

**HEALTH-RELATED QUALITY OF LIFE OF CAREGIVERS OF  
CHILDREN WITH ATTENTION DEFICIT HYPERACTIVITY  
DISORDER: A CASE OF MUHIMBILI NATIONAL HOSPITAL**

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**MMed (Psychiatric and Mental Health) Dissertation  
Muhimbili University of Health and Allied Sciences  
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**Muhimbili University of Health and Allied Sciences  
Department of Psychiatry and Mental Health**



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DISORDER: A CASE OF MUHIMBILI NATIONAL HOSPITAL**

**By**

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**A Dissertation Submitted in (Partial) Fulfillment of the Requirements for the Degree  
of Master Medicine (Psychiatry and Mental Health) of**

**Muhimbili University of Health of Health and Allied Science  
October, 2021**

## **CERTIFICATION**

The Undersigned certify that she has read and hereby recommended for acceptance by Muhimbili University of Health and Allied Science dissertation entitled; **“Health-related quality of life of caregivers of children with attention deficit hyperactivity disorders: A case of Muhimbili National Hospital”**, in (partial) fulfillment of the requirements for the degree of Master of Medicine (Psychiatry and Mental Health) of Muhimbili University of Health and Allied Sciences.

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**Prof. Sylvia Kaaya**

(Supervisor)

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**Date**

**DECLARATION AND COPYRIGHT**

I, **Patricia Kassange**, declare that this **dissertation** is my own original work and that it has not been presented and it will not be presented to any other University for similar or any other degree award.

**Signature**.....

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Last but not least many thanks to all the entire Department of Psychiatry and Mental Health for changing my perspective on mental health and to all clients who volunteered and those who did not participate directly; however, some of their records were used in this study.

## **DEDICATION**

This work is dedicated to my late father and mother, Mr. Steven Paul Kassange and Mrs. Pauline Steven Kassange who inspired me a lot to be a hard worker, to always aim higher and they encouraged me in my academic career.

## ABSTRACT

**Background:** Raising a child with attention deficit hyperactivity disorder (ADHD) is known to decrease the well-being and health status of caregivers, however, not much is known about the extent of these effects in low-income countries including Tanzania. Understanding and preserving caregivers' quality of life is broadly considered to be a final goal that professional mental health services should provide to families.

**Aim of the study:** This study aims to determine factors associated with health-related quality of life (HRQoL) of caregivers of children with attention deficit hyperactivity disorder attending outpatient services at the Muhimbili National Hospital, Tanzania

**Materials and Methods:** This descriptive cross-sectional hospital-based study utilized a consecutive sampling procedure to recruit 64 caregivers of children aged 3 to 16 years attending the child and adolescent psychiatry clinic over a period of 2 months (32 clinic days) at the Muhimbili National Hospital, and who were diagnosed with ADHD using the Kiddie-SADs-Present and Lifetime Version (K-SADS). The data collected between September 2020 to November 2020 assessed caregiver's health related quality of life (HRQoL); using the quality-of-life survey short-form SF 12. Risk factors data included social-demographic measures, and psychosocial risk factors of interest including perceived social support, level of affiliated stigma, parental stress and depressive symptoms. Data were analyzed using the Statistical Package for the Social Science (SPSS) version 23 software. Bivariate analyses determined biological, psychological and social risk factors of interest associated with caregiver HRQoL; and select variables to include in linear regression analysis (associations with  $p < 0.2$ ). Stepwise linear regression analyses determined factors independently associated with HRQoL at p-value of  $< 0.05$ .

**Results:** All the participants (N=64) were aged between 20-60 years (mean age 34.9 years  $\pm 9.6$  standard deviation), most being aged 35 years or younger. Their mean (SD) scores of the HRQoL physical functioning and mental functioning dimensions were  $48.0 \pm 3.8$  and  $43.6 \pm 10.8$  respectively. Risk factors independently associated with the physical functioning domain were high compared to low affiliated stigma ( $\beta = 0.357$ ,  $p = 0.009$ , Partial  $r^2 = -0.343$ , 95% CI) and secondary/college/university compared to lower levels

( $\beta=-0.473$ ,  $p=0.004$ , Partial  $r^2=0.380$ ,95% CI). Furthermore, factors independently associated with mental functioning domain were secondary/college/university versus lower levels ( $\beta=-0.520$ ,  $p=0.003$ , Partial  $r^2=-0.394$ ,95% CI), having more than three versus lower numbers of children in the caregiver's household ( $\beta=0.316$ ,  $p=0.007$ , Partial  $r^2=0.362$ ,95% CI), high/clinically relevant versus lower parenting stress in the past six months ( $\beta=-0.274$ ,  $p=0.026$ , Partial  $r^2=-0.302$ ,95% CI), and high versus low depression symptom severity ( $\beta=-0.435$ ,  $p=0.000$ , Partial  $r^2=-0.509$ ,95%CI).

**Conclusion and recommendations:** High levels of affiliated stigma, parental stress and depressive symptoms were significant intervenable factors associated with low HRQoL. Caregivers with less than three children in the home should be particularly targeted for interventions. Further studies using larger samples of caregivers are required to confirm these observations. Pilot studies to determine the feasibility and acceptability of ADHD treatment modalities that include psychosocial programs targeting the intervenable risk factors identified by this study should also be determined, including a better understanding of caregiver experiences in providing care for their children with ADHD in order to better determining their needs for the development of targeted caregiver interventions.



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**LIST OF ABBREVIATIONS**

ADHD	Attention deficit hyperactivity disorder
CAIA	Child and adolescent impact assessment
DSM	Diagnostic and Statistical Manual of Mental Disorders
GV	Group visit
HRQOL	Health-Related Quality of Life
HIS	Home Situations Inventory
ICD	International Classification of Diseases
K-SADS	Kiddie-Sads-Present and Lifetime Version
PHQ- 9	Patient Health Questionnaires – 9
PSI-SF	Parenting Stress Index-short form
SRGS	Stress-related growth scale
SPSS	Statistical Package for Social Sciences
WHO	World Health Organization
WMH	World Mental Health
WHOQOL	World Health Organization Quality of Life
WBG	World Bank Group

## OPERATIONAL DEFINITIONS

**Caregiver:** He or she is usually an unpaid family member or friend who provides care to a person who, due to an illness, disability, or mental health issue, cannot cope without support.(Pearlin et al., 1990)

**WHOQOL:** Is individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept incorporating in a complex way the persons' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment. (WHO, 2012)

**Attention-deficit/hyperactivity disorder ADHD:** Is a mental disorder of the neuro developmental type characterized by difficulty paying attention, excessive activity, and acting without regards to consequences, which are otherwise not appropriate for a person's age. Some individuals with difficulty regulating emotions or problems with executive function.(DuPaul et al ., 2012; Faraone et al., 2019; Sroubek et al., 2013; Tenenbaum et al., 2019)

**Public stigma:** Is the kind of stigma that can be noticed when a large population collaboratively accepts discrediting stereotypes about out-group members or more cursory, individuals from groups that are perceived to differ in physical, behavioral, or other intrinsic characteristics.(Mueller et al, 2012)

### **Affiliated**

**Stigma:** Refers to the extent of self-stigmatization among associates of the targeted minorities. This kind of stigma among family members/parents, is called affiliate stigma when it is internalized.(Mak et al ., 2008)

## CHAPTER ONE

### 1.0 INTRODUCTION

#### 1.1 Background

ADHD is a mental disorder of the neurodevelopmental type characterized by difficulties in paying attention, excessive activity, and acting without regards to consequences; behaviors are otherwise not appropriate for a person's age. Some individuals may have difficulties regulating emotions or problems with executive functioning. (DuPaul et al., 2012; Faraone et al., 2019; Sroubek et al., 2013; Tenenbaum et al., 2019). Multisite data from twenty nations using the Composite International Diagnostic Interview, report that ADHD prevalence averaged at 2.8%; was higher in high (3.6%) and upper-middle (3.0%), then in low/lower-middle-income countries (1.4%) (Fayyad et al., 2017). While rates of disorder in childhood decrease over time, symptoms persist into adolescence for 80% of children with ADHD and in adulthood rates are about 4% (Chao et al., 2008)

Quality of life (QoL) and its evaluation has become an increasingly important measure of outcome in mental health clinical and research work. It is a broad ranging concept incorporating, in a complex way, the persons' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of the environment (WHO, 2012). Children with ADHD compared with healthy children have been reported to have wide-ranging functional impairments, lower quality of life (QOL), diminished family functioning, and hindered parental well-being (Uneri et al., 2015).

A survey in western Uganda reported a 6% overall prevalence of ADHD (n = 81); with several caregiver factors found to be associated with ADHD than no ADHD, including socio-demographics (age, sex, level of educational attainment (marginally), and socio-economic status); and psychological distress (Mpango et al., 2017). A meta-analysis reporting studies exploring HRQOL of caregivers of children with mental disorders compared to that of caregivers in the community, show reductions in HRQOL of caregivers of children with mental disorder that range between -0.63 (compared with caregivers from community



normative samples; CI -0.89 to -0.38) and -0.66 (compared with caregivers with healthy children; CI -0.85 to -0.48) (Dey et al, 2018). In a meta-analysis of North-American and European studies, that compared parenting stress in parents of children with ADHD with either non-clinical (well children) parents and/or clinical (ill children) parents; authors showed higher parenting stress in parents of children with ADHD in particular, in the child domain of the parenting stress index measures used (Theule et al 2013). While falling short of assessing parental quality of life, these studies do suggest ADHD in a child confers significant parenting challenges, particularly for stress stemming from sources in the child's behavior. No study could be retrieved that addresses the HRQOL of caregivers of children with attention deficit hyperactivity disorder and associated risk in the low-income countries of sub-Sahara Africa (SSA), including Tanzania. Adult care-givers are the mainstay for the care for children with ADHD, hence it's important to assess their HRQOL in Tanzania and associated risk factors, in order to inform interventions that can improve their ability to provide care.

Psychosocial factors that have been associated with the reports of lower HRQOL of caregivers of children with ADHD include caregivers' level of depression, and experiences with societal stigmatizing responses towards their ADHD affected children. For example, in Taiwan in 398 recruited care giving mothers, of the 60.3% that completed interviews, 25.7% screened positive for depression; mothers screened negative for depression reported higher levels of HRQoL, assessed using the WHOHRQOL (Chen et al., 2014). There are also documented associations between caregiver's experiences of affiliated stigma towards the child's illness (ADHD) and caregiver HRQoL. For example, in Hong Kong, recruited caregivers (N=271) assessed using the three domains (cognitive, affect, and behavioral) of the affiliated stigma scale measures, demonstrated each domain correlated negatively and significantly with QoL ( $r = -0.590$  to  $-0.365$ ). All four domains of the QOL measure (physical, psychological, social and environment QOL scores) also showed significance associations with stigma with correlations from  $-0.464$  to  $-0.494$ . with p values  $<0.001$  (Bauer et al., 2019; Chang et al., 2016). The presence of stigma may create barriers to the proper management of the child with ADHD and the well-being of the family.

Parents' concerns about societal labelling of their child, increases feelings of social isolation and rejection and may also increase the burden of care (Psy-, 2010). No studies from SSA could be retrieved that determined levels of caregiver affiliated stigma due to having a child with ADHD; this is important as it is an intervenable risk factor. Hence, exploring the associations between caregiver affiliated stigma towards their child with ADHD and HRQOL will be a new contribution to science from this study.

## **1.2 Problem Statement**

HRQOL has become increasingly important in health research and clinical practice. It measures caregivers psychological, physical, environmental and social well-being states. Children with ADHD have been reported to have a wide-range of functional impairments, and social difficulties in the home, as well as with peers at school. Overall extraordinary hyperactivity can trouble others and take a lot of time and energy from mothers to handle, leading to excessive toil, exhaustion, constant worry, disappointment and frustration and hence contribute to lower quality of life (Johnston et al ., 2001)

The prevalence of ADHD in the general population, in hospital settings and schools is not known in Tanzania. In Tanzania, a study using in-depth interviews with caregivers who attended the psychiatric clinic with their children at the Muhimbili National revealed psychological, social, and economic challenges caregivers endure while living with mentally ill children. Psychological and emotional challenges included being stressed, worries, feelings of sadness, while more social challenges involved having to cope with stigma, lack of social support and other problems in their social lives (Ambikile et al, 2012). In other African countries, such as South Africa, the Democratic Republic of Congo, and Ethiopia, the prevalence of ADHD has been reported to vary from 5.4% to 8.7% among school children (Chinawa et al., 2014).

Very little literature is found that address the HRQOL of caregivers of children with attention deficit hyperactivity disorder and caregiver factors that are associated with reduced HRQOL in sub-Saharan and low-income countries including Tanzania.

Therefore, this study aims to bring provide preliminary information that may guide future research endeavors in this area and perhaps inform improvements in treatment modalities and psycho-social intervention programs targeting management of ADHD in children and their caregivers attending out-patient services at the Muhimbili National Hospital.

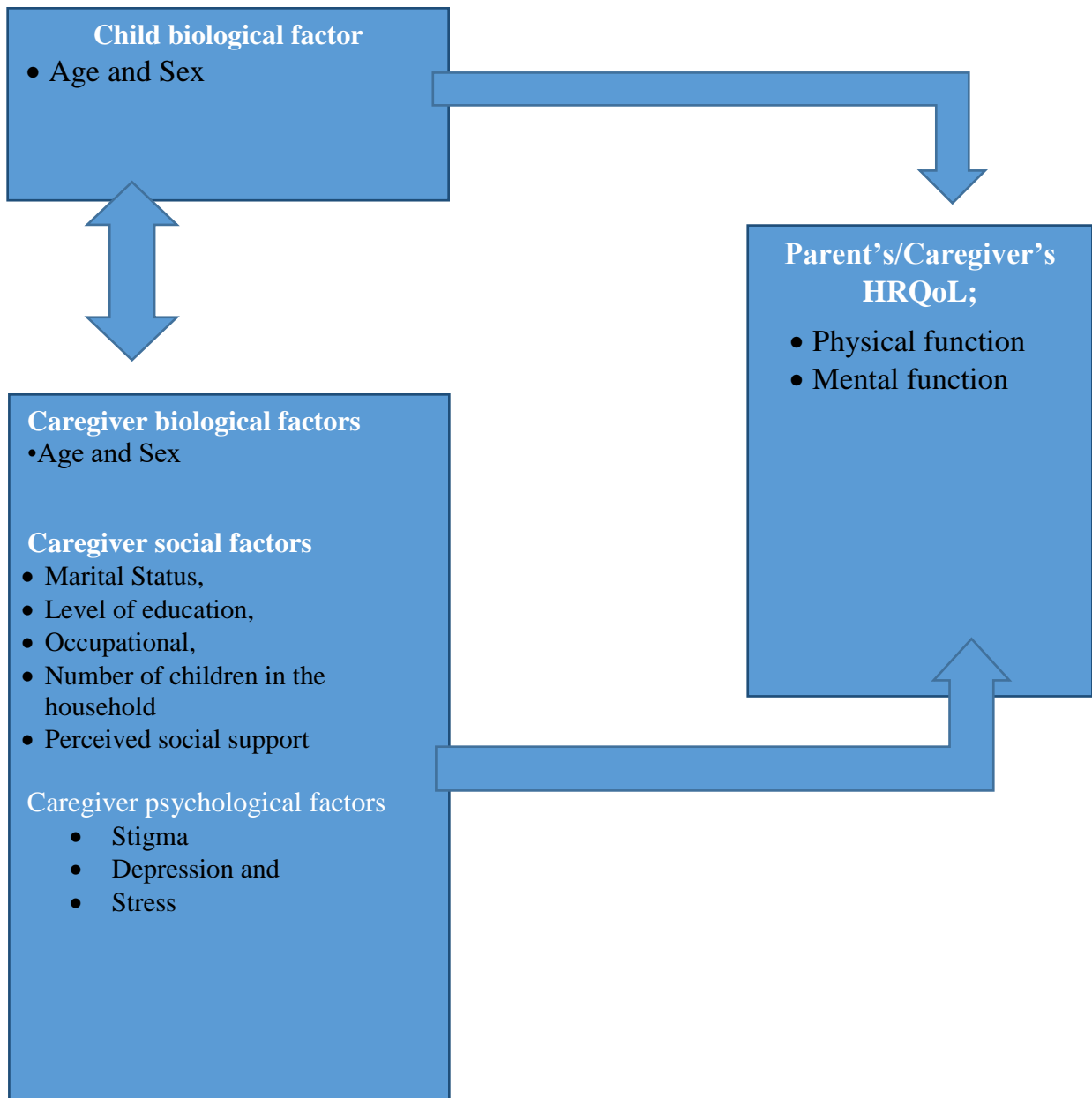
The evidence suggests that in order to determine HRQOL in caregivers of children with ADHD and its associated risk factors, a biopsychosocial conceptual framework will be best suited for the study.

A understanding of the caregiver's HRQoL experiences when providing care for their children with ADHD, will help health service providers and social service networks to better determine the needs of caregivers for targeted caregiver interventions.

### **1.3 Conceptual Framework**

The biopsychosocial model (BPS) developed by George L. Engel in 1977 is a framework explaining the biological, psychological, and social factors that can contribute to an individual's health (Engel et al., 1980). The model adopts a holistic approach to health and suggests that health is best understood in terms of a combination of biological, psychological, and social factors (Upadhyay et al., 2006). The model represents an integrated approach to human behavior and disease where several elements including one's genetic makeup e.g. biology, mental health and personality e.g. psychological, and sociocultural environment e.g. social continuously are acknowledged to interact with each other and contribute to health or illness (Colvin et al., 2016). Quality of life has been used to assess the outcome of medical and non-medical consequences of illness, as well as the assessment of medical and non-medical effects of health-care and treatment on the patient's well-being in almost all branches of medicine such as psychiatry, oncology, cardiology, rheumatology and others (Lodziensis et al., 2006). Several theoretical models have been conceived to explain the variety of bio-psycho-social factors that determine the quality of life. The adapted bio-psychosocial theoretical model summarized in Figure 1, that will be used in this study, will be important for understanding the mechanisms that determine caregiver' health-related quality of life. More specifically, as have been reported, understanding what factors determine health-related quality of life enables proper evaluation of these factors for a better understanding of a caregivers state during chronic illness (Sosnowski et al., 2017)

This study's conceptual framework as summarized in Figure 1 will determine associations between caregivers HRQL and the child's and caregivers age and sex (biological). Furthermore; and social factors in a caregiver's life including reported marital and employment status, educational attainment, number of children below 18 years in the home, as well as perceived social support. Caregiver psychological factors including their level of affiliated stigma, stress and depressive symptoms as well as clinically significant depression will also be assessed.



**Figure 1: The Biopsychosocial model to show the effect of the variables related to caregiver and child factors associated with HRQOL score of the caregiver of the children with ADHD (Upadhyay et al 2006.), (Engel, 1980)**

#### **1.4 Rationale**

This study will identify a knowledge gap by determining the level of caregiver HRQOL and its related factors using a biopsychosocial theoretical framework to better understand HRQOL and risk factors that are amenable to interventions. This would be a preliminary step for better information that can guide more holistic management of children with ADHD and determine what early interventions with caregivers can be provided. By improving the HRQOL of caregivers, it is anticipated that their ability to provide care for children with ADHD will also improve.

#### **1.5 Research Questions**

1. What are the sociodemographic factors associated with HRQOL domains of caregivers of children with ADHD?
2. What child and caregiver biological factors are associated with the level of physical and mental HRQOL domains of caregivers of the children with ADHD?
3. What caregiver psychological factors are associated with the levels of the physical and mental HRQOL domains among caregivers of children with ADHD?
4. What are social factors in caregivers of children with ADHD are associated with their physical and mental HRQOL domains?

## **1.6 Objectives**

### **1.6.1 Broad Objectives**

To determine the factors associated with the health-related quality of life in caregivers of children with attention deficit hyperactivity disorder (ADHD) attending outpatient services at the Muhimbili National Hospital.

### **1.6.2 Specific Objectives**

- i. To determine associations between the age and sex (biological factors) of children with ADHD and their caregivers HRQOL, when attending outpatient services at the Muhimbili National Hospital
- ii. To determine associations between caregivers age and sex (biological factors) and health-related quality of life domains amongst caregivers of children with ADHD attending outpatient services at the Muhimbili National Hospital
- iii. To determine associations between social factors in caregivers' lives (including marital status, educational attainment, occupation, number of children in the household and perceived social support) and their health-related quality of life domains amongst caregivers of children with ADHD attending outpatient services at the Muhimbili National Hospital
- iv. To determine the associations between caregivers' psychological factors (including, affiliated stigma due to the child's ADHD symptoms, depression, and perceived stress) and their health-related quality of life domains amongst caregivers of children with ADHD attending outpatient services at the Muhimbili National Hospital



## CHAPTER TWO

### 2.0 LITERATURE REVIEW

#### 2.1 The level of health quality of life for caregivers among children with ADHD

The HRQOL of caregivers of children with ADHD compared to that of caregivers of children who do not have any disorder has been found in studies across different countries to be poorer. Several studies from upper- and middle-income countries (UMIC), for example, in Hong Kong a study examining the HRQOL in parents of children with ADHD compared with the general population, using a sample of 77 of 98 parents of children with ADHD who were approached, measured parents HRQOL using the World Health Organization's 26-item WHOQOL (brief) with its four subscales or domains of HRQOL that included physical health, psychological health, social relationship, and environmental factors. The results showed that the parents QOL mean scores were significantly poorer when compared to community norms in Hong Kong across all four domains (physical health 15.9 vs 13.3 respectively; psychological health 14.8 vs 13.4 respectively; social health 14.3 vs 13.5 respectively; and environmental health 13.7 vs 12.9 vs respectively) (Xiang et al., 2009). An Iranian cross-sectional hospital-based case control study assessed maternal HRQOL in mothers of children with ADHD and in a control group of mothers with a healthy child in primary school. The HRQOL measure from the Medical Outcomes Study assessed eight subscales or domains of HRQOL including physical functioning (PF), role limiting physical problems (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role limiting emotional problems (RE) and mental health (MH). The results of the study showed that mothers of children with ADHD had significantly lower HRQOL scores than control group mothers. HRQOL, mean scores were 10 points or more lower in mothers with children with ADHD compared to those with healthy children in the following HRQOL dimensions Physical functioning mean  $74.25 \pm 30.80$  vs  $87.55 \pm 9.16$  respectively, Vitality mean  $42.50 \pm 17.87$  vs  $56.20$ , role limitation due to emotional problems means  $19.66 \pm 26.84$  vs  $69.66 \pm 20.15$ , bodily pain means  $52.06 \pm 26.28$  vs  $48.11 \pm 20.14 \pm 15.78$  respectively, social functioning means  $56.62 \pm 24.96$  vs  $64.00 \pm 13.44$  respectively and mental health means  $49.08 \pm 16.98$  vs  $63.64$

$\pm 10.26$  respectively also impact to physical problem  $52.50 \pm 26.35$  vs  $61.75 \pm 31.06$  and the general health ( $42.08 \pm 19.60$  vs  $53.17 \pm 17.95$  respectively (Hadi et al, 2013).

Few studies in SSA have explored the HRQOL of caregivers of children with ADHD. In Egypt, a cross-sectional hospital-based study was implemented to describe QOL in parents of children with ADHD, and also determined the associations between parental QOL and family functioning adjusting for sociodemographic measures. The WHOQOL BREF's four dimensions of QOL (physical, psychological, social and environmental) were used to assess HRQOL. The median scores for the physical, psychological and social domains were 12.0, while the mean score for the environmental domain was 11.9. The median score for perception of health and QOL of the parents was 3.0. The authors in their discussion noted the parent's perceived QOL was at an average level, when taking into consideration comparisons from median and mean scores from studies in other adult populations and countries. These findings suggest quality of life may be adversely affected when parents' have the role of main caregiver for children with ADHD. It is likely similar findings may be found in low-income countries such as Tanzania, however, no studies from low-income countries that assess QOL in parents of children with ADHD could be retrieved. This lack of information may influence the management of children with ADHD, where there is high reliance on parents as caregivers. Information is needed to determine the need for clinic-based support needs for parents of children with ADHD.

## **2.2 Factors Associated with Health-Related Quality of Life of Caregivers**

### **2.2.1 Social-demographic factors associated with HRQoL of caregivers**

Several socio-demographic characteristics of caregivers of children with ADHD have been identified to be associated with lower caregiver HRQOL. For example, an observational study in Taiwan that determined symptoms of ADHD in school-age children and the HRQOL of their mothers enrolled 392 (60.3% retention) mothers whose QOL was assessed using the WHOQOL BRIEF Taiwanese version. Factors identified to be associated with lower HRQOL scores in mothers were older maternal age, lower levels of education, family residential status and the fathers level of education (Chen et al., 2014). Studies high and middle-income

countries have also assessed socio-demographic factors associated with caregiver QOL. Researchers in Hong Kong used the WHOQOL BREF four domains to assess caregiver's QOL, while in Iran, the Medical Outcomes Study's eight QOL dimension short form (MOS SF 36) was used. Both studies showed some similarities in factors associated with low levels of caregiver HRQOL. For example, both studies showed poorer HRQoL was associated with lower levels of education in the physical and psychological dimensions of HRQOL ( $Z= 0.31$ ;  $p < 0.01$ ); lower household income and marital relationship was associated with poorer HRQOL in the environmental dimension of HRQOL ( $Z= 0.49$ ;  $p < 0.01$  and  $Z=0.29$ ;  $p < 0.05$  respectively) (Hadi et al. 2013, Xiang et al., 2009). In an Egyptian cross-sectional study, significant associations between all the four domains of caregivers HRQL assessed using the WHOQOL BRIEF, were found with the caregivers' levels of education (between  $Z=12.6-9.0$ ;  $p < 0.017$ ). Furthermore, for the physical health domain of HRQOL, female gender, ( $Z=11.7$ ;  $p < 0.001$ ) lack of compared to presence of employment ( $Z=2.71$ ;  $p 0.007$ ) and low compared to high income ( $Z=2.32$ ;  $p 0.021$ ) were associated with lower HRQOL. For the psychological health domain, lower HRQOL was associated with urban residence ( $Z=11.3$ ;  $p 0.008$ ) and levels of education ( $Z=9.33-16.7$ ;  $p 0.001$ ) while for the environmental domain of HRQOL associations were with older age ( $Z=3.40$ ;  $p0.001$ ), lower income ( $Z=3.36$ ;  $p 0.001$ ), and marital status ( $Z= 2.67$ ;  $0.002$ ). Finally only illiteracy compared to higher levels of education ( $Z=3.60$ ,  $p < 0.001$ ) in this study was associated with lower scores on the HRQOL social dimension (Azazy et al., 2018).

### **2.2.2 Caregivers perception of social support and QOL**

Adequate social support has been reported to result in many health benefits. A study in Ireland reported that caregivers who perceived greater benefits from social supports, showed more positive overall quality of life; in a sample of  $N= 84$  caregivers, with positive perceptions of their quality of life ( $M = 79.05$ ,  $SD = 19.72$ ), had social support benefits scores above the average for the measure ( $M = 2.27$ ,  $SD = 0.39$ ) (Brand et al, 2016). Furthermore, in this study caregivers reporting social support as being available more than 'some of the time' ( $M = 3.07$ ,  $SD = 1.00$ ), also showed optimism levels that were above the average for the scale ( $M = 2.82$ ,  $SD = 0.70$ ). Overall social support was positively correlated with caregiver HRQoL (Brand et

al., 2016). Similarly, in a Taiwanese study in elementary schools, 392 (return rate of 60.3%) mothers who providing data, showed that higher compared with lower perceived family support was independently associated with higher HRQoL scores in all the four domains assessed of physical capacity, psychological well-being, social relationships and the environment (-0.069;  $p < 0.01$ , -0.048;  $p < 0.001$ , -0.2;  $p < 0.001$  and -0.131;  $p < 0.001$  respectively) (Chen et al., 2014).

### **2.3 Depression**

Several studies have been reported that there is association between depression and HRQoL in caregivers of children with ADHD. Amongst Taiwanese mothers providing care for children with ADHD (N=398), 25.7% screened positive for depression; and . all four domains of maternal HRQoL assessed using the WHOHRQOL measure shown to have significantly lower scores in mothers that were depressed versus not depressed (i.e psychological well-being(-1.801;  $p < 0.001$ ; physical capacity(-1.329;  $p < 0.001$ ); social relationships (-1.469;  $p < 0.001$ ) and the environment domain (-1.374;  $p < 0.001$ ); after adjusting for relevant socio-demographic and clinical Chen et al., 2014). An Australian school-based study that assessed associations between caregiver quality of life (QoL) and an ADHD diagnosis in the child found 16% of 186 children screened positive for ADHD; the parents of children screening positive for ADHD compared to those whose children screened negative had higher parental depression (mean difference 6.8,  $p = 0.009$ ) and poorer HRQoL after adjusting for socio-demographic characteristics. (Cussen et al., 2012).

Findings of a case control study, in Lebanon that assessed the mental health of caregivers with and without children with ADHD, which recruited 120 parent suggests mothers may be affected more by mental health concerns than fathers. In this study, psychological health measures were compared in 48 versus 72 caregivers of children with ADHD (C-ADHDC) and with normal development (C-NDC). The mean (standard deviation [SD]) depression scores for the parents of C-ADHD and parents of C-NDC assessed using the DASS-21 (Depression Anxiety and Stress Scale) were 14.98 [ 6.2]) and 4.31 [4.24] respectively; with 58% vs 26% respectively screening positive for depression). Amongst parents of C-ADHD that were

depressed most (64%) were mothers. This study however, did not determine parents HRQoL. (Matar et al, 2019). While few studies could be retrieved from SSA that explored depressed mood and HRQOL in caregivers of children with ADHD, a recent study in Ethiopia amongst 416 caregivers of children and adolescents with mental illness measured parental depressive symptoms using Patient Health Questionnaire-9 (PHQ9) and found a prevalence of probable depression of 57.6%, while rates were higher in female primary caregivers (64.6%; n=181); and having a child diagnosed with ADHD, increased to likelihood of a probable maternal depression diagnosis by more than five times (AOR=5.3) (Minichil et al, 2019).

#### **2.4 Affiliated Stigma**

Affiliated stigma develops among caregivers, through perceiving and internalizing public stigma towards caregivers of people with mental illness (Mak et al, 2008). Caregivers of people with mental illness with intense affiliated stigma may agree with public stigma toward them (cognitive component); feel shame, embarrassment, and negative emotions stemming from internalized stigma (affective component); and may withdraw from social relationships or alienate themselves from closely affiliated stigmatized family members or people (behavioral component) (Mak et al, 2008; Mak et al, 2012). Affiliated stigma may not only enhance caregivers' psychological distress, but also reduces their quality of life (Chien et al, 2016; Wu et al, 2016). For example, a study in the United States explored stigma in African-American caregivers of children with ADHD. Forty-eight parents were recruited if their child was aged between 6 and 18 years and was newly diagnosed with ADHD. Stigmatizing experiences were noted by 77% of the sample. Nearly half (44%) expressed concerns about how society would label their child, 40% felt socially isolated or rejected, and 21% perceived health care professionals and school personnel as being dismissive of their concerns. Parents' own attitudes about ADHD treatment were shaped by their exposure to negative media (21%), mistrust of medical assessments (17%), and the views of the general public (6%) (Dosreis et al, 2010). All three domains (cognitive, affect, and behavior) of the affiliated stigma scale were reported to be significantly correlated with the QoL ( $r = -0.590$  to  $-0.365$ ) score in 271 caregivers of children with ADHD; as well as with all of its four physical,

psychological, social and environment dimension scores ( $-0.464$  to  $-0.494$ , with  $P$  values  $<0.001$ ) (Chang et al., 2016). While no studies from SSA have explored associations between affiliated stigma and the HRQoL of caregivers of children with ADHD, a study amongst immigrants from the low and middle income countries of Cuba, the Dominican Republic, and Puerto Rico in the US, showed high levels of internalization in mothers ( $N=62$ ), of stigmatizing experiences towards their children with ADHD. About 39% of these mothers of children between the ages of 4 and 10 years reported feeling stigmatized; these findings supported by qualitative findings where 52 mothers (83%) provided narratives reflecting feelings of stigma or blame and the most common reaction was isolation. This included restrictions of their personal or family social activities because of the child's behaviors (72%); their being definitely rejected by peers (21%); and four mothers volunteered that their relatives refused to care for their child with ADHD (Fernández, et al 2004).

It has been reported from a study in Singapore, in that explored the association between HRQoL and mental illnesses stigma in 350 primary caregivers of children with mental illness, using the Family Stigma Scale, and the WHO Quality of Life-BREF (WHOQOL-BREF) measures, that more than 90% (94.5%) of the total sample population endorsed at least one positive answer on the stigma scale. The most frequently reported items were 'you have helped other people to understand what it is like to have a family member with mental health problems' (endorsed by 62.6%), followed by 'you felt grief or depression because of it' (endorsed by 60.2%). It was of interest that the least endorsed item was 'you felt ashamed or embarrassed about it' (18.9%). Higher scores on the stigma scale were significantly associated with poorer HRQoL among caregivers in three of four domains; psychological ( $\beta=-0.09$ ,  $p < 0.001$ ), social relationship ( $\beta=-0.17$ ,  $p < 0.001$ ) and environment ( $\beta=-0.12$ ,  $p < 0.001$ ); after adjusting for socio-demographic variables including age, gender, ethnicity, education and employment (Zhang et al., 2018).

This study will be the first to look at the association between caregiver of children diagnosed with ADHD having affiliated stigma and the level of the HRQoL domain scores in a sub-Saharan African population.

## **2.5 Stress**

Caregiver stress is determined by the health status of the care recipient and advancement of debilitating illness; the existence of any problematic behavior from the care recipient; the level of daily dependency of the care recipient; sharing a home with the care recipient; conflictual familial relations; occupational conflicts or strains; financial hardships; and the constriction of social and recreational roles in the caregiver's life by caregivers can result from changes in any of these variables (Pearlin et al, 1990). For example, a study shows that caregivers of children with ADHD have higher anxiety and stress levels based on the DASS-21 assessment scores compared to caregivers of normally developing children (Cussen et al., 2012). Findings from an Australian community-based sample, which included 202 parents of a children who were screened for ADHD and who also completed validated measures of family quality of life (QoL), showed parents of children screening positive for ADHD versus not, reported poorer family HRQoL in the domains of emotional impact (mean difference [MD] -20.1; p=0.03) after adjusting for socio-demographic characteristics and the child's conduct symptoms. Parents of children screening positive for ADHD also reported higher stress parenting (MD 4.5; p=0.007) than parents of ADHD screen negative children after adjusting for socio-demographic factors (Cussen et al., 2012). No study could be accessed from the literature that has explored stress levels in caregivers of children with ADHD in the SSA context.

## **2.6 Evidence-based interventions to improve caregiver quality of life**

It would be important to query if interventions to improve caregiver quality of life have been associated with better health outcomes in children with ADHD and/or caregivers. Some studies show ADHD follow-up care delivered as group visits (GV) that include multiple children and their caregivers, results in improved parental emotional health and their perceptions of their child's behavior. For example, a study in the USA with children with ADHD (aged 6–12 years) and their caregivers (N=84), comparing outcomes when treatment was delivered as individual (IND) or group visits (GV) showed significant differences at 12 months follow-up in several domains that include child problem behaviors and the home situation.

Within group differences when comparing GV to IND exposed participant groups showed less negative home situations assessed using the Home Situations Questionnaire (mean difference (MD) -0.9; SD: 0.3,  $p=0.01$  vs. IND (md) -0.2; SD: 0.4,  $p=0.6$  respectively), improved parental emotional health (MD 6, SD: 3;  $p=0.04$  vs. MD 3, SD:3,  $p=0.3$  respectively); less overall misbehavior in the child [MD -0.5, SD: 0.2,  $p=0.02$  vs MD 0.2, SD:0.2,  $p=0.5$ ) respectively] and more time in caregivers for themselves, other siblings and routine household chores [MD -0.5, SD: 0.2,  $p<0.01$  vs. MD -0.1, SD: 0.2,  $p=0.6$  respectively). .Between group comparisons of outcomes of interest showed significant improvements in parent-reported child misbehavior in those that attended GV versus IND (Bauer et al., 2019).The outcome shows significant improvements in the caregiver's emotional health, parent reported child misbehavior, and caregiver time for activities other than looking after the child with ADHD when the form of care delivered is offered as group vs individual visits.



## **CHAPTER THREE**

### **3.0 METHODOLOGY**

#### **3.1 Study Design**

The study was designed as a hospital-based descriptive cross-sectional study using quantitative research methods to collect data.

#### **3.2 Study Population**

All caregivers of children aged of 3 to 16 years diagnosed with ADHD, attending the child and adolescent psychiatry clinic at Muhimbili National Hospital, were sampled from a wider study focused on piloting the implementation of the use of the Kiddie-SADS-Present and Lifetime Version (K-SADS-PL) Diagnostic Interview for Clinical Assessment of ADHD in this age group. Sixty-four among 150 children identified with ADHD by the wider study, that attended the child and adolescent clinic during the study period were included in this study.

#### **3.3 Study duration**

This study was conducted between September 2020 and February 2021.

#### **3.4 Study area and setting**

The study was conducted at the Child and Adolescent Clinic in the Department of Psychiatry and Mental Health of the Muhimbili National Hospital (MNH). MNH is a national referral and teaching hospital, located in the Ilala municipality of the Dar es Salaam region, in Tanzania.

The units in the Department of Psychiatry and Mental Health include occupational therapy, medical social work, and clinical psychology. Services are organized within four firms that include a mental health care team comprising psychiatrists, nurses, social workers, clinical psychologists, and occupational therapists; each offering services in one of four administrative and judicial catchments of the Dar es Salaam regions. Each firm offers both outpatient and inpatient services. Each firm provides adult outpatient services (OPD) once a week, (Temeke

Firm-Monday, Kinondoni Firm-Tuesday, Magomeni Firm-Wednesday, Ilala firm- Friday). Child and adolescent follow-up clinics are held, in a designated space at the hospital's pediatric care and treatment complex on Tuesdays (Magomeni and Ilala firms), and Wednesdays (Temeke and Kinondoni firm), while the assessment of new child and adolescent outpatients occurs on every day of the week. For any psychiatry emergency, the doctor assigned to on-call duty attends patients regardless of firm assignment. Occupational therapy services are provided daily, throughout the week from Monday to Friday, at the child and adolescent clinic. According to records obtained from the clinical departments data base , about 30 children and adolescents were seen every week.

### 3.5 Sample size estimation

In the absence of information on the mean HRQoL in caregivers of children with ADHD in Tanzania, sub-Saharan African samples or other low-income countries outside of Africa, the minimum estimated sample size was determined from formulae for an unknown population using the A-priori Sample Size for Multiple Regression Calculator (found at: [www.danielsoper.com /statcalc/calculator.aspx? id=47](http://www.danielsoper.com/statcalc/calculator.aspx?id=47)) for Student t-Tests. Computations were conducted to provide a minimum required and per-group sample size for a one-tailed or two-tailed t-test study with a power of 90%, significance level at  $\alpha = 0.05$ . For a medium to moderate number of predictors ( $n=13$ ) of the continuous caregiver HRQoL outcome measure, assumed to be from a normal distribution. The ability to detect a Cohen's d range of 0.3 – 0.5 mostly used in the social sciences was also assumed (Gandek et al., 1998) . The sample size of the study was estimated using version 3.0 of the sample size calculator statistics calculator, with the formula as summarized below.

$$n = \frac{(r+1) \sigma^2 (Z_{1-\beta} + Z_{\alpha/2})^2}{\text{r-difference}^2}$$

Where n = sample size

r = ratio of larger group to smaller group for paired data r = 1

$\sigma$  = standard deviation of the characteristic

difference = clinically meaningful difference in means of the outcome (0.5)

$Z_{1-\beta}$  = corresponds to power (90% power)

$Z_{\alpha/2}$  = corresponds to two tailed significant level (1.96 for  $\alpha = 0.05$ )

$$\text{Hence} = \frac{2\sigma^2 (Z_{1-\beta} + Z_{\alpha/2})^2}{\text{difference}^2}$$

Using these assumptions, the minimum required sample size (N) of 58 participants was estimated with an additional 10% assumed to adjust for non-response to some questions providing a final minimum sample size of 64 caregiver of children with ADHD aged  $3 \leq 16$  years.

### **3.6 Sampling Technique**

All children who had been formally diagnosed with ADHD using Kiddie-Sads, who attended the outpatient clinic on the day of data collection were included with their caregiver. For children with an ADHD diagnosis that did not appear for scheduled follow-up visits, contact information was sought in their records and caregivers were called and invited to participate. About 8-10 caregivers were interviewed on each clinic day during the course of data collection.

### **3.7 Inclusion and exclusion criteria**

#### **3.7.1 Included if:**

1. Caregivers of children with ADHD age  $3 \leq 16$  years diagnosed using Kiddie-SADS-Present and Lifetime Version (K-SADS)

#### **3.7.2 Excluded if:**

1. Caregiver's reporting having being treated for a psychiatric illness or a chronic physical illness.

### **3.8 Independent and dependent variable**

The independent risk factors of interest included biopsychosocial factors including selected socio-demographic measures (Child's age and sex, caregiver's age and sex, relationship and marital status, level of education, employment status, and number of children in the

household). Psychosocial factors of interest included the caregivers perceived social support during the past six months; the caregiver's levels of affiliated stigma, stress, and depressive symptoms all determined in the past two weeks prior to assessment. The dependent or outcome variable was the caregivers' health-related quality of life

### **3.9 Ethical Considerations**

The Muhimbili University of Health and Allied Sciences (MUHAS) Senate Research and Publication Committee granted research clearance reference No.DA.282/298/01.C and permission to collect data attained from the Executive Director of the Muhimbili National Hospital through the Director of Medical Services and the Head of Psychiatry Department.. Eligibility to participate in the study was assessed by research assistants making sure participants had meant inclusion criteria and had not meant exclusion criteria. The potential study participants were provided with written informed consent, provided with detailed information. The consent form clearly stated the benefits, alternatives and risk of participations in the study. The research assistants interviewed the participants only after they had provided verbal information consent. The participants were informed that there would be no immediate financial gain from participating in the study, although bus fare was reimbursed for all participants.

### **3.10 Data collection tools**

The study used the following measurement tools for data collection

*Structured demographic information questionnaire:* An English semi structured questionnaire was developed and translated into Swahili by the study team. This was administered to collect socio-demographic information from participants including (the child age and sex, caregiver's age, sex, relationship and marital status, level of education, employment status and number of children in the household)

*The quality-of-life survey short-form SF 12 (HRQoL SF 12):* The SF-12 is a brief, generic 12-item questionnaire was used to assesses eight dimensions of HRQOL which were expanded from two main components physical health (PCS) and Mental health (MCH). In Physical Health (PCS) we assessed (general health perceptions Q 74, physical functioning Q 75 and Q 76, role limitations due to physical health Q 77 and Q 78, and bodily Pain Q 81). Mental Health (MCH): assessed (role limitations due to emotional health Q 79 and Q 80, vitality Q 82, social functioning Q 85, and mental health Q 82 and 84). The health-related quality of life assessment indicates caregivers' level of functioning and their perceived wellbeing in terms of both physical and mental health.

The quality-of-life survey short-form SF 12 was adopted from the 36 items RAND Medical Outcome Survey (MOS) short form SF 36. The aim of developing SF 12 was to develop a user-friendly tool that gives a similar outcome as SF 36 (Gandek et al., 1998). The SF 36 (HRQOL instrument) was a translated, adapted and validated Kiswahili version which was equivalent to the US English SF 36 (Wyss et al., 1999). When used in the Dar es Salaam population the median internal consistency of the scale was very good at 0.81 (range 0.70 – 0.92) and the normative mean SF 36 scale scores for all eight domains were 93.8 (SD=12.3) for physical function, 84.2 (SD=30.8) for role functioning limited by physical health, 82.8 (SD=24.7) for bodily pain, 62.9 (SD=18.5) for general health, 74.9 (SD=18.5) for Vitality, 88.2 (SD=18.5) for social functioning, 86.3 (SD=30.8) for role function limited by emotional problems, and for mental health 82.2 (SD=18.5) (Wagner et al., 1999). The SF 12 has also been used among adult HIV/AIDS patients attending public clinics that were receiving anti-retroviral treatment (ART) in Tanzania (Chariyalertsak et al., 2011).

*Perceived social support:* The 12-items Multi-Dimensional Perceived Social Support Scale (MDPSS) was administered to collect information on perceive levels of social support in the past six months, with its response options using a Likert scale ranging from 1= very strongly disagree to 7= very strongly agree for each of the 12 items assessed. The items were organized in three subscales assessing social support at family (Fam), friends (Fri) and significance other (SO) levels. When used in Tanzanian populations as recommended a total score below 2.9 is

considered low social support, 3 to 5 considered moderate social support and above 5 considered higher social support (The multidimensional scale of perceived social support: Scoring guidance, 1988). This scale when used to measure perceived social support in a Ugandan sample, showed a very good Cronbach's alpha scores of 0.83 with very good internal consistencies of .82, .80 and .79, for the family, friends, and significant other subscales (Nakigudde et al., 2009)

*Parenting Stress Index:* The PSI-SF is a 36-item self-reported questionnaire designed to measure stress associated with parenting among parents of children younger than 12 years of age. The measure has three subscales, each consisting of 12 items: Parental Distress (PD), Parent-Child Dysfunctional Interaction (PCDI), and Difficult Child (DC) (Cutler et al., 2013). The PD sub-scale measures parents' perceptions of their own behavior; while the PCDI sub-scale measures the parents' view of expectations and interactions with their child. The DC sub-scale measures the parents' perceptions of their child's temperament, demandingness, and compliance. The PSI-SF also has a reliability scale (Defensive Responding) consisting of seven items from the PD scale. Respondents scoring of less than a raw score of 10 on this reliability scale, is thought to signify that parents are minimizing parenting stress. Percentile scores are easier to interpret because they describe parent's relative standing within all of the parents assessed. The PSI Parental Distress (PD) subscale provides for typical stress percentiles of 15-80, while high stress percentiles range from 81-89 and clinically significant stress percentiles from 90-100 (Cutler et al., 2013), in this study, the score for the defensive responding reliability scale was 23 (standard deviation  $\pm 5.7$ ) indicating the potential for valid results from subsequent analyses. The response items for the scale range from 1 (strongly disagree) to 5 (strongly agree) and was developed to reflect a 5th grade reading level (Cutler et al., 2013). Cronbach's  $\alpha$  is the most frequently used internal consistency (statistical reliability) statistic for composite measures (Whiteside-Mansell et al., 2007), (Pérez-Padilla et al., 2015) reported an  $\alpha$  of .91 for the PSI-SF, and .87 for the PD subscale as well as .80 and .85 for the PCDI and DC subscales respectively (Neong et al., 2018).

*Depression assessment (Patient Health Questionnaire (PHQ)-9):* This is a nine-item depression module from the full PHQ. Diagnostic and Statistical Manual version four criteria for major depression is met if 5 or more of the 9 depressive symptoms have been present at least on “more than half the days” in the past 2 weeks, and 1 of the symptoms is depressed mood or anhedonia. The severity measure score can range from 0 to 27 since each of the 9 items is scored from 0 (not at all) to 3 (nearly every day). The PHQ-9 demonstrated reliability and validity among adult males and females accessing primary health care in Dar es Salaam, with a very good Cronbach’s alpha of 0.83 and the optimal cut-off score for moderate to severe depression in this population was nine, with a sensitivity of 78% and specificity of 87%, indicating that it can serve as a useful tool in identifying patients with depression in primary care settings in Tanzania (Fawzi et al., 2020). A cut-off score of 9 or above for moderate to severe depression will be used in this study.

*Parental affiliate stigma*—We used an affiliate stigma questionnaire adapted from (Mak & Cheung, 2008) to be specific to ADHD. Parents completed five items<sup>1</sup> each answered on a 5-point metric (1 = not at all; 5 = very much). Parents completed five items, with responses scored on a 5-point metric (1 = not at all to 5 = very much). This scale assesses the affective (item a), cognitive (items b and c), and behavioral (items d and e) components of caregiver affiliate stigma experiences after the onset of the child’s mental illness. The mean of all items provides a composite score, with higher scores indicating greater stigma. The psychometric properties of the 5-item Affiliate Stigma Scale reported has been positive, including very good internal consistency ( $\alpha = 0.83$ )(Das et al., 2017)

### **3.11 Data collection process**

#### **3.11.1 Research assistants training**

One research assistant was recruited for collection of data (a registered doctor working in the psychiatry department) Training for data collection was done seven days prior to initiation of data collection. Training included the translation and adaptation of the questionnaires, other data collection tools and procedures related to sampling and ethical issues. The first five patients were rated by the principle investigator and research assistant at the same time to

ensure inter examiner reliability. Findings demonstrated that there were no major inconsistencies between raters. Available time did not allow for a full assessment of inter-rater reliability.

### **3.11.2 Data collection procedures**

The principal investigator conducted eligibility screening and consenting for all the eligible participants. Eligible participants were given a full explanation of what the study would require of them and the importance for future improvements in treatment modalities including the psychosocial programs related to ADHD management among caregivers attending outpatient services for children with ADHD at the Muhimbili National Hospital. The minimal risk potential of participation included distress when answering questions and participants informed that research assistants would respect when this happens and give participants time to collect themselves as well as asking their permission to continue with the interview or not. Participant were informed that at any time, they could request not to continue with the interview and that this would be respected with no consequences to services provided or their relationship to staffs in the child and adolescent psychiatry clinic. The research assistant administered the study structure interview tool in Swahili, using face to face interviews and paper and pencil for data collection. Filled data forms were collected by research assistant and checked for completeness prior to allowing the participant to leave the clinic. Completed forms were then submitted to the principal investigator for data entry and analysis.

### **3.12 Data Management and Analysis**

The data obtained were storage by the principal investigator. Though regular checks were done in the field to ensure non-missing or inconsistencies of data. Data was entered in the computer, coded, cleaned and data analysis was conducted using the statistical package for the Social Sciences (SPSS for window version 23). The descriptive statistics are summarized as frequencies distribution tables for socio-demographic and biopsychosocial risk factors of HRQoL were summarized with percentages ,percentiles or means with standard deviation(SD). The outcome of interest or dependent variable was summarized with health-related quality of life domains.



### 3.12.1 Hypotheses

It was hypothesized that, there would be an association between caregivers HRQL and the child's and caregivers age and sex (biological). Furthermore; and social factors in a caregiver's life including reported marital and employment status, educational attainment, number of children below 18 years in the home, as well as perceived social support. Caregiver psychological factors including their level of affiliated stigma, stress and depressive symptoms as well as clinically significant depression

### 3.12.2 Analysis Plan

#### **Independent Variables:**

##### *Biological and socio-demographic covariate measures*

The independent risk factors included biological factors related to some of the socio-demographic measures; Child age in months, sex of the child dichotomized as male and female. Caregiver's; age in years was grouped into two main group ( $\leq 35$  years and  $\geq 36$  years), sex dichotomized as male and female, relationship to child dichotomized as father or mother, marital status is grouped into two statuses of married and unmarried and divorced/separate. Education level is also grouped into three groups never went to school, Primary school, Secondary/College/university and Postgraduate levels of education. Occupation was grouped into three statuses of the employed, unemployed and self-employed, number of children below 18 years in the household were also grouped in one child, two children or three children and more. The biological and other socio-demographic risk factors were then summarized in frequency distribution tables.

##### *Psychosocial factors of interest included:*

- a) *Caregivers perceived social support during the past six months:* The multidimensional perceived social support scale results were analyzed by mean of the total score of 12 items was categorized into three levels low social support below 2.9 scores, moderate level social support 3 to 5 score, and high-level social support above 5 score.
- b) *Caregiver's affiliated stigma:* Affiliated stigma experiences of caregivers after diagnosis of ADHD was were measured by completing five items each answered on a 4-point

metric (1=strongly disagree; to 4=strongly agree) assessing affective, cognitive and behavioral components of affiliated stigma. Results were analyzed by using mean scores and dichotomized as low and higher levels of affiliated stigma.

- c) *Caregiver stress in the past six months*: The PSI-SF three subscales of Parental Distress (PD), Parent-Child Dysfunctional Interaction (PCDI), and Difficult Child (DC), with a total of 36 items each answered on 5-point metric (1=strongly disagree;5=strongly agree) was computed a total mean score and then categorized into four stress levels; low, typical, high and clinically significant stress.
- d) *Caregiver's level of depression in the past two weeks prior to assessment*: The PHQ-9 severity score with a range from 0 to 27 was computed and then dichotomized at a cut-off score of 9 and above for clinically significant depression, and scores below 9 for its absence.

### **Dependent Variables:**

*Health related quality of life SF-12*: General scoring for the SF-12 and aggregating them into multi-items scale was done in steps for data entry. The reversing of scores for Q74, Q81, Q82 and Q83 then summation of items in the same scale (PF: Q75+Q76, RP: Q77+Q78, RE: Q79+Q80 and MH: Q82+Q84) to ensure all scores were in the same direction of higher or lower levels of HRQOL items. The Transformation of the raw scale scores of the 0-100 scale to get Norm Based Scores (NBS) of each SF-12 was accomplished using the recommended formula (E. Jr & Keller, 1998). The mean and SD used in NBS come from the 1988 general US population. Finally, aggregate physical HRQoL (PCS) and mental HRQoL (MCS) scores were standardized using Linear Z score transformation so that all 8 items of the SF-12 items scale had a mean of 50 and SD of 10.

### ***Bivariate analysis***

Independent T tests were used for the continuous outcomes (Physical HRQoL and Mental HRQoL) to determine associations with the independent variables. , association with p-value <0.05 were considered statistically significant and included in liner regression analyses

models. All subsequent analyses were conducted separately for each measure of HRQOL. For binary measures (e.g. age in months, Sex of the child, caregiver sex, caregiver age in years, caregiver relationship, marital status, parental social support, affiliated stigma and depression), a 2-group test was used to compare mean the HRQOL scores. For discrete measures with more than two levels (e.g., stress, lever of education, occupational, number of children in the household) analyses one way Anova tests were used to compare the HRQOL scores across the groups.

### ***Multivariable analysis***

All variables that had a significant bivariate correlation to HRQoL that is, sex, age marital status, educational level, occupational, number of children in the house hold, perceived social support, parental stress, affiliated stigma and depression were entered as independent variables and each HRQoL domain was entered as a dependent variable.

Standard linear regression analyses were used to determine the strength of associations as well as the independence of association of risk factors identified in bivariate analyses associations with the HRQoL outcome at p- value 0.05. The standardized (Beta) coefficients and their 95.0% Confidence Intervals, R Square, adjusted R Squares , are reported and p – values of < 0.05 considered as statistically significant independent associations.

## CHAPTER FOUR

### 4.0 RESULTS

This chapter provides the results of the detailed analysis of the data collected. The results on the biological/sociodemographic characteristics, and psychosocial factors (perceived social support, affiliated stigma, parenting stress and depression) associated with HRQoL of the caregivers of the children with ADHD at Muhimbili National Hospital. A total of 64 caregivers were recruited and completed data was available for all study participants.

#### 4.1 Socio-demographic characteristics of the study population

As summarized in Table 1, the participant's response rate was 100% (N=64). Caregivers of children with ADHD, were aged between 20-60 years, with a mean age (standard deviation, SD) of 34.9 ( $\pm$ 9.6) years. Among the 64 participating caregivers, the majority had children age 72 months or younger, with mean age (SD) of 78.34 $\pm$ 33.79 months. More than half of the children were male (n=55, 85.9%). Most (67.2%; n=43) caregivers were mothers, 73.4% (n=47) were either married or living with partners, and 45.3% (n=29) reported a postgraduate level of education and more than half (54.7%, n=35) were self-employed. Almost 50% (48.4%; n=31) reported living with more than three children in the home.

**Table 1: Distribution of socio-demographic characteristics of caregivers of children with Attention Deficit Hyperactivity Disorder, in Dar es Salaam, Tanzania, 2021**

Socio-demographic characteristic assessed	N(%)	Mean(SD)
Age of the child with ADHD in months		78.34(33.79) Range 40-192
≤72 months	37(57.8)	
≥73 months	27(42.2)	
Sex of the child		
Male	55(85.9)	
female	9(14.1)	
Caregivers sex		
Male	21(32.8)	
Female	43(67.2)	
Caregivers age in years		34.8 (9.6)Range 21-60
≤35 years	35(54.7)	
≥36 years	29(45.3)	
Caregiver's relationship to the child with ADHD		
Father	21(32.8)	
Mother	43(67.2)	
Marital status		
Married/living with partner	47(73.4)	
Unmarried/Divorced/separate	17(26.6)	
Level of education		
Primary school	18(28.1)	
Secondary/College/university	17(26.6)	
Postgraduate/master	29(45.3)	
Occupational		
Employed	25(39.1)	
Unemployed	4(6.3)	
Self employed	35(54.7)	
Number of children in caregiver household		
One	20(31.3)	
Two	13(20.3)	
Three or more	31(48.4)	

#### 4.2 Distribution of psychosocial risk factors of interest

In Table 2, summarized frequency distributions and mean scores are presented for the study biopsychosocial risk factors of interest. These include perceived social support in the past six months, affiliated stigma since child's ADHD diagnosis, past six months' caregivers stress and recent depression severity. The perceived social support mean score (SD) was 52.27( $\pm$ 8.80). While none of the participants scored at low levels of social support from family, friends or others, most reported moderate levels of support (85.9%, N=55) with far fewer reporting high levels of social support (14.1%; N=9).

**Table 2: Frequency distributions with mean scores of psychosocial risk factors for HRQoL of caregivers of children with attention deficit hyperactivity disorder, in Dar es salaam, Tanzania, 2021**

Risk factors of interest	N(%)	Mean(SD)
Perceived social support in past six months		52.27(8.80)
Moderate (score 3-5)	55 (85.9)	
High(Score >5 )	9 (14.1)	
Affiliated stigma caregiver experience after the onset of the child mental illness		12.31(2. 64)
Low $\leq$ 12	34 (53.1)	
High 13+	30 (46.9)	
Parenting stress in past six months		123.14(9.92)
Low stress	8(12.5)	
Typical stress	43(67.2)	
High Clinically significant stress	13(20.3)	
Depression in past two weeks		3.34 (1.77)
Absence of depression(<9score)	61 (95.3)	
Depression ( $\geq$ 9score)	3 ( 4.7)	

Also reported in Table 2 is the caregivers affiliated stigma score after diagnosis of ADHD, that had a mean score (SD) of 12.31 ( $\pm 2.64$ ). While just over half the caregivers experienced mild levels of such stigma, almost 47% (46.9%) had relatively higher levels of affiliated stigma. Parenting stress in past six months had a mean score (SD) of 123.14 $\pm$ 9.92, with most categorized as having experienced typical stress (67.2%; n=43), 20.3%, (n=13) experienced high or clinical stress and far fewer reported low stress levels (12.5%; n=8). Caregivers past two weeks mean depression scores (SD) were 3.34 ( $\pm 1.77$ ), with 4.7% (n=3) scoring above the threshold for probable depression.

### 4.3 Quality of Life of Participants

Table 3 summarizes caregivers HRQoL mean scores (SD) on the broad physical (48.0 $\pm$ 3.8) and mental health functioning (43.6 $\pm$ 10.8) dimensions of this measure, as well as for all its eight sub dimensions.

**Table 3: Summarized caregiver HRQoL mean scores for broad and specific dimensions of the SF-12 in Dar es Salaam, Tanzania, 2021**

<b>HRQoL broad and sub-dimensions</b>	<b>Mean <math>\pm</math> SD</b>
<b>Health related quality of life broad categories</b>	
<i>Physical Functioning</i>	48.0 $\pm$ 3.8
<i>Mental Functioning</i>	43.6 $\pm$ 10.0
<b>Health related quality of life sub-dimensions</b>	
<i>Physical Health</i>	55.5 $\pm$ 3.8
<i>Role Physical</i>	29.1 $\pm$ 1.9
<i>Body Pain</i>	49.6 $\pm$ 10.5
<i>General Health</i>	42.0 $\pm$ 8.6
<i>Energy</i>	62.4 $\pm$ 10.6
<i>Social Function</i>	21.0 $\pm$ 3.5
<i>Role Emotional</i>	49.5 $\pm$ 11.6
<i>Mental Health</i>	54.0 $\pm$ 10.5

The results generally show better physical than mental HRQoL domain mean scores within these two broad categories of the measure. Within the sub-dimensions of HRQoL, particularly low mean scores were reported for social functioning, role physical functioning, role emotional functioning and general health, all of which had mean scores below 50.0.

#### **4.4 Associations of biopsychosocial risk factors of interest with HRQoL**

Table 4, presents summary results for the bivariate associations between the study biopsychosocial risk factors of interest and the two broad domains (mental and physical) of assessed caregivers reported HRQoL.

##### **4.4.1 Biological risk factors**

The risk factors included in these analyses were the age and sex of the child with ADHD and the caregiver, and associations were determined separately for the physical functioning and mental functioning broad domains of HRQoL. Two biological risk factors, one significantly and one marginally, were associated with the mental HRQoL domain and one with the physical HRQoL domain. Having a male compared to a female child with ADHD was significantly associated with lower HRQoL mean scores of the mental functioning domain (mean 42.8 SD±10.6 versus mean 48.1 SD± 1.9 respectively; p-value 0.001); and marginal associations were noted for lower HRQoL mean scores in the mental functioning domain if the child was younger than 72 months compared to older (41.7 SD± 12.2 versus 46.1 SD ±5.2 respectively, p=0.05). Older caregivers had lower physical HRQoL mean scores (46.5 SD±3.3), than younger caregivers (49.1 SD ± 2.6; p=0.006). Variations in both domains mean scores did not vary by the sex of the caregiver or his/her relationship to the child as a mother or father.

##### **4.4.2 Social risk factors**

Two social risk factors, level of education and the number of children in the household were associated with both physical and mental domains of HRQoL. Marital status was associated with physical HRQoL only, while both occupation and perceived social support in the past six months was associated with mental HRQoL.



As summarized in Table 4, a “U” shaped association was evident for associations between level of education and both mental and physical HRQoL domain mean scores in caregivers. The mental HRQoL mean score for those that had attained secondary to college/undergraduate levels of training was lower (mean score mental HRQoL 33.9 SD± 13.7) compared to mean scores for caregivers with primary levels only of education as well as in those with post-graduate levels of education (mean score mental HRQoL 45.0 SD± 6.4 and mean score mental HRQoL 48.4 SD ± 3.6 respectively;  $p < 0.001$ ). However, the mean physical HRQoL score of caregivers that had attained secondary to college/undergraduate levels of training of 50.0 SD ± 2.8, were significantly higher than in caregivers reporting primary levels only of education and in those with post-graduate levels of education (mean physical HRQoL scores 47.2, SD ± 5.3 and 47.2 SD ± 2.6 respectively;  $p = 0.024$ ). Caregivers mean mental HRQoL was lowest in those reporting having one child (mean score 37.7 SD± 14.0) compared to two or three or more children in the home (41.6 SD ± 8.3 and 48.3 SD ± 3.7 respectively;  $p < 0.001$ ). For physical HRQoL mean scores were lowest in those reporting having three or more children in the home (46.2 SD± 3.6), compared to one or two children (49.0 SD ± 2.3 and 50.4 SD ± 4.2 respectively,  $p = 0.001$ ). Physical but not mental HRQoL mean scores of married caregivers were significantly lower than in those not living with a partner due to being single, divorced or separated (47.3 SD ± 3.7 versus 49.7 SD ± 3.6;  $p = 0.02$ ). Mental but not physical HRQoL mean scores were lowest in those reporting lack of employment (47.7 SD ± 4.2) compared to those that were self-employed or employed (48.1 SD ± 4.7 and 47.1 SD ± 3.3) respectively;  $p = 0.011$ ). Finally, the mental HRQoL domain mean score was lower in caregivers reporting moderate (42.9 SD ± 10.9) compared to higher perceived social support (48.1 SD ± 3.6;  $p = 0.008$ ).

#### **4.4.3 Psychological Factors**

Affiliated stigma and clinically significant levels of depressive symptoms were associated with both the physical and mental domains of HRQoL in caregivers. Past six months’ report of parenting stress was however only associated with the mental domain of caregivers HRQoL.

For both mental and physical HRQoL domains, higher compared to lower levels of reported affiliated stigma by caregivers was associated with significantly lower HRQoL mean scores (40.4 SD  $\pm$  12.0 versus 46.4 SD  $\pm$  6.8;  $p=0.02$ ; and 46.9 SD  $\pm$  4.2 versus 48.9 SD  $\pm$  3.2 respectively;  $p=0.04$ ). Furthermore, both domains of HRQoL probable depressive disorder was associated with significantly lower mental and physical HRQoL mean scores (16.5 SD  $\pm$  0.0 versus 44.9 SD  $\pm$  8.2 respectively;  $p=0.02$ ; and 50.6 SD  $\pm$  0.0 versus 47.8 SD  $\pm$  3.8 respectively;  $p<0.001$ ). Parenting stress amongst caregivers was associated with the mental HRQoL domain mean score, with the score being significantly lower for clinically significant stress (mean 36.2 SD  $\pm$  12.7), compared to with typical and low reported stress levels (50.3 SD  $\pm$  4.8 and 44.6 SD respectively;  $p=0.003$ ). See Table 4.

**Table 4: Unadjusted associations between biopsychological risk factors of interest in caregivers of children with ADHD and their HRQoL, in Dar es Salaam, Tanzania, in 2021**

Biopsychosocial Risk factors in the lives of caregivers of children with ADHD	Broad Domains of HRQoL			
	SF 12-Physical		SF12-Mental	
	Mean(SD)	p	Mean(SD)	p
Age of the child in months		0.744		0.055
≤72 months	47.8(4.7)		41.7(12.2)	
≥73 months	48.1(2.8)		46.1(5.2)	
Sex of the child		0.783		<b>0.001</b>
Male	47.9(4.0)		42.8(10.6)	
female	48.1(1.6)		48.3(1.9)	
Caregivers sex		0.092		0.948
Male	46.7(4.6)		43.7(10.1)	
female	48.5(3.3)		43.5(9.7)	
Caregivers Age in years		<b>0.006</b>		0.061
≤35	49.1(2.6)		41.6(12.2)	
≥36	46.5(4.4)		46.0(5.9)	
Caregiver relationship to child with ADHD		0.092		0.948
Father	46.7(4.5)		43.7(10.8)	
Mother	48.5(3.3)		43.5(9.7)	
Marital status		<b>0.023</b>		0.078
Married	47.3(3.7)		45.2(8.5)	
Unmarried/Divorced/separate	49.7(3.6)		39.1(12.6)	
Level of education		<b>0.024</b>		<b>0.000</b>
Primary school	47.2(5.3)		45.0(6.4)	
Secondary/College/university	50.0 (2.8)		33.9(13.7)	
Postgraduate/master	47.2(2.6)		48.4(3.6)	
Occupational		0.487		<b>0.011</b>
Employed	48.0(1.8)		47.7(4.2)	
Unemployed	45.7(4.0)		47.1(3.3)	
Self employed	48.1(4.7)		48.1(4.7)	
Number of children in caregiver household		<b>0.001</b>		<b>0.000</b>
One	49.0(2.3)		37.7(14.0)	

Biopsychosocial Risk factors in the lives of caregivers of children with ADHD	Broad Domains of HRQoL			
	SF 12-Physical		SF12-Mental	
	Mean(SD)	p	Mean(SD)	p
Two	50.4(4.3)		41.6(8.3)	
Three or more	46.2(3.6)		48.3(3.7)	
Perceived social support in past six months		0.254		<b>0.008</b>
Moderate(3-5score)	48.1(3.8)		42.9(10.9)	
High(>5 score)	46.7(3.3)		48.1(3.6)	
Affiliated stigma caregiver experience after the onset of the child mental illness		<b>0.039</b>		<b>0.019</b>
Low $\leq 12$	48.9(3.2)		46.4(6.8)	
High 13+	46.9(4.2)		40.4(12.0)	
Parenting stress in past six months		0.890		<b>0.003</b>
Low stress	48.3(1.1)		50.3(4.8)	
Typical stress	47.8(3.5)		44.6(8.6)	
High/Clinically significant stress	48.2(5.5)		36.2(12.7)	
Depression in past two weeks		<b>0.000</b>		<b>0.000</b>
Absence of depression	47.8 (3.8)		44.9 (8.2)	
depression	50.6 (0.0)		16.5 (0.0)	

#### 4.5 Factors independently associated with HRQoL

Tables 5a and 5b summarize the findings of linear regression models describing the direction, strength and the independence of associations between risk factors identified in bivariate analyses and caregivers HRQoL, disaggregated by physical and mental health functioning domains.

For the physical HRQoL domain, the levels of caregiver's educational attainment and caregivers affiliated stigma were significant and independent risk factors for the physical HRQoL domain. Caregivers that had attained secondary to undergraduate levels of education scored .473 points higher physical HRQoL scores than those that had attained a post-graduate level of education on ( $\beta=0.473$ ; (95% CI 1.375, 6.638);  $p=0.004$ ). Furthermore, caregivers with higher compared to lower affiliated stigma had a decrease by -.357 points in physical HRQoL scores ( $\beta=-0.357$ ; 95% CI -4.651, -0.697;  $p=0.009$ ). (See Table 5a).

**Table 5a: Regression of risk factors of interest on the physical HRQoL domain assessed in caregivers of children with ADHD in Dar es Salaam, Tanzania, in 2021**

Risk factor assessed	SF- 12 Physical HRQoL Domain R <sup>2</sup> =0.388				
	B	p-value	Partial r <sup>2</sup>	95.0% Confidence Interval (CI)	
				lower Bound	Upper Bound
Caregivers age in years ≤35(ref) ≥36	-0.189	0.210	-0.169	-3.674	0.826
Marital status Married(ref) Unmarried/Divorced/separate	0.209	0.202	-0.169	-0.974	4.508
Number of children in caregiver household 1(ref) 2 3+	-0.066 -0.137	0.693 0.475	-0.053 -0.097	-3.694 -3.867	2.472 1.823
Level of education Primary school Secondary/College/university Postgraduate (ref)	0.179 <b>0.473</b>	0.180 <b>0.004</b>	0.180 0.380	-0.709 1.375	3.690 6.638
Caregivers level of affiliated stigma Low (score less than 12) (ref) High (score 13 and higher)	-0.357	<b>0.009</b>	-0.343	-4.651	-0.697
Depression in past two weeks Absence or mild symptoms (ref) Moderate to severe symptoms	-0.058	0.688	-0.054	-6.132	4.076

These findings are adjusted for the other risk factors included in the model as summarized in Table 5a. Regression of risk factors identified on the mental HRQoL domain, showed low levels of educational attainment, the number of children below the age of 18 years in the home, parenting stress and moderate to severe depressive symptoms independently predicted this HRQoL domain, as summarized in Table 5b. Caregivers with between secondary to undergraduate levels of education scored -0.52 lower on the HRQoL domain measure compared to their graduate peers ( $\beta=-0.520$ ; 95% CI -19.325, -4.112;  $p=0.003$ ). Being in the group of caregivers with two compared to three children below the age of eighteen in the household was associated with .316 points higher scores in the mental HRQoL domain. Both higher parental stress and past 2 weeks' depressive symptoms at moderate to severe levels were independently associated with a decrease of -0.274 points ( $\beta=-0.274$ ; 95% CI -17.546, -1.139;  $p=0.03$ ) and -0.435 points ( $\beta=-0.435$ ; 95% CI -30.061, -10.830;  $p<0.001$ ) respectively of the mental HRQoL domain score. These findings are adjusted for the other risk factors included in the model as summarized in Table 5b.

**Table 5b: Regression of risk factors of interest on the mental HRQoL domain assessed in caregivers of children with ADHD in Dar es Salaam, Tanzania, in 2021**

Risk factor assessed	SF- 12 Mental HRQoL Domain R <sup>2</sup> =0.673				
	B	p-value	Partial r <sup>2</sup>	95.0% Confidence Interval	
				lower Bound	Upper Bound
Level of education					
Primary school	-0.206	0.259	-0.156	12.549	3.453
Secondary/College/university	-0.520	<b>0.003</b>	-0.394	-19.325	-4.112
Postgraduate (ref)					
Employment status					
Employed(ref)					
Unemployed	-0.066	0.563	-0.081	-11.961	6.578
Self employed	0.000	0.998	0.000	-7.536	7.553
Number of children in caregiver's household					
One (ref)					
Two	0.185	0.255	0.158	-3.398	12.530
Three or more	0.316	<b>0.007</b>	0.362	1.780	10.776
Caregivers reported level of affiliated stigma after the onset of the child's mental illness					
Low ≤12(ref)					
High 13+	-0.012	0.917	-0.015	-4.964	4.472
Parenting stress in past six months					
Low stress (ref)					
Typical stress	-0.187	0.092	-0.232	-8.598	0.666
High/Clinically significant	-0.274	<b>0.026</b>	-0.302	-17.546	-1.139
Perceived social support in past six months					
Moderate	0.022	0.816	0.032	-4.822	6.097
High(ref)					
Depression in past two weeks					
Absence or mild symptoms (ref)					
Moderate to severe symptoms	-0.435	<b>0.000</b>	-0.509	-30.061	-10.830-

## CHAPTER FIVE

### 5.0 DISCUSSION

The study aimed to determine the factors associated with the health-related quality of life for the caregivers of children with attention deficit hyperactivity disorder; a case of Muhimbili National Hospital. We determined a mean score of the HRQoL physical functioning domain of  $48.0 \pm 3.8$  and the mental functioning domain of  $43.6 \pm 10.8$  amongst caregivers. Independent risk factors associated with poor HRQoL for one or other of the mental or physical HRQoL domains were; high caregivers reported level of affiliated stigma and level of education (physical HRQoL domain) level of education, number of children in caregiver's household, parenting stress in past six months and depression (mental HRQoL domain). These will be discussed in detail below.

#### 5.1 Levels of educational attainment and caregiver HRQoL;

Levels of educational attainment were independently associated with both domains of HRQoL but not in similar directions. For the physical dimension of HRQoL, this was poorest in caregivers with a graduate compared to undergraduate education and not significantly different between graduate and primary school level education of caregivers. For the emotional dimension of HRQoL, compared to caregivers with undergraduate educational levels, those with postgraduate levels had higher levels of HRQoL, while differences in this group and those with primary education were not significant. These results are contrary to others that show inverse relationships i.e., higher levels of education attainment associated with better reported HRQoL (Azazy et al., 2018; Chen et al., 2016; Hadi et al., 2013; Xiang et al., 2009). These results need to be interpreted with caution as though the level of education in Tanzania has increased the population average is still of most Tanzanians having predominantly attained basic education (preprimary and primary school) (URT; Development Plan, 2018); our sample over-represented persons with higher levels of education. The sample hence may reflect a population sub-set with higher education and greater access to the limited child and adolescent psychiatry services in the country. Furthermore, having postgraduate



qualifications being associated with poor HRQoL in the physical functioning domain, is not easy to explain, speculative explanations may include more occupational demands and older age in this analysis, making it more difficult to both meet the physical needs of a very active child and other social and work responsibilities requiring physical engagement. In Future research, better detailing of the physical and mental domains by education levels may benefit using experiential data (qualitative study) which would help provide an in-depth understanding of the way caregivers living with the child with ADHD manage their day-to-day situations.

### **5.2 Numbers of children in the home and caregiver HRQoL**

Having three or more children in the home compared to fewer, was associated with significantly higher mean scores for the mental functioning dimension of caregivers HRQoL. A plausible explanation could be cultural, in that older siblings may assist in the care of a child with ADHD and perhaps reduce parenting stress and improve the caregivers HRQoL. However, this was the opposite for the physical functioning domain which shows no association with HRQoL. This is contrary to what has been reported in other studies example Iran having more than one child shown to improve physical functioning domains (Hadi et al., 2013). In Brazil regarding the number of children in the home, having more than one child was associated with low mean score of caregiver HRQoL(Silva et al., 2016).

### **5.3 Caregiver parenting stress, social support and HRQoL**

Parenting stress has been shown to reduce the HRQoL mental functioning of the caregiver of ADHD. Other studies have similarly shown impairments in HRQoL, when caregiver parenting stress is high (Cussen et al., 2012). Caregiver stress includes the health status of the recipient, the existence of any problematic behaviors from the care recipients, the level of daily dependency of recipients, family relationships, and occupational demands that can result from change in this variable (Pearlin et al., 1990) Social support has been consistently reputed to reduce caregiver stress.(Glozman et al., 2004). It is hence counter-intuitive to find an association between parental stress and low score in the mental functioning domain of

HRQoL. In the analysis, we did not find a significant association between parenting social support and the HRQoL mental domain. It is likely the measure used was sufficiently countermeasure low level of social support as well score low in social support. It is also possible that the study context is characterized by high social capital and this explains social measure. Future studies should consider culture adapted power social support measure in the population subgroup of the caregiver of children with ADHD

#### **5.4 Caregiver affiliated stigma and HRQoL**

Affiliated stigma has been reported to not only enhance caregiver psychological distress but also reduce HRQoL. In the adjusted analysis higher levels of affiliated stigma compared to lower levels was significantly associated with a reduction physical functioning mean scores. A similar significant association was found between reported high compared to lower levels of affiliated stigma and lower mental functioning mean scores in the adjusted analyses. The findings of associations between high affiliated stigma and lower reported levels of HRQoL has been observed in other studies.(Mak et al, 2008); Mak et al, 2012; (Chang et al., 2016) (Wu et al ., 2016);(DosReis et al., 2010);(Chang et al., 2016);(Fernández et al ., 2004); (Zhang et al., 2018).

#### **5.5 Caregiver moderate to severe depression and HRQoL**

Caregivers of children with ADHD scoring positive for probable depression compared to not, were also significantly more likely to have lower mean scores on the mental functioning HRQoL domain. This finding supports what has been observed in other studies(Chen et al., 2014);(Cussen et al., 2012). The mechanism of the association may be partly due to low passive social support which has been reported to be associated with increased risk for depression and worse HRQoL.(Chen et al., 2014); (Minichil et al., 2019). However, more analysis is needed to allow for this conclusion.

## CHAPTER SIX

### 6.0 CONCLUSION AND RECOMMENDATION

#### 6.1 Conclusion

Caregivers of children with ADHD experience many psychological and social challenges. These include level of education, affiliated stigma, number of children in caregiver household, parenting stress in six months and depression. The study found the caregivers of children with ADHD at Muhimbili National hospital mean score of HRQoL Physical function  $48.0 \pm 3.8$  and Mental function  $43.6 \pm 10.8$  dimension. Independent risk factors associated with physical function were level of education and affiliated stigma and mental function were lever of education, number of children in caregiver household, parenting stress in past six months and depression. Professional assistance, public awareness of children with ADHD and caregiver challenges. Social support, government, private sector, and NGOs are important in addressing these challenges.

#### 6.2 Recommendation

Based on the finding of this study The following recommendation are made

1) *Research;*

(a) There is need of explore the feasibility and acceptability including screen for parenting stress, depression, social support and affiliated stigma of caregiver of children with ADHD and HRQoL as well as occurs effect on the western culture

(b) Further research is needed to find measure for perceived social support and Parenting stress tool which has been validated for screening instrument also local cultural acceptance context in caregivers of children with ADHD given its important to improve.

2) *Health services practice:* There is need to improvements treatment modalities and psychosocial programs related to ADHD management among caregivers attending out-patient services for children with ADHD at the Muhimbili National Hospital.

3) *Policy*: The government of Tanzania under the ministry of Health, Community Development, Gender, Elderly and Children (MoHCDEC) consider police on adolescent Mental Health in Tanzania given the burden on ADHD and the HRQoL of caregiver. Also through acceleration of action, Policy guideline and Plan of action can be implemented and applied at Muhimbili National Hospital.

### **6.3 Study limitations and mitigation**

- 1) The data collection relied on self-reported information from study participants, hence there is always a risk of over reporting or under- reporting phenomena depending on what participants may have believed the researchers wanted to hear (desirability bias). Bias was reduced by framing the questions in a positive light, using questions requiring thought with more than one option for responses and keeping sensitive questions at the end of the questionnaire.
- 2) The tool used to assess parenting stress and parenting social support have not been validated for use in the East African region countries including Tanzania. There should be a consideration in the future to validation these screening instruments for the local cultural context to facilitate evidence-based parenting stress and parenting social support assessments.
- 3) The standard population mean scores for HRQoL dimensions that were used in this study are based on data from the United Kingdom. However, this is also the case for all the SSA studies whose findings were reviewed as a basis of my literature review. Hence differences in the findings between this and studies from other non-SSA countries may be influenced by the same conclusions found in studies from SSA. .Further studies from Sub Saharan countries are needed to determine standard population means for HRQoL.

#### **6.4 Strengths**

- 1) This is the first study in Tanzania to determine the HRQoL of caregiver of a child with ADHD and associated risk factories of interest.
- 2) The methodology part was well-designed, sample was representative of study population and relatively well analyzed
- 3) Furthermore, the sample of children with ADHD was derived from an evidence-based assessment tool (K-SADs), currently being piloted for implementation in order to derive a diagnosis of ADHD at the study clinic.

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## APPENDICES

### **Appendix I: Informed Consent Form-English**

To be read and questions answered in a language in which the study subject is conversant (English or Kiswahili)

My name is Patricia Steven Kassange, I am pursuing a master's degree in Psychiatry and mental health at Muhimbili the University of Health and Allied Sciences. I am doing a study Health-Related Quality of Life of the caregivers of the children with mental health disorders as part of my degree award fulfillment. Being one among the caregiver attending psychiatry and mental health pediatric clinic at Muhimbili; I would like to ask you to participate in this study. First I will explain to you about the study and I will be ready to answer any question that you have.

This study aims to determine the health-related quality of life of caregivers and the association between sociodemographic data, depression, affiliated stigma, stress and social support of caregiver of the child with attention deficit hyperactivity disorder (ADHD).

This study will be conducted by me under my supervisor.

This is an academic research and you are required to understand the following which applies to all in the research

Your participation is completely voluntary and you may withdraw consent at any time in the course of the interview

Refusal to participate will not in any way affect your health services/benefits which you are entitled

After reading the explanation, don't hesitate to ask any questions in case you need clarifications

I will assess you using an instrument which will take about 30 to 45 minutes

No invasive procedures such as drawing blood will be involved

All information obtained from this study will remain confidential. Code numbers instead of your name will be used in this study for identification.

There will be no direct benefits to you. However, the overall study will be of benefit for providing information that can be used to improve treatment modalities and psychosocial programs related to management among caregiver. In understanding of caregiver experiences in providing care for their children with ADHD will help health service providers and social service networks to understand the needs of caregivers when targeted caregiver interventions are planned and assess the effectiveness and relative different treatment as well as health services evaluation.

If you have any questions related to this study, or your health you can contact principle researcher 0713-231065 or my lead supervisor Prof Sylvia Kaaya at the Department of Psychiatry and Mental Health, Muhimbili University Health and Allied Sciences or. you can also contact the chairperson of the Research Senate and Publication Committee, P.O. Box 65001 Dar es Salaam.

I the undersigned do hereby volunteer to participate in this study. Nature and purpose have been fully explained to me.

I understand that all the information obtained will be used for this study only.

Signed..... Date.....

Witnessed.....Signature.....Date.....

## **Appendix II: Fomu ya Ridhaa-Swahili**

FOMU YA RIDHAA KUSHIRIKI KWENYE UTAFITI KUHUSU KIWANGO CHA UBORA WA MAISHA KIAFYA YA MLEZI WA MTOTO MWENYE TATIZO LA UPUNGUFU WA UMAKINI KUTOKANA NA UTENDAJI WA KUPITA KIASI KATIKA KILNIKI YA WATOTO IDARA YA AFYA NA MAGONJWA YA AKILI KATIKA HOSPITALI YA TAIFA MUHIMBILI

Jina langu ni Patricia Steven Kassange

Ninatokea chuo kikuu cha tiba na afya Muhimbili katika idara ya afya na magonjwa ya akili ninafanya, utafiti kuhusu kiwango cha ubora wa maisha kiafya ya mlezi wa mtoto mwenye tatizo la upungufu wa umakini kutokana na utendaji wa kupita kiasi katika kliniki ya watoto Idara ya afya na magonjwa ya akili katika Hospitali ya Taifa Muhimbili

Ikiwa huu ni utafiti wa sayansi ya tiba unapaswa ufahamu yafuatayo kabla ya kushiriki;

### **Dhumuni la Utafiti huu**

Kama nilivyo sema hapo awali dhumuni nikufanya utafiti kuhusu kiwango cha ubora wa maisha kiafya ya mlezi wa mtoto mwenye tatizo la upungufu wa umakini kutokana na utendaji wa kupita kiasi katika kliniki ya watoto Idara ya afya na magonjwa ya akili katika Hospitali ya Taifa Muhimbili

### **Namna ya kushiriki**

Ushiriki wako kwenye utafiti huu ni wa hiari kabisa na unaweza kukataa kushiriki au kusitisha mahojiano wakati wowote. Kukataa kushiriki hautaingilia huduma zako za tiba wala faida unaotakiwa kuzipata hapa kliniki.

Unaweza kuuliza swali lolote pale unapona kuna sababu. Kama ukikubali kushiriki mahojiano yataendeshwa kwa kutumia dodoso maalum.

### **Madhara**

Ikiwa wakati unajieleza ukipata kikwazo na kuona unahitaji mshauri nasaha au mtoa huduma wa afya ya akili kwa mazungumzo zaidi tutakuwa tayari kusaidia

**Usiri**

Taarifa zako utakazozitoa hazitawekwa hadharani kwa namna yeyote ile kwa hiyo ushiriki wako hautafahamika. Jina lako au taarifa zozote zinazokutambulisha hazitaambatanishwa na taarifa zako utakazozitoa.

Mwisho wa ufafiti taarifa hizi zitafungiwa na baadaye kuharibiwa baada ya kuwekwa na kutunzwa kwenye mfumo wa elektroniki

**Kumbuka**

Hakutakuwa na faida ya moja kwa moja kwako kutokana na utafiti huu ila matokeo ya utafiti yatasaidia katika ubohoresaji wa mpango wa tiba kwa wagonja na walezi wa mtoto mwenye tatizo la upungufu wa umakini kutokana na utendaji wa kupita kiasi

**Nani wa kumuuliza**

Kama una maswali zaidi ambayo ungependa kuuliza kuhusiana na utafiti huu, tafadhali wasiliana na

Mtafiti Mkuu

Patricia Steven Kassange

Idara ya magonjwa ya akili

Chuo Kikuu cha afya Muhimbili

Mwenyekiti wa kamati ya utafiti na machapisho ya chuo

S.L.P. 65001 Dar es salaam, Tanzania

Sahihi.....

Unakubali Kushiriki?.....

Mshiriki amekubali.....

Nimesoma au nimeambiwa kuhusu yaliyomo humu ndani. Maswali yangu yamejibiwa. Nakubali kushiriki katika utafiti huu.



**Appendix III: Questionnaire- English version**

Please fill the answer with the correct answers.

**I. GENERAL INFORMATION**

Date of interview: {...../...../2020}      Questionnaire serial No: .....

Name of interviewer: .....

**II. DEMOGRAPHIC CHARACTERISTICS OF RESPONDENT**

- 1. Number of interviews.....
- 2. Age of the child in months.....
- 3. Sex of the child
  - 1. Male
  - 2. Female
- 4. Caregiver sex
  - 1. Male
  - 2. Female
- 5. Caregiver age in years
  - 1. Less than 20 years
  - 2. 21 to 40 years
  - 3. 41 to 60 years
  - 4. 61 to 80 years
  - 5. Above 80 years
- 6. Relationship of the child
  - 1. Father
  - 2. Mother
  - 3. Others

7. What is your marital status?

- 1. Married
- 2. Unmarried
- 3. Divorced/separated
- 4. Widow
- 5. Cohabiting

8. What is your highest level of education?

- 1. Never went to school
- 2. Primary school
- 3. Secondary school
- 4. College/University
- 5. Postgraduate/Masters
- 6. Adult education

9. Work status

- 1. Employed
- 2. Unemployed – looking
- 3. Unemployed – not looking
- 4. Other

10. Number of children in Parents/Caregiver household

- 1. 1
- 2. 2
- 3. 3+

**III) MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT: Here is a list of things other people go for us or give us that may be helpful or supportive. Please tick in the box below the number that is closest to your situation**

Circle the “1” if you **Very Strongly Disagree** / Circle the “2” if you **Strongly Disagree**

Circle the “3” if you **Mildly Disagree** / Circle the “4” if you are **Neutral**

Circle the “5” if you **Mildly Agree**/ Circle the “6” if you **Strongly Agree**

Circle the “7” if you **Very Strongly Agree**

<b>Family:</b>	Very Strongly Disagree (1)	Strongly Disagree (2)	Mildly Disagree (3)	Neutral (4)	Mildly Agree (5)	Strongly Agree (6)	Very Strongly Agree(7)
11)I get the emotional help and support I need from my family.							
12)My family tries to help me.							
13)My family is willing to help me make decisions.							
14)I can talk about my problems with my family.							
<b>Friends:</b>							
15)My friends try to help me.							
16)I can count on my friends when things go wrong							
17)I can talk about my problems with my friends.							
18) I have friends with							

whom I can share my joys and sorrows							
<b>Significant Other:</b>							
19)There is a special person in my life that cares about my feelings.							
20)I have a special person who is a real source of comfort to me.							
21)There is a special person who is around when I am in need.							
22)There is a special person with whom I can share my joys and sorrows							

#### **IV) MENTAL ILLNESS OR INTELLECTUAL DISABILITY IN AFFILIATED**

**STIGMA SCALE:** The modified each item posed a scenario designed to measure affiliated stigma, and respondents were then asked to choose one of the following selections from the Likert scale:

- i. Strongly disagree (1 POINT)**
- ii. Disagree (2 POINT)**
- iii. Agree (3 POINT)**
- iv. Strongly agree (4 POINT)**

**Affective**

23)	A1	Are you ever embarrassed by your child's inattentive or hyperactive/impulsive behaviors	Strong disagree(1)	Disagree(2)	Agree(3)	Strongly agree(4)
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**Cognitive**

			Strongly disagree	Disagree	Agree	Strongly agree
24)	C1	Do you worry that others view you as a "bad parent" because of your child's of inattentive or hyperactive/impulsive behaviors				
25)	C2	Do you ever worry that, as a parent, you should have prevented your child's inattentive or hyperactive/impulsive behaviors				

**Behavior**

			Strongly disagree	Disagree	Agree	Strongly agree
26)	B1	Does embarrassment about your child's inattentive or hyperactive/impulsive behaviors ever decrease your likelihood of pursuing social relationships with other adults				
27)	B2	Does embarrassment about your child's inattentive or hyperactive/impulsive behaviors ever decrease your likelihood of pursuing social interactions for your child with other children?				

**V) THE PARENTING STRESS INDEX-SHORT FORM**

The PSI-SF consists of 36 items derived from the PSI which comprise three scales: Parental Distress(PD), Difficult Child Characteristics(DC), and Parents Child Dysfunctional (PCD) Interaction. It is recommended that all PSI-SF users to consider using the regular PSI given that the savings of 10-15 minutes is not worth the loss of the information from the PSI subscales, each of which have established validity.

**i) Strong Disagree=1**

**ii) Disagree=2**

**iii) Not sure=3**

**iv) Agree=4**

**v) Strong Agree=5**

**Parental Distress (PD)**

	<b>Items</b>	<b>Strongly disagree(1)</b>	<b>Disagree(2)</b>	<b>Not Sure(3)</b>	<b>Agree(4)</b>	<b>Strongly agree(5)</b>
28/Pd1	I often have the feeling that I cannot handle things very well					
29/Pd2	I find myself giving up more of my life to meet my child's needs than I ever expected					
30/Pd3	I feel trapped by my responsibilities as a parent.					
31/Pd4	Since having my child I have been unable to try new and different things					
32/ Pd5	Since having my child I feel that I am almost never able to do things that I like to do					
33/ Pd6	I am unhappy with the last purchase of clothing I made for myself					
34/Pd7	There are quite a few things that bother me about my life					
35/Pd8	Having a child has caused more problems than I expected in my relationship with my spouse					
36/Pd9	I feel alone and without friends					
37/Pd10	When I go to a party I usually expect not to enjoy myself					
38/Pd11	I am not as interested in people as I used to be					
39/Pd12	I don't enjoy things as I used to.					

**Parents Child Dysfunctional (PCD)**

40/pcdi13	My child rarely does things for me that make me feel good					
41 /pcdi14	Most times I feel that my child likes me and wants to be close to me					
42 /pcdi15	My child smiles at me much less than I expected					
43/pcdi16	When I do things for my child, I get the feeling that my efforts are not appreciated very much					
44 /pcdi17	When playing, my child doesn't often giggle or laugh.					
45/pcdi18	My child doesn't seem to learn as much as most children					
46 /pcdi19	My child is not able to do as much as I expected.					
47 /pcdi20	My child doesn't seem to smile as much as most children					
48/pcdi21	It takes a long time and it is really hard for my child to get used to new things					
49 /pcdi22	I feel that I am being a parent					
50/pcdi23	I expected to have closer and warmer feelings for my child than I do and this bothers me					
51 /pcdi24	Sometimes my child does things that bother me just to be mean					



**Difficult Child Characteristics (DC)**

52 /dc25	There are some things my child does that really bother me a lot.					
53 /dc26	My child generally wakes up in a bad mood					
54 /dc27	I feel that my child is very moody and easily upset					
55/dc28	My child does a few things that bother me a great deal					
56 /dc29	My child reacts very strongly when something happens that my child doesn't like					
57 /dc30	My child gets upset easily over the smallest thing					
58/dc31	My child's sleeping and eating schedule was much harder to establish than I expected.					
59 /dc32	I have found that getting my child to do something is difficult					
60 /dc33	Think carefully and count the number of things which your child does that bothers you.					
61 /dc34	My child turned out to be more of a problem than I expected.					
62 /dc35	My child makes more demands on me than most children.					
63 /dc36	My child seems to cry more often than most children					

**VI) DEPRESSION ASSESSMENT (PHQ-9)**

Now I am going to ask you about symptoms that you may have had in the past two weeks. For each symptom, I will also ask if you currently have the symptom for at least two weeks or if you had the symptom in the period after you delivered until your child was one-year-old.

**RESPONSE CODES:**

Not at all=0; Several days =1; More than half the days= 2; Nearly every day 3

<b>Label</b>	<b>Over the past two weeks, how often have you been bothered by the following problems?</b>	
64:1	Trouble falling asleep or staying asleep, or sleeping too much?	
65:2	Feeling tired or having little energy?	
66:3	Poor appetite or overeating?	
67:4	Feeling bad about yourself, or that you are a failure or have let yourself or your family down?	
68:5	Trouble concentrating on things, such as reading the newspaper or watching TV?	
69:6	Moving or speaking so slowly that other people have noticed? Or the opposite- being so fidgety and restless that you have been moving around a lot more than usual?	
70:7	Thoughts that you would be better off dead or of hurting yourself in some way?	
71:8	Little interest or pleasure in doing things?	
72:9	Feeling down, depressed, or hopeless?	
73:10	If any problems were checked off, ask how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people? Please respond if 0=Not difficult at all; 1= Somewhat difficult; 2=Very difficult, 3=Extremely difficult	

**VII) SF 12; THE WORLD HEALTH ORGANIZATION QUALITY OF LIFE**

**ASSESSMENT (WHOQOL) Instructions:** This assessment asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures, and concerns. We ask that you think about your life in the last two weeks.

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you: This information will help your doctors keep track of how you feel and how well you can do your usual activities. If you are unsure about how to answer a question, please give the best answer you can and make a written comment besides your answer.

**User Guide: FGD or IDI; Perceived quality of life:**

1. Clients understanding of the quality of life (Probe: what does he/she regard them as good or poor quality of life? how so?)
2. How does one measure those reported dimensions for quality of life (Probe: how does one measure good/poor QOL)
3. What are some of the things can completely alter or make a shift from one state to the other (i.e. from good to poor QOL or vice versa)?

74:1. In general, would you say your health is?

- \_\_\_\_\_ Excellent (1)  
 \_\_\_\_\_ Very Good (2)  
 \_\_\_\_\_ Good (3)  
 \_\_\_\_\_ Fair (4)  
 \_\_\_\_\_ Poor (5)

The following two questions are about activities you might do during a typical day. Does YOUR HEALTH NOW LIMIT YOU in these activities? If so, how much?

75:2. MODERATE ACTIVITIES, such as moving a table, pushing a vacuum cleaner, **bowling**, or playing golf:

\_\_\_\_\_ Yes, Limited A Lot (1)

\_\_\_\_\_ Yes, Limited A Little (2)

\_\_\_\_\_ No, Not Limited at All (3)

76:3. Climbing SEVERAL flights of stairs:

\_\_\_\_\_ Yes, Limited A Lot (1)

\_\_\_\_\_ Yes, Limited A Little (2)

\_\_\_\_\_ No, Not Limited at All (3)

During the PAST 4 WEEKS have you had any of the following problems with your work or other regular activities AS A RESULT OF YOUR PHYSICAL HEALTH?

77:4. ACCOMPLISHED LESS than you would like:

\_\_\_\_\_ Yes (1)

\_\_\_\_\_ No (2)

78:5. Were limited in the KIND of work or other activities:

\_\_\_\_\_ Yes (1)

\_\_\_\_\_ No (2)

During the PAST 4 WEEKS, were you limited in the kind of work you do or other regular activities AS A RESULT OF ANY EMOTIONAL PROBLEMS (such as feeling depressed or anxious)?

79:6. ACCOMPLISHED LESS than you would like:

\_\_\_\_\_ Yes (1)

\_\_\_\_\_ No (2)

80:7. Didn't do work or other activities as CAREFULLY as usual:

\_\_\_\_\_ Yes (1)

\_\_\_\_\_ No (2)

81:8. During the PAST 4 WEEKS, how much did PAIN interfere with your normal work (including both work outside the home and housework)?

\_\_\_\_\_ Not at All (1)

\_\_\_\_\_ A Little Bit (2)

\_\_\_\_\_ Moderately (3)

\_\_\_\_\_ Quite A Bit (4)

\_\_\_\_\_ Extremely (5)

The next three questions are about how you feel and how things have been DURING THE PAST 4 WEEKS. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the PAST 4 WEEKS –

82:9. Have you felt calm and peaceful?

\_\_\_\_\_ All of the Time (1)

\_\_\_\_\_ Most of the Time (2)

\_\_\_\_\_ A Good Bit of the Time (3)

\_\_\_\_\_ Some of the Time (4)

\_\_\_\_\_ A Little of the Time (5)

\_\_\_\_\_ None of the Time (6)

83:10. Did you have a lot of energy?

\_\_\_\_\_ All of the Time (1)

\_\_\_\_\_ Most of the Time (2)

\_\_\_\_\_ A Good Bit of the Time (3)

\_\_\_\_\_ Some of the Time (4)

\_\_\_\_\_ A Little of the Time (5)

\_\_\_\_\_ None of the Time (6)

84:11. Have you felt downhearted and blue?

- \_\_\_\_\_ All of the Time (1)
- \_\_\_\_\_ Most of the Time (2)
- \_\_\_\_\_ A Good Bit of the Time (3)
- \_\_\_\_\_ Some of the Time (4)
- \_\_\_\_\_ A Little of the Time (5)
- \_\_\_\_\_ None of the Time (6)

85:12. During the PAST 4 WEEKS, how much of the time has your PHYSICAL HEALTH OR EMOTIONAL PROBLEMS interfered with your social activities (like visiting with friends, relatives, etc.)?

- \_\_\_\_\_ All of the Time (1)
- \_\_\_\_\_ Most of the Time (2)
- \_\_\_\_\_ A Good Bit of the Time (3)
- \_\_\_\_\_ Some of the Time (4)
- \_\_\_\_\_ A Little of the Time (5)
- \_\_\_\_\_ None of the Time (6)

Did someone help you to fill out these forms?.....

How long did it take to fill this form out?.....

Do you have any comment about the assessment?.....

**THANK YOU FOR YOUR HELP**

## **Appendix IV: Dodoso**

### **I.MAELEZO YA AWALI**

Tarehe ya Mahojiano (...../...../2020)      Namba ya Dododso.....

Jina la Msaili.....

### **II. MAELEZO BINAFSI**

1) Namba ya mshiriki anayehojiwa.....

2) Umri wa mtoto kwa miezi.....

3) Jinsia ya Mtoto

1. Mume

2. Mke

4) Jinsia ya mlezi

1) Mume

2) Mke

5) Umri wa Mlezi

1) Chini ya miaka 20

2) Kati ya miaka 21-40

3) Kati ya miaka 41-60

4) Kati ya miaka 61-80

5) Miaka zaidi ya 80

6) Uhusiano wa mlezi na mtoto

1) Baba

2) Mama

3) Uhusiano mwingine

7) Nini hali yako ya ndoa

- 1) Nimeoa/Nimeolewa
- 2) Sijaoa/sijaolewa
- 3) Tumeachana/Tumetengana
- 4) Mjane
- 5) (Naishi na mwanamke/Bwana)

8) Unakiwango gani cha Elimu

- 1) Sijasoma
- 2) Elimu ya msingi
- 3) Elimu ya sekondari
- 4) Elimu ya chuo/chuo kikuu
- 5) Nina shahada ya pili/stashahada
- 6) Elimu ya watu wazima

9) Unafanya kazi gani?

- 1) Nimeajiliwa
- 2) Sijaajiliwa-natafuta kazi
- 3) Sijaajiliwa-sitafuti kazi
- 4) Mengineyo

10) Kuna watoto wangapi ndani ya nyumba unayoishi

- 1)1
- 2)2
- 3)3+

### III) MAMBO TUYAPATAYO KIJAMII KAMA MSAADA

Hii ni orodha ya baadhi ya mambo amabayo wengine wanatufanyia au kutupatia kama msaada. Tafadhari zungushia jibu ambalo lipo karibu na hali yako halisi

Zugushia '1' kama **Nakata asana**/Zungushia '2' kama **Nakataa kiasi**/

Zungushia '3' kama **Nakataa kidogo**/Zungushia '4' kama **Sijui**



Zungushia ‘5’ kama **Nakubali kidogo**/Zungushia ‘6’ kama **Nakubali kiasi**

Zungushia ‘7’ kama **Nakubali sana**

<b>FAMILIA</b>	<b>Nakataa sana (1)</b>	<b>Nakataa kiasi (2)</b>	<b>Nakataa kidogo(3)</b>	<b>Sijui (4)</b>	<b>Nakubali kidogo(5)</b>	<b>Nakubali kiasi (6)</b>	<b>Nakubali sana (7)</b>
11)Napata msaada wa kimihemko kutoka kwa wanafamilia							
12)Familia yangu inajitahidi kunisaidia							
13)Familia yangu inautayari wa kunisaidia katika maamuzi							
14)Naweza kuongea matatizo yangu na wanafamilia							
<b>MARAFIKI</b>							
15)Marafiki zangu inajitahidi kunisaidia							
16)Nategemea rafiki zangu kwa tatizo lolote likitokea							
17)Naweza kuongea matatizo yangu na rafiki zangu							
18)Ninarafiki ambao naweza kuwashirikisha							

kwenye shida na raha							
<b>JAMII</b>							
19)Kuna mtu maalum anaenijari mihemko yangu							
20)Kuna mtu maalum anaenipa faraja							
21)Kuna mtu maalum unisaidia kila nipatapo shida							
22)Kuna mtu maalum ninaemshirikisha wakati wa shida na raha							

**IV) MAGONJWA YA AKILI/ULEMAVU WA KUELEWA KIELIMU UNAVYOSHIRIKISHA UNYANYAPAA.**

**Kauli mbalimbali zifuatazo zinaeleza hisia mbalimbali za kujihisi kupitia unyanyapaa. Tafadhari zungushia jibu linaloelezea kwa kiwango gani umekuwa na hisia kama hizi baada ya kuuguza mgonjwa wa akili.**

**i)Hapana ‘1’ (ii)Kidogo ‘2’ (iii)Kiasi ‘3’ (iv)Sana ‘4’**

**UTAMBUZI**

			Hapana(1)	Kidogo(2)	Kiasi(3)	Sana(4)
23	C1	Una wasiwasi kwamba watu wengine wanakuona mzazi usiofaa kwa sababu ya mtoto kuwa na tabia ya upungufu wa umakini kutokana na utendaji wakupita kiasi/msukumo				
24	C2	Uliwahi kujihisi kama mzazi ungeweza kuzuia mtoto kuwa na tabia ya upungufu wa umakini kutokana na utendaji wakupita kiasi/msukumo				

**KUATHIRI**

			Hapana(1)	Kidogo(2)	Kiasi(3)	Sana(4)
25	A1	Umewahi kujihisi aiibu kwa sababu ya mtoto kuwa na tabia ya upungufu wa umakini kutokana na utendaji wakupita kiasi/msukumo				

**TABIA**

			Hapana	Kidogo	Kiasi	Sana
26	B1	Je tabia ya mtoto ya upungufu wa umakini kutokana na utendaji wakupita kiasi/msukumo inaaibisha mpaka kusababisha kupunguza uwezekano wa kushawishika kushirikiana katika shughuri za kijamii na watu wazima.				
27	B2	Je tabia ya mtoto ya upungufu wa umakini kutokana na utendaji wakupita kiasi/msukumo inaaibisha mpaka kusababisha kupunguza uwezekano wa kushawishika kushirikianashughuri za kijamii na watoto wenzake				

### V) KIWANGO CHA MFADHAIKO KWA MZAZI

Dodoso lenye maswari 36 yanayoopima kiwango cha mfadhaiko kwa mzazi (PD), tabia za mtoto zenye changamoto (DC), tabia za mtoto zinasosababisha changamoto kwa mzazi(PCD).

- i) Nakataa sana=1
- ii) Nakataa=2
- iii) Sina Uhakika=3
- iv) Nakubali=4
- v) Nakubali sana=5

### (I)KIWANMGO CHA MFADHAIKO KWA MZAZI (PD)

		Nakataa sana(1)	Nakataa(2)	Sina Uhakika(3)	Nakubali(4)	Nakubali sana(5)
28/ Pd1	Kila mara najihisi kwamba nafanya vitu sivyosahihi					
29 /Pd2	Najikuta mara nyingi kwenye maisha ya kila siku nafanya matendo ya kumridhisha mtoto kuliko nilivyo panga					
30/Pd3	Najihisi nimefungwa namajukumu yangu binafsi kama mzazi					
31/Pd4	Toka niwe na mtoto nimeshindwa kujaribu kitu kipya au tofauti katika maisha yangu ya kilasiku					

32/Pd5	Toka niwe na mtoto najihisi kwamba nashindwa kufanya vitu navyombendelea katika maisha yangu					
33/Pd6	Nikijitathimini manunuzi yangu ya wishoni,siridhiki navitu navyojinunulia kama nguo,					
34/Pd7	Kuna vitu vichache vinavyonikera katika maisha yangu					
35 /Pd8	Kuwa na mtoto imenisababishia matatizo Zaidi kuliko ni nilivyotarajia kwenye mahusioano na mwenzu wangu					
36 /Pd9	Najihisi mpweke bila rafiki					
37/Pd1 0	Napohudhuria tafrija najihisi kutokufurahia sherehe					
38/Pd1 1	Sivutiwi kuwa na watu kama zamani					
39/Pd1 2	Sifurahii vitu mbalimbali kama zamani					

**(II)TABIA ZA MTOTO ZINASOSABABISHA CHANGAMOTO KWA MZAZI(PCD)**

40/pcdi13	Mara chache mtoto wangu unifanyia vitu ambavyo vitanifurahisha					
41/pcdi14	Mara nyingi nahisi mtoto wangu ananinepanda na anaitaji kuwa karibu na mimi					
42/pcdi15	Mara chache mdogo wangu unitabasamia kuliko navyodhania					
43/pcdi16	Napomuhudumia mtoto wangu nahisi juhudi zangu hazidhaminiki					
44/pcdi17	Wakati mtoto anacheza mara uchekeheka					
45/pcdi18	Mtoto wangu anashida katika kuelewa ukilinganisha na watoto wengine					
46/pcdi19	Mtoto wangu awezi kufanya vitu kama navyomtegemea kuweza kufanya					
47/pcdi20	Mtoto wangu haonyeshi tabasamu kama watoto wengine					
48/pcdi21	Ni ngumu na inachukua muda mtoto wangu kuzoea vitu vipya					
49/pcdi22	Najihisi mimi ni kama mzazi					
50/pcdi23	Natarajia kuwa na uhusiano wa karibu sana na mtoto kuliko nilionao sasa nah ii hali inasumbua					
51/pcdi24	Wakati mwingine mtoto ufanya vitu viavyonisumbua bila kujali					

**(III)TABIA ZA MTOTO ZENYE CHANGAMOTO (DC)**

52/dc25	Kuna matendo mtoto wangu uyafanya ambayo yanigafirisha					
53/dc26	Mara nyingi mtoto uamka na mihemko mibaya					
54/dc27	Mara nyingi mtoto wangu anamabadiriko ya tabia mara kwa mara na mwepesi kukasirika					
55/dc28	Kuna vitendo vichache ambavyo mtoto ufanya na vinanipa changamoto kubwa					
56/dc29	Mtoto uwa na hasira sana anapofanyiwa vitu ambavyo havipendi					
57/dc30	Mtotoukasirika kwa upesi kwa jambo dogo					
58/dc31	Utaratibu wa mtoto kula na kulala na wa shida sana tofauti na matarajio yangu					
59/dc32	Nimegundua kufanya mtoto afanye jambo ni vigumu sana					
60/dc33	Fikiria kwa makini ni mara nyingi mtoto anapokuwa akifanya kitu anakupa changamoto					
61/dc34	Mtoto uzidi kunipa changamoto Zaidi ya mategemeo yangu					
62/dc35	Mtoto wangu ananiitaji Zaidi kuliko watoto wengine					
63/dc36	Uwa na tabia ya kulia marakwamara ukilinganisha na watoto wenine					

## VI) MSONGO WA MAWAZO

Sasa nitakuuliza kuhusu dalili ambazo umekuwa nazo wiki mbili zilizopita, kwa kila dalili uliyoipata angalau wiki mbili zilizopita

Tafadhali jibu kama dalili hizi umezipata kwa siku nyingi, kama umezipata nusu siku kwa angalau wiki mbili, au kama dalili umezipata karibu kila siku.

JIBU;

Haijawahi tokea=0; siku kadhaa =1; zaidi ya nusu siku= 2; karibu kila siku =3

Label		Dalili	
64	B1	Shida ya kukosa usingizi au kulala sana?	
65	B2	Kuchoka au kua na nguvu kidogo?	
66	B3	Kukosa hamu ya kula au kula sana?	
67	B4	Kujiskia vibaya kuhusu wewe mwenyewe, au kushindwa, kujiangusha mwenyewe au kuiangusha familia yako?	
68	B5	Unapata shida kua makini, kwa mfano wakati wa kupika, kusoma gazeti au kuangalia runinga?	
69	B6	Kutembea au kuzungumza taratibu kiasi kwamba watu wengine wanagundua? Au kinyume kutokua na utulivu au kuzunguka zunguka bila sababu?	
70	B7	Mawazo kua ni bora ufe au ya kujiumiza kwa namna yoyote ile?	
71	B8	Kua nashauku kidogo au kutokufurahia shughuli zako za kawaida?	
72	B9	Hisia za kutokua na raha, kusononeka au kukata tamaa?	
73	B10	(Kama vipengele vyote vimejazwa 0, jaza 9) .kama matatizo yeyote yameonyeshwa uliza: ni kwa jinsi gani matatizo haya yamekufanya ushindwe kufanya kazi zako, kushughulikia vitu vya nyumbani, au kua na mahusiano mazuri na watu?0=Haijawai tokea,1=Siku kadhaa,2=Zaidi ya nusu siku,3=Karibu kila siku	



**VII) KIWNGO CHA UBORA WA MAISHA KIAFYA; SF-12** (Swahili version) Habari hii itamuwezesha mtoa huduma ya afya kuweka rekodi ya jinsi unavyojihisi na ni kwa vizuri kiasi gani unaweza kufanya shughuli za kawaida. Jibu kila swali kwa kuweka alama juu ya mstari mbele ya swali husika. Endapo huna hakika kuhusu kujibu la swali, tafadhali toa jibu bora utakavyoweza na weka maoni kwa maandishi pembezoni mwa jibu

74). Kwa KAWAIDA, unaweza kusema afya yako ni:

- a. Nzuri mno (1)
- b. Nzuri sana (2)
- c. Nzuri (3)
- d. Inaridhisha (4)
- e. Dhaifu (5)

Maswali mawili yanayofuata ni kuhusu shughuli unazoweza kufanya katika siku za kawaida. Je, AFYA YAKO SASA INAKUZUIA katika shughuli hizi? kama ndio, kwa kiasi gani?

75). KAZI ZA KIASI, kama vile kuhamisha meza, kusukuma kizoa vumbi, kuviringisha tufe, au kucheza mpira wa miguu

- a. Ndio, ukomo sana (1)
- b. Ndio, ukomo kidogo (2)
- c. Hapana, hakuna ukomo kabisa (3)

76). Kupanda ngazi KADHAA:

- a. Ndio, ukomo sana (1)
- b. Ndio, ukomo kidogo (2)
- c. Hapana, hakuna ukomo kabisa (3)

77). Katika kipindi cha WIKI 4 ZILIZOPITA je, umekuwa na matatizo yafuatayo na kazi yako au shughuli za kawaida KUTOKANA NA SABABU YA AFYA YAKO YA MWILI? UMETIMIZA KIDOGO kuliko ambavyo ungependa:

- a. Ndio (1)
- b. Hapana (2)

78). Je, kulikuwa na ukomo kwako wa AINA ya kazi au shughuli nyingine:

- a. Ndio (1)
- b. Hapana (2)

79). Katika kipindi cha WIKI 4 ZILIZOPITA, ulishindwa kufanya aina yoyote ya kazi au shughuli nyingine za kawaida KUTOKANA NA SABABU YA MATATIAZO YA MSONGO (kama vile kuhisi msongo au wasiwasi)?

UMETIMIZA KIDOGO kuliko ambavyo ungependa:

- a. Ndio (1)
- b. Hapana (2)

80). Hukufanya kazi au shughuli nyingine kwa UANGALIFU kama kawaida:

- a. Ndio (1)
- b. Hapana (2)

81). Katika kipindi cha WIKI 4 ZILIZOPITA, ni kwa kiasi gani MAUMIVU yaliingiliana na kazi zako za kawaida (pamoja na kazi zote za nje na nyumbani)?

- a. Sio kabisa (1)
- b. Kidogo tu (2)
- c. Wastani (3)
- d. Kiasi kidogo (4)
- e. Mno (5)

Maswali matatu yafuatayo ni kuhusu unajihisi vipi na mambo yalikuwaje KATIKA WIKI 4 ZILIZOPITA. Kwa kila swali tafadhali toa jibu moja ambalo linakuja karibu na jinsi ulivyojihisi. Ni kwa kiasi gani cha muda katika WIKI 4 ZILIZOPITA

82). Je, ulijihisi utulivu na amani?

- a. Wakati wote (1)
- b. Wakati mwingi (2)
- c. Kiasi kizuri kidogo cha muda (3)
- d. Wakati mwingine (4)
- e. Wakati mdogo kiasi (5)
- f. Hakuti wakati (6)

83). Je, ulikuwa na nguvu nyingi?

- a. Wakati wote (1)
- b. Wakati mwingi (2)
- c. Kiasi kizuri kidogo cha muda (3)
- d. Wakati mwingine (4)
- e. Wakati mdogo kiasi (5)
- f. Hakuti wakati (6)

84). Je, ulihisi kuvunjika moyo au huzuni?

- a. Wakati wote (1)
- b. Wakati mwingi (2)
- c. Kiasi kizuri kidogo cha muda (3)
- d. Wakati mwingine (4)
- e. Wakati mdogo kiasi (5)
- f. Hakuti wakati (6)

85). Katika MIEZI 4 ILIYOPITA, ni kwa kiasi gani cha muda HALI YA MATATIZO YAKO YA AFYA AU MSONGO iliingilia shughuli zako za kijamii (kama kutembelea marafiki, ndugu n.k.)?

- a. Wakati wote (1)
- b. Wakati mwingi (2)
- c. Kiasi kizuri kidogo cha muda (3)
- d. Wakati mwingine (4)
- e. Wakati mdogo kiasi (5)
- f. Hakuti wakati (6)

## Appendix V: Approval of ethical clearance

**MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES  
OFFICE OF THE DIRECTOR OF RESEARCH AND PUBLICATIONS**

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Ref. No.DA.282/298/01.C/

Date: 05/08/2020

MUHAS-REC-08-2020-327  
PATRICIA STEVEN KASSANGE  
School of Medicine  
MUHAS

**RE: APPROVAL FOR ETHICAL CLEARANCE FOR A STUDY TITLED: THE  
HEALTH-RELATED QUALITY OF LIFE OF CAREGIVERS OF CHILDREN  
WITH ATTENTION DEFICIT HYPERACTIVITY DISORDER AT THE  
MUHIMBILI NATIONAL HOSPITAL, DAR ES SALAAM**

Reference is made to the above heading.

I am pleased to inform you that the Chairman has on behalf of the University Senate, approved ethical clearance of the above-mentioned study, on recommendations of the Senate Research and Publications Committee meeting accordance with MUHAS research policy and Tanzania regulations governing human and animal subjects research.

APPROVAL DATE: 05/08/2020  
EXPIRATION DATE OF APPROVAL: 04/08/2021

**STUDY DESCRIPTION:**

**Purpose:**

Purpose of this observational cross sectional study is to provide information that will help to improve in treatment modalities and psychosocial programs related to ADHD management among caregivers attending out-patient services for children with ADHD, by improving caregiver HRQoL will also help good caregiving/management for the child with ADHD.

The approved protocol and procedures for this study is attached and stamped with this letter, and can be found in the link provided:  
<https://irb.muhas.ac.tz/storage/Certificates/Certificate%20-%2094.pdf> and in the MUHAS archives.

**The PI is required to:**

1. Submit bi-annual progress reports and final report upon completion of the study.
2. Report to the IRB any unanticipated problem involving risks to subjects or others including adverse events where applicable.
3. Apply for renewal of approval of ethical clearance one (1) month prior its expiration if the study is not completed at the end of this ethical approval. You may not continue with any research activity beyond the expiration date without the approval of the IRB. Failure to receive approval for continuation before the expiration date will result in automatic termination of the approval for this study on the expiration date.
4. Obtain IRB amendment (s) approval for any changes to any aspect of this study before they can be implemented.
5. Data security is ultimately the responsibility of the investigator.
6. Apply for and obtain data transfer agreement (DTA) from NIMR if data will be transferred to a foreign country.
7. Apply for and obtain data transfer agreement (DTA) from NIMR if data will be transferred to a foreign country.
8. Apply for and obtain material transfer agreement (MTA) from NIMR, if research materials (samples) will be shipped to a foreign country,
9. Any researcher, who contravenes or fail to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine as per NIMR Act No. 23 of 1979, PART III section 10 (2)
10. The PI is required to ensure that the findings of the study are disseminated to relevant stake holders.
11. PI is required to be versed with necessary laws and regulatory policies that govern research in Tanzania. Some guidance is available on our website <https://drp.muhas.ac.tz>



Dr. Bruno Sunguya

Chairman, MUHAS Research and Ethics Committee



**Appendix VI: Introduction Letter**

**MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES  
OFFICE OF THE DIRECTOR OF POSTGRADUATE STUDIES**

P.O. Box 65001  
DAR ES SALAAM  
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Ref. No. HD/MUH/T.207/2017

05<sup>th</sup> August, 2020

The Executive Director,  
Muhimbili National Hospital,  
P.O. Box 65000,  
**DAR ES SALAAM**

**Re: INTRODUCTION LETTER**

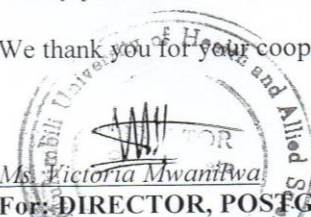
The bearer of this letter is Patricia Steven Kassange, a student at Muhimbili University of Health and Allied Sciences (MUHAS) pursuing MMed. Psychiatry and Mental Health.

As part of her studies she intends to do a study titled: **“THE HEALTH-RELATED QUALITY OF LIFE OF CAREGIVERS OF CHILDREN WITH ATTENTION DEFICIT HYPERACTIVITY DISORDER AT THE MUHIMBILI NATIONAL HOSPITAL, DAR ES SALAAM.”**

The research has been approved by the Chairman of University Senate.

Kindly provide her the necessary assistance to facilitate the conduct of her research.

We thank you for your cooperation.

  
*Ms. Victoria Mwanitwa*  
**For: DIRECTOR, POSTGRADUATE STUDIES**

cc: Dean, School of Medicine, MUHAS  
cc: Patricia Steven Kassange