

AN ASSESSMENT OF BURDEN OF CARE FOR PARENTS OF AUTISTIC
CHILDREN AND THEIR COPING STRATEGIES: A CASE OF SELECTED GROUPS
IN NAIROBI COUNTY, KENYA

by

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A thesis presented to the School of Applied Human Sciences,

Of

Daystar University
Nairobi, Kenya

In partial fulfilment of the requirements for the degree of

MASTER OF ARTS
In Counselling Psychology

October 2023

APPROVAL

AN ASSESSMENT OF BURDEN OF CARE FOR PARENTS OF AUTISTIC CHILDREN AND THEIR COPING STRATEGIES: A CASE OF SELECTED GROUPS IN NAIROBI COUNTY, KENYA

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DECLARATION

AN ASSESSMENT OF BURDEN OF CARE FOR PARENTS OF AUTISTIC CHILDREN AND THEIR COPING STRATEGIES: CASE OF SELECTED GROUPS IN NAIROBI COUNTY, KENYA

I declare that this thesis is my original work and has not been submitted to any other college or university for academic credit.

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ACKNOWLEDGEMENTS

All glory to God almighty, by the grace provided through our Lord Jesus Christ. This far, I am encouraged that indeed apart from Him I can do nothing.

I wish to acknowledge my supervisors Dr. Jared Menecha and Dr. Elizabeth Wangari Gichumu for their never ending support, sacrifice and much needed advice through this journey.

Special mention to my dear classmates and friends who became family by the end of the journey. Many times we almost gave up, but by God's grace, we encouraged each other and made sure nobody stayed behind. I sincerely appreciate the support that we rendered to each other. May God bless you all.

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DEDICATION

All glory to God for the grace and strength to come this far. Only through Him can we be able to do anything. I dedicate this thesis proposal to my family, my dear father and mother for their support and encouragement.

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LIST OF ABBREVIATIONS AND ACRONYMS

ADHD	Attention Deficit/Hyperactive Disorder
ASD	Autism Spectrum Disorder
APA	American Psychiatry Association
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, fifth edition
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder Not Otherwise Specified
SD	Standard Deviation
SDQ	Social Demographic Questionnaire

ABSTRACT

Autism Spectrum Disorder (ASD) presents numerous challenges not only to the persons living with the disorder, but also to the people around them like the family and society. The purpose of this study was to investigate the burden of care experienced by parents of children who were members of select groups within Nairobi County Kenya; the Autism Society of Kenya (ASK) and Differently Talented Society of Kenya (DTSK), and their coping strategies. The study aimed at assessing the level of burden of care faced by these caregivers, the gender differences in the experience of the psychosocial challenges, to analyse the coping strategies the parents employed and to assess the factors that contributed to the burden of care among these parents. The study adopted the Kubler-Ross Model of stages of grief and the psychoanalytic coping theories. A sample of 60 parents of autistic children was recruited into the study. The study adopted a descriptive research study that employed a mixed method design. Data was gathered using a social demographic questionnaire, Caregiver Burden Inventory (CBI) and the Brief Cope Inventory. The Statistical Package for Social Sciences (SPSS version 21.0), descriptive and inferential statistics were used. Parents showed a significant time dependency, developmental and physical burdens, female caregivers were more burdened than male, there was a significant relationship between gender and avoidance and problem focus coping strategies. The study recommended emotional support, psycho-education and counselling programs for parents of ASD children. The study suggested further research on parents with grown up ASD children, and ASD children and their coping strategies.

CHAPTER ONE

INTRODUCTION AND BACKGROUND OF THE STUDY

Introduction

This chapter gives the introduction to the study and background to the study. It provides the statement of the problem and purpose of the study on the assessment of burden of care for parents of autistic children in Nairobi County highlighting the objectives, research questions, justification and significance of the study. This chapter highlights a set of assumptions the study takes, the scope of the study and the limitations and delimitations of the study.

299.00 (F84.0) ASD (Autism Spectrum Disorder) is a neurodevelopmental disorder marked by challenges with social interaction, social communication, and fewer repetitive behaviors or activities (American Psychiatric Association. , 2013). The term "spectrum" is used in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). Autism Spectrum Disorder (ASD), Asperger's Disorder, Childhood Disintegrative Disorder (CDD), and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), which are all discrete Pervasive Developmental Disorder (PDD) diagnoses in the DSM-IV, were combined to create the ASD diagnosis (Hodges et al., 2020).

Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5) provides a 5 A-E diagnostic criterion for ASD. Criterion A entails social interaction and communication deficiencies, which show up as deficits in socio-emotional reciprocity, nonverbal communication behaviours, and deficits in establishing, sustaining, and

comprehending relationships. Criterion B involves restricted patterns of behaviour, activities or interests manifested by at least two of: repetitive motor movements, insistence on sameness e.g. same shirt or trouser, highly fixated interests or focus or hypo/hyperactivity on sensory input. The symptoms must be present during the early stages of development, according to criteria C. The symptoms must significantly affect two or more settings, such as social, occupational, educational, or other crucial areas of functioning, in order to satisfy criterion D. Criterion E requires that the disturbances interpreted as ASD are not better explained by intellectual disability.

The diagnosis of ASD is ideally made prior to the age of 3 years as in the requirement of Criterion C (Guillermo Montes & Halterman, 2007), however if the diagnosis is made later in life, these symptoms must have been present in the early developmental years. This means the symptoms are observed from infancy.

“ASD can sometimes be detected at 18 months or younger. By age 2, a diagnosis by an experienced professional can be considered very reliable. However, many children do not receive a final diagnosis until much older. Some people are not diagnosed until they are adolescents or adults. This delay means that children with ASD might not get the early help they need.” (Centers For Disease Control and Prevention, 2022)

While there are no apparent known causes of ASD, there are risk factors said to be closely related to its development, these are: genetic component -as is seen in siblings (Chaste & Leboyer, 2012), Among others, traumatic delivery, autoimmune diseases where the body creates chemicals against its own tissues, lead poisoning, infections during and during pregnancy, and perinatal infections are all examples of toxic

substances (Ashmawi & Hammoda, 2022). Gertrude's Children Hospital (2018), which noted that there has been an ambiguous rise in the prevalence of ASD and labelled it as one of the modern medical difficulties, supports this.

Posar and Visconti (2019) observed that autism has no treatment to completely do away with it as also supported by the DSM-5. However, specialists at Gertrude's Children Hospital believe that even though Autism is a life-long disorder, many of the symptoms and quality of life can be improved through therapy. Many ASD patients, but not all, need ongoing support throughout their lives (Lord, Elsabbagh, Baird, & Veenstra-Vanderweele, 2018). They recommended that as part of this support, speech therapy and occupational therapy be provided, as these treatments work best when started as early in the child's life as feasible.

ASD characteristics should become apparent by the age of three and can last a lifetime, but symptoms may improve over time. Some children may have ASD symptoms as early as their first year of life. Other people might not get symptoms until they are 24 months or older, (Riccio, 2011). Some children with ASD reach developmental milestones and pick up new abilities up until the age of 18 to 24 months. After that, they either quit or lose the abilities they formerly had.

Teenagers and young adults with autism spectrum disorders (ASD) may find it challenging to keep friendships, communicate with peers and adults, or comprehend what actions are acceptable at work or in the classroom as they get older (van Heijst & Geurts, 2015). They may be seen by medical professionals due to co-occurring disorders such as anxiety, depression, or attention-deficit/hyperactivity disorder, which are more common in people with ASD than in people without ASD (Cage, Di Monaco, & Newell, 2018).

This indicates that people on the autistic spectrum frequently experience mental health issues.

The personal journey in the world of autism can be frustrating to any parent. From the beginning, a parent sees their child struggle immensely; a parent may notice the child to be very restless and always unsettled, lacking of recognition in his eye, difficulties eating and sleeping. As each day pass and the child continues to develop, they continue to recognize more 'red flag' characteristics of autism with repetitive behaviours and speech delays (Cohrs A. C., 2017). A parent whose two children were diagnosed with ASD stated "While typical children are scheduling play dates and extracurricular activities, our children's lives are about therapies, day after day, year after year, usually 7 days a week. People on the outside cannot grasp the necessary skills that our children require help with..." The struggles parents go through is immense, and thus requiring support.

Notable studies as cited have repeatedly shown that Autism Spectrum Disorders (ASD) can be detected as early as infancy. However, research indicates that Africans are less aware of ASD and its late detection (Bello-Mojeed, Bakare, & Munir, 2014). Mamah, Mutiso, Gitonga, Tele, and Ndeti, (2022) detected that some of these children in Sub-Saharan Africa are not given adequate care because of poverty, as a result the children suffer because of burden of care of parents. Smith-Young, Chafe, Audas, and Gustafson, (2022) noticed that not all parents and guardians are in a position to effectively advocate for a kid with ASD despite the fact that parents are thought of as natural advocates due to their alleged devotion to the well-being of their child.

Background of the study

Autism is one disorder among a spectrum of disorders known as Autism Spectrum Disorders (ASD). During the early stages of development, this spectrum is defined by a variety of symptoms and traits, such as constrained and repetitive patterns of behavior, interests, and activities. Others display anxiety, anger, and hyperactivity. Functionality of the person is compromised and requires early attention. ASD can appear in a variety of combinations, and those who have it can display any behaviors at any level of severity as per the DSM-5. (Irer et al., 2017).

Autism prevalence is the estimated number of autistic people in a particular area. It differs from the proportion of autistic people with a diagnosis. It is observed that many autistic people might not have been identified or even know yet themselves as observed by Chris Packham, a National Autistic Society (NAS) ambassador. This means that even, especially, in our African society we may be having so many parents who have autistic children, but because of lack of information and a formal diagnosis, interpret as having a difficult, cursed or a bad child (Darrat & Zeglam, 2008).

Autism affects all age groups, regardless of country or culture, and it is on the rise across all racial and socioeconomic categories. (Whelan, 2009). Whelan termed ASD as an “an equal opportunity disorder”, meaning it affects all. Just like any other mental disorder, ASD is a significant social issue that affects both the wealthy and the poor, as well as many different nations and ethnic groups.

Poslawsky et al., (2014) in a study in Netherlands to explore the subsequent reactions of 77 parents whose children had been given a diagnosis of ASD, observed a difference in their reactions in two categories; one category was classified as “resolved”

and the other as “unresolved”. More than half of parents were categorized as “resolved”. Conversely, the parents of children with more severe ASD symptoms were more likely to be classified as “unresolved”. This means that the severity of ASD as understood by parents, affects their reaction to the diagnosis. Subsequently the severity of the symptoms also affects the on-going mental health stability of the parents.

Based on predictions from the Centre for Disease Control (CDC, 2014), 1 in 59 US children are predicted to have an ASD diagnosis. In the Nairobi region alone, it is estimated that 25,000 children suffer from a disease on the autistic spectrum (Riccio, 2011). In 2014, Pooja Panesar of the Kaizora Institute conducted study on how Kenyans saw and understood different disabilities. She found a correlation between educational background and exposure level and how different disabilities were perceived. It was shown that people from rural regions with limited access to education had a higher perception of disability as the result of being cursed or subject to witchcraft. They looked for medical assistance from a variety of sources, including traditional healers and prayer. The concept of autism as an impairment, for which a doctor should be contacted before any actions, was more widely understood in urban areas. All of these are efforts to deal with the difficulties brought on by autism.

Autism is a phenomenon that has for the longest time been misunderstood in Africa alongside other mental disorders, especially for kids. In the African culture, it is observed that bizarre behaviour is attributed to witchcraft, bad parenting or other inaccurate explanations given to it (Masaba, Taiswa, & Mmusi-Phetoe, 2021). This has done much harm not only to the autistic individual but also to the relatives of the individual. There have been unreported cases where such individuals with mental

disorders have been locked up, mistreated as captured by different as reported by Masaba and company. Most of these individuals pay the price for superstitions. They are hunted down for organ trafficking and/or killed with the assumption of their sacrifice to witchcraft can lead to wealth gain same as with the case of Albinism (Daghar, 2022).

Deficiencies in social interaction and communication are hallmarks of autism spectrum disorder. Due to the wide range of symptoms that children with autism may experience, their peers frequently view them as socially uncomfortable.

The diagnosis of ASD has a significant effect on a family. Parents may experience a range of emotions after receiving a diagnosis of autism. Some people can suffer an initial wave of panic or distress, while others might feel relieved once they can identify the problems their child is having. While other parents of autistic children experience helplessness, feelings of inadequacy, rage, shock, and guilt, African parents of autistic children go through moments of incredulity, great sadness and melancholy, and self-blame and guilt (Ayinla, 2019).

Many parents experience feelings of grief and loss for the future that they had anticipated, which now may not eventuate. This becomes a stressful time for the parent. Some may feel a mixture of all these:

“An autism diagnosis can be perceived as a loss for the family. The grieving process associated with the birth of a child with disabilities is complicated by the parents’ grieving the death of the ‘expected’ baby while at the same time trying to accept the ‘imperfect’ baby. Even though they have the joy of being able to hold

and love their baby, their life is suddenly and drastically changed” (Hooyman & Kramer, 2006).

It is possible that the emotions that come to parents after their child has been diagnosed with autism are immense. The family might therefore have to adapt and develop an alternative lifestyle that suits their child in relation to variables like the severity of member condition, additional life stressors in the family like divorce or illness, financial resources, and family external support (Meleady, Nearchou, Bramham, & Carr, 2020). Families find themselves unable to do some of the things they used to be able to do due to increased daily routine complexity, difficult planning of family vacations, and other factors (Hartmann, 2012). In addition to parents having to deal with the new situation of ASD diagnosis, the siblings if any, are also impacted in similar fashion as their parents.

The autism diagnosis may not be understood by siblings, who may feel anxious, angry, or embarrassed (Watson, Hanna, & Jones, 2021). This is not to mention that much of their parents’ attention will be shifted to the child with ASD and as a result, they may start to deteriorates in areas like school performance. In terms of the parent-child connection, siblings of ASD children report increased levels of independence as a tactic to preserve the family's cohesiveness while pursuing their own goals in life, (Chan & Goh, 2014; Mokoena & Kern, 2022). These parents may therefore feel fatigued and overwhelmed caring for their family. Yaacob, Yaacob, Muhamad, & Zulkifli (2021) add that this comes with feelings of guilt as parents feel they have not been ‘parents’ to their other children.

Children are social beings, (Fattore & Mason, 2017), and from infancy they show curiosity by turning towards voices, grasping at fingers, smiling and gazing at people (American Psychiatric Association. , 2013). This is not usually the case as observed through the symptomology of ASD described in the DSM-5 (2013) where autistic children do not show special interest in faces and keeping up with what is considered normal day to day human interaction. Initiating and sustaining friendships often proves difficult. Parents' concerns about their child's development usual emerge during the first two years of life (Karst & Van Hecke, 2012). Children with autism may experience social alienation because of their social 'weirdness' (Richards, Mossey , & Robins , 2017). This can easily become a stressor to parents as it is not easy observing other children playing and enjoying life as 'normal' kids while theirs is struggling.

Riccio, (2011) observed that treatment solutions for children and adults with any form of handicap were still being researched and investigated in undeveloped countries. There has been some ignorance in what is understood as autism and a huge gap exists among the public. Due to this gap, diagnostic and treatment services for autistic children are not readily available, and there is a lack of effective government policy to support these people and the people who care for them (Maulik & Darmstadt, 2007).

Africa is a continent with many countries and communities within it with vast cultural diversities (Van Pinxteren, 2019). Kenya, a country within this continent, is made up of diverse ethnic community, races, culture and nationalities. Its multi-ethnic nature is constituted by more than 40 ethnic communities, some being large and others small. Nairobi being the capital city of the nation and a metropolitan area, it has a mixture of different communities and cultures. All these are relevant because cultural background is

an influence on the impact of Autism on parents (Ilias, Cornish, Kummar, & Park., 2018). Parents' responses, coping mechanisms, and decision-making may be influenced by their knowledge of and views on the genesis and prognosis of ASD (Hebert & Koulouglioti, 2010).

African cultural understanding on mental disorders has for the longest time been attributed to 'bad spirits' of witchcraft. Because of taboo, stigma, and conjecture, ignorance about autism has been left unaddressed (Ayinla, 2019). A society's view of mental illnesses is influenced by a variety of elements, including the historical context, societal influences, our level of scientific knowledge and our capacity for doing scientific study (Njenga, 2007). The impact of any mental disorder diagnosis is directly proportionate to what the setting of that individual interprets the disorder.

Although there have been different studies that capture the aspects of burden of care among caregivers of children with autism in Kenya, these studies, however, don't exclusively and inclusively capture the burden of care among the caregivers in urban settings. The documented studies have added variables to them that compromise the object of the study, which is the burden of care among caregivers. Masaba, Taiswa, and Mmusi-Phetoe, (2021) did a systematic review study on the challenges of caregivers having children with autism in Kenya. The goal of this study was to examine the difficulties faced by carers of autistic children. The findings and of this study, similar to different other studies like Gona, et al., (2016) did on the Challenges and coping strategies of parents of children with autism on Kenyan coast came down to stigma, financial burden and caregiving burden.

These studies do not conclusively identify and analyse the burden of care but instead are preoccupied to touch and do justice on the other challenges identified. Additionally, most of the documented studies done are in the rural settings. This study however addressed the burden of care of parents of children with autism in Nairobi County, Kenya.

Statement of the problem

The better we comprehend ASD and how it affects parents and their families, the simpler it will be to identify the help and resources that may be needed in each unique case. Research, studies and reports done in Europe, North America, Australia and the Middle East around the theme of ASD and parenting show that parents face caring burdens, poor prognosis and negative public attitude (Alkhateeb, Hadidi, & Mounzer, 2022; Chou, Jiann-Chyun, & Chu, 2002; Hebert & Koulouglioti, 2010; Yaacob, Yaacob, Muhamad, & Zulkifli, 2021). Same conclusions can possibly be inferred to African experience of parents to autistic children.

A study done in Coastal Kenya on “The Challenges and coping strategies of parents of children with autism” found that, regardless of their religion or cultural background, parents of children with autism face the same difficulties with stigma, a lack of adequate treatment, and financial and caring pressures (Gona, et al., 2016). The study found that there was a dearth of knowledge about autism, which prevented some children from receiving the right services that would enhance their quality of life and prognosis. Instead, it has been noted that parents in many areas of Kenya have resorted to locking the child inside the house or hiding them in a rear room (Riccio, 2011). These reports show that supernatural and biological elements were both considered to be the causes of

autism. These opinions have an impact on the difficulties and coping mechanisms faced by parents in this area who have autistic children.

Autism in a child has a ripple effect to the parents. “Stress proliferation” is a term that can better explain the burden of care and the psychological impact autism has on caregivers. Stress proliferation happens when an original stressor in one area of life stimulates added stressors in other life areas (Benson, 2006). He points out that the management of the initial stressor adversely distresses the activities, roles and relationships in other different domains- creating new sources of stress (p. 686). All of a sudden, the family has to adjust and include the expense for doctor’s visit, diet or medication into their monthly/weekly bills. This can present strain in other areas that need financial attention.

The levels of impact of the child’s ASD condition on parents can also be determined by the severity of the emotional and behavioural problems exhibited by the child. This is exacerbated worse by the overwhelming caregiving duties, financial strain, inadequate parenting coping mechanisms, lack of support, and parental view and comprehension of ASD (Leyfer, et al., 2006; Karst & Van Hecke, 2012; Baker, Seltzer, & Greenberg, 2012; Weiss, Wingsiong, & Lunsky, 2014) (Ou, et al., 2015; Ilias, Cornish, Kummar, & Park, 2018)

In addition to melancholy, anxiety, obsession-compulsion, interpersonal sensitivity, wrath, schizoid features, paranoia, and schizophrenia, parents of autistic children frequently face other psychological distresses (Karst & Van Hecke, 2012). Even just having a child with a disability can be stressful. Understanding the child’s

requirements, many areas of primary care, access to medical and educational assistance, and financial difficulties are all challenges.

At the time of diagnosis and during the entire process of providing for their children's needs, parents need to be taken care of and empathized with. It is more challenging for each individual parent to take care of their ASD child and still be effective in all their other duties. The effects may start showing in their family lives (P & M Kalimo, 2018).

In a study done on the impact of ASD on parents in Arab cultures by Alkhateeb, Hadidi, and Mounzer (2022), also noted that, according to substantial research, parents of children with ASD frequently report high parenting stress levels, increased mental health issues, and poor physical health. They noted that not only does ASD tremendously impact family life but it also affects the marriage life.

Apart from the psychological challenges the parents experience, the parents of autistic children also incur social and financial burdens. P & M Kalimo (2018) came to the conclusion that, compared to parents of typically developing children, parents of 50 ASD children had more parenting stress. These parents had also been found to report poorer health and more illness than parents of normal children. According to a study by the National Survey of Children's Health (2003), which included mothers of 61,772 kids between the ages of 4 and 17, 364 of whom had been diagnosed with autism, the mothers of these kids were more stressed out and more likely to report having poor mental health than mothers in the general population.

Often times in the African societies any type of illness is blamed on the mother of the child (Riccio, 2011). Because of fear of having another autistic child it is not unheard-of a father abandoning his wife and mother to his autistic child. He may proceed to get another wife or fleeing and abandoning their parental duties. Due to ingrained family beliefs in witchcraft or sorcery, they are frequently left to care for their crippled kid alone without the child's father's assistance (Moriyama, 1974). This puts financial strain to the remaining parent and impairs any effort in seeking interventions for the child with autism. The marriage may in turn crumble

Autism Spectrum Disorder can occur with comorbidities. Almost half of children with ASD have been found to be having comorbid to Attention Deficit/Hyperactive Disorder, Intellectual Disorder or epilepsy (Kałużna-Czaplińska et al., 2018). Up to 85% of kids with autism also have a comorbid mental health diagnosis of some kind (Children's Hospital of Philadelphia, 2017). The three most frequently identified co-occurring disorders are ADHD, anxiety, and depression, with anxiety and depression being especially crucial to check for in older children as they grow more self-aware (Al-Beltagi, 2021). Since the primary symptoms of ASD, such as lack of eye contact and repetitive behaviors, can resemble attention deficit disorder or hyperactivity, it can be difficult to distinguish between ADHD and ASD.

The average expenditures of parents with children with comorbidities are twice as high as those with ASD without co-occurring conditions. An inference can be made from this about the intense burden of care and psychological impact such parents experience.

Caregiving for disadvantaged children becomes a hardship that families are unable to bear as the moral and financial load on caretakers grows (Tursuslu,, Merve, & Demet,

2015). ASD is a lifelong condition, meaning the parents incurs a never ending and lifelong financial and emotional expense of caring for the individual.

Parents of children with ASD go through so much socially and psychologically. The adjustment strategies some parents employ are very ineffective and only end up hurting them and destroying their families while affecting the child with ASD. This study sought to find out the psychosocial impact of autism to the parents and how the parents adjust to these challenges and offer recommendations on better coping strategies.

The purpose of the study

The main purpose of the study was to assess the burden of care for parents of autistic children in Nairobi County and analyse the coping strategies they employ. This was to come up with knowledge that would be helpful in developing interventions in offering psychosocial support to the parents. This study held the premise that if the parents are well understood and cared for, they will be better equipped to care for their child with autism.

Objectives of the study

- i. To assess the burden of care among parents with autistic children in selected groups, Nairobi County, Kenya.
- ii. To investigate the gender differences in the experience of psychosocial challenges among parents of autistic children in selected groups, Nairobi County, Kenya.
- iii. To analyse the coping strategies employed by the parents of autistic children in relation to their demographics in selected groups, Nairobi County, Kenya.

- iv. To determine the factors that contribute to the burden of care among parents with autistic children in selected groups, Nairobi County, Kenya.

Research Questions

The study answered the following research questions:

- i. What are the levels in burden of care among parents with autistic children in selected groups, Nairobi County, Kenya?
- ii. What are the gender differences in the experience of psychosocial challenges among parents of autistic children in selected groups, Nairobi County, Kenya?
- iii. What are the coping strategies employed by the parents of autistic children in relation to their demographics in selected groups, Nairobi County, Kenya?
- iv. What are the factors that contribute to the burden of care among parents with autistic children in selected groups, Nairobi County, Kenya?

Rationale of the Study

Parents should be well cared for because if their mental health were to deteriorate, their social participation will be non-existent. Additionally, they would not be able to participate in economic, social activities or get involved in their family duties. This would result to the children in these families being neglected.

Therefore, the goal of this study was to evaluate the caregiving responsibilities and coping mechanisms of parents of autistic children in Nairobi County. The knowledge from this research will help different children's Hospitals' management know how to best provide care for the child by considering the challenges the parents face. The study provides knowledge to other stake holders in special needs institutions on how best to

care for children with ASD and their parents. This study's findings and recommendations will serve as the foundation for suggestions to the Kenyan government, non-governmental organizations (NGOs), the general public, schools, counselors, and both public and private hospitals for how to best support parents of children with ASD.

Significance of the Study

The result of this study have a potential contribution; first to inform different children's hospitals that not only deal with children diagnosed with ASD only but also other developmental disorders on the challenges the parents go through. Secondly, the study will educate the public, including potential parents and relatives on the psychosocial challenges faced by parents whose children have been diagnosed with ASD. Thirdly, the results of the research will form a basis of recommendations to the policy makers in the government and NGOs in relation to the struggles these parents go through. Since effective treatment for ASD depends on early diagnosis, public opinion and governmental policy should be informed and changed to better serve these people and provide better diagnostic and therapeutic services, (Daley, 2002).

The study aimed at coming up with recommendations of providing psychosocial support to parents with autistic children. Finally, the study may aid current scholars, medical professionals, and clinical psychologists in determining the most important areas for further investigation. The study's deficiencies can serve as the basis for more research.

Assumptions of the Study

The study made assumptions that most of the parents who are members of the Autism Society of Kenya living within Nairobi County would participate in the study.

The study assumed that the respondents would understand the instruments used in the study and answer honestly.

The study further made an assumption that the results gotten from the research were to be useful for generating knowledge and informing policy makers in the hospitals and the government on what needs to be done in supporting the parents of children diagnosed with ASD.

The study made another assumption that from the knowledge generated from the study the public will be more understanding and empathetic on the struggles these parents go through as they care for their children.

The study assumed that it would get sufficient and significant male and female respondents to give a clear representation of the variables measured.

Finally, from the gaps identified, future research topics can be sparked that will lead to more knowledge being generated.

Scope of the Study

The study was limited to only parents who are members of the Autism Society of Kenya and residents of Nairobi County. These are the respondents the study focused on to give reliable data.

This study was done in a period of 3 months. It was restricted to the assessment of burden of care for parents of autistic children and their coping strategies among members of select groups, Nairobi County Kenya.

Limitations and Delimitations of the Study

The study covered the burden of care and the coping strategies employed by the parents of autistic children who exclusively resided in Nairobi County and were members of the Autism Society of Kenya. The literature review done in coming up with knowledge in relation to the challenges the parents experience was to be inferred to parents who do not necessarily come from this locality of study.

Due to the parents' tight schedule balancing between their other life responsibilities and being there for their children's caring. They had limited time to participate in the study and this may have impaired the data collection and interview sessions. The study adopted the use of self-administered questionnaires for the parents to fill at their own time and hand in after a set time.

Definitions of Significant Terms

This section stated what the significant terms used mean as in the context of the study. The definitions are as found in dictionary.com. The study uses these definitions as such.

Gender: The condition of being male, female or neutral. It encompasses the psychological, behavioural, social, and cultural aspects of being male or female.

Demographics - the statistical data of a population, especially those showing average age, income, education etc.

Psychosocial: of or relating to the interaction between social and psychological factors.

Neurodevelopmental disorders - Brain disorders that impair a child's behavior, memory, or capacity to learn, such as autism, dyslexia, mental retardation, and

attention deficit hyperactivity disorder (ADHD), as well as learning difficulties (American Psychiatric Association. , 2013).

Parents: These are biological mother and father or primary caregivers of a child who are primarily responsible for providing the child's both physical and emotional needs.

Stress proliferation: A technique whereby when someone is affected by an outside force, it increases their stress levels, which could be caused by an imaginative force or a collection of stressors. (Benson, 2006).

Summary

The introduction and background of the study have been presented in this chapter, which also highlighted the psychosocial struggles parents of children with an ASD diagnosis face. The problem statement, objectives of the study, research questions, justification, significant assumption, scope, limitation, delimitation, and description of words used throughout the study were among the highlights provided.

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CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter focused on theoretical framework of the study and gives an integrative review of the relevant literature seeking to understand the burden of care experienced by parents with autistic children and their coping strategies. This chapter also provides a conceptual framework indicating the relationship of the variables in the study.

Theoretical framework

Children with autism display difficulties in social relationships, communication, activities, and interests, (American Psychiatric Association. , 2013). Autism impacts a child's ability to communicate, engage with others, think critically, and develop their motor skills. Although the precise cause of ASD is still unknown, it is currently believed to be a syndrome with several causes that incorporates children's genetic, neurological, and social components. According to statistics, there are around 70 occurrences of ASD per 10,000 people worldwide, and boys are four times more likely than girls to have this condition, (Pinto, et al. 2016).

From infancy, which is mostly characterised by reciprocate interactions, the toddler may not make eye contact despite the mother's efforts, smile or respond to their caregivers or play with them (Nolen-Hoeksema, 2014, p. 291). As the child grows older in its early childhood years, it may have a delayed speech and be engrossed in routines

whereby if broken, can be a source of major tantrums. This can easily be a major stressor to a parent and a major source of adjustment to the family.

This study used Kubler-Ross Model of stages of grief to explain the burden of care and psychological journey as the parents walk with their autistic children and the psychoanalytic coping theory further developed by Richard Lazarus, PhD. (1984) assessing the coping strategies employed by these parents.

Hartmann (2012) observed that all of a sudden, a family is forced to transform and adapt to a new lifestyle to accommodate their developing autistic child. The family is forced to deviate from the normal life as it is used to, all to cater for their special needs' child-who needs extra attention. This presents numerous challenges to the parents and the family. Parents are often gripped with feelings of grief, stress and confusion after learning that their child is autistic.

The grieving process associated with the birth of a child with disabilities is complicated by the parents' grieving the death of the "expected" baby while at the same time trying to accept the "imperfect" baby. Even though they have the joy of being able to hold and love their baby, their life is suddenly and drastically changed (Hooyman & Kramer, 2006, p. 200).

In the Kubler Ross' Model of Stages of grief, according to her, grief progresses through a succession of recognizable stages of denial, anger, resentment and guilt, depression and finally acceptance (Hamilton, 2016). These parents go through these stages and experience the same emotions after their child has been diagnosed with autism.

Hooyman & Kramer, (2006) found that when people experience something they believe to be negative, they experience a sense of loss that causes long-term alterations to their social settings, relationships, and mental and emotional patterns. When the parents get an official diagnosis for their child of autism, they go through these stages of grief of denial, anger, resentment and guilt, depression and acceptance during the course of the child's life. These stages are not sequential, thus some people may only go through two of the five, one, or three stages (Gregory, n.d.).

There is also a difference on how both men and women grieve, as influenced by our cultures (Konigsberg, 2011). Inferences can be made from Konigsberg (2011); suggesting that the mother and father of the child who has been diagnosed with autism grieve differently and how they progress through the stages of grief is not similar, but gender influenced. This difference points to a likelihood of a variance in the grieving and coping mechanisms employed by the mother and father of the autistic child. In an exploratory study on the gender differences in bereavement among couples after Loss of a child, Welte, (2013, p. 27) observed that "All of the participants identified that males and females exhibited several differences during the bereavement process...the participants found the biggest bereavement differences in couples to be that females generally grieve more externally and openly, whereas, males tend to grieve more internally." Just like grieving to a loss, the ultimate stage is coming at peace with the loss- that the child whom they have has a 'mind defect' - autism diagnosis.

Lazarus, (1993) introduces 2 approaches to coping emphasizing on the style of coping and the process of coping. The coping theory credits its existence from the work of Sigmund Freud (1894, 1896) of psychoanalytic ego defences. Lazarus credits ego

defence mechanisms as one of the intrinsic coping mechanisms humans have to their psychological integrity. Defense mechanisms are psychological strategies that people reflexively use to protect themselves against discomfort caused by unfavourable thoughts or experiences (Paulhus et al., 1997). Defense mechanisms are reflexes that are common and natural. They work subconsciously to ward off unpleasant emotions like anxiety or enhance positive experiences for the person, (McLeod, 2019). McLeod noted that neuroses like anxiety states, phobias, obsessions, or hysteria may emerge when they are exaggerated and utilized frequently.

Stages of grief after the autism diagnosis

After the parents get to learn that their child has been diagnosed with autism, a range of emotions may run through them. The parents may take the news and go try to find a second and third diagnosis. This is a classic case of denial where they try to get a second diagnosis in hopes of a different explanation to their child's behaviour. The parent may be in a state of shock and denial at this stage (Kubler-Ross & Kessler, 2014). The parent may be frustrated because of the diagnosis.

After confirming the diagnosis, the parents may get to the anger phase. Kubler-Ross and Kessler report this stage as to being important for healing- coming to terms with their child's diagnosis. They report that this anger has no limit; it may extend to friends, the doctors, towards other family members or towards God. Underneath the anger, there is pain. This anger may be magnified if the parents observe other "normal" kids playing outside and getting easy with the things their child has deficits on.

Bargaining stage can be referenced to the life after the diagnosis where the parents try to get necessary help so that the child can live a normal life. This may be by going for prayers and religious consultations for the disorder to go away.

Depression kicks in when the parents are faced with the reality. This comes when after different second opinions and doctors' visit, they realize the child cannot be made better. A parent may be gripped with a general feeling of sadness when he/she sees how different their child is from other children. This may be magnified when he/she observes the social challenges the child may have in forming friendships. Children with autism have a desire to make friends and participate in plays with their peers but have an inability to do this because their social interaction is impaired as described in the DSM-5. This can be a major stressor to the parent because he/she is unable to help the child. In a study about *Problem Solving Skills Training for Parents of Children with Chronic Pain*, it was noted that parents were psychologically affected while caring for their children with chronic pain which led to changes in their own psychological and behavioural functioning (Palermo et al., 2016). Many parents reported clinically significant role stress, anxiety, and depressive symptoms.

An emotional unblocking needs to be acknowledged in order to take place after a loss. When this is done, new skills can be developed, used, and fine-tuned before being reintroduced to life with fresh vigour (Leick & Davidsen-Nielsen, 1990). Acceptance comes after all the efforts to work around the child's autism are futile and the family has adjusted accommodate their autistic child into the family system. The majority of people never truly recover from the loss of a loved one. At this stage, you must embrace the fact that "our loved one is physically gone" and realize that autism is the new, ongoing reality

(Kubler-Ross & Kessler, 2014). The parents don't like the reality or make it okay but eventually accept it.

In a study focused on male grieving, it was noted that men experienced a wide range of reactions in relation to their experience of loss (Spaten, Byrjalsen, & Langdridge, 2011). Because of the effects of losing a loved one, they were less motivated and active in daily life. Some experienced reactions and feelings of anger, sorrow, emptiness, fatigue, guilt, apathy and self-destructive behaviours. All these experiences relate to feelings of meaninglessness following the loss- the perceived loss of the desired child.

How a parent comes to the point of accepting the child's diagnosis depends on their coping mechanism. There are factors that can either delay or accelerate the grieving process. How parents grieve in this process is also influenced by aspects of religion (Flatt, 1987). In a passionate attempt to emphasize the nature of coping strategies and to refute the casting stone nature of some scholars' critique on some ego defense mechanisms, Lazarus, (1993, p. 235) postulated that a coping strategy's effectiveness depended on the individual, the particular encounter, the result modality being researched, the morale, social functioning, or bodily health. According to him, there are neither generally excellent nor harmful coping mechanisms.

As presented by (Ayinla, 2019), parents are the main caregivers of their children. "Parents and caregivers make sure children are healthy and safe, equip them with the skills and resources to succeed as adults, and transmit basic cultural values to them" (American Psychological Association, 2009). While caring for their children, parents of children with ASD face social and psychological difficulties. In a study on the

psychosocial burden experienced by parents of children with autism spectrum condition that was conducted in India's Najaf Province (Al-Dujaili, 2017), more negative effects and poor psychological wellness were reported by carers. Their likelihood of developing depression, stress, anxiety, and discomfort seemed to be very high. Parenting "normal" children without ASD is different from parenting an ASD child. This is due to the fact that they frequently need more specialist and long-term medical care in addition to more general care. Functional restrictions may need structural or technological changes to the actual home environment, (Al-Dujaili, 2017). This not only presents the parents with financial burdens but also psychological burdens.

Parkes, (1972) provided a strong evidence in his book 'Bereavement studies on grief in adult life' of a link between grief and physical and mental health. Based on his findings, he came to the conclusion that it was important for researchers to work toward a better comprehension of bereavement, health, and life's purpose in order to develop effective interventions for those providing assistance, such as therapists and clinicians.

Burden of Care

Many parents of severely disabled children appear to be split between wanting to be with their child and wanting to escape the continual suffering that their child experiences, (Bullock , 1981). Depending on the severity of the burden of care and problematic behaviour of autism manifested in the child, it is not unheard-of parents consciously or subconsciously hating their autistic child. Some may subconsciously wish death on their kids just to stop the emotional torture they experience seeing them struggle and not having any ability to help them. Bullock terms this a "Grief-relief process" that is life long, manageable but cannot be resolved until the death of the child.

The burden of care refers to how much taking care of a loved one affects a caregiver's emotional, physical, social, and economic well-being, (Zarit, Reever, & Bach-Peterson, 1980; Pearlin & Skaff, 1995; Ogunmodede , Abiodun , Makanjuola , & Olarinoye, 2019). The burden of caring for a family member who is chronically ill, disabled, or old is known as the caregiver burden, (Liu, Heffernan, & Tana, 2020). Pearlin and Skaff believed that burden of care is similar to an extreme chronic long-term stressor, in this case, the challenges of having an autistic child.

Liu and company analysed caregiver burden as being influenced by how caregivers reflected on their experience during the caregiving process (self -perception), multifaceted strain (loss of weight, sleep disturbances, emotional distress or deterioration of family and social relationships and the enduring nature of the care (duration of care over a long time). Major contributing factors to the strain of providing care include a lack of social activities, conflict between many tasks, and insufficient financial resources, (Liu, Heffernan, & Tana, 2020) . Their data analysis revealed that the negative effects of caregiver burden included reduced care provision, a decline in quality of life, and a decline in physical and mental health. Hoenig & Hamilton, (1966) came up with the concept of caregiving burden and divided it into Subjective burdens and Objective burdens. In contrast to objective burdens, which are events or actions connected to bad experiences, such as the child throwing a tantrum in front of the caregiver, subjective burdens involve the personal feelings of care created when doing care obligations.

Parents and caregivers are impacted differently socially by their children's diagnosis of autism. The child's deficiencies and the degree of their autism diagnosis may require changes to the school curriculum and special education programs. The parent is

met with the need to seek educational and recreational accommodations so that their child is not left behind.

People with ASD frequently repeat behaviors or have constrained, specific interests. This may influence one's eating patterns and food preferences. Some children may be sensitive to the taste, smell, colour and texture of foods according to the American Psychiatric Association, (2013). This limits or rules out some food options a parent may have for the child like flavoured foods, fruits and vegetables or certain textures such as slippery or soft foods (*Autism Spectrum Disorders and Diet*, n.d.). Due to their potential trouble focusing on one job for an extended amount of time, children with autism may find it challenging to sit down and consume a meal from beginning to end. The child might also struggle with constipation caused by his or her limited food choices, low physical activity levels or medications. Certain stimulant drugs used to treat autism can reduce appetite. This may cause a youngster to consume less food, which could have an impact on growth. Eventually, parents of children living with autism experience a hard time potty training their children. The child may have challenges expressing his or her needs which leads to tantrums and frustrations to both the child and the parents.

Another struggle parents may have is interacting in the society with their autistic child. Hartmann, (2012) observed that this was a big problem because the society might not understand the condition of the child and think the parents just being bad parents. These parents face a lot of stigmas. People experience stigma when they feel humiliated, inferior, and alone because they are different from others, (Fischbach, 2015). The parent's social lives are more difficult because of the child's autistic behaviors, which are

exacerbated by social stigma and isolation, (Gray, 1993; Kinnear et al., 2016; Link & Phelan, 2001).

University of Missouri-Columbia, (2008) highlighted the financial implications the autism diagnosis has to parents. Deanna Sharpe, an associate professor at the university and a mother to an autistic child observed that there is a strong pressure for a parent to do everything they can for the child. She pointed out that there is a risk that families spend a lot of money on treatment or novel approaches that may not work. According to the study, some expenses associated with raising an autistic kid include specialized child care, speech and language therapy, different forms of one-on-one therapy, specific interventions, and pricey food or medication supplements. The likelihood of financial problems can also be positively associated with having relatively lower income (Sharpe & Baker, 2007).

Families experience these struggles differently. The dynamics of the family may also influence how the diagnosis is received: Single-parent households are more likely to experience financial difficulties, which could have an adverse effect on mental health, (Stack & Meredith, 2018).

Gona et al. (2016) noted that the strain of having an autistic child can impact parents' psychological and emotional well-being and cause them to argue. Parental conflicts are bound to come up as the parents display their frustrations on their social, psychological and financial struggles. Because the parents cannot direct their frustration to the child, they may direct their frustrations towards each other by quarrelling or even blaming each other (Hartmann, 2012). This is a form of ego defence mechanism towards the stress they encounter.

The coping strategies and Ego defences

Defense mechanisms can help people cope with stress, but they can also be counterproductive when used to avoid painful feelings or rationalize unhealthy or antisocial behavior (Sissons , 2020). Defense mechanisms originate from the works of Sigmund Freud in the structural theory of the mind, which he posits the human mind as divided into a triad entity: internal drive (Id), Ego, and Superego (Freud, 1967). The Id, which is the part of the psyche that calls for immediate gratification of pleasures, consists of a person's unconscious instincts. The ego restrains these subconsciously held fundamental desires, which Freud termed as the executive organ of the psyche. By using defense mechanisms, the Ego, which is the reality entity, controls the id's desires. The superego, which supersedes ego, is what drives ego's quest for perfection, ideals, and spiritual objectives. Morality, guilt, and conscience are the results of this ego-superego relationship. The ego employs a variety of defense mechanisms to preserve mental homeostasis and shield the conscious mind from the impacts of such conflicts. These mechanisms are of paramount importance in maintaining mental stability in people in face of crises.

Coping is the process of repeatedly altering one's cognitive and behavioral attempts to manage a particular set of external or internal demands that have been determined to be more demanding than one's available resources, (Folkman & Lazarus, 1985). Parents to a special needs' child are presented with various challenges. The process of locating and paying for appropriate services as well as attending several appointments can quickly overwhelm families. Some families could feel lost, alone, and bewildered (Chukwu et al., 2019). Hooyman & Kramer (2006) observed that parents go

through the same emotions as though they lost a child when their child is born with disabilities. Coping is important in the grieving process when presented with an autism diagnosis, (Hartmann, 2012, p. 16). Having a kid with a disability can have a variety of effects on parents, depending on how they handle and view the situation.

In a study to examine the impact of parents' coping methods on their mental health when raising a kid with a handicap, Cauda-Laufer (2017) identified 9 coping techniques that parents frequently use. She described them as confrontive coping, positive reappraisal distancing, accepting responsibility, self-controlling, escape-avoidance, planful problem solving, and seeking social support. She published the findings, which showed that positive adaptive coping did not lead to better mental health outcomes and that parents' coping strategies did not significantly relate to their suffering. However, research as cited by Cauda-Laufer (2017, p. 10), has shown that parents of disabled children face higher levels of stress and are more likely to suffer from mental health problems. "All parenting is challenging, but being the parent of a child with special needs, whether mental, physical, or medical, comes with its own unique set of challenges."(8 *Coping Strategies for (Special Needs) Moms*, 2017).

Parents also employ coping like denial/passive coping, empowerment coping, social withdrawal, and acceptance coping (Chukwu et al., 2019). These contribute to most of the maladaptive coping by parents. Maladaptive coping may include one of the parents, mostly the father neglecting not necessarily financial provision but emotional care of the special needs child to the mother and focusing on his other children, some parents have been reported to have remarried and let the child under the care of the other spouse who they claim is to blame for the child's disability.

There exists a network of parents with special needs kids who offer support to each other. From an interview with a Kenyan mother whose son was newly diagnosed with autism during the Pre-Testing, she described how these groups have been of great help to her. Most parents with special needs children draw their support from close family members and social service workers, occupational therapists and other mental health professionals (Cauda-Laufer, 2017).

Two organizations; the Autism Society of Kenya and Autism Awareness Kenya, were founded in an effort to close the information and support gaps in the public for children and families suffering with ASD. Both initiatives were launched by parents and educators to encourage one another and provide opportunities for kids with ASD, (Riccio, 2011).

In a research examining the difficulties and coping mechanisms faced by parents of autistic children on the coast of Kenya, Gona et al. (2016) revealed two primary coping mechanisms that the parents used to care for their autistic child on a daily basis. The first strategy was problem-focused and the second was emotion-focused. The problem-focused strategies were those directed at managing or altering the problem that brought the distress whereas the emotion-focused strategies are directed at regulating the emotional response of the problem. They noted spiritual coping as an important coping strategy mentioned by the participants. Faith is important in support of the family emotional unity when served with proper information about the disability even as they proceed with the difficult part of treatment intervention (Riccio, 2011).

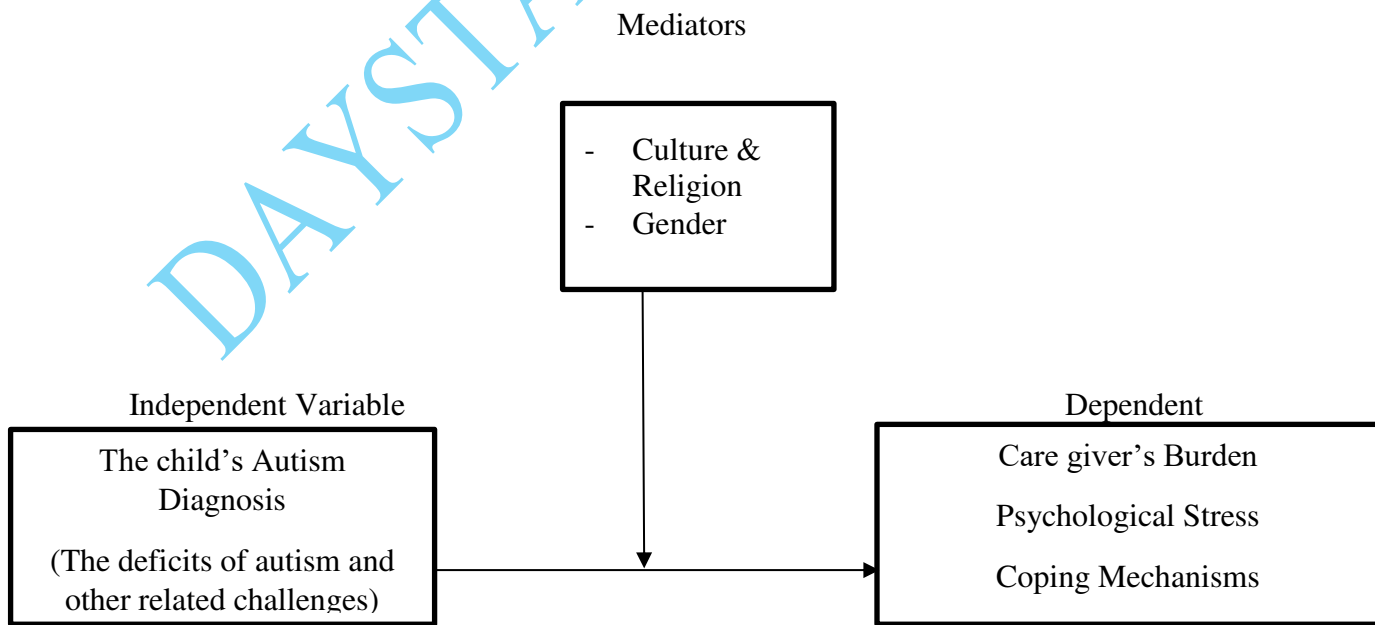
Financial ability is also a major factor in coping with the diagnosis as the parents can take advantage of available resources so that their child can improve on his/her deficits.

Most parents never have a comprehension of what autism is. From the moment they get to learn that their child has a mental illness, some may adopt a problem focused coping strategy where they seek information in order to understand what their child has been diagnosed with (Chukwu et al., 2019). They try get information from professionals and media programmes that help them gain knowledge on the different aspects of autism.

This study blends and assumes the understanding from Cauda-Laufer, Chukwu and company and Gona and friends of the coping strategies from their researches and relates to how both mother and father separately cope with the burden of care that comes with having an autistic child.

Conceptual Framework

Figure 2.1 illustrates the relationship between the variables in the study. The reviewed literature highlights the grief process as related to the autism diagnosis of a child to the parents which brings out the caregiver's burden and psychological challenges the parents go through.



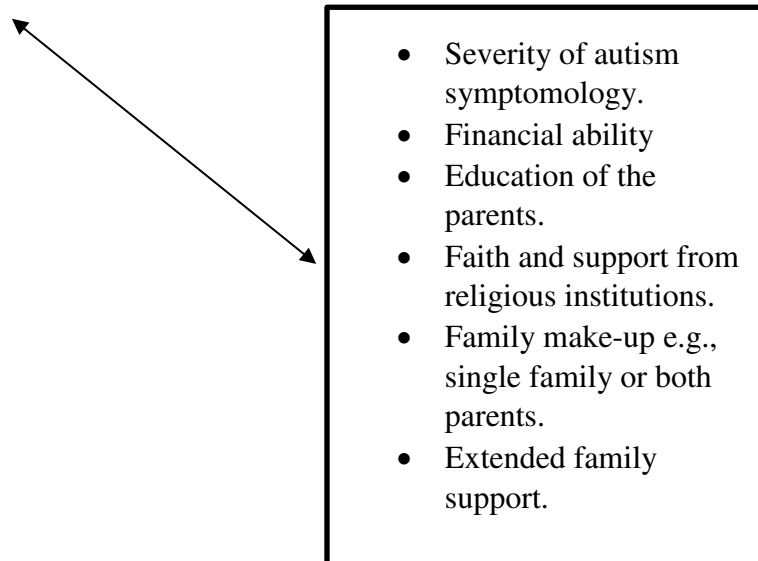


Figure 2.1: Conceptual Framework
Source: Author 2023

For example, because of the deficits and challenges that come with the autism diagnosis, parents are psychologically and socially affected. The degree to which they experience the challenges and the coping strategies they employ is determined by confounders like the severity of autism symptomology manifested in the child, their financial ability, their education & how well they understand what autism is, their faith and the support they get from their religious institution, extended family and the family make-up (single family or both parents). However, this study focuses on a complete family setup - both parents' families. Culture, religion and gender are mediating factors that influence how parents cope with these challenges.

Summary

This chapter deals with the theoretical framework of the study giving a literature review on the psychological and socio-economic challenges parents face in dealing with their children's diagnosis and deficits of autism. It proposes the theories of Grief by Kubler Ross and Psychoanalytic coping theory. The study uses Kubler Ross' theory of

grief to give a similarity of the stages of grief when having a child diagnosed with autism as to that of losing a child. These stages of grief of denial, anger, blaming, depression and acceptance aim at highlighting the psychological and social challenges these parents go through. The Psychoanalytic coping theory highlights the coping strategies employed by these parents in dealing with these challenges. The study gives a conceptual framework highlighting the relationship of the variables in the study.

CHAPTER THREE

RESEARCH METHODOLOGY

Introduction

The study's research technique was covered in this chapter. It concentrated on the research design, the target population, the sample size and sampling techniques that was employed, the data collection tools that were be taken into account, the data collection methods/procedures, the data analysis, and the ethical considerations the study took.

Research Design

A research design outlines the path a study took from the research questions to the conclusions, (Abutabenjeh & Jaradat, 2018). It is a thorough planning procedure used to gather and analyze data in order to better understand the subject being studied.

This is descriptive research study that employs a mixed method research design in the assessment of burden of care for parents of autistic children in Nairobi County, Kenya.

The study is descriptive as defined by McCombes(2019) who defines a descriptive research as that which accurately and systematically describes a population, situation or phenomenon. He argues descriptive research answers the what, where, when and how questions, but not the why questions. In this study, it answers what burden of care of parents with autistic children while paying attention to the psychosocial challenges they experience. The study also sought to find out the where, when and how these challenges are impactful on the parents of children diagnosed with autism.

The research employed a mixed method design: a combination of surveying and meta-analysis. The study employ survey as a design because of expected ease of participation by respondents partly contributed by the physical restrictions brought about by the COVID-19 pandemic where physical interactions between people had been advised to be reduced. Additionally, the study assumed the caregivers of parents with autistic children juggle through a lot as they try to make ends meet. Respondents were sent questionnaires via mail or through electronic medium they are comfortable with, example via email or WhatsApp. The questionnaires used in the study survey were used in assessing the burden of a care and psychological challenges the parents of children living with autism experience in relation to the literature reviewed.

The study also employed a meta-analysis research design to assess and critique previous research and studies done on the burden of care and psychosocial challenges parents of children living with autism experience, and benchmark with the study's findings to develop stronger findings on the study. This was for the aim of giving a correct explanation on the phenomena under study; the assessment of burden of care for parents of autistic children and their coping strategies in Nairobi county, Kenya.

Target Population

The target population is “the entire set of units for which the survey data are to be used to make inferences.” In a study, the term "population" also refers to the complete group of people who share certain traits, (Mugenda & Mugenda, 1999).

The target population of this study is exclusive to parents of children with autism who are members of the specific groups and residents of Nairobi County. This location was chosen for the research due to the concentration of social needs resources and medical facilities essential for the care of autism. All these factors make it easy for the study to access, select and interact with the participants about the study's thesis.

About 25,000 children are expected to be affected by an autism spectrum disease in the Nairobi area alone, according to estimates made by Jon Onala, a researcher, director, and early intervention specialist (Riccio, 2011). This is the population of this study.

Sample Size

A sample is a group of individuals chosen at random from a population for the sole purpose of estimating the population's characteristics (Cramer & Howitt, 2004). This study aimed at involving 65 parents drawn from a sampling frame of the two main autism society groups that support parents of children on the autism spectrum. Riccio, (2011) observed in her research that many members of the autism population in Nairobi had relocated from rural areas to the city. Nairobi was selected for the study because of the concentration of resources for people with special needs there. Because it is estimated over 25,000 cases of autism exist in Nairobi alone, the study's population was known but willingness to participate was assumed.

Sampling Technique

The study aimed at selecting willing caregivers who were active as the study population. A non-probability sampling technique was used to carefully select the final study sample as by the respondents' willingness to participate in the study and availability.

From the number study population, the study employed both probability and non-probability sampling techniques in order to cope up with the sample size. Simple random sampling was used to select 65 parents who were willing to participate.

Inclusion and exclusion criteria

The research interviewed participants who were parents of children with autism who signed an informed consent to voluntarily participate in the study.

Data Collection Instruments

The Caregiver Burden Inventory (CBI) was used to measure the burden of caring, and the Brief Cope Inventory was used to gauge how well these parents coped. Various instruments, including questionnaires, were used to gather the data. The social demographic questionnaire (SDQ) was used to record the participants' basic demographic information. Amount of care required and psychological effects of their encounter were being evaluated.

Appendix B1: Caregiver Burden Inventory (CBI)

Caregiver Burden Inventory (CBI) is an assessment tool for caregiving which can be self-administered or administered by a researcher. It was developed in 1989 by

Canadian researchers Novak & Guest, (1989). In contrast to global or uni-dimensional scores, they emphasized the significance of employing a multidimensional measurement of burden with individual scores for each dimension.

The Caregiver Burden Inventory is a 24-question survey with closed-ended answers that is broken down into five subscales: Time-dependence, Developmental, Physical, Social, and Emotional Burdens. Each dimension has five things, with the exception of physical burden, which has four items. Scores for each item are evaluated using a 5- point Likert Scale ranging from 0 (not at all descriptive) to 4 (very descriptive) (Caserta, Lund, & Wright, 1996) . There is no threshold for defining caregiver load; a higher score indicates a greater burden. Therefore, the sum of the scores for factors 1, 2, 4, and 5 might be between 0 and 20. The total items in this dimension can be multiplied by 1.25 to get an equal score for physical burden, (Valer , Aires, Fengler , & Paskulin , 2015)

All the scores of the 24-item scale are summed and a total of >36 is indicative of a risk of burn out whereas scores near or slightly above 24 indicates a need to seek some form of respite care (Chou, Jiann-Chyun, & Chu, 2002).

CBI was used to assess the caregiver burden for the parents in the 5 domains while caring for their children. Special focus was on the gender difference among the parents: fathers and mothers, of the child in the caregiving burden to assess if there is a disparity.

Appendix B2: The “Brief” Cope Inventory

The Cope Inventory was developed by Carver in 1989 to evaluate a wide range of coping responses theoretically derived based on various models of coping. Because each scale is unipolar, which means the lack of one reaction does not necessarily imply the existence of its opposite, the inventory contains responses that are anticipated to be dysfunctional as well as those that are interpreted as functional with at least two pairs of polar-opposite tendencies, (Carver, Scheier, & Weintraub, 1989).

The items in the inventory are used in at least 3 formats. One is a "dispositional" or trait-like variant in which participants report how often they typically engage in the activities mentioned when under stress. The second is a time-limited variation that asks participants to rate how much of each answer they actually had during a specific time in the past, (Poulus, Coulter, Trotter, & Polman, 2020). The third variation is a time-limited one where participants rate how frequently they have encountered each response throughout a time period that ends in the present. The verb tenses used in the various formats differ: the dispositional format uses the present tense, the situational-past format uses the past tense, and the third format uses either the present tense perfect (I am...) or the present tense progressive (I have been...).

This study however used The Brief Cope Inventory in the third format where respondents were giving their response in a present tense progressive or present perfect tense. The study chose to use the brief cope inventory because it found responding to the full instrument of the 60 item Cope scale (Carver, Scheier, & Weintraub, 1989) as time consuming and some respondents might become impatient as alluded by Carver C. S., (1997).

The Brief-COPE is a 28-item self-report questionnaire created to assess the efficiency of various coping strategies for stressful life events, (Carver C. S., 1997). The scale measures a person's primary coping styles with the subscales of; Problem-Focussed Coping, Emotion-Focussed Coping and Avoidant Coping (Dias, Cruz, & Fonseca, 2012) . It highlights self-distraction, denial, substance use, behavioural disengagement, emotional support, venting, humour, acceptance, self-blame, religion, active coping, use of instrumental support, positive reframing, and planning as facets in coping.

When 316 e-sports players were used to validate the scale, Poulus, Coulter, Trotter, and Polman (2020) discovered that each subscale had averages and standard deviations of 2.47 (0.63), 2.23 (0.49), and 1.64 (0.45) respectively.

Three general coping styles are scored, with average scores (sum of item scores divided by number of items) offered to show the respondent's use of each coping strategy: The options are: (1) I haven't been doing this at all, (2) a little, (3) a fair amount, and (4) a lot.

In interpretation, focus is on the pattern of responding across the three subscales. The respondent may not feel they have many stressors to deal with, lack of reflective capacity, reluctance to divulge personal information, or a lack of coping mechanisms if they consistently receive low scores on all subscales.

Data Collection Procedures

This study was conducted using both closed ended questionnaires and open-ended questionnaires to measure the psychosocial challenges and the coping strategies respectively. Each participant first filled in the consent form, the SDQ and proceeded

with responding to the tests of Caregiver Burden Inventory (CBI), and The Brief Cope Inventory. These were administered by the research assistants trained by the researcher. After the stated period of 2 weeks, the data collected was submitted for analysis.

Pre-Testing

Pre-testing helps to evaluate the reliability and validity of research instruments prior to their final distribution (Michalos, 2014). It helps the researcher decide whether they want to make any changes in their data collection instruments by analysing whether the instruments made them achieve their study objectives. An interview was scheduled, and questionnaires administered to a couple who have a child living autism in Nairobi County. The purpose of this pre-test was to ensure the items in the interview questions and the items in the questionnaire were clear to the respondents without regards to their education.

The participants for the pre-test were purposively chosen because of their availability and nearness to the researcher. In agreement with Reynold, Diamantopoulos, & Schlegelmilch (2017) who suggested pretesting as a useful stage in development of a questionnaire that helps to determine the effectiveness of the questionnaire to identify errors apparent only to the target population, this made it possible for the researcher to evaluate the research worthiness of the topic and anticipate the challenges that the study was to face.

Methods of Data Analysis

The study used both qualitative and quantitative approach for data analysis. The study's objective involved seeking to find out both qualitative and quantitative data.

Interviews and questionnaires are chosen as data collection tools for qualitative and quantitative data respectively.

To provide the quantitative data as tables based on the main study topics, descriptive statistics like frequency and percentages were performed using the Statistical Package for Social Sciences (SPSS) version 21.0.

Ethical Consideration

Ethics in this study focused on the application of ethical standards in the planning of the research, how research data was collected and analysed and how the research results and conclusion was shared. Vanclay et al.,(2013) defines ethics as a branch of philosophy that seeks to address questions of morality. Morality is a set of beliefs or standards about concepts like good and bad, right and wrong (Jennings, 2003). This forms the ethical principles of research.

“Ethical principles include: respect for participants, informed consent, specific permission required for audio or video recording, voluntary participation and no coercion, participant right to withdraw, full disclosure of funding sources, no harm to participants, avoidance of undue intrusion, no use of deception, the presumption and preservation of anonymity, participant right to check and modify a transcript, confidentiality of personal matters, data protection, enabling participation, ethical governance, provision of grievance procedures, appropriateness of research methodology, and full reporting of methods”. (Vanclay et al., 2013, pp. 1–2).

Vanclay et al. (2013) advice if a research involves humans as the subjects, the first step should be to look for regional and national declarations from governments or government bodies. The National Commission for Science, Technology, and Innovation (NACOSTI) was contacted by the researcher to request authorization to conduct the study and permission letters from the management of the selected groups; Autism Society of Kenya and Autism Awareness Kenya.

The study sought to get an informed consent from the respondents by explaining what the study is all about, the objectives of the study and how they could be part of the study. Their rights in participating in the study were explained and what was to be expected of them. The respondents were asked to sign a consent form that was to show they willingly accepted to participate in the study.

Confidentiality was maintained in the entire process of the research. The information from the research findings was only to be used for academic purposes and developing an intervention plan to help the respondents.

Anonymity of the respondents was to be maintained by the study. The identity of the respondents was kept confidential by the researcher in data analysis and presentation. The researcher also asked for special consent and signed permission for audio recording during interviews. This was so to maintain the confidentiality of the respondents.

Summary

This chapter discusses the various procedures that were used to carry out the research. It introduces the research methodology and discussing the research design, the target population, the sample size, sampling techniques that were considered and the

inclusion and exclusion criteria. It highlighted the data collection instruments that were used, the data collection procedures, pre-test that was done, the methods of data analysis and the ethical considerations of the study.

CHAPTER FOUR

DATA PRESENTATION, ANALYSIS AND INTERPRETATION

Introduction

This chapter covers data presentation, and analysis. The presentation is in numerical and tabular forms. The chapter also covers vast and insightful explanations of the descriptive and inferential statistics, as the key research findings.

Analysis and Interpretation

Response Rate

A total of 65 questionnaires were dispersed out to the participants, out of which, 60 were filled and returned for analysis. This gave a response rate of 92.31% of the

administered questionnaires. This was exceptional for analysis as Mugenda & Mugenda (1999), indicates that a response rate of 50% is fair, 60% is good, and more than 60% is exceptional for analysis and interpretation.

Table 4.1: Response rate

Responses	Number	Percentages
Administered Questionnaires	65	100%
Returned Questionnaire	60	92.31%
Questionnaire Return Rate	60	92.31%

Table 4.1 gives information on the administration of the questionnaires to the respondents for this research. The table displays 92.31(60) of all respondents filled and returned the questionnaires given to them. This remarkable response rate pointed to enhanced reliability of the study findings and the potential of the applicability of the findings to a broader population.

Socio- Demographic Information

The study aimed to evaluate the burden of caregiving for parents of autistic children and their coping strategies. In order to effectively do it, it was necessary to obtain information on the age, gender, religion, highest education level, marital status and length in marriage, employment status of the respondents, as well as the number of children, age and gender of the child with autism. This specific socio-demographic information was crucial for the research objectives, as it allows for the examination of probable correlations between the different demographic characteristics of parents and that of their children with autism.

Gender of Respondents

The study sought to determine the gender of the respondents and the findings are shown in the table 4.2.

Table 4.2: Distribution of Respondents' Gender

	Frequency	Percent	Valid Percent	Cumulative Percent
Female	49	81.7	81.7	81.7
Male	11	18.3	18.3	100.0
Total	60	100.0	100.0	

Table 4.2 serves as a brief description of the gender of the study respondents. Understanding the gender distribution offers meaningful understandings into the composition of the respondent pool. Data findings indicated that that a substantial majority of the participants, were women, accounting for 81.7% (49 individuals). On the centrally, a smaller but still important portion of the respondents, were men, constituting 18.3% (11 individuals).

This gender distribution is an intriguing component of the study's demographic composition. The prevalence of female participants in the study is an interesting finding that may have important implications for the broader context of caregiving and the role of women in this context. It is worth noting that the higher proportion of female responders may be indicative of the prominent and complex roles that women frequently play in caregiving situations and gives way to greater and in-depth inquiries into the roles and experiences of caregivers, particularly women, within the context of autism care. However, this can be indicative of the father- mother involvement into their child's wellbeing whereby 81.7% are female and only 18.3% are male, meaning that mothers are more involved than fathers that they would be willing to create a community and learn how to better support their child with ASD.

Age of Respondents

The research also sought to understand the age distribution of the respondents. Findings are presented in table 4.3.

Table 4.3: Distribution of Respondents by Age

	Frequency	Percent	Percent	Cumulative Percent
17-22	3	5.0	5.0	5.0
23-30	14	23.3	23.3	28.3
31-37	30	50.0	50.0	78.3
38-44	13	21.7	21.7	100.0
Total	60	100.0	100.0	

Table 4.3 gives a detailed breakdown of the ages of carers caring for autistic children, providing vital insights into the demographic makeup of this critical group. The data shown in this table demonstrates a wide range of ages among caregivers. The findings show that a small but significant proportion of respondents, 5%, was between the ages of 17 and 23 years, indicating the presence of relatively young caregivers who are navigating the complexities of autism caregiving at an early stage in their own lives.

Moving along the age spectrum, the table shows that 23.3% of the respondents were between the ages of 22 and 30 years. This group of carers accounts for a sizable proportion of the study's sample, indicating the prevalence of young to young-adult caregivers who are actively involved in giving support and care to autistic children. The majority of respondents (50%) were between the ages of 31 and 37 years, highlighting the importance of individuals in their early to mid-adult years in the role of autism caregiving. The findings also show that 21.7% of respondents were between the ages of 38 and 44 years. These findings emphasize the broad and multi-generational nature of the caregiver population, accentuating the necessity of understanding how persons of various ages manage the complexities of autism caregiving.

Marital status of Respondents

This study also sought to discover the marital status of the respondents who are caregivers of autistic children. It was envisaged that the marital status of the caregivers, had an influence on the burden posed by caregiving and shade light into possible social support available to the caregivers. A summary of the findings on the marital status of the respondents is summarised in table 4.4.

Table 4.4: Distribution of Respondents by Marital Status

	Frequency	Valid Percent	Cumulative Percent
Married	35	58.3	58.3
Single	15	25.0	83.3
Separated	4	6.7	90.0
Cohabiting with significant other	1	1.7	91.7
Prefer not to say	5	8.3	100.0
Total	60	100.0	

The results encapsulated in Table 4.4, discloses a comprehensive summary of the diverse marital statuses among the study's respondents. Results as presented in shows that the respondents comprising a substantial majority at 58.3% who are married. The study found that 24% of the participants were single individuals. The study also found out that a substantial number of caregivers who were in different stages of relational transitions; 6.7% of respondents were separated and 1.7% individuals were cohabiting with significant others.

This can be interpreted to mean that different respondents have different levels of responsibilities, burdens, support and coping mechanisms for the respondents. While the married respondents could be getting mutual support in the caregiving, the separated could be navigating both the complexities of autism caregiving and the challenges associated with relationship separations and have to shoulder the duties of caregiving for children with autism without the required support. It is important to note that 5% of

respondents chose not to disclose their marital status, reflecting the importance of respecting respondents' privacy and level of disclosure regarding their private life.

Length of Stay in Marriage

The research sought to ascertain the length of stay in marriage. This was deemed important to shed light into understanding the caregiver's experience, resources, coping strategies, and resilience in the context of caregiving for autistic children. Findings are presented in table 4.5.

Table 4.5: Distribution of Respondents by Marital Status

	Frequency	Percent	Valid Percent	Cumulative Percent
0-5	15	25.0	25.0	25.0
6-10	14	23.3	23.3	48.3
11-15	12	20.0	20.0	68.3
16-20	8	13.3	13.3	81.7
Never been married	11	18.3	18.3	100.0
Total	60	100.0	100.0	

Results as presented in table 4.5 indicates that 15% of the respondents have been in marriage for a period between 0 and 5 years, 23.3% have been in marriage for a period between 6 and 10 years, 20% between 11 and 15 years, 13.3% between for a period between 16 and 20 years and 18.3% have never been married.

These findings give a diversity in the length of marriages among the respondents in the study, hence providing valuable insights into the marital background of caregivers of children with autism. The newly married (0-5 years), who are fairly new to marriage, could be in a stage where they are adjusting to the dynamics in marriage and parental responsibilities, with an additional burden of caregiving to an autistic child.

A significant proportion of caregivers have been married for a period ranging from 6 to 10 years. They could have settled down in their marriages, could be having other children to take care of, but also likely that they have developed strategies to help them manage the complexities of autism caregiving within the context of their relatively stable marriages. The respondents who have been in marriage for 11-15 years, constituted 20% of the respondents. These caregivers may possibly have accumulated useful experience and resilience over the years, which is important for their caregiving roles for children with autism. Another significant proportion (13.3%) of the respondents have been in marriage for a period of 16-20 years. This category can be assumed to have extensive experience in both marriage and caregiving, possibly bringing up other children, potentially offering unique insights into the long-term challenges and rewards associated with autism caregiving. The remaining 18.3% of the respondents have never been in a marriage. They could be potentially in non-marital relationships or who provide care as singly. Their unique experiences may reflect different support systems and challenges compared to married caregivers.

Religion of the respondents

Table 4.6: Distribution of Religion of the respondents

	Frequency	Percent	Valid Percent	Cumulative Percent
Christian	54	90.0	90.0	90.0
Muslim	3	5.0	5.0	95.0
Other	3	5.0	5.0	100.0
Total	60	100.0	100.0	

The information in Table 4.6 provides a clear picture of the religious connections of the study's respondents. The highest proportion of respondents, 90% (54 people), identified as Christians, indicating the prevalence of Christianity among the study

respondents. There was only 5% (3 individuals), identified as Muslims, and another 5% (3 individuals) who belonged to other religious affiliations. Christianity was the single largest proportion of the respondents, and by extension, the population. Religious affiliations form a very important caregivers' backgrounds and beliefs in the context of autism caregiving. The affiliation influences the support system, coping strategies, and cultural views related to caregiving.

Respondents Level of Education

Table 4.7: Respondents Highest Level of Education

	Frequency	Percent	Valid Percent	Cumulative Percent
Doctorate/Masters	6	10.0	10.0	10.0
Undergraduate	33	55.0	55.0	65.0
Diploma	16	26.7	26.7	91.7
Certificate	2	3.3	3.3	95.0
Secondary Education	2	3.3	3.3	98.3
Primary Education	1	1.7	1.7	100.0
Total	60	100.0	100.0	

The study deemed it necessary to ascertain the respondents' highest level of education, noting the critical impact that education may play in influencing perspectives, problem-solving abilities, and access to resources. The findings from the study as presented in table 4.7 were 10% (6 individuals) of the respondents have Doctorate or Master's degree as their highest levels of education, a sizable majority, 55% (33 people), have completed Undergraduate degrees as their highest level of study, indicating a

sizable group of participants with a good foundation in higher education. 26.7% (16 individuals) have a Diploma as their highest level of education, 3.3% (2 individuals) have a certificate and a similar number have a Secondary Education as their highest level of education, while only 1.7% (1 individual) had Primary Education as the highest level of education.

These findings display a diversity of educational backgrounds among caregivers of autistic children. This complete grasp of the educational spectrum within the sample group provides for a more personalized approach to understanding the views, capabilities, and potential needs of caregivers in the context of autism caregiving.

Respondents Employment Status

Table 4.8: Respondents Employment Status

	Frequency	Percent	Valid Percent	Cumulative Percent
Formal employment	24	40.0	40.0	40.0
Self-employed	31	51.7	51.7	91.7
Unemployed	5	8.3	8.3	100.0
Total	60	100.0	100.0	

Table 4.8 provides a useful summary of the respondents' employment statuses, thus, giving insights into the different professional contexts represented in the study's respondents. The information in this table demonstrates a diverse landscape of work statuses among caregivers of autistic children. Notably, 40% (24) respondents were actively in formal employment. This group includes a sizable proportion of participants who mix caregiving responsibilities with their work in typical employment contexts, highlighting the dual commitments they manage in their daily lives. The largest category

of respondents, 51.7% (31 individuals) were self-employed. This referred to caregivers who had chosen entrepreneurial or freelance work arrangements, which sometimes offer greater freedom but also present distinct concerns. The entrepreneurial spirit of this group may be a pointer to their adaptability and resourcefulness in balancing the demands of autism caregiving with their own commercial pursuits.

A smaller number of 5 (8.3%) respondents were reported to be unemployed. While these caregivers may be adequately available and flexible to their caregiving roles, it may also bring financial and support concerns. Additionally, they could be unemployed because of the burden of caregiving to their autistic child.

Respondents Number of Children

Table 4.9: Respondents Number of Children

	Frequency	Percent	Valid Percent	Cumulative Percent
1	17	28.3	28.3	28.3
2	27	45.0	45.0	73.3
3	14	23.3	23.3	96.7
4	2	3.3	3.3	100.0
Total	60	100.0	100.0	

Table 4.9 summarizes the number of children in the families of the study's respondents, with an emphasis on autistic children. Notably, 28.3% of caregivers had only one child, the autistic one, indicating the presence of devoted caregivers who provide particular care and support to their autistic child. A significant proportion (45%) of the respondents had two children under their care, of which, one of them was autistic. Additionally, 23.3% of the study respondents are caring for three, while only 3.3% of

caregivers had four children. The families with more than one child could be a depiction of more challenges of childcare and resource allocation challenges.

Age of Respondent's Autistic Child

Table 4.10: Age of Respondents' Autistic Child

	Frequency	Percent	Valid Percent	Cumulative Percent
1-8	45	75.0	75.0	75.0
9-16	11	18.3	18.3	93.3
17-24	4	6.7	6.7	100.0
Total	60	100.0	100.0	

Table 4.10 presents details of the ages of autistic children within the families of the study's respondents. From the findings, a significant proportion (75%, 45 caregivers) of respondents are currently caring for an autistic child, aged between 1 and 8 years. This number alludes to the fact to the prevalence of caregivers who are in the early stages of their children's autism journey, requiring support and intervention during the critical developmental phase of these children. 18.3% (11 caregivers) had autistic children aged between 9 and 16 years, who were navigating the unique challenges of adolescence and autism. Only 6.7% (4 caregivers) of the respondents had autistic children aged between 17 and 24 years. These findings show the diverse age ranges of autistic children within the caregiver's population and underscore the need for tailored interventions and support services that address the inimitable developmental needs and challenges of autistic individuals across various developmental and growth stages.

Gender of Respondent's Autistic Child

Table 4.11: Gender of Respondent's Autistic Child

	Frequency	Percent	Valid Percent	Cumulative Percent
Male	51	85.0	85.0	85.0
Female	9	15.0	15.0	100.0
Total	60	100.0	100.0	

The data presented in Table 4.11 provides a summary of an important glimpse into the gender variation among the autistic children of the respondents. Males are the majority, constituting 85% (51) of the autistic children. The remaining 15% of the autistic children are female. These research findings are key for decision making on appropriate gender tailoring interventions and support services for autistic individuals and their families. Although we have 85% male autistic children, we have 81.7 % female caregivers. This can be attributed to the fact that women are socially assigned the caregiving role, besides that fact that majority (75%) of the autistic children are aged between 1-9 years.

The Burden of Autistic Caregiving

The first objective of this study was to assess the burden of care among parents with autistic children in selected groups, Nairobi County, Kenya. To gain insights into this, The Caregiver Burden Inventory (CBI); consisting of 24 closed-ended questions was administered to the respondents. CBI has five subscales: Time-dependence Developmental, Physical, Social, and Emotional burdens. Each of the sub-scales had 5 items, except physical burden, which had four items dedicated to it. Scores for each item were evaluated using a 5- point Likert Scale ranging from 0 (not at all descriptive) to 4 (very descriptive). Although there were no thresholds for determining caregiver burden; a higher score indicates a greater burden.

The total score for each sub-scales was done by adding the scores of the five items, as rated by the respondents. To get the total score for physical burden, which had a total of four items, the total was multiplied by 1.25 to get an equal score for physical burden, that is similar to the other sub-scales.

The overall scores of the 24-item scale were summed to determine the overall burden that caregiving places on the respondents. Whereas there are no set cut-offs for burden, scores near or slightly above 24 indicates a need to seek some form of relief, while those above 36 are indicative of a risk of burn out/burden. The findings of this study are summarised in table 4.12.

Table 4.12: Burden of Autistic Caregiving on Parents

	Time dependency burden	Development Burden	Physical health burden	Emotional health burden	Social relationships	Total score for CBI
N	60	60	60	60	60	60
Mean	14.25	8.45	7.32	2.92	6.77	38.97
Std. Deviation	4.960	4.739	6.013	2.830	5.241	19.381
Sum	855	507	439	175	406	2338

Table 4.12 gives a summary of the research findings, which shades light on the multifaceted hardships faced by parents of autistic children. Autism caring is a complicated path, and these findings illustrate the many facets of this experience. Findings show that parents have a significant time dependency burden, with a mean score of 14.25 and a standard deviation of 4.96. This suggests that caregivers frequently devote

a large amount of time to addressing the requirements of their autistic children, such as therapy sessions, educational support, and everyday caregiving activities, which can interfere with their regular routines and obligations.

While caring for the autistic children, parents also face a developmental burden, as evidenced by a mean score of 8.45 and a standard deviation of 4.739. This shows that caregivers have obstacles and duties related to their autistic children's developmental trajectories, such as milestones, skill acquisition, and educational preparation. They also experience a physical burden with a mean score of 7.32 and a standard deviation of 6.013. This highlights the physical toll that caregiving can have on parents' physical well-being, possibly as a result of the responsibilities of providing hands-on care, attending medical visits, and maintaining their autistic children's general health.

Caregivers also experience emotional health, which had a mean score of 2.92 and a standard deviation of 2.83. This shows that caregivers may have emotional difficulties as a result of stress, worry, and emotional well-being, reflecting the emotional toll of autism caregiving.

Finally, the social relationship stress had a mean score of 6.77 and a standard deviation of 5.241. As parents manage the complexity of autism caring, this exposed the strain that caregiving can impose on social interactions, including marital partnerships, friendships, and extended family dynamics.

All the sub-scales had a minimum score of zero and a maximum score of 20. From these findings, time dependency burden was ranked the highest burden, at an average score of 14.15, followed by developmental burden at an average score of 8.45,

physical burden at an average score of 7.32, social burden at an average score of 6.77 and lastly, emotional burden at an average score of 2.83. The total caregiving burden experienced by parents of autistic children was calculated by aggregating the sub-scale scores, resulting in an average overall caregiving burden score of 38.97. This total score represents the variety of obstacles and obligations that caregivers confront in their roles. It is important to note that this overall score was within the range that indicates a high caregiving load. According to the Caregiver Burden Inventory (CBI) rating system, any score more than 36 indicates a burden level that is at a risk of burnout. This numerical barrier serves as a vital indicator, indicating that the carers in this study have carried a significant burden throughout their journey of caring for autistic children. It emphasizes the critical need for support and assistance to alleviate the challenges that these caregivers face, highlighting the importance of interventions and resources aimed at promoting their well-being and resilience.

Gender Difference in Relation to the Burden of Caregiving

The second objective of the study was to investigate the gender difference in relation to the burden of caregiving experienced by parents with autistic children in selected groups, Nairobi, Kenya. In order to respond to this objective, an Independent Sample T-Test was conducted on the gender and caregivers burden subscales. Findings were summarised in tables 4.13 and 4.14.

Table 4.13: Respondents Gender and Caregivers Burden

	Respond's gender	N	Mean	Std. Deviation
Time dependency burden	Female	49	14.55	4.891
	Male	11	12.91	5.281

Development Burden	Female	49	8.71	4.805
	Male	11	7.27	4.452
Physical health burden	Female	49	7.88	6.160
	Male	11	4.82	4.771
Emotional health burden	Female	49	2.78	2.860
	Male	11	3.55	2.734
Social relationships burden	Female	49	6.76	5.364
	Male	11	6.82	4.895
Total score for CBI	Female	49	40.71	19.578
	Male	11	31.18	17.169

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Table 4.14: T-Test on Caregiving Burdens

	Levene's Test for Equality of Variances		t-test for Equality of Means						
	F	Sig.	t	Df	Sig. (2- tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
								Lower	Upper
Time dependency burden	.063	.803	.992	58	.325	1.642	1.655	-1.671	4.955
			.944	14.11	.361	1.642	1.739	-2.085	5.369
Development Burden	.224	.638	.910	58	.366	1.442	1.583	-1.728	4.611
			.956	15.69	.353	1.442	1.508	-1.759	4.643
Physical health burden	2.716	.105	1.543	58	.128	3.059	1.983	-.910	7.029
			1.814	18.35	.086	3.059	1.686	-.479	6.597
Emotional health burden	.016	.901	-.813	58	.420	-.770	.947	-2.666	1.126
			-.837	15.32	.415	-.770	.920	-2.727	1.187
Social relationships burden	.263	.610	-.036	58	.972	-.063	1.764	-3.593	3.467
			-.038	15.88	.970	-.063	1.663	-3.591	3.465
Total score for CBI	.152	.698	1.489	58	.142	9.532	6.401	-3.280	22.345
			1.620	16.40	.124	9.532	5.884	-2.916	21.981

As presented in table 4.13, the total number of female care givers was 49, while that of male was 11. On the Time Dependency Burden sub-scale, the research found out that caregivers' perceptions of how time-consuming their obligations are, found that female caregivers had a somewhat higher mean score (14.55) than male caregivers (12.91). However, the standard deviations showed significant variability within each group, raising the likelihood that the difference in means was not statistically significant. To ascertain whether the difference was significant, a T Test was ran, which validated this idea, that there was no statistically significant difference in time dependency burden scores between male and female caregivers. Whether equal variances were assumed or

not, the p-values of 0.325 and 0.361, respectively in table 4.14 were above the normal alpha level of 0.05, indicating that there was no compelling evidence to support the argument that gender significantly influences perceptions of time dependency burden among caregivers.

As presented in table 4.13, female caregivers reported a somewhat higher mean score of 8.71 compared to the male caregivers' which was 7.27 in the context of the developmental burden. The standard deviations, on the other hand, of 4.805 and 4.452 for female and male demonstrated significant variability within each group, suggesting the likelihood that the difference in means was not statistically significant. The t-test findings confirmed this finding, revealing that there is no statistically significant difference in developmental burden scores between male and female caregivers. Whether equal variances were assumed or not, the p-values (0.366 and 0.353) presented in table 4.14 were above the conventional significance level of 0.05, demonstrating that gender does not significantly influence caregivers' judgments of developmental burden.

Regarding the Physical Health Burden sub-scale, which assesses the impact of caregiving on caregivers' physical well-being, female caregivers had a significantly higher mean score (7.88) than male caregivers (4.82), indicating that female caregivers perceive a greater physical health burden on average. However, the presence of standard deviations shows that these scores are variable. However, the results of the subsequent t-test show no statistically significant difference in physical health burden levels between male and female caregivers. Whether equal variances were assumed or not, the p-values (0.128 and 0.086) presented in table 4.14 were above the standard significance level of

0.05, showing that gender has no significant impact on caregivers' assessments of physical health burden.

On the Emotional Health Burden sub-scale which assessed the emotional toll of caregiving, male caregivers reported a marginally higher mean score (3.55) than female caregivers (2.78) as presented in table 4.13, implying that male caregivers perceive a slightly greater emotional health burden on average. The occurrence of variability in scores, on the other hand, is consistent with the other dimensions. However, no statistically significant difference in emotional health burden scores between male and female carers is revealed by the subsequent t-test results. Whether equal variances are assumed or not, the p-values (0.420 and 0.415) as presented in table 4.14, both exceed the standard significance level of 0.05, demonstrating that gender has no significant influence on caregivers' assessments of emotional health burden.

As presented in table 4.13, both female (6.76) and male (6.82) caregivers reported nearly identical mean scores on the Social Relationships Burden Sub-scale, which examines the pressure on caregivers' social contacts and relationships as a result of their caregiving responsibilities. The similarity in their mean scores suggests that both genders reported a comparable level of pressure on their social interactions. Additionally, the t-test results support this conclusion by indicating no statistically significant difference was found in social connection burden levels between male and female caregivers. Regardless of whether equal variances were assumed, the p-values (0.972 and 0.970) both exceed the conventional significance level of 0.05, demonstrating that gender had no effect on caregivers' perceptions of social relationship burden.

Total Score for CBI showed that the cumulative caregivers' burden score across all dimensions, female carers have a significantly higher mean total burden score (40.71) than that of male (31.18). This showed that, on average, female caregivers perceive a greater total burden of caregiving. The standard deviations reflect variation within each group. The findings of the subsequent t-test show no statistically significant difference in overall caregiver burden score between male and female caregivers. Whether equal variances are assumed or not, the p-values (0.142 and 0.124) both exceed the standard significance level of 0.05, demonstrating that gender has no effect on carers' assessments of the overall caregiver burden score.

Coping Strategies Employed by the Parents of Autistic Children

The third objective of the study sought to analyse the coping strategies employed by the parents of autistic children in relation to their demographics in selected groups, Nairobi County, Kenya. The researcher used The Brief-COPE tool; a 28 item self-report questionnaire designed to measure effective and ineffective ways to cope with a stressful life event. The tool measured the respondents' coping styles with the three subscales of; Problem-Focussed Coping, Emotion-Focussed Coping and Avoidant Coping. The coping strategies were analysed against the demographic characteristics of the respondents. Findings were presented below.

Gender and Coping Techniques

Table 4.15a: Respondent's Gender and Brief Cope (Avoidance Focus) Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	29.833 ^a	11	.002
Likelihood Ratio	30.095	11	.002
Linear-by-Linear Association	.034	1	.854

N of Valid Cases	60
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Table 4.15b: Respondent's Gender and Brief Cope (Emotional Focus) Chi-Square Tests

	Value	Df	Asymptotic Significance (2-sided)
Pearson Chi-Square	15.444 ^a	13	.280
Likelihood Ratio	16.459	13	.225
Linear-by-Linear Association	2.103	1	.147
N of Valid Cases	60		

Table 4.15c: Respondent's Gender and Brief Cope (Problem Focus) Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	23.941 ^a	13	.032
Likelihood Ratio	25.566	13	.019
Linear-by-Linear Association	1.925	1	.165
N of Valid Cases	60		

The Chi-Square Tests findings on gender and indicate p-values of .280 and .225 when investigating the association between respondents' gender and coping (Avoidance Focus) were; Pearson Chi-Square and Likelihood Ratio, produce p-values of .002 in the examination of gender and avoidance-focused coping techniques. These p-values are less than 0.05, showing a statistically significant relationship between gender and avoidance-focused coping while the Linear-by-Linear Association, with a p-value of .854, suggests that the association is not linear.

Emotional-focused coping scored p-values of 0.280, which are greater than the standard level of significance of 0.05. This implies that there is no statistically significant relationship between gender and emotionally focused coping techniques. This finding is supported by the Linear-by-Linear Association, which has a p-value of .147, showing that there is no significant linear trend in the association.

Problem Focus coping scored a p-values of .032 (Pearson Chi-Square) and .019 (Likelihood Ratio) for the link between gender and problem-focused coping techniques.

Both of these p-values are less than 0.05, agreeing to a statistically significant relationship between gender and problem-focused coping. The Linear-by-Linear Association, like the other categories, has a p-value of .165, indicating that the linear association may not be significant.

These findings mean that gender plays a significant role in avoidance-focused and problem-focused coping techniques. However, while gender influences coping strategies, these associations may not follow a straightforward linear trend.

Religion and Coping Techniques

Table 4.16a: Respondents Religion and Brief Cope (Avoidance Focus) Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	25.000 ^a	22	.297
Likelihood Ratio	20.336	22	.562
Linear-by-Linear Association	.299	1	.584
N of Valid Cases	60		

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	44.226 ^a	26	.014
Likelihood Ratio	27.182	26	.400
Linear-by-Linear Association	2.738	1	.098
N of Valid Cases	60		

Table 4.16b: Respondent's Religion and Brief Cope (Emotional Focus) Chi-Square Tests

Table 4.16c: Respondent's Religion and Brief Cope (Problem Focus) Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	44.226 ^a	26	.014
Likelihood Ratio	27.182	26	.400
Linear-by-Linear Association	2.738	1	.098
N of Valid Cases	60		

To ascertain the relationship between relationship between religion and coping strategies, a Chi-Square Tests were run in SPSS. Results were obtained and summarized in tables 4.16a, 4.16b and 4.16c. The three Chi-Square statistic findings for religion and avoidance focus scored p-values more than 0.05, namely .297 (Pearson), .562 (Likelihood Ratio), and .584 (Linear-by-Linear Association). This means that religion and avoidance-focused coping techniques have no statistically significant relationship. On religion and problem focus coping techniques, Pearson Chi-Square provided a p-value of .014 (table 4.16b), which is less than 0.05, showing a statistically significant link in between religion and problem-focused coping. The Likelihood Ratio and Linear-by-Linear Association statistics gave a p-values that are greater than 0.05, meaning that although the relationship between religion and problem-focused coping is statistically significant, it may not assume a linear trend. Chi-Square yields a p-value of .280 for religion and emotional-focused is greater than 0.05, indicating that there is no statistically significant relationship, while the Linear-by-Linear Association statistic, of a p-value of .014, which is less than 0.05, indicates a statistically significant linear trend. These variations show that religion and emotional-focused.

Respondents Age and Coping techniques

Table 4.17: Respondents Age and Coping Techniques Chi-Square Tests

		Value	Df	Asymptotic Significance (2-sided)
Avoidance focused	Pearson Chi-Square	81.995 ^a	33	.000
	Likelihood Ratio	63.722	33	.001
	Linear-by-Linear Association	.122	1	.727
Problem focused	Pearson Chi-Square	67.561 ^a	39	.003
	Likelihood Ratio	63.915	39	.007
	Linear-by-Linear Association	.163	1	.687

Emotional focused	Pearson Chi-Square	77.013 ^a	39	.000
	Likelihood Ratio	76.370	39	.000
	Linear-by-Linear Association	.495	1	.482
N of Valid Cases		60		

Table 4.17 summarises the findings of the relationship between the respondent's age, and the coping techniques. All three Chi-Square statistics the respondent's age and Avoidance-Focused Coping produced p-values less than 0.001, specifically .000 (Pearson Chi-Square), .001 (Likelihood Ratio), and .727 (Linear-by-Linear Association). These findings show a statistically significant relationship between avoidance-focused coping and the age of the respondent. However, the p-value of the Linear-by-Linear link implies that this link may not follow a linear trend.

For respondents' age and Problem Focused coping, Pearson Chi-Square and Likelihood Ratio statistics provide p-values of .003 and .007, respectively, demonstrating a statistically significant link with Problem-Focused Coping technique and the age of the respondent. With a p-value of .687, the Linear-by-Linear Association shows that this association may not follow a significant linear trend.

Similarly, all three Chi-Square statistics for Emotional-Focused Coping produced p-values less than 0.001, indicating a statistically significant relationship between emotional-focused coping and the age of the respondents. However, the p-value of .482 for the Linear-by-Linear Association suggests that this association may not have a significant linear trend.

Respondents Education Level and Coping techniques

Table 4.18: Respondents Level of Education and Coping Techniques Chi-Square Tests

		Value	Df	Asymptotic Significance (2-sided)
Avoidance focused	Pearson Chi-Square	89.051 ^a	55	.002
	Likelihood Ratio	70.017	55	.084
	Linear-by-Linear Association	1.582	1	.208
Problem focused	Pearson Chi-Square	96.059 ^a	65	.007
	Likelihood Ratio	69.530	65	.328
	Linear-by-Linear Association	.043	1	.835
Emotional focused	Pearson Chi-Square	144.093 ^a	65	.000
	Likelihood Ratio	72.392	65	.247
	Linear-by-Linear Association	5.557	1	.018
N of Valid Cases		60		

Table 4.18 shows results of a Chi-Square Test results for the association between education level and coping mechanisms classified as avoidance-focused, problem-focused, or emotional-focused. These data revealed a p-value of .002 for Avoidance-Focused Coping, demonstrating a statistically significant relationship between education level and avoidance-focused coping mechanisms. However, the Likelihood Ratio p-value of .084 implies that the association may be less significant when the likelihood ratio is taken into account. With a p-value of .208, the Linear-by-Linear Association suggests that this association may not follow a significant linear trend, implying that while education level plays a role in avoidance-focused coping, the link may not be clear. The p-value of .007 for Problem-Focused Coping and education level reveal a statistically significant relationship between education level and problem-focused coping strategies. Similar to

the avoidance, the Likelihood Ratio p-value of .328 suggests that this relationship may not hold when the likelihood ratio is considered. With a p-value of .835, the Linear-by-Linear Association suggests that there is no significant linear trend in this association, underlining the intricacy of the relationship between education level and problem-focused coping.

The Pearson Chi-Square produced a highly significant p-value of .000 for Emotional-Focused Coping, demonstrating a strong link between education level and emotional-focused coping approaches. A p-value of .247 for the Likelihood Ratio implies a similar but slightly less strong link. With a p-value of .018, the Linear-by-Linear Association indicates that this association follows a significant linear trend. Overall, these data indicate that education level has a significant influence on emotional-focused coping mechanisms, with higher education levels likely leading to more widespread usage of these tactics. However, the links between avoidance-focused and problem-focused coping are less clear and may not follow a linear pattern.

Respondents Relationship Status and Coping techniques

Table 4.19: Respondents' Relationship Status and Coping Techniques Chi-Square Tests

		Value	df	Asymptotic Significance (2-sided)
Avoidance focused	Pearson Chi-Square	92.024 ^a	44	.000
	Likelihood Ratio	61.567	44	.041
	Linear-by-Linear Association	.239	1	.625
	N of Valid Cases	60		
Problem focused	Pearson Chi-Square	123.449 ^a	52	.000
	Likelihood Ratio	69.456	52	.053
	Linear-by-Linear Association	8.670	1	.003
Emotional focused	Pearson Chi-Square	112.304 ^a	52	.000
	Likelihood Ratio	63.357	52	.134
	Linear-by-Linear Association	.128	1	.720

N of Valid Cases	60
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The table 4.19 displays Chi-Square Test results that investigate the association between respondents' relationship status and coping mechanisms classified as avoidance-focused, problem-focused, or emotional-focused. These data showed that both the Pearson Chi-Square and the Likelihood Ratio reveal highly significant p-values of .000 for Avoidance-Focused Coping, indicating a strong correlation between relationship status and avoidance-focused coping techniques. However, the p-value of .625 for the Linear-by-Linear Association implies that this association did not have a significant linear trend, emphasizing the complexities of the relationship between relationship status and avoidance-focused coping.

In terms of Problem-Focused Coping, the Pearson Chi-Square and Likelihood Ratio both produce highly significant p-values of .000, indicating a strong relationship between relationship status and problem-focused coping mechanisms. Additionally, the Linear-by-Linear connection has a significant p-value of .003, showing that this connection has a significant linear trend. This implies that relationship status had a significant influence on problem-focused coping techniques.

The Pearson Chi-Square and Likelihood Ratio reveal extremely significant p-values of .000 for Emotional-Focused Coping, indicating a strong correlation between relationship status and emotional-focused coping mechanisms. However, the Linear-by-Linear link's p-value of .720 shows that, the link does not follow a significant linear trend. Overall, our data show that relationship status has a considerable influence on the choice of coping techniques, with particularly strong relationships reported for problem-focused and emotional-focused coping.

Respondents Year in Marriage and Coping techniques

Table 4.20: Respondents' Years in Marriage and Coping Techniques Chi-Square Tests

time		Value	df	Asymptotic Significance (2-sided)
Avoidance focused	Pearson Chi-Square	81.840 ^a	44	.000
	Likelihood Ratio	79.151	44	.001
	Linear-by-Linear Association	.152	1	.696
Problem focused	Pearson Chi-Square	100.083 ^a	52	.000
	Likelihood Ratio	101.546	52	.000
	Linear-by-Linear Association	.362	1	.547
Emotional focused	Pearson Chi-Square	87.259 ^a	52	.002
	Likelihood Ratio	95.251	52	.000
	Linear-by-Linear Association	1.831	1	.176
N of Valid Cases		60		

Table 4.20 displays Chi-Square Test results that investigated the association between the number of years in marriage and coping techniques. Findings indicate that both the Pearson Chi-Square and the Likelihood Ratio reveal highly significant p-values of .000 for Avoidance-Focused Coping. These results showed that there is a strong link between the number of years in marriage and avoidance-focused coping mechanisms. However, the p-value of .696 for the Linear-by-Linear connection implies that this connection may not follow a significant linear trend.

Concerning Problem-Focused Coping, both the Pearson Chi-Square and Likelihood Ratio produced highly significant p-values of .000, indicating a strong relationship between the number of years in marriage and problem-focused coping mechanisms. Furthermore, the Linear-by-Linear Association yields a p-value of .547, showing that no significant linear trend exists in this association. This showed that the

association between years of marriage and problem-focused coping does not necessarily follow a straight line.

The Pearson Chi-Square produces a significant p-value of .002 for Emotional-Focused Coping, but the Likelihood Ratio produces a highly significant p-value of .000. These findings suggest a link between the number of years married and emotional-focused coping mechanisms. However, the p-value of .176 for the Linear-by-Linear link shows that this link may not follow a significant linear trend. The association between years in marriage and emotional-focused coping may be complex and nonlinear, as it is with avoidance-focused coping.

Overall, these findings showed that the number of years in marriage is highly related to coping techniques, especially avoidance-focused, problem-focused, and emotional-focused coping. The linear trends in these links, however, may not be statistically significant, signaling that the relationships seemed more complicated and influenced by a variety of factors.

Respondents Employment Status and Coping techniques

Table 4.21: Respondents' Employment Status and Coping Techniques Chi-Square Tests

		Value	Df	Asymptotic Significance (2-sided)
Avoidance focused	Pearson Chi-Square	47.378 ^a	22	.001
	Likelihood Ratio	41.911	22	.006
	Linear-by-Linear Association	.886	1	.347
Problem focused	Pearson Chi-Square	64.821 ^a	26	.000
	Likelihood Ratio	68.355	26	.000
	Linear-by-Linear Association	14.184	1	.000
Emotional focused	Pearson Chi-Square	47.093 ^a	26	.007
	Likelihood Ratio	52.373	26	.002

Linear-by-Linear Association	.290	1	.590
N of Valid Cases	60		

Table 4.21 displays Chi-Square Test results that investigated the association between respondents' employment status and their coping mechanisms. Chi-Square Test results for avoidance-focused coping mechanisms demonstrate statistically significant relationships with respondents' employment status. The Pearson Chi-Square ($p = .001$) and Likelihood Ratio ($p = .006$) generated significant p-values, demonstrated a substantial link between employment status and avoidance-focused coping methods. The p-value of .347 for the Linear-by-Linear connection indicates that this connection may not follow a significant linear trend, showing that the relationship between job status and avoidance-focused coping may be influenced by a variety of factors.

The findings of the Chi-Square Test for problem-focused coping techniques demonstrated a statistically significant relationship with respondents' employment level. The Pearson Chi-Square ($p = .000$) and Likelihood Ratio ($p = .000$) both produce highly significant p-values, demonstrating a robust association between employment status and problem-focused coping techniques. Furthermore, the Linear-by-Linear connection yields a p-value of .000, indicating that this connection has a significant linear trend. This means that the adoption of problem-focused coping techniques tends to alter in a linear way when work status changes.

The Pearson Chi-Square provided p-value of .007 for emotional-focused coping approaches, while the Likelihood Ratio yielded a p-value of .002. These findings show a statistically significant link between employment status and emotionally focused coping mechanisms. However, the p-value of .590 for the Linear-by-Linear link shows that this

link does not follow a significant linear trend. These findings generally indicate that employment status is highly related to coping strategies, notably avoidance-focused, problem-focused, and emotional-focused coping. While there is a substantial overall relationship, the exact nature of these interactions varies and do not always follow a straight line.

Respondents' Number of Children and Coping techniques

Table 4.22: Respondents' Number of Children and Coping Techniques Chi-Square Tests

		Value	df	Asymptotic Significance (2-sided)
Avoidance focused	Pearson Chi-Square	41.157 ^a	33	.156
	Likelihood Ratio	43.887	33	.097
	Linear-by-Linear Association	4.267	1	.039
Problem focused	Pearson Chi-Square	55.434 ^a	39	.042
	Likelihood Ratio	58.104	39	.025
	Linear-by-Linear Association	.564	1	.453
Emotional focused	Pearson Chi-Square	61.515 ^a	39	.012
	Likelihood Ratio	63.462	39	.008
	Linear-by-Linear Association	.880	1	.348
N of Valid Cases		60		

Table 4.22 displays Chi-Square Test results that investigated the association between the number of children caregivers have and their coping strategies. Findings Pearson Chi-Square and Likelihood Ratio Chi-Square Test results for avoidance-focused coping approaches show p-values of .156 and .097, respectively. While these values are not statistically significant, they do point to a possible link between the number of children caregivers have and avoidance-focused coping mechanisms. With a p-value

of.039, the Linear-by-Linear Association implies a significant linear trend in this association. This means that when the number of children caregivers have, the usage of avoidance-focused coping techniques may shift in a linear fashion.

The Pearson Chi-Square produced a p-value of.042 for problem-focused coping approaches, while the Likelihood Ratio yields a p-value of.025. These p-values suggest a link between the number of children caregivers have and problem-focused coping mechanisms. However, the p-value of.453 for the Linear-by-Linear link shows that this link may not follow a significant linear trend.

For emotional-focused coping tactics, the Pearson Chi-Square yields a p-value of.012, whilst the Likelihood Ratio yields a p-value of.008. These findings indicate a statistically significant link between the number of children caregivers have and emotional-focused coping mechanisms. However, the p-value of.348 for the Linear-by-Linear link suggests that this link may not follow a significant linear trend. This implies that the association between the number of children and emotional-focused coping is impacted by factors other than a straightforward linear pattern.

These findings seem to suggest that the number of children caregivers have is related to their coping strategies, particularly problem-focused and emotional-focused coping. While the overall associations were statistically significant, the nature of these relationships did not follow a predictable pattern.

Factors that Contribute to the Level of Burden Experienced by Caregivers

The fourth objective of the study was to investigate the factors that contribute to the level of burden experienced. Caregiving is a complex and challenging path for parents of autistic children, and frequently marked with anxieties. Several factors contribute to the

burden that these caregivers bear. These factors are more often associated with the demands for caring for autistic children can be overwhelming, expensive, time consuming. Table 4.23 summarizes the research findings, on factors that contribute to the caregivers' burden.

Table 4.23: Factors that Contribute to the Burden Experienced by Caregivers

	Time dependency burden	Development Burden	Physical health burden	Emotional health burden	Social relationships	Total score for CBI
N	60	60	60	60	60	60
Mean	14.25	8.45	7.32	2.92	6.77	38.97
Std. Deviation	4.960	4.739	6.013	2.830	5.241	19.381
Sum	855	507	439	175	406	2338

From the study, time demands emerged to be the greatest factor contributing to the burden of caregivers while caring for their autistic children. This factor scored a mean of 14.25 and a SD of 4.96. The time demands come about since the autistic children need a lot of care and attention. They need help to perform basic functions and a constant watch. This means that the caregiver needs to dedicate his/her time and therefore had to sacrifice other social and economic activities or find a reliever.

Developmental challenge came in as the second ranking factor that contributed to the burden of caregiver. The Developmental Burden had a mean score of 8.45 and a SD of .739, which implied that managing autistic children's developmental characteristics and milestones is another key element leading to caregiver burden.

Physical health burden which had a mean score of 7.32 and a SD of 6.013. Several factors that contribute to the physical drain, contribute to this stated mean. They collectively contribute to the caregivers' physical well-being load. This load is exacerbated by physical health problems and stressors associated to providing care. Some

of the items that contribute to physical burden are the comes about when they make the caregiver does not get adequate sleep, feel tired or become physically ill.

Social relationship factors affect the caregivers' social life and inter-relationships because their caregiving responsibilities. The responsibilities put the caregivers under pressure as they cannot adequately meet their social interactions and relationships obligations. Social factors contributed to a mean score of 6.77 and a SD of 5.241, giving an indication that it is difficult for carers to maintain social ties and relationships.

Overall Caregiver Burden: The overall caregiver burden, which had a mean score of 38.97, is represented by the "Total Score for CBI". This comprehensive score combines all the subscales and captures the overall hardship that caregivers bear. It implies that the entire caregiver load is a result of a confluence of time demands, developmental obligations, physical health effects, and social relationship strain.

Lastly, emotional factors also contributed to the caregivers' burden, with a mean score of 2.92 and a SD of 2.830. This mean shows that emotional burden was the lowest and items that contributed to emotional burden include aspects such as anger, shame, embarrassment, being uncomfortable and resentful about the autistic child.

These findings shade light on the multifaceted nature of caregiving role for parents of autistic children. Time demands emerged as the most substantial factor that contribute to their burden. This translates into sacrifices that were made by caregivers in terms of giving their time to careering activities and it often come at the expense of career, employment and other personal and economic pursuits, ruin social relationships and could bring many other impacts.

Summary of Key Findings

The following were the key findings of the study:

Parents had a significant time dependency burden, with ($14.25 \pm 4.96SD$); developmental burden ($8.45 \pm 4.739SD$); physical burden ($7.32 \pm 6.013SD$); physical toll ($2.92 \pm 2.83SD$) and social relationship stress ($6.77 \pm 5.241SD$).

Regarding gender differences in relation to the burden of caregiving experienced by parents with autistic children, female caregivers had a somewhat higher mean score (14.55) than male caregivers (12.91); on emotional toll of caregiving, male caregivers reported a marginally higher mean score (3.55) than female caregivers (2.78); female caregivers reported a somewhat higher mean score of 8.71 compared to the male caregivers' which was 7.27 in the context of the developmental burden.

Both female (6.76) and male (6.82) caregivers reported nearly identical mean scores on the Social Relationships Burden Sub-scale, which examines the pressure on caregivers' social contacts and relationships as a result of their caregiving responsibilities.

The association between respondents' gender and coping (Avoidance Focus) were statistically significant ($\chi^2=29.833^a$, $p=0.002$); gender and emotional-focused coping ($\chi^2=15.444^a$, $p=0.280$); gender and Problem Focus coping ($\chi^2=77.013^a$, $p=.032$)

Findings showed that the number of years in marriage is highly related to coping techniques, especially avoidance-focused, problem-focused, and emotional-focused coping.

The overall caregiver burden had a mean score of 38.97. This implies that the entire caregiver load is a result of a confluence of time demands, developmental obligations, physical health effects, and social relationship strain.

Emotional factors contributed to the caregivers' burden, with a mean score of 2.92 and a SD of 2.830. This mean shows that emotional burden was the lowest and items that contributed to emotional burden including aspects such as anger, shame, embarrassment, being uncomfortable and resentful about the autistic child.

Summary

Chapter four presented the findings of the study in line with the study's objectives. The summary of key findings and finally the chapter summary were presented.

CHAPTER FIVE

DISCUSSIONS, CONCLUSIONS, AND RECOMMENDATIONS

Introduction

In this chapter, the researcher analysed the study's findings in line with the study's objectives. Further results were drawn, and recommendations for future research were made. The recommendations and conclusions were based on the study objectives and results.

The study's target population were parents of autistic children. A total of 65 questionnaires were dispersed out to the participants, out of which, 60 were filled and returned for analysis. The researcher interviewed participants who were parents of children with autism who signed an informed consent to voluntarily participate in the study.

Discussions of Key Findings

The Burden of Autistic Caregiving

The first objective of this study was to assess the burden of care among parents with autistic children in selected groups, Nairobi County, Kenya. To gain insights into this, The Caregiver Burden Inventory (CBI); consisting of 24 closed-ended questions was administered to the respondents. CBI has five subscales: Time-dependence, Developmental, Physical, Social, and Emotional burdens.

This study found out that parents had a significant time dependency burden, with ($14.25 \pm 4.96SD$); developmental burden ($8.45 \pm 4.739SD$); physical burden ($7.32 \pm 6.013SD$); physical toll ($2.92 \pm 2.83SD$) and social relationship stress ($6.77 \pm 5.241SD$).

This study's findings agree with those of Hartmann (2012) which observed that there was a big problem because the society might not understand the condition of the child and think the parents just being bad parents. These parents faced a lot of stigmas. This is further supported by Fischbach (2015).

In line with the findings of this study were those of University of Missouri-Columbia, (2008) which highlighted the financial implications the autism diagnosis has to parents.

The results also supported the fact that families experience these struggles differently. Family makes up can determines the impact of the diagnosis as well: Single-parent households are more likely to experience financial difficulties, which could have an adverse effect on mental health (Stack & Meredith, 2018). This also agrees with those of Gona et al. (2016) that noted that the strain of having an autistic child can harm parents' psychological and emotional well-being and cause them to fight.

Gender Difference in Relation to the Burden of Caregiving

The second objective of the study was to investigate the gender difference in relation to the burden of caregiving experienced by parents with autistic children in selected groups, Nairobi, Kenya. Regarding gender differences in relation to the burden of caregiving experienced by parents with autistic children, female caregivers had a somewhat higher mean score (14.55) than male caregivers (12.91); on emotional toll of caregiving, male caregivers reported a marginally higher mean score (3.55) than female caregivers (2.78); female caregivers reported a somewhat higher mean score of 8.71 compared to the male caregivers' which was 7.27 in the context of the developmental

burden. Both female (6.76) and male (6.82) caregivers reported nearly identical mean scores on the Social Relationships Burden Sub-scale, which examines the pressure on caregivers' social contacts and relationships as a result of their caregiving responsibilities. The association between respondents' gender and coping (Avoidance Focus) were statistically significant ($\chi^2=29.833^a$, $p=0.002$); gender and emotional-focused coping ($\chi^2=15.444^a$, $p=0.280$); gender and Problem Focus coping ($\chi^2=77.013^a$, $p=.032$)

These findings are consistent with the findings of Pandey and Sharma (2018) that demonstrated that there were no gender differences in the burden of care.

Coping Strategies Employed by the Parents of Autistic Children

The third objective of the study sought to analyse the coping strategies employed by the parents of autistic children in relation to their demographics in selected groups, Nairobi County, Kenya. This study found out that the overall caregiver burden had a mean score of 38.97. This implies that the entire caregiver load is a result of a confluence of time demands, developmental obligations, physical health effects, and social relationship strain.

Emotional factors contributed to the caregivers' burden, with a mean score of 2.92 and a SD of 2.830. This mean shows that emotional burden was the lowest and items that contributed to emotional burden including aspects such as anger, shame, embarrassment, being uncomfortable and resentful about the autistic child.

The findings agree with those of Cauda-Laufer (2017) in a study to investigate the relationship between coping mechanisms of parents raising a child with disability on their mental health. They observed that there were 9 coping strategies parents tend to

employ. She described them as confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem solving, and positive reappraisal. According to the findings of her study, parents' coping strategies did not significantly relate to their level of distress, and good adaptive coping did not produce better mental health outcomes. However, research as cited by Cauda-Laufer (2017, p. 10), has demonstrated that parents of children with impairments are more likely to endure stress and to develop mental health problems. Additionally, it supports the findings of Gona et al. (2016) Gona et al. (2016), which identified two primary coping mechanisms used by parents to provide day-to-day care for their autistic kid. The first strategy was problem-focused and the second was emotion-focused. The problem-focused strategies were those directed at managing or altering the problem that brought the distress whereas the emotion-focused strategies are directed at regulating the emotional response of the problem.

Factors that Contribute to the Level of Burden Experienced by Caregivers

The fourth objective of the study was to investigate the factors that contribute to the level of burden experienced. Caregiving is a complex and challenging path for parents of autistic children, and frequently marked with anxieties. Several factors contribute to the burden that these caregivers bear. These factors are more often associated with the demands for caring for autistic children can be overwhelming, expensive, time consuming.

The study observed that the level of education within the sample group accounted to less on how parents cope with the challenges of having a child with ASD. However, it noted willingness to a more personalized approach to understanding the views,

capabilities, and potential needs of the child as the levels went up. The level of education was compounded by other factors like employment status and support from spouses and family, and financial ability to employ a house manager to take care of the child. The study noted that the more respondents were learned, the more they were capable of being financially able.

From the findings, time demands emerged to be the greatest factor contributing to the burden of caregivers while caring for their autistic children. This factor scored a mean of 14.25 and a SD of 4.96. The time demand comes about since the autistic children need a lot of care and attention. They need help to perform basic functions and a constant watch. This means that the caregiver needs to dedicate his/her time and therefore had to sacrifice other social and economic activities or find a reliever.

Developmental challenge came in as the second ranking factor that contributed to the burden of caregiver. The Developmental Burden had a mean score of 8.45 and a SD of .739, which implied that managing autistic children's developmental characteristics and milestones is another key element leading to caregiver burden.

Physical health burden which had a mean score of 7.32 and a SD of 6.013. Several factors that contribute to the physical drain, contribute to this stated mean. They collectively contribute to the caregivers' physical well-being load. This load is exacerbated by physical health problems and stressors associated to providing care. Some of the items that contribute to physical burden are the comes about when they make the caregiver does not get adequate sleep, feel tired or become physically ill.

Social relationship factors affect the caregivers' social life and inter-relationships because their caregiving responsibilities. The responsibilities put the caregivers under

pressure as they cannot adequately meet their social interactions and relationships obligations. Social factors contributed to a mean score of 6.77 and a SD of 5.241, giving an indication that it is difficult for carers to maintain social ties and relationships.

The findings were in line with those of a study by Cetinbakis et al. (2020) on what causes Turkish mothers of children with autism spectrum disorders to bear a heavier burden of caregiving. The study found out that in Turkish children with ASD, higher parental caregiving stress was associated with lower life satisfaction and a higher level of impairment. Additionally, greater social support and dyadic adjustment among mothers of children with ASD were linked to greater life satisfaction, as well as lower levels of expressed emotions.

Conclusion

The study found out that parents of kids with ASD experienced a significant time dependency burden hence need support. Since there were no gender variations in the burden of care, parents with such children regardless of gender need support.

Recommendations

The study makes the following recommendations:

1. Since parents with ASD children had a significant time dependency burden, there ought to be programs that can support them through the emotional process.
2. There should be no discrimination across gender in the provision of support and care for parents with ASD children.
3. Psycho-education and counselling programs should be developed to support parents with ASD.

4. The government need to develop a special fund for parent with ASD children to support their special needs.

Areas for Further Research

In accordance with the study's findings, additional investigation is advised in the following fields.

1. Similar studies should be done for parents with grown up ASD children.
2. More studies should be done for ASD children and their coping strategies.
3. A similar study should be done on the psychological challenges facing such children.

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DAYSTAR UNIVERSITY

APPENDICES

Appendix A: Letter of Introduction

25th January 2023

National Commission for Science, Technology and Innovation
P. O. Box 30623-00100 Nairobi
KENYA

Dear Sir/Madam,

RE: OSCAR ONYANGO ODHIAMBO ADM NO: 19-1470

The above-named is a student in the Masters of Arts in Counselling Psychology program at Daystar University, Nairobi Campus.

He has completed his coursework for his Master's, defended his Master's proposal, done corrections as recommended by examiners, and is now ready to go to the field to collect data.

His topic of study is

“Thesis Topic: An Assessment Of Burden Of Care For Parents Of Autistic Children And Their Coping Strategies: Case Of Selected Groups In Nairobi County, Kenya ”.

He is hereby authorized by the University to carry out his study by collecting data from the field. He requires your authorization such that he can be able to access and identify his target population. Thank you in advance for your willingness to give this opportunity. We are truly grateful for your partnership and for your organization's contribution to the education of Daystar University students.

If you have any queries, please do not hesitate to contact me.

Yours faithfully,



FOR: Dr. Jared Menecha
HOD Counselling Psychology



Athi River Campus
P.O. Box 17, Daystar University,
90145, Athi River, Kenya

Valley Road Campus
P.O. Box 44400 - 00100,
Nairobi, Kenya

Tel: 0709 972 000 (Pilot Line)
0716 170 313 (Marketing)
0748 100 759 (PR Line)

E-mail: admissions@daystar.ac.ke OR
info@daystar.ac.ke

Website: www.daystar.ac.ke

Appendix B. Consent Form

Participant Consent Form

AN ASSESSMENT OF BURDEN OF CARE FOR PARENTS OF AUTISTIC
CHILDREN AND THEIR COPING STRATEGIES: CASE OF SELECTED GROUPS
IN NAIROBI COUNTY, KENYA

Consent to take part in research

- I..... voluntarily agree to participate in this research study.
- I understand that even if I agree to participate now, I can withdraw at any time or refuse to answer any question without any consequences of any kind.
- I understand that I can withdraw permission to use data from my interview within two weeks' after the interview, in which case the material will be deleted.
- I have had the purpose and nature of the study explained to me and I have had the opportunity to ask questions about the study.
- I understand that participation involves honestly filling in the questionnaires provided by the researchers.
- I understand that I will not benefit directly from participating in this research.

- I agree to my interview being audio-recorded.
- I understand that all information I provide for this study will be treated confidentially.
- I understand that in any report on the results of this research my identity will remain anonymous. (This will be done by changing my name and disguising any details of my interview which may reveal my identity or the identity of people I speak about.)
- I understand that disguised extracts from my interview may be quoted in the dissertation when published.
- I understand that if I inform the researcher that myself or someone else is at risk of harm they may have to report this to the relevant authorities - they will discuss this with me first but may be required to report with or without my permission.
- I understand that signed consent forms and original audio recordings will be retained with the researcher under a safe until the when the exam board confirms the results of their dissertation.
- I understand that a transcript of my interview in which all identifying information has been removed will be retained for two years from the date of the exam board.
- I understand that under freedom of information legalization I am entitled to access the information I have provided at any time while it is in storage as specified above.

I understand that I am free to contact any of the people involved in the research to seek further clarification and information.

Names, degrees, affiliations and contact details of researchers (and academic supervisors when relevant).

Signature of research participant

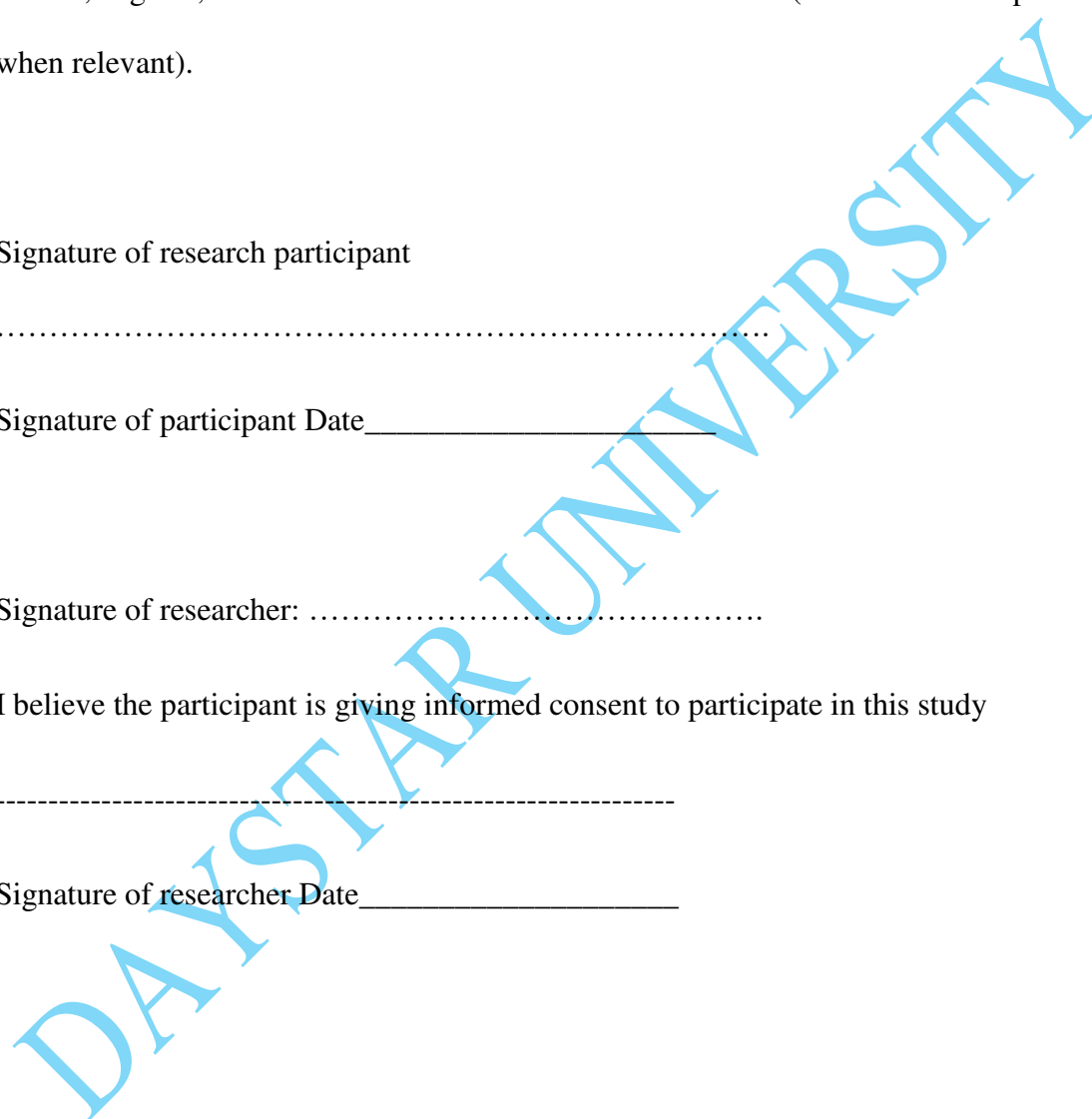
.....

Signature of participant Date _____

Signature of researcher:

I believe the participant is giving informed consent to participate in this study

Signature of researcher Date _____



Appendix C: Caregiver Burden Inventory

Caregiver Burden Inventory (Novak and Guest, 1989)

The Case Manager will administer the inventory by reading the statement and marking the responses.

Choose the number that best represents how often the statement describes your feelings.

- 0 - Never
- 1 - Rarely
- 2 - Sometimes
- 3 - Quite Frequently
- 4 - Nearly Always

Client Name _____ Caregiver Name _____ Date _____

Time Dependency Items	
He/she needs my help to perform many daily tasks	① ① ② ③ ④
He/she is dependent on me	① ① ② ③ ④
I have to watch him/her constantly	① ① ② ③ ④
I have to help him/her with many basic functions	① ① ② ③ ④
I don't have a minute's break from his/her chores	① ① ② ③ ④

Development Items	
I feel that I am missing out on life	① ① ② ③ ④
I wish I could escape from this situation	① ① ② ③ ④
My social life has suffered	① ① ② ③ ④
I feel emotionally drained due to caring for him/her	① ① ② ③ ④
I expected that things would be different at this point in my life	① ① ② ③ ④

Physical Health Items	
I'm not getting enough sleep	① ① ② ③ ④
My health has suffered	① ① ② ③ ④
Care giving has made me physically sick	① ① ② ③ ④
I'm physically tired	① ① ② ③ ④

Emotional Health Items	
I feel embarrassed over his/her behavior	① ① ② ③ ④
I feel ashamed of him/her	① ① ② ③ ④
I resent him/her	① ① ② ③ ④
I feel uncomfortable when I have friends over	① ① ② ③ ④
I feel angry about my interactions with him/her	① ① ② ③ ④

Social Relationships Items	
I don't get along with other family members as well as I used to	① ① ② ③ ④
My care giving efforts aren't appreciated by others in my family	① ① ② ③ ④
I've had problems with my marriage (or other significant relationship)	① ① ② ③ ④
I don't get along as well as I used to with others	① ① ② ③ ④
I feel resentful of other relatives who could but do not help	① ① ② ③ ④

Total Score: _____

Scores near or above 36 indicates a greater need for respite and other services.

It is important to seriously look at any item on the burden scale where the answer was scored as a 3 or 4 ('quite frequently' or 'nearly always'). If you have a 3 or 4 as an answer, give careful thought about why the caregiver scored so high on the question and see if you can find away to reduce the stress.

Comments: _____

Appendix D: The Brief Cope Inventory

Brief - Coping Orientation to Problems Experienced Inventory (Brief-COPE)

Instructions:

The following questions ask how you have sought to cope with a hardship in your life. Read the statements and indicate how much you have been using each coping style.

		I haven't been doing this at all	A little bit	A medium amount	I've been doing this a lot
1	I've been turning to work or other activities to take my mind off things.	1	2	3	4
2	I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
3	I've been saying to myself "this isn't real".	1	2	3	4
4	I've been using alcohol or other drugs to make myself feel better	1	2	3	4
5	I've been getting emotional support from others.	1	2	3	4
6	I've been giving up trying to deal with it.	1	2	3	4
7	I've been taking action to try to make the situation better.	1	2	3	4
8	I've been refusing to believe that it has happened.	1	2	3	4
9	I've been saying things to let my unpleasant feelings escape.	1	2	3	4
10	I've been getting help and advice from other people.	1	2	3	4
11	I've been using alcohol or other drugs to help me get through it.	1	2	3	4
12	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
13	I've been criticizing myself.	1	2	3	4
14	I've been trying to come up with a strategy about what to do.	1	2	3	4
15	I've been getting comfort and understanding from someone.	1	2	3	4
16	I've been giving up the attempt to cope.	1	2	3	4



		I haven't been doing this at all	A little bit	A medium amount	I've been doing this a lot
17	I've been looking for something good in what is happening.	1	2	3	4
18	I've been making jokes about it.	1	2	3	4
19	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
20	I've been accepting the reality of the fact that it has happened.	1	2	3	4
21	I've been expressing my negative feelings.	1	2	3	4
22	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
23	I've been trying to get advice or help from other people about what to do.	1	2	3	4
24	I've been learning to live with it.	1	2	3	4
25	I've been thinking hard about what steps to take.	1	2	3	4
26	I've been blaming myself for things that happened	1	2	3	4
27	I've been praying or meditating	1	2	3	4
28	I've been making fun of the situation.	1	2	3	4

Developer Reference:

Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the brief cope. *International journal of behavioral medicine*, 4(1), 92-100.

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Appendix E: Social Demographic Questionnaire

STUDY QUESTIONNAIRE

Dear répondent,

My name is Oscar Onyango Odhiambo, a student undertaking a Master's Degree in Counselling Psychology at Daystar University. I am expected to conduct a scientific research study in partial fulfilment to complete my studies.

The study has been approved by the university and the department of psychology and Counselling at Daystar University. The study is entitled "An Assessment of Burden of Care for Parents of Autistic Children and Their Coping Strategies: Case of Selected Groups in Nairobi County, Kenya".

The study aims to assess the burden of care for parents of autistic children and their coping strategies. The study will also provide knowledge to other stakeholders in special needs institutions, hospitals, and society on how best to care for children with ASD and their parents. This study will form a basis for making recommendations to the Government of Kenya, Non-Governmental Organizations (NGOs), the public, schools, Counsellors, and public and private hospitals in providing necessary support to parents while caring for their children diagnosed with ASD.

Very strict ethical considerations have been and will be put in place to ensure confidentiality and anonymity. You are advised **not to write/type your name** on the questionnaire as all of them have been given anonymous numbers. There are no invasive procedures that will be conducted on you. If however any uncomfortable psychological feelings are evoked in the course of completing the questionnaire which you cannot

handle, you may call **0729 558 635** for any counselling help. All the questionnaires will only be handled by the statistician and the researcher after which they will be put under key and locked until when the study will be completed. They will then be destroyed.

Some of the respondents will receive the questionnaires through hand delivery while others will receive them through their emails.

For those who will receive a hand copy, I humbly request you to complete the questionnaire, staple it, and put it in the envelop provided and put the sealed envelope in the ballot box with the research assistant who will deliver it to me to be opened by the data analyst for purposes of data analysis.

For those who receive this document by email, kindly complete it and send it to this email: oscarbiggo@gmail.com, which will be disbanded after all data has been uploaded.

Thank you very much for your involvement in this study.

God bless you

SECTION A

1. Gender: Male () Female ()
2. Religion:
Christian () Atheist ()
Muslim () Others ()
Hindu ()
3. Age Group (years):

17-23 ()

31-36 ()

43-49 ()

24-30 ()

37-42 ()

Above 50 ()

3. Marital Status:

Married ()

Single Parent ()

Widowed ()

Separated ()

4. Age of the Child:

1-8 ()

9-16 ()

17-24 ()

25-32 ()

Above 32 ()

5. Gender of the Child:

Male ()

Female ()

6. How many children do you have?.....

7. How many years have you been in marriage?

1-5 years ()

6-10 years ()

11- 20 years ()

More than 20 years ()

6. Kindly indicate your Level of Education

Doctorate/Masters ()

Undergraduates ()

Diploma ()

Certificate ()

Secondary ()

Primary ()

None ()

8. What is your employment Status?

Formal employment ()

Self-Employed ()

Unemployed ()

SECTION B

Please select the appropriate response that best describes the challenges you go through as a parent to a child with Autism

Note: SA: Strongly Agree A: Agree D: Disagree SD: Strongly Disagree

Statement	SA	A		N	D	SD
I am coping better with the challenges posed by having a child with ASD						
My duties as a parent to my child with ASD have affected my marriage						
My spouse is supportive of me in caring for our child with ASD						
I am content with my performance as a mother to my other children						

I am overwhelmed by my duties as a mother/father because of the challenges of ASD						
Money is a problem						
I am confident my child will get better						
Caring for my child with ASD has affected my work (career)						
I understand the cause of ASD to my child.						
My marriage is in turmoil because of the challenges we have caring for our child						
Our extended family is supportive in caring for our child with ASD						
My faith in God has been instrumental in helping me cope with the challenges associated with ASD						
I have given up						
I blame myself for my child's ASD diagnosis						
I blame my spouse for my child's ASD diagnosis						

Appendix F: Ethical Clearance.

VERDICT: APPROVED WITH COMMENTS

Daystar University Institutional Scientific and Ethics Review Committee (DU-ISERC)

Our Ref: **DU-ISERC/ 07/07/2023/000894**Date: 7th July 2023To: **Oscar Odhiambo**

Dear Oscar,

AN ASSESSMENT OF {THE} BURDEN OF CARE FOR PARENTS OF AUTISTIC CHILDREN AND THEIR COPING STRATEGIES: CASE OF SELECTED GROUPS IN NAIROBI COUNTY, KENYA

Reference is made to your ISERC application reference No. **080623-01** dated **8th June 2023** in which you requested for ethical approval of your proposal by Daystar University Ethics Review Board.

We are pleased to inform you that ethical review has been done and the verdict is to **Revise, to the satisfaction of the Supervisors and then proceed to the next stage**. As guidance, ensure that the attached comments are addressed.


Please be advised that it is an offence to proceed to collect data without addressing the concerns of Ethics Review board. Your application approval number is **DU-ISERC-000894**. The approval period for the research is **between 7th 2023 to 6th July 2024** after which the ethical approval lapses. Should you wish to continue with the research after the lapse you will be required to apply for an extension from DU-ERB at half the review charges.

This approval is subject to compliance with the following requirements.

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

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

Yours sincerely



Dr. Susan Muriungi PhD
Ag. Chair, Daystar University Institutional Scientific and Ethics Review Committee

Encl. Review Report



"...until the day dawn and the
DAYSTAR arise in your hearts"
2 Peter 1:19 KJV

Appendix H: Plagiarism Report

Submission date: 17-Oct-2023 02:02PM (UTC+0300)

Submission ID: 2198510678

File name: Oscar_Odhiambo_Thesis.docx (266.21K)

Word count: 21294

Character count: 118990

Oscar Odhiambo Thesis

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