PREVELANCE OF PSYCHOLOGICAL DISTRESS, DYSFUNCTIONAL CORONAVIRUS ANXIETY AND IMPACT OF COVID 19 PANDEMIC AMONG CAREGIVERS OF CHILDREN WITH MENTAL ILLNESS AT MATHARI NATIONAL TEACHING AND REFERRAL HOSPITAL

THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE AWARD OF THE DEGREE OF MASTER OF MEDICINE IN PSYCHIATRY, UNIVERSITY OF NAIROBI

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DECLARATION OF ORIGINALITY OF STUDY

I, declare that this thesis is my original work and has not, to the best of my knowledge, been submitted to any other University for the award of any degree

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   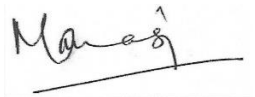

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DEDICATION

I dedicate this thesis to all the caregivers of children with developmental disorders and other chronic illnesses, who have had to bear daily with the added responsibility of providing extra care. Though the COVID 19 pandemic had additional challenges, they have been able to take up the extra responsibility and withered the storm. I hope that through this study the challenges faced by caregivers will be highlighted and addressed through various support mechanisms.

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LIST OF ABBREVIATIONS

ERC: Ethics and Research Committee

KNH: Kenyatta National Hospital

MNTRH: Mathare National Teaching and Referral Hospital

UoN: University of Nairobi

DASS 21: Depression, Anxiety and Stress Scale 21 items

CAS: Coronavirus Anxiety Scale

COVID 19: Coronavirus Disease 2019

SARS – COV – 2: Severe Acute Respiratory Syndrome Coronavirus 2

KISE: Kenya Institute of Special Education

KFF: Kaiser Family Foundation

ASD: Autism Spectrum Disorder

ADHD: Attention Deficit Hyperactivity Disorder

OCD: Obsessive Compulsive Disorder

PTSD: Post Traumatic Stress Disorder

SDQ: SOCIO DEMOGRAPHIC QUESTIONNAIRE

PHQ 9: PATIENT HEALTH QIESTIONNAIRE 9

GAD 7: GENERAL ANXIETY DISORDER 7

CESD R: CENTRE FOR EPIDEMIOLOGICAL STUDIES DEPRESSION SCALE REVISED

PCRI: PARENT CHILD RELATIONSHIP INVENTORY

PCS: PERCIEVED CONTROL OVER STRESSFUL EVENTS SCALE

CSI: CAREGIVER STRAIN INDEX

HADS: HOSPITAL ANXIETY AND DEPRESSION SCALE

PSSI: PTSD SYMPTOM SCALE INTERVIEW

CDS: CAREGIVER DIFFICLULTIES SCALE

BDI II: BECKS DEPRESSION INVENTORY

GHQ: GENERAL HEALTH QUESTIONNAIRE

PSS: PERCEIVED STRESS SCALE

OPERATIONAL DEFINITIONS

Caregiver: a paid or unpaid member of a person's social network who helps with activities of daily living. Since they may have no specific professional training, they are often described as informal caregivers. Includes parents (biological or adopted, grandparents and other relatives, friends, well-wishers etc.

Coronavirus Disease 2019 (COVID 19): a communicable respiratory disease caused by a new strain of coronavirus that is suspected to have crossed over from animals and currently transmissible among humans (SARS-COV-2), it causes acute respiratory disease and mortality among humans. Spreads from person to person via air droplets projected during sneezing, coughing or contact with infected surfaces.

COVID 19 pandemic: ongoing global pandemic of coronavirus disease 2019 (COVID 19), caused by SARS-COV-2. First identified in Wuhan, china in 2019. Declared a public health emergency of global concern by WHO on 30TH Jan 2020, and later a global pandemic on 11th March 2020. Virus first confirmed to have reached Kenya on 12 March 2020.

Coronavirus Anxiety Syndrome: maladaptive response occasioned by COVID 19 pandemic related psychological distress. It is characterized by avoidance, checking, worrying and threat monitoring. Can be characterized by psychosomatic symptoms e.g. lack of appetite, insomnia, altered bowel patterns etc. on exposure to COVID 19 related information.

Depression: a mood disorder characterized by persistently depressed (low) mood, loss of interest in activities, sadness etc. that causes significant impairment in daily living

Anxiety: it is a body's natural response to a stressor. It is a fear or apprehension about what is to come, causes increased alertness, fear and physical signs. It is characterized as a mental health disorder when the feelings of worry, anxiety or fear are strong enough to interfere with one's daily activities.

Stress: it is a feeling of psychological, emotional or physical tension related to an event or thought that makes one feel frustrated, angry or nervous. These activities require the body to mobilize neuro-moral responses to trigger fight or flight responses to cope with the stressor. Chronic stressors interfere with the relaxation response thus can have adverse effects on the body.

Child: By Kenyan Law, anyone below the age of 18 years

Children with mental illness: any child diagnosed with mental illness in infancy, childhood or adolescence. These disorders adversely affect the psychological, social and educational functioning of the child

ABSTRACT

Introduction: Those who provide care to children with developmental disorders and other special needs are at increased risk of psychological distress due to emotional and physical demands of caregiving, predisposing them to developing psychological distress. The effects of COVID 19 pandemic as well as public health measures instituted to control it are significant contributors to a new range of stressors that threaten caregiver's health, safety and economic well-being. Dysfunctional coronavirus anxiety occasioned by the COVID 19 pandemic places additional strain on these caregivers due to concerns about the health and safety of children under their care, especially if they have special needs, as well as the caregiver's own wellbeing as a consequence of the emergent challenges.

Purpose: the purpose of this study was to find out how prevalent is psychological distress as a result of caregiving, dysfunctional coronavirus anxiety due to the pandemic and the influence of COVID 19 among those who offer care to children with mental illnesses.

Methodology: this study was a descriptive cross sectional study conducted in a hospital (clinical) setting. It was a quantitative study using a questionnaire with open and closed ended questions. One hundred caregivers of mentally ill children who attend child psychiatry clinic at Mathari National Teaching and Referral Hospital were recruited via purposive sampling to participate in the study. Upon giving informed consent, data was collected. The socio demographic questionnaire was used to collect sociodemographic characteristics of the caregivers. The overall impact of the COVID 19 pandemic on caregivers, as well as problems encountered and coping mechanisms were evaluated using open ended questions. To determine the severity of depressive, stress and anxiety symptoms, the depression, anxiety and stress scale was administered (DASS 21). To evaluate dysfunctional symptoms secondary to coronavirus anxiety, the Coronavirus Anxiety Scale was used.

Data analysis: data collected was entered into Ms Excel software, checked for errors and analyzed using SPSS version 25.0 software. For discrete variables; frequency tables, pie and bar charts were used. For continuous variables means and standard deviations have been provided. For data gathered from open ended questions, main themes were identified, coded and presented in tabular format and graphs. For Bivariate analysis, correlation using Fischer's exact test was done to investigate relationships between study variables. For Multivariate analysis, regression analysis was applied to provide adjusted odds ratios. In this study the confidence interval (C.I.) was 95%, with statistical significance level set at $p<0.05$.

Study results: 75% of the caregivers were found to have psychological distress. The prevalence of depression was 36%, anxiety 38% and stress 29%. The prevalence of dysfunctional coronavirus anxiety was 20%. There was significant association between dysfunctional coronavirus anxiety with psychological distress ($p=0.0212$) and COVID 19 vaccination status ($p=0.011$). There was significant association ($p<0.05$) between depression with dysfunctional coronavirus anxiety, gender of caregiver, functional status of child and lack of psychosocial

support. There was significant association ($p<0.05$) between anxiety with dysfunctional coronavirus anxiety, gender of caregiver, employment status and psychosocial support. There was significant association ($p<0.05$) between stress with education status and functional status of the children under care

Conclusion: there was a high prevalence of psychological distress parameters among these caregivers. This was compounded by the effects of the COVID 19 pandemic. There were significant associations with gender, employments status, education level, functional status of the children and psychosocial support to the caregivers.

Recommendation: Regular psychological support was noted to be protective from psychological distress associated with caregiving especially during COVID pandemic. Caregivers should be encouraged to seek psychological support (whether formal or informal) to avoid being overwhelmed

CHAPTER 1

INTRODUCTION AND BACKGROUND INFORMATION

1.1: INTRODUCTION

Caregivers of mentally ill children at a significantly elevated risk of strain occasioned by emotional and physical demands of caregiving. In our African setting the bulk of caregiving is left to parents or relatives of the affected children to act as informal caregivers. This may be accompanied by stigma and social isolation as the parents or relatives of the affected children may deem it as bad luck or have self-blame for having such an affliction in the family. To the surrounding community it may be accompanied by stigma and social isolation.

In Uganda, a study was done to evaluate caregiver's and health worker's experiences while attending to children with neurodevelopmental impairments, (Namazizi et al, 2017). Due to high expenses associated with care, the caregivers in the study reported their experiences as being bankrupting and degrading, as well as challenges associated with nursing and limited financial resources. The costs and feelings associated with lack of progress in the health influenced the perception of seeking care. Due to significant responsibility associated with nursing, caretakers also reported sensation of isolation and mental turmoil.

In Gachie, a rural setting located in Kiambu county (Kenya), a community based study was conducted to evaluate how prevalent were depressive symptoms amongst family members who take care of children with intellectual impairments, (Mbugua et al, 2007). 79 percent of the study participants (caregivers) were identified to have been at heightened threat of developing clinical depression in this study. A hospital based study was conducted at Kenyatta National Hospital to establish how prevalent was depression among caregivers of children with psychiatric disorders who frequent outpatient clinics (Onyango et al, 2013). In this study 56.2 percent of the caregivers were found to be depressed. These studies revealed that locally there is a high burden of psychological distress associated with caregiving.

Earlier studies have concluded that providing care to a child with special needs in the household is likely to cause mental anguish (to various degrees) among other close members of the family set up. Anxiety and catastrophic thinking along with numerous physical ailments such as palpitations and headaches are common signs and symptoms of psychological distress.

For the caregivers being in a state of psychological distress can predispose to high risk of developing chronic diseases. Parents, especially mothers, with chronically unwell children have inferior medical outcomes with significant risk of heart disease and death than those of unaffected children, (Cohn et al, 2019). A study by Foody et al, (2015), examining if there was a difference in levels of stress due to parenting, blood pressure and salivatory biochemical markers among parents of children with Autism Spectrum Disorder (ASD). It found that there was significant elevation of anxiety symptoms in parents of children with ASD in comparison to a control group of those without ASD. As a result, it was established that parents of children

with ASD had significantly elevated stress levels and more health concerns than parents of typically developing children.

These studies reveal that focused treatment strategies are needed to improve well-being as well as quality of life of the parents. These studies also highlight an alarming trend: those who take up the responsibility of offering care to children with mental/ developmental conditions are in danger of developing psychiatric illnesses by virtue of caring for them.

1.2: BACKGROUND INFORMATION

In a study done by Onyango et al, (2013), at Kenyatta National Hospital, it was noted that the symptoms of depression among parents and guardians of children with mental illnesses were mostly under-reported in Kenya. The reason for this being that more attention was directed towards the affected children rather than those tasked with care.

For most caregivers, a diagnosis of mental illness on those under their care is usually a period of extreme anguish. Part of the added burden of care may involve constant observation, purchase of medication, procurement of services of additional caregivers (house helps/ relatives), frequent clinic visits for clinical review as well as rehabilitation services involving physiotherapists and occupational therapists. There may also be need for enrollment to special schools.

The COVID 19 pandemic in Kenya has been taunted as much more than a health crisis with potential to create devastating economic, social and political crises. According to United Nations Developmental Programme, (UNDP) Kenya, development issues secondary to this pandemic affect the entire socio economic spectrum of each country. The impact on every aspect of Kenyan society will continue to be felt for many years to come even after the crisis is over even as there will be economic recovery after the pandemic is over.

The first incidence of SARS-COV-2 was verified in Kenya on March 13th, 2020 in a female visitor from London. This news was met with panic and extreme uncertainty. Initially Nairobi was considered the epicenter of the pandemic, the virus was subsequently confirmed in other counties as the spread continued in surges. A multi-sectorial task force, National Emergency Response Committee (NERC) was formed to coordinate COVID 19 response in the country to address emergent health, security and economic issues among others.

To mitigate spread, the Kenyan government through the Ministry of Health instituted several public health measures to contain the spread. These included: school closures, mandatory quarantine, countrywide night curfews, closure of recreational facilities, suspension of international flights and partial lockdowns especially for Nairobi and surrounding counties. Policies of social distancing, working from home, ban on public gatherings were also instituted.

Most health facilities suspended some outpatient clinics and elective surgeries as well as limiting admissions and hospital visits. These actions were meant to concentrate staff and hospital facilities towards dealing with the pandemic.

For caregivers of children with mental illness this presented unique challenges, namely:

1) With clinics having been suspended and hospital visits reduced due to risk of virus transmission, caregivers had to offer more informal caregiving at home. This would have been distressing for children in need of constant occupational therapy and physiotherapy services since this affected their rehabilitation and level of care.
2) Job losses due to the effects of the pandemic meant some parents couldn't afford the cost of care to their children including medication costs.
3) Lockdowns meant caregivers who stayed out of Nairobi and usually brought their children to hospitals within Nairobi e.g. Mathare hospital were unable to access care at their preferred facility.
4) Prolonged school closures meant that children who attended special school and other integrated facilities spent a long time at home thus impeding their progress
5) Children as well as other individuals with disability were characterized as 'at risk' population meaning the fear of the children getting infected by the coronavirus was a constant worry for parents especially for children who had challenges with mask wearing, social distancing and hand hygiene depending on their level of development and disability. Also there was the fear that if the caregiver contracted the virus, who would be left to take care of the children

All these variables suggest that the pandemic occasioned by COVID 19 and the subsequent efforts taken to control it, could have led to significant consequences on the psychological health of those who provide care to the disabled children. This situation could have been an extra source of stress for those tasked with care of children with mental illnesses, some of whom were already vulnerable by virtue of the burden of caregiving.

1.3: PROBLEM STATEMENT

In the Kenyan set up, the bulk of caregiving is provided informally by relatives who include biological or adopted parents, grandparents and other relatives. This is mostly done in the backdrop of limited resources as well as limited knowledge of unique needs of these children especially children with mental illnesses.

The COVID 19 pandemic has presented additional strain to caregivers who have had to bear extra burden of care due to containment measures instituted to contain the pandemic. This involved reduced services at hospitals, school closures, lockdowns and curfews.

The added effect of reduced household incomes, parents spending more time at home due to job losses or being forced to work from home and lockdowns meant that the parents have been strained both by the burden of caregiving as well as worries about the future wellbeing of themselves as well as those under their care. The added concern about children contracting illness due to their reduced ability to take care of themselves further predisposed them to more risk for anxiety, depression and stress.

A study was conducted in Surat, (India) to examine the mental health implications of the plague pandemic in 1994 (Ramalingaswami et al, 2011). It was revealed that he outbreaks of infectious diseases had a significant effect on psychological well-being of those affected due to massive disruptions in their economic activities.

There has been an upsurge in mental health strain among the general public, this can be attributed to the pandemic occasioned by COVID 19. According to a study conducted to investigate the effects of the COVID 19 pandemic on psychological well-being and stress of those who provide care to special needs children, there was a demonstrable elevation in prevalence of depressive symptoms compared to the period prior to the pandemic, (Dhiman et al, 2020). For those patients who had a prior history of mental illness, they were noted to be at greater risk of having a relapse in their conditions and this was connected to COVID 19, (Yao et al,2020.)

Caregiver concerns about the well-being of their children during the pandemic have been demonstrated to be valid. There is an elevated risk of contracting and transmitting infections among children with disorders of development (Alexander et al, 2020 and McDermott et al 2020).

Caregivers who are battling depression or anxiety have been shown to have adverse effects on the overall care they provide. Yue et al, (2018), conducted a study in a rural part of China to evaluate caregiver depression and its association with development of children under their care in their formative years. The levels of depression were found to be at 23.6% among the caregivers in the study which was higher than the global average (13-21%, de Castro et al, 2017). 37.6% of the children in this study had cognitive developmental delay, 52% language development delay, 46.2% had social emotional delay. This is of concern since the effects of parental psychological distress as a result of caregiving can lead to developmental delay among other children under their care. Another study conducted among impoverished populations in rural China explored factors that contributed to developmental delays, (Zhang et al, 2018). In this study caregivers care and stimulus factors were directly correlated with developmental delay indicating the provision of a nurturing environment during child upbringing is key to adequate development.

Thus there is demonstrated evidence that depression, anxiety and stress have more effects not just limited to the caregiver but also those under their care, including other children in the household and other family members. These effects can also spill over to the work environment and put him/her at risk of job underperformance and job loss in an already job scarce economy.

It has been demonstrated that there is a significant correlation between a parent's temperament and the behavioral patterns of a child with ADHD symptoms during the COVID 19 pandemic, (Zhang et al, 2020). A child with ADHD who might have difficulty coping with a restrictive environment will react with tantrums and this was noted to have a direct effect on the parent's mood state. This indicated that the mental health of the caregiver and the range of

symptoms of the children under care may have a correlational relationship. Thus addressing mental health challenges faced by caregivers of children with mental illness may improve their level of caregiving and reciprocally the well-being of those under their care.

Since the time when COVID 19 was declared a pandemic in Kenya, there has been no study conducted to investigate how prevalent mental health problems are among those providing care to children with mental illnesses (special needs). The goal of this study will be to determine how prevalent are psychological distress and dysfunctional symptoms secondary to coronavirus anxiety among the caregivers of children with mental illnesses at Mathare National Teaching and Referral hospital. It will also explore the challenges experienced by the caregivers as well as their coping mechanisms.

In the Kenyan context, the wake of the COVID 19 pandemic has been accompanied by numerous fake stories and allegations regarding the coronavirus true origins and unapproved therapies (including off label use of certain medications and inoculations). Irrational fear of the virus has escalated, as has vaccine apprehension. Kenya's ministry of health has undertaken various education and awareness campaigns, on multiple conventional and social media platforms to counter any disinformation. The target has been to raise public enlightenment and encourage cooperation with the polices and strategies implemented.

Because caregivers play such an important part in management of conditions attributed to mental as well as other development disorders in children during the pandemic, their mental turmoil and subsequent psychological distress during the COVID 19 pandemic necessitates further enquiry and relevant intervention.

CHAPTER 2

2.1: LITERATURE REVIEW

2.1.1: INTRODUCTION

The literature from relevant empirical research studies on the prevalence of psychological distress among those who take care of children with mental (developmental) disorders will be highlighted in this chapter. The effects of the COVID 19 pandemic will be considered first, both among the general population as well as the caregivers. This will be followed by giving consideration to common mental health issues among children and adolescents and how they relate with the psychological well-being of those who provide care.

Mental health is recognized as a fundamental and vital component of health by the World Health Organization (WHO). In this context, mental health implies a condition of wellbeing whereby a person can recognize his or her own capabilities, deal with everyday struggles, work efficiently and give back to society. An individual's psychological health status can be attributed to combination of a multitude of varied interpersonal, cognitive and physiological variables at any one time.in all countries, it has been established that the impact of psychiatric ailments among the public at large continues to rise, having a considerable impact on people's health and significant cultural, civil dignity and economic ramifications.

Psychological distress is described by the American Psychological Association as a collection of unpleasant psychological and physical symptoms linked with mood changes in most persons. It could, however, signal the commencement of a significant mood disorder, psychotic episode, anxiety disorder. Disorders of mental health are the leading causes of years lived with disability (YLDs), as well as disability adjusted life years, (DALYs). They thus have been noted to account for 13% of DALYs and 32.4% of YLDs, (Bruha et al, 2018).

We also need to consider effects of what are termed as determinants of health which include individual attributes e.g. dealing with one's thoughts, conduct, emotional reactions and dealing with other people. Also to be considered are cultural context, economic, social and the effects of the environment one exists in, for example social protection mechanisms, the conditions under which one works, standards of living, support of the community as well as government policies. Additional factors that would contribute to mental disorders include nutrition, stress, genetics and exposure to hazards in the environment

The following will be covered in subsequent subheadings: depression, anxiety, stress, effects of COVID 19 pandemic. Literature will be compared on prevalence of the above among the general population, caregivers as well as prevalence before as well as after the onset of the COVID pandemic

2.1.2: DEPRESSION

This is the commonest mental illness globally affecting 264 million individuals globally (WHO), it is marked by chronic unhappiness as well as lack of pleasure and enjoyment (anhedonia), low

self-esteem, guilt feelings, altered sleep pattern and multiple psycho-somatic complaints. It has the possibility or being long term or persistent as well as severely limiting someone's capacity to perform at school or place of occupation. Depending on the severity and without adequate intervention it can lead to suicide. Prevention programs as well as timely interventions when symptoms are detected, have been shown to reduce the prevalence. Compared to men, women are more affected and coincidentally women form the majority of informal caregivers. Management involves both pharmacotherapy and psychotherapeutic interventions. Identification of risk factors as well as psychosocial contributing factors are key in management e.g. financial problems, difficulty at work or home, physical and mental abuse, stressful life events etc.

2.1.3: ANXIETY

When faced with a threat, anxiety is a warning signal that allows a person to take action. Enhanced autonomic as well as somatic activity accompany the preparation for this action, which is medicated by interplay between the parasympathetic and sympathetic neuronal systems. The type of threat, prior encounter, individual resources, coping strategies and psychological defenses all have a role as to whether an experience is seen as stressful. Anxiety affect one's thinking, perception of situations and learning from the experience. Anxiety disorders are major contributors to psychiatric morbidity.

With regards to biopsychosocial model of psychiatric diseases, Biological mechanisms have been demonstrated to be involved in anxiety/ stress response. It is preceded by identification of a stressor followed by sympathetic nervous system activation as well as the hypothalamo-pituitary-adrenal axis (HPA), this process leads to catecholamine release (noradrenaline) and cortisol (stress hormone) release from adrenal cortex. Excessive HPA activation leads to increase in cortisol release thus predisposing to hypertension, insulin resistance, cardiovascular diseases, osteoporosis, lowered immunity, dyslipidemia, dyscoagulation and atherosclerosis.

Individuals experiencing elevated anxiety states have been noted to be at risk of developing cardiovascular conditions as well as sudden death due to cardiovascular diseases (Roest et al, 2010). It has previously been acknowledged that those who provide care to children suffering from chronic diseases may have an elevated risk of death compared to those parents of children without chronic diseases, adjusted hazard ratio 1.22, 95% CI, 1.15-1.29 (Cohn et al, 2019). This shows that anxiety if not diagnosed early and managed adequately can lead to adverse health outcomes.

2.1.4: STRESS

Stress can be defined as a state of emotional or physical tension. It normally develops when one has exhausted their coping capabilities. In less formal terms, we could say we feel stressed when we feel that situations are beyond our control. Stress can be classified as either the acute or chronic stress. Some acute stress conditions can produce feelings of frustration and some anxiety. Chronic stress predisposes to anxiety disorders, depression and burnout. These can also lead to additional health problems as highlighted previously.

Female caregivers have been found to be more prone to stress in comparison to male caregivers, (Penning & Wu, 2007). Gender is thus an important factor regarding our resilience to stress. The severity of symptoms experienced by the child has also been noted to be a significant contributor to caregiver stress, (Shepherd et al, 2018).

Events in life which often happen by coincidence, have been seen to present challenges to which an individual must respond appropriately, (Holmes & Rahe, 1978). The social readjustment rating scale (SRRS), which was developed to enable an individual to approximate the stress load and make appropriate interventions. Accumulation of 200 or more life change units in a single year was noted to increase risk of developing psychosomatic disorders. Among the items rated include: significant personal injury or being unwell (53), loss of employment (47), major business readjustment (39), loss by death of a close member of the family (63), altered health status of a close member of the family (44) etc. These categories indicate that family related events are major contributors to accumulation of annual life change units and ultimately increased stress load.

2.1.5: DYSFUNCTIONAL CORONAVIRUS ANXIETY

The pandemic brought about by COVID 19 has brought with it a slew of new challenges: job losses, unprecedented school closures, extra public health measures (washing of hands, keeping social distance and wearing of masks), some parts of the economy being shut down while others are still struggling to reopen. Individuals have been characterized according to their level of risk of contracting the virus, with those with chronic conditions and over 58 years being encouraged to work from home. All media channels were flooded with reports of deaths due to the Coronavirus and hospitals being flooded with cases of those infected. The rise in the number of infected persons was used as a guide to determine prevalence and thus institute strict control measures. Concerns about the pandemic were associated with anxiety regarding the pandemic. This was associated with difficulty sleeping, loss of appetite among other psychosomatic symptoms. Fears about the COVID 19 pandemic put additional mental/ emotional distress on individuals, in this case we will consider caregivers who apart from concerns about their own health also have to worry about children who may have challenges coping with the strict public health measures or the challenge of loss of income that may impair their ability to offer adequate care.

Vaccination distribution among African countries has proven to be a challenge with limited stocks as well as low vaccine uptake due to misinformation among the populace. There is one question among individuals globally," *when is this pandemic going to end*?" it is evident that there is a lot of uncertainty surrounding the COVID 19 pandemic making it easy to catastrophize and spiral into overwhelming dread and panic.

A term 'corona-phobia' was proposed as a distinct global pandemic construct with substantial links to functional impairment and mental anguish, (Arora et al, 2020). After analysis, incremental corona-phobia accounted for the variance observed in psychological distress compared to the preceding period. (Lee et al, 2020).

Functional impairment brought about by coronavirus dread and apprehension was accompanied by high levels of despondency, suicide thoughts, existential crises and substance abuse as a means of coping than those who were worried but not disabled, (Lee et al, 2020). This demonstrated that apart from the effect of anxiety regarding the pandemic the maladaptive coping mechanisms could also predispose to more challenges.

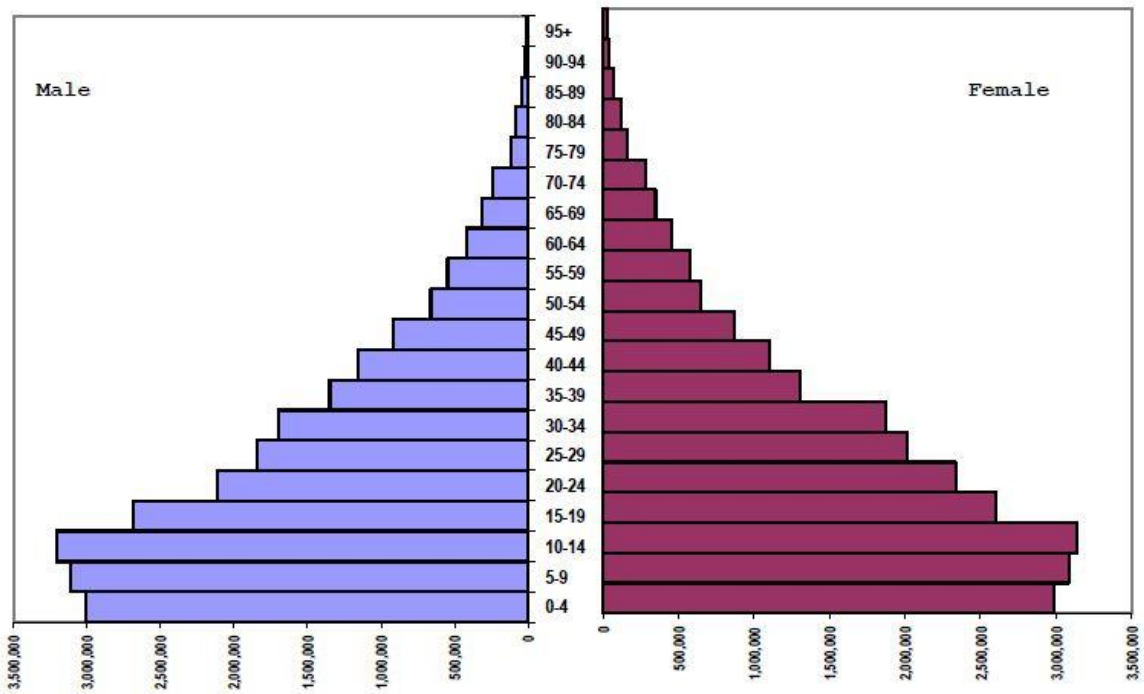
COVID 19 anxiety syndrome has been developed to describe the dread and anxiety symptoms linked with the pandemic. The manifestations of this syndrome are similar to those of other psychiatric illnesses such as PTSD, OCD as well as other disorders that appear to have been triggered by pandemic related circumstances. This unlikely situation has been precipitated by disruption of people's lives similar to what occurred in previous disaster conditions.

2.1.6: BURDEN OF PSYCHIATRIC CONDITIONS AMONG ADOLESCENTS AND CHILDREN

On average about 15% of children and adolescents worldwide are affected by disorders of mental health, with fifty percent being diagnosed by the age of 14 years and about seventy-five percent the age of 24 years, (Polanczyk et al, 2015),

Kenya's economy is classified under the low middle income category. It has a significant youthful population made up of 48% children and adolescents. Findings from the year 2019 Kenyan National Census exercise conducted by the Kenya National Bureau of Statistics, confirmed a population increase with the Kenyan Population set at 47.5 million people, with a predominantly youthful population. There were 12.2 million households with a typical household containing 3.9 members on average.

Figure 1: Kenyan population pyramid, courtesy KNBS, 2019 census report



As a country, Kenya has a significant burden of mental health disorders among children. A study done by Ndetei et al, (2015), among school age children in upper primary school classes reported a prevalence of mental disorders at 37.7 percent (95% C.I.: 35.7-39.7), with 18.2 percent (95% C.I.:16.6-19.8), suffering from one or more concurrent mental illnesses. This study also found the child's gender, location during upbringing, academic performance, parental marital status and employment status of parents especially mother being significant contributors.

2.1.7: CHILD CHARACTERISTICS AS MAJOR CONTRIBUTORS OF CAREGIVER MENTAL DISTRESS

Individual child characteristics e.g. age, functionality status, diagnosis and duration of disability have been noted to be major contributors to parental psychological distress.

Williams et al, (2019), observed that that 40 percent of caretakers of children with congenital anomalies due to zika virus, experienced depression from mild to moderate levels. This was attributed to lack parental stress and resource deficiency.

Kuper et al, (2017), in a study among children with regards to congenital zika syndrome, a comparison was made among parents with and those without the disorder. A large percentage of mothers (36%), reported high stress levels, sadness (18%), and anxiety (27%) respectively. Elevated levels of depression, worry and tension were associated with minimal social support.

According to Reilly et al, (2017), 72 percent of mothers of children with convulsive disorder had a heightened likelihood of psychological distress in contrast to 49% of mothers of children without the disorder. Being female ($p<0.05$) and the child's behavior challenges ($p<0.04$), were significant.

Based on findings by Vagner et al, (2020), mothers grappling with childcare had substantially greater rates of joblessness (38%), than fathers (11%). Child issues as reported by parents were linked with significant levels of PTSD and perceived psychological distress.

According to Algorta et al, (2017), parents to children with bipolar spectrum illness were much more likely to have symptoms of depression, antisocial tendencies as well as parental stress. Anxiety and gloomy behaviors among the children were also found to be linked to parental stress.

Another study looked at the effect of taking care of a child with cerebral palsy on the wellbeing, fatigue, despair and anxiety, (Basaran et al, 2013). When compared to controls, guardians of children with cerebral palsy reported lower standards of living, mental wellbeing and exhaustion scores. The carer's unhappiness and poor quality of life were linked to limitations in function of the children

These studies show that the child characteristics are major contributors to psychological distress among caregivers.

2.1.8: EFFECT OF THE COVID 19 PANDEMIC ON MENTAL HEALTH

A disaster can be said to be an unexpected devastating event that severely interrupts the way a community ordinarily functions. In this way it has significant impact on the people affected, thus threatening the mental health of a population especially those who are considered to be vulnerable. In this regard, the COVID 19 as pandemic, fits this definition leading to its consideration in various circles as a healthcare catastrophe of immense proportions.

An article published in 'Mental Health America- 2021' indicated that the number of people looking for help with psychologically distressing symptoms in the United States of America had markedly increased in the year 2020 (period Jan- Sept) with the number of cases of depressive illnesses having increased by more than 93 percent compared to the preceding 2019 levels and anxiety symptoms also increasing by 62 percent compared to the same period. The number of people who were screened for moderately elevated to severely elevated symptoms of depression and/or anxiety had continuously increased throughout the year 2020 compared to the pre-Covid 19 levels.

There is proof that the current pandemic has had widespread mental health repercussions. There has been a startling increase in anxiety symptoms as well as stimulation of future anxieties and feelings of uncertainty that are frequent during times of strife (Allyson et al, 2020.

A study by Piotrowsky et al (2020) concluded that unlike transient events we experienced and considered traumatic for example natural disasters, the COVID 19 pandemic could only fit the definition of a chronic stressor that affects every possible facet of our psychological, social and public health vulnerabilities. The conclusion being that the pandemic related effects will be perceived for long beyond the pandemic is over.

Wu et al (2009) and Wheaton et al (2012), established that outbreaks associated with infectious diseases were linked with higher levels of mental distress, worry and psychological strain in the general populace.

During the pandemic, it became clear that the anxieties and concerns associated with mourning, loneliness, loss of money and dread can induce mental health issues or intensify those that already existed. A large number of people are reported to have attempted to cope by resorting to increasing their substance usage, insomnia and worry, all of which care considered as maladaptive coping mechanisms.

COVID 19 was found to have a bidirectional association with psychiatric illnesses, (Taquet et al, 2020).it was discovered that receiving a diagnosis of COVID 19 had an association with elevated risk of depression in the 14 0 90 days following the diagnosis in those who had no previous history of mental illness. A past history of psychiatric diagnosis especially in the preceding year was shown to be substantially linked to a higher risk of COVID 19 diagnosis (Relative Risk of 1.65, 95% CI, 1.59-1.71; $p<0.0001$). As a result, children with mental illnesses as well their caretakers were found to be at risk of poorer mental health as well as increased risk of infection.

A study by Panchal et al, (2020), found that the COVID 19 pandemic and the ensuing economic downturn has a detrimental impact on a large portion of the populace and posed new issues to those who were already dealing with the struggles of mental illness and/ or substance abuse. In the first 6 months of 2020 it was revealed that 40 percent of the adults in the United States of America struggled with psychological distress, this was in comparison to 10 percent in a similar period the previous year.

During the pandemic, a large number of people have highlighted concerns regarding threats to their mental health and general state of well-being. The closure of schools and shortage of child care services for the children who were constrained to staying at home owing to lockdown measures presented difficulties to the parents, especially mothers. 49 percent of the mothers were more likely to report symptoms of psychological distress compared to 40 percent of fathers.

Since the beginning of the COVID 19 pandemic some factors have been demonstrated to contribute to psychological distress:

1) General health status: compared to adults with good health status, those with poorer health status reported higher likelihood of psychological strain. This was accompanied by categorization into the at risk group of contracting COVID 19. This necessitated extra precautions being taken to decrease the risk of infection, to some this affected their productivity and to others even their employability.
2) Age: suicidal ideations, insomnia and psychological distress were noted to have been elevated among youth and young adults during the pandemic. Some plausible related factors included loss of income/ employment, transitioning to working from home which was encouraged to maintain productivity while avoiding redundancies, this also led to loss of the social attributes of being at work with colleagues. For those in school they couldn't be with their friends and classmates.

TABLE 1: Courtesy: KFF analysis of household pulse survey (USA, 2020)

AGE	ANXIETY/ DEPRESSIVE DISORDERS	INCREASED SUBSTANCE USE (during pandemic)	SUICIDAL THOUGHTS
18 -24 YRS	56.2%	25%	26%
25 – 49 YRS	48.9%	13%	11%
50 – 64 YRS	39.1%		
> 65 YRS	29.3%		

3) Loss of employment: compared to adults who did not lose their employment due to redundancies occasioned by the pandemic, those who were affected reported higher depressive symptom indices at 59 percent, compared to those who weren't at 32 percent, (Panchal et al, 2020). This could have contributed to certain maladaptive habits

like increased substance use. Those with lower incomes and less reserves were at more risk.

4) Parents and children: the age of children and number of children in the household were contributors to elevated levels of psychological distress. Mothers, at 50 percent, were more affected than fathers, at 40 percent. Having children below the age of eighteen years was associated with elevated levels of distress at 45 percent, compared to not having young children under the age of 18 years, at 41 percent.
5) Gender: at 47%, women were reported to have been more affected by the pandemic effects than men, at 38%. This could be attributed to extra household responsibilities. 25 percent of the women expressed unwillingness to go back to their places of work after the pandemic.
6) Children with mental illness: pre-existing mental illnesses among children were reported to have been exacerbated by pandemic associated factors like closure of schools, reduced visits to the hospital hence lowered access to key support services. With social gatherings discouraged, children could not play outside with their friends, go to recreation facilities as well as the need to wear masks and wash hands frequently like the adults.

Compared to non-caregivers, there was a significantly higher risk of depression among caregivers, OR 1.22 (95% CI: 1.05-1.40, p=0.008), (Gallagher et al, 2020). There was a 4 times risk of psychological distress due to being lonely as a result of public health and other containment restrictions, OR 3.85 (95% CI 3.08-4.85, p<0.001). Although 60% of the caregivers reported that they didn't access social support avenues, for those who did it was noted that it reduced the risk of depression by 43 percent.

Under normal conditions (in this case pre pandemic period), caregivers reported having little opportunity to rest (for relief), having minimal time for self-care and also reported higher levels of social isolation. Thus the pandemic and public health control measures encouraging social distancing and social isolation further increased the risk of depression in these individuals.

It has also been noted that children with ADHD affected their parent's mood state during the pandemic (Zhang et al, 2020). An example would be a child with hyperactive type ADHD being fussy due to being restricted at home due to the COVID restrictions, this was accompanied by elevated levels of depression in the caregivers.

For caregivers the current COVID 19 pandemic presented various pandemic related emotional burden concerns, grouped under:

1) Personal concern- about their own state of health
2) Child related concern- since they fall into the at risk group of contracting the virus
3) Personal emotional burden- increased responsibilities due to additional burden of care
4) Child related emotional burden- effects of the restrictions and also concern about the future

2.1.9: PREVALENCE OF PSYCHOLOGICAL DISTRESS AMONGST THE GENERAL POPULACE BOTH BEFORE AND DURING THE COVID 19 PANDEMIC

Research findings on how prevalent are psychiatric illnesses among the general populace, can serve as a benchmark against which caregiver's levels can be compared. As a result, the high incidence of psychological discomfort in the general community raises the question of whether there is a difference between them and the caregivers and what the reasons for that are. Another concern is whether there is a difference in psychological distress during the present scenario vs the pre COVID scenario and what the reasons are?

According to a study done among the Yazidi community, (Iran) revealed that 29 percent, 32.2 percent and 34.8 percent of the populace were depressed, had anxiety and stressed respectively, significant findings being gender of the caregiver, education level and marriage status, $p<0.001$, (Mohsen et al, 2015). A study done in Korea to assess how prevalent was depression among the populace, established that 6.7% were depressed, (Cheolmin et al, 2016). The difference between the values may be attributed to the Yazidi population being exposed to more stressors since they were in hardship conditions compared to the Korean study population.

A comprehensive review of multiple articles, (Nader et al, 2020), revealed the prevalence of stress at 29.6%, anxiety 31.9% and depression at 33.7%. Significant findings were that women were at more risk of pandemic related stress and Post traumatic stress disorder. People who followed COVID news were at more risk of anxiety (this could be postulated by the constant sad news aired in news regarding the surging COVID pandemic). Under developed countries were at more risk of pandemic related anxiety, stress and depression due to concerns about the capabilities of their health facilities to manage the pandemic. Prior medical history was associated with elevated levels anxiety as well as depressive symptoms due to the categorization into the at risk group of contracting the infection.

Lakhan et al (2020), reviewed multiple articles to assess how prevalent the effects of the pandemic revealed, the prevalence of depression was at 20%, anxiety at 35% and stress at 53%. This revealed that during the COVID pandemic, the depressive, stress and anxiety symptoms were all highly prevalent during the pandemic. These levels were also higher than during the pre-pandemic period.

Thus the COVID pandemic and the associated stressors had significant contribution to the psychological wellbeing of the general population with regards to the pre pandemic period.

2.1.10: PSYCHOLOGICAL DISTRESS AMONGST CAREGIVERS OF CHILDREN WITH PSYCHIATRIC ILLNESSES COMPARED TO THE GENERAL POPULATION – PRE COVID 19 PANDEMIC

Among those who took care of children with Autism spectrum disorder, a study conducted in Oman revealed that 45.9 percent were stressed, 45.9 percent had anxiety and 48.6% were depressed (Farsi et al, 2016)

Lushin et al (2016), was able to establish that mothers of children with Autism spectrum disorder had a 3 times elevated risk of being depressed, half of the study participants were diagnosed to be clinically depressed with 41% suffering from anxiety disorders.

Frutos et al (2016) conducted a study among family members who acted as caregivers of children with disabilities in Mexico, 22.7 percent of the study population were depressed, 43.6 percent reported to be struggling with burden and 11.8 percent confirmed family dysfunction.

Thus caregivers were at significant risk of psychological distress due to the challenges they have had to cope with.

2.1.11: PSYCHOLOGICAL DISTRESS AMONGST CAREGIVERS OF CHILDREN WITH MENTAL ILLNESS DURING THE COVID 19 PANDEMIC

It has been established that the strain accompanied with caregiving especially during the pandemic being associated with markedly increased levels of psychological distress. The pandemic and the challenges related to it had significant association with being stressed ($p<0.001$), being anxious ($p<0.01$) and having notable depressive symptomatology ($p0<0.001$). having a sense of control over the pandemic ($p<0.05$) and having adequate support ($p<0.001$) were protective.

A study by Dhiman et al (2020), revealed that 62.5 percent of those who took care of children with special needs were depressed, 20.5 percent were anxious and 36.4 percent were stressed. This was huge jump in comparison to the established levels prior to the pandemic ($p<0.001$, effect size 0.93)

A study was done by Russel et al, (2020) in the USA during the pandemic. After analysis it was established that the impact on mental and psychological wellbeing of the communities after catastrophes was immense. Caregiver distress spilt over onto those under their care, with these children having worse impact. Parental conflict with the children was found to be as a result of this strain. In a way it was said that this was a compensatory mechanism for distressed parents to pass on their frustrations onto their children.

Transition to homeschooling and working from home was a significant stressor. 34.7 percent of the parents reported that they had noted their children had changed in behavior. The parents also had to bear the burden of having extra duties thus eventually 40 percent were found to be depressed, with 39.7 percent ranging from moderate levels to severe. This group that had elevated depression scores also had significant associations with having anxious children. $P<0.001$ (Hue et al, 2020).

Personality of the caregivers was also an important consideration with regards to risk of distress. These effects were more notable during the pandemic due to the multiple extraneous stressors on the caregivers. Hence some parents were more at risk than others by virtue of their personality which mediated their interpretation of their stressors and acting out their challenging circumstances, (Maza et al, 2020).

The diagnosis of the child was also a significant contributor to parental distress. In one study amongst parents of individuals with Intellectual developmental disorder. There were elevated levels of symptoms of depression, antisocial traits and perceived stress due to parenting, (Wilner et al, 2020).

2.1.12: EVALUATING THE EFFECT OF COVID 19 PANDEMIC ON CAREGIVERS OF CHILDREN WITH DEVELOPMENTAL DISABILITY IN COMPARISON TO THOSE WITHOUT DEVELOPMENTAL DISABILITY

In a study, a comparison was made between 225 caregivers of children with Autism spectrum disorder and Attention deficit hyperactivity disorder vs 182 of those who took care of typically developing children. It was established that there was a higher burden associated with caregiving as well as psychological distress. This was evidenced by higher symptoms associated with sadness, strain and persistent worry, (Chafoules et al, 2020)

A study conducted by Gallagher et al (2020, UK., compared a study population consisting of 1349 caregivers vs 6178 non caregivers. There was a significant odds ratio of a caregiver being depressed was at 1.22 (95% CI 1.05 – 1.40, p=0.008) in comparison to pre-pandemic levels the levels of depression had risen in both caregivers (16.7% to 21.6%) as well as non-caregivers (12.1% to 17.9%). The higher the sense of loneliness on the caregiver, the higher the threat of being depressed, the odds rising by about 4 fold due to this. 43 percent of those who were able to access timely intervention and therapy, it was noted to be protective

These studies reveal that the COVID 19 pandemic has been a significant contributor to additional mental distress to caregivers of children with mental and other developmental disorders.

2.1.13: ASSESSING IMPACT OF PREVIOUS INFECTIOS DISEASE EPIDEMICS ON CAREGIVERS IN THE AFRICAN CONTEXT

A qualitative study done in Eastern Uganda by Matua and Wal (2015), study participants were considered to have been living under the constant threat during the outbreak and included survivors as well as caregivers. The defining features of the experience were taken into account under the following identified main themes: (1) constant state of being afraid and being discriminated, (2) possibilities and experiences of the victims were felt to have been obliterated, (3) they were constantly re-experienced and were aware of the lingering effects of the tragic event, (4) due to worries about the outbreak they experience d physical symptomatology due to worry, (5) they felt the outbreak could not be escaped. They prioritized pursuing self-preservation as well as safety in their reaction to the horrific experiences and felt emboldened by overcoming helplessness.

A qualitative study among fathers, by McLean (2016) assessing caregiving crisis in Sierra Leone. 106 fathers were included in the study that involved in-depth semi structured interviews. It was noted that: (1) men who had financial difficulties were more severely affected by the financial inequality, (2) some men were forced to defy public health containment measures to provide for their families, (3) some men took up jobs shunned by others (dirty jobs e.g. burial teams,

hospital cleaning staff) in order to provide for their families despite the health risk posed, and were shunned by society, (4) some men prioritized new forms of care to protect their families i.e. wives and children, involved restricting mingling with others and some even opted not to work in order to protect them and (5) some men took up care roles they previously considered 'feminine', these included intimate care of sick loved ones e.g. washing and feeding them.

These studies reveal that there has been a great burden on the caregivers in the African context to go to extreme measures to provide for their families. The unique challenges in the African context highlighted were absence of adequate Government funded social support systems.

2.2.1: THEORETICAL FRAMEWORK

Provision of caregiving to a child with mental illness among other developmental disabilities is an enormous responsibility that exceeds typical parental care. Unfortunately, as a result of the pressures of caregiving, some caregivers may experience negative physical and psychological health repercussions due to their responsibilities. There may be a number of mental and sociological mechanisms that mediate the influence of stress on the caregiver, this in turn may have an effect on their state of health. This factors may attempt to give insight on why some caregivers are at more risk than others bearing in mind the burden they are under due to caregiving. These may include characteristics of the caregiver, recipient of care (child with special needs), shared history (between child and caregiver), socioeconomic and cultural contexts that influence initiation, interpretation and management of stress, (Raina et al, 2004).

Psychological distress as a result of caregiving arises at the confluence of one's external environment (circumstances they exist in) and internal state (interpretation of events, personality etc.). It can be equated to a situation where there is a collision between the demands of caregiving and the caregiver's subjective ability to respond to those demands while at the same time pursuing other objectives e.g. career, family, education etc.

In this regard various theories have been put forward to find explanations to the challenges experienced by caregivers compared to the general population as well as why some caregivers are more affected than others. As is customary, theories are developed to guide research and the findings from the research investigations are used to revise theories.

1) Risk-resilience model has been used as a theoretical framework to try answer that questions raised above. In this regard the term risk implies the challenges experienced by the caregiver and resilience implies what makes a caregiver able to cope and withstand those challenges. When risks overweigh resilience, psychological distress develops. Wallander et al, (1989), proposed that there were several resistance factors that influence this process: factors such as human stability, stress processing and social ecological processes all play a role. A hypothesis was made in this regard that there is a process that involves altering interactions between threat and resilience factors throughout time. Some risk factor categories to be borne in mind include: individual factors, child disability factors, functional independence levels among others.

The perception of the parent regarding the quality of care they offer can be added to this framework. Demographic characteristics, impairment parameters, parenting processes, sociocultural factors, psychological issues and coping techniques are all accounted for in this regards.

The strategy will result in better parent emotionally driven well-being and eventual contentment with care. The presence of mitigating socioecological parameters, the presence of reduced child behavioral difficulties and improved contentment with care are all linked to parent emotionally derived well-being.

2) Caregiver stress process model makes an assumption that the experience of caring and the accompanying stress evolve over time, (Pearlin et al, 1990). The susceptibility of stress on the caregiver is the result of a process involving a number of interconnected factors including the caregivers economic and social factors, capabilities and exposure to the various stressors.
   - Primary stressors are connected to the function of caregiving- difficulties, obstacles and other issues that are strongly attributable to care giving.
   - Secondary stressors are the pressures that individuals face in tasks and activities that are not related to caregiving. They also involve intra-psychic stresses that cause a reduction in self-concept. Multiple sits along the stress process pathway can be influenced by coping and social support networks. In this way social support can be referred to as a stress moderator. Maturity of self-efficacy can explain why, though many individuals may face the same affliction, they respond to it differently.
3) Multidimensional model has also been proposed, (Raina et al, 2004), as better means of contextualizing the process of caregiver strain as a result of caregiving. It takes into account various elements including the child's features, caregiver stress levels, intrapsychic issues and factors associated with coping. In this regard the author equated caregiving to a career, unlike a normal career pathway which is preceded by training and recruitment with job evaluation along the way, in caregiving in most cases the role is taken up when the event has already happened and the caregiver with minimal knowledge has to take up the responsibility, hence the strain. Caregiving doesn't occur in a vacuum and there is interplay of multiple factors that affect the caregiver as well as the role of caregiving, they include:
   - Background/ context: there doesn't exist a vacuum situation when it comes to caregiving, it is influenced by one's social and personal experiences, both from the past as well as the present circumstances. As a result, it is necessary to evaluate the context in which caregiving occurs with focus on interaction between various socioeconomic factors of the family such a parental education, profession, average family income and so on. A hypothesis can be postulated that high socioeconomic status can be associated with fewer caregiving demands, improved psychological health etc. in this regard, during the pandemic, we can consider the many emergent challenges that have been shown to increase psychological distress affecting both

the caregivers as well as those under their care, which will be important to bear in mind when interpreting results of research studies done during this period.

- Child characteristics: literature highlights child disability and behavior as key factors associated with caregiver mental health and wellbeing. We can hypothesize that fewer child problems and increased functional independence will eventually lead to more promising caregiver state of psychological well-being.
- Caregiver strain: can be considered a byproduct of caregiver demands and how the caregiver evaluates their performance in caregiving. caregiver demands can be considered in the context of daily demands of caregiving and conflict between caregiving and occupational roles as well as career demands. Emergent concerns during the COVID 19 pandemic can include change in employment status, income status, altered school calendars that put additional demand on the resources available to the caregiver, thus increasing risk of strain.
- Caregiver intrapsychic factors: this entails identifying one's role as a caregiver as well as evaluating one's performance in that capacity. As a result, self-perception is a crucial intrapsychic element. Higher levels of self-perception are likely to be linked to increased levels of social engagement and better family harmony.
- Coping/ supporting factors: individuals have differences in levels of access to and use of coping mechanisms. Informal assistance generated from social interactions with caregivers such as family, relatives or friends is called social support. The amount to which a family functions as a whole is referred to as family function, in this case family situations including marital status and individual family situations can be considered. In reaction to stressful conditions, the caregiver's methods and behaviors are crucial components of stress management strategies. We can speculate that the better the strategies, the higher the psychological health levels.
- Caregiver health and well-being: these affect both the role of caregiving as well as independently predisposing to development of psychological distress. Psychological distress as a result of caregiving could also predispose to poor health. Putting this in context, the COVID 19 pandemic has put emphasis on individual health status and even categorized individuals into at risk groups. A caregiver of a child with mental illness, apart from having concerns about their well-being, also has to consider the health status of the child under their care. this further complicates the role of the caregiver during the pandemic and can contribute to greater psychological distress by virtue of the pandemic.

2.2.2: CONCEPTUAL FRAMEWORK

The goal of this study was to determine how prevalent is psychological distress and dysfunctional coronavirus anxiety amongst caregivers of children with mental illnesses at Mathare National teaching and Referral hospital. With regards to psychological health of the caregivers, the researcher considered the levels of stress, anxiety and depressive symptoms. The dysfunctional coronavirus anxiety levels were associated with effects of the COVID 19 pandemic. The researcher sought to find the relationship between the moderating variables and how they influence the dependent variables.

Using the multidimensional theoretical framework model (Raina et al, 2004), the following were the variables in this study;

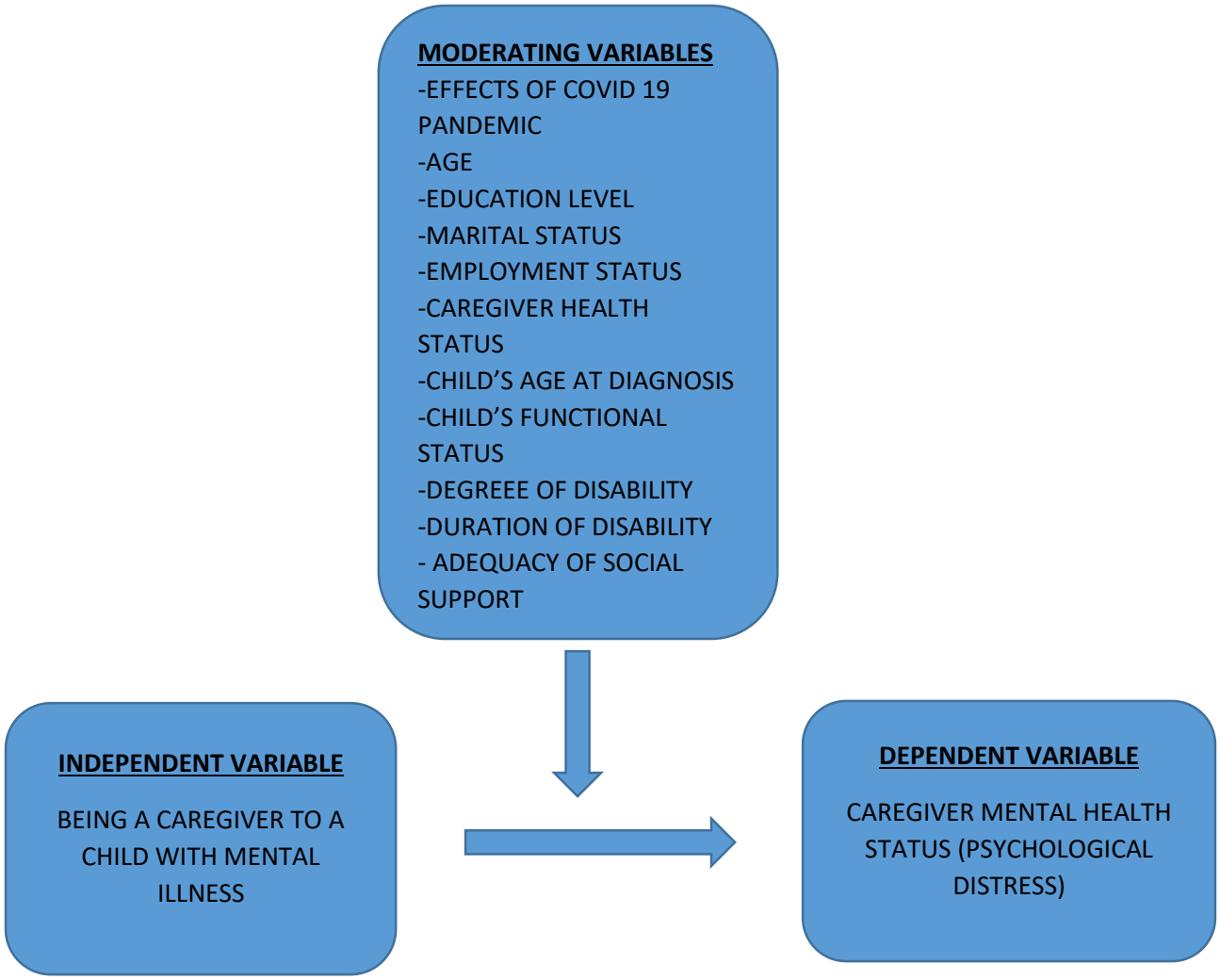
The independent variable was being a caregiver to a child with mental illness

The dependent variable was the presence of psychological distress (i.e. depression, anxiety and stress)

The moderating variables considered in this study were considered under individual, family level, socio economic and cultural factors, they include:

- The COVID 19 pandemic and its associated challenges (dysfunctional coronavirus anxiety)
- Age
- Gender
- Health condition of the caregiver e.g. chronic diseases or health conditions
- Marital status of the caregiver
- Socioeconomic characteristics of the caregiver: education level, employment status, change in income during the pandemic etc.
- Child characteristics: diagnosis, age, duration of caregiving, degree of disability and functional status
- Social support received by the caregiver

FIGURE 2: CONCEPTUAL FRAMEWORK



2.3: SIGNIFICANCE AND RATIONALE OF THE STUDY

During a multi-sectoral meeting in Nairobi, Kenya on 17/5/2021, the Director General in the Ministry of Education, was quoted as stating that the cases of child mistreatment and abuse had skyrocketed during the pandemic. It was noted that this was an indicator of mental states of parents that had been compounded by the COVID 19 pandemic. During the same meeting the UNDP country representative was quoted saying that while COVID 19 was a health crisis, it could be a major mental health crisis if action was not taken. The conclusion made was that reducing the effects of mental health strain required multi-sectoral effort.

The studies quoted in the literature reviewed previously, reveal that caregiving is a significant contributor to elevated levels of states of sadness, worry and strain among caregivers of children with mental as well as other developmental needs. These levels are quite high in comparison to the general populace as well as amongst the parents of typically developing children. The difficulties associated with caregiving place a considerable strain on the mental health of guardians especially parents of children with disabilities and other special needs. A parent's (caregiver's) mental wellbeing has a spill-over effect and may affect the health of other children under their care with notable effects on their state of physical and mental health as well as on cognitive development.

These studies also reveal that COVID 19 pandemic has been a significant contributor to elevated levels of mental anguish and worry among caregivers in comparison to the Pre-pandemic period. More research is recommended to ascertain how prevalent psychological distress is among this unique population as well as the long term effects. Due to emergent challenges described above, research led objective findings will help ascertain levels and areas of caregiver challenges. This knowledge will guide interventions geared towards building resilience and coping with the adverse health, psychological and economic challenges facing caregivers during the COVID 19 pandemic.

The study population in this study comprised of resource limited individuals who depend on public healthcare facilities. The ability of this study to highlight their challenges that may have gone unnoticed will go a long way to improve eventual outcomes on a disadvantaged populace.

Findings from this research study will enable the researcher understand and to the consumers of this information, it will contribute to understanding how the COVID 19 pandemic has affected the caregivers of children with mental illness in Kenya, as well as their coping strategies. This will add to existing literature and fill the knowledge gaps after which further studies and interventions can be done to mitigate the effects of the burden of caregiving as well as long term effects of caregiving through and after the COVID 19 pandemic.

This study's findings will enable the Ministry of Health and various hospital management boards to come up with policy recommendations that can enable institution of appropriate interventions not only addressing the children with mental illness and other special needs but also the caregivers of these children.

2.4: MAIN OBJECTIVE

1) To ascertain the prevalence of psychological distress, dysfunctional coronavirus anxiety and impact of COVID 19 pandemic on caregivers of children with mental illnesses attending child psychiatry clinic at Mathare National Teaching and Referral hospital

2.5: SPECIFIC OBJECTIVES

1) To ascertain the risk and protective sociodemographic characteristics of caregivers of children with mental illnesses at Mathare National Teaching and referral hospital.

2) To determine the levels of depression, stress, anxiety and dysfunctional coronavirus anxiety among caregivers of children with mental illness at Mathare National Teaching and Referral hospital.

3) To determine the association between sociodemographic characteristics, anxiety, depression, stress and dysfunctional coronavirus anxiety among caregivers of children with mental illness at Mathare National Teaching and Referral hospital.

4) To evaluate the self-reported parental perception of the challenges and coping strategies of caregiving for children with mental illnesses during the COVID pandemic

CHAPTER 3

RESEARCH METHODOLOGY

3.1: INTRODUCTION

The methodology of the study will be highlighted in this chapter. This will include study design, sampling methods and procedures that guided the researcher to identify the sources of data, sample size, sample data collection methods, instruments and ethical considerations.

Given the study was conducted against the backdrop of the COVID 19 pandemic, this chapter will detail the researcher's procedures to guarantee that both the researcher and study participants were safe during the data collection process.

3.2: STUDY DESIGN

The study was a hospital based study, incorporating descriptive cross sectional, quantitative study design. A questionnaire with both closed and open ended questions was used, this enabled assessment of the sociodemographic factors as well as the perceived impact of the COVID 19 pandemic. The prevalence of psychological distress amongst the caregivers of children with mental illness was assessed using Depression, Anxiety and Stress scale 21 (DASS 21), The Coronavirus anxiety scale was used to assess dysfunctional coronavirus anxiety symptoms.

3.3: STUDY SITE

The study was conducted at the Child psychiatry clinic at Mathari National Teaching and Referral hospital. This clinic is run every Wednesday by two consultant psychiatrists assisted by psychiatry residents as well as clinical psychologists, occupational therapist and nursing staff. It is one of the two child psychiatry clinics run at public hospitals within Nairobi county, the other being Kenyatta National Hospital child psychiatry clinic.

The colonial authorities of British-Kenya established the Mathari National Teaching and Referral hospital in 1910 as a small pox isolation center. It was later converted to an asylum for the insane. Currently it serves as a dedicated hospital for mental health teaching and research public health institution in Kenya. It is located west of Nairobi and across the Muthaiga police station along the Thika-Nairobi highway. It serves both inpatients and a large number of outpatients daily. It contains approximately six hundred beds with a third dedicated for female patients. It is Kenya's foremost public psychiatric hospital as well as the biggest public funded, psychiatric teaching and referral hospital. Patients with serious psychiatric conditions who can't be managed as outpatients or in other public facilities are admitted to the facility.

The facility's catchment population comprises predominantly of Nairobi metropolitan populace, as well as rural and peri-urban areas of Nairobi county. The majority of patients are unable to carter for medical fees at the private hospitals with psychiatric units. Though occasionally patients travel from long distances away despite the presence of psychiatric units in nearby health facilities, this is due to their preference for this institution. Due to the need to carter to

outpatients the hospital has 6 outpatient adult psychiatry clinics, that are affiliated to the hospital's wards, which run from Monday to Wednesday.

Patients are initially reviewed at the psychiatric outpatient clinic after which they are either admitted or medication prescribed before they are given a return date for review though the clinics. Psychiatric patients younger than 18 yrs. are referred to the child psychiatry clinic for specialized review. The child psychiatry clinic is one of the outpatient clinics and it runs each Wednesday from 8 am to 2 pm. Within Nairobi county there are 2 dedicated child psychiatry clinics in public hospitals, one is the one conducted at Mathari National Teaching and Referral Hospital (MNTRH), the other being at Kenyatta National Hospital.

The child psychiatry clinic at Mathari NTRH has a holistic approach to health care with patients reviewed both by consultant psychiatrists, psychiatry residents, clinical psychologists, occupational therapists and nursing staff. The clinic facilitates assessment, treatment, prognostication and recommendation for other services like occupational therapy, physiotherapy services. Apart from these services liaison is done with Kenya Institute for Special Education (KISE) for recommendations to special educational facilities for children who will benefit from rehabilitation and special training. On average 10 children are seen each Wednesday (clinic day), with the numbers varying during periods of school closure where a bulk of the children are reviewed before they resume school in case they are in boarding institutions.

Other clinics run at the hospital include the medical outpatient clinic, maternal and child health clinic, rehabilitation as well as substance abuse clinics. Patients who need additional review are referred to these clinics for further review. There are also functional laboratory and radiology departments.

3.4: STUDY POPULATION

The study population comprised of caregivers who accompanied children under their care to attend the child psychiatry clinic at Mathare National Teaching and Referral hospital. This included parents (biological or adopted, grandparents, relatives or other significant caregivers who fit our inclusion criteria)

Inclusion criteria:

- All caregivers of children attending child psychiatry clinic who met the criteria of being a significant caregiver for the child and played an active role in the child's upbringing particularly during the COVID 19 pandemic (past two years)– parents, grandparents, relatives, adopted parents or other non-relative significant caregivers and had capacity to give informed consent.
- caregivers above 18 years of age

exclusion criteria

- caregivers who opted out of the study and/ or refused to give informed consent

3.5: SAMPLE SIZE CALCULATION

Using Cochran's formula (Cochran 1977) with an estimated prevalence of depression among caregivers of 56.2% from a hospital based study at KNH (Onyango et al, 2013). The sample size was calculated using the following formula with a margin of error (precision) of 5% as well as a confidence interval of 95%:

$$n_0 = \frac{z^2 pq}{e^2}$$

where:
n_0= sample size
z= standard normal deviation corresponding to 95% with the confidence interval set at 1.96
p= hypothesized prevalence of caregiver depression at 56.2% (Onyango et al, 2013)
q= 1-p
e= desired level of precision set at 0.05 (5%)
thus

$$n_0 = \frac{1.96^2 * 0.562 * 0.438}{0.05^2}$$

n_0=378 participants

The sample size was adjusted to the child psychiatry clinic attendance at Mathari NTRH. Ten children, on follow up at the child psychiatry clinic, were booked to attend each weekly clinic, run on Wednesday. Forty children were to be reviewed per month (4-week period). The study period was 12 (twelve) weeks (January to March 2022). One caregiver was selected for each child, the projected number of caregivers available for the study was 120 (one hundred and twenty) study participants

Adjustment using the finite population correction:

$$n = \frac{n_0}{1 + \frac{(n_0 - 1)}{N}}.$$

Where:
n= adjusted sample size
n_0= sample size (378)
N= population size (120)
Substituted values:

$$n = \frac{378}{1 + \frac{(378 - 1)}{120}}.$$

n= 91 study participants

Allowing for 10% non-response rate which was about 9 participants, the expected minimum sample size was **100 study participants**

3.6: SAMPLING PROCEDURE

The study participants who fit the inclusion criteria were recruited through purposive sampling. One caregiver who accompanied their children to the child psychiatry clinic was evaluated to fit the inclusion criteria, given a comprehensive explanation about the study, then informed consent was obtained and study tools administered. This procedure was repeated until the desired sample size was achieved.

3.7: RECRUITMENT, CONSENT ACQUISITION AND DATA COLLECTION PROCEDURE

On the clinic day there was a health talk prior to the commencement of the child psychiatry clinic (during registration), whereby the caregivers present on the clinic day were notified that a study would be ongoing during the clinic day. Adequate information on the need and benefits of the study were communicated. Participation was voluntary and only those who were willing to take part, met the inclusion criteria and gave informed consent were included in the study.

The researcher was available to provide adequate explanation of the purpose of the study and significance to all who arrived, including those who arrived late. Caregivers who agreed to participate, fulfilled the eligibility requirements and provided informed consent were ushered into an empty quiet room that guaranteed confidentiality throughout the data collection process. The study participants were assured that their identity and responses would be kept confidential both during and even after the data collection session.

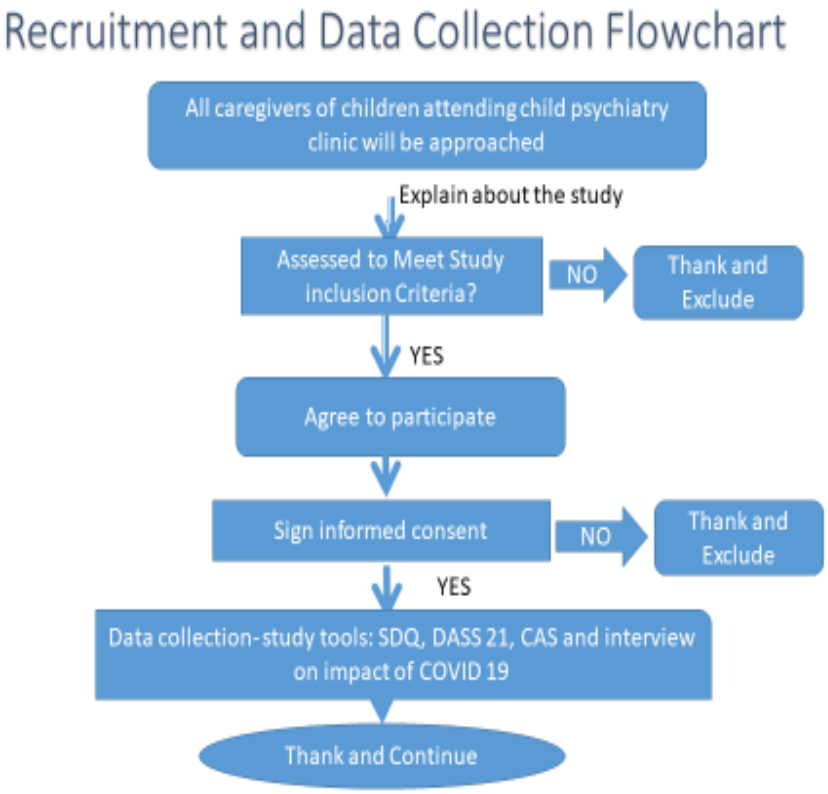
The study participants were guided through both the consent form and study tools in the language of their choice, (English or Kiswahili). The study tools were only administered after informed consent was obtained and this confirmed by a legitimate mark either a signature or thumb print. The study tools included a sociodemographic questionnaire that included closed and a pre-selected set of open ended questions, DASS 21 tool and coronavirus anxiety scale.

The participants who were assessed to be in psychological distress were attended to by the researcher and mental health workers available at the clinic depending on their level of distress. Psychological first aid was offered after which they were referred appropriately for further review.

The researcher gave a contact to the study participants in case they had more questions regarding the study after the study was complete.

The researcher thanked each study participant for their participation in the study. This same procedure was repeated till the required sample size was achieved.

Figure 3



3.8: VARIABLES

The independent variable was caregivers whose children attend the child psychiatry clinic at Mathare National Teaching and Referral hospital.

The dependent variable was psychological distress i.e. presence of Depression, Anxiety and Stress.

The Moderating Variables were: emergent challenges associated with COVID 19 pandemic including dysfunctional coronavirus anxiety, age, gender, employment status, education status, social support, child characteristics (diagnosis, age, duration of caregiving and child's functional status)

3.9: DATA COLLECTION TOOLS

A sociodemographic questionnaire, the DASS 21 instrument, the coronavirus anxiety scale and an open ended guided questionnaire were utilized to collect data.

3.9.1: RESEARCHER GUIDED QUESTIONNAIRE

A researcher guided questionnaire incorporated both closed and open ended questions.

The first portion entailed the use of closed ended questions structured to capture the respondent's sociodemographic characteristics. These had been noted from literature review to be significant variables to be investigated in the study: gender, age, matrimonial status, educational levels, occupational status, financial status, length of caregiving, age of child, child's mental health diagnosis, child's functionality status (self-care capability), number of children and sources of psychosocial support.

The second portion of the questionnaire entailed use of open ended questions to determine the influence of the COVID 19 pandemic. This involved enquiry regarding emergent challenges, coping strategies employed by the caregivers as well as any recommendations from their experience.

Open ended questions:

1) Since the COVID 19 pandemic was declared in this country in March 2020, what have been the main challenges you have experienced associated with caregiving in the midst of a global pandemic?
2) What coping mechanisms have you adopted to enable you to cope with the challenges you have mentioned above, associated with caregiving in the midst of a global pandemic?
3) From your experiences, what recommendations would you make that you feel will enable caregivers cope better with the duty of caregiving?

3.9.2: DASS 21

The depression, anxiety and stress scale 21, is a questionnaire that comprises of twenty-one questions that examine unpleasant emotional symptoms utilizing a four point Likert scale, the higher the DASS 21 rating number, the more severe or frequent these unpleasant symptoms. This tool comprises a set of three self-report scales useful for describing, comprehending and quantifying unpleasant emotional conditions classified under anxiety, depression as well as stress.

Each of the DASS scales in DASS 21 has seven items separated into subscales of two to five items with comparable content;

- D: depressive moods, devaluation of life, pessimism, loss of interest, apathy and lethargy
- A: autonomic activation, skeletal muscle reactions, anxiety symptoms and subjective sensation of anxious effect
- S: levels of persistent non-specific arousal are sensitive to the scale measuring stress. It evaluates restlessness, anxious arousal and a state of easy irritation.

The sum of the values for each item was used to determine the scores for each parameter under evaluation.

The scales are intended to suit the demands of both researchers and physicians who want to assess the current state or change in indicated parameters following an intervention. Language proficiency is the sole restricting factor, but can be used on individuals as young

as seventeen years or even as young as twelve years since there is no convincing evidence against.
It has been interpreted into various languages, validated and utilized in various studies all over the world, including here in Kenya.
The DASS 21 scale is a validated tool with good Cronbach's alpha values of 0.81. 0.78 and 0.89 for each of the subscales of depression, stress and anxiety respectively. It was thus able to adequately measure the dependent variables in this study. It is a highly reliable tool, with adequate validity and easily administered. It is easy to use and may be completed in 3 to 5 minutes.
This tool has been used locally, validated and even translated to Kiswahili. The Kiswahili version has been used in various studies an example is a study used to measure how prevalent was psychological distress among preterm mothers at KNH, (Nyaribari et al, 2015).
In this current study a score of 10 or more on the depression subscale was used to identify depression, a score of 8 or more on anxiety subscale was used to identify anxiety while a score of 10 or more on the stress subscale was used to identify stress.

TABLE 2: DASS 21 SCORING GUIDE

SEVERITY	DEPRESSION SCORES	ANXIETY SCORES	STRESS SCORES
NORMAL	0 – 9	0 – 7	0 -14
MILD	10 – 13	8 – 9	15 – 18
MODERATE	14 – 20	10 – 14	19 – 25
SEVERE	21 – 27	15 – 19	26 – 33
EXTREMELY SEVERE	28+	20+	34+

3.9.3: CORONAVIRUS ANXIETY SCALE (CAS)

CAS is among the initial documented assessment tools for psychopathology associated with COVID 19 that has been validated on a large sample of individuals who experienced considerable anxiety as a result of the outbreak, (Lee et al, 2020). It was developed during the initial periods of worldwide surge in the pandemic, March 2020.
It is a valid tool, its themes have been noted to be consistent and it has been demonstrated to be highly reliable: Cronbach's alpha = 0.93, (Lee et al, 2020). The arousal symptoms linked with high levels of dread and anxiety were used to illustrate its content validity. It has been adapted in Brazil (CAS Br), with a high reliability comparable to the USA version, Cronbach's alpha=0.84, (Neto et al, 2020).
It distinguishes well between people with dysfunctional coronavirus anxiety and those without, 90 percent sensitivity and 85 percent specificity. The cut off scoring equal to or more than 9 was considered dysfunctional.

TABLE 3: CAS SCORING GUIDE

DYSFUNCTIONAL CORONAVIRUS ANXIETY	SCORE
ABSENT	≤ 8
PRESENT	≥ 9

3.10: QUALITY CONTROL DURING DATA COLLECTION

3.10.1: QUALITY CONTROL BEFORE DATA COLLECTION - PRETEST

A pretest was facilitated prior to commencement of the study, whose objectives included:
(1) To determine the duration of data collection for each questionnaire.
(2) Ascertain any verified flaws identified within the data collection tools.
Thus a pilot study was conducted among a small group of respondents. Feedback obtained was used to improve on the data collection tools as well as familiarized the researcher with the study tools, procedure during data collection and time required to conduct the study. This was important since the actual study was conducted concurrently during the clinic day, hence the target was not to inconvenience the study participants.

3.10.2: QUALITY CONTROL DURING DATA COLLECTION

Data collection entailed obtaining data from eligible study participants who were approached, explained to the purpose and significance of the study. They were given the option of voluntarily taking part in the study. There was no victimization of those who did not participate in the study.

The study participants were assessed to check eligibility; if they met the inclusion criteria they were given a thorough explanation about the study. All relevant questions were answered before informed consent was obtained, only after which, did the data collection process proceed. Informed consent was confirmed with signing on the form or use of a thumb print as an alternative. There was no use of names on the tools and a unique identifier was used only known to the researcher. Data was collected in the language that the study participant was comfortable in, either English or Kiswahili. Data was filled in using pens provided by the researcher on the data collection tools and questionnaires provided. After the study participant had filled in the questionnaires a check for completeness was done. After which the study participant was thanked for taking part in the study. All completed questionnaires were scrutinized in the field by the researcher to ensure completeness of the data including the unique identifier in case of need to follow up in the future.

3.11: DATA COLLECTION PERSONNEL- ROLES AND TRAINING

Data was collected by the researcher. Training on all aspects regarding the study was undertaken prior to commencement of the study. The researcher familiarized himself with the study tools, procedures, ethical considerations and confidentiality once the data was collected. Safe storage of all study material after data collection was the researcher's responsibility

3.12: COVID 19 MITIGATION MEASURES

The study participants were screened for any respiratory diseases as well as other primary COVID 19 disease symptoms such as hotness of the body, cough as well as shortness of breath. Temperature checks were done on both researchers and study participants before commencement of any interview.

The data collection was conducted in a well ventilated room and efforts were made to ensure that social distancing (1.5 meters) was maintained during the study. Both the researcher and study participant were required to wear a facemask correctly, at all times during the data collection process. The researcher also provided facemasks to those study participants without a facemask.

Hand sanitizers were provided and be made available to both the researcher and study participant.

3.13: DATA MANAGEMENT

3.13.1: DATA STORAGE

All fully filled questionnaires were collected after each clinic day till the completion of the study. They were stored by the researcher in a lockable cupboard with a lock and key. Only the researcher had access to the storage and retrieval of the stored questionnaires. Data collected for analysis was entered in a password protected computer and kept in a safe and secure place by the researcher.

3.13.2: DATA CLEANING, CODING AND ENTRY

A template was created using Microsoft excel. The template defined the variables of interest to the researcher. Data collected using open ended questions was coded prior to data entry. Data cleaning and validation was done prior to data entry with precautions being taken to ensure accuracy of the information entered. Data entry was done in a central place by the researcher.

Caregiver characteristics were categorized under: age, marital status, level of income, education level, preexisting mental/ physical health status, employment status, duration of caregiving, number of children, DASS 21 and CAS scores

Child characteristics were categorized under: age of child, diagnosis, level of disability/ independent functionality status

COVID 19 associated factors: knowledge about pandemic, challenges experienced during the pandemic, coping mechanisms, attitude and experiences related to caregiving during the pandemic.

3.13.3: DATA ANALYSIS

SPSS version 25.0 was used to analyze the data. The general distribution of the data as well as the scores from DASS 21 and CAS were analyzed using descriptive statistics. Continuous variables were depicted as median, mean and standard deviation. The Categorical variables were presented as proportions. Using Fischer's exact test analysis for categorical data, inferential statistics was applied to establish an association between depression, anxiety, stress with dysfunctional coronavirus anxiety and various sociodemographic characteristics. At the bivariate level, correlation was done to investigate relationships between study variables. At the multivariate level, multivariable logistic regression analysis was applied to provide adjusted

odds ratios. The level of statistical significance was set at $p<0.05$, with a 95% confidence interval. For open ended questions data, the emergent themes were noted, coded and presented in tabular format and graphs. Presentation of data was done in form of tables, charts and descriptions.

3.14: MINIMIZATION OF BIAS

1) Measurement bias: there was careful planning of the data collection procedure and pretesting of the tools to be used to collect data was done.
2) Sampling bias: only the study participants who fulfilled criteria for inclusion into the study and provided informed consent were included in the study
3) Information bias: familiarization of the researcher with the information to be collected prior to data collection. The researcher endeavored not to ask leading questions. The method of asking questions and guidance on questionnaire filling were harmonized.

3.15: ETHICAL CONSIDERATIONS

3.15.1: ETHICAL APPROVAL

Ethical approval for the research study was sought prior to commencement of the study from University of Nairobi/ Kenyatta National Hospital Ethics and Research Committee (KNH/UoN ERC), approval number: P725/09/2021.
Prior to the start of the study, a research permit was sought from the National Commission for Science, Technology and Innovation (NACOSTI): permit number: NACOSTI/P/22/15439.
Permission to conduct the research at Mathare National Teaching and Referral hospital was sought prior to conducting the study at the Child Psychiatry Clinic.

3.15.2: OBTAINING INFORMED CONSENT

All study participants were assessed to fit the inclusion criteria before data collection. Before commencement of the data collection process, informed consent was sought from all eligible study participants who met the inclusion criteria followed by provision of adequate explanations about the study and allowing any questions or concerns about the study to be voiced. This was followed by study participant indicating on the consent form that they were satisfied with the explanations about the study by signing or thumb print on the consent form. This was accompanied by the researcher signing as well, indicating that an adequate explanation had been given. The consent form as well as all explanations were done in English and Kiswahili in case of any language barrier

3.15.3: POTENTIAL BENEFITS OF THE STUDY

The findings from this study will be useful to policy makers and hospital managers in developing ways to reduce the risks and problems faced by carers of children with mental illness during and after the COVID pandemic. Clinicians will be enlightened on the prevalence of depression, anxiety and stress among caregivers of children with mental illnesses, this will enable adequate screening mechanisms and interventions targeted to caregivers and this to be included as part of the clinics. The caregivers will be appraised on the risk factors and challenges noted. They

will be taught about coping mechanisms and advised on the importance of support networks so they do not succumb to sadness, anxiety or stress as a result of caring for others. During data collection, any study participant noticed to be in distress will be assessed by the researcher, psychological first aid offered and referred appropriately for further intervention.

3.15.4: POTENTIAL RISKS OF THE STUDY

No physical harm was anticipated as a result of the study since there would be no sample collection required for this study. In case psychological distress was be noted among the study participants, assessment and psychological first aid were offered by the researcher. This was followed, depending on the level of severity, by referral to an appropriate mental health professional to enable adequate intervention.

3.15.5: CONFIDENTIALITY

All eligible study participants were assured that the study was solely for research/ academic reasons and that any information provided would be regarded with utmost confidentiality. To ensure this, all questionnaires were coded so that the study participants didn't have to reveal their identities. Their information was only known to the researcher. All questionnaires obtained were kept securely by the researcher in a lockable cupboard, all information would be kept in a password protected computer to which only the researcher had access. During the data collection procedure, the interview took place in a quiet and secure environment where anonymity will be assured.

3.15.6: VOLUNTARY PARTICIPATION

The study participants were informed that their participation in the study was completely voluntary. All explanations regarding the study were offered. The study participants were also informed that they were allowed to refuse involvement in the study and could pull out at any time with no risk of any repercussions.

3.15.7: MONETARY BENEFIT

There was no monetary benefit as a result of this study.

3.16: STUDY RESULTS DISSEMINATION

Upon finalization of data analysis, the study findings were presented to the Department of Psychiatry, School of Medicine (UoN). After dissertation defense, the final dissertation has been submitted as part of the Master of Medicine, Psychiatry degree award requirements. Research study findings will be shared with the relevant authorities to add to the fund of knowledge as well as to guide hospital administrators for policy formulation to address challenges experienced by those who take care of children with mental illnesses. These caregivers of children can be educated on the common challenges facing them and how to cope. The findings can be published as a research paper in peer reviewed journals.

CHAPTER 4: STUDY RESULTS

4.1: SUMMARY OF THE SOCIO-DEMOGRAPHIC CHARACTERISTICS

The sample size of one hundred (100) caregivers was achieved adequately, thus response rate was 100 percent (%). The sociodemographic characteristics were thus compiled as frequency among the 100 caregivers and percentages out of 100%.

Baseline characteristic of the study population indicated that male patients constituted 27.0 %, with female caregivers accounting for 73.0%. Twenty-nine (29.0 %) caregivers were aged between 18 and 30 years while 40 (40.0 %) patients were aged between 31 and 43 years. A total of 31 (31.0%)patients were aged above 43 years. Out of 100 caregivers, 25 (25.0 %) were single, 50 (50.0%) were married while 25 (25.0%) had lost their spouses, separated from or divorced their partners. Twenty-four (24.0 %) caregivers had attained primary school education, 36 (36.0%) had attained secondary school education while 40 (40.0 %)had attained tertiary education. Eighty-seven (87%) were biological parents to the children under their care while thirteen (13%) were not biological parents (adopted, siblings, grandparents etc.). Thirty-three (33.0%) reported that the children under their care were independent while 67 (67.0%) required constant care. A total of 32 (32.0%) caregivers were employed while only 37 (37.0 %) reported no change in income since March 2020, when COVID 19 was declared a global pandemic. Thirty-three (33.0%) had received no COVID 19 vaccination, twenty (20.0 %) had received one dose, 47 (47 %) had received 2 or more COVID 19 vaccine doses.

Table 1 below summarizes this information.

Table 4: Socio-Demographic Characteristics of Study Population - caregivers

Characteristic	**Category**	**Frequency n=100 (percentage)**
Gender	Male	27 (27.0)
	Female	73 (73.0)
Age (years)	18 - 30	29 (29.0)
	31 - 43	40 (40.0)
	>43	31 (31.0)
		Mean age: 36.3, SD ±11.13
		Median: 35.5
		Range: 18 – 70 years
Marital Status	Single	25 (25.0)
	Married	50 (50.0)
	Separated/Divorced/ Widowed	25 (25.0)
Education	Primary school	24 (24.0)
	Secondary school	36 (36.0)
	Tertiary	40 (40.0)

Employment Status	Employed	32 (32.0)
	Unemployed	34 (34.0)
	Self Employed	34 (34.0)
Change in Household Income since March 2020	No Change	37 (37.0)
	Changed	63 (63.0)
Age of child attending clinic (Years)	<5	18 (18.0)
	6 - 10	34 (34.0)
	>10	48 (48.0)
Relationship to child	Biological parent	87 (87.0)
	Not Biological parent	13 (13.0)
Duration of Caregiving (years)	<10	56 (56.0)
	>10	44 (44.0)
Number of children in the household	1	23 (23.0)
	2 – 4	62 (62.0)
	≥5	15 (15.0)
Diagnosis of child (DSM V)	ADHD	22 (22.0)
	Autism SD	24 (24.0)
	Communication DO	6 (6.0)
	Conduct disorder	1 (1.0)
	Learning disorder	2 (2.0)
	Cerebral palsy	2 (2.0)
	E. O Schizophrenia	14 (14.0)
	Mood Disorder	6 (6.0)
	Epilepsy	18 (18.0)
	IDD	5 (5.0)
Child's functional status	Independent	33 (33.0)
	Constant care	67 (67.0)
Presence of chronic illness in caregiver	Yes	8 (8.0)
	No	92 (92.0)
Psychosocial support sources	None	74 (74.0)
	Formal	26 (26.0)
COVID 19 Vaccination status of caregiver	None	33 (33.0)
	One Dose	20 (20.0)
	≥Two Doses	47 (47.0)

4.2: PREVALENCE OF PSYCHOLOGICAL DISTRESS AND DYSFUNCTIONAL CORONAVIRUS ANXIETY

A total of 36 (36.0 %) patients were confirmed to be suffering depression while 38 (38.0 %) patients were suffering from anxiety. Twenty-nine (29.0 %) patients had stress symptoms while 20 (20.0 %) patients had dysfunctional coronavirus anxiety. The majority of those found to have depression, anxiety and stress had mild and moderate symptoms. Tables 5 and 6 as well as figure 4 summarize this information.

Table 5: severity of psychological distress parameters

PREVALENCE	CATEGORY	FREQUENCY		CUMMULATIVE FREQUENCY (%)	PARAMETERS
DEPRESSION=36% (CI: 26.4-44.8)	**NORMAL (0-9)**	**64**		64%	MEAN score 6.8 SD ±6.8 MEDIAN 5 TOOL: DASS 21
	MILD (10-13)	**18**	*50%*	18%	
	MODERATE (14-20)	**12**	*33.3%*	12%	
	SEVERE (21-27)	**5**	*13.9%*	5%	
	EXTREMELY SEVERE (28+)	**1**	*2.8%*	1%	
	TOTAL	**100**		**100%**	
ANXIETY=38% (CI: 30.0-48.8)	**NORMAL (0-7)**	**62**		62%	MEAN score 5.56 SD ±4.9 MEDIAN 4 TOOL: DASS 21
	MILD (8-9)	**18**	*47.4%*	18%	
	MODERATE (10-14)	**16**	*42.2%*	16%	
	SEVERE (15-19)	**3**	*7.9%*	3%	
	EXTREMELY SEVERE (20+)	**1**	*2.6%*	1%	
	TOTAL	**100**		**100%**	
STRESS=29% (CI: 21.0-38.5)	**NORMAL (0-14)**	**71**		71%	MEAN score 9.25 SD ±8.9 MEDIAN 7 TOOL: DASS 21
	MILD (15-18)	**15**	*51.7%*	15%	
	MODERATE (19-25)	**7**	*24.1%*	7%	
	SEVERE (26-33)	**5**	*17.2%*	5%	
	EXTREMELY SEVERE (34+)	**2**	*6.9%*	2%	
	TOTAL	**100**		**100%**	
DYSFUNCTIONAL CORONAVIRUS ANXIETY=20% (CI: 13.3-28.9)	**NEGATIVE (≤8)**	**80**		80%	MEAN score 3.61 SD ±3.4 MEDIAN 3 TOOL: CAS
	POSITIVE (≥9)	**20**		20%	
	TOTAL	**100**		**100%**	

Figure 4: severity of psychological distress parameters

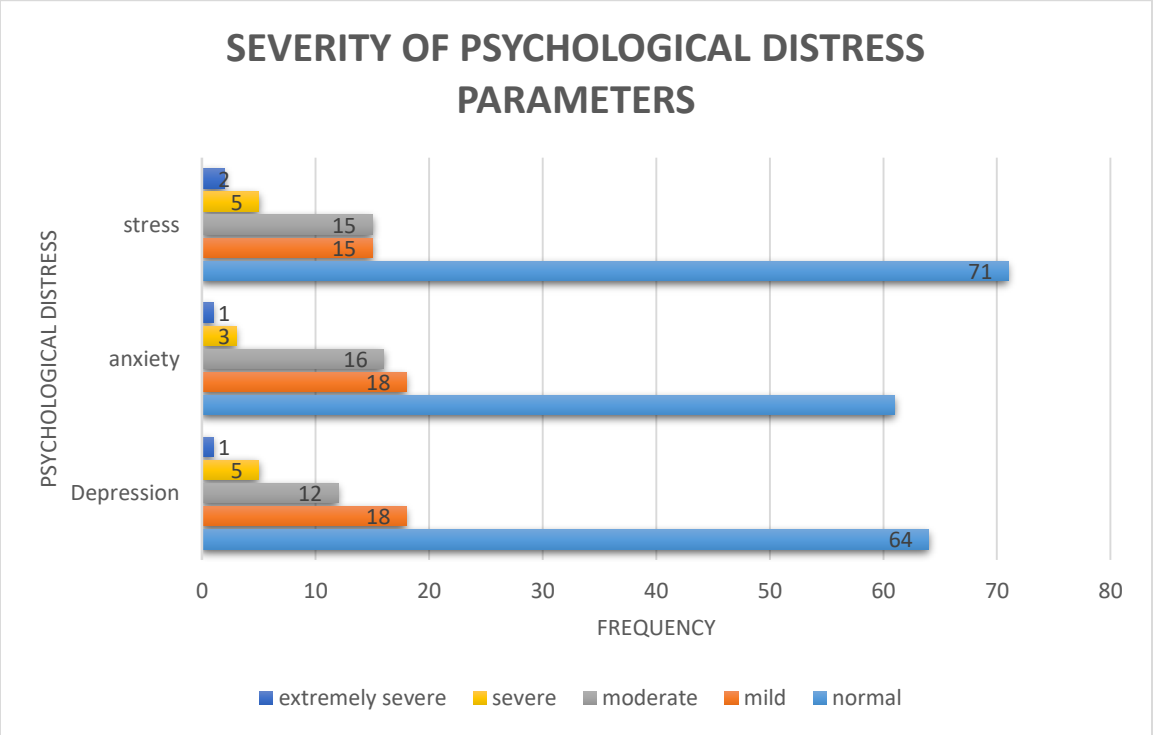


Table 6: Prevalence of Depression, Anxiety, Stress and Dysfunctional coronavirus anxiety

Characteristics	Category	N = 100 (%)
Depression	Yes	36 (36.0)
	No	64 (64.0)
Anxiety	Yes	38 (38.0)
	No	62 (62.0)
Stress	Yes	29 (29.0)
	No	71 (71.0))
Dysfunctional coronavirus anxiety	Yes	20 (20.0)
	No	80 (80.0)

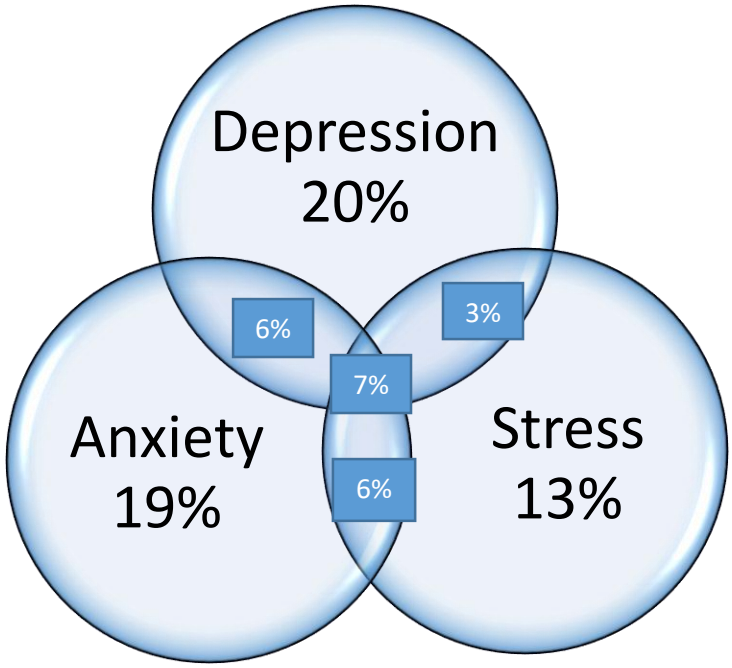
4.3: COMORBID PSYCHOLOGICAL DISTRESS PARAMETERS AMONG THE CAREGIVERS

Caregivers found to have had above normal levels of depression, anxiety and stress from DASS 21 were deemed to have psychological distress. Some caregivers were noted to have more than one psychiatric condition. 20% had depression alone, 19% had anxiety alone, 13% had stress alone, 6% had depression and anxiety, 3% had depression and stress, 6% had anxiety and stress while 7% had depression, anxiety and stress, as depicted in the table and pie chart below:

Table 7: **comorbid psychological distress parameters among the caregivers and association with dysfunctional coronavirus anxiety**

	VARIABLE	FREQUENCY		CUMMULATIVE FREQUENCY (%)	DYSFUNCTIONAL CORONAVIRUS ANXIETY	
					YES	NO
PSYCHOLOGICAL DISTRESS	DEPRESSION	**20**	*26.7%*	**20%**	2	18
	ANXIETY	**19**	*25.3%*	**19%**	6	13
	STRESS	**13**	*17.3%*	**13%**	2	11
	DEPRESSION + ANXIETY	**6**	*8.0%*	**6%**	2	4
	DEPRESSION + STRESS	**3**	*4.0%*	**3%**	1	2
	ANXIETY + STRESS	**6**	*8.0%*	**6%**	3	3
	DEPRESSION + ANXIETY + STRESS	**7**	*9.3%*	**7%**	3	4
	TOTAL	**75**		**75%**	**19**	**56**
NO PSYCHOLOGICAL DISTRESS	**NORMAL**	**25**		**25%**	**1**	**24**
TOTAL		**100**		**100%**	**20**	**80**

Chart 5: comorbid psychological distress parameters among caregivers



4.4: ASSOCIATION BETWEEN PSYCHOLOGICAL DISTRESS (DEPRESSION, ANXIETY AND STRESS) WITH PRESENCE OF DYSFUNCTIONAL CORONAVIRUS ANXIETY

Nineteen caregivers reported both psychological distress and dysfunctional coronavirus anxiety while twenty-four caregivers reported none of the two conditions. One caregiver without psychological distress had coronavirus anxiety. Fishers exact test revealed that there was a significant association between psychological distress and dysfunctional coronavirus anxiety, p value=0.0212. Thus having psychological distress increased the odds of being diagnosed with dysfunctional coronavirus anxiety by a factor of 8.14 (CI 1.03-64.3).

Table 8: Association Between Psychological Distress and dysfunctional coronavirus anxiety

Psychological Distress	Coronavirus Anxiety		Total
	Yes (%)	No (%)	
Yes (%)	19 (19.0)	56 (56.0)	75 (75.0)
No (%)	1 (1.0)	24 (24.0)	25 (25.0)
Total	20 (20.0)	80 (80.0)	100 (100.0)

OR = 8.14 (95% CI: 1.03-64.3), p value: 0.0212

4.5: ASSOCIATION BETWEEN DYSFUCNTIONAL CORONAVIRUS ANXIETY AND COVID 19 VACCINATION STATUS

Fifty-three caregivers received less than 1 dose of the COVID 19 vaccine, while forty-seven received 2 doses and above, which according to WHO requirements was deemed to offer protection from Coronavirus infection. Among those who received 1 dose and below sixteen were found to have dysfunctional coronavirus anxiety while thirty-seven had normal levels. Among those who received 2 doses and above four were found to have dysfunctional coronavirus anxiety while forty-three were found to have normal levels. The Fischer's exact test found that receiving 2 doses and above of the COVID vaccine lowered the odds of having dysfunctional coronavirus anxiety by a factor of 0.22 (CI 0.07-0.70). The association was significant, (p=0.011).

Table 9: association between COVID 19 vaccination status with dysfunctional coronavirus anxiety

COVID 19 VACCINATION STATUS	Coronavirus Anxiety		Total
	Yes (%)	No (%)	
≥2 DOSES	4(4.0)	43 (43.0)	47 (47.0)
≤1 DOSE	16(16.0)	37 (37.0)	53 (53.0)
Total	20 (20.0)	80 (80.0)	100 (100.0)

OR = 0.22 (0.07-0.70), p value=0.011

4.6: ASSOCIATION BETWEEN DEPRESSION, DYSFUNCTIONAL CORONAVIRUS ANXIETY AND SOCIODEMOGRAPHIC CHARACTERISTICS

Bivariate analysis was done to find association between depression, as the dependent variable and the sociodemographic characteristics of the caregivers as well as dysfunctional coronavirus anxiety. There was a significant association between the presence of depressive symptoms and gender of the caregiver, age of the caregiver, relationship of the child to the caregiver, number of children in the household, child's functional status, psychosocial support sources as well as dysfunctional coronavirus anxiety

There was no significant association marital status of the caregiver, education level, employment status, change of income since March 2020, age of child attending clinic, duration of caregiving, diagnosis of child, presence of chronic illness by the caregiver and coronavirus vaccination status.

Having attained the 31 to 43-year age bracket increased the odds of suffering depression by a factor of 3.14 (1.13, 9.48), compared to those aged 18-30 years (p value=0.032). There was no significant association between depression and caregivers above 43 years.

The odds of non-biological parents suffering depression was 0.11 (0.003, 0.92) folds that of caregivers who were biological parents to the children. Caregivers who were not biological parents to the children were therefore less probable to suffer depression as compared to those who were biological parents to children (p = 0.028).

Caregivers who had more than four children in their household were less likely to suffer depression compared to those with only one child (OR= 0.11, p = 0.049). The significance of the association was however marginal. There was no significant difference in the probability of caregivers with 2 to 4 children in their household suffering depression compared to those with only one child (OR = 1.12, p = 0.815).

The odds of a caregiver to a child who needed constant care being diagnosed with depression was 6.51 times that of a caregiver to a child that was independent (p = 0.003). The probability of suffering from depression by a caregiver to a child that needed constant care was therefore significantly higher than that of a caregiver to a child that was independent.

Caregivers to children diagnosed with early onset schizophrenia and/ or IDD were less likely to suffer depression compared to caregivers of children diagnosed with ADHD (OR = 0.18, p = 0.027). There was no significant difference in the difference in the occurrence of depression among caregivers of patients diagnosed with Autism Spectrum Disorder (p = 0.777), Epilepsy (p = 0.158) and those diagnosed with other conditions (p=0.098)

The provision of regular of psychosocial support, whether formal or informal, to the caregiver decreased the odds of suffering depression by a factor of 0.23 (p = 0.015). Caregivers who had received either formal or informal psychosocial support were less likely to suffer depression compared to the caregivers who had not received any form of psychosocial support.

A multivariate model was fitted to adjust the significant variables obtained from bivariate analysis. Stepwise model selection method was used to arrive at the final parsimonious model which featured depression as the dependent variable and presence of dysfunctional

coronavirus anxiety, gender of the caregiver, relationship of caregiver to the child, the child's functional status and availability of psychosocial support as other covariates. The model had an AIC value of 114.43.

After adjusting for other variables there was significant association between depression with dysfunctional coronavirus anxiety, being female caregiver, having a child in need of constant care and receiving regular psychological support was found to be protective by lowering the odds of depression as summarized in the table below.

Table 10: Association between Depression with Regards to Variables of Interest Among Caregivers

	Depression		**Crude OR (0.95 CI)**	**P-Val**	**Adj OR**	**P-VAl**
	Yes, n=36(%)	**No, n=64(%)**				
Coronavirus Anxiety						
Yes	**12 (33.3)**	**8 (12.5)**	**3.5(1.27, 9.65)**	**0.0185**	**2.71 (1.93, 4.81)**	**0.0493**
No	24 (66.7)	56(87.5)	Ref	Ref		
Gender						
Male	5 (13.9)	22 (34.4)	Ref	Ref		
Female	**31 (86.1)**	**42 (65.6)**	**3.25 (1.11, 9.53)**	**0.0346**	**2.85(1.17, 6.47)**	**0.0264**
Age (years)						
18 - 30	7 (19.4)	22 (34.4)	Ref	Ref		
31 - 43	**20 (55.6)**	**20 (31.3)**	**3.14 (1.13, 9.48)**	**0.032**		
>43	9 (25.0)	22 (34.4)	1.28 (0.40, 4.18)	0.668		
Marital Status						
Single	7 (19.4)	18 (28.1)	Ref	Ref		
Married	18 (50.0)	32 (50.0	1.44 (0.52, 4.13)	0.489		
Divorced/Widowed	11 (30.6)	14 (21.9)	2.02 (0.63, 6.80)	0.242		
Education						
Primary school	10 (27.7)	14 (21.9)	Ref	Ref		
Secondary school	13 (36.1)	23 (35.9)	0.79 (0.27, 2.30)	0.665		
Tertiary	13 (36.1)	27 (42.2)	0.69 (0.23, 1.93)	0.460		
Employment Status						
Employed	9 (25.0)	23 (35.9)	Ref	Ref		
Unemployed	12 (33.3)	22 (34.4)	1.39 (0.49, 4.04)	0.533		
Self Employed	15 (41.7)	19 (29.7)	2.01 (0.73, 5.79)	0.180		
Change in Household Income since March 2020						
No Change	10 (27.7)	27 (42.2)	1.89 (0.73, 5.15)	0.196		
Change	26 (72.2)	37 (57.8)	Ref	Ref		
Age of child attending clinic (Years)						
<5	7 (19.4)	11 (17.2)	Ref	Ref		
6 - 10	12 (33.3)	22 (34.4)	0.85 (0.26, 2.86)	0.798		
>10	17 (47.2)	31 (48.4)	0.86 (0.28, 2.72)	0.794		

Relationship to child						
Biological parent	35 (97.2)	52 (81.3)	Ref	Ref		
Not Biological parent	1 (2.8)	12 (18.7)	0.13 (0.003, 0.92)	0.028	0.11 (0.01, 0.72)	0.052
Duration of Caregiving (years)						
10 and below	20 (55.6)	36 (56.3)	Ref	Ref		
Above 10	16 (44.4)	28 (43.7)	1.02 (0.44, 2.34)	0.946		
Number of children in the household						
1	9 (25.0)	14 (21.9)	Ref	Ref		
2 – 4	26 (72.2)	36 (56.3)	1.12 (0.43, 3.06)	0.815		
>4	**1 (2.8)**	**14 (21.9)**	**0.11 (0.01, 0.71)**	**0.049**		
Diagnosis of child (DSM V)						
ADHD	11 (30.6)	11 (17.2)	Ref	Ref		
Autism Spectrum DO	13 (36.1)	11 (17.2)	1.81 (0.36, 3.81)	0.777		
Epilepsy	5 (13.9)	13 (20.3)	0.38 (0.09, 1.40)	0.158		
E. O Schizophrenia, IDD	**3 (8.4)**	**16 (25.0)**	**0.18 (0.03, 0.76)**	**0.027**		
Others	4 (11.1)	13 (20.3)	0.20 (0.06, 1.18)	0.098		
Child's Functional Status						
Independent	4 (11.1)	29 (45.3)	Ref	Ref		
Constant care	**32 (88.9)**	**35 (54.7)**	**6.51 (1.97, 28.29)**	**0.003**	**8.32 (2.72, 31.86)**	**<.001**
Presence of chronic illness (caregiver)						
Yes	5 (13.9)	3 (4.7)	3.24 (0.59, 22.22)	0.132		
No	31 (86.1)	61 (95.3)				
Psychosocial support						
None	32	42	Ref	Ref		
Formal/ Informal	**4**	**22**	**0.23 (0.06, 0.69)**	**0.015**	**0.27 (0.06, 0.91)**	**0.045**
Covid 19 Vaccination						
None/ One Dose	22 (61.11)	31 (48.4)	Ref	Ref		
Two/ Three Doses	14 (38.9)	33 (51.6)	0.59 (0.25, 1.36)	0.225		

AIC for final multivariate model = 114.43

4.7: ASSOCIATION BETWEEN CAREGIVER ANXIETY, SOCIODEMOGRAPHIC CHARACTERISTICS AND DYSFUNCTIONAL CORONAVIRUS ANXIETY

Bivariate analysis was done featuring the occurrence of anxiety as the dependent variable vs the sociodemographic variables and dysfunctional coronavirus anxiety. It was found that age of the caregiver, marital status, education level, change in household income since March 2020, age of child attending clinic, relation between caregiver and the child, duration of caregiving, number of children in the household, diagnosis of the child, child's functional status, presence

of chronic illness and covid-19 vaccination status on the other side were all non- significant (p > 0.05).

There was a significant association between being diagnosed with anxiety with dysfunctional coronavirus anxiety, gender of the caregiver, employment status and psychological support. Having been diagnosed with anxiety increased the odds of being diagnosed with dysfunctional coronavirus anxiety by a factor of 4.02 (1.30, 13.47), the association was significant (p=0.009). Caregivers who had anxiety were therefore more likely to suffer from dysfunctional coronavirus anxiety as compared to those who had not been diagnosed with anxiety.

Female caregivers had higher odds of having anxiety by a factor of 3.63 (1.24, 3.63) compared to the male caregivers. This was significant with a p value of 0.0197.

Bivariate analysis also revealed a significant association between anxiety and employment status. The odds of self-employed caregivers suffering general anxiety increased 3.34 (1.07, 11.80) times that of the employed. Self- employed caregivers therefore had a higher probability of suffering general anxiety compared to employed caregivers (p = 0.044). Likewise, unemployed caregivers had a greater increase, of 7.71 (2.53, 27.34) folds that of the employed, in the odds of suffering general anxiety. Unemployed caregivers therefore had a higher probability of suffering general anxiety compared to employed caregivers (p = 0.001).

Caregivers who received regular psychological support had lower odds of having anxiety compared to those who did not receive psychological support by a factor of 0.21 (0.07, 0.68), this was significant with a p value of 0.0089

A multivariate model was fitted to adjust the estimates obtained from bivariate analysis. Stepwise model selection method was used to arrive at the final parsimonious model which featured coronavirus anxiety gender, psychological support and employment status as covariates; with a AIC value of 121.39.

Both associations between anxiety on one side and dysfunctional coronavirus anxiety, gender, psychological support and employment status on the other side remained significant (p = 0.021, p=0.0202, p=0.0145 and p = 0.001 respectively). The odds of caregivers who were suffering dysfunctional coronavirus anxiety also suffering anxiety was adjusted downwards to 3.71 (1.24, 12.01) folds that of caregivers who were not suffering coronavirus anxiety (p = 0.021). After adjusting for other variables the level of significance for the association between unemployed caregivers with depression remained constant (p=0.001), while that for the self-employed caregivers was no longer significant (p=0.084). Gender and psychological support still were significant after accounting for effects due to other variables (p=0.0202 and p=0.0145).

Table 11 summarizes this information.

Table 11: Association between Anxiety with Regards to Variables of Interest Among Caregivers

	Anxiety		Crude OR (0.95 CI)	P-Val	Adjusted OR (0.95 CI)	P-Val
	Yes, n=38(%)	No, n=62(%)				
Coronavirus Anxiety						
Yes	**13 (34.2)**	**7 (11.3)**	**4.02 (1.30, 13.47)**	**0.009**	**3.71 (1.24, 12.01)**	**0.021**
No	25 (65.8)	55 (88.7)	Ref	Ref		
Gender						
Male	5 (13.2)	22 (35.5)	Ref	Ref		
Female	**33 (86.8)**	**40 (64.5)**	**3.63(1.24, 10.63)**	**0.0197**	**3.87(2.07,6.49)**	**0.0202**
Age (years)						
18 - 30	13 (34.2)	16 (25.8)	Ref	Ref		
31 - 43	14 (36.8)	26 (41.9)	0.66 (0.24, 1.76)	0.410		
>43	11 (28.9)	20 (32.3)	0.67 (0.23, 1.90)	0.461		
Marital Status						
Single	11 (28.9)	14 (22.6)	Ref	Ref		
Married	16 (42.1)	34 (54.8)	0.59 (0.22, 1.62)	0.309		
Divorced/Widowed	11 (28.9)	14 (22.6)	1.00 (0.32, 3.07)	1.000		
Education						
Primary school	11 (28.9)	13 (21.0)	Ref	Ref		
Secondary school	17 (44.7)	19 (30.6)	1.05 (0.37, 3.01)	0.915		
Tertiary	10 (26.3)	30 (48.4)	0.39 (0.13, 1.14)	0.089		
Employment Status						
Employed	5 (13.2)	27 (43.5)	Ref	Ref	Ref	Ref
Unemployed	**20 (52.6)**	**14 (22.6)**	**7.71 (2.53, 27.34)**	**0.001**	**7.09 (2.22, 26.22)**	**0.001**
Self Employed	**13 (34.2)**	**21 (33.9)**	**3.34 (1.07, 11.80)**	**0.044**	2.92 (0.89, 10.72)	0.084
Change in Household Income since March 2020 (KSh)						
No Change	13 (34.2)	24 (38.7)	1.21 (0.48, 3.11)	0.676		
Change	25 (65.8)	38 (61.3)				
Age of child attending clinic (Years)						
<5	6 (15.8)	12 (19.4)	Ref	Ref		
6 - 10	11 (28.9)	23 (37.1)	0.95 (0.28, 3.35)	0.943		
>10	21 (58.3)	27 (43.5)	1.55 (0.51, 5.10)	0.445		
Relationship to child						
Biological parent	34 (89.5)	53 (85.5)	0.69 (0.14, 2.74)	0.761		
Not Biological parent	4 (10.5)	9 (14.5)				
Duration of Caregiving (years)						
10 and below	18 (47.4)	38 (61.3)	Ref	Ref		
Above 10	20 (52.6)	24 (37.1)	1.75 (0.77, 4.01)	0.175		
Number of children in the household						

1	7 (18.4)	16 (25.8)	Ref	Ref		
2 – 4	26 (68.4)	36 (58.1)	1.65 (0.61, 4.82)	0.336		
>4	5 (13.2)	10 (16.1)	1.14 (0.27, 4.61)	0.851		
Diagnosis of child (DSM V)						
ADHD	7 (18.4)	15 (24.2)	Ref	Ref		
Autism Spectrum DO	7 (18.4)	17 (27.4)	0.88 (0.24, 3.14)	0.845		
Epilepsy	8 (21.1)	10 (16.1)	1.71 (0.47, 6.42)	0.413		
E. O Schizophrenia, IDD	10 (26.3)	9 (14.5)	2.38 (0.67, 8.83)	0.181		
Others	6 (15.7)	11 (17.7)	1.16 (0.29, 4.51)	0.819		
Child's Functional Status						
Independent	9 (23.7)	24 (38.7)	2.02 (0.76, 5.73)	0.132		
Constant care	29 (7.6)	38 (61.3)				
Presence of chronic illness (caregiver)						
Yes	4 (10,5)	4 (6.5)	1.69 (0.29, 9.73)	0.474		
No	34 (89.5)	58 (93.5)				
Psychosocial support sources						
None	34 (89.5)	40 (64.5)	Ref	Ref		
Formal/ Informal	**4 (10.5)**	**22 (35.5)**	**0.21(0.07,0.68)**	**0.0089**	**0.28(0.056,0.51)**	**0.0145**
Covid 19 Vaccination						
None/ One Dose	20 (52.6)	33 (53.2)	Ref	Ref		
Two/ Three Doses	18 (47.4)	29 (46.7)	1.02 (0.45, 2.30)	0.953		

AIC for final multivariate model = 121.39

4.8: ASSOCIATION BETWEEN STRESS, SOCIODEMOGRAPHIC VARIABLES AND DYSFUNCTIONAL CORONAVIRUS ANXIETY

Bivariate analysis revealed that the association between occurrence of stress and dysfunctional coronavirus anxiety was non-significant (OR = 1.87, p = 0.230). Caregivers who had been diagnosed with stress were therefore not at increased risk of having dysfunctional coronavirus anxiety compared to those who were not stressed.

Education status, Employment status, duration of caregiving, child functional status and Covid-19 vaccination status were all significantly associated with occurrence of stress in the bivariate analysis. The odds of unemployed caregivers suffering stress was 5.4 times that of the employed (p = 0.004). Unemployed caregivers were more likely to suffer stress than those who were employed. There was no significant difference in the occurrence of stress among caregivers who were self-employed and those who were employed.

Caregivers who had attained secondary education were less likely to suffer stress compared to those who had attained primary education only (OR = 0.20, p = 0.004). The odds of suffering stress among the former group was 0.20 times that of the latter group. Likewise, those who had attained tertiary education were less likely to suffer stress compared to those who had attained primary education only (OR = 0.08, p < 0.001). Their odds of suffering stress was 0.08, which folds smaller than that of caregivers who had attained primary education only.

Caregivers of children less than 5 years old had higher odds of being stressed compared to the caregivers with age above 5 years by a factor of 2.7 (1.06, 6.9), this was significant with a p value of 0.0458

Last among the significant association was that of coronavirus vaccination. Caregivers who had received at least two doses of Covid-19 vaccine were less likely to suffer stress compared to those who had received less than two doses of the same (OR= 0.24, p = 0.007).

The multivariate logistic regression model was applied to all significant variables at multivariate level, it had an AIC value of 109.41. The association between dysfunctional coronavirus anxiety and stress was adjusted downwards but remained non-significant after adjusting for the effects of employment status, education status, duration of caregiving and Covid-19 vaccination status (OR= 1.56, p = 0.467). Caregivers who had been diagnosed with coronavirus anxiety were therefore as likely to experience stress in the same proportions as those who had not been diagnosed with coronavirus anxiety.

Education levels remained significant after accounting for other variable with p values of 0.017 for secondary school level education and 0.004 for tertiary level education with odds of 0.22 (0.06, 0.75) for the latter and 0.12 (0.02, 049) for the former. This indicated that higher education offered a level of protection from stress which could be attributable to various socioeconomic factors to be discussed later.

The odds of caregivers taking care of children in need of constant care remained significant after multivariate analysis with odds being 2.81 (1.87, 4.75) with a p value of 0.044.

The odds of employment status, duration of caregiving and COVID 19 vaccination status were non-significant after adjusting for other variables.

Table 7 below depicts this information.

Table 12: Association between Stress with Regards to Variables of Interest Among Caregivers

	Stress		**Crude OR (0.95 CI)**	**P-Val**	**Adjusted OR (0.95 CI)**	**P-Val**
	Yes, n=29(%)	**No, n=71(%)**				
Coronavirus Anxiety						
Yes	8 (27.6)	12 (16.9)	1.87 (0.65, 5.18)	0.230	1.56 (0.45, 5.28)	0.467
No	21 (73.4)	59 (83.1)				
Gender						
Male	4 (13.8)	23 (32.4)	2.96 (0.87, 13.09)	0.081		
Female	25 (86.2)	48 (67.6)				
Age (years)						
18 - 30	10 (34.5)	19 (26.8)	Ref	Ref		
31 - 43	12 (41.4)	28 (39.4)	0.81 (0.29, 2.28)	0.693		
>43	7 (24.1)	24 (33.8)	0.55 (0.17, 1.71)	0.309		
Marital Status						

Single	8 (27.6)	17 (23.9)	Ref	Ref		
Married	10 (34.5)	40 (56.3)	0.53 (0.17, 1.60)	0.255		
Divorced/Widowed	11 (37.9)	14 (19.7)	1.66 (0.53, 5.43)	0.383		
Education						
Primary school	15 (51.7)	9 (12.7)	Ref	Ref		
Secondary school	**9 (31.0)**	**27 (38.0)**	**0.20 (0.06, 0.59)**	**0.004**	**0.22 (0.06, 0.75)**	**0.017**
Tertiary	**5 (17.2)**	**35 (49.3)**	**0.08 (0.02, 0.28)**	**<.001**	**0.12 (0.02, 0.49)**	**0.004**
Employment Status						
Employed	5 (17.2)	27 (38.0)	Ref	Ref		
Unemployed	**17 (58.6)**	**17 (23.9)**	**5.40 (1.77, 18.97)**	**0.004**	2.04 (0.53, 8.18)	0.297
Self Employed	7 (24.1)	27 (38.0)	1.40 (0.39, 5.25)	0.602	0.12 (0.12, 2.46)	0.442
Change in Household Income since March 2020 (KSh)						
No Change	13 (44.8)	24 (33.8)	0.63 (0.23,1.68)	0.363		
Change	16 (55.2)	47 (66.2)				
Age of child attending clinic (Years)						
<5	8 (27.6)	10 (14.1)	Ref	Ref		
6 - 10	10 (34.5)	24 (33.8)	0.52 (0.15, 1.71)	0.281		
>10	11 (37.9)	37 (52.1)	0.37 (0.11, 1.18)	0.091		
Relationship to child						
Biological parent	26 (89.7)	61 (85.9)	0.70 (0.11, 3.05)	0.751		
Not Biological parent	3 (10.3)	10 (14.1)				
Duration of Caregiving (years)						
10 and below	**21 (72.4)**	**35 (49.3)**	**2.7(1.06 ,6.9)**	**0.0458**	2.21(1.64, 7.06)	0.0773
Above 10	8 27.6()	36 (50.7)	Ref	Ref		
Number of children in the household						
1	7 (24,1)	16 (22.5)	Ref	Ref		
2 – 4	17 (58.6)	45 (63.4)	0.86 (0.30, 2.57)	0.783		
>4	5 (17.2)	10 (14.1)	1.14 (0.27, 4.61)	0.851		
Diagnosis of child (DSM V)						
ADHD	8 (27.6)	14 (19.7)	Ref	Ref		
Autism Spectrum DO	7 (24.1)	17 (23.9)	0.72 (0.20, 2.48)	0.604		

Epilepsy	5 (17.2)	13 (18.3)	0.67 (0.16, 2.55)	0.565		
E. O Schizophrenia/ IDD	3 (10.3)	16 (22.5)	0.32 (0.06, 1.38)	0.148		
Others	6 (20.7)	11 (15.4)	0.95 (0.24, 3.58)	0.945		
Child's Functional Status						
Independent	4 (13.8)	29 (40.8)	Ref	Ref		
Constant care	**25 (86.2)**	**42 (59.2)**	**4.32 (1.36, 13.72)**	**0.01**	**2.81(1.87, 4.75)**	**0.044**
Presence of chronic illness (caregiver)						
Yes	2 (6.9)	6 (8.5)	0.80 (0.07, 4.87)	1.000		
No	27 (93.1)	65 (91.5)				
Psychosocial support sources						
None	25 (86.2)	49 (69.1)	2.81(0.87, 9.03)	0.0848		
Formal/ Informal	4 (13.8)	22 (30.9)				
COVID 19 Vaccination						
None/ One Dose	21 (72.4)	32 (45.1)	Ref	Ref		
Two/ Three Doses	**8 (27.6)**	**39 (54.9)**	**0.24 (0.08, 0.66)**	**0.007**	0.56 (0.18, 1.70)	0.306

AIC for the final multivariate model = 109.41

4.9: CHALLENGES EXPERIENCED BY CAREGIVERS DURING THE COVID 19 PANDEMIC

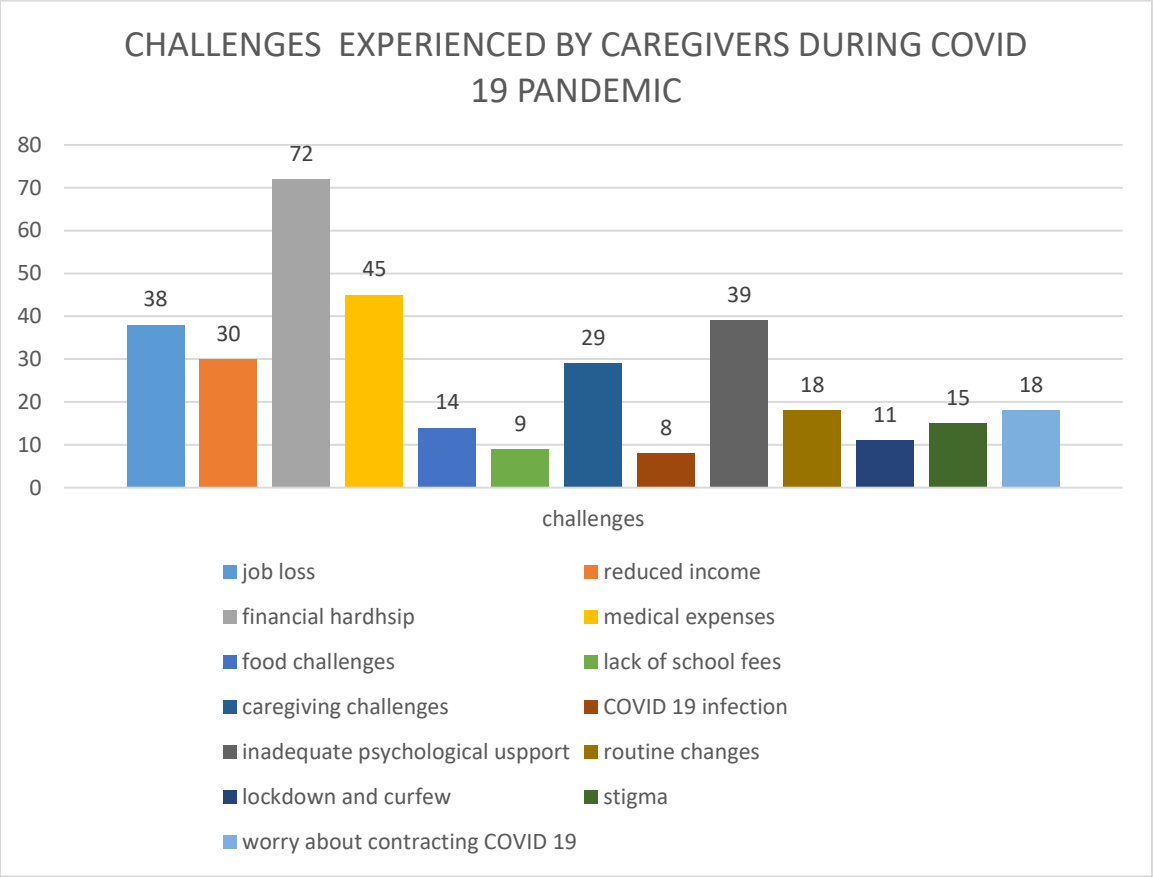
Open ended question responses regarding challenges experienced by the caregivers during the COVID 19 pandemic were noted and the table and graph below summarize the main themes. It was noted that a majority of the caregivers suffered from various financial related challenges brought on by the COVID 19 pandemic related factors:

Table 13: challenges experience by the caregivers during the COVID 19 pandemic

CHALLENGES	NUMBER OF RESPONSES
JOB LOSS	38
REDUCED INCOME	30
FINANCIAL HARDSHIPS AND DIFFICULTY AFFORDING BASIC NECESSITIES	72
HIGH MEDICAL EXPENSES AND ASSOCIATED COSTS EG TRANSPORT, COST OF MEDICATION AND CLINIC REVIEW FEES	45
DIFFICULTIES OBTAINING FOOD	14
LACK OF SCHOOL FEES	9
CAREGIVING CHALLENGES	29
CAREGIVER HAD COVID 19 INFECTION	8
INADEQUATE PSYCHOLOGICAL SUPPORT	39

CAREGIVER ROUTINE CHANGES DUE TO SCHOOL CLOSURES AND SUBSEQUENT ALTERED SCHEDULES	18
LOCKDOWN AND CURFEW LIMITING MOVEMENT	11
STIGMA	15
WORRY ABOUT CHILD OR CAREGIVER CONTRACTING COVID 19	18

Chart 6: challenges experienced by caregivers during the COVID 19 pandemic



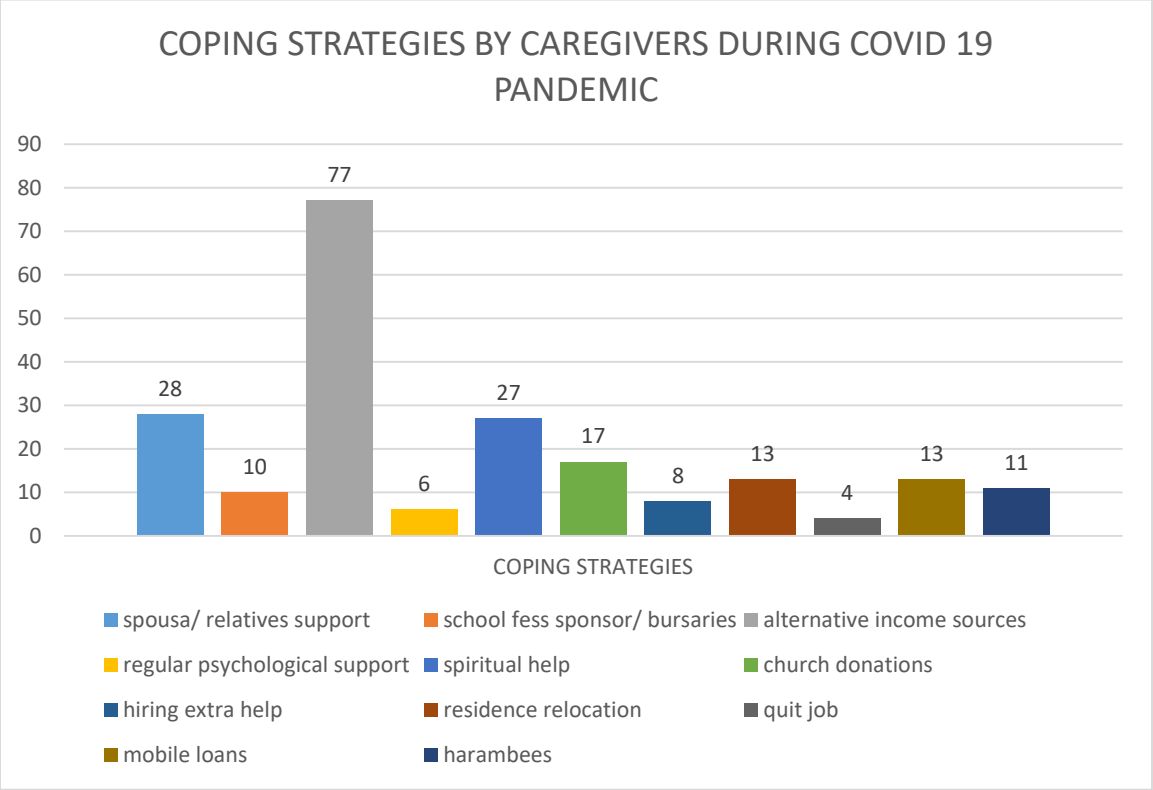
4.10: COPING STRATEGIES ADOPTED BY THE CAREGIVERS DURING THE COVID 19 PANDEMIC

Open ended question responses regarding coping strategies adopted by the caregivers during the COVID 19 pandemic were noted and the table and graph below summarize the main themes. Bearing in mind that majority of the challenges highlighted earlier were financial related, a majority of the caregivers adopted means to increase/ supplements their earnings, these included seeking alternative sources of income, donations and harambees. Others resorted to use of mobile loans. Psychological support was sought from spouses, family as well as from spiritual leaders. Others changed residence due to inability to afford rent.

Table 14: coping strategies adopted by caregivers during COVID 19 pandemic

COPING STRATEGIES	NUMBER OF RESPONSES
SPOUSAL AND RELATIVES SUPPORT	28
SCHOOL FEES SPONSOR AND BURSARIES	10
ALTERNATIVE INCOME SOURCES TO ENABLE THEM AFFORD MEDICAL AND SCHOOL EXPENSES DESPITE CHANGE IN HOUSEHOLD INCOME	77
REGULAR PSYCHOLOGICAL SUPPORT	6
SPIRITUAL HELP	27
CHURCH DONATIONS	17
HIRING EXTRA HELP TO ASSIST WITH CAREGIVING	8
RELOCATION OF RESIDENCE DUE TO INABILITY TO AFFORD RENT	13
QUIT JOB TO TAKE BETTER CARE OF CHILDREN IN NEED OF MORE CARE	4
REGULAR USE OF MOBILE PHONE LOANS	13
HARAMBBES TO BE ABLE TO AFFORD MEDICAL AND SCHOOL EXPENSES	11

Chart 7: coping strategies adopted by caregivers during COVID 19 pandemic



4.11: RECOMMENDATIONS FROM CAREGIVERS

Open ended question responses regarding recommendations from the caregivers on how they could be assisted to cope better with their duties of caregiving were noted and the table and graph below summarize the main themes:

Table 15: recommendations from caregivers

RECOMMENDATION	NUMBER OF RESPONSES
INCREASE CAREGIVER SENSITIZATION	19
INCREASE PSYCHOLOGICAL SUPPORT	30
INCREASE CLINIC FREQUENCY	6
LINK TO SUPPORT ORGANISATIONS FOR CAREGIVERS OF CHILDREN WITH SPECIAL NEEDS	59
LOWER THE COST OF MEDICATION	34
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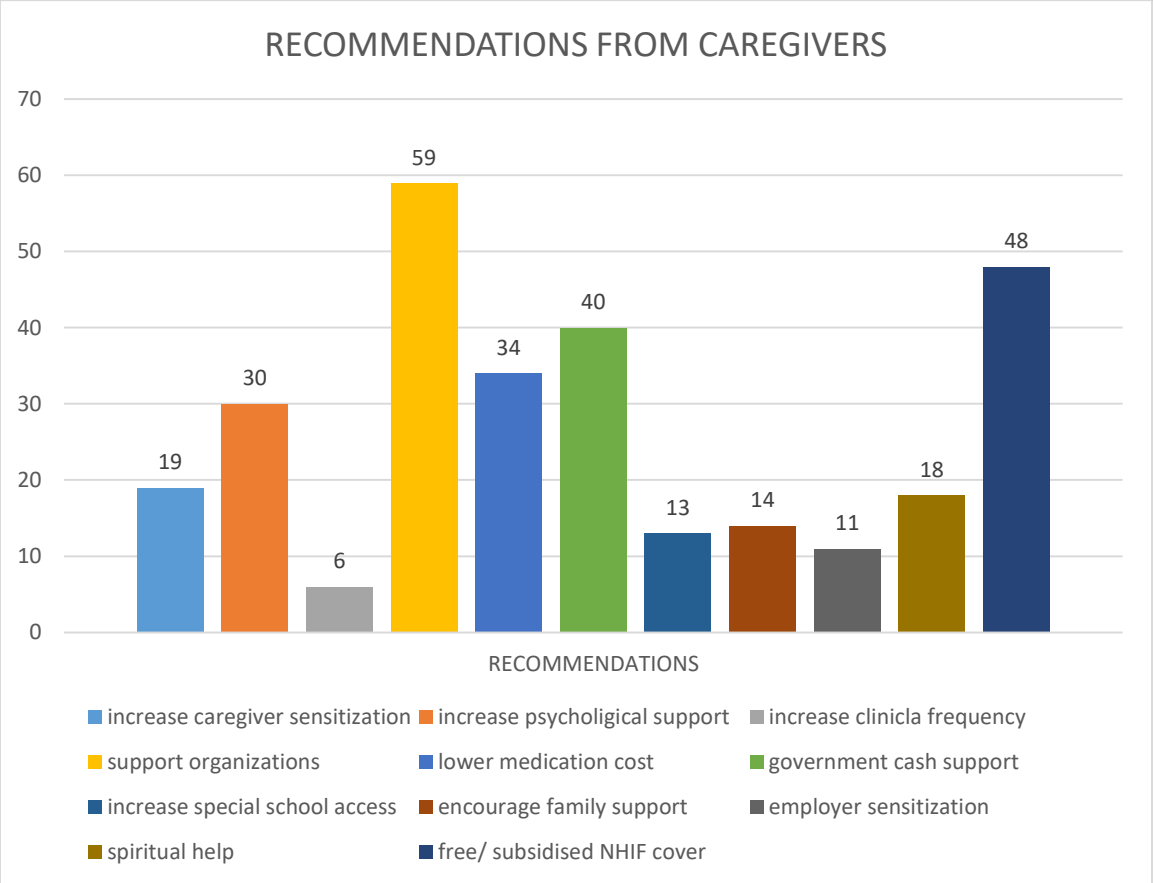

CHAPTER 5: DISCUSSION

5.1: PREVALENCE OF PSYCHOLOGICAL DISTRESS AMONG CAREGIVERS OF CHILDREN WITH MENTAL ILLNESS AT MATHARE NATIONAL TEACHING AND REFERRAL HOSPITAL

This study was able to demonstrate that there is a high prevalence of psychological distress among caregivers of children with mental illness attending child psychiatry clinic at Mathare National Teaching and Referral Hospital, which was found to be at 75% of the study population. Among these caregivers, the prevalence of depression was found to be 36%, anxiety 39% and stress at 29%.

The World Health Organization has acknowledged depression and anxiety as among the commonest mental health challenges among the general population. It has been estimated that about 5% and 1 in 13 (7.7%) of the general population are at risk of developing either depression or anxiety at one point in their lives. Various studies have demonstrated that the risk of depression could go as high as 15% among the general population. These have been attributed to various lifetime risk factors. This study shows that the prevalence of depression among the caregivers of children at the child psychiatry clinic in Mathare NTRH is higher than the global estimates among the general population.

Being a caregiver to a child has been demonstrated to be a significant risk factor to the development of psychological distress, more so for caregivers of children with developmental disorders. The family caregiver alliance (2001) reported a 30% to 59% prevalence rate of depression among caregivers. Of note is that in this study the prevalence rate for depression was 36%, which lies within this range.

A study by Feldman et al (2007) found that 20% of caregivers of children with developmental delay scored above cut off score for depression. As demonstrated in this study, 36% of the caregivers were depressed. This finding is in line with previous studies which have found that the prevalence of depression is higher among caregivers of children with developmental disorders compared to the general population as well those caregivers with normally developing children.

A study to assess stress, anxiety and depressive symptoms among parents of children with Autism Spectrum Disorder (ASD) in Oman by Al Farsi et al (2016) demonstrated the levels of anxiety and stress at 45.9% with depression at 48.6%. This was higher than in the current study population (depression 36%, anxiety 39%, stress 29%), this could be attributed to differences in the study population characteristics.

GENDER OF THE CAREGIVER

With regards to gender of the caregiver, Lushin et al (2016) in a study conducted in the USA among mothers of children with ASD, it was demonstrated that mothers had 3 times risk of having depression with 50% being diagnosed with depression and 41% with anxiety disorders. These findings are consistent with this study which found a significant association between depression and gender, mothers had increased odds of depression by a factor of 2.85(CI 1.17, 6.47), p value=0.0264. Among the mothers, 42.5% had depression while 45.2% had anxiety, hence the findings in this study correspond to the previous study though with slight differences.

A study in Ethiopia by Minichil et al (2018) demonstrated that female gender (aOR 2.4: CI 1.18,4.89), being a mother (aOR 3.9: CI 1.90, 8.04), poor social support (aOR 5.5: CI 2.04, 15.02) were significant correlates to caregiver depression. This study similarly demonstrated significant correlates to Female gender (aOR 2.85: CI 1.17, 6.47), being non biological caregiver was associated with reduced odds of depression (aOR 0.11: CI 0.01,0.72) and regular psychological support lowered odds of depression (aOR 0.27: CI 0.06, 0.91). Thus regionally it has been demonstrated that gender, relationship to the child and psychological support have significant associations to psychological distress in the caregivers.

A study by Onyango et al (2012) was conducted among caregivers of children with mental disorders at Kenyatta National Hospital, the prevalence of depression was found to be 56.2% unlike in this study which was 36%. Being female had a significant association with depression (p=0.007) just as it was found in this study (p=0.0264). Both were hospital based studies thus the difference in depression prevalence could be attributed to difference in study population characteristics. Thus in the Kenyan context being female was a significant finding with regards to depression and adequate measures should be put in place to support mothers of children with mental illnesses as demonstrated in both studies

Globally female caregivers account for a majority of caregivers, this study demonstrated the same with a majority of the caregivers being female (73%). Hence female caregivers especially mothers of children with developmental disorders are at increased risk of psychological distress compared to male caregivers and are in need of adequate support and empowerment.

FUNCTIONAL STATUS OF THE CHILD

This study was able to demonstrate that apart from gender (being female), the child's functional status had significant association with depressive symptoms among caregivers (p<0.001). This is similar to studies among caregivers of pediatric patients in Mexico by Frutos et al (2016) which found prevalence of depression to be at 22.7% with significant association with degree of disability(p=0.001). A similar study among parents of children with intellectual developmental disorders in the United Kingdom, Schere et al (2019) found that 31% of caregivers met clinical cut off for depression and anxiety with a significant association with the child's functional status (p<0.001). Hence caregivers of children in need of constant care are at increased risk of psychological distress and in need of adequate support.

DURATION OF CAREGIVING AND AGE OF CHILD

This study had initially found that duration of caregiving below 10 years increased the odds of stress by a factor of 2.7 (CI 1.06, 6.9), P=0.0458, but when adjusted for other variables no significant association was established (p=0.0773). With regards to other parameters under study there was no association with age of the child or duration of caregiving. McKonnie et al (2018) in a study among parents of children with undiagnosed diseases found that 40% of the caregivers had high rates of depression and anxiety. The symptoms were found to be better in parents with older children and longer duration of illness with mothers at more risk of stress and anxiety. This could be attributed to the development of greater ability for the older children to perform some tasks on their own and development of emotional resilience in parents of older children.

PSYCHOLOGICAL SUPPORT

Venessa et al (2021) noted that sources and types of social support had a protective role against depression among caregivers. It was demonstrated that there was a positive association between lowered depressive symptoms and positive sources of support, regardless of support type. A study by Masulani et al (2015) in Malawi among parents with intellectual developmental disorder demonstrated the prevalence of psychological distress was at 41.2% with association to low socio economic status ($p<0.05$), knowledge of one's child's disability ($p<0.05$) and increased perceived burden ($p=0.05$). Lack of sources of psychological support was noted to have significant association with psychological distress. These findings were similar to this study whereby receiving regular psychological support was associated with reduced depressive ($p=0.045$) and anxiety symptoms ($p=0.0145$) among caregivers of children with mental illness. In this study, caregivers of children in need of constant care were significantly associated with high depressive ($p<0.001$) and anxiety symptoms ($p=0.0145$). Thus psychosocial support is a necessity to help caregivers cope with the challenges they encounter brought about by various factors among them, those related to their socioeconomic status and the child's functional status. Thus regular psychosocial support has been demonstrated to be associated with lower levels of psychological distress among the caregivers.

EDUCATIONAL LEVEL OF THE CAREGIVER

Mbugua et al (2007) in a study among caregivers of children with intellectual disability in a rural setting found a significant association between depression and educational status of the caregivers, especially those with Primary education. This study found no significant association with either depression or anxiety but there was significant association with stress. After adjusting for other variables, Secondary education lowered the odds of having stress by a factor of 0.22 (CI 0.06, 0.75), $p=0.017$ and tertiary education by a factor of 0.12(CI 0.02, 0.49), $p=0.004$. Thus the higher the education level of the caregiver, the more the socioeconomic opportunities that were available and in turn this lowered the stress levels among the caregivers. It could also the postulated that higher education improved the understanding of the caregiver about the child's condition and this in turn enlightened them on remedial measures that could be taken as well as enable early intervention and better outlook.

SOCIOECONOMIC FACTORS AFFECTING THE CAREGIVERS

A study by Masulani et al (2015) in Malawi, demonstrated that low socio-economic status of the caregivers was associated significantly ($p<0.05$) with psychological distress in the caregivers as well as perceived burden of care among caregivers ($p<0.05$).

Since March 2020, 63% of the caregivers reported a change in family income related either to job loss or reduced incomes due to the economic challenges encountered during the COVID 19 pandemic. Among the caregivers in this study, 72% reported encountering financial challenges during the pandemic with 38% reporting reduced incomes and 30% having lost their sources of income. Additionally, 34% of the caregivers were unemployed with another 34% self-employed, meaning they were at increased risk of the economic challenges encountered.

Being unemployed ($p=0.001$) and self-employed ($p=0.044$) were significantly associated to anxiety but after adjustment for other variables, being unemployed was found to be

significantly associated with high anxiety symptoms (p=0.001). the high anxiety levels in this population and the association with their unemployment status suggests a majority of the caregivers were concerned about their economic outlook and ability to provide for their families or even afford care for their children with developmental disabilities in need of various support services including medication, occupational therapy or even clinic appointment charges. Thus this was a highly vulnerable population and adequate measures could have been put in place to assist caregivers of children with mental illness meet their basic needs as well afford the cost of medication and associated expenses.

A study by Namazizi et al (2017), among caregivers of children with neurodevelopmental disability in Uganda had similar findings to this study. A majority of the caregivers reported financial challenges with associated difficulty in affording basic necessities and medical expenses. Limited psychosocial support had significant association with high depressive and anxiety symptoms among the caregivers. Care seeking was affected by high cost of medical expenses. The caregivers reported challenges relating to caregiving of children with developmental disorders as well as experiencing stigma due to having a child with a disability.

5.2: IMPACT OF COVID 19 PANDEMIC ON CAREGIVERS OF CHILDREN WITH MENTAL ILLNESS ON FOLLOW UP AT MATHARE TEACHING AND REFERRAL HOSPITAL

The COVID 19 pandemic has had a significant impact on the caregivers psychological wellbeing as demonstrated in this study.

DYSFUNCTIONAL CORONAVIRUS ANXIETY

The prevalence of dysfunctional coronavirus anxiety was 20% among this study population which in comparison to a study by Lee et al (2020) found a prevalence of 25.4 percent among the general population in the USA. No comparative study was found assessing prevalence of psychological distress among caregivers of children with mental illness. These studies imply that there has been a high prevalence of undiagnosed dysfunctional coronavirus anxiety among the general populace during the COVID 19 pandemic. The levels of dysfunctional coronavirus anxiety have also been postulated to vary with the surges of the COVID 19 pandemic, with the levels being high during periods when the infection rates are high.

FACTORS THAT MEDIATED CAREGIVER PSYCHOLOGICAL DISTRESS DURING THE PANDEMIC

There was a significant association between psychological distress and dysfunctional coronavirus anxiety. Having psychological distress increased the odds of having dysfunctional coronavirus anxiety by a factor of 8.14 (CI 1.03, 64.3), p value= 0.0212. After adjustment for other variables, significant association was found between depression (p=0.0493) and anxiety (p=0.021) but no significant association with stress. These findings are in line with previous studies by Kim et al (2020) that found that being worried about one's health mediated the relationship between dysfunctional coronavirus anxiety with depressive, anxiety and hypochondrial symptoms among the general population.

Lee and Crunk (2020), found that coronavirus anxiety predicted generalized anxiety, depression and functional impairment. The exposure to sad and worrying news regarding the pandemic

with increasing numbers of infections have been noted to be important mediators to the high levels of psychological distress during the pandemic.

Farazjadeh et al (2020), in a study in Iran to assess the predictors of mental health among caregivers of children with cerebral palsy during the COVID 19 pandemic, found the prevalence of depression to be at 45% and anxiety at 40.6%. These levels are relatively higher than in this study (36% and 39% respectively) which can be attributed to population differences.

Zhang et al (2020) in a study to assess mental health issues among caregivers of young children in rural China found the prevalence of depression to be at 32%, anxiety 42% and stress 30%, these findings are nearly similar to this study (Depression 36%, anxiety 39% and stress 29%).

Amundson et al (2020), found that the psychological impact of the COVID 19 pandemic, measured by COVID stress scale, was more pronounced among people with anxiety and mood disorders than those without mental disorders or other mental disorders. These findings are consistent with this study. The finding that overall distress during the pandemic was higher among individuals with anxiety symptoms more than those with mood disorders is similar to these study findings. There was a more significant association between dysfunctional coronavirus anxiety and anxiety ($p=0.021$) than in caregivers with depression ($p=0.0493$). Thus caregivers who had anxiety had increased risk of adverse psychological events regarding the pandemic in comparison to caregivers who were depressed.

Lee et al (2020) while assessing mental health characteristics associated with dysfunctional coronavirus anxiety, noted that individuals who were functional impairment relating to fear and anxiety of Coronavirus, exhibited greater levels of hopelessness, suicidal ideation and spiritual crisis, with many resorting to coping through use of substances. Individuals and especially caregivers of children with special needs whose mental health was already at risk due to challenges brought about by caregiving, were more vulnerable to psychological effects occasioned by the pandemic. The significance of this is that individuals at risk of adverse psychological effects due to the pandemic are in need of greater support and assistance during this and other similar pandemics.

Gerweniger et al (2020), in a study in Germany during the COVID pandemic among caregivers of children with special health care needs found the prevalence of psychological distress was at 57.4% with depression at 30.9%. there was significant association with low socioeconomic status ($p<0.001$) and complex chronic diseases ($p<0.001$). The level of psychological distress among our study population was higher at 75% with depression also higher at 36%. In line with this study as well, it was found that there was a significant association between mental wellbeing of the caregivers with low socio economic status and especially between anxiety and the employment status of the caregivers (unemployed caregivers, $p=0.001$). This implies that apart from worries about the health status of the caregivers and the children under their care, the worry about their economic status brought about by the pandemic have been significant mediators to the mental well-being of the caregivers.

Brown et al (2020) found that parental support ($p<0.001$) and perceived control over the pandemic ($p<0.05$) were protective factors that reduced psychological distress among caregivers of children with special needs in the USA. Althiabi et al (2020) found that mental

health issues among caregivers of children with ASD during the COVID 19 pandemic were related to lack of confidence, feelings of worthlessness and depression. This study demonstrated that regular psychological support among caregivers during the pandemic was a significant mitigating factor to reduce depressive (p=0.045) and anxiety symptoms (p=0.0145). Thus caregivers should be considered and encouraged to seek regular psychosocial support to avert psychological distress.

SOCIOECONOMIC IMPACT OF THE COVID 19 PANDEMIC ON CAREGIVERS

The responses to the open ended questions revealed that many caregivers suffered challenges regarding financial instability, high medical costs and challenges with caregiving with many resorting to seeking assistance from well-wishers and seeking alternative sources of income to enable them meet their obligations as caregivers.

The COVID 19 pandemic was accompanied by job losses, reduced incomes, school closures as well as other challenges that increased the burden of caregiving. Farazjadeh et al, (2020) found that burden of care was a significant contributor to mental health problems during a crisis, in this case the COVID 19 pandemic. This study found that there was significant association of the functional status of the child under care to the mental health of the caregivers, depression (p=0.045) and anxiety (p=0.0145). Horiuchi et al (2020), while assessing caregiver mental distress and child health during COVID 19 outbreak in Japan, found a correlation between child health status with moderate mental distress (OR 2.24, CI 1.59-3.16) and severe mental distress (OR 3.05, CI 2.17-4.29), thus the severity of the child health issues compounded the mental health issues of the caregivers by increasing the odds of having psychological distress. The caregiving challenges during the pandemic have been attributed to curfews/ lockdowns, reduced clinic visits, school closures, fear by the caregivers of infection by COVID 19, economic pressures as well as lifestyle changes occasioned by the pandemic. Thus caregivers have had to cope with immense pressure due to changes brought about by the pandemic that may have compounded their mental health issues.

PSYCHOLOGICAL FACTORS ASSOCIATED WITH COVID 19 VACCINATION STATUS AMONG CAREGIVERS

This study was also able to demonstrate that there was significant association between dysfunctional coronavirus anxiety and COVID 19 vaccination status. The caregivers who received 2 or more doses (boosters) of the COVID 19 vaccine, which has been recommended by World Health Organization and FDA to increase immunity to coronavirus infection and reduce symptomatology in case one is infected, had a lowered risk of dysfunctional coronavirus anxiety (p=0.011). A study by Perez-Arce et al (2021), reported reduced mental distress levels after receiving the first dose of the vaccine equivalent to 4% of the PHQ-4 scores (p value<0.01) compared to those who received none.

Though no significant association was established between COVID 19 vaccination status and depression and anxiety. Receiving 2 or more doses of the COVID vaccine was initially noted to be associated with low stress levels (p=0.007), but after adjustment for other variables there was no significant association (p=0.306). With regards to vaccination rates, more needs to be done to encourage the caregivers to get vaccinated with only 47% having reported to have

received 2 or more doses of the vaccine. COVID 19 hesitancy among people dealing with anxiety and phobias has been noted as a challenge (Payberah et al, 2021) and more needs to be done to address their concerns through educational interventions.

EXPERIENCES OF CAREGIVERS IN PREVIOUS GLOBAL PANDEMICS – EBOLA PANDEMIC

Wu et al (2009) and Wheaton et al (2012), established that outbreaks associated with infectious diseases were linked with higher levels of mental distress, worry and psychological strain in the general populace. Wheaton et al (2016) assessed caregiving crisis in Sierra Leone during the Ebola pandemic and established that caregivers who had financial challenges were more adversely affected, some caregivers had to defy public health measures in order to provide for their families and took up jobs that could put their health at risk and took up new roles within the family set up. In this context, the financial challenges experienced by the caregivers COVID 19 pandemic were similar to the Experience sin West Africa during the Ebola pandemic in 2015, with many caregivers reporting financial related challenges and being forced to put extra effort in order to provide for their families that compounded their mental health challenges.

CHAPTER 6: SUMMARY, CONCLUSION, RECOMMENDATIONS AND STUDY LIMITATIONS

6.1: SUMMARY

- There was high prevalence of psychological distress (75%) among caregivers of children attending child psychiatry clinic at Mathare NTRH. The levels of depression (36%), anxiety (38%) and stress (29%) were higher than in the general population
- There was significant association between dysfunctional coronavirus anxiety with psychological distress and COVID vaccination status
- There was significant association between depression with dysfunctional coronavirus anxiety, female caregivers, children in need of constant care and inadequate psychosocial support
- There was significant association between anxiety with unemployed caregivers and inadequate psychosocial support
- There was significant association between stress with low education level and having children in need of constant care

6.2: CONCLUSION

- Caregivers of children with mental illness are at increased risk of psychological distress with levels of depression, anxiety and stress higher than among the general population.
- The COVID 19 pandemic has had adverse effects on the socioeconomic and psychological status of caregivers
- Adequate COVID 19 vaccination status lowered anxiety relating to the COVID pandemic among the caregivers
- Adequate Psychosocial support was noted to be protective and mitigated against adverse psychological effects related to the challenges of caregiving.

- The gender of the caregiver, functional status of the child under care, education level of the caregiver, low socio economic status and lack of stable income sources by caregivers were noted to confer additional risk of psychological distress to the caregivers.
- A majority of the caregivers experienced financial challenges relating to the COVID 19 pandemic, with a majority having to seek alternative income sources in order to support themselves. A majority advocated for increased psychological and government support to enable them cope with the challenges they experienced while caregiving.

6.3: RECOMMENDATIONS

- Regular psychological support has been noted to be protective from psychological distress especially during COVID pandemic. Caregivers should be encouraged to seek psychological support (whether formal or informal) to avoid being overwhelmed.
- Mathari National Teaching and Referral Hospital and other hospitals attending to children with chronic diseases can be encouraged to avail additional mental health services to provide psychological support to caregivers (forgotten patients).
- Encourage sensitization and support among caregivers especially among those with low education and low economic status. For those employed workplace support mechanism can be set up and flexible work schedule for those with children in need of constant care
- Caregivers who can't afford formal psychosocial support be encouraged to seek spiritual and family support
- Male parental figures can be encouraged to take up more caregiving responsibilities so as to lessen the burden of caregiving on the female caregivers who have been noted to be at increased risk of psychological distress. Spousal psychosocial support is also encouraged.
- The Government through various mechanisms including through legislative means, to set up social welfare support mechanisms, subsidize psychiatric medication and free NHIF as part of Universal Health Coverage to enable caregivers afford cost of care.
- Access to integrated schools and special schools be facilitated for children with developmental disorders with significant functional impairment to enable them adapt and acquire skills thus lessen caregiver burden
- Caregivers can be linked to support organizations e.g. Autism Association of Kenya for psychosocial support and psychoeducation
- More studies can be conducted to longitudinally monitor long term effects of COVID 19 related experiences on caregivers and the children under their care

6.4: STUDY LIMITATIONS

- This was a hospital based study at child psychiatry clinic Mathare NTRH. Findings may not be generalizable to the general population. Study can be replicated in a larger study population using different study methods
- This was a descriptive cross sectional study, may not account for temporal sequence of psychological status of the caregivers. A longitudinal study would be recommended to fill this gap.
- This study was conducted over 3 months- seasonal variability in psychological status of the caregivers may not have been factored in the results
- Despite these limitations this study used validated and reliable tools and was able demonstrate that the challenges associated with caregiving as well as the experiences during the COVID 19 pandemic had significant impact of the psychological well-being of caregivers of children with mental illness.

STUDY TIMELINE

ACTIVITIES	APRIL TO JULY 2021	AUGUST TO SEPTEMBER 2021	SEPTEMBER TO NOVEMBER 2021	DECEMBER 2021 TO MARCH 2022	APRIL 2022	MAY 2022	JUNE 2022
Proposal writing and approval by supervisors							
Submission of final copy of proposal							
Ethics approval							
Data collection							
Data analysis							
Results presentation							
Working on panel recommendations and submission of final research project							

BUDGET AND BUDGET JUSTIFICATION

STUDY BUDGET ESTIMATES

CATEGORY	REMARKS	UNITS	UNIT COST (KSHS)	TOTAL (KSHS)
Proposal development	Printing drafts (paper, cartridge)	1	10,000	10,000
	Proposal copies	8 copies	500	4,000
Data collection	Stationery packs (pens, papers and study definitions)	10	200	2,000
	Training	1 day	2,000	2,000
Data analysis	Statistician	1	50,000	50,000
Thesis write up	Computer services	1	5,000	5,000
	Printing questionnaires	120	100	12,000
	Master's Thesis printing and binding costs – UoN library	4	1,950	7,800
National Commission for Science and Technology (NACOSTI) permit	Research (academic) Masters - permit	1	1,000	1,000
KNH-UoN Ethics and Research Committee	Application fees	1	2,000	2,000
Transport – researcher	Transport	12 weeks	1,000	12,000
Airtime	Airtime vouchers	1	1,000	1,000
Hand sanitizers and facemasks				2,200
Contingency funds				39,000
Total				150,000

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APPENDICES

APPENDIX 1: PARTICIPANT INFORMATION AND CONSENT FORM

APPENDIX 1.1: CONSENT FORM ENGLISH

TITLE OF STUDY: PREVALENCE OF PSYCHOLOGICAL DISTRESS, DYSFUNCTIONAL CORONAVIRUS ANXIETY AND IMPACT OF COVID 19 PANDEMIC AMONG CAREGIVERS OF CHILDREN WITH MENTAL ILLNESS AT MATHARE NATIONAL TEACHING AND REFFERAL HOSPITAL

INVESTIGATOR: DR CALEB WAMBUA MBITHI,

MASTERS OF MEDICINE, PSYCHIATRY RESIDENT

UNIVERSITY OF NAIROBI

CONTACTS: 0777880683

SUPERVISOR: DR MANASI KUMAR

UNIVERSITY OF NAIROBI

INTRODUCTION

I would like to tell you about a study being conducted by the above listed researchers. The purpose of this consent form is to give you information you will need to help you decide whether or not to be a participant in the study. Feel free to ask any questions about the purpose of the research, what happens if you participate in the study, the possible risks and benefits, your rights as a volunteer and anything else about the research or this form that is not clear. When we have answered all your questions to your satisfaction, you may decide to be in the study or not. This process is called 'informed consent'. Once you understand and agree to be in the study, I will request you to sign your name on this form. You should understand the general principles which apply to all participants in medical research:

i) Your decision to participate in this study is entirely voluntary
ii) You may withdraw from the study at any time without necessarily giving a reason for your withdrawal
iii) Refusal to participate in the research will not affect the services you are entitled to in this health facility or other facilities

We will give you a copy of this form for your records:

May I continue? YES/ NO

This study has approval by the Kenyatta National Hospital – University of Nairobi Ethics and Research committee: No…….

WHAT IS THIS STUDY ABOUT?

The researcher above is interviewing individuals who are caregivers of children with mental illness attending outpatient child psychiatry clinic at Mathare National Teaching and Referral hospital. The purpose of this study is to find out the prevalence of depression, anxiety, stress and dysfunctional coronavirus anxiety. Participants will be asked questions about their sociodemographic characteristics and using psychometric tools the levels of depression, anxiety, stress and coronavirus anxiety will be assessed. There will be approximately one hundred (100) participants who will be selected using purposive sampling method to participate in the study.

WHAT WILL HAPPEN IF YOU DECIDE TO BE IN THE RESEARCH STUDY?

if you agree to participate in this study, the following things will happen:
You will be interviewed by a researcher in a private area where you feel comfortable to answer questions. The interview will last approximately 40 minutes. The interviewer will cover topics such as the effects of the COVID 19 pandemic, challenges experienced and coping strategies.
After the interview is complete the researcher will thank you and the data collected and analysed. There is no requirement for any invasive procedures or sample collection during this study.
You will be asked for your telephone number where you can be contacted if necessary. If you agree to provide your contact information, it will be used only by the personnel working for this study and will never be shared with others. The reason why we may need to contact you would include to clarify on any unclear information or check on your progress if psychological distress was noted during the interview.

ARE THERE ANY RISKS, HARMS OR DISCOMFORTS ASSOCIATED WITH THIS STUDY?

Medical research has the potential to introduce psychological, social and physical risks. Efforts should always be put in place to minimize risks. One potential risk of being in this study is the loss of privacy. The researcher will keep everything you divulge as confidential as possible. A unique code number will be used to identify you in a password protected computer database and will keep all of your paper records in a locked file cabinet. However, no system of protecting your confidentiality can be absolutely secure, so it is still possible that someone could find out you were in this study and could find out information about you. The researcher will take all measures capable to ensure that incident doesn't occur.
Also answering questions in the interview can be uncomfortable for you. If there are any questions you do not want to answer, you can skip them. You have the right to refuse the interview of any question asked during the interview.
It may be embarrassing for you to be found have psychological distress secondary to depressive, stress, anxiety or dysfunctional coronavirus anxiety symptoms. We will do everything we can to ensure that this interview is done in a private setting. Furthermore, all study staff and interviewers are professionals with special training in these interviews. Psychological first aid will be offered and you will then be referred to an appropriate mental health professional to offer more assistance.
In case of any discomfort or distress as a consequence of recalling specific stressful events relating to the study in the course of the interview or afterwards, inform the study staff on the number provided at the end of this document. The researcher will offer assistance in form of psychological support and refer you when necessary.

ARE THERE ANY BENEFITS BEING IN THIS STUDY?

You may benefit from the screening of any symptoms of depression, stress, anxiety or dysfunctional coronavirus anxiety. Psychological support offered and advice offered may help you get in touch with institutions or professionals who may offer more support regarding issues noted when necessary.
We hope that the information obtained will be used to address issues affecting caregivers of children with mental illnesses since it will enable us to learn how prevalent are depression, anxiety, stress, dysfunctional coronavirus anxiety and other challenges relating to caregiving. Besides this, during this COVID 19 pandemic there are new emergent challenges which we hope to find out and share our findings with the relevant authorities to enable timely interventions addressing caregiver concerns and challenges.

WILL BEING IN THE STUDY COST YOU ANYTHING?

No, there will be no costs relating to participating in this study.

WILL YOU GET ANY REFUND FOR ANY MONEY SPENT AS PART OF THE STUDY?

The researcher does not anticipate any study participant incurring any expense relating to taking part in this study. But you are advised to get in touch with the researcher in case of any eventuality and any justifiable issue regarding the study will be discussed.

PRIVACY AND CONFIDENTIALITY

All responses given in the questionnaires provided will be treated with utmost confidentiality. You will be assigned a unique study identification number. All information obtained will be under the sole custody of the researcher and stored securely. Your name or identity will not be used in any reports. We will use the information obtained solely for research purposes only.

WHAT IF YOU HAVE QUESTIONS IN FUTURE (RELATING TO THE STUDY)?

If you have any further questions or concerns about participating in the study, please call or send a text message to the researcher (Dr. Wambua) on the phone number provided (**0777880683).**

For more information about your rights as a research participant, you may contact the Secretary/ Chairperson, Kenyatta National Hospital – University of Nairobi Ethics and Research Committee telephone number **2726300 ext. 44102,** email: **uonknherc@uonbi.ac.ke**.

The researcher will refund any call charges incurred if the call is for study related communication.

WHAT ARE YOUR OTHER CHOICES?

Your decision to participate in the research is voluntary. You are free to decline participation in the study and you can withdraw from the study at any time without injustice or loss of benefits.

CONSENT FORM (STATEMENT OF CONSENT)

PARTICIPANT'S STATEMENT

I have read this consent form or had the information read to me. I have had the chance to discuss this research study with a study counselor. I have had my questions answered in a language that I understand. The risks and benefits have been explained to me. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that all efforts will be made to keep information regarding my identity confidential.

By signing this consent form, I have not given up any of the legal rights that I have as a participant in a research study.

I agree to participate in this research study	YES	NO
I agree to provide contact information for follow up	YES	NO

Participant's name ……

Participant signature/ thumbprint: ……

Date: ……

RESEARCHER'S STATEMENT

I, the undersigned have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has willingly freely given his/ her consent.

Researcher's name: ……

Signature: ……

Date: ……

For more information regarding the study contact the researcher (Dr. Wambua) on the contacts provided

APPENDIX 1.2: CONSENT FORM KISWAHILI

KIAMBATISHO CHA KWANZA: HABARI YA MSHIRIKI NA FOMU YA IDHINI

KICHWA CHA UTAFITI: KUENEA KWA WASIWASI, UNYONGOVU, DHIKI NA WASIWASI KUHUSIANA NA VIRUSI VYA KORONA KATI YA WENYE KUWAANGALIA WATOTO WENYE MAGONJWA YA AKILI WANAOHUDHURIA KLINIKI KATIKA HOSPITALI YA MAFUNZO NA RUFAA YA MATHARE.

Mtafiti: Dkt. Caleb Wambua Mbithi,
Mwanafunzi shahada ya uzamili, magonjwa ya akili
Chuo kikuu cha Nairobi
Mtafiti mwenza: Dkt Manasi Kumar
Chuo kikuu cha Nairobi

Utangulizi

Ningependa kukueleza juu ya uchunguzi unaofanywa na watafiti waliotajwa hapa juu. Madhumuni ya fomu hii ya idhini ni kukupa habari utakayohitaji kukusaidia kuamua ikiwa ni mshiriki wa utafiti huo au la. Jiskie huru kuuliza maswali juu ya kusudi la utafiti, ni nini kitatokea ikiwa utashiriki katika utafiti, hatari na faida zinazowezekana, haki zako kama kujitolea, bila chochote kingine juu ya utafiti au fomu hii ambayo haijulikaniwazi. Wakati tumejibu maswali yako yote kukuridhisha, unaweza kuamua kujihusisha kwenye somo au la. Utaratibu huu unaitwa “idhini ya habari ya Mara tu utakapoelewa na kukubali kuwa kwenye utafiti, nitakuomba utie sahihi jina lako kwenye fomu hii. Unapaswa kuelewa kanuni za jumla ambazo zinatumika kwa washiriki wote katika utafiti wa matibabu:

i) Uamuzi wako wa kushiriki ni wa hiari kabisa,
ii) Unaweza kujiondoa kutoka kwa utafiti wakati wowote bila lazima kutoa sababu ya kujiondoa kwako
iii) Kukataa kushiriki katika utafiti haitaathiri huduma unazostahiki katika kituo hiki cha afya au vituo vingine. Tutakupa nakala za fomu hii kwa kumbukumbu zako**,**

Mtafiti atakupea fomu hii, ili uwe na nakala yako

Naomba niendelee? NDIO _____ LA_____

Utafiti huu umeidhinishwa na Itifaki ya Kamati ya Maadili na Utafiti ya Hospitali ya Kitaifa ya Kenyatta – Chuo Kikuu cha Nairobi **Nambari _____**

KUSUDI LA UTAFITI HUU

Mtafiti aliyetajwa hapo awali anawahoji watu wanao waangalia watoto wenye magonjwa mmali mbali ya akili ambao wanakuja kliniki katika hospitali ya mafunzo nna rufaa ya Mathare. Kusudi la utafiti huu ni kudadisi: Kuenea kwa wasiwasi, unyongovu, dhiki na wasiwasi kuhusiana na virusi vya Korona kati ya wenye kuwaangalia watoto wenye magonjwa ya akili wanaohudhuria kliniki katika hospitali ya Mafunzo na rufaa ya Mathare. Washiriki wataulizwa maswasli juu ya

tabia zao za kijamii na idadi ya watu, unyongovu, wasiwasi,dhiki na wasiwasi kuhusiana na virusi vya Korona. Kutakuwa na takriban washiriki 100 (mia moja) ambao watachaguliwa kwa makusudi

NINI KITAKACHOTOKEA UKIAMUA KUWA KWENYE UTAFITI HUU?

Ikiwa unakubali kushiriki katika utafiti huu, mambo yafuatayo utahojiwa na mchunguzi katika eneo la kibinafsi ambapo unahisi raha kujibu maswali. Mahojiano hayo yatachukuwa takriban Dakika 40.

Utaulizwa maswali kuhusu vile janga la Korona limeku dhuru, changamoto ambazo umepitia na vile umeweza kustahimili. Baada ya kumaliza uchunguzi, mtafiti atakushukuru na nakala itachunguzwa na kudadisiwa. Hakutrakuwa na haja ya utaratibu wowote wa kuchukua sampuli yoyote kwa ukaguzi Zaidi.

Utaulizwa kama ungependa kutupa nambari yako ya simu ndiposa kukiwa na hoja lolote tuweze kukupata. Ukikubali kutupa nambari yako ya simu, itatumikapekee na watafiti katikia uchunguzi huu, hautatumika kwa madhumuni yoyote ingine. Nia yetu ya kukuuliza nambari yako itakuwa kama kuna dhana yoyote ambayo tungependa ufafanuzi Zaidi au kukuuliza vile unaendelea kama kutakuwa na dhiki ya kisaikolojia itakayo onekana wakati wa uchunguzi.

KUNA HATARI ZOZOTE ZINAZODHURU AU KULETA HASARA ZINAZOHUSIANA NA UTAFITI HUU?

Utafiti wa kimatibabu una uwezo wa kuanzisha hatari za kisaikolojia, kijamii, kihemko,na kiafya. Hatari moja iwapo ya kuwa katika utafiti ni kupoteza faragha. Mtafiti ataweka kila kitu utamueleza kama siri iwezekanavyo. Nambari ya kipekee ya kukutambulisha itatumika katika hifadhidata ya kompyuta iliyolindwa na nywila na tutaweka kumbukumbu zetu zote za karatasi kwenye kabati la faili iliyofungwa.Ikiwa kuna uwezekano kuwa mbinu za kutokutambulisha zitafeli, mtafiti mkuu atachukua hatua yote awezayo kuhakikisha kwamba swala kama hilo halitokei.

Kuna maswali mengine katika uchunguzi huu ambayo yaweza kufanya ujihisi kukosa utulivu. Kama kuna swali lolote ambalo haungependa kujibu, waweza kuiruka. Uko na haki ya kukataa kujibu swali lolote katika uchunguzi huu.

Kuna uwezekano waweza kujihisi kuwa na aibu kama utapatikana na dhiki ya kisaikolojia kutokana na wasiwasi, unyongovu, dhiki au wasiwasi kuhusiana na virusi vya Korona. Tutachukua hatua zozote kuhakikisha kwamba uchunguzi huu utafanyika katika mahali fiche. Pia watafiti wote ni wataalamu wenye mafunzo maalum kufanya utafiiti huu. Ikiwa kuna maswali ambayo yatakudhuru kisaikolojia, tutaiacha mara moja na kuanza usaidizi wa dharura na kukutuma kwa mhudumu wa afya anayewezana kukupa usaidizi unaofaa.

Kama kutakuwa na dhiki au ukosefu wa utulivu kutokana na ukombusho wa tukio lolote lihusishacho utafiti huu wakati wa maswali au baadaye, tafadhali julisha mtafiti mkuu kwenye nambari ya simu utakayopewa kwenye waraka huu. Watafiti watakupa usaidizi wa kisaikolojia na kukuelekeza pahala ambapo utapata usaidizi Zaidi.

KUNA FAIDA ZOZOTE ZINAKUWA KATIKA UTAFITI HUU?

Hakuna faida ya moja kwa moja kwako kwa kushiriki katika utafiti huu. Utaweza kupata kukaguliwa iwapo una dalili zozote za wasiwasi, unyogovu, dhiki au wasiwasi kuhusiana na virusi

vya Korona. Pia utapewa mawaidha vile ya kujimudu na kuelekezwa pahala ambapo utaweza pata usaidizi Zaidi kama itahitajika.

Walakini, tunatumahi kuwa, watu wengine wanaweza kufaidika na utafiti huu kwa sababu itaturuhusu kujifunza zaidi juu ya kuenea kwa wasiwasi, unyongovu, dhiki na wasiwasi kuhusiana na virusi vya korona kati ya wenye kuwaangalia watoto wenye magonjwa ya akili. Pia habari tutakayopata kutoka kwa utafiti huu utatumwa kwa idara ya afya na wenye kusimamia hospitali ili kuwawezwsha kuweka mipango maalum ya usaidizi. Kushiriki katika utafiti huu hautakugharimu chochote isipokuwa dakika zako 40 au zaidi zako

JE, UTAGHARIMIKA KWA KUSHIRIKI KATIKA UTAFITI HUU?

Kushiriki katika utafiti huu hakutakugharimu chochote isipokuwa muda wako wa takriban dakika arobaini.

UTAPATA PESA ZOZOTE KWA KUSHIRIKI KATIKA UTAFITI HUU?

Hakuna malipo yoyote utakayopata kwa kushiriki katika utafiti huu. Mtafiti hajakusudia mtu yoyote kuhitaji malipo yoyote kuhusiana na utafiti huu. Kama kuna hoja lolote kuhusiana na utafiti utaelekezwa kuzungumza na mtafiti mkuu.

USIRI

Habari unayotoa itashughulikiwa kwa siri na wanachama tu walioidhinishwa wa timu ya utafiti. Utapewa kitambulisho cha kipekee cha kusoma na hakuna majina yatakayopewa kuandika kwenye fomu za mahojiano. Jina lako au habari nyingine ya kibinafsi haitatumika katika ripoti zozote au kushirikishwa na mtu mwingine yeyote. Tutatumia habari hiyo kwa madhumuni ya utafiti tu pekee.

NA UKIWA NA MASWALI BAADAYE?

Ikiwa una maswali zaidi au wasiwasi juu ya kushiriki katika utafiti huu, tafadhali piga simu au tuma ujumbe mfupi kwa mtafiti (Dkt Wambua) kwa simu **0777880683**

Kwa habari zaidi juu ya haki zako kama mshiriki wa utafiti , unaweza kuwasiliana na Katibu / Mwenyekiti Barua pepe: uonherc@uonbi.ac.ke, au nambari ya simu 2726300 ext 44102.

Mtafiti atakupea fidia kwa fedha za simu utakazotumia kuuliza jambo lolote kuhusiana na utafiti huu.

CHAGUO ZAKO ZINGINE NI NINI?

Uamuzi wako wa kushiriki katika utafiti ni wa hiari. Uko huru kukataa kushiriki katika utafiti na unaweza kujiondoa kutoka kwa utafiti wakati wowote bila udhalimu na upotezaji wa ada yoyote

FOMU YA IDHINI

Taarifa ya mshiriki

Nimesoma fomu hii idhini au habari hiyo imesomwa kwangu. Nimepate nafasi ya kujadili utafiti huu na mshauri wa masomo nimajibiwa maswali yangu kwa lugha ambayo inayoeleweka. Nimeelezwa hatari na faida za kushiriki. Ninaelewa kuwa kushiriki kwangu katika utafiti huu ni kwa hiari na kwamba ninaweza ujiondoa wakati wowote. Ninakubali kwa hiari kushiriki katika utafiti huu.

Ninaelewa kuwa juhudi zote zitafanywa kutunza habari kuhusu kitambulisho changu kuwa siri

_____ _____

(Saini (Thumb) Uchapa wa Mshiriki) (tarehe)

Taarifa ya Mtafiti Ambaye Amepata Idhini

Maelezo katika hati hii yamejadiliwa na mshiriki au inapofaa, na mwakilishi aliyeidhinishwa kisheria. Mshiriki ameonyesha kuwa anaelewa hatari, faida, na taratibu zinazohusika katika utafiti huu.

_____ _____

(Saini ya mtu aliyepata Idhini tarehe

APPENDIX 2: STUDY QUESTIONNAIRE

APPENNDIX 2.2: STUDY QUESTIONAIRE – ENGLISH

INSTRUCTIONS: this is a 2-part questionnaire; responses will be obtained only from caregivers who have given informed consent to participate in this study. Indicate the study participant number before commencing data collection. All responses will be confidential and the interview should be conducted in a secure, quiet room. Part 1 will involve ticking in the spaces provided the most appropriate response. Part 2 has 3 open ended questions that will serve as the interview guide whereby the study participant will be encouraged to answer and adequate time should be given for each response.

STUDY PARTICIPANT IDENTIFICATION NUMBER…….

PART 1: SOCIODEMOGRAPGHIC QUESTIONNAIRE

	DEMOGRAPHIC INFROMATION		TICK
Q 1	GENDER (RECORD MALE OR FEMALE AS OBSERVED)	MALE	
		FEMALE	
Q 2	AGE IN YEARS		
Q 3	AGE CATEGORY	18 – 30 YRS	
		31 – 43 YRS	
		44 – 56 YRS	
		≥ 57 YRS	
Q 4	WHAT IS YOUR MARITAL STATUS?	SINGLE	
		MARRIED	
		SEPARATED / DIVORCED	
		WIDOWED	
Q 5	WHAT IS THE HIGHEST LEVEL OF EDUCATION YOU HAVE ATTAINED?	NO FORMAL	
		PRIMARY LEVEL	
		SECONDARY LEVEL	
		TERTIARY LEVEL	
Q 6	WHAT IS YOUR EMPLOYMENT STATUS?	EMPLOYED	
		UNEMPLOYED	
		SELF EMPLOYED	
Q 6	HAS THERE BEEN ANY CHANGE IN MONTHLY INCOME SINCE MARCH 2020?	NO CHANGE	
		INCREASED	
		DECREASED	
Q 7	WHAT IS THE AGE OF THE CHILD ATTENDING CHILD PSYCHIATRY CLINIC?	≤ 5 YRS	
		6 – 10 YRS	
		≥ 11 YRS	

Q 8	WHAT IS YOUR RELATIONSHIP TO THE CHILD?	BIOLOGICAL PARENT	
		PARENT BY ADOPTION	
		GRANDPARENT	
		OTHER (INDICATE) ……	
Q 9	HOW LONG HAS BEEN YOUR DURATION OF CAREGIVING FOR THIS CHILD?	≤ 5 YRS	
		6 – 10 YRS	
		≥ 10 YRS	
Q 10	HOW MANY CHILDREN ARE IN YOUR HOUSEHOLD?	1 CHILD	
		2 – 4 CHILDREN	
		≥ 5 CHILDREN	
Q 11	WHAT IS THE DIAGNOSIS FOR THE CHILD ATTENDING CHILD PSYCHIATRY CLINIC? (CONFIRM FROM THE PATIENT FILE)	ATTENTION DEFICIT HYPERACTIVITY DISORDER	
		AUTISM SPECTRUM DISORDER	
		COMMUNICATION DISORDER	
		SPECIFIC LEARNING DISORDER	
		MOTOR DISORDER	
		DISRUPTIVE, IMPULSE CONTROL, CONDUCT DISORDER	
		EARLY ONSET SCHIZOPHRENIA	
		MOOD DISORDER	
		OTHER (INDICATE) ……..	
Q 12	WHAT IS THE CHILD'S FUNCTIONAL STATUS?	INDEPENDENT	
		REQUIRES SOME CARE	
		REQUIRES CONSTANT CARE	
Q 14	DO YOU HAVE ANY CHRONIC ILLNESSES? Including any mental illness,if yes, specify: ……..	YES, I AM ON FOLLOW UP FOR A CHRONIC ILLNESS	
		NO, I AM NOT ON FOLLOW UP FOR ANY CHRONIC ILLNESS	
Q 15	DO YOU HAVE ANY SOURCES OF PSYCHOSOCIAL SUPPORT?	NONE	
		FORMAL	
		INFORMAL	

PART 2: OPEN ENDED QUESTIONS

1) Since the COVID 19 pandemic was declared in this country in March 2020, what have been the main challenges you have experienced associated with caregiving in the midst of a global pandemic?
2) What coping mechanisms have you adopted to enable you to cope with the challenges you have mentioned above, associated with caregiving in the midst of a global pandemic?
3) From your experiences, what recommendations would you make that you feel will enable caregivers cope better with the duty of caregiving?

THANK YOU FOR YOUR RESPONSES

APPENDIX 2.2: STUDY QUESTIONNAIRE – KISWAHILI

MAELEKEZO: Fomu hii ina vitengo viwili vya maswali. Hakikisha kwamba majibu yanachukuliwa kutoka kwa walezi ambao wamekwisha jaza fomu ya idhinisho pekee. Majibu yote yatakuwa ya siri na mahojiano yatafanyika kwenye chumba bila kelele. Kitengo cha kwanza kitahusisha kuweka alama kwenye nafasi ipasayo kulingana na jibu litakalopatikana. Kitengo cha pili kina maswali matatu yatakoyokelekeza kupata majibu.

Nambari maalum ya mshiriki…….

MASWALI YA JAMII NA DEMOGRAFIA

	HABARI YA KIDEMOGRAFIA		TICK
Q 1	JINSIA (REKODI MWANAUME AMA MWANAMKE KAMA INAVYOONEKANA)	MWANAUME	
		MWANAMKE	
Q 2	UMRI KATIKA MIAKA		
Q 3	KITENGO CHA UMRI?	MIAKA 18 – 30	
		MIAKA 31 – 43	
		MIAKA 44 – 56	
		MIAKA ≥ 57	
Q 4	HALI YA NDOA?	MSEJA	
		NIMEOLEWA	
		TUMETENGANA/ NIMEPATA TALAKA	
		MJANE	
Q 5	JE, NI KIWANGO KIPI CHA JUU ZAIDI YA MASOMO ULIYOHITIMU?	SIJAPATA ELIMU RASMI	
		SHULE YA MSINGI	
		SHULE YA SEKINDARI	
		SHAHADA/ KOLEJI/ CHUO KIKUU	
Q 6	JE, HALI YAKO YA KIKAZI NI IPI?	NIMEAJIRIWA KAZI	
		SIJAAJIRIWA KAZI KWA WAKATI HUU	
		NIMEJIAJIRI KWENYE BIASHARA YANGU	
Q 6	JE, KUMEKUWA NA MABADILIKO KWENYE MAPATO YAKO TANGU MWEZI WA MECHI, 2020?	HAKUNA MABADILIKO	
		MAPATO YAMEONGEZEKA	
		MAPATO YAMEPUNGUA	
Q 7	MTOTO ULIYEMLETA KWENYE KLINIKI ANA UMRI UPI?	MIAKA ≤ 5	
		MIAKA 6 – 10	
		MIAKA ≥ 11	
Q 8	UNA UHUSIANO UPI NA MTOTO HUYU?	MZAZI WA KIBAYOLOJIA	
		MZAZI WA KUPITILIWA (KULEA)	
		BABU AU NYANYA WA MTOTO HUYU	
		NYINGINE (FAFANUA) ……	
Q 9		MIAKA ≤ 5	

	JE, UMEKUWA MLEZI WA MTOTO HUYU KWA MUDA GANI?	MIAKA 6 – 10	
		MIAKA ≥ 11	
Q 10	KUNA WATOTO WANGAPI NYUMBANI KWAKO?	MTOTO 1	
		WATOTO 2 – 4	
		WATOTO ≥ 5	
Q 11	NI UGONJWA UPI UMETAMBILIWA KWENYE MTOTO HUYU UNAYEMLEA? (HAKIKISHA KUTOKA KWENYE FAILI YA KLINIKI)	ATTENTION DEFICIT HYPERACTIVITY DISORDER	
		AUTISM SPECTRUM DISORDER	
		COMMUNICATION DISORDER	
		SPECIFIC LEARNING DISORDER	
		MOTOR DISORDER	
		DISRUPTIVE, IMPULSE CONTROL, CONDUCT DISORDER	
		EARLY ONSET SCHIZOPHRENIA	
		MOOD DISORDER	
		INGINE (FAFANUA) ……..	
Q 12	MTOTO HUYU ANAUWEZO GANI WA UHURU KATIKA KUJIANGALIA?	NI HURU	
		ANAHITAJI USAIDIZI KIDOGO	
		ANAHITAJI USAIDIZI WAKATI WOTE	
Q 14	JE, UNA UGONJWA WOWOTE AMBAO UMEKUWA KWA MUDA MREFU? KAMA JIBU NI NDIO, FAFANUA ……	NDIO, NINA UGONJWA AMBAO NINATIBIWA KWA MUDA MREFU	
		LA, SINA UGONJWA WOWOTE AMABAO NIMETIBIWA KWA MUDA MREFU	
Q 15	JE, NI WAPI AMBAPO UNAPATA USAIDIZI WA KISAIKOLOJIA?	HAKUNA	
		USAIDIZI WA RASMI	
		USAIDIZI USIO RASMI	

MASWALI SIMULIZI

1) Tangu janga la Korona lilipotangazwa nchini humu mnamo Mechi 2020, ni changamoto zipi ambazo umepitia kuhusiana na kumlea mtoto huyu?
2) Ni hatua gani ambazo umechukua kukuwezesha kujimudu dhidi ya changamoto ulizozisema hapo awali?
3) Ni mapendekezo yapi ambayo unaona yanaweza kuwa yenye manufaa Zaidi kuwasaidia wazazi na wale wanaowalea watoto wenye mahitaji maalum wakati wa jangwa hili la Korona?

SHUKRANI KWA MAJIBU YAKO

APPENDIX 3: PSYCHOMETRIC TOOLS

APPENDIX 3.1.1: DASS 21 - ENGLISH

DASS 21 – DEPRESSION, ANXIETY AND STRESS SCALE - 21 ITEMS

Number: …….

Date: ……

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you **over the past week**.

There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all – NEVER (N)

1 Applied to me to some degree, or some of the time – SOMETIMES (S)

2 Applied to me to a considerable degree or a good part of time – OFTEN (O)

3 Applied to me very much or most of the time – ALMOST ALWAYS (AA)

		N	S	0	AA	OFFICIAL USE		
						D	A	S
1	(s) I found it hard to wind down	0	1	2	3			
2	(a) I was aware of dryness of my mouth	0	1	2	3			
3	(d) I couldn't seem to experience any positive feeling at all	0	1	2	3			
4	(a) I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3			
5	(d) I found it difficult to work up the initiative to do things	0	1	2	3			
6	(s) I tended to over-react to situations	0	1	2	3			
7	(a) I experienced trembling (e.g. in the hands)	0	1	2	3			
8	(s) I felt that I was using a lot of nervous energy	0	1	2	3			
9	(a) I was worried about situations in which I might panic and make a fool of myself	0	1	2	3			
10	(d) I felt that I had nothing to look forward to	0	1	2	3			
11	(s) I found myself getting agitated	0	1	2	3			
12	(s) I found it difficult to relax	0	1	2	3			
13	(d) I felt down-hearted and blue	0	1	2	3			
14	(s) I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3			
15	(a) I felt I was close to panic	0	1	2	3			
16	(d) I was unable to become enthusiastic about anything	0	1	2	3			
17	(d) I felt I wasn't worth much as a person	0	1	2	3			
18	(s) I felt that I was rather touchy	0	1	2	3			
19	(a) I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)	0	1	2	3			
20	(a) I felt scared without any good reason	0	1	2	3			
21	(d) I felt that life was meaningless	0	1	2	3			
		TOTALS						

	D	A	S
*2			

DASS-21 Scoring Instructions

Recommended cut-off scores for conventional severity labels (normal, moderate, severe) are as follows:

NB Scores on the DASS-21 will need to be multiplied by 2 to calculate the final score.

	Depression	Anxiety	Stress
Normal	0 - 9	0 – 7	0 – 14
Mild	10 - 13	8 – 9	15 – 18
Moderate	14 – 20	10 – 14	19 – 25
Severe	21 - 27	15 – 19	26 – 33
Extremely severe	28+	20+	34+

APPENDIX 3.1.2: DASS 21 – KISWAHILI

UNYOGOVU, WASIWASI NA KIWANGO CHA MAFADHAIKO- VIPENGEE ISHIRINI NA MOJA

Nambari : …….
Siku : ……
Tafadhali soma kila kauli na kuweka alama kwa nambari 0, 1, 2 au 3 ili kuonyesha kwa kiasi kipi kila kauli kimehusiana na wewe kwa **wiki moja (1) ambao umepita.**
Hakuna jibu lolote la haki ama makossa. Usitumie muda mwingi kwa kauli yoyote
Kiwango cha ukadriaji ni kama ifuatavyo:
0 Hainihusishi vyovyote – kamwe (K)
1 inanihusu kwa kiwango kidogo au wakati mwingine (WM)
2 ilinihusu kwa kiwango Zaidi au wakati wangu Zaidi (WZ)
3 ilinihusu kwa kiwango kikubwa au muda wangu mwingi sana (WMS)

		K	WM	WZ	WMS	MATUMIZI RASMI		
						D	A	S
1	(s) nilihisi nikiwa na ugumu wa kutulia	0	1	2	3			
2	(a) nilihisi mdomo wangu ukiwa umekauka	0	1	2	3			
3	(d) sijaweza kuwa na hisis zozote za kunichangamsha	0	1	2	3			
4	(a) Nilihisi ugumu wa kupumua (kupumua kwa mwendo wa kasi, kukosa pumzi bila kufanya kazi yoyote)	0	1	2	3			
5	(d) nilihisi ugumu kujichangamsha kufanya kazi	0	1	2	3			
6	(s) nilikuwa na mguso kupita kiasi katika hali tofauti	0	1	2	3			
7	(a) nilihisi nikiwa natetemeka (kwa mfano yangu ilikuwa inatetemeka)	0	1	2	3			
8	(s) nilijipata nikiwa katika hali ya kutokutulia na kutumia nguvu mingi kuliko kiasi	0	1	2	3			

9	(a) nilikuwa na hofu kwamba hali zingine zingenifanya niwe na wasiwasi na kufanya vitendo vya kuniaibisha	0	1	2	3			
10	(d) nilihisi kwamba sikuwa na kitu ya kunifanya niwe na matumaini ya mambo ya baadaye	0	1	2	3			
11	(s) nilijipata nikiwa mtu mwenye kufadhaika	0	1	2	3			
12	(s) nilikuwa na ugumu kutulia	0	1	2	3			
13	(d) nilijihisi kana kwamba nimevinjika moyo	0	1	2	3			
14	(s) singeweza kustahimili kitu chochote ambacho kingenifanya nishindwe kuendelea kufanya mambo ambayo nilikuwa najihusisha nayo	0	1	2	3			
15	(a) nilihisi kwamba nilikuwa na hofu	0	1	2	3			
16	(d) nilijipata mwenye shauku kwa mambo mengi	0	1	2	3			
17	(d) nilihis kana kwamba sina manufaa kama mtu	0	1	2	3			
18	(s) nilijihisi kukasirika kwa haraka	0	1	2	3			
19	(a) nilihisi moyo wangu ukipiga kwa kasi bila ya kufanya kazi ya kuchosha, kwa mfano moyo kupiga kwa mwendo wa kasi, kuhusu kama moyo unaruka mipigo	0	1	2	3			
20	(a) nilijihisi mwenye uoga bila sababu yoyote	0	1	2	3			
21	(d) nilihisi kwamba masiha ilikuwa imepoteza maana	0	1	2	3			
		TOTALS						
					*2	**D**	**A**	**S**

APPENDIX 3.2.1: CORONAVIRUS ANXIETY SCALE – ENGLISH

CORONAVIRUS ANXIETY SCALE

By Sherman A. Lee
Department of Psychology, Christopher Newport University, Newport News, Virginia, USA

How often have you experienced the following activities over the last 2 (two) weeks?

	Questions	Not at all	Rare, less than a day or (2) two	Several days	More than (7) seven days	Nearly every day over the last (2) two weeks
		0	**1**	**2**	**3**	4
1	I felt dizzy, light headed or faint when I read or listened to news about the coronavirus					
2	I had trouble falling or staying asleep because I was thinking about the coronavirus					

3	I felt paralyzed or frozen when I thought about or was exposed to information about the coronavirus					
4	I lost interest in eating when I thought about or was exposed to information about the coronavirus					
5	I felt nervous or had stomach problems when I thought about or was exposed to information about the coronavirus					
	TOTAL		+	+	+	+

TOTAL SCORE……

APPENDIX 3.2.2: CORONAVIRUS ANXIETY SCALE – KISWAHILI

MIZANI YA WASIWASI KUHUSIANA NA VIRUSI VYA KORONA

Limeundwa na Sherman A. Lee
Idara ya saikolojia, chuo kikuu cha Christopher Newport, Newport News, Virginia, USA

Katika wiki mbili zilizopita ni mara ngapi umejihisi hivi?

	Maswali	**Hakuna**	**Mara chache, chini ya siku moja ama mbili**	**Masiku kadhaa**	**Zaidi ya siku saba**	**Karibu kila siku katika hizi wiki mbili zilizopita**
		0	**1**	**2**	**3**	4
1	Nilijihisi nikiwa na kizunguzungu, kuhisi kupoteza fahamu wakati nilisoma ama kusikia habari kuhusiana na virusi vya korona					
2	Nilikuwa na shida kuenda kulala ama					

	kupata usingizi kwasababu nilikuwa na mawazo mengi kuhusiana na virusi vya korona					
3	Nilijihisi ni kama nimepooza ama kuganda nilipo pata fikira ama kupata habari kuhusu virusi vya korona					
4	Nilipoteza hamu ya kula nilipowaza ama kupata habari kuhusiana na virusi vya korona					
5	Nilijihisi mwenye wasiwasi au kuwa na shida ya tumbo nilipopata fikira ama kupata habari kuhusiana na virusi vya korona					
	TOTAL		+	+	+	+

APPENDIX 4: ETHICAL APPROVAL

1) KENYATTA NATIONAL HOSPITAL/UNIVERSITY OF NAIROBI ETHICS AND RESEACH COMMITTEE (KNH/UON ERC)

REF: KNH-ERC/A/485

APPLICATION APPROVAL NUMBER: P725/09/2021

ISSUE DATE: 20/12/2021

2) NATIONAL COMMISSION FOR SCIENCE, TECHNOLOGY AND INNOVATION:

APPLICATION IDENTIFICATION NUMBER: 191784

LICENSE NUMBER: NACOSTI/P/22/15439

3) APPROVAL FROM RESEARCH COMMITTEE MATHARI NATIONAL TEACHING AND REFERRAL HOSPITAL TO CONDUCT STUDY AT CHILD PSYCHIATRY CLINIC