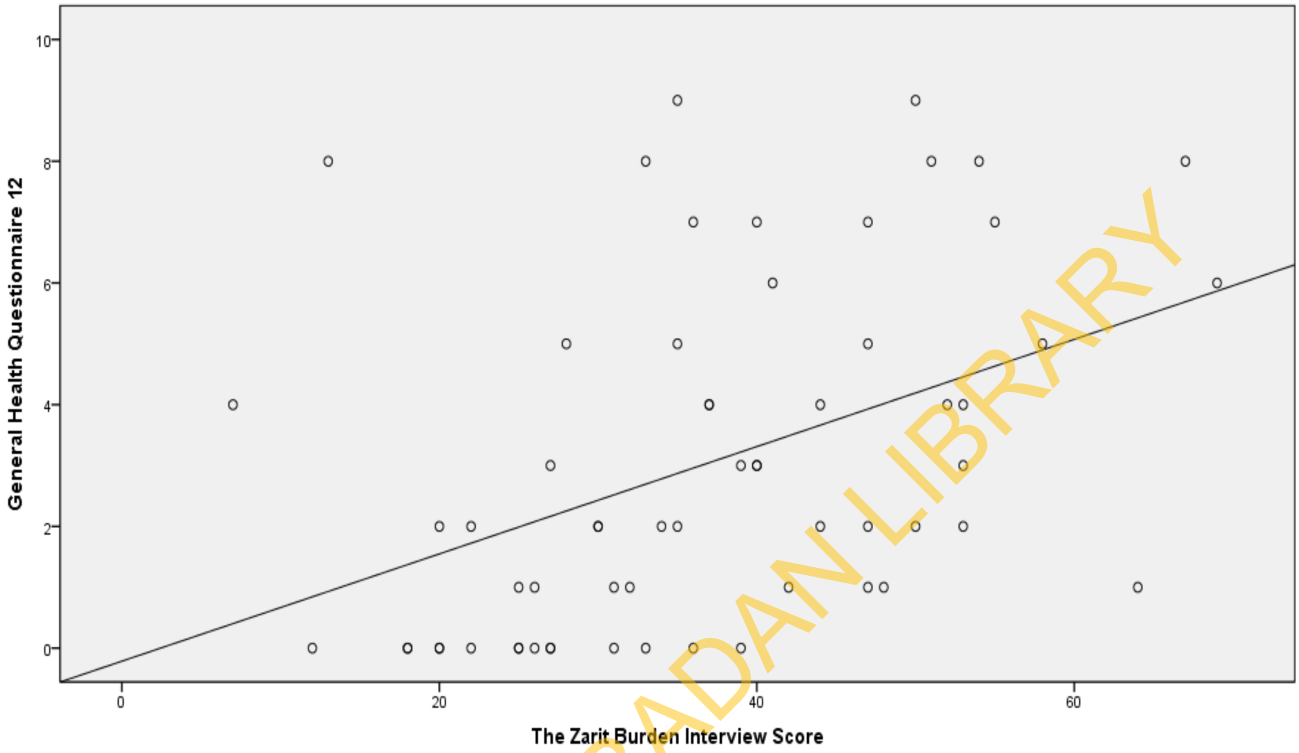

Fig 4.2: Correlation between psychiatric morbidity and burden of care

4.9. Predictors of Psychiatric Morbidity and high caregiver burden

Table 4.9 shows the logistic regression analysis of variables that were found to be significantly associated psychiatric morbidity and a high burden of care.

Caring for a child who was either a second or third born, was statistically and independently associated with a caregiver being 4 more times at risk of having psychiatric morbidity, as compared to caring for a first born child (unadjusted OR= 4.03, 95% CI 1.28 – 12. 62, p = 0.017). In the case of a 4th to 5th born, even though the odds of having psychiatric morbidity was almost 5 times higher, this was however, found not to be statistically significant (p = 0.106).

Caregivers who were unemployed were about 7 times more likely to have high burden as compared to those who employed (unadjusted OR=6.94, 95% CI 1.60 – 30.16). When a potential confounder age, was adjusted for, the association remained significant (p = 0.008) with an increase to about 8 times likelihood (adjusted OR=7.69, 95% CI 1.71 – 34.68).

Table 4.9: Multivariate logistics regression analysis of factors associated with psychiatric morbidity and high burden

Psychiatric Morbidity			
Factors	Odds ratio at 95% CI		p value
	Unadjusted	**Adjusted**	
Child's birth order			
1st	1.00		
2nd – 3rd	4.03 (1.28 – 12. 62)		**0.017***
4th – 5th	4.60 (0.72 – 29.33)		0.106

High Burden			
Factors	Odds ratio at 95% CI		p value
	Unadjusted	**Adjusted**	
Employment status of caregiver			
Unemployed	6.94 (1.60 – 30.16)	7.69 (1.71 – 34.68)	**0.008***
Employed	1.00	1.00	

p value significant at 5%, ***p**<0.05

4.10. Results from focus group discussions

Some of the caregivers (n = 19), conveniently sampled, were interviewed in a focus group discussion (3 groups) to discuss their perception about the child's condition, challenges and needs as they cared for the children. Emerging themes included causes of autism, challenges of dealing with the condition and care-giving, stigma and social exclusion, financial problems, relationship problems, coping with challenges and the need for support.

4.10.1. Causes of autism

Caregivers had varying ideas as to the cause of their child's condition. Some felt that autism could be a spiritual condition, caused by dwarves, a medical/physical condition, caused by old age, birth complications or trauma, medication given during ante-natal care and combination of spiritual and medical causes. Some also did not know what was responsible for the condition. The following are excerpts from some of the caregiver's perception about the causes of autism.

'As for me, I took him for prayers in EFG (a town) with a certain pastor X and I was told that dwarves were responsible for his condition. After that a certain man who came to work in my house, an Alhaji, asked me whose child this was, whilst I was cooking one day. I replied that it was my sister's child and he told me that, this child is not sick but is being worried by dwarves. So, two people have confirmed this.' –Madam C.

'*I think it is spiritual, the spiritual is involved, and that is what my mind tells me. But I felt that even if it has a spiritual backing, I should bring him for physical help because it could help me and lessen my stress.'* – Madam H

'I did not understand what was going on, I didn't know what it was, until one day when I was watching a documentary on TV, I watched a man who was saying that he trains children with autism. And as he was mentioning the symptoms, I could see some in my son. So, I realised that then, it could be autism that was bothering my child.' – Madam V

I had decided I was not going to give birth again after my fourth child. There is an 11-year gap between him and the older sibling… I don't know if it is the old age.' –Mr A

4.10.2. Challenges of dealing with the condition and care-giving

Some of the challenges experienced by caregivers of children with autism had to do with the day to day care of the child and the effects it has on their personal, social and work life. Challenges that were spoken of included problems with maintaining their personal hygiene, toilet training and feeding. Other areas with problems were having to deal with challenging behaviours that the children had, sleep problems, mood problems, among others.

Many caregivers described taking care of their children as very stressful and burdensome to the extent that they had no freedom unless the children were asleep. Others also said that this stress was affecting their health and productivity.

'Every day, all round, 24/7, unless he's asleep before you can get some little freedom. It makes me stressed.' - Mad V. Another female caregiver further described her stress of care-giving in the following statement; '*the stress involved eh, by the time you realise, you the parent are getting ill.'* – Madam W

A father's concern with care-giving was captured in the following vignette. '*When he goes to school, I'm a bit free, otherwise, I'm not free when he is at home (and on vacation) … Taking care of him is very difficult. Even when you are at work, you'll be thinking about what is* *happening at home. Sometimes you have to sneak out to check what's going on. This (*stress*) has even given me hypertension'* – Mr B

On maintaining their personal hygiene, one caregiver (an aunt) recounted the difficulty she had in getting him to comply. She said, '*when I want to brush his teeth, I would need about four males to hold him before I can do that for him'* – Madam C

With regards to feeding, one mother said this about her child*, 'He eats a lot. He alone can eat two cups of rice a day,'* – Madam W. Madam P also described this about her son's eating pattern; *'The way he eats, if you don't give him food early and the time elapses, you will suffer. So, you yourself have to know the time he eats.'*

Sleep problems, challenging behaviours such as destructiveness and tantrums were of great concern to many caregivers as this was a source of distress to them. Some caregivers had to stay up at night with their children during some of the times. Madam Q said of one instance, *'Sometimes, during the night, she can't sleep. And if she can't, then I also can't sleep.'* A father during a discussion also said, '*The whole night he won't sleep. He will just be moving from room to room.'* – Mr T

One caregiver expressed concerns about the fact that, *'If you don't keep an eye on him, he can spoil things…* Madam H. Similarly, another mother narrated an incident, when her son would dismantle many electrical gadgets in the house, but child someway, would find a way to fix some.

With respect to other unfamiliar behaviours and mood changes one mother said '…*But the day he is in a sad mood, you will call out several times, but he won't respond. So, you have to try and find out what is wrong with him. I try to do something that would make him happy. So, I* *will keep changing things such as food, because you may give him one food and he would reject it… We keep at it till the day ends.'* – Madam V

Many caregivers told of instances where they had to stay at home with the child or take the child with them wherever they went to. An example is *'Because of his behaviour, other children look at him in a peculiar way… some haven't seen some before, as in when he is screaming. It is a burden; you have to take him with you everywhere you go.'* – Madam H

Madam S reported that, *'going out was a problem, you can't just leave him at home.'* Similar sentiments were shared by Madam E who captured her concerns like this; *'I can't send her to the market. When she sees things, she will pick them up…. I have to put her at my back…'*

4.10.3. Stigma and social exclusion

Stigma and social exclusion were issue that resonated throughout most of the focus group discussions. Instances where caregivers perceived they were discriminated against and socially excluded because of their child's condition. Caregivers narrated occasions when they had problems with housing, work related problems, unfair treatment by others among a host of other issues. Quotes to capture these issues follow;

'The stigmatisation in the system does not make us comfortable as parents. I can say that is one of my problems. Wherever you take the child, you would get only one out of twenty people welcoming you.' – Madam V

A father had this to say. '*Many people stare at us, even when we sit in a car and he touches someone, it's a problem…. He's a very sociable person too. When he meets people, he would extend his hands and say greet me, but some people feel like he's sick'* Mr A

Madam V, continued to say, '*I quite remember one day, a certain lady kept staring at us that she fell into a gutter. She was just staring at us. I don't know what was going on in her mind, but her walking changed… I myself helped her out of the gutter and said sorry to her… The education must go around that children like these are not a curse. They are human beings too.'* Madam V

Frequently moving to a new house or being evited from a house especially in compound houses (houses with many room/apartments for different families) was a major challenge. Excerpts extracted follows;

'Wherever I rent, I'm evicted because of the noise she makes.' – Mr B. Madam P tells of her torments of frequent moving until she finally settled in an uncompleted building. *'I usually say that it is a heavy load for me to carry because every house I live in, I'm evicted, and then, I'm evicted (amidst tears). Sometimes they don't even play with my children… And it makes me exasperated because I don't know where to go and live. Wherever I go and pay the money (rent) and they see the child, we won't last more than 2 weeks. They would sack us and give me back my money'*. – Madam P

Similarly, children were said to be changing schools because of behaviours they exhibited especially in mainstream schools. A mother told us during a discussion that, '*I* (*she) thought his behavior will change so I sent him to a normal school. I however kept receiving complaints and was asked to withdraw him. I would take him to other schools, but would still receive the same complaints, until a teacher advised that I take him to a special school.' – Madam W*

One caregiver whose child was able to attain secondary education described her current state in this vignette: '*because she can't further her education, she has to learn a trade. At the workplace, because she can't concentrate, she is neglected. Sometimes, this bring hurt and sadness… we buy medication which at the moment, isn't difficult…but the stigma, neglect and other difficulties… that is difficult.'* – Madam Q

Madam P shared an experience she had at a place she was formerly employed at. '*Where I used to work, the moment they saw my child, they told me that they suspect I have done something bad, because of his disorder. And they think this can affect the business, so they dismissed me.'*

4.10.4. Financial problems

Countless caregivers reported having difficulty coping with finances for the care of the affected child and the family as a whole. Some spoke about challenges of caring for the needs of other children in school in addition to affected children. According to some caregivers, it was hard at times to buy medication for the children because the medications were often expensive and frequent shortages made the situation worse. This accounted for default in treatment by some families. This matter was particularly strong among caregivers who were unemployed or had unemployed partners. Some also spent money moving around from place to place in search of a possible cure. Very few felt that they had enough money to provide adequate care.

When asked how easy it was to cope with finances, one male caregiver responded; '*It's not easy, it's not easy at all. Sometimes to the extent that… there are occasions, money gets finished in the house … and I begin to wonder if I have misplaced the money… the stress in that area is high'* – Mr T

In expectation of a possible cure, one caregiver added, *'When you get money, then someone will show you this place, go here and try this, do this, do that. So, you can't save money…. We spend a lot of money on him.' – Madam* H

Concerning coming to the hospital and medication issues, complaints about cost of transportation, consultation ad medication were raised. A male participant said, *'Even what you'll eat (money to be spent on food), you have to use it for medication.'* – Mr A

Another participant said*, 'It's not easy to cope with it (finances). If I remember, last year November or December, I had to buy medicine for him but the elder who helps me had travelled…what I did was that, sometimes, I had to fast and keep the money (pocket money)… the medications also makes him put on weight so you have to keep changing his clothing*' – Mad V

Whilst many people felt finances were problematic, a few people felt money was not a problem for them.

'*As for money matters, I'm ok. My husband provides enough for our upkeep.*' – Madam X Another caregiver who is an aunt also stated that '*in terms of finances, I don't have a problem.*' This was mainly because the child's mother usually sent money for their upkeep from abroad

4.10.5. Relationship problems

Relationship problems traversed past and current relationships with partners, relationship with family members and neighbours. Some caregivers said during the interviews that, the child's disorder had accounted for the breakdown of their marriages and for some this had affected future chances of getting into other relationships.

'He was one year when his father and I divorced. ABC is (he's) now 9 years. It's not that we are not attracted to men. But when they come around and they see that you have a child like this, they will run away. They will shun you… So, it's quite difficult… I've closed my mind… its's difficult for me to open up.' Madam V

'Because of him, my relationship with his father broke down and all the children are now with me… He sends money but he seems to be more concerned about the other two children than the affected one.' – Madam W

Married caregivers also expressed concern that the stress and burden of caring occasionally led to tensions in the marriage. For some, they wished they could turn back the hands of time. A Participant admitted, *'In fact, there have been occasions that there have been misunderstandings between my wife and me. I understand. It's the stress.'* Mr T

One caregiver seemed to express regret as he said the following; *'When I die and come back again, God shouldn't allow me to give birth. Even if I see a woman, I won't even go near and propose. Then I'll just be on my own.'* – Mr A

4.10.6. Coping with challenges

Caregivers had several ways of coping with the challenges that they faced during care giving. Some said they had come to terms with the child's disorder and had accepted them as such. Others relied on God for strength and help and were hopeful for a possible change in the child. Some vignettes capturing this matter are as follows;

'I just have to console myself by praying and hoping God is still there. In his own good time….' Madam Q.

'People stare at us, but what can you do? You'll take it like that. You can't do anything. Whatever you do, it's your child so you can't say you'll abandon him.' – Mr B

'I once told my Doctor that I'm on retirement and he told me not to worry because once God had given him (child) to me, God knows I can take care of him and that there was hope. I was very happy when the Doctor told me that.' – Mr A

'…What helps is that, if God's word is in you, it helps you… but it's not an easy thing… If the parent becomes stressed, how will he get the strength to take good care of the child' – Mr T

'It is a huge burden, but because it is my own child, even if it worries me, it doesn't worry me too much.' – Madam E

'When he offends someone, I quickly have to go and apologise, then tell him not do that again' – Madam V

4.10.7. Need for support

Many caregivers reported not having support from both extended family and the society even though majority felt that they needed a lot of help to be able to care for these children. Majority of them had no supporting formal caregiver or belonged to a support group system. Several of them felt that if they had adequate help from various sources including family members, the community and the government, they could be more productive and be able to fend for themselves. Others agreed that id the government of Ghana will stop playing politics and play their part by providing the needed infrastructure, policies and the like, thing would be better. They reckoned that the support was necessary to lessen their stress and burden. However, this hope and wish was either non-existent or too little.

Concerning the presence of family and other support, this is what some participants had to say;

'I don't have enough help. Even her father thinks there's nothing we can do. So, when you suggest something, he doesn't want to do it… that is the help that I'm not getting that worries me.' – Madam Q

'When it comes to this issue, many people ignore it. it is as if you have been rejected. That's what happens… When you tell family members, they hear, but no help comes from anywhere. Even my brother abroad, I've told him several times to help with medication, but he wouldn't…. there's no one who has helped me on this earth' - Mr B

'They don't help. Even if they have money, they will use it to take care of their own children.' – Madam P

'I often wonder who will even sacrifice to take care of the child after my death…I can think and ponder so much that, even sometimes after midnight, I can't sleep again;' Mr B

'We really wish there was a school,… just that we are not getting some.' – Madam C

'If I get someone to support me to take him to school, I will not sit at home. I will force to go and work. – Madam V

'No one is ready in the society to offer help to the children. When he is happy and playing and screaming, people get annoyed.' – Mr A

When participants were asked what help they wished they had from their families, the community and the government, numerous needs were mentioned. A summary of their responses has been tabulated in Table 4.10.

Table 4.10: Felt needs of caregivers of children with autism

Source	Felt Needs
Family	Compassion and Understanding Acceptance Help with caring for the child Financial support
Community	Acceptance Playgrounds in protected areas Community school Support and special care
Government	Affordable Special schools More Boarding schools Day care Centre for respite Free education Special syllabus in mainstream school Free or subsidised medication, fund to provide medication, Vocational and other Skills training Monetary support for starting up business Job opportunities for caregivers Social welfare support with caregivers Public education and sensitisation Early detection services Well-resourced Education Assessment Centre More Mental Health personnel for consistency in Care

Word Count = 3950

CHAPTER 5 – DISCUSSION, RECOMMENDATIONS, CONCLUSIONS

5.1. Discussion

5.1.1. Introduction

This study set out to determine the prevalence of psychiatric morbidity and the level of burden of care among informal caregivers of children with autism spectrum disorder (ASD), as well as sociodemographic and clinical correlates of psychiatric morbidity and burden. It was a cross-sectional descriptive study carried out among caregivers attending the outpatient clinics of selected hospitals in Accra and Kumasi, Ghana.

5.1.2. Sociodemographic and clinical characteristics of care recipients

The mean age of the children (care recipients) in this study was 10.64 ± 5.15 years. A study conducted among children with ASD attending a neurodevelopmental clinic in Nigeria reported a similar finding. A mean age of 9.45 ± 4.33 years was found in Nigeria (Bello – Mojeed et al., 2017, Bello – Mojeed et al., 2013b) and a study in Ghana documented a mean age of 9.24 ± 5.47 years (Thomas et al., 2015).

The majority of the children in this study were at the age 12 years and below. This observation is similar to findings of previous studies on autism in Africa. In a child psychiatric clinic in South western Nigeria, Aina et al. (2003) and Bello-Mojeed et al. (2017) documented that the age range of majority of the children with neurodevelopmental disorder were 12 years and below. This finding further characterizes ASD as a neurodevelopmental disorder of early onset (APA, 2013). Also, this age group could signify that children attending the clinics are mainly in the pre-adolescent stage and older children may be lost to follow up as a result of fatigue and burden due to the caregiver burnout and stigma linked to the disabling and lifelong course of the disorder.

It was found that male children formed 73.8% of the child population. This male preponderance has also been found in studies involving children with ASD in Ghana by Thomas et al. in 2015 (76%), in Nigeria by Nwanze, in 2016 (72.7%), Bello – Mojeed et al., in 2017 (70.0%), Oshodi et al., 2017 (79.3). This result is also in keeping with other documented studies worldwide where it has been shown that ASD occurrence has a higher male to female ratio (Al-Dujaili and Al-Mossawy, 2017; Tongerloo et al., 2014)

It was observed that more than a third of children were out of school (36.1%). This observation is consistent to findings in Nigeria (Bello-Mojeed et al, 2016). could be because many schools for children with autism in Ghana are privately owned and comes with a high cost. So many caregivers are unable to afford as was discussed in the focus group discussion and documented in literature (Thomas et al., 2015; Agyekum, 2018a; Agyekum, 2018b). Another reason is that available schools may not be able to adequately provide the needs of these children and parents are forced to withdraw their wards. A study done by Omigbodun (2004) among children attending a child psychiatric clinic in Nigeria found that children with autism were significantly more unlikely to find schools which met their special needs.

About a quarter of parents of the children with autism were separated, divorced or widowed. This figure, though higher than what was found (10%) in a study among Nigerian mothers with children with ASD in Lagos, Nigeria (Bello – Mojeed et al., 2017, Bello – Mojeed et al., 2013b) is not surprising. The stress of caregiving could lead to disturbances in the relationship among family members, with resultant marital conflicts, difficulties between the parents and other children, as well as extended family members (Divan et al.,2012). This could be a possible reason for the above finding.

On average, children had their first contact with a health facility at a mean age of 3.62 ± 2.19 years for specialised care. This finding is lower than the mean of 8.13 ± 3.98 years found among children attending a child mental health service centre in Lagos, Nigeria (Bello – Mojeed et al., 2017.)

Children were diagnosed with autism between 1 to 17 years, with the mean age of diagnosis at 4.90± 3.38 years. This mean age is higher than a mean age of 3.1 years found by Nwanze (2016) but is lower than a mean of 9.0 years found by Bello – Mojeed et al. in 2017. It is possible that because the children in the study presented early, they were diagnosed early. However, there is still a lag of averagely, about 1.3 years from presentation at a specialised clinic till diagnosis was made. It is possible that the earlier presentation could be due to increased awareness on the part of the parent about the disorder, necessitating early action.

A percentage of 26.2% of the children were reported to have other medical or mental health conditions apart from autism. Comorbid neuropsychiatric conditions mentioned included seizure disorder, Intellectual disability and ADHD and medical conditions such as asthma, visual impairment and mild hydrocephalus. This is not a surprising finding as some studies have found comorbid disorders such as tic disorders, epilepsy, ADHD, OCD, anxiety, depression, oppositional defiance disorder (ODD), intellectual disabilities, tuberous sclerosis and emotional disorders present in children with ASD (Hayes and Watson, 2013; Bello-Mojeed and Bakare, 2013, Bello-Mojeed et al., 2011, 2013a; Oshodi et al., 2017). However, the co-morbid conditions were based on caregivers report with no objective assessment rating during the conduct of this study.

5.1.3. Sociodemographic characteristics of caregivers

From the study population, the mean age of the caregivers was found to be 43.53 (SD 8.97) years with a range from 24 to 65 years. Among caregivers of children with neurodevelopmental disorders at a clinic in Lagos, Nigeria, the mean age of caregivers was found to be 41.5 years ± 8.9 (Okewole et al., 2011; Dada et al., 2011). Bello – Mojeed *et al.* (2013b) also found the age range of mothers of children with autism in Nigeria to be 25 to 54 years with a mean age of 38.93 ± 6.99 years. These mean age values are similar as they all hover around 40 years. The slight differences could be due to differences in the sample size composition for gender and the different diagnosis of the children.

Females constituted 82% of the caregiver population. This finding is in keeping with similar studies in Nigeria, where females formed the majority of caregivers with children with neurodevelopmental disorders (Okewole et al., 2011; Dada et al., 2011). This study found mothers to be the majority of caregivers (73.8%) followed by fathers (16.4%) and other caregivers included grandmothers, uncles and aunts. This compares with other findings in the sub-region and globally. Mothers mainly are the primary caregivers in many homes across the globe. It stands to reason that they will care for these children with special needs. It will be prominent in Africa and other regions of the world where the mother usually stays home for the father, man, to work and provide the financial needs of the family. (Al-Dujaili and Al-Mossawy, 2017(Olagunju et al., 2017, Okewole et al., 2011; Dada et al., 2011)). Similar results of 74.3% being mothers have been found in Iraq and in Nigeria rates of 71.7% and 78.0% have been found.

Majority (75.4%) of caregivers of the children with autism were married. This is similar to findings in different parts of the world (Al-Dujaili and Al-Mossawy, 2017; Bello – Mojeed *et al.*,2013b; Dada et al., 2011; Tilahun et al., 2016). Of the caregivers, 55.7% had basic to secondary education similar to a rate of 63.3% who had a minimum of secondary school education in a study by Bello – Mojeed *et al.* (2013b) and Al-Dujaili and Al-Mossawy, (2017) also found similar rates in Iraq.

It is not surprising to see that the Akan ethnic group formed the majority (80.3) as the Akans are the largest Ethnic group in the Country (47.3%), followed by others such as Mole Dagbani (16.6%), Ewe (13.9%), Ga-Dangme (7.4%), Gurma (5.7%) and Guan (3.7%) according to GSS et al., 2015. Other ethnic groups found in this study included Mole Dagabni, Ewe, Ga- dangbe, Guan, Bulesa, Nzema and Dagarti . Majority (88.5%) of caregivers lived in urban areas. This is consistent with the location of the study site since Accra and Kumasi are both urban areas. This finding is corroborated by the 2010 Population and Housing census which indicates that the proportion of the urban population in Greater Accra (Capital – Accra) and Ashanti region (Capital – Kumasi) were 90.5% and 60.6% respectively (GSS, 2013). Similar greater urban dwellers have been found worldwide (Al-Dujaili and Al-Mossawy, 2017; Bello – Mojeed et al., 2017)

An interesting finding from this study is that less than half of caregivers (n=22) stated their incomes or allowances received per month. As compared to the income of their spouses for those married, a lesser number (n = 8) was recorded. This could be an indication that many people are not comfortable disclosing their incomes to others, as some failed to tell even after persuasion. In the case of their spouses, a few caregivers admitted not knowing how much their spouse earned in a month. Since financial problems were a significant concern during the focus group discussions, it may compound the stress of the unemployed partner, if she or he is the caregiver, as they may be unable to plan adequately while in oblivion. Also, it is possible that the participants earned low incomes and were ashamed to disclose.

Nevertheless, it was seen that the mean income of the spouses of caregivers was higher ($487.01 ± $429.59) than for caregivers themselves ($304.69 ±$357.29). This could be explained by the observation that more than half of the spouses (55.1%) had highly skilled jobs (ISCO Class 1 – 3) strengthened by the finding that 56.4% of them had tertiary level education. On the other hand, majority of caregivers (41.0) belonged to ISCO Class 4 – 6 group (Semi – skilled) and 42.6% had tertiary education as seen in Table 3. This comparison, however, may not be too reliable as sample sizes of caregivers and spouses are not equal.

5.1.4. Psychiatric morbidity and burden among caregivers

Caregivers scores on the GHQ – 12 ranged from 0 to 9 with a mean score of 3.08 (SD 2.82). This mean score indicates that averagely, caregivers of children with ASD had psychiatric morbidity. The prevalence of psychiatric morbidity among caregivers was 45.9% (score ≥3). ZBI scores of caregivers ranged from 7 to 69, with a mean score of 37.00 (SD13.82). About half (50.8%) of all caregivers had mild to moderate burden and more caregivers were found to have low burden (63.9%) compared to high burden (36.1%) when ZBI scores were further dichotomised using 40 as a cut off mark.

This study found a high rate of psychiatric morbidity (45.9%) and burden (36.1%) among caregivers of children with autism. A rate of 45.9% for psychiatric morbidity found in this study is higher than the 38.3% reported by Olagunju et al (2017) as rates of psychiatric morbidity among caregivers of children with neurodevelopmental disorder in Lagos, Nigeria.. This differences in methodology could account for the observed contrast. The study by Olagunju et al (2017) is similar to the present study in that they are both cross-sectional and similar sample size, but Olagunju et al recruited 60 caregivers of children with neurodevelopmental disorders while the present study is specific for Autism. Consistently, previous studies have documented caregivers of children with autism experience a higher level of stress and emotional problems as compared to typically developing children and children with other neurodevelopmental disorders (Bitsika & Sharpley, 2004; Hayes and Watson, 2013; Al-Farsi et al., 2016; Almansour et al., 2013, Lai et al, 2015).

Al-Dujaili and Al-Mossawy (2017) found a prevalence of psychological distress or psychiatric morbidity to be 25% and a mild and moderate burden level of 30% and 50% respectively among caregivers of children with ASD. The prevalence of psychiatric morbidity found here is higher than was found in Iraq while more people had a lower burden as compared to what was found in Iraq. The reason for this difference is not clear but it is possible that differences in methodology or personal characteristics of respondents could account for this. Also, the sample sizes used in this study (61) was less than the 170 which was used in Iraq. Thus, this could also be a contributing factor.

A study among Nigerian mothers of children with autism found 65% of mothers having psychological distress and 70% being rated as having a high burden of care (Bello – Mojeed et al., 2013b). Compared to this current study with corresponding values of 45.9% having psychiatric morbidity and 36.1% having a high level of burden, it can be seen that lower proportion of caregivers had psychiatric morbidity and high burden. On the converse, it can be said that Ghanaian caregivers in this study had less psychiatric morbidity and lower burden as compared to the study population in Nigeria.

It is important to note however that, the study in Nigeria comprised of only mothers while this study had about three-quarters of caregivers being mothers. This fact could be an underlying factor accounting for the differences seen in psychiatric morbidity and level of burden.

5.1.5. Factors associated with and predictors of psychiatric morbidity and burden among caregivers.

Many factors have been found worldwide to be associated with psychiatric morbidity of caregivers of children with chronic mental health problems and neurodevelopmental disorders such as intellectual disability and autism. From this study, the birth order of the child was found to be associated with psychiatric morbidity ($p = 0.029$). The employment status of the caregiver was also found to be significantly associated with a high burden of care ($p = 0.012$). Furthermore, having a psychiatric morbidity was shown to be positively correlated with burden of care, though this linear relationship is moderately strong ($r = 0.430$, $p=0.001$). However, it implies that, as psychiatric morbidity increases, the burden of care also increases and vice versa.

This study found birth order to be an predictor of psychiatric morbidity. In a study in Turkey, the rate of being a firstborn child, among children with ASD, was significantly more frequent compared to controls (Ugur et al., 2018). This is consistent with a finding of 54.1% of children being firstborn children in this study. However, the birth position was not tested against the psychiatric morbidity or burden of caregivers in that study. An association between parenting distress, child's gender and birth order was found by Mohammed (2015) in Baghdad. However, in this study, parenting stress scale was used, which makes it difficult to compare the results with what was found in this study. Nevertheless, birth order has no strong linkage with high burden in this study.

Possible explanations for the experience of having a lower psychiatric morbidity whilst caring for a first born child could be due to the fact that, one is able to adequately provide from the early onset and caregivers may be able to cope as the child grows. In the case of lower morbidity whilst caring for 4th or 5th born children, it is possible that a caregiver may have older children who may help with the caregiving process and in effect experience less stress. It is also possible that a caregiver, especially parents, may take comfort in the fact that they have other typically developing children, and this way of coping may result in less stress and psychiatric morbidity.

Some studies have found that employment status is not significantly associated with burden of care among caregivers (Dada et al., 2011; Pandey and Sharma, 2018), however, the converse was found in this study. Caregivers who were employed had less burden as compared to those who were not employed, and unemployment predictive of high burden. Dardas and Ahmad (2014) in a study in Jordan found that high income parents reported lower levels of parental distress, parent – child dysfunctional interaction and a higher level of quality of life. This fact stands true, as it is likely that unemployed caregivers may have less money to care for the needs of their children. Also, income from one partner may not be enough to cater for needs.

Gallagher *et al.* (2008) and Shanthi et al. (2015) found that high burden was a predictor of psychological distress among caregivers of children with intellectual disability. Research finding from this study has been shown to be in keeping with like studies which showed high burden to be a predictor of psychological distress and vice versa in among caregivers of children with autism (Pandey and Sharma, 2018; Dada et al., 2011; Bello-Mojeed et al., 2013b; Al-Dujaili and Al-Mossawy, 2017).

Factors that could be accounting for the presence of psychiatric morbidity and burden could include the degree of impairment of the child, coping mechanisms by the parent, financial problems, presence of emotional problems among caregivers, quality of life, among others. However, some of these factors were not measured in this study. It is of interest to note that some studies have found no significant association between some child and caregiver socioeconomic and clinical variables (Dada *et al.*, 2011; Al-Dujaili and Al-Mossawy, 2017).

Although it was seen that increasing age, being a male caregiver, being a father and living in a rural area was associated with the presence of psychiatric morbidity, these were not found to have significant association. Also, being a father and living in a rural place of abode were also seen to be associated with high burden of care. However, no significant association was found between these variables and high burden.

5.1.6. Causes of autism, challenges of caregiving and unmet needs of caregivers of children with ASD

Children with ASD face many challenges in their daily lives and so do the caregivers who take care of them. From focus group discussions, emerging themes that were derived included caregiver's perception about the cause of autism, challenges of dealing with the disorder and caregiving, stigma and social exclusion, financial problems, relationship problems, coping with the challenges and the need for support.

Perception about the cause of ASD found in this study included, spiritual causes (unknown spiritual entities, dwarves), biomedical causes such as birth complications, trauma and a combination of medical and spiritual cause. These perceptions seem to be a common African one. Some of these factors have been documented by Tilahun et al., (2016) in a study done in Ethiopia, a developing country in Africa, like Ghana. Some explanations about the aetiology of ASD in that study included, spirit possession, sinful acts, bewitchment, punishment from God, head injury, epilepsy, and birth complications. In a study among health workers in Nigeria, Bakare et al. (2009) found similar opinions that the cause of autism could be natural (genetics, birth injury maternal infections,), supernatural or preternatural such as caused by lineage curses, the work of the devil, enemies, among several opinions.

Caring for children with ASD is burdensome and takes a toll on the physical and psychological wellbeing of caregivers (Divan et al., 2012; Tongerloo et al., 2014). In this study, caregivers expressed concern about the stress in attending to the special needs of the children as caring for them meant performing tasks that they (Children) otherwise would have been able to do on their way. Some of the tasks included maintain personal hygiene and feeding. They also had to deal with challenging behaviours, sleep and mood problems, among others. For some caregivers, this had affected their work life, social life and health as well.

A study carried out in Ghana and the Netherlands exploring the challenges and coping among parents of children with autism, found reports from caregivers about the burden and stress of caregiving activities (Agyekum, 2018a; Tongerloo et al., 2014). This stress they said, was not easy as the children could not do anything for themselves and many parents had to struggle with or without support from nannies or family. This finding is similar to what was found in this study, where many caregivers did not have enough help. This study also found some of the challenges of parents to be barriers in communicating with the children and dealing with society's reaction to the child (Agyekum, 2018a).

Stigma is a major finding that resonates over the world among people with disability. This stigma is extended to children with neurodevelopmental problems including autism. Caregivers of children with ASD in this study experienced stigma and social exclusion. They perceived they were discriminated against and socially excluded because of their child's condition in areas such as work, housing interpersonal relationships, among a host of other issues. Similar issues have been raised in Ghana by parents of children with ASD (Agyekum 2018a; Agyekum, 2018b). In Ethiopia, as a result of stigma, some caregivers felt ashamed about their children, worried about the treatment they would receive by others and tried to keep their child's condition a secret (Tilahun et al., 2016). Stigma could affect the mental health of the caregiver as negative experiences could tend to make people isolate themselves and could lead to more psychological distress and burden.

Almost all caregivers interviewed had difficulty coping with finances for the care of the affected child and the family as a whole. Financial challenges included caring for the needs of the affected child, other children, school related costs, medication costs, transportation among others. Many specials schools in Ghana are owned by private individual and this makes the fee very high. Also, most medications used I metal health are not covered by the National Health Insurance Scheme, so parents have to pay out of pocket. Financial problems in similar areas were found in a study among caregivers of children with ASD in Ghana (Agyekum 2018a; Agyekum, 2018b). However, among caregivers who were of higher socioeconomic status surveyed by Thomas et al. (2015), financial problems were not reported to be a main problem for these caregivers.

The stress and stigma of caring for children with ASD was said to affect relationships between spouses, with some leading to divorce and marital disputes and between caregivers and family members and neighbours. Divan et al (2012), found similarly that, the stress of caregiving led to disturbances in the relationship among family members, with resultant marital conflicts, difficulties between the parents and other children as well as extended family members in India. It is possible that couples may blame each other for the child's disorder which may result in misunderstanding. Other factors that could account for relationship problems are misperception about the disorder (cultural, religious, etc), other children seeking attention and difficulties accepting diagnosis.

Coping mechanisms adopted by many caregivers was religious coping where hope and drawing strength from God were the main means of coping. Others coped by accepting the child the way he was. Ghanaian's have a typical '*fa ma Nyame'* attitude, which literally means 'leave it to God, when dealing with many challenges. In a study in Ethiopia, caregivers coped by talking to health professionals and family, seeking religious support and finding relief in using drugs and substance (Tilahun, 2016). Similarly, Agyekum (2018a), found that in Ghana, parents of children with ASD coped by relying on spirituality, encouragement from friends and family and by acceptance. Unlike the previous studies, a study in Singapore parents of children with ASD found that parents coped by active avoidance, which is a type of maladaptive emotional coping mechanism (Lai et al., 2015)

Results from this study revealed a major gap in the support that is available for caregivers of children with ASD. Support was lacking from family members, the community and the Government of Ghana ass a whole. Acceptance, understanding and compassion from family and community were important. The need for affordable and accessible special education or inclusion or a special curriculum for mainstream schools was a major unmet need. Also, the need for public education, skills training, respite care, scaling up of health and social services and monetary support for medication and jobs were important findings. Tilahun (2016), documented similar findings that providing education for children was the most reported unmet need in an Ethiopian sample. Other unmet needs were financial support, inadequate access to health workers and needed expert to provide support and information about the child's condition and skills training.

Agyekum (2018a), in a similar study in Ghana, identified major areas and challenges that parents faced. The difference in her study is that, all the caregivers were recruited from an institution for parents of children with ASD, which could serve as a support group system. Also, these caregivers had support from their extended families and some even had support from work, even though they still had other unmet needs. Another study based in Ghana revealed areas of desired need to include support groups, parent training and behaviour management assistance for parents as well as professional support services such as Healthcare workers and teacher education (Thomas et al., 2015).

The implication from the unmet needs found in this study and other studies in Ghana (Thomas et al., 2015; Agyekum, 2018a; Agyekum, 2018b) is that there is a huge gap in terms of infrastructure and services (health, social, educational, financial) to cater for the needs of children with ASD. Unfortunately, some health, education and religious sector professionals are not aware of the peculiar needs of families living with ASD and this further worsens the burden (Divan et al., 2012). Measure will have to be put in place to ensure that special education is made more available and affordable, especially public ones, which would incorporate skills training for the children. Services for respite care and leisure for children must also be considered. Parents also, would need skills training and behaviour management training. Thus, a multidisciplinary approach must be taken to address the needs of the children with ASD and their caregivers.

5.2. Limitations

The following are limitations of the study;

- The study was a cross – sectional one, hence, causal inferences could not be made.
- This was largely a hospital-based study, so generalisation of the results may be limited to an extent.

- The sample size used in the study was small. This is because it was difficult recruiting participants as many had defaulted treatment so hospital attendance was low, some contact numbers in folders were wrong (so could not be reached) and thus, had been lost to follow up.

5.3. Conclusion

Psychiatric morbidity among caregivers of children with autism is common with a prevalence of 45.9%, implying that about 5 in 10 caregivers are affected. Also, 36.1% of all caregivers had a high level of burden of care. A predictor of high burden was found to be the employment status of the caregiver and unemployed participants were found to likely 8 times burdened as compared to the employed. Challenges experienced by the caregivers included dealing with the disorder and caregiving, stigma and social exclusion, financial problems, relationship problems, coping with the challenges and the need for support. Unmet needs included acceptance from family and the society, special schools, support systems (social, financial, skills training), advocacy and education.

5.4. Recommendations

At the end of the study, the recommendations include;

1. Caregivers of children with ASD should be routinely screened for psychiatric morbidity, as part of management of their children.
2. Intervention programs for caregivers should include support group systems and provision of respite care.

3. Intervention programs should also include training for both the caregivers and children.
4. There should be provision of more affordable and accessible special schools.
5. A special curriculum should be in place in mainstream schools to cater for educational needs children with special needs.
6. There should be more advocacy and public education on autism to decrease stigma and social exclusion.
7. More health facilities and personnel should be put in place to aid diagnosis and consistency in care

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APPENDIX 1: QUESTIONNAIRE and INTERVIEW GUIDE

Questionnaire

Sociodemographic Questionnaire

Serial Number : _______________

Today's Date : __ __/__ __/__ __

Phone number : _______________

Please write the answers to the questions or draw a circle where it applies to you.

SECTION I: CHILD VARIABLES

1. Child's initials_____________________
2. Age of the child _____________
3. Date of Birth: _____ ______ ________

   Day Month Year
4. Gender (a) boy (b) girl
5. Educational level (a) none (b) Nursery (c) Primary (d)JSS (e) SSS
6. Marital Status of Parents:

   (a) Married (b)Separated/Divorced (c) Father is dead (d) Mother is dead

   (e) Mother & Father are dead (f) co habiting
7. Family Type: (a) Monogamous (b) Polygamous (c) Foster Care
8. Child's position among siblings_______________
9. Child's age at first contact with a health facility for care _____________________
10. Child's age at first diagnosis with Autism _____________________
11. Total length of time child has lived with Autism____________________
12. Has child been diagnosed with any other condition ? (a) Yes (b) No

If yes, what condition _______________________________

SECTION II: CAREGIVER VARIABLES

1. Caregiver's initials______________________
2. How old are you at your last birthday ? ____Date of Birth: _____ ______ ________

   Day Month Year

3. Gender (a)Male (b) Female
4. Marital status

   (a) Single (b)Married (c) Separated/Divorced (d) co-habiting (e) widowed (f Other

   (please specify)___________________

5. Level of education

   (a) No Formal Education (b) Primary /JSS/Middle School (c) Secondary School/Standard 7/O level (d) Post-Secondary (Non-University) /Vocational

   (f) Tertiary (g) Postgraduate/Professional

   (h) Other (please specify)___________________

6. Occupation ______________________
7. Monthly income _____________________
8. Ethnicity

   (b) Akan (b) Ga/Dangbe (c) Ewe (d) Mole-Dagbani (e)Other

   (please specify)___________________

9. Where do you live? (Address of Present Abode):_________________________

10. Do you practise any religion? (a) Yes (b) No

11. Please write down the exact place you attend for worship

____

(a) Islam (b) Orthodox Christian (c) Pentecostal Christian

(d)Traditional religion (e)Other (please specify)_________________

12. Relationship to child

(a) Mother (b) Father (c) Sibling (d) Guardian (e) Grandmother

(f) Grandfather (g) Other [please specify] _________________

13. Level of education of Spouse/Partner

14. (a) No Formal Education (b) Primary /JSS/Middle School (c) Secondary School/Standard 7/ o level (d) Post-Secondary (Non-University) /Vocational

(f) Tertiary (g) Postgraduate/Professional

(h) Other (please specify)_________________

15. Occupation of Spouse/Partner _____________________

16. Monthly income of Spouse/Partner ___________________ don't know

17. Have you ever been diagnosed as having a mental health condition ?(a) Yes (b) No

18. If yes, what condition _______________________________________

19. Have you ever had treatment for the condition (a) Yes (Please specify)____________

(b) No

20. Are you currently on treatment for the condition (a) Yes (Please specify)____________

(b) No

General Health Questionnaire-12

This section is about how you have been feeling recently.
Please underline or circle a response, which you think most nearly applies to you.

1. Have you recently been able to concentrate on whatever you are doing?
   1. Better than usual 2. same as usual 3. less than usual 4. much less than usual

2. Have you recently lost much sleep over worry?
   1. Not at all than usual 2. no more than usual 3. rather more than usual 4. much more than usual

3. Have you recently felt you are playing a useful part in things?
   1. More so than usual 2. same as usual 3. less useful than usual 4. much less useful

4. Have you recently felt capable of making decisions about things?
   1. More so than usual 2. same as usual 3. less so than usual 4. much less capable

5. Have you recently felt constantly under strain?
   1. Not at all 2. no more than usual 3. rather more than usual 4. much more than usual

6. Have you recently felt you couldn't overcome your difficulties?
   1. Not at all 2.no more than usual 3. rather more than usual 4. much more than usual

7. Have you recently been able to enjoy your normal day-to-day activities?
   1. More so than usual 2. same as usual 3. less so than usual 4. much less than usual

8. Have you recently been able to face up to your problems?
   1.More so than usual 2. same as usual 3. less able than usual 4. much less able

9. Have you recently been feeling unhappy and depressed?
   1.Not at all 2. no more than usual 3. rather more than usual 4. much more than usual

10. Have you recently been losing confidence in yourself?
    1.Not at all 2. no more than usual 3. rather more than usual 4. much more than usual

11. Have you recently been thinking of yourself as a worthless person?
    1.Not at all 2. no more than usual 3. rather more than usual 4. much more than usual

12. Have you recently been feeling reasonably happy, all things considered?
    1. More so than usual 2. about same as usual 3. less so than usual 4. much less than usual

The Zarit Burden Interview

Please tick the response the best describes how you feel.

Question	**Score**				
	NEVER (0)	RARELY (I)	SOMETIMES (2)	QUITE FREQUENTLY (3)	NEARLY ALWAYS (4)
1 Do you feel that your child asks for more help than he/she needs?					
2 Do you feel that because of the time you spend with your child that you don't have enough time for yourself?					
3 Do you feel stressed between caring for your child and trying to meet other responsibilities for your family or work?					
4 Do you feel embarrassed over your child's behaviour?					
5 Do you feel angry when you are around your child?					
6 Do you feel that your child currently affects your relationships with other family members or friends in a negative way?					
7 Are you afraid what the future holds for your child?					
8 Do you feel your child is dependent on you?					
9 Do you feel strained when you are around your child?					
10 Do you feel your health has suffered because of your involvement with your child?					
11 Do you feel that you don't have as much privacy as you would like because of your child?					
12 Do you feel that your social life has suffered because you are caring for your child?					
13 Do you feel uncomfortable about having friends over because of your child?					
14 Do you feel that your child seems to expect you to take care of him/her as if you were the only one he/she could depend on?					
15 Do you feel that you don't have enough money to take care of your child in addition to the rest of your expenses?					
16 Do you feel that you will be unable to take care of your child much longer?					
17 Do you feel you have lost control of your life since your child's illness?					
18 Do you wish you could leave the care of your child to someone else?					
19 Do you feel uncertain about what to do about your child?					
20 Do you feel you should be doing more for your child?					
21 Do you feel you could do a better job in caring for your child?					
22 Overall, how burdened do you feel in caring for your child?					

Interview Guide for Focused Group Discussion to Explore Burden Of Care Of Caregivers

We are going to discuss issues that have to do with care that you give to the children and adolescents with autism spectrum disorder, on a day to day basis.

NOTE: Kindly introduce yourself before you contribute. Thank you

Questions

- Please tell me a little about the child you are caring for.
- What do you think is the reason for his/her disorder?
- Can you describe to me what a typical day for you is like?
- Do you think the disorder is a source of stress or burden to you? Please explain
- Apart from the disorder, which aspects of caregiving do you find challenging?
- Why do you find it challenging?
- How do you manage some of the challenges?
- Do you think you have enough help in caring for the child
    - If yes, kindly explain.
    - If no, kindly tell me which areas you need help with

- What support is available to you?
- How easy is it to cope with your finances as you take care of the child?
- Do you have other people helping you to take care of the child?
- What do you think your family can do to alleviate your burden?
- What do you think the community can do to alleviate your burden?
- What do you think the government can do to alleviate your burden?

APPENDIX 2: Patient information leaflet and Consent Form

Participant Information Leaflet

This leaflet must be given to all prospective participants to enable them know enough about the research before deciding to or not to participate

Title of Research: Psychiatric Morbidity and Burden among Caregivers of Children with Autism Spectrum Disorder in Selected Hospitals in Ghana

Name(s) and affiliation(s) of researcher(s): This study is being conducted by Peggy Asiedu Ekremet of the Accra Psychiatric Hospital, Accra and Centre for Child and Adolescent Mental Health, University of Ibadan, Nigeria.

Background (Please explain simply and briefly what the study is about): Taking care of children with special needs require extra attention and can be stressful. This study is going to evaluate the presence of psychological distress and burden of care among caregivers of children with autism spectrum disorder

Purpose(s) of research: The purpose of this study is to find out how the people taking care of children with autism are stressed psychologically and the burden that they experience during the caregiving process

Procedure of the research, what shall be required of each participant and approximate total number of participants that would be involved in the research: If you agree to take part in this study, you will receive a questionnaire and two instrument that will require you to answer questions about yourself, how you have been feeling and your ward. Some of the participants will also be randomly chosen to take part in a focus group discussion.

Risk(s): Answering the questions may take a bit of your time and energy but will not affect the care given to your ward in the facility.

Benefit(s): we hope that knowledge obtained from this study will serve as a basis for putting in place interventions to help and empower caregivers to cope with the stresses of taking care of children with autism. Also, participants who may be picked up as having severe burden and psychological distress will be referred for expert management.

Confidentiality: All information collected in this study will be given code numbers. No name will be recorded so data collected cannot be linked to you in anyway. No name or identifier will be used in any publication or reports from this study.

Voluntariness: Taking part in this study should be out of your own free will. You are not under obligation to. This research is entirely voluntary.

Alternatives to participation: If you choose not to participate, this will not affect the treatment your ward in this hospital in any way.

Withdrawal from the research: You may choose to withdraw from the research at any time without having to explain yourself. You may also choose not to answer any question you find uncomfortable or private.

Consequence of Withdrawal: There will be no consequence, loss of benefit or care to you if you choose to withdraw from the study. Please note however, that some of the information that may have been obtained from you without identifiers (name etc), before you chose to withdraw, may have been modified or used in analysis reports and publications. These cannot be removed anymore. We do promise to make good faith effort to comply with your wishes as much as practicable.

Costs/Compensation: For your time and inconvenience spent, if chosen to take part of the focus group discussion, we will compensate you with some snacks to show our appreciation for your time and goodwill.

Contacts: If you have any question concerning this study, please do not hesitate to contact Dr. Peggy Asiedu Ekremet on 0243340317

Further, if you have any concern about the conduct of this study, your welfare or your rights as a research participant, you may contact:

The Office of the Chairman
Committee on Human Research and Publication Ethics
Kumasi
Tel: 03220 63248 or 020 5453785

Consent Form

Statement of person obtaining informed consent:

I have fully explained this research to ________________________________ and have given sufficient information about the study, including that on procedures, risks and benefits, to enable the prospective participant make an informed decision to or not to participate.

DATE: ___________________ NAME: ______________________________

Statement of person giving consent:

I have read the information on this study/research or have had it translated into a language I understand. I have also talked it over with the interviewer to my satisfaction.

I understand that my participation is voluntary (not compulsory).

I know enough about the purpose, methods, risks, and benefits of the research study to decide that I want to take part in it.

I understand that I may freely stop being part of this study at any time without having to explain myself.

I have received a copy of this information leaflet and consent form to keep for myself.

NAME:____

DATE: ___________ SIGNATURE/THUMB PRINT: _________________

Statement of person witnessing consent (Process for Non-Literate Participants):

I __________________________ (Name of Witness) certify that information given to

___________________________(Name of Participant), in the local language, is a true reflection of what l have read from the study Participant Information Leaflet, attached.

WITNESS' SIGNATURE (maintain if participant is non-literate): ______________________

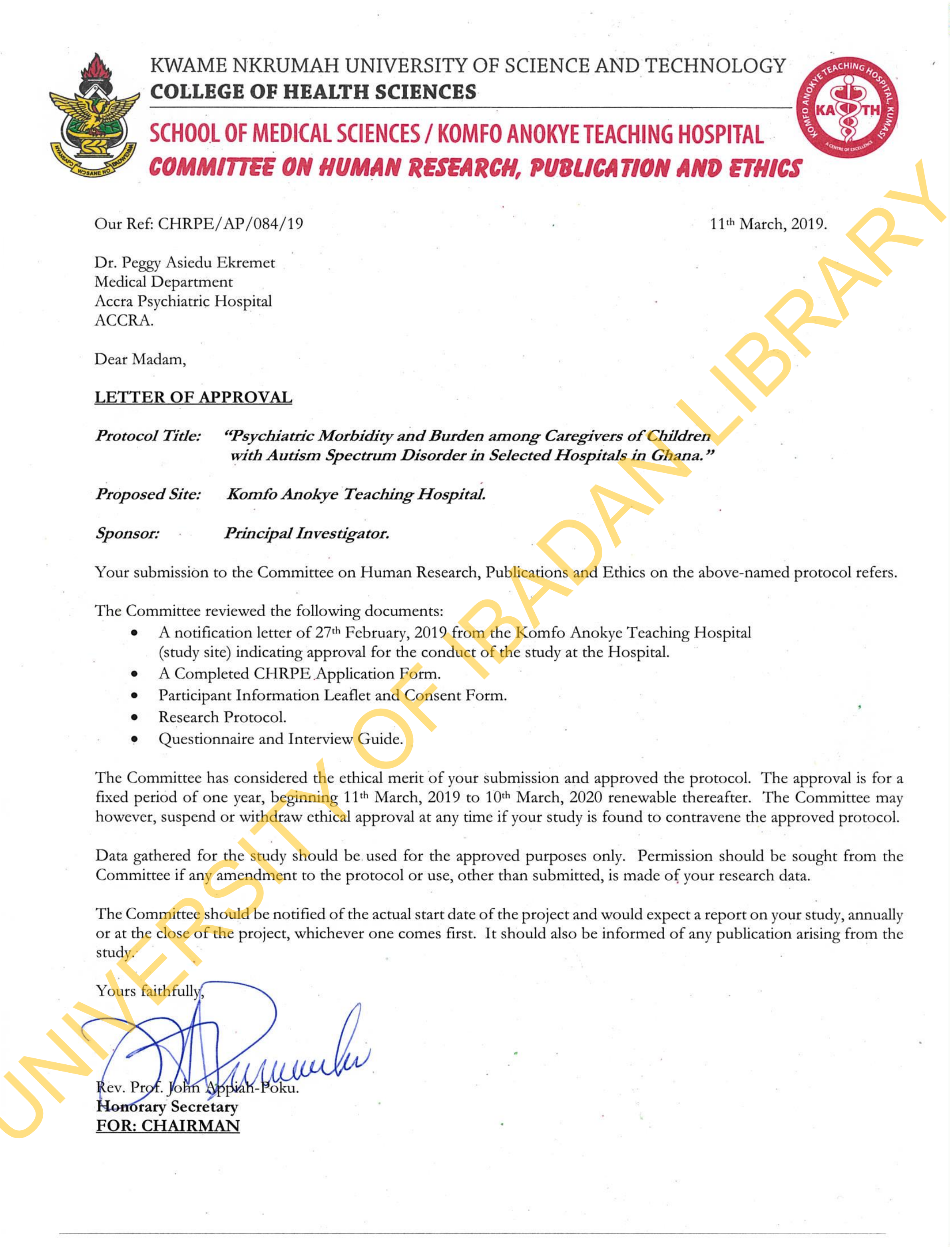
MOTHER'S SIGNATURE (maintain if participant is under 18 years): __________________

MOTHER'S NAME: ____

FATHER'S SIGNATURE (maintain if participant is under 18 years): __________________

FATHER'S NAME: ____

APPENDIX 3: Ethical Approval and Approval letters



KWAME NKRUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY
COLLEGE OF HEALTH SCIENCES
SCHOOL OF MEDICAL SCIENCES / KOMFO ANOKYE TEACHING HOSPITAL
COMMITTEE ON HUMAN RESEARCH, PUBLICATION AND ETHICS

Our Ref: CHRPE/AP/084/19 11th March, 2019.

Dr. Peggy Asiedu Ekremet
Medical Department
Accra Psychiatric Hospital
ACCRA.

Dear Madam,

LETTER OF APPROVAL

Protocol Title: ***"Psychiatric Morbidity and Burden among Caregivers of Children with Autism Spectrum Disorder in Selected Hospitals in Ghana."***

Proposed Site: ***Komfo Anokye Teaching Hospital.***

Sponsor: ***Principal Investigator.***

Your submission to the Committee on Human Research, Publications and Ethics on the above-named protocol refers.

The Committee reviewed the following documents:

- A notification letter of 27th February, 2019 from the Komfo Anokye Teaching Hospital (study site) indicating approval for the conduct of the study at the Hospital.
- A Completed CHRPE Application Form.
- Participant Information Leaflet and Consent Form.
- Research Protocol.
- Questionnaire and Interview Guide.

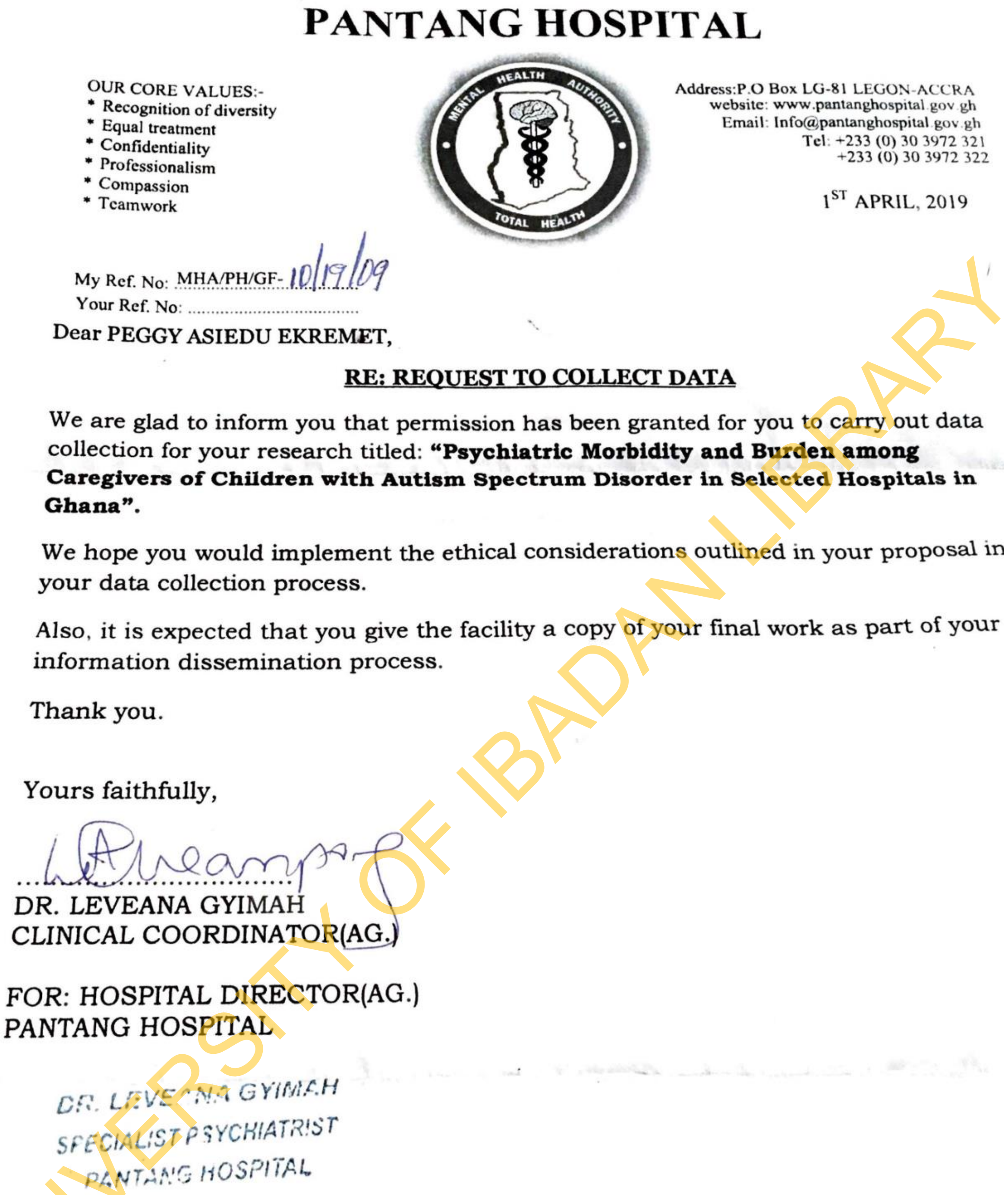
The Committee has considered the ethical merit of your submission and approved the protocol. The approval is for a fixed period of one year, beginning 11th March, 2019 to 10th March, 2020 renewable thereafter. The Committee may however, suspend or withdraw ethical approval at any time if your study is found to contravene the approved protocol.

Data gathered for the study should be used for the approved purposes only. Permission should be sought from the Committee if any amendment to the protocol or use, other than submitted, is made of your research data.

The Committee should be notified of the actual start date of the project and would expect a report on your study, annually or at the close of the project, whichever one comes first. It should also be informed of any publication arising from the study.

Yours faithfully,

Rev. Prof. John Appiah-Poku.
Honorary Secretary
FOR: CHAIRMAN



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OUR CORE VALUES:-
- Recognition of diversity
- Equal treatment
- Confidentiality
- Professionalism
- Compassion
- Teamwork

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+233 (0) 30 3972 322

1ST APRIL, 2019

My Ref. No: MHA/PH/GF- 10/19/09
Your Ref. No: ....

Dear PEGGY ASIEDU EKREMET,

RE: REQUEST TO COLLECT DATA

We are glad to inform you that permission has been granted for you to carry out data collection for your research titled: **"Psychiatric Morbidity and Burden among Caregivers of Children with Autism Spectrum Disorder in Selected Hospitals in Ghana".**

We hope you would implement the ethical considerations outlined in your proposal in your data collection process.

Also, it is expected that you give the facility a copy of your final work as part of your information dissemination process.

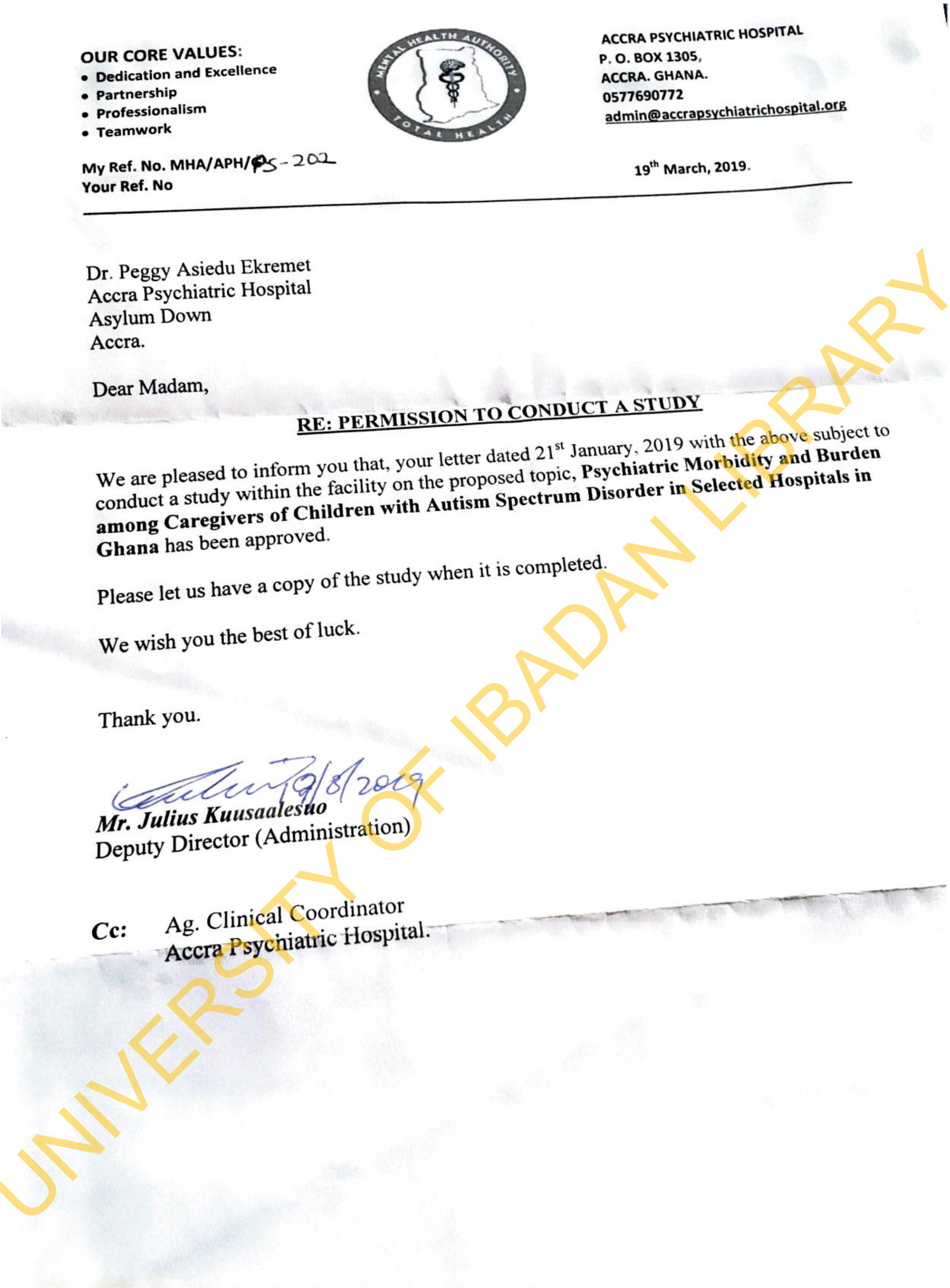
Thank you.

Yours faithfully,

....
DR. LEVEANA GYIMAH
CLINICAL COORDINATOR(AG.)

FOR: HOSPITAL DIRECTOR(AG.)
PANTANG HOSPITAL

DR. LEVEANA GYIMAH
SPECIALIST PSYCHIATRIST
PANTANG HOSPITAL



OUR CORE VALUES:
- Dedication and Excellence
- Partnership
- Professionalism
- Teamwork

ACCRA PSYCHIATRIC HOSPITAL
P. O. BOX 1305,
ACCRA. GHANA.
0577690772
admin@accrapsychiatrichospital.org

My Ref. No. MHA/APH/PS-202
Your Ref. No

19th March, 2019.

Dr. Peggy Asiedu Ekremet
Accra Psychiatric Hospital
Asylum Down
Accra.

Dear Madam,

RE: PERMISSION TO CONDUCT A STUDY

We are pleased to inform you that, your letter dated 21st January, 2019 with the above subject to conduct a study within the facility on the proposed topic, **Psychiatric Morbidity and Burden among Caregivers of Children with Autism Spectrum Disorder in Selected Hospitals in Ghana** has been approved.

Please let us have a copy of the study when it is completed.

We wish you the best of luck.

Thank you.

9/8/2019
Mr. Julius Kuusaalesuo
Deputy Director (Administration)

Cc: Ag. Clinical Coordinator
Accra Psychiatric Hospital.