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PSYCHOLOGICAL BURDEN AND REPORTED MEDICATION ADHERENCE IN CARING FOR CHILDREN AND ADOLESCENTS WITH MENTAL DISABILITIES IN GHANA

BY

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DECLARATION

This thesis is my original work with the exception of references made from people's work which has been acknowledged.

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DEDICATION

This dissertation is dedicated to my dear Emmanuel Asamoah-Brako and my supervisor Dr. Irene Kretchy for their immense support during this period of my education. I am highly grateful.

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I am grateful to God for all that he has done for me during the period I was working on this dissertation. I am also grateful to my academic supervisor for her help and kind guidance throughout the project period.

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ABSTRACT

Introduction: One in every five children suffer from a mental disorder. Unfortunately, two out of the five who seek mental health services do not receive adequate care. Mental disabilities result in defective intellectual growth and functioning. As these special children and adolescents take medications for their condition, the stress, anxiety and depression caregivers experience while taking care of these children cannot be overlooked as it may affect medication adherence. However, little is known about the psychological burden and reported medication adherence in taking care of children and adolescents with mental disabilities in Ghana.

Method: This study was a cross-sectional quantitative study. Questionnaires on psychological burden and reported medication adherence in caring for children and adolescents with mental disabilities were administered. Items on the questionnaire include parenting anxiety, stress and depression as well as reported medication adherence. The data collected were categorized, summarized and presented using simple descriptive statistics. Chi-square and logistic regression were used to establish associations between categorical variables such as age, gender and reported medication adherence.

Results: Two hundred and ten caregivers were engaged in this study and the majority of the caregivers were female. About 66.7% (140) were females. The following socio-demographic factors: gender, age, education and marital status were statistically associated with medication adherence ($p<0.05$). The study showed that the majority of the caregivers experienced severe forms of anxiety and depression with some experiencing moderate forms of stress. Medication adherence was statistically associated with anxiety and depression.

Conclusion: The study established an association between depression, anxiety and medication adherence. This clearly shows that the mental health of the caregiver cannot be overlooked as it affects medication adherence in their children and adolescents.

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LIST OF ABBREVIATIONS

APA	American Psychological Association
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CDC	Center for Disease Control and Prevention
DASS	Depression Anxiety and Stress Scale
DSM	Diagnostic and Statistical Manual
MARS	Medication Adherence Report Scale
OPD	Outpatient department
BAI	The Beck Anxiety Inventory
BDI	The Beck Depression Inventory
WHO	World Health Organization

DEFINITION OF TERMS

Adolescent: A person between the ages of 10 years to 19 years.

Caregiver: An individual who does not get paid for caring for a mentally disabled ward and has lived with this ward for over one year assisting him or her.

Children: A person between the ages of 0 to 10 years.

Mental disability: A clinical condition that distorts a person's disposition, reasoning and how the individual interacts with other persons

Psychological burden: This refers to the anxiety, depression and stress that caregivers go through when taking care of children and adolescents with mental illnesses.

CHAPTER ONE

INTRODUCTION

1.0 BACKGROUND STUDY

Mental disability is a challenge in Ghana (Oppong et al., 2016) . It can affect both the young and old. Mental disability can be described as the absence of emotional as well as intellectual growth which leads to one depending on another (caregiver) for survival. One aspect of health which is essential is mental health as every person needs a sound mind to function well (Connell, O'Cathain, & Brazier, 2014). According to the Diagnostic and Statistical Manual (DSM) 5th edition, the American Psychiatric Association refer to mental disability as an obvious change in emotional and behavioral functioning as a result of pain or injury in any part of life, be it work related, social or domestic (DSM-5, 2013).

The Disability Act of Ghana, describes an individual with disability as one with mental, physical and mental impairment which restricts the individual in all aspects of life be it physical, social or cultural (Stickney, Nathan & Oye-Lithur, 2007). According to the World Health Organization, the proportion of mental disabilities in the world is 1-3% (Al-Kuwari, 2007). A global study revealed that children and adolescents who experience mental disabilities is about 10%-20% (WHO, 2018). This clearly indicates that quite a number of children and adolescents have one form of mental disability.

In Africa, due to stigma and beliefs associated with developmental disabilities, the prevalence of mental disability in both adults and younger ones is not accurate. However, according to Solarsh and Hofman (2006), the inability of Africa as a continent to obtain accurate data concerning mental disability is rather due to economic difficulties not the stigma associated with it. This claim may be true but most cases of mental disabilities are not reported to health facilities for the appropriate measures to be taken as a result of stigma (Malla, Joober, & Garcia, 2015). Some studies conducted in sub-Saharan Africa specifically South Africa showed that the prevalence of disability ranged from eleven (11) to sixty (60), per thousand children. According to the Ghana Statistical Service (2012), 3% of the total population represented by seven hundred and forty-three individuals have some form of developmental disabilities. About, one hundred and twelve thousand, eighty-two individuals (15%) of the disabled population in Ghana also have intellectual disability.

Depression, bipolar affective disorders, cerebral palsy intellectual disabilities and attention deficit hyperactivity disorder (ADHD), autism spectrum disorders, and Down syndrome are forms of mental illnesses. These conditions negatively affect a person's intellectual functioning and behavior as a whole (DDRC, 2015).

Children and adolescents experience several forms of anxiety in their growth development. These mental disabilities disrupt the normal childhood growth of such children and it is made evident in their intellectual development as well as their eating pattern (O'Neil et al., 2014). Their condition may worsen and have a detrimental effect on them and their caregivers if extra care is not taken. Ideally, children with such peculiar challenges need assistance from others. In most of the communities the onus lies on the immediate parents that is the mother and father to take care of the ever-growing need of the disabled children. They serve as the immediate point of call when it comes to issues concerning the children. These special individuals are known as the caregivers. They understand the children's special language better than anyone else does.

Mentally disabled people tend to burden those from whom they seek help (Addo, Nonvignon, & Aikins, 2013). In delivery of this essential health care service, family caregivers are very essential persons. There are a lot of burden and issues caregivers undergo in caring for the children and adolescents. The challenges of such caregivers are however underestimated. Living with such children can be tough and caregivers must be made aware of these challenges that come with caring for these children. They should be well informed and given adequate counselling in order to help them handle the situation (Ambikile, & Outwater, 2012). One important role of family caregivers is to ensure that the medications are given in the right doses and at the right time to ensure medication adherence in these children. Generally, when caregivers experience some form of depression, anxiety and stress, they could give their wards an underdose, overdose or even forget to give them their medications (Caqueo-Urizar et al., 2015).

This is a major concern as this goes a long way to influence the management of mental disability in these children and adolescents. Caregivers' knowledge on the side effects of their wards medication also affects the way they administer medication to these special wards (Floersch et al. 2009). Commitment to taking the medication and adhering to the medication routine is very essential. It helps to control and minimize the mental health problem (Hamrin, McCarthy, & Tyson, 2010). It is also prudent to assess the extent of medication adherence in clients in order to monitor the progress of their condition. In the clinical setting, adherence can be measured by checking serum levels of drug, using the pill count in which the patients return the pills he or she is unable to take. The quickest way to monitor adherence is by patient or caregivers reporting to the physician

1.1 Problem Statement

According to WHO, everyone experiences one form of mental disability in their lifetime. Several studies have been done to assess the psychological burden of caring for adults globally (Janardhana et. al., 2015). However, a few studies have been done on caregivers with mental disabled wards (Ambikile & Outwater, 2012). In Ghana, there are scanty records on the psychological burden of caregivers in caring for children and adolescents with mental disabilities.

Caregivers with mentally disabled wards experience psychological, financial and physical stress which impact the quality of life of the caregivers (Delalibera, Presa, Barbosa, & Leal, 2015). It is however disturbing that the difficulties of these caregivers are not regarded most of the time. Caring for these mentally disabled children can be one of the most stressful engagements. The stress and anxiety these caregivers go through could affect the manner in which they administer medication to their wards. They could give an overdose with the intent to eliminate the condition quickly or an underdose due to negligence and this practice only worsens the mental condition of the children.

There could be an association between the psychological burden of caregivers and reported medication adherence in caring for mentally disabled children. In Ghana just like other developing countries, little is known about the psychological burden of the caregivers of children and education adherence is affected in these children. This study therefore sought to investigate the psychological burden of caring for mentally disabled children and whether or not it has an implication on their medication adherence.

1.2 Objectives of the Study

1.2.1 General Objective

To assess depression, anxiety and stress levels of caregivers of children with mental disabilities and its implication on medication adherence.

1.2.2 Specific Objectives

1. To assess the level of depression, anxiety and stress of the caregivers

2. To assess the association between socio-demographic characteristics and caregiver burden

3. To assess level of caregivers reported-medication adherence in children with mental disabilities.

4. To measure the association between depression, anxiety and stress of caregivers and medication adherence.

1.3 Research Questions

1. What are the levels of stress, anxiety and depression of the caregivers?

2.What is the association between socio-demographic characteristics and caregiver burden?

3. What is the level of caregivers reported-medication adherence in children with mental disabilities?

4.What is the association between depression, anxiety and stress and medication adherence?

1.4 Significance of the Study

Though Ghana successfully passed a Mental Health Act in March 2012, the psychological burden of caregivers is still a major challenge. In taking care of children and adolescents with mental disabilities in Ghana, there is few data on the caregivers' psychological burden in relation to reported medication adherence in children and adolescents. This study seeks to investigate how psychological burden of caregivers influence reported medication adherence in mentally disabled children and adolescents.

Mental health is an essential part of the health of the children and adolescents. A good state of mental health contributes to a healthy growth. Good policies and counseling tips concerning this matter can be formulated to support both the caregivers and the mentally disabled children. The gap in knowledge in regard to psychological burden and reported medication adherence in caring for mentally disabled children will be addressed.

1.5 Conceptual Framework

Conceptual framework of psychological burden and reported medication adherence issues in caring for children and adolescents with mental disabilities in Ghana.

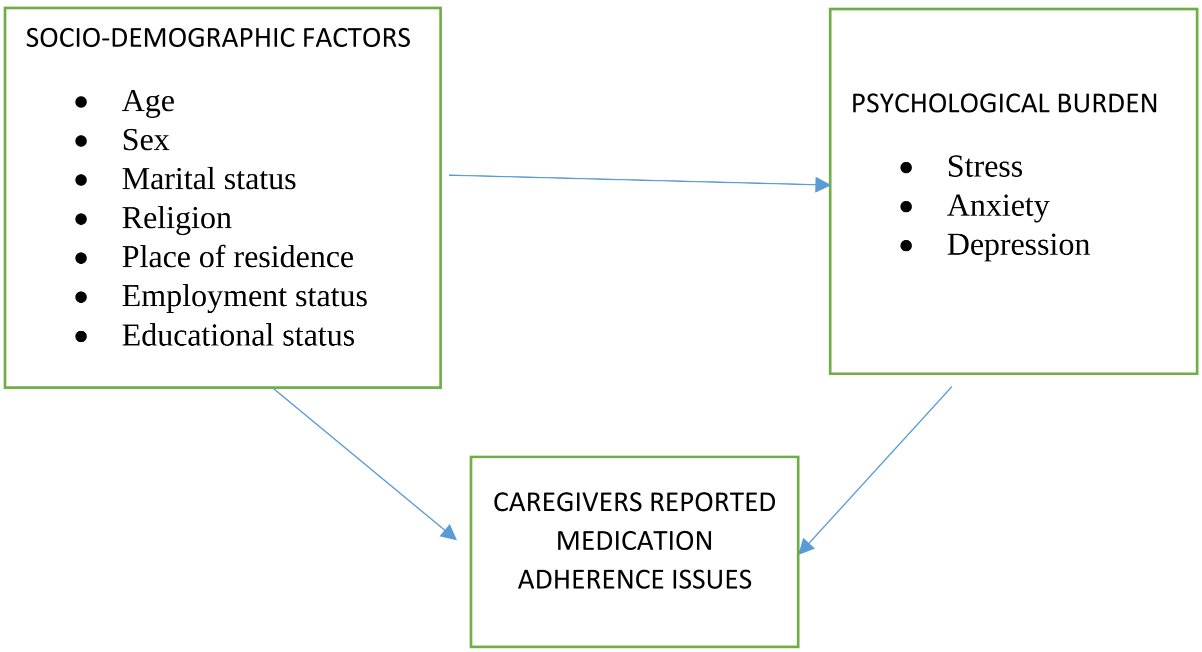

Figure 1: Conceptual Framework

There are several factors that contribute to psychological burden including socio- demographic factors such as age, sex, marital status, religion, employment status and educational status. Older people are more burdened than younger ones when assisting mentally disabled children (Janardhana et al., 2015). Some studies have shown that women also suffer a great deal when it comes to taking care of children with such abilities (Sharma, Chakrabarti, & Grover, 2016) . One's occupation can also have effect on psychological burden because tight schedules at work can affect one's responsibility in taking care of a mentally disabled child leading to more stress.

Those with lower educational qualifications may have a problems with medication administration as a result of fear of side effects as it is even a challenge for the educated ones (Jimmy & Jose, 2011). Other specific factors include stress, anxiety and depression. Stress, anxiety as well as depression builds up when caring for these children and this may affect the way they administer medication to their mentally disabled wards. A study indicated that medication adherence in mentally disabled wards may be improved by managing the stress, anxiety and depression they experience (Smith et al., 2017).

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This section is a review of literature in line with the objectives of this study. This chapter is an elaboration of the concept, causes and types of mental disabilities in children and adolescents. This chapter also captured psychological burden of caregivers as well as reported medication adherence in caring for children and adolescents with mental disabilities.

2.1 Concept of Mental Disabilities in Children and Adolescents

Mental health issues are one of the challenges that affect children. Developmental disorders, mental and behavioral disorders are detected in early childhood (Bitsko et al., 2016)**.** Mental disabilities in children and adolescents is made evident in the way they act, study and manage their emotions which causes distress. In most cases, children with mental disability challenges tend to have low educational achievements due their retarded cognitive growth. Attention-deficit/hyperactivity disorder (ADHD), anxiety, and behavior disorders are among the common mental illnesses in children and adolescents (CDC, 2018). As children are not too developed, the intensity of their malfunctioning cognitive growth is very much prominent and some children are not able to pull through with this disability. It has been speculated that if measures are not put in place to address the increase in mental disability especially with suicide in children and adolescents, in the next decade, it will account for more deaths(Wasserman, Cheng, & Jiang, 2005).

In the United States, most children with depression have anxiety and behavioral problems: about three in four children between the ages of 3-17 years having depression also experience anxiety (73.8%) and almost one in two have behavioural disorders (47.2%) (Ghandour et al., 2018). This statistic shows that mental disorders do not occur in isolation as mental conditions commonly occur together.

The situation is particularly alarming in developing countries. In Africa, it is documented that about 20% of children have mental disabilities (Belfer, 2008). In Ghana, with the 21.6 million people residing in the country, about 650,000 have been diagnosed with severe mental disorder and 2,166, 000 suffer from moderate to mild mental disorder (WHO, 2010).

The situation may differ a little in the developed countries as they have better measures put in place to address the situation of mental disability in both children and the adults (Remschmidt & Belfer, 2005). In order to aid in the early diagnoses of a mentally disabled child, there is the need for thorough medical, mental health and developmental assessment. Sufficient information can be collected from caregivers, the health facilities they attend and also from their educational facilities to help make informed decisions.

2.2 Types of Mental Disabilities in Children and Adolescents

According to Elia (2017), as many as 20% of children and adolescents worldwide have one or more diagnosable mental disorders. Mental disabilities in children include depression, attention deficit hyperactivity disorder (ADHD), anxiety disorders, separation disorder and autism. Those in their adolescent stages experience bipolar disorders, eating disorders with just a few experiencing schizophrenias. Depression and anxiety are easily identified in females whilst attention deficit hyperactivity disorder and autism are more easily identified in males (Skogli, Teicher, Andersen, Hovik, & Øie, 2013).

Hyperactivity disorder can be defined as a neurodevelopmental inability that affects the brain. It is a serious mental disorder. It is characterized by difficulty in controlling the behavior and children find it difficult to pay attention to situations. Children with this kind of disorder find it very difficult to interact normally with their peers. They are unable to perform well academically (Loe & Feldman, 2007).

Anxiety disorder in children is also another form of mental disorder. It presents with high levels of fear and nervousness. Mostly this type of mental disorder is evident in adolescents who have had a family history of mental disorder, have poor family financial states or experienced abusive upbringing (Behere, Basnet, & Campbell, 2017).

Depression is characterized by low mood and lack of excitement about situations. Depression can lead to suicidal thoughts in most adolescents (Galaif, Sussman, Newcomb, & Locke, 2007).Some children experience a form of anxiety disorder known as the separation anxiety disorder. Separation anxiety disorder is experienced when the children are separated from their homes or their parenting figures. It can affect the mental development of the children as their parental figures are absent from their lives. They do not get people who will coach them through their development.

Dipolar disorder is sometimes termed as maniac depression. Adolescents who experience this form of mental disorder have elevated forms of mood. Some people excessively happy, some irritated in an unusual way. Some adolescents who experience this disorder are unable to sleep well and some conceive the thought of committing suicide.

Autism is a form of mental disability that is evident in the early stages of the development of the children. Autism affects one in fifty-nine children across the world. In India a study showed that Autism Spectrum Disorder is increasing just like in the developing countries (Divan et.al., 2012).

Children with this form of disorder also experience seizures, disturbances in their sleep pattern as well as difficulty in eating.

Schizophrenia which is rare but occurs in some adolescents too. Schizophrenia affects how the adolescent behaves, feels and acts. They do not behave normally as it seems they have lost contact with normal life. However, this form of mental disorder is prominent among adults. Unfortunately, these conditions remain underdiagnosed and undertreated (WHO, 2018).

There are the biological, psychological and environmental factors that affect their development (Halpern & Figueiras, 2004). The biological factors come into play when there is an increase in activity in one part of the brain, unusual levels of neurotransmitters. There could be decreased size of the brain too in children and adolescents with mental disabilities. Risk factors considered as psychological result in low self-esteem and dealing with negative thoughts. Environmental factors are interlinked with psychological factors. Premature birth, high burden of disease, being born from a problematic pregnancy, conflicts in the house and disruptions and living in poverty result in the development of mental disabilities in children and adolescents (Larson, 2007).

Children with mental disabled parents stand a higher chance of getting mental disorder (Mattejat & Remschmidt, 2008). This known challenge must have factored in the practical provision of health care.

2.3 Caregiving in Children and Adolescents with Mental Disabilities

Every parent desires to have a child as in most societies it is deemed as a sign of success. They are seen as a couple's epitome of care and love. When children are born with any form of disability, their parents come to the realization that their ward is not a normal child, different from what they had anticipated. This is accompanied with a feeling of blame, despair, anger and frustration (Chandramuki et.al., 2012). Parents of wards with disabilities tend to blame themselves for the disabilities and mostly have a sense of guilt. Narrowing it to the Ghanaian setting, caring for these children can be mindboggling and stressful.

Attitudes of parents towards children with disabilities was investigated with a research aimed at investigating parents' attitude and views on related to students with special needs in a regular school(Elkins, van Kraayenoord, & Jobling, 2003). A total of 354 parents responded to the questionnaire used with the survey method. After analysis it was deduced that caregivers showed positive attitude towards the inclusion of their wards into mainstream. They were elated their wards were treated just like any other ward. Another study assessed the factors that determine caregivers' views in providing care for relatives with mental disability (Mbwilo, Smide, & Aarts, 2010). Qualitative method was used and the study analysed using the thematic content analysis. The study found that family traits, health care resources and inadequate knowledge about the mental disability were found to be associated with caring for children and adolescents with mental disabilities. Effects of the presence of mental disability in the family brought certain challenges associated with discriminations and interpersonal relationships problems. In conclusion the study stated that lack of knowledge of the disability and the lack of social support affected the perception of family members with children and adolescents with mental disability.

An investigation by Chandramuki, Shastry and Vranda (2012) investigated caregiver's dispositions towards wards with explicit learning incapacities. The investigation test contained guardians of 60 kids with Specific Learning Disability (SLD). The mentalities of guardians were surveyed utilizing the Parental Attitude Scale. Results demonstrated contrasts in parental recognitions identified with the sex of their kids. Besides, guardians experienced more tension, blame, weakness, passionate shakiness, self-centeredness and sadness when the child is male.

There is therefore the need for adequate understanding and education on how to handle these children. It is important to comprehend the experiences and the challenges these caregivers go through examining their state so that better measures can be put be in place to manage the situation (Reinhard, Given, Petlick, & Bemis, 2008). Re-examining the conditions present will help to better understand the situation and what conditions need to be improved and made better.

Social workers and health workers need to play a crucial role in the wellbeing of these children. A joint collaboration between the social workers and the parents is very essential to help in monitoring the condition as well as easing the burden on the caregivers (Akbari, Alavi, Irajpour, & Maghsoudi, 2018b)

2.4 Psychological Burden in Caring for Children and Adolescents with Mental Disabilities

Burden refers to the untoward effect of the clients disabilities on the person who cares for the them daily (Shamsaei, Cheraghi, & Bashirian, 2015). Out of every four families sampled, one member is currently suffering from a mental or behavioral disorder. Family members are vulnerable to the stigma and discrimination associated with mental ill health in addition to the obvious distress of seeing a loved-one having a mental disability.

A developing assortment of research proposes that essential parental figures of kids with formative handicap endure poor mental wellbeing. Essential guardians of formatively handicapped wards, encounter altogether larger amounts of negative effect, insignificantly poorer mental prosperity, and fundamentally increasingly physical indications(Smith et al., 2010).

This suggests that primary caregivers of developmentally disabled children experience relatively poorer psychological wellbeing than individuals who are not primary caregivers of developmentally disabled children. It has been found that there is a relation between stigma as a result of caring for mental disabled individuals and the psychological wellbeing of their caregivers (Mak & Kwok, 2010)

The proportion of caregivers stress globally is greater in the developing countries. In Ghana and other African countries, the onus lies on the family members or the church in assisting people with such mental disabilities (Ae-Ngibise, Doku, Asante, & Owusu-Agyei, 2015)

In the Ghanaian setting, defamation might be unavoidable for essential parental figures of a developmentally disabled children and adolescents. This is on the grounds that mental disabled individual is by and large viewed as an unthinkable or an illegal impact on an individual and his family (Hodkinson, 2011). Mill operator and Kaiser (2001) supported the argument that understanding the impact of disgrace that is the stigma in this case, offers space to investigate its effect on mental wellbeing of their caregivers.

A subjective investigation of Ghanaian groups of individuals with inabilities was done by Anum (2011). This investigation investigated the encounters of Ghanaian families with a handicapped kid. Utilizing subjective systems, that includes, semi-organized meetings, member perception and account investigation, and the specialist investigated encounters of four families with handicapped children in the Dangme West District. The examination's discoveries demonstrated that groups of impaired children and adolescents encounter disgrace, strain on family connections and need institutional help in all probability since they encounter shame. One clarification that was given to why families, particularly the mothers who are the essential parental figures, felt derided was the social clarifications of incapacity in the Ghanaian setting. This impression of shame was additionally found as one of the reasons for the strains in intra-family and between family connections.

There are physical, emotional, financial difficulties that caregivers of clients face which impact the quality of life of the caregivers. Caregivers aside their normal household work and professional work have to engage in extra duties as a result of the mental disabilities (Macedo, da Silva, Paiva, & Ramos, 2015). This sometimes tends to distort the relationship between the parents and their wards.

There have been several studies conducted to analysis the psychological stress of caregivers in children with mental disabilities. A few others have been conducted in Kenya and some few other countries.

In Malawi, studies in the psychological burden of caregivers of mental disabled children was conducted. From the studies, there was 41% level of psychological stress among caregivers of children with mental disabilities (Masulani-Mwale, Kauye, Gladstone, & Mathanga, 2018).

2.5 Concept of Caregivers Reported Medication Adherence among Children and Adolescents with Mental Disabilities

Nonadherence to psychiatric medication is a global problem (Semahegn et al., 2018). Studies were carried out by reviewing literature on medication compliance. The prevalence of non-compliance was between 13.2% to 64%. More studies have been carried out in children than in adults in this regard (Adler et al., 2010).

In dealing with these patients, psychotropic drugs are for the most part utilized. Since the vast majority of these conditions are perpetual cases, the prescriptions are expended for delayed timeframes. Be that as it may, there exists a nonattendance of data on adequacy, symptoms, availability and medicine practices of psychotropic drug usage from the perspective of the specialists who are principally engaged with prescribing, dispensing and administering these medications of outpatients with mental disorders (Chapman & Horne, 2013).

Ongoing exploration has featured non-adherence as a key problem to mental health care in South America, Asia, Europe, Australia, North America, the Middle East and Africa. In Africa, Alene et al. assessed adherence rates to antipsychotic drug in patients accepting consideration at an Ethiopian medical clinic. They found that, while 52.1% detailed that they had never missed a portion or gone outdoors the time taught, just 19.6% were completely adherent when surveyed utilizing drug store refill records, representing that non-adherence can be underrated in this setting, comparatively to inconsistencies that appeared in different settings, for instance in a South Korean. Significant concern has been raised about improper recommending of psychotropic medications given to children and adolescents. Be that as it may, these reactions have been essentially founded on narrative reports, investigations of little unrepresentative clinical examples, and auxiliary examinations of extensive databases on physician endorsed medication utilize that need itemized clinical data about individual patients. In spite of the fact that there has been an alarming increment in medicines for psychotropic prescriptions in youth over the previous decade, there is an absence of observational information on examples of drug use among youth with explicit mental disarranges. Without precise clinical appraisals, it is beyond the realm of imagination to expect to assess connections between network psychotropic recommending rehearses and mental disorders(Merikangas, He, Rapoport, Vitiello, & Olfson, 2013b).

Past reports taking drugs treatment patterns among youth with explicit issue in community samples of specific areas of the United States have created generally variable rates of prescription use for attention-deficit/hyperactivity issue (ADHD) (eg, 7.0%-72.2%) and depression (7.4%-31.0%) basically as a result of methodologic and test contrasts. In any case, as far as anyone is concerned, no past investigation has inspected examples of explicit classes of psychotropic medicine use among youth over the full scope of basic mental issue and administration areas in an enormous sample of young people(Merikangas, He, Rapoport, Vitiello, & Olfson, 2013a)

In the United States, the proportion of ADHD increased from 3% to 5% to around 12%. In the United State of America, the prevalence of non-adherence to medication was very high. The reasons given in one study conducted for non-adherence to ADHD medications were as follows suboptimal effect (14.6%), ‘own wish/ don’t need (19.9%), withdrew consent (16.2%), adverse effects (15.1%).

Factors that influenced medication adherence include the stability level in the family, caregivers knowledge of the wards condition and the levels of undesirable effects (Chadda, 2014) . According to American Psychological Association (APA), mental illness in children can be managed using good medicines, good counselling and education concerning the disease and psychotherapy can also be used(“Overcoming Depression: How Psychologists Help With Depressive Disorders,” n.d.). This supports the need to ensure medication adherence in children and adolescents with mental disabilities.

2.6 Conclusion

In conclusion, psychological burden affects caregivers in diverse ways. Administration of medication in children can be very challenging for the caregivers. Unfortunately, there is little is known about the relationship between psychological burden and reported medication adherence in caring for children with mental disabilities in Ghana. This study therefore identifies the challenges these caregivers go through and their problem with drug administration to these children.

CHAPTER THREE

METHODS

3.0 Introduction

In this chapter, the methods and procedures used in order to achieve the objectives of the study are explained.

3.1 Study Design

The study was a cross-sectional quantitative study. It was a hospital-based study.

3.2 Study Area

The study was undertaken in Accra and in the Central Region. The hospitals were the Ankaful Psychiatric Hospital in Cape Coast, Central Region, Accra Psychiatric Hospital and the Pantang Psychiatric Hospital. Both the Accra and Pantang Psychiatric Hospitals are in Greater Accra Region.

The Ankaful psychiatric hospital was established in 1965. It was established by the late President of Ghana, Dr. Kwame Nkrumah. It is located in Ankaful, a suburb of the Central Region. The hospital has eleven (11) wards but at the moment only 7 are in operation. It serves both as a psychiatric hospital and a general hospital. It serves not only the people in the Central Region but those in the Western Region as well as those in the Greater Accra Region.

The Pantang Psychiatric Hospital is also one of the largest psychiatric hospitals in Ghana. It is located in the Greater Accra Region. Work started officially in 1965. The hospital serves all the regions in Ghana. It has about 500 bed capacity. The hospital has about 28 departments. Cases mostly reported to the hospital include schizophrenia, depression, substance abuse and epilepsy.

The Accra Psychiatric Hospital is located at Adabraka in the Greater Accra Region and it was commissioned in 1906. It has about 600 bed capacity. The facility not only serves the people in Ghana but all the people in the neighbouring countries which include Togo, Burkina Faso and Ivory Coast.

These three psychiatric facilities serve all the regions in Ghana and collecting data from all three facilities will give a good data of the psychiatric condition in Ghana.

3.3 Variables

- Independent
  - caregivers stress, anxiety and depression (parenting stress index)
  - clinical factors- disorder type, duration of illness, past hospitalisations
  - socio-demographic- child age and sex, caregiver age, sex, education, employment status, health insurance coverage
  - caregiving characteristics- Time spent caregiving, caregiving assistance

- Dependent- caregivers reported medication adherence

3.4 Study Population

This study concentrates on caregivers of children with mental disabilities who report at the outpatient department of all three study sites.

Inclusion criteria: Caregivers of children with mental disabilities who visit the OPD of the three named psychiatric hospitals during the time of study. Caregivers to be included may or may not report with their wards at the time of study.

Exclusion criteria: Caregivers of children with mental disabilities who are inpatients will be excluded. Again, caregivers who are not primary caregivers of the wards will be excluded.

3.5 Sample Size Determination

- The sample size estimation was based on the idea of Cochran (1963:75)

- n $= \frac{\left(Z_{\frac{\alpha}{2}}\right)2\, p(1-p\,)}{e^2}$

- Where n is the minimum required sample size
- Z= can be obtained from the table.
- P is the estimated proportion of children and adolescents with mental disorders that is present in the population which is 14.3% based on a meta-analysis on studies in Sub-saharan Africa was used as the countries share similar characteristics with Ghana (Cortina, Sodha, Fazel, & Ramchandani, 2012)
- For 95% confidence interval, Z (∝/2) is 1.96 and the level of precision "e" (margin error for the study was 5%). A minimum sample size

  $$n= \frac{1.96^2 \times 0.143 \times 0.857}{0.05^2} = 188.3 \approx 189$$

- Plus 10% of 189= 18.9=19 (non-respondent) 18.9=19
- Minimum sample size= 208

Number of mental disabled children seen at Accra Psychiatric Hospital in 2018………….1317

Number of mental disabled children seen at the Pantang Psychiatric Hospital in 2018…….118

Number of mental disabled children seen at the Ankaful Psychiatric Hospital in 2018……745

Total= 2180 (from all facilities)

The assumption is that each child has one caregiver, the sample size of the caregivers from each facility were calculated as follows

$$\frac{\textit{Number of caregivers of children with mental disabilities at hospiital A}}{\textit{Number of caregivers of children with mental disabilities at hospital A+B+C}} \times 208$$

A- Number of caregivers at Accra Psychiatric hospital (1317)

B- Number of caregivers at Pantang Psychiatric hospital (118)

C- Number of caregivers at Ankaful Psychiatric hospital (745)

For Accra psychiatric hospital, sample size was $\frac{1317}{2180} \times 208 = 125$

For Pantang psychiatric hospital, sample size was $\frac{118}{2180} \times 208 = 12$

For Ankaful psychiatric hospital, sample size was $\frac{745}{2180} \times 208 = 71$

3.6 Sampling Technique

This study used the proportionate sampling method. The total attendance for the year 2018 was obtained from the three psychiatric hospitals. The number of caregivers from each facility was obtained as a fraction of the total attendance at the three psychiatric hospitals multiplied by the total sample size. The total sample size of the study was 208.

For the purpose of this study, caregivers were identified as people who are primary caregivers of the children and adolescents. The folders of the mentally disabled children and adolescents who visit these psychiatric hospitals on an out-patient basis was obtained. Their respective caregivers were interviewed in order to identify them as the main caregivers or otherwise. The main caregiver refers an individual who does not get paid for caring for a mentally disabled ward and has lived with this ward for over one year assisting him or her. Those who were identified as the main caregivers were interviewed in order to get the sample size for the study.

3.7 Data Collection Tool

A structured questionnaire was used to collect data for this research. The questionnaire had sections with questions on the demography of the caregivers, a tool to measure anxiety, depression and stress associated with caring for mentally disabled wards and finally questions on medication adherence.

3.7.1 Questionnaire Items

3.7.1.1 The Beck Anxiety Inventory (BAI)

The BAI made by Aaron T. Beck and partners, is a 21-question numerous decision self-report stock that is utilized for estimating the seriousness of nervousness in children and grown-ups (Leyfer, Ruberg, & Woodruff-Borden, 2006) The tools measure uneasiness of participants within the previous week targeting symptoms such as deadness and shivering, perspiring not because of warmth, and dread of the most exceedingly awful occurring. The 21 questions are each scored on a scale of 0 (not at all) to 3 (severely). Higher absolute scores show progressively serious uneasiness more severe anxiety symptoms. The scores are categorized as 0–9 for normal to minimal anxiety, 10–18 for mild to moderate anxiety, 19–29 for moderate to severe anxiety and 30–63 for severe anxiety.

3.7.1.2 The Beck Depression Inventory (BDI)

The Beck Depression Inventory (BDI), developed by Aaron T. Beck, is a 21-question multiple-choice self-report inventory, one of the most widely used psychometric tests for measuring the severity of depression. It consists of items relating to symptoms of depression such as cognitions such as guilt or feelings of being punished, hopelessness and irritability, as well as physical symptoms such as weight loss, fatigue, and lack of interest in sex. Each question has four options to choose from. For example:

0. I am not particularly discouraged about the future

1. I feel discouraged about the future

2. I feel I have nothing to look forward to.

3. I feel the future is hopeless and that things cannot improve.

The scores are categorized as 1-10 for these ups and downs are considered normal, 11-16 for mild mood disturbance, 17-20 for borderline clinical depression, 21-30 for moderate depression, 31-40 for severe depression and over 40 for extreme depression.

3.7.1.3 Parental Stress Scale

Parental Stress Scale is an 18 – item self-report scale developed by Berry and Jones (1995) as a substitute to the 101-item Parenting Stress Index representing positive (e.g. emotional benefits, personal development) and negative (demands on resources, restrictions) themes of parenthood. Respondents agree or disagree in terms of their typical relationship with their child or children. It comprises a 5 – Point scale; strongly disagree, disagree, undecided, agree, and strongly agree. This tool measures changes in parental stress levels of parents/carers and it is aimed at enhancing parenting abilities. A low score signifies a low level of stress and a high score will signify a high level of stress. The scores on the scale range from 18 to 90. Higher scores will signify higher measured level of parental stress.

3.7.1.4 Medication Adherence Report Scale (Mars-5)

The MARS-5 measures self-reported adherence to medicines, it assesses both intentional and unintentional non-adherence. The original MARS, developed by Horne, measures the frequency of non-adherent behaviors and it has two translations relating to the period covered that is either general overview of adherence and specific adherence over the last month. However, the latter was used in this study. Reported medication adherence was measured with the modified version of MARS-5 which allows caregivers report on how they administer medications to their wards (Kretchy et al., 2018). The MARS consist of 5-items and a Likert scale of five points measures each item. Participants respond to each item in the scale with 5=always, 4=often, 3=sometimes, 2=rarely and 1=never. Scores are summed, and totals range from 5 to 25, with higher scores indicating higher caregivers reported adherence.

3.8 Data Quality Control

Research assistants with knowledge on mental health in children were engaged and trained. The training was to ensure that they understood the subject matter to better explain the questionnaire to the participants. They were also trained to respect the privacy of the participants. The data collected from both the pilot study and the main study were double checked to ensure accuracy in analysis.

3.9 Pilot Study

The purpose of the pilot study was to help the researcher correct all deficiencies and make amends before the actual data collection. It also gave the researcher assurance that the questionnaire is well understood. Three research assistants employed for the research were trained to acquire enough knowledge on the research topic. Research assistants engaged were those who could read and write English and also fluent in the local dialects (Ga, Fante and Ewe). They were trained in accordance with ethical guidelines concerning the study.

During the process of the training, the research assistants were given the opportunity to administer questionnaires at the pre-testing phase. Before the final administration of the questionnaire to the study population, the questionnaire was pre-tested on main caregivers who accompany children and adolescents with mental disabilities to the OPD of Accra Psychiatric Hospital.

3.10 Data Entry and Analysis

Data were entered into Microsoft excel. It was analyzed using the SPSS. The data collected was categorized, summarized and presented using simple descriptive statistics such as mean. Chi-square was used to establish association between categorical variable such as age, gender and reported medication adherence. Multivariate multiple regression analysis was also used where necessary.

3.11 Ethical Approval

Ethical clearance was sought from the The Ghana Health Service Ethical review committee.

Introductory letters were served at to all three study sites and each respondent prior to participating in the study was required to give consent by signing a consent form. There were interpreters who explained vividly in the local dialects to the caregivers who did not have formal education They were served with an introductory letter from the Department of Social and Behavioural Science of the School of Public Health. All necessary and sufficient information about the study were laid bare to participants to enable them to make informed judgment about their participation in the study.

No participant was coerced, intimidated or induced financially to participate in the study. They were informed that the data collected from them were going to be held confidential and it was meant for academic purposes.

CHAPTER FOUR

RESULTS

4.0 Introduction

This chapter presents the results of the finding.

4.1 Socio-demographic characteristics of caregivers

The number of caregivers of children and adolescents involved in the study were 210. About 66.7% (140) were females. About 71.9% (151) were single parents representing majority of the respondents and 53.3% (112) resided far from the hospital's premises. For employment status, the majority of the caregivers worked in the public sector 38.1% (80) and about 12.9% (27) were unemployed. About 11.9% (25) of caregivers had no level of education while majority had attained tertiary education 51.4% (108).

Table 1: Socio-demographic characteristics of caregivers

Variables	Frequency	Percentage
Sex		
Male	70	33.3
Female	140	66.7
Age		
20-29	71	33.8
30-39	82	39.0
40-49	39	18.6
>50	18	8.6
Marital status		
Married	42	20.0
Single	151	71.9
Divorced	11	5.2
Widow/widower	5	2.4
Missing	1	.5
Place of residence (Perceived distance)		
Closer to the facility	95	45.2
Far from the facility	112	53.3
Missing	3	1.4
Religion		
Christian	154	73.3
Muslim	47	22.4
Traditionalist	2	1.0
Missing	7	3.3
Highest level of education		
No education	25	11.9
Primary education	22	10.5
Junior level	13	6.2
Secondary level SHS	19	9.0
Secondary level (technical)	11	5.2
Secondary level (vocational)	7	3.3
Tertiary graduate/post graduate	20	9.5
Tertiary cert/diploma/post diploma	88	41.9
Missing	5	2.4
Employment status		
Self-employed	44	21.0
Private sector	12	5.7
Public sector	80	38.1
Unemployed	27	12.9
Student/apprentice	43	20.5
Missing	4	1.9

4.2 Anxiety, depression, stress and reported medication adherence levels of caregivers

Many caregivers 40% reported having moderate to severe forms of anxiety, 35% reported having severe anxiety followed by 21% of them reporting mild to moderate forms of anxiety and 5% reporting normal to minimal forms of anxiety.

There were about 36.95% of the caregivers who experienced extreme depression, 25.62% having severe depression, 13.79% had moderate depression, 4.43% had borderline clinical depression, 7.88% had mild mood disturbance and 11.33% had normal form of depression.

Most caregivers 60.2% had mild to moderate stress, 30.1% had moderate to severe stress, 0.5% having severe stress and 9.2% normal to minimal stress.

A large section of the caregivers, 89.5% were non-adherent whilst 10.5% were very adherent in administering medications to their wards.

Table 2: Anxiety, depression, stress and reported medication adherence levels of caregivers

Variables	Frequency	Percentage
Anxiety		
Normal to minimal	10	4.78
Mild to moderate	43	20.57
Moderate to severe	83	39.71
Severe	73	34.93
Depression		
Normal	23	11.33
Mild mood disturbance	16	7.88
Borderline clinical depression	9	4.43
Moderate depression	28	13.79
Severe depression	52	25.62
Extreme depression	75	36.95
Stress		
Normal to minimal	19	9.22
Mild to moderate	124	60.19
Moderate to severe	62	30.1
Severe	1	0.49
Medication Adherence		
Non-adherence	188	89.5
Adherence	22	10.5

4.3 Association between socio-demographic and anxiety

Anxiety level was statistically associated with the following socio-demographic factors: educational level and employment status ($p<0.05$)

Table 3: Association between socio-demographic and anxiety

	Anxiety level					
	1	2	3	4		
variables	**n(%)**	**n(%)**	**n(%)**	**n(%)**	**Chi-square**	**P-value**
Gender					3.03	0.387
Male	3(4.29)	19(27.14)	27(38.57)	21(30)		
Female	7(5.04)	24(17.27)	56(40.29)	52(37.41)		
Age group					11.97	0.215
20-29	1(1.41)	13(18.31)	30(42.25)	27(38.03)		
30-39	5(6.58)	16(21.05)	28(36.84)	27(35.53)		
40-49	2(5.13)	6(15.38)	20(51.28)	11(28.21)		
>50	2(11.11)	7(38.89)	3(16.67)	6(33.33)		
Education					32	0.001
No education	0(0)	4(16)	8(32)	13(52)		
Primary education	2(9.09)	5(22.73)	8(36.36)	7(31.82)		
Junior level	3(23.08)	2(15.38)	5(38.46)	3(23.08)		
Secondary level	3(8.11)	15(40.54)	14(37.84)	5(13.51)		
Tertiary level	2(1.87)	16(14.95)	46(42.99)	43(40.19)		
Marital status					13.35	0.147
Married	3(7.32)	11(26.83)	11(26.83)	16(39.02)		
Single	7(4.64)	25(16.56)	64(42.38)	55(36.42)		
Divorced	0(0)	4(36.36)	5(45.45)	2(18.18)		
Widow/widower	0(0)	3(60)	2(40)	0(0)		
Place of residence (perceived distance)					4.34	0.227
Closer to the facility	3(3.19)	15(15.96)	37(39.36)	39(41.49)		
Far from the facility	6(5.36)	28(25)	44(39.29)	34(30.36)		
Religion					6.12	0.106
Christian	10(6.54)	33(21.57)	56(36.6)	54(35.29)		
Muslim	0(0)	7(14.29)	25(51.02)	17(34.69)		
Employment status					24.91	0.015
Self-employed	1(2.27)	8(18.18)	19(43.18)	16(36.36)		
Private sector	3(27.27)	3(27.27)	1(9.09)	4(36.36)		
Public sector	1(1.25)	16(20)	32(40)	31(38.75)		
Unemployed	0(0)	8(29.63)	11(40.74)	8(29.63)		
Student/apprentice	5(11.63)	7(16.28)	18(41.86)	13(30.23)		

4.4 Association between socio-demographic and depression

Table 4: Association between socio-demographic and depression

Depression level was statistically associated with the following socio-demographic factors: gender, employment status, age and marital status (p<0.05)

	Depression level							
	1	**2**	**3**	**4**	**5**	**6**		
variables	**n(%)**	**n(%)**	**n(%)**	**n(%)**	**n(%)**	**n(%)**	**Chi-square**	**P-value**
Gender							18.89	0.002
Male	10(15.15)	9(13.64)	4(6.06)	11(16.67)	21(31.82)	11(16.67)		
Female	13(9.49)	7(5.11)	5(3.65)	17(12.41)	31(22.63)	64(46.72)		
Age group							26.42	0.034
20-29	7(10.29)	5(7.35)	0(0)	9(13.24)	15(22.06)	32(47.06)		
30-39	12(16)	5(6.67)	4(5.33)	6(8)	23(30.67)	25(33.33)		
40-49	1(2.63)	4(10.53)	2(5.26)	10(26.32)	9(23.68)	12(31.58)		
>50	3(17.65)	2(11.76)	3(17.65)	1(5.88)	3(17.65)	5(29.41)		
Education							23.34	0.272
No education	0(0)	1(4)	1(4)	2(8)	9(36)	12(48)		
Primary	1(4.55)	2(9.09)	2(9.09)	3(13.64)	3(13.64)	11(50)		
Junior level	3(23.08)	0(0)	0(0)	1(7.69)	4(30.77)	5(38.46)		
Secondary level	3(8.82)	6(17.65)	3(8.82)	4(11.76)	6(17.65)	12(35.29)		
Tertiary level	16(15.38)	7(6.73)	3(2.88)	17(16.35)	27(25.96)	34(32.69)		
Marital status							36.84	0.001
Married	5(13.16)	5(13.16)	1(2.63)	5(13.16)	7(18.42)	15(39.47)		
Single	16(10.81)	10(6.76)	5(3.38)	18(12.16)	41(27.7)	58(39.19)		
Divorced	0(0)	1(9.09)	1(9.09)	5(45.45)	3(27.27)	1(9.09)		
Widow/widower	2(40)	0(0)	2(40)	0(0)	1(20)	0(0)		
Place of residence (perceived distance)							9.45	0.092
Closer to the facility	6(6.82)	5(5.68)	2(2.27)	15(17.05)	20(22.73)	40(45.45)		
Far from the facility	16(14.29)	11(9.82)	6(5.36)	13(11.61)	32(28.57)	34(30.36)		
Religion							5.97	0.31
Christian	21(14.09)	12(8.05)	5(3.36)	19(12.75)	36(24.16)	56(37.58)		
Muslim	1(2.13)	4(8.51)	2(4.26)	8(17.02)	15(31.91)	17(36.17)		
Employment status							40.49	0.004
Self-employed	1(2.27)	2(4.55)	5(11.36)	3(6.82)	15(34.09)	18(40.91)		
Private sector	2(20)	1(10)	0(0)	1(10)	2(20)	4(40)		
Public sector	10(12.66)	6(7.59)	3(3.8)	13(16.46)	21(26.58)	26(32.91)		
Unemployed	1(3.85)	2(7.69)	0(0)	2(7.69)	3(11.54)	18(69.23)		
Student/apprentice	9(22.5)	5(12.5)	0(0)	9(22.5)	10(25)	7(17.5)		

4.5 Association between socio-demographic and parental stress level

Stress level was statistically associated with marital status and employment status (p<0.05)

Table 5: Association between socio-demographic and parental stress level

	Stress level					
	1	2	3	4		
Variables	**n(%)**	**n(%)**	**n(%)**	**n(%)**	**Chi-square**	**P-value**
Gender					1.4	0.705
Male	7(10.29)	38(55.88)	23(33.82)	0(0)		
Female	12(8.7)	86(62.32)	39(28.26)	1(0.72)		
Age group					13	0.163
20-29	6(8.82)	44(64.71)	18(26.47)	0(0)		
30-39	7(9.09)	41(53.25)	29(37.66)	0(0)		
40-49	3(7.89)	28(73.68)	6(15.79)	1(2.63)		
>50	3(16.67)	8(44.44)	7(38.89)	0(0)		
Education					15.79	0.201
Low education	1(4)	17(68)	7(28)	0(0)		
Primary education	2(9.09)	11(50)	9(40.91)	0(0)		
Junior education	1(7.69)	7(53.85)	5(38.46)	0(0)		
Secondary education	1(2.78)	18(50)	16(44.44)	1(2.78)		
Tertiary education	14(13.33)	67(63.81)	24(22.86)	0(0)		
Marital status					23.16	0.006
Married	2(4.88)	25(60.98)	14(34.15)	0(0)		
Single	17(11.49)	90(60.81)	41(27.7)	0(0)		
Divorced	0(0)	7(63.64)	3(27.27)	1(9.09)		
widow/widower	0(0)	2(40)	3(60)	0(0)		
Place of residence (perceived distance)					4.21	0.24
Closer to the facility	9(9.78)	62(67.39)	21(22.83)	0(0)		
Far from the facility	10(9.01)	62(55.86)	38(34.23)	1(0.9)		
Religion					4.75	0.191
Christian	16(10.6)	88(58.28)	47(31.13)	0(0)		
Muslim	3(6.25)	32(66.67)	12(25)	1(2.08)		
Employment status					21.52	0.043
Self-employed	3(6.82)	25(56.82)	16(36.36)	0(0)		
Private sector	0(0)	7(58.33)	5(41.67)	0(0)		
Public sector	10(12.66)	52(65.82)	16(20.25)	1(1.27)		
Unemployed	0(0)	11(42.31)	15(57.69)	0(0)		
Student/apprentice	6(14.63)	27(65.85)	8(19.51)	0(0)		

4.6 Association between socio-demographic and medication adherence

The following socio-demographic factors: gender, age, education and marital status were statistically associated with medication adherence ($p<0.05$)

Table 6: Association between socio-demographic and medication adherence

	Medication adherence			
	0	**1**		
Variables	**n(%)**	**n(%)**	**Chi-square**	**P-value**
Gender			4.98	0.026
Male	58(82.86)	12(17.14)		
Female	130(92.86)	10(7.14)		
Age group			10.99	0.012
20-29	66(92.96)	5(7.04)		
30-39	69(89.61)	8(10.39)		
40-49	36(92.31)	3(7.69)		
>50	12(66.67)	6(33.33)		
Education			15.86	0.003
No education	24(96)	1(4)		
Primary education	18(81.82)	4(18.18)		
Junior education	12(92.31)	1(7.69)		
Secondary Education	27(72.97)	10(27.03)		
Tertiary Education	102(94.44)	6(5.56)		
Marital status			12.01	0.007
Married	35(83.33)	7(16.67)		
Single	141(93.38)	10(6.62)		
Divorced	8(72.73)	3(27.27)		
Widow/widower	3(60)	2(40)		
Place of residence (perceived distance)			3.44	0.064
Closer to the facility	89(93.68)	6(6.32)		
Far from the facility	96(85.71)	16(14.29)		
Religion			0.33	0.565
Christian	137(88.96)	17(11.04)		
Muslim	45(91.84)	4(8.16)		
Employment status			6.28	0.179
Self-employed	38(86.36)	6(13.64)		
Private sector	9(75)	3(25)		
Public sector	70(87.5)	10(12.5)		
Unemployed	26(96.3)	1(3.7)		
Student/apprentice	41(95.35)	2(4.65)		

4.7 Association among anxiety, depression, stress and medication adherence

Anxiety and depression were statistically significant (p<0.05) whilst stress was not statistically significant

Table 7: Association among anxiety, depression, stress and medication adherence

	Medication adherence			
	0	**1**		
Variables	**n(%)**	**n(%)**	**Chi-square**	**P-value**
Anxiety			14	0.003
Normal to minimal	6(60)	4(40)		
Mild to moderate	36(83.72)	7(16.28)		
Moderate to severe	75(90.36)	8(9.64)		
Severe	70(95.89)	3(4.11)		
Depression			16.28	0.006
Normal	20(86.96)	3(13.04)		
Mild mood disturbance	12(75)	4(25)		
Borderline clinical depression	6(66.67)	3(33.33)		
Moderate depression	24(85.71)	4(14.29)		
Severe depression	50(96.15)	2(3.85)		
Extreme depression	72(96)	3(4)		
Stress			1.79	0.617
Normal to minimal	18(94.74)	1(5.26)		
Mild to moderate	112(90.32)	12(9.68)		
Moderate to severe	53(85.48)	9(14.52)		
Severe	1(100)	0(0)		

4.8 Factors associated with medication adherence

The odds of medication adherence as a female is 0.63 or 63% decreased compared to males without adjusting for other socio-demographic factors. The odds of medication adherence in females is 0.76 lower than that of males when all other socio-demographic factors are adjusted for.

Table 8: Factors associated with medication adherence

	Unadjusted model		**Adjusted model**	
	UOR (95% CI)	**P-value**	**AOR (95% CI)**	**P-value**
Gender		0.03		0.034
Male	1.00 (reference)		1.00 (reference)	
Female	0.37 (0.15, 0.91)		0.24 (06, 0.89)	
Age		0.026		0.40
20-29	1.00 (reference)		1.00 (reference)	
30-39	1.53 (0.48, 4.92)		0.75 (0.14, 3.88)	
40-49	1.1 (0.25, 4.87)		0.16 (0.02, 1.55)	

>50	6.6 (1.73, 25.12)		0.75 (0.06, 10.32)	
Education		0.009		0.28
No education	1.00 (reference)		1.00 (reference)	
Primary education	5.33 (0.55, 51.88)		2.66 (0.18, 39.94)	
Junior education	2 (0.11, 34.82)		0.55 (0.02, 16.41)	
Secondary education	8.89 (1.06, 74.64)		5.55 (0.43, 71.23)	
Tertiary education	1.41 (0.16, 12.28)		0.95 (0.07, 12.25)	
Marital status		0.017		0.814
Married	1.00 (reference)		1.00 (reference)	
Single	0.35 (0.13, 1)		0.57 (0.1, 3.33)	
Divorced	1.88 (0.4, 8.88)		1.73 (0.15, 19.5)	
Widow/widower	3.33 (0.47, 23.77)		1.55 (0.04, 62.83)	
Residence(Perceived distance)		0.070		0.075
Closer to the facility	1.00 (reference)		1.00 (reference)	
Far from the facility	2.47 (0.93, 6.6)		4.23 (0.86, 20.75)	
Anxiety		0.011		0.294
Severe	1.00 (reference)		1.00 (reference)	
Normal to minimal	15.56 (2.8, 86.3)		15.15 (0.69, 333.38)	
Mild to moderate	4.54 (1.11, 18.6)		0.79 (0.12, 5.24)	
Moderate to severe	2.49 (0.63, 9.76)		1.42 (0.27, 7.43)	
Depression		0.024		0.485
Extreme depression	1.00 (reference)		1.00 (reference)	
Normal	3.6 (0.67, 19.22)		1.48 (0.12, 18.81)	
Mild mood depression	8 (1.59, 40.3)		4.05 (0.49, 33.43)	
Borderline clinical depression	12 (1.98, 72.89)		5.25 (0.31, 90.11)	
Moderate depression	4 (0.84, 19.16)		3.63 (0.48, 27.22)	
Severe depression	0.96 (0.15, 5.96)		0.78 (0.09, 6.53)	
Stress		0.448		0.742
Normal to minimal	1.00 (reference)		1.00 (reference)	
Mild to moderate	1.93 (0.24, 15.75)		1.06 (0.08, 14.57)	
Moderate to severe	3.06 (0.36, 25.83)		1.74 (0.13, 23.95)	

UOR: unadjusted odds ratio. AOR: adjusted odds ratio. CI: confidence interval

CHAPTER FIVE

DISCUSSION

This chapter throws more light on the findings of the study. The study was aimed at assessing the anxiety, depression, stress and reported medication adherence in caring for children and adolescents with mental disabilities in Ghana.

From the study, it was observed that the majority of the caregivers' experienced severe forms of anxiety, depression and moderate levels of stress. A greater proportion of the caregivers were females. Reported medication adherence was rather on the lower side.

5.1 Levels of anxiety, depression and stress of the caregivers.

5.1.1 Depression

From the study, it was discovered that the majority of the caregivers experienced moderate to severe forms of anxiety (74.64%) and moderate to severe forms of depression (62.57%) which is similar to a study in Pakistan which demonstrated that a high percentage of caregivers had high levels depression, anxiety or both (Azeem et al., 2013). Another study conducted in Kenya showed that 79% of caregivers had depression (Mbugua, Kuria, & Ndetei, 2011). Having a ward with mental disability frequently requires a reorientation and reexamination of family objectives, duties and connections and this can negatively impact on the emotions of the caregiver leading to depression or anxiety. These caregivers may experience nervousness, discouragement or both and a study observed that a greater percentage of caregivers were mothers and depressed (Olsson & Hwang, 2001). It is important to note that most caregivers are depressed about the condition of their wards because they are not assured of when their wards may get better. Their desire will be for their wards to get better, but they may not achieve that. These health concerns can also lead to poor sleeping patterns for the caregivers and this may also account for the symptoms of depression that caregivers experience (Castro et al., 2009).

5.1.2 Anxiety

A study conducted by Bitsika and Sharpley (2004) showed that almost half of the guardians were severely anxious. In an investigation done in Turkey, Firat et al. (2002) reported high rates of anxiety among caregivers with children with mental disabilities.

The significantly high levels of anxiety could be attributed to the fact that most parents were worried about their children's wellbeing (Akbari, Alavi, Irajpour, & Maghsoudi, 2018a) or concerned about the constant reminder of having a child with mental illness (Gallagher, Phillips, Oliver, & Carroll, 2008). Most caregivers find themselves anxious because their wards condition may get worse or their wards may not recover significantly. The caregivers who showed severe forms of anxiety were mostly those with low levels of education with some anxious caregivers also gainfully employed. For those who had low levels of education, their lack of knowledge of the mental condition, prescribed drugs and its importance could have resulted in that feeling. A previous study showed that the majority of caregivers with low educational background had more anxiety (Al-Farsi et al., 2016). This could be attributed to the fact that they did not have much knowledge of the condition and had little to no insight on what exactly the situation might be hence that feeling of anxiety. Again, being employed and having to combine it with the duty of caregiving can be tiring and cumbersome. This was the case of most caregivers with mentally disabled children. These high levels of anxiety in caregivers were recorded in this study which is similar to previous studies(Murphy, Christian, Caplin, & Young, 2007)

5.1.3 Stress

The stress levels among the majority of caregivers (60.19%) were rather on the moderate side. It is however an interesting finding as most studies on caregiving usually show high levels of stress. There are studies that showed high levels of stress among caregivers of children and adolescents with mental disabilities though this study did not show very high levels of stress. A study however also recorded even lower levels of psychological stress (41%) among caregivers of children with mental disabilities (Masulani-Mwale et al., 2018).

A probable reason for the significantly low level of stress could be that they may be stressed one way or the other but since it is their own wards involved, they may not see the stress associated with caring for their own children as burdensome according to Green (2007) hence the moderate level of stress recorded in this study. The caregivers may also be focused in doing their possible best just to ensure that their wards get better and recover.

5.2 Socio-demographic characteristics and caregiver burden (anxiety, depression and stress)

From literature, women were found to have high levels of stress, anxiety and depression compared to men when caring for children with mental disabilities (Souza et al., 2017). The females were seen to have more burden than the males. Those who were employed were found to have some high levels of anxiety as it is not easy combining work with taking care of sick relatives (Markey, 2015)

Most caregivers experienced one form of anxiety, depression or stress (Dada, Okewole, Ogun, & Bello-Mojeed, 2011). The level of depression was again more significant in the females as per literature. Females were found to be the majority among the caregivers and they put undue burden on themselves as they cater for their disabled wards. A study showed that older caregivers had more depression levels (Barros et al., 2017). In another study by Goodhead & McDonald (2007), younger caregivers were found to have higher levels of depression which is similar to this study. In this study, the younger aged caregivers had severe forms of depression. This could be attributed to the fact their young age made it difficult for them to have the maturity needed to manage the caregiving process. Married caregivers were found to have severe forms of depression which is similar to this current study which showed that married people had severe forms of depression (Mbugua et al., 2011). This can be due to lack of physical and emotional support from their spouses Those who were unemployed had severe forms of depression as this could be attributed to the lack of financial and emotional support in caring for their children. A study conducted in the tertiary psychiatric hospital of Singapore gave similar reasons as to why unemployed caregivers experience severe forms of depression (Chang et al., 2016).

Stress was seen in a small percentage of those who were divorced as well as those who were employed. Those who were divorced may have difficulty singlehandedly taking care of sick relatives or wards as combining caregiving task and working is not an easy responsibility (Thyen, Kuhlthau, & Perrin, 2004).

5.3 Level of caregivers' reported-medication adherence in children with mental disabilities.

Reported medication adherence among children with mental illness was low and this is similar to what is in literature (Semahegn et al., 2018). Generally, non-adherence rates are in the range of 30% and 60% with patients having challenging emotional well-being issues (Gearing & Mian, 2005). There is however less information on the adherence levels in caregivers of children and adolescents with mental disabilities in Ghana and the world at large.

The high levels of medication non-adherence is as a result of the fear of side effects associated with the medications taken (Bordenave-Gabriel, Giraud-Baro, De Beauchamp, Bougerol, & Calop, 2003). Most caregivers live with the notion that their wards will have issues with the continuous usage of the medication that is given to them. They therefore make changes in the doses when giving them medication for their conditions. The lack of sufficient knowledge on the medication given to the wards is also another reason for non-adherence (Robinson et al., 2002).

A study conducted also revealed the rate of non-adherence among adolescent out-patients with bipolar disorder, a form of mental disorder was 66% which was reported by their parents (Coletti, Leigh, Gallelli, & Kafantaris, 2006). Though the figure in literature is less than the 89.5% non-adherence from this study, the percentages are all on the higher side indicating that medication adherence is a problem in mental health issues in children and adolescents.

The results from the study showed that the younger caregivers could not adhere to the medication regimen. This was however not the case in another study as the older ones were found to have issues sticking to the medication regimen (Charach & Gajaria, 2008)

Those with lower levels of education also reported higher levels of non-adherence as they may not fully understand the importance of the medications (Velligan, Sajatovic, Hatch, Kramata, & Docherty, 2017). Those who are single also had high cases of non-adherence. This could be attributed to the fact that unmarried caregivers may have to carry out a lot of tasks and they may not have any helping hand which results in increase physiological burden (Raina, 2005) hence the high cases of non-adherence

5.4 Depression, anxiety and stress of caregivers and medication adherence.

Depression and anxiety affect medication adherence. This is because mothers are more under pressure to balance child care needs and household chores (Gupta, Mehrotra, & Mehrotra, 2012). The results of this study revealed that the high levels of depression and anxiety of the caregivers affected the administration of medication to their wards. Altering medication regimen in mentally disabled children and adolescent leads to worse disease outcomes (Parens & Johnston, 2010).

According to Chadda (2014), most issues of medication adherence are as a result of family instability. Family instabilities could result in tension in the household. This goes a long way to affect the quality of care rendered to the children with mental disabilities thus affecting medication adherence. Smith et al., (2010) conducted a study that confirmed that pyschologcal burden of caregivers go a long way to affect their quality of live and all other activities they engage in including ensuring adherence to medicines.

Depression and anxiety which mainly affect medication adherence can be properly handled in caregivers of children with mental disabilities.

5.5 Limitations of the study

1. The research too longer than anticipated due to issues of illiteracy and language as quite a number of the caregivers were uneducated.
2. Due to poor attendance to the psychiatric hospitals, getting the sample size for the research took a longer time than anticipated.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusion

The study sought to examine the association between psychological burden that is the stress, anxiety, depression of caregivers and medication adherence in children and adolescents with mental disabilities. The study showed that there were severe levels of anxiety, depression as well as moderate levels of stress which caregivers experience. The study showed that caregivers were unable to stick to the medication regimen of their wards as a result of these anxiety and depression that they experience.

6.2 Recommendations

Based on the results from this study the following recommendations have been made:

1. Health workers should show interest in the mental wellbeing of caregivers of children and adolescents with mental disabilities.
2. Other family members should come on board to aid primary caregivers cater for the wards with mental disabilities as a greater percentage of primary caregivers experience stress, anxiety and depression.
3. There should be recreational centers made for caregivers so that they can release some stress, depression and anxiety that comes with taking care of children with mental disability. These recreational centers can be built by the government by providing funds to the psychiatric hospitals.

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APPENDIX A: INFORMATION SHEET

Title of research: Psychological burden and reported medication adherence in caring for children and adolescents with mental disabilities in Ghana.

Introduction: I am Ocansey Patience Maame Egyimah a student offering Masters of Public Health programme with the Social and Behavioural Sciences Department, University of Ghana Legon. I am here together with my research assistants to conduct a survey on the topic "Psychological burden and reported medication adherence in caring for children and adolescents with mental disabilities in Ghana". This is a requirement for the award of Master of Public Health Degree. Telephone number: 0265787837. Email**:** pocansey583@gmail.com

Background: The purpose of the research is to determine the psychological burden and reported medication adherence in caring for children and adolescents with mental disabilities in Ghana.

Nature of research: In this survey, questionnaire on psychological burden and reported medication adherence in caring for children and adolescents with mental disabilities in Ghana will be provided. This research will help to measure the levels of stress, anxiety and depression among caregivers of children with mental disabilities and how it affects medication adherence.

Duration: Questionnaires will be used in the data collection process. The questionnaire will be administered to caregivers who have mental disabled wards who visit the hospital on out-patient basis. The duration for answering the questionnaire will not exceed an hour.

Potential risks: This study has no known risks and for any further clarifications I will be available. Incentives in the form of small chops will be given.

Benefits: The results from this study will help to bridge the gap in this aspect of study and it will also inform policy makers.

Costs: The cost involved in this research will be self-funded.

Compensation: The participants will be given small chops such as biscuits and drinks.

Confidentiality: No name will be recorded. Your name and personality are not required in the study. You are guaranteed of all out secrecy to the data you will give.

Voluntary participation: Participation in this study is voluntary. You are allowed to answer part or the whole survey. You can pull back from the study whenever you need. You can likewise decide not to answer any question(s) you find awkward about.

Outcome and Feedback: Aside from the researcher and supervisor of this study, nobody else will approach data gave whether to a limited extent or entirety. Information gathered will be put away carefully guarded at that point demolished following at least three years according to investigate convention.

Funding information: This project will be self-funded.

Sharing of participants Information/ Data: Discoveries and suggestions would be accessible at the School of Public Health and it will likewise be discussed various stakeholders at the end of the study.

A copy of the Information sheet and consent form will be given to you.

Do you have any questions you wish to ask about the study? Yes/No

If yes, kindly state below:

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

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

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

For further clarifications, kindly contact the individuals below

Ocansey Patience Maame Egyimah, School of Public Health, University of Ghana, Legon pocansey583@gmail.com. Tel: 0265787837. Dr Irene Kretchy, School of Pharmacy, University of Ghana, ikretchy@ug.edu.gh.

In case of any further clarifications on ethical clearance contact Hannah Frimpong, The Administrator of the Ghana Health Service Ethics Review Committee Tel: 0507041223.

CONSENT FORM

PARTICIPANTS' STATEMENT

I acknowledge that I have read or have had the purpose and contents of the Participants' Information Sheet read and that all questions have been satisfactorily explained to me in a language I understand (English□ / Twi □/ Ga □). I fully understand the contents and any potential implications as well as my right to change my mind or withdraw from the research even after I have signed this form.

I voluntarily agree to be part of this research.

Name or Initials of Participant………………………….. ID Code ……………………………..

Participants' Signature ………OR Thumb Print………… OR Mark (Please specify)………….

Date…

INTERPRETERS' STATEMENT

I interpreted the purpose and contents of the Participants' Information Sheet to the afore named participant to the best of my ability in the (English□ / Twi □/ Ga □) language to his proper understanding.

All questions, appropriate clarifications sort by the participant and answers were also duly interpreted to his/her satisfaction.

Name of Interpreter……………………………

Signature of Interpreter……………………….. Date…

Contact Details ……………………………………………………………….

STATEMENT OF WITNESS

I was present when the purpose and contents of the Participant Information Sheet was read and explained satisfactorily to the participant in the language he/she understood (English□ / Twi □/ Ga □)

I confirm that he/she was given the opportunity to ask questions/seek clarifications and same were duly answered to his/her satisfaction before voluntarily agreeing to be part of the research.

Name……………………

Signature……………. OR Thumb Print ………... OR Mark (please specify) ………………..

Date……………………………

INVESTIGATOR STATEMENT AND SIGNATURE

I certify that the participant has been given ample time to read and learn about the study. All questions and clarifications raised by the participant have been addressed.

Researcher's name……………………………………….

Signature ………………………………………………….

Date…………………………………………………………

APPENDIX B: QUESTIONNAIRE

PSYCHOLOGICAL BURDEN AND REPORTED MEDICATION ADHERENCE IN CARING FOR CHILDREN AND ADOLESCENTS WITH MENTAL DISABILITIES IN GHANA

Dear Respondent,
I will like to take a little time with you to answer these questions. You are assured that the answers you give will be strictly confidential and would not be held against you.

Name of Hospital ……………………….

Please will you like to take part in this interview? 1. Yes |___| 2 .No |___|

Unique ID for Respondent |___||___||___||___|

Date of interview (dd/mm/yyyy): |___|___|______|

Interviewer Name…

Section A	**Socio-demographic Information**	
1.	Gender 1. Male |___| 2. Female |___|	
2.	What is your age in years (i.e. age at last birthday)?	……………………………………… years
3.	Marital status 1. Married |___| 2. Single |___| 3. Divorced |___| 4. Widow/widower |___|	
4.	Place of residence 1. Rural area |___| 2. Urban |___|	
5.	Religion 1. Christian |___| 2. Muslim |___| 3. Traditionalist |___| 4. Others (specify) … …………………………	
6.	What is your current level of education? 1. No education 2. Primary level 3. Junior level 4. Secondary/Technical / Voc level 5. Tertiary - Cer /Diploma/ Post Diploma 6. Tertiary - Graduate / Post Graduate 7. Others (Specify) ………………………………………	|___|
7.	Employment status	

	1. Self-employed |___| 2. Private sector |___| 3. Public sector |___| 4. Unemployed |___| 5. Student/ apprentice |___|

Section B: Below is a list of common symptoms of anxiety. Please carefully read each item in the list. Indicate how much you have been bothered by that symptom during the past month, including today, by circling the number in the corresponding space in the column next to each symptom.

0 =Not at all 1=Mildly, but it didn't bother me much 2= Moderately – it wasn't pleasant at times

3= Severely – it bothered me a lot

		Not at all =0	Mildly, but it didn't bother me much =1	Moderately – it wasn't pleasant at times = 2	Severely – bothered me lot =3
1	Numbness or tingling	0	1	2	3
2	Feeling hot	0	1	2	3
3	Wobbliness in legs	0	1	2	3
4	Unable to relax	0	1	2	3
5	Fear of worst happening	0	1	2	3
6	Dizzy or lightheaded	0	1	2	3
7	Heart pounding / racing	0	1	2	3
8	Unsteady	0	1	2	3
9	Terrified or afraid	0	1	2	3
10	Nervous	0	1	2	3
11	Feeling of choking	0	1	2	3
12	Hands trembling	0	1	2	3
13	Shaky / unsteady	0	1	2	3
14	Fear of losing control	0	1	2	3
15	Difficulty in breathing	0	1	2	3
16	Fear of dying	0	1	2	3
17	Scared	0	1	2	3
18	Indigestion	0	1	2	3
19	Faint / lightheaded	0	1	2	3
20	Face flushed	0	1	2	3
21	Hot / cold sweats	0	1	2	3

Section C: Beck's Depression Inventory. Please carefully read each item in the list. For each question, indicate which statement applies to you.

1. 0 I do not feel sad

1 I feel sad.

2 I am sad all the time and I can't snap out of it.

3 I am so sad and unhappy that I can't stand it.

2. 0 I am not particularly discouraged about the future

1 I feel discouraged about the future

2 I feel I have nothing to look forward to.

3 I feel the future is hopeless and that things cannot improve.

3. 0 I do not feel like a failure.

1 I feel I have failed more than the average person.

2 As I look back on my life, all I can see is a lot of failures.

3 I feel I am a complete failure as a person.

4. 0 I get as much satisfaction out of things as I used to.

1 I don't enjoy things the way I used to.

2 I don't get real satisfaction out of anything anymore.

3 I am dissatisfied or bored with everything.

5. 0 I don't feel particularly guilty

1 I feel guilty a good part of the time.

2 I feel quite guilty most of the time.

3 I feel guilty all of the time.

6. 0 I don't feel I am being punished.

1 I feel I may be punished.

2 I expect to be punished.

3 I feel I am being punished.

7. 0 I don't feel disappointed in myself.

1 I am disappointed in myself.

2 I am disgusted with myself.

3 I hate myself.

8. 0 I don't feel I am any worse than anybody else.

1 I am critical of myself for my weaknesses or mistakes.

2 I blame myself all the time for my faults.

3 I blame myself for everything bad that happens.

9. 0 I don't have any thoughts of killing myself.
1 I have thoughts of killing myself, but I would not carry them out.
2 I would like to kill myself.
3 I would kill myself if I had the chance.

10. 0 I don't cry any more than usual.
1 I cry more now than I used to.
2 I cry all the time now.
3 I used to be able to cry, but now I can't cry even though I want to.

11. 0 I am no more irritated by things than I ever was.
1 I am slightly more irritated now than usual.
2 I am quite annoyed or irritated a good deal of the time.
3 I feel irritated all the time.

12. 0 I have not lost interest in other people.
1 I am less interested in other people than I used to be.
2 I have lost most of my interest in other people.
3 I have lost all of my interest in other people.

13. 0 I make decisions about as well as I ever could.
1 I put off making decisions more than I used to.
2 I have greater difficulty in making decisions more than I used to.
3 I can't make decisions at all anymore.

14. 0 I don't feel that I look any worse than I used to.
1 I am worried that I am looking old or unattractive.
2 I feel there are permanent changes in my appearance that make me look Unattractive.
3 I believe that I look ugly.

15. 0 I can work about as well as before.
1 It takes an extra effort to get started at doing something.
2 I have to push myself very hard to do anything.
3 I can't do any work at all

16. 0 I can sleep as well as usual.
1 I don't sleep as well as I used to.

2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.

3 I wake up several hours earlier than I used to and cannot get back to sleep.

17 0 I don't get more tired than usual.

1 I get tired more easily than I used to.

2 I get tired from doing almost anything.

3 I am too tired to do anything.

18. 0 My appetite is no worse than usual.

1 My appetite is not as good as it used to be.

2 My appetite is much worse now.

3 I have no appetite at all anymore.

19. 0 I haven't lost much weight, if any, lately.

1 I have lost more than five pounds.

2 I have lost more than ten pounds.

3 I have lost more than fifteen pounds.

20. 0 I am no more worried about my health than usual.

1 I am worried about physical problems like aches, pains, upset stomach, or constipation.

2 I am very worried about physical problems and it's hard to think of much else.

3 I am so worried about my physical problems that I cannot think of anything else.

21. 0 I have not noticed any recent change in my interest in sex.

1 I am less interested in sex than I used to be.

2 I have almost no interest in sex.

3 I have lost interest in sex completely

Section D: The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of how your relationship with your child or children typically is. Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.

1 = Strongly disagree 2 = Disagree 3 = Undecided 4 = Agree 5 = Strongly agree

1	I am happy in my role as a parent	
2	There is little or nothing I wouldn't do for my child(ren) if it was necessary.	

3	Caring for my child(ren) sometimes takes more time and energy than I have to give.		
4	I sometimes worry whether I am doing enough for my child(ren).		
5	I feel close to my child(ren).		
6	I enjoy spending time with my child(ren).		
7	My child(ren) is an important source of affection for me.		
8	. Having child(ren) gives me a more certain and optimistic view for the future.		
9	The major source of stress in my life is my child(ren).		
10	Having child(ren) leaves little time and flexibility in my life.		
11	Having child(ren) has been a financial burden.		
12	It is difficult to balance different responsibilities because of my child(ren).		
13	The behaviour of my child(ren) is often embarrassing or stressful to me.		
14	If I had it to do over again, I might decide not to have child(ren).		
15	I feel overwhelmed by the responsibility of being a parent.		
16	Having child(ren) has meant having too few choices and too little control over my life.		
17	I am satisfied as a parent		
18	I find my child(ren) enjoyable		

Section F:

Below you will find 5 questions that will answer how you administer medication to your ward. Please read each statement and circle a number 1, 2,3,4,5 which indicates how much the statement applied to you.

1 Always

2 Often

3 Sometimes

4 Rarely

5 Never

1. I forget to give my ward his or her medicines 1 2 3 4 5

2. I alter the dose of my ward's medicines	1	2	3	4	5
3. I stop giving my ward his or her medicines for a while	1	2	3	4	5
4. I miss out on a dose of my ward's medicine	1	2	3	4	5
5. I give my ward less medicine than instructed	1	2	3	4	5

THANK YOU