FACTORS CONTRIBUTING TO ROLE STRAIN AMONG CAREGIVERS OF CHILDREN WITH EXTREME DISABILITIES AT THIKA LEVEL 5 HOSPITAL OCCUPATIONAL CENTER, KENYA

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Factors Contributing to Role Strain among Caregivers of Children with Extreme Disabilities at Thika Level 5 Hospital Occupational Center, Kenya

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DECLARATION

This thesis is my original work and has not been presented for a degree in any other University

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This thesis has been submitted for examination with our approval as the University Supervisors

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DEDICATION

To my family and sons, and to my lecturers

ACKNOWLEDGEMENT

I sincerely acknowledge my supervisors for their support throughout this research.
I wish you God's blessings

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF APPENDICES

ACRONYMS AND ABBREVIATIONS

AOR	Adjusted Odds Ratios
CI	Confidence Interval
CWD	Children with Disabilities’
FGDs	Focused Group Discussions
HPM	Health Promotion Model
JKUAT	Jomo Kenyatta University of Agriculture and Technology
KEMRI	Kenya Medical Research Institute
MoH	Ministry of Health
NACOSTI	National Commission of Science Technology and Innovation
OR	Odds Ratio
QoL	Quality of Life
SPSS	Statistical Package of Social Science
SSA	Sub-Saharan Africa
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization

DEFINITION OF OPERATIONAL TERMS

Caregiver	This refers to a trained or untrained person or a close family member who is paid to care for a disabled child, sick or elderly
Disability	Refers to having a situation that limits a person physically or mentally from performing his/her basic life activities.
Extreme Disability	Refers to limitation of one or many areas of functioning that affect individual performance.
Social Culture	Refers to behavior of certain group of people living together by friendship or related to each other sharing a common behavior or a common geographical region.
Strain	Making extra great effort that one makes consume more energy.

ABSTRACT

Caregiver role strain occurs when an individual caring a child with disability exceeds his/her resources and ability to cope with the demands of the caregiving. Caregivers of children with disabilities repeatedly have feelings of discrimination, stigma and exclusion in many aspects of live. The study aimed to assess factors contributing to role strain among caregivers of children with extreme disabilities at Thika level 5 hospital Occupational Care Center, Kenya. The study was mixed study design that utilized a case control and a phenomenological study design. A sample size of 136 caregivers of children with extreme disability were selected using a consecutive sampling technique. Semi-Structured questionnaire and focused group discussion guide was used to collect data. Data analysis was done using descriptive and inferential analysis by use of statistical package of social sciences (SPSS) version 26 software. Inferential statistics was done using binary and multivariate logistic regression to determine relationship between the independent and dependent variables. Multivariable analysis revealed that caregivers who were single (AOR =2.16, 95% CI:1.01 – 4.63, p =0.048), caregivers who were contented with the stigma labelled against them in the society (AOR =2.59, 95% CI:1.20 – 5.57, p=0.015), those who had minimal financial support (AOR =0.39, 95% CI: 0.17 – 0.87, p =0.002), those who asserted that poverty was observed in the standard of the housing, number of meals eaten per day and the quantity of food served (AOR =2.28, 95% CI:1.01 – 5.16, p =0.048) and those who agreed that there is high cost of materials such as wheelchairs and food (AOR =0.26, 95%CI:0.11 – 0.63, p =0.003) were independent factors associated with role strain. Caregivers of children with disability have a higher role strain which has been associated with marital status, content with stigma, minimal financial support, poverty in household, high cost of materials such as wheelchair and number of meals per day. Thus, there is need for the government in partnership with non –state actors to ensure the provision of support at centers that offer counseling services to individuals, groups or families who have children with disabilities. The government needs to introduce a grant for primary caregivers and encourage them to be self-employed from home

CHAPTER ONE

INTRODUCTION

1.1 Background of Study

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) considers persons with disability as those who have long-term physical, mental, intellectual or sensory impairments which hinder their full and effective participation in society on an equal basis with others. The major cause of disability includes congenital abnormalities, injuries/accidents, old age and diseases (Ghazawy et al., 2020;Burchell, 2018). Globally, people who live with some form of disability constitute approximately 15% of the population, and children constitute the larger proportion (Ghazawy *et al* 2020; Sammon & Burchell, 2018).

Caregivers role strain is defined as a feeling of being overwhelmed, overloaded, or no longer being able to continue with care (Klutse, 2018; Lin, 2016). Care of children with extreme disabilities entails provision of intense, prolonged and substantial care, by assisting them to perform activities that are key for survival, which in their capacity they are unable to perform (Klutse, 2018; Lin, 2016). These activities include assisting a child with mobility, dressing and bathing (Alariefy, 2016; Ndirangu & Midigo, 2018). Caregiver role strain occur when care giving exceeds the resources and ability to cope with the demands of care (Alariefy, 2016; Ndirangu & Midigo, 2018). This occurrence can be measured by Caregiver Burden Inventory (CBI) scale (Tong *et al.,* 2017).

The World Health Organization (WHO) reports that around 1.3 billion people, or 16% of the global population, experience some form of disability, a significant public health challenge largely linked to the increasing burden of non-communicable diseases (NCDs) (World Health Organization, 2023).These chronic conditions—such as heart disease, diabetes, cancer, and chronic respiratory diseases—often lead to long-term complications that impair daily functioning and quality of life. As the global population ages, the prevalence of both NCDs and disabilities rises, particularly among older adults who are more susceptible to conditions like arthritis and dementia. Socioeconomic factors further exacerbate this issue, as individuals in poorer communities face limited access to healthcare and preventive measures. Additionally, mental health disorders, which are also classified as NCDs, contribute significantly to disability, highlighting the need for integrated healthcare approaches that address both physical and mental health needs (Keletwaetse et al., 2023; Sakwape et al., 2023).

A report published by UNICEF showed that almost 240 million children live with disabilities with children aged 6 – 14 years children with disability requiring personal assistance (UNICEF, 2021). These children and their families face many challenges which includes social discrimination, neglect, abandonment, poverty, economic deprivation, education challenges, violence, and metal and psychological challenges.

Caregivers of children with disability are faced with burden caring for these children which may lead to physical, mental, social and financial challenges. These challenges faced by caregivers are known as the 'caregivers' burden' and may be described as feeling of heavy responsibility, constant worries, and uncertainty about patients' needs and constraints in caregivers' social life (Olusanya et al., 2022). Limited resources in developing countries contribute to higher role strain among caregivers. In Kenya, the concerns of caregivers of children with extreme disabilities have been ignored and there is little research done on factors contributing to role strain among caregivers. Therefore, this study seeks to determine the caregivers' role strain affecting care provided to children with extreme disabilities at Thika Occupational care center.

1.2 Statement of the Problem

Globally, people who live with some form of disability constitute approximately 15% of the population, and children constitute the larger proportion (Ghazawy *et al* 2020). In the US, people living with extreme disability are estimated to be 48.9 million people, or 19.4% of the non-institutionalized civilians, of which an estimated 24.1 million people have a severe disability (UNICEF, 2021). The same report estimated 34.2 million people, or 17.5%, have a functional limitation. The Report further estimates that there are currently over 400 million people with disability who live in developing countries and 80 million in Africa (UNICEF, 2021). However, it has been reported that about forty percent of Africa's population consists of people with disabilities, including 10-15 percent of school-age children. This percentage would translate into about 300 million people with disabilities in Africa (Lawson et al., 2020). Significantly, over 0.8% are children with extreme disability in the Sub-Saharan Africa (Zhang & Holden, 2024).

The care of children with extreme disability poses many challenges to caregivers. It is reported that burnout due to non-existence of policies, unavailability of resources and infrastructure for care of children with extreme disabilities contributes to caregiver role strains. Over 1-3% of caregivers' face burnout related to caregiving, a phenomenon that further escalate to caregiver burden (Moosa-Tayob & Risenga, 2022). It is reported in Ghana that raising children with intellectual disability has enormous psychological challenges often expressed as depression, anxiety, and somatic symptoms among caregivers (Abeasi et al., 2024). Caregivers face financial burden, when seeking treatment for children with extreme disabilities. The findings from their study also showed that in Ghana reported that families experienced financial challenges related to caregiving as they had to engage experts (Abeasi et al., 2024). Due to this, they may financially depend on relatives who may not cater for all their needs. This contributes to poor health and prognosis of these children. In the health care facilities, there is lack specialized treatment which increase burden of care to the caregivers.

Culture discriminates caregivers with extremely disabled children as they are considered misfit in the society. Some African culture see children with extreme disability as a curse in the societies, forcing caregivers to shy off from sending them to health and educational facilities, further making caregiving a challenge (Olusanya et al., 2022). Caregivers also cannot participate in community activities since they are protective of their disabled children, who they feel should not be exposed to the community (Zeeshan et al., 2022).

Consequently, they are affected psychologically and socially, thus cannot be able to offer comprehensive care.

In Mbagathi Occupational Care Center, research had indicated that caregivers of children with disabilities experienced psychological trauma that had negative impact on care they provided to their children (Mattison et al., 2017). Similarly, in Thika Occupational Care Center, unpublished reports indicated that 85% of caregivers did express role strain in caring children with extreme disability. Due to this, there was an increasing trend of hospital admission of extremely disabled children after discharge from an average of 12.1% in 2016 to 13% in 2019 (Thika Occupational care centre Records, 2019). Despite this, there are few documented studies done to determine factors contributing to role strain among caregivers of children with extreme disabilities at Thika level 5 Hospital Occupational Care Center, Kenya.

1.3 Justification of the Study

Provision of care to extremely disabled children has significant benefits with regard to patient compliance to treatment and decrease in associated complications. In addition, a caring environment provided to extremely disabled children reduces underlying social and economic costs, such as those related to health care (including hospital admissions/readmissions and estimated lifetime health care costs related to disability complications, loss of income, social expenditure, loss of productivity, and also costs associated with missed opportunities for economic development (Moosa-Tayob & Risenga, 2022). Further, there is a decrease in morbidity and mortality related to disability, improvement in quality of life and an increase in length of life (Abeasi et al., 2024). It also meets the children with disabilities health care needs, benefit them directly and also positively influence attitudes of the caregivers.

Few studies have been conducted on caregivers role strain affecting care provided to children with extreme disabilities (Gulabani *et al.*, 2014). Therefore, findings from this study will act as a spring board for other relevant studies to be done among children with extreme disabilities. The findings will provide information to the clinical staffs, administrators of the hospital, county government and the national government on the importance of caregivers’ role strain affecting care provided to children with extreme disabilities, especially at a time when the Kenya government is in the process of curbing down the morbidity and mortality related to disabilities. The findings will also lead to identification of key factors that contribute to a higher occurrence of role strain among caregivers which will inform countermeasures to improve their wellbeing.

1.4 Research Questions

1. What are the socio-cultural factors contributing to role strain among caregivers of children with extreme disabilities at Thika level 5 Hospital Occupational Care Center, Kenya?
2. What are the psychological factors contributing to role strain among caregivers of children with extreme disabilities at Thika Level 5 Hospital Occupational Care Center, Kenya?
3. What are the economic factors contributing to role strain among caregivers of children with extreme disabilities at Thika level 5 Hospital Occupational Care Center, Kenya?

1.5 Objective of the Study

1.5.1 Broad Objective

To determine factors contributing to role strain among caregivers of children with extreme disabilities at Thika level 5 Hospital Occupational Care Center, Kenya.

1.5.2 Specific Objectives

1. To assess socio-cultural factors contributing to role strain among caregivers of children with extreme disabilities at Thika level 5 Hospital Occupational Care Center, Kenya

2. To determine psychological factors contributing to role strain among caregivers of children with extreme disabilities at Thika level 5 Hospital Occupational Care Center, Kenya.
3. To determine economic factors contributing to role strain among caregivers of children with extreme disabilities at Thika level 5 Hospital Occupational Care Center, Kenya

1.6 Hypothesis of the Study

H_{01}: There is no significant association between socio-cultural factors and role strain among caregivers of children with extreme disabilities at Thika level 5 hospital occupational care center, Kenya

H_{02}: There is no significant association between psychological factors and role strain among caregivers of children with extreme disabilities at Thika level 5 hospital occupational care center, Kenya.

H_{03}: There is no significant association between economic factors and role strain among caregivers of children with extreme disabilities at Thika level 5 hospital occupational care center, Kenya.

1.7 Theoretical Framework

This study was underpinned by the social cultural theory. This theory was developed by Lev Vygotsky in 1934 and modified in 1978 (McLeod, 2024). Social-Cultural Theory provides a valuable framework for understanding the role strain experienced by caregivers of children with extreme disabilities. This theory posits that individual behavior and identity are shaped by social interactions and cultural contexts. For caregivers, the expectations and norms surrounding caregiving roles can create significant strain, particularly when caring for children with complex needs. These caregivers often grapple with societal pressures that define ideal caregiving practices, which may not align with their actual experiences and capabilities. The demands of caregiving can lead to feelings of inadequacy and isolation, especially when cultural narratives emphasize self-sacrifice and resilience (McLeod, 2024).

Moreover, the intersectionality of caregiver identities such as gender, ethnicity, and socioeconomic status which further complicates their experiences. For instance, many caregivers are women who face additional societal expectations related to domestic responsibilities, which can amplify feelings of being overwhelmed. Cultural stigmas surrounding disability can also affect caregivers' social interactions, leading to a lack of support from their communities (Muriuki et al., 2023). The absence of culturally competent resources and services can exacerbate the challenges caregivers face, leaving them without essential coping mechanisms or emotional outlets.

1.8 Conceptual Framework

The framework depicts variables that contributed to role strain among caregivers of children with extreme disabilities at Thika level 5 Hospital Occupational Care Center, Kenya. From the literature review of the specific objectives; socio-cultural, economic and psychological factors were impendent variables influencing dependent variables.

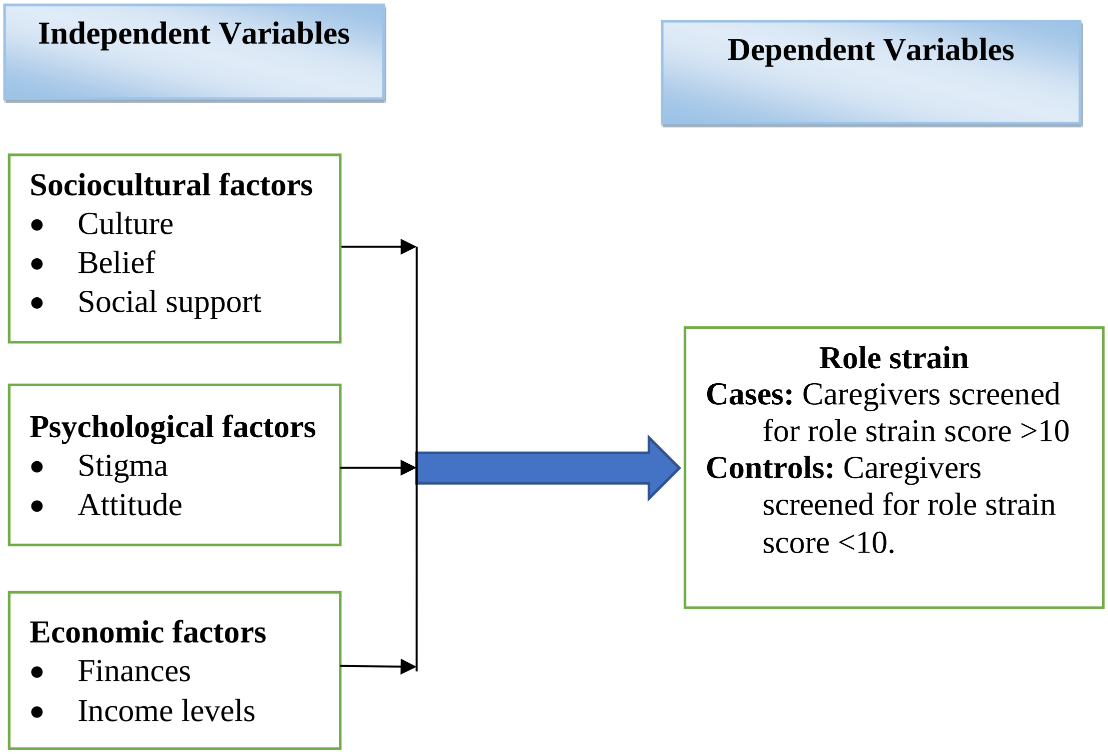

Figure 1.1: Conceptual Framework

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

The cultural environment and expectations of caregivers predict the way in which caregiver burden is understood and evaluated (Cobbinah, 2015; Klutse, 2018). Culture expects caregivers to offer continuous care to the disabled child or otherwise are perceived punitive. Secondly, psychological factors effects such as symptoms of anxiety, depression and physical distress (Tong et al., 2017) empathy and commitment to caregiving among others have been documented as some of the influencing factors to role strains. These may compromise the health of caregivers as they may neglect their own health. Thirdly, economic factors such as financial challenges and income levels of families have been documented as key influencers to caregiver role strain. The purpose of this chapter will review some of these factors in relation to the effects on caregiver's role strains in caring children with extreme disabilities in Kenya and globally.

2.2 Socio-Cultural Factors Contributing to Role Strain among Caregivers Of Children with Disabilities

The family is an important institution for building relationships. In the African context, the culture provides a structured way of expressing oneself. Families support their members to overcome emerging challenges. Social- cultural practices and economic cooperation focuses that each family member has a set of responsibilities for the survival of others. In most cultures, the adult family members are responsible for the young (Chabeda-Barthe et al., 2019). Benavides, (2019), in a study on "Stress Among Caregivers of Individuals with Special Needs" reported that 67% of caregivers experienced role strain in care of children with extreme disabilities. In the same study, Benavides noted that culture regards the caregivers and their family of children with extreme disabilities as outcast and therefore are discriminated from the family systems are extensive and bound by values of caring and sharing (Acheampong et al., 2019). However, families with disabled children in the community are stigmatized and rejected. Thus there is little time for community participation and socialization following much of the time is taken during caregiving (Ndadzungira, 2016). Most of the caregivers' have little time to care for their partners and other siblings in that household. Consequently, people who are divorced or separated experience chronic stressors relating to their marital situation thereby resulting in magnified negative effects on psychological wellbeing. This is supported by (Tong et al., 2017) study which revealed that as a result of the overload of pressures, divorced or separated caregivers may be more vulnerable to developing a psychological disorder.

Taboos and belief systems in Kenya cause stigma on development of a disabled child and their caregivers (Chabeda-Barthe et al., 2019) reported that in some traditional cultures, it is believed that meeting a disabled child spells doom for the rest of the life. He further reported that pregnant women are also admonished to stay away from caregivers of children with disabilities due to the belief that they would give birth to children with similar disabilities bringing burdens on caregivers. Interestingly, the study by Chabeda-Barthe, *et al* (2019) in Kenya observed that parents with children with disability are ready to do anything including migrating to other countries /areas where positive acknowledgement and support for care of their children. The study concludes that much needs to be done to change the attitude towards disability from the medical and moral (religious/cultural models to social models that care of these children is seen as a social responsibility.

2.3 Psychological Factors Contributing to Role Strain among Caregivers of Children with Disabilities

Caregivers' psychological wellbeing affects the care provided to children with extreme disabilities. The work of caregiving to normal children is psychologically draining and worse to children with extreme disability these children require a lot of attention in care. Caregivers' disabled individuals have a negative assessment of their own wellbeing. In (Elford, 2015) study investigating the subjective wellbeing among caregivers of individuals with severe disabilities, it was revealed that subjective wellbeing of family caregivers was below the average normative level and that the strongest predictors of subjective wellbeing were caregivers’ self-esteem, social support, positive meaning in care giving and affiliate stigma. Caregivers’ feelings of low self-esteem predict negative psychological wellbeing while perception of reliable social support and positive reaction to care giving and affiliate stigma lead to positive subjective assessment of psychological wellbeing of primary caregivers. These findings therefore indicate the importance of supporting caregivers across their life-span in order to decrease stigma, improve social support and self-esteem and improve subjective wellbeing (Cristea, 2016).

According to (Nicholl, 2018), considerable strain is placed onto care givers creating a position whereby their health, psychological may be compromised while (Kohlakali, 2016), in his study describe caregiving as both extremely taxing and exhausting, with a multitude of contributing factors affecting the caregiver’s well-being, such as coping, burden, stress, burnout, and compassion fatigue. These unrealistic expectations then get placed on the individual and can create situations whereby the caregiver has a substantial amount of stress and burden relating to the caregiving process and the research in this study is aiming at providing insight information of having effective coping strategies which are paramount given the elevated number of contributing factors to the expectations on caregiving. These negative experiences are not isolated from the other responsibilities each caregiver carries on a daily basis and consequently, have a continuous and cumulative effect (Stylianou, 2017).

A study by (Rangnamei & Lisham, 2017) on affiliate stigma of caregivers of children with intellectual disabilities showed that caregivers generally experience poorer psychological wellbeing than individuals who do not have the caregiver status. They further discovered that caregivers with better resources appeared to have coped better and had lower psychological distress, lower anxiety and a higher level of personal empowerment. (Cunningham, 2014) argue that greater perceptions of stigma towards caregivers were associated with significantly higher levels of depressive symptoms. Findings from their studies suggested that in addition to posing a barrier to the recovery of people with developmental disabilities, stigma erodes the morale of the family members who help care for them.

A study was conducted by (Allred, 2013) interviewed 162 caregivers of patients with extreme disabilities. Majority of caregivers experienced mental health problems because they perceived stigma regardless of the characteristics of their patients. A majority of caregivers experienced psychological distress associated with the stigma they perceived. Ten percent had had suicidal thoughts and 18% wished death for their extreme disabled patients.

2.4 Economic Factors Contributing to Role Strain among Caregivers of Children with Disabilities

Caregiving of a child living with a disability results in several challenges to the caregivers, such as high cost of medication for treating the child's condition, finding ways to deal with the child's difficult behaviour, and stigma from the community against people with disabilities (Abudllahi, 2018). In the Southern African Development Community (SADC) region, most countries do not have grants to give to children with disability with the exception of South Africa and Namibia. In Namibia, children with disabilities are given an amount equivalent to 250 rand. There is no grant for the caregiver in Kenya, unlike in the UK where the caregiver is given a grant. This poses a great threat to the economic life of the primary caregiver.

Inherent within caregiving is the cost of care which increases with time. This is supported by (Kadungure & Dano, 2017) who state that families find that their expenditure increases and simultaneously their capacity to earn and eke out a proper living is reduced. High costs are incurred with respect to the special diets for some disabilities in children, fuel, transport, relocation to more suitable and conducive homes, and all place extra financial strain on the families (Michalak, 2013). It can also be noted that women and low earning primary caregivers may have enhanced challenges. This appreciably reduces the income of the family while the child’s care expenditures increase, although the costs are varied (Chabeda-Barthe et al., 2019; Oyegbile & Brysiewicz, 2017).

Physical disabilities in children can impose considerable costs on families caring for them. (Kamundia, 2016) stated that the increased financial burden may be attributed to the special medical care, education, therapeutic and other special needs. (Glidden, 2018) carried out a study in the USA and derived that 40 percent of families of children living with exceptional health care needs face financial burdens as a result of the disability of the child. Irrespective of the nature of the disability, the cost of care for a severely disabled child is three times that of a child that is not disabled. In addition, these costs are often long term, even lifelong costs (Nicholl, 2018).

The cost of care giving for a child with physical disability can strain financial resources of the family. (Blackwill, 2013) used the Human Capital Approach to expound the economic effect of caring for children with chronic disabilities and ailments which majors its focus on the direct and indirect cost of medical care. Direct costs include rehabilitative or curative services, medical services and the cost of hospitalization, home health care and special equipment. These direct costs can strongly increase the risk of families gliding into poverty. (Ndirangu & Midigo, 2018) stated that medical care which includes tests, hospital stays or therapies, as well as unique equipment, such as wheelchairs, crutches or braces, are at the forefront of major expenditures for the families of a child with physical disability. The effect these costs have on families with disabled children is also strongly dependent on the availability of health insurance and similar state measures, for example, social grants. Ndirangu & Midigo, (2018) in his study indicated that less than 10 percent of the parents and guardians of children with disabilities in the United States have no form of health insurance coverage. Thus, out of pocket expenditure becomes higher. Ndirangu & Midigo, (2018) thus suggest that most families who have low-income face difficulties to meet the total cost of the requirements of the children with physical disabilities.

It is vital to note that caring for a child with physical disabilities can result in indirect costs. (Teboho, 2015) state that indirect cost can result from the foregoing other beneficial activities, such as loss of income, associated with the degree and intensity of caregiving activities. (Thwala et al., 2015) observe that 32 per cent of the mothers were hindered from working other jobs because of the special care that they are providing. The increase of single parent households, as well as the economic need for two incomes in two parent families, exacerbates the impact of these costs. The employment situation can further exacerbate the risk of sliding into poverty. Ndirangu & Midigo, (2018), in a research on mothers with children living with disabilities, noted that their engagement in activities that bring income were limited to only small portion of the day and mostly in low income and unskilled jobs that do not require professional skills. The study revealed that the mothers preferred such jobs since it gave them more time with their children if they are not at school. Caregivers of children with physical disabilities stated that their employers understood their situation and hence would give them time off to collect their children when they fell sick, got injured or had a medical appointment. In other words, mothers selected jobs that suited their demands at home and their caring role (Stylianou, 2017). According to (Ngoma, 2018), the existence and severity of a child’s physical disability plays an important role in making work related decisions for about one third of the families, especially the mothers. Ndirangu and Midigo, (2018) stated that the fear of being isolated at work has resulted in the mother care giver not to bring the issues they need help with to the other professionals they might be working with. This is because of the fear of the professionals’ judgement of their parenting or questioning their motivation for supporting for their children and hence they continue being quiet.

A study on employment noted that mothers whose children are not having disabilities are having a higher employment level compared to the mothers of children with disabilities (Ramsamy, 2013). Primary caregivers who are not earning an income cannot gain from the likely cushioning effects of many roles that are, being involved in both work that gives an income and childcare. Olsson and Hwang (2016) fear that the primary caregivers might develop negative feelings about the other role and hence might not be more effective at work which might result in them negative stress reactions. Children with physical disabilities whose caregivers are employed have been noted to show little undesirable effects related with care they offer for a child with disabilities. The involvement of the father in the upbringing of the child with a disability can lead to the positivity of the parental well-being. The nature of the marital relationship can affect the conduct of mothers of children with disabilities who are employed and might result in unsatisfactory employment. For most of the caregivers, this state is unwanted and discordant with their individual goals. All these issues, including the inability to work so that they can provide full time care for their disabled child, as well as resulting issues, are strongly exacerbated by an already precarious economic situation of the family, or mother, in, for example, low income communities (Smith & Grzywacz, 2014). Absence of data on the financial costs incurred by primary caregivers in Kenya makes it difficult to know the cost of caring for children living with disabilities. The nature of care for a child with a physical disability has been noted to an overwhelming task for caregivers and hence costs of care might be high (Gatere & Shale, 2014).

2.5 Summary of Literature

Caring for a child with extreme disabilities can be a demanding and challenging role. Caregivers of children with disabilities often face a unique set of circumstances that can lead to role strain. Role strain refers to the difficulties and conflicts experienced when an individual has multiple roles and responsibilities that are difficult to fulfill simultaneously. Caregivers of children with extreme disabilities face significant role strain due to the physical, emotional, financial, and social challenges associated with caregiving. However, by seeking support, accessing available resources, prioritizing self-care, and advocating for supportive policies, caregivers can alleviate the strain and find ways to balance their responsibilities effectively. It is crucial for society to recognize and support these caregivers, ensuring they receive the assistance and understanding they need to provide the best possible care for their children.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

This chapter the research process for the study, detailing the methodologies that were employed. It begins with an explanation and justification of the selected research design. The chapter also identifies the target population and describes the sampling methods used to select participants, along with the criteria for their inclusion in the study. Additionally, this section describes the instruments that were utilized for data collection and the procedures followed to conduct the research. The latter parts of the chapter focus on the techniques that were used for data analysis. Finally, it addresses the ethical and legal considerations that were adhered to throughout the research process.

3.2 Research Design

This study used a mixed study design approach utilizing the convergent parallel design. In this approach, qualitative and quantitative data were collected simultaneously but analyzed separately. The results were then compared or combined to draw comprehensive conclusions. Case control and phenomenological study designs were utilized for quantitative and qualitative data respectively. The caregivers of children with extreme disabilities had role strain and as a result case-control study design would be the best to assess the factors associated with role strain. Phenomenological study design was considered more appropriate because it was likely to yield more accurate measurements, characteristics and tributes as well as provided eminent opinions and facts of caregivers under study. In addition, phenomenological approach was used as it was more appropriate to help find out lived experiences of the caregivers through focused group discussion

3.3 Study Site

The study was carried out in Thika Level 5 Hospital occupational center in Kiambu County. The hospital has a bed capacity of 265 catering for almost one million patients annually. Thika is an industrial town that lies on the A2 road 40 km (25 miles) north east of Nairobi, latitude and longitude 1.0500° S, 37.0833° E and an altitude of 1528 metres. Thika Level 5 Hospital began its operations in 1941 and is strategically located at the heart of Thika Town of Kiambu County. It is situated in a 7.97 Hectares land. The hospital is run by a cohesive, highly trained, dedicated and specialized human resource team of 550 members firmly anchored on the pillars of teamwork and self-sacrifice (Kiambu County Report, 2014).

Thika Level 5 Hospital occupational centre provides health services to an average of 500 inpatients and 10,000 outpatients annually (Kiambu County Report, 2014). This translates to 833 clients seen in outpatients monthly. The occupational center caters for children with disabilities by providing diagnosis, evaluations, treatment management e.g., physiotherapy and caregivers guidance etc. The hospital's provision of quality health services has blurred inter-county boundaries which has seen patients trickle in from more counties including Nairobi, Murang'a, Kirinyaga and Machakos, translating to a catchment population of 3-5 Million people on average. Ever since the healthcare devolution journey begun in the year 2010 to date, the hospital has always pledged to relentlessly pursue its objective of providing high quality and cost-effective healthcare to its patients (Kiambu County Report, 2014).

3.4 Study Population

Study population constitutes all the items or people under considerations in any field of inquiry (Orodho, 2008). The study population comprised of caregivers of children living with extreme disabilities. The choice of participants was based on their role as stakeholders in caring for children with extreme disabilities. The population size was 300 caregivers of children with extreme disability who attended TL5H occupational clinic per month..

3.5 Sample Size Determination

A sample size is a subset of the elements (population) to which the researcher intends to make generalization of the results (Amin, 2005). The population size was 300 caregivers of children with extreme disability who attended TL5H occupational clinic per month.

Charan and Biswas (2013) sample size calculation was used to determine the sample size for a study. $Sample\ size = \frac{r+1}{r}\frac{(p*)(1-p*)(Z_{\beta}+Z_{\frac{\alpha}{2}})2}{(p_1-p_2)2}$

Where

r = Ratio of control to cases,
1 for equal number of case and control
p* = Average proportion = proportion of cases + proportion of control/2 use 0.5
Z□ = Standard normal variate for power = for 80% power it is 0.84 and for 90% value is 1.28 (typically 90%).
Z □/2 = Standard normal variate for level of significance (typically 1.96).
$p_1 – p_2$ = Effect size or different in proportion expected based on previous studies (p1 is proportion in cases and p2 is proportion in control). Use 0.5

Therefore, with the application of the above formulae;

Ratio of cases to control =1:1
Proportion of control = 240/540 x 100/1 =44.4%
Proportion of cases with role strain = 300/540 x 100/1= 55.6%
Average proportion of exposed = (0.44+0.56)/2=0.5

$$n = \frac{(2)\ (0.5)\ (1-0.5)\ (0.9+1.96)^2}{(0.556-0.444)^2} \qquad =68$$

(68 cases and 68 controls in a ratio of 1:1)

Therefore, a minimum of 68 respondents in each group was used so as to cater for cases 68 for controls. Therefore, total sample size was 136

In the qualitative arm of the study, four focus group discussions were utilized to ensure integration of diverse experiences from different caregivers. Each FGD included between 8 and 12 participants. Data collection lasted for approximately one month.

3.6 Inclusion and Exclusion Criteria

3.6.1 Inclusion Criteria

Cases- Caregivers of children with extreme disability attending and admitted at Thika level 5 hospital occupational center screened for role strain with a score ≥10. **Controls** - Caregivers with children with extreme disability attending and admitted at Thika level 5 hospital occupational center, screened for role strain with a score <10. This was determined using a screening tool that was modified caregiver's role strain index, to differentiate cases (those with role strain) and controls (those without role strain). The Modified Caregiver Strain Index (MCSI) is a tool that is used to quickly screen for caregiver role strain.. It is a 16-question tool that measures role strain related to care provision. There is at least one item for each of the following major domains: Financial, Physical, Psychological, Social, and Personal. This instrument is used to assess individuals of any age who have assumed the caregiving role. The MCSI was modified and developed in 2003 with a sample of 158 family caregivers aiding older adults living in a community-based setting. Scoring is 2 points for 'yes' and 1 point for 'sometimes' response. The higher the score, the higher the level of caregiver strain.

3.6.2 Exclusion Criteria

Caregivers with children with extremely disability who were mentally or physically sick

3.7 Sampling Technique

This study utilized consecutive sampling method to obtain the sample. All the caregivers of children with extreme disability were taken and screened for role strain using modified caregiver index tool where they were grouped as either cases or controls until the sample size was attained.

The study participants for the focus group discussions (FGDs) were selected using a purposive sampling method. Four FGDs were conducted to gather insights into the attitudes and opinions of caregivers regarding the care they provide to children with extreme disabilities.

3.8 Data Collection Tools

A structured questionnaire and focus group discussion guide were used. This contained closed-ended and Likert type of questions capturing the study objectives. It comprised four (4) sections: socio-demographic characteristics; socio-cultural factors; economic factors; and psychosocial factors to obtain quantitative data. Qualitative data was collected using the FGD guide.

3.9 Pre-testing of the Study Instruments

Data collection tools were pretested and suggestions incorporated in the final version of the questionnaire and FGD guide. Pre-testing was done at Kiambu level 5 hospital occupational centres, since it had the same characteristics as the area of study. Fourteen caregivers of children with extreme disabilities were used to pretest the tools which was 10% of the sample size (seven cases and seven controls). This gave the researcher an opportunity to revise the data collection tools and correct errors in the questionnaire such as questions that respondents did not understand or misinterpret, ambiguous questions, questions that combine two or more issues in a single question and questions that make respondents uncomfortable.

3.10 Validity and Reliability of the Study Instruments

3.10.1 Validity of the Study Instruments

Content validity was determined by pretesting the study instruments. This involved actual data collection on a few caregivers of children with extreme disabilities from Kiambu level 5 hospital occupational centre to get feedback on whether or not the instrument worked as expected...

3.10.2 Reliability of the Instruments

According to Andres (2012), reliability refers to the extent to which the finding of a study can be replicated with similar samples. It is a measure of the degree to which a research instrument yields consistent results or data after repeated trials (Cherry, 2014). It contributes to standardization of research instruments which in turn enables the results of a study to be generalized to the larger population. The reliability of the research instruments was established by way of testing and retesting. The Cronbach Alpha Reliability Coefficient test revealed that reliability results for the questionnaire for socio-demographic characteristics was 0.894; socio-cultural factors contributing to role strain was 0.807; psychological factors contributing to role strain was 0.786; and economic factors contributing to role strain was 0.779.

Table 3.1: Cronbach Alpha Reliability Coefficient

Variables	Cronbach Alpha Coefficient
Socio-demographic characteristics	0.894
Social-cultural factors	0.807
Psychological factors	0.786
Economic factors	0.779
Average	**0.817**

3.10 Data Collection Procedure

Once the informed consent was obtained, the researcher took the study participant to a quiet place within the clinic. The researcher then administered a questionnaire for those participating in the quantitative arm of the study. The questionnaire included sections as per the study objective.

Interviewer administered structured questionnaire was used to collect quantitative data. Focused group discussions were used to know opinions of caregivers to care given to children with disability. The study participants who participated in FGDS were purposively selected. Four (4) FGDs were used to explore the attitudes and opinions of the caregivers on care provided to children with extreme disabilities. The FGD consisted of 8-12 participants. Data collection took approximately one month.

3.11 Data Analysis

Once data was collected, it was coded and entered into a computer. Data analysis was conducted using SPSS version 26 statistical software. Descriptive and analytical statistics were done. Binary logistic regression was employed to test the relationship between independent and dependent variables. A significance level of $p<0.05$ was significant. Odds Ratio (OR) and 95% Confidence Interval (CI) were used to estimate the strength of association between independent variables and the dependent variable. On multivariate analysis, all independent variables identified to be significantly associated at bivariate analysis were considered for multivariate analysis. This was performed using a multiple logistic regression. Data was presented inform of frequency tables and pie charts.

Qualitative data from FGDs was audio-taped and transcribed, thereafter, translated into English. Thematic analysis was used for qualitative data. Qualitative data was translated, cleaned and coded using NVIVO software. This involved examining the data to identify common themes – topics, ideas and patterns of meaning that come up repeatedly and results was presented in verbatim form.

3.12 Ethical Considerations

Proposal approval was obtained from school of Nursing, Jomo Kenyatta University of Agriculture and Technology (JKUAT), and then was submitted to JKUAT Ethical Review Committee for ethical approval. A permit to carry out the research was obtained from National Commission of Science Technology and Innovation (NACOSTI) and approval from County government of Kiambu. Permission was also obtained from the Thika Level 5 Hospital. An Informed consent was obtained from the study participants. No rewards or inducement was given. Confidentiality and anonymity were maintained at all times. The study participants were not subjected to any invasive procedures.

CHAPTER FOUR

RESULTS

4.1 Introduction

The study sought to determine factors contributing to role strain among caregivers of children with extreme disabilities at Thika level 5 hospital Occupational Care Center, Kenya. The specific objectives that were assessed include socio-cultural, psychological and economic factors contributing to role strain among caregivers of children with extreme disabilities. A total of 136 questionnaires were distributed,68 for cases and 68 for controls. All the questionnaires were returned representing 100% response rate.

4.2 Socio-Demographic Characteristics of Caregivers of Children with Extreme Disabilities at Thika Level 5 Hospital Occupational Care Center

The findings showed that 35(23.3%) of the caregivers were aged between 18 – 29 years and 94(62.7%) were female. In investigating marital status, 80(53.3%) were single. Fifty-one (34%) of the caregivers had tertiary level of education, 57(38%) were unemployed and while assessing the relationship with the child, 66(44%) of the respondents were parents (Table 4.1).

Table 4.1: Socio-Demographic Characteristics of Caregivers of Children with Extreme Disabilities at Thika Level 5 Hospital Occupational Care Center

Socio- demographic factors		**Case n(%)**	**Control n(%)**	**Total n(%)**
Age group	18-29 years	19(25.3)	16(21.3)	35(23.3)
	30 - 39 years	18(24.0)	19(25.3)	37(24.7)
	40 - 49 years	15(20.0)	15(20.0)	30(20)
	50 - 59 years	12(16.0)	7(9.3)	19(12.7)
	≥60 years	11(14.7)	18(24)	29(19.3)
Gender	Male	28(37.3)	28(37.3)	56(37.3)
	Female	47(62.7)	47(62.7)	94(62.7)
Marital status	Single	46(61.3)	34(45.3)	80(53.3)
	Married	29(38.7)	41(54.7)	70(46.7)
Education level	Primary	29(38.7)	21(28)	50(33.3)
	Secondary	21(28)	28(37.3)	49(32.7)
	Tertiary	25(33.3)	26(34.7)	51(34)
Occupation	Unemployed	30(40)	27(36)	57(38)
	Self employed	22(29.3)	23(30.7)	45(30)
	Employed	23(30.7)	25(33.3)	48(32)
Relationship with child	Parent	33(44)	33(44)	66(44)
	Sibling	12(16)	9(12)	21(14)
	Grandparent	7(9.3)	12(16)	19(12.7)
	Relative	12(16)	14(18.7)	26(17.3)
	Friend	11(14.7)	7(9.3)	18(12)

4.3 Socio-Cultural Factors Contributing to Role Strain among Caregivers of Children with Extreme Disabilities at Thika Level 5 Hospital Occupational Care Center

Among the cases, a significant number of caregivers reported difficulty in accepting their role, with 53.3% agreeing with this statement, compared to 50.7% of controls. Similarly, when considering the availability of support options, 50.7% of cases agreed that minimal support, such as counselling and respite care, was available, which was comparable to 53.3% of controls.

Interestingly, a marked difference emerged regarding the belief in seeking alternatives for cures. Only 38.7% of cases agreed with this notion, while a higher percentage of controls (58.7%) shared the same sentiment. This resulted in an OR of 0.44 and a p-value of 0.011, highlighting a statistically significant difference that indicates cases are less likely to engage in searching for cures compared to controls. Additionally, 74.7% of cases felt that caregiving was burdensome due to a lack of societal support, whereas only 42.7% of controls agreed. The OR was 1.96, although not statistically significant with a p-value of 0.071, suggests a strong trend toward greater burden among cases.

Conversely, 70.7% of caregivers of children with disabilities believed their children would contribute to the family's future prosperity, compared to 41.3% of controls, yielding an OR of 3.42 and a significant p-value of <0.001. On issues related to societal misconceptions and poor attitudes toward disabilities, 57.3% of cases agreed that these factors lead to self-blame and superstitions, while 46.7% of controls agreed, resulting in an OR of 1.54 but no statistical significance (p = 0.253).

Regarding coping strategies, 54.7% of cases felt the need to learn from others in similar situations, compared to 50.7% of controls, leading to an OR of 1.17, which again suggested no significant difference (p = 0.744). The formation of networks for support was similarly viewed, with 50.7% of cases agreeing that such institutions would be beneficial, while 57.3% of controls shared this view. The OR of 0.76 and a p-value of 0.512 indicate no substantial difference in this perception either (Table 4.2).

Table 4.2: Socio-Cultural Factors Contributing to Role Strain among Caregivers of Children with Extreme Disabilities at Thika LEVEL 5 Hospital Occupational Care Center

Socio-cultural factors		Case n(%)	Control n(%)	Total n(%)	OR(95%CI)	P-value
Difficult to accept situation	Agreed	0(53.3)	38(50.7)	78(52)	1.11(0.59 - 2.11)	0.435
	Disagreed	5(46.7)	37(49.3)	72(48)	Ref	
Presence of minimal support	Agreed	8(50.7)	40(53.3)	78(52)	0.89(0.47 - 1.71)	0.87
	Disagreed	7(49.3)	35(46.7)	72(48)	Ref	
Presence of alternatives options	Agreed	9(38.7)	44(58.7)	73(48.7)	0.44(0.23 - 0.85)	0.011
	Disagreed	6(61.3)	31(41.3)	77(51.3)	Ref	
Lonely and without hope	Agreed	5(46.7)	38(50.7)	73(48.7)	0.85(0.45 - 1.62)	0.744
	Disagreed	0(53.3)	37(49.3)	77(51.3)	Ref	
Bank on children for future prosperity	Agreed	3(70.7)	31(41.3)	84(56)	3.42(1.74 - 6.73)	<0.001
	Disagreed	2(29.3)	44(58.7)	66(44)	Ref	
Care-giving was burdensome	Agreed	6(74.7)	32(42.7)	88(58.7)	1.96(0.98 - 7.92)	0.071
	Disagreed	9(25.3)	43(57.3)	62(41.3)	Ref	
Presence of poor attitude and societal misconceptions	Agreed	3(57.3)	35(46.7)	78(52)	1.54(0.81 - 2.93)	0.253
	Disagreed	2(42.7)	40(53.3)	72(48)	Ref	
Presence of coping strategy	Agreed	1(54.7)	38(50.7)	79(52.7)	1.17(0.62 - 2.23)	0.744
	Disagreed	4(45.3)	37(49.3)	71(47.3)	Ref	
Presence of good network	Agreed	8(50.7)	43(57.3)	81(54)	0.76(0.4 - 1.46)	0.512
	Disagreed	7(49.3)	32(42.7)	69(46)	Ref	

4.3.1 Qualitative Data on Socio-Cultural Factors Contributing to Role Strain among Caregivers of Children with Extreme Disabilities at Thika Level 5 Hospital Occupational Care Center

Theme: Lack of Social Support Systems

The subthemes were lack of family support and non-governmental programs

Sub-Theme 1: Lack of Family Support

Lack of family support contributed to role strain among caregivers of children with extreme disability. One participant said:

"*My family has been a bit supportive but it reached a time when they do not support me financially to take care of my son*" [participant 7, FGD2].

Another participant added:

"I have tried seeking help from my family members but it has all been difficult" [Participant 3, FGD2]

Sub-Theme 2: Lack of Non-Governmental Programs

Participants stated that they hardly know of any civil society organizations that were dealing with disability issues in the region.

A participant asserted that:

"There are no social support groups, governmental and non-Governmental Organizations in our community supporting caregivers with CWD disability issues …. If there is any, I have not heard about it" [Participant 4, FGD3].

Another participant expressed similar sentiments:

"……..I have not heard of any or seen any Non-Governmental Organization that deals with disability issues" [Participant 2, FGD2].

Another participant asserted that:

"In our area there is no Non-Governmental Organization that I know of that helps people like us…. the only one that is there deals with HIV and AIDS. We cannot get help there because they only help people living with HIV or AIDS" [Participant 7, FGD3].

4.4 Psychological Factors Contributing to Role Strain among Caregivers of Children with Extreme Disabilities at Thika Level 5 Hospital Occupational Care Center

Eighty-five (56.7%) of the caregivers affirmed that they generally had negative attitude concerning children with disability and 87(58%) affirmed that lack of choice in becoming the caregiver was associated with higher subjective burden. More than half, 79(52.7%) agreed that sharing of experiences with one another was a mode of meeting emotional demands and 77(51.3%) of the caregivers affirmed seeking spiritual interventions for emotional satisfaction. Most of the respondents 84(56%) agreed that most of the caregivers found it frustrating that the CWD under their care had to be assisted in doing everything, 91(60.7%) affirmed that they had stress in the form of insufficient time for other chores and responsibilities and isolation from community activities. Further, half of the caregivers 75(50%) agreed that care giving was a taxing exercise, 84(56%) affirmed that they were contend with the stigma labelled against them in the society.

The results established that caregivers who affirmed that lack of choice in becoming the caregivers was associated with higher subjective burden were 2.6 times more likely to have role strain compared to those who did not affirm, (OR = 2.6, 95%CI: 1.32 – 5.04, p= 0.008). Further, caregivers who agreed that they were frustrated with the CWD being assisted in doing everything were 3.86 times more likely to have role strain compared to those who disagreed (OR = 3.86, 95%CI: 1.95 – 7.64, p<0.001). Caregivers who agreed that most of them were contended with the stigma labelled against them in the society were 2.7 times more likely to have role strain compared to those who disagreed, (OR = 2.71, 95%CI: 1.49 – 5.26, p =0.005) (Table 4.3).

Table 4.3: Psychological Factors Contributing to Role Strain among Caregivers of Children with Extreme Disabilities at Thika Level 5 Hospital Occupational Care Center

Psychological		**Case n(%)**	**Control n(%)**	**Total n(%)**	**OR(95%CI)**	**P-value**
Negative attitudes towards CWD	Agreed	47(62.7)	38(50.7)	85(56.7)	1.63(0.85-3.13)	0.187
	Disagreed	28(37.3)	37(49.3)	65(43.3)	Ref	
Had higher subjective burden.	Agreed	52(69.3)	35(46.7)	87(58)	2.6(1.32 - 5.04)	0.008
	Disagreed	23(30.7)	40(53.3)	63(42)	Ref	
Sharing of experiences with one another was a mode of meeting emotional demands.	Agreed	36(48)	43(57.3)	79(52.7)	0.69(0.36-1.31)	0.327
	Disagreed	39(52)	32(42.7)	71(47.3)	Ref	
Sorted spiritual interventions for emotional satisfaction	Agreed	42(56)	35(46.7)	77(51.3)	1.46(0.77-2.77)	0.307
	Disagreed	33(44)	40(53.3)	73(48.7)	Ref	
Frustrated that the CWD under their care had to be assisted in doing everything.	Agreed	54(72)	30(40)	84(56)	3.86(1.95-7.64)	<0.001
	Disagreed	21(28)	45(60)	66(44)	Ref	
Had stress	Agreed	51(68)	40(53.3)	91(60.7)	1.86(0.96-3.61)	0.094
	Disagreed	24(32)	35(46.7)	59(39.3)	Ref	
Care giving for CWD was a tasking exercise	Agreed	37(49.3)	38(50.7)	75(50)	0.95(0.5 - 1.8)	1.000
	Disagreed	38(50.7)	37(49.3)	75(50)	Ref	
Contended with the stigma labelled against them	Agreed	51(68)	33(44)	84(56)	2.71(1.49 - 5.26)	0.005
	Disagreed	24(32)	42(56)	66(44)	Ref	

4.4.1 Qualitative Data of Psychological Factors Contributing to Role Strain among Caregivers Of Children With Extreme Disabilities at Thika Level 5 Hospital Occupational Care Center

Theme: Emotional Distress

The subthemes were low self-esteem and social seclusion and stigma due to having a CWD.

Sub-Theme 1: Low Self Esteem

Participants pointed out that the role of care giving to CWD brought to them feeling of low self-esteem. One participant said:

"I experience a lot of stress because the care is demanding; I fail to cope at times. This often lowers my self-esteem" [Participant 3 FGD4].

Similarly, another participant said:

"It is always difficult to deal with the double role of being a mother and care giver…this is just too much for me. Many times, I get stressed because of the things that I am supposed to do but cannot, because of this child. This lowers my self-esteem." [Participant 6, FGD1].

Sub-Theme 2: Social Seclusion and Stigma Due to Having a CWD

Participants perceived social seclusion and stigma due to having CWD. One participant said:

"I am isolated and stigmatized with my extended family and friends because of my child with disability. This annoys me so much because it is not my wish to have such a child." [Participant 2 FGD3].

Similarly, another participant stated that;

““…..Having a child with disability is a silent and gradual killer. It induces some discomfort in my body and because of this, l does not attend most of social events.” [participant8, FGD1]

4.5 Economic Factors Contributing to Role Strain among Caregivers of Children with Extreme Disabilities at Thika Level 5 Hospital Occupational Care Center

In examining the economic factors affecting caregivers of children with disabilities, several significant differences emerged between the cases and controls. Among the cases, only 26.7% reported having minimal financial support options, compared to 45.3% of controls who agreed with this statement. Regarding the high cost of essential materials such as wheelchairs and food, only 20% of cases agreed that these costs were prohibitive, in stark contrast to 45.3% of controls. In terms of poverty indicators, a substantial 76% of caregivers in the case group reported observing poverty reflected in their housing standards and food availability, compared to 56% of controls.

The findings revealed that caregivers who agreed there were minimal financial support options for the caregivers were 56% less likely to have role strain compared to those who disagreed, (OR=0.44 95% CI: 0.22 – 0.87, p =0.027). The findings further established that caregivers who agreed with high cost of materials such as wheelchairs and food were 70% less likely to have role strain compared to those who disagreed, (OR= 0.3, 95% CI: 0.15 – 0.62, p =0.002). Caregivers who asserted that Poverty was observed in the standard of the housing, number of meals eaten per day and the quantity of food served were 2.5 times more likely to have role strain compared to who disagreed be cases than controls, (OR = 2.5, 95%CI: 1.24 – 5.01, p = 0.015) (Table 4.4).

Table 4.4: Economic Factors Contributing to Role Strain among Caregivers of Children with Extreme Disabilities at Thika Level 5 Hospital Occupational Care Center

Economic factors		Case n(%)	Control n(%)	Total n(%)	OR(95%CI)	P-value
Minimal financial support options	Agreed	20(26.7)	34(45.3)	54(36)	0.44(0.22 - 0.87)	0.027
	Disagreed	55(73.3)	41(54.7)	96(64)	Ref	
High cost of materials	Agreed	15(20)	34(45.3)	49(32.7)	0.30(0.15 - 0.62)	0.002
	Disagreed	60(80)	41(54.7)	101(61.3)	Ref	
Poverty was observed in the standard of the housing, number of meals eaten per day, the quantity of food served.	Agreed	57(76)	42(56)	99(66)	2.5(1.24 - 5.01)	0.015
	Disagreed	18(24)	33(44)	51(34)	Ref	

4.5.1 Qualitative Data on Economic Factors Contributing to Role Strain among Caregivers of Children with Extreme Disabilities at Thika Level 5 Hospital Occupational Care Center

Theme: Financial Constraints

The subtheme identified was insufficient funds

Sub-Theme: Insufficient Funds

Funding of the activities and wellbeing of children with disability was identified as a major burden. One of the participants stated that: -

"*……Yes, indeed money is a challenge because apart from their care, we also wish to live a comfortable life, which is difficult with insufficient funds."* [Participant 1, FGD2].

Another participant stated that*:*

"…Looking after my child has affected my family budget so much. …… (Sobbing). We do not have enough to cater for our needs" [Participant 4, FGD2].

4.6 Multivariable Analysis of Factors Contributing to Role Strain among Caregivers of Children with Extreme Disabilities at Thika level 5 hospital Occupational Care Center, Kenya

The findings established that caregivers who were single were 2.2 times more likely to have role strain compared to those who were married (AOR =2.16, 95% CI:1.01 – 4.63, p =0.048). Caregivers who were contented with the stigma labelled against them in the society were 2.6 times more likely to have role strain compared to those who disagreed (AOR =2.59, 95% CI:1.20 – 5.57, p=0.015).

Those who agreed that there were minimal financial support options for the caregivers were 61% less likely to have role strain compared to those who disagreed (AOR =0.39, 95% CI: 0.17 – 0.87, p =0.002).

Those who agreed that poverty was observed in the standard of the housing, number of meals eaten per day and the quantity of food served were 2.3 times more likely to have role strain compared to those who disagreed (AOR =2.28, 95% CI:1.01 – 5.16, p =0.048). Further, those who agreed that there is high cost of materials such as wheelchairs and food were 74% less likely to have role strain, (AOR =0.26, 95%CI:0.11 – 0.63, p =0.003) (Table 4.5).

Table 4.5: Multivariable Analysis of Factors Contributing to Role Strain among Caregivers of Children with Extreme Disabilities at Thika Level 5 Hospital Occupational Care Center

Factors	**AOR(95%CI)**	**P-value**
Marital status		
Single	2.16(1.01 - 4.63)	**0.048**
Married	Ref	
Presence of alternatives options		
Agreed	0.56(0.26 - 1.22)	0.144
Disagreed	Ref	
Bank on children for future prosperity		
Agreed	0.85(0.38 - 1.91)	0.698
Disagreed	Ref	
Hadhigher subjective burden.		
Agreed	0.41(0.11 - 1.96)	0.611
Disagreed	Ref	
Frustrated that CWD under their care had to be assisted in doing everything.		
Agreed	1.87(0.86 - 4.03)	0.113
Disagreed	Ref	
Contended with the stigma labelled against them		
Agreed	2.59(1.20 - 5.57)	**0.015**
Disagreed	Ref	
Minimal financial support options		
Agreed	0.39(0.17 - 0.87)	**0.022**
Disagreed	Ref	
Poverty was observed in the standard of the housing, number of meals eaten per day, the quantity of food served.		
Agreed	2.28(1.01 - 5.16)	**0.048**
Disagreed	Ref	
High cost of materials such as wheelchairs and food.		
Agreed	0.26(0.11 - 0.63)	**0.003**
Disagreed	Ref	

CHAPTER FIVE

DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Discussion

5.1.1 Socio-Demographic Characteristics of Study Participants

The present study revealed that caregivers who were single were more likely to have role strain compared to those who were married. These findings were comparable to a study conducted in Taiwan which revealed that caregivers who were married had lower role strain score compared to those who were single (Tsai & Wang, 2009). Similarly, in another study conducted in United States, it was found that there was a significant association between marital status and role strain among caregivers of children with disability. Those who had partners had lower role strain score compared to those without spouse (Litzelman et al., 2015). Studies have found that married caregivers of children with disabilities are less likely to experience role strain than their unmarried counterparts. Married caregivers often have access to greater social support, including emotional, instrumental, and informational support, which can help to alleviate the stress of care giving. They may also be better able to share care giving responsibilities with their spouse, which can help to reduce the burden of care.

Children with extreme disabilities were overly dependent on their caregivers which increase the level of burden which was significantly overwhelming to a caregiver who was single (Kilmer et al., 2010). In addition, married caregivers were more likely to get support from their partners which were crucial in alleviating role strain because of increased role sharing. Consequently, individuals who had gone through a divorce or were separated were subjected to persistent stressors that were associated with their current marital status. This, in turn, had the consequence of exacerbating the adverse impact that these stressors had on their psychological wellness. This was confirmed by a study that was conducted in United States by Tong et al., 2017, which found that caregivers who had been divorced or separated were more susceptible to having a psychological disorder as a result of the excessive amount of pressures they were under.

Our present findings revealed that there was no association between occupation and role strain. However, the findings contrast those obtained by Gordon *et al.,* (2012) who found that caregiver occupation was significantly associated with role strain. Those who were employed had difficult time in provision of care considering that patients require total support. Some of the caregivers were forced to resign from their jobs to concentrate on care delivery (Gordon et al., 2012). These findings illustrated that caregivers who worked in high-demand jobs struggled to balance the demands of their work and care giving responsibilities, which led to increased stress. Additionally, caregivers who worked in jobs with limited flexibility found it challenging to attend medical appointments or provide care during the day, which further exacerbated their role strain.

5.1.2 Socio-Cultural Factors Contributing to Role Strain Among Caregivers

The current findings established that caregivers who were continuously engaged in looking for alternatives were less likely to have higher role strain. This was mainly because they still believed in finding solutions to their child condition. These findings were consistent with those from (Chabeda-Barthe et al., 2019) who affirmed that it was the responsibility of parents to take care of their children regardless of the underlying challenges such as disability. In addition, Larson and Miller-Bishoff (2014) also stated that majority of caregivers continuously provided care to their children with disability with the hope of improving their quality of life which was essential for their development. Caregivers who actively sought and utilize resources and support, such as respite care, support groups, and community services, experienced lower levels of stress and better manage their care giving responsibilities. Moreover, caregivers who were continuously engaged in looking for alternatives felt more empowered and in control of their care giving situation. This sense of control helped to reduce feelings of stress and anxiety and improved their overall well-being.

The current findings also revealed that caregivers who banked on their children for future prosperity were more likely to have higher role strain compared to those who did not have such expectations. These findings were echoed by a study done in USA by (Vanegas & Abdelrahim, 2016) who established that overdependence on children prosperity was a common phenomenon in African context which resulted in low quality of life among parents in case a child was unable to meet those expectations. In African context, children had always been considered as security for their parents and thus their prosperity was considered essential in meeting the needs of their parents during old age. However, any change to these expectations created a higher level of stress to the parent (Devkota et al., 2019). Caregivers who had high expectations for their child's future success and viewed their care giving responsibilities as a means to achieve this success experienced increased pressure and stress. These caregivers felt a strong sense of responsibility for their child's future and believed that their care giving efforts were essential to their child's success. This created a significant burden, as caregivers felt that they must constantly push their child to excel and meet their expectations.

The current study also revealed that caregivers who did not understand the care needs of their child with disability were more likely to have higher role strain score. This was mainly due to negativity that surrounded children with disability in the society. These findings were comparable to a study done in Ghana, which had found that cultural and societal burden had a significant influence on role strain among caregivers (Ndadzungira, 2016) (Acheampong et al., 2019). Families who had children with disabilities faced stigma and were often rejected. Dueto this, there was not much time left over for participation in community activities and for making social connections as a result of the amount of time spent providing care (Ndadzungira, 2016). Caregivers who do not fully understand their child's care needs felt overwhelmed and unsure of how to provide the best possible care. This led to increased stress and feelings of frustration and helplessness. Additionally, caregivers who do not understand their child's care needs struggled to effectively communicate with healthcare providers and other professionals, which further exacerbated their role strain.

5.1.3 Psychological Factors Contributing to Role Strain among Caregivers of Children with Extreme Disabilities

The present study found that lack of choice in becoming the caregiver was associated with higher subjective burden and role strain among caregivers. Most of the caregivers were parents to the children hence predominantly had a responsibility to their children regardless of their physical wellbeing. These findings were consistent with those done in South Africa by Allred (2013) who established that majority of the caregivers had increased distress because they did not have an option to change the situation. The majority of caregivers had reported experiencing psychological anguish as a direct result of the stigma they had experienced. The major problem that caregivers of children with extreme disabilities experience was dependence in accomplishing simple tasks. This means that it was the caregivers who were tasked with ensuring that these common tasks were accomplished. These findings were comparable to a study done in Egypt by (Stylianou, 2017) who found that care giving was both taxing and exhausting with many factors contributing to this situation. Caregivers were expected to do everything for children with extreme disabilities which created major challenges in care. These unrealistic expectations were then placed on the individual, which led to circumstances in which the caregiver experiences a significant amount of stress and burden related to the process of providing care for another person. These negative experiences were not divorced from the other obligations that each caregiver carried with them on a daily basis, and as a result, they had an effect that was both continuous and cumulative.

The current findings found that caregivers who were contended with the stigma from the community were more likely to have higher role strain. This was majorly because they had lost hope and unwilling to make major decisions which were essential in improving quality of life of their children. This had also been associated with increased mental challenges among caregivers. Similarly, a study done in Swizerland by (Cunningham, 2014) argued that greater perceptions of stigma towards caregivers was associated with significantly higher levels of depressive symptoms. Findings from their studies suggested that in addition to posing a barrier to the recovery of people with developmental disabilities, stigma eroded the morale of the family members who helped in care of individuals with disabilities. A study conducted in South Africa by (Allred, 2013) found that majority of caregivers experienced mental health problems because they perceived stigma regardless of the characteristics of their patients. A majority of caregivers experienced psychological distress associated with the stigma they perceived.

5.1.4 Economic Factors Contributing to Role Strain among Caregivers of Children with Extreme Disabilities

The present findings had revealed that caregivers who had minimal financial support options were more likely to have higher role strain score. This was mainly due to the need to purchase most of the materials and medications which required financial support. These findings aligned to a study done in Kenya by Glidden (2018) and Nicholl (2018) who found that extreme disability among children was highly a lifelong which burdens the family immensely especially when looking at their financial situation. (Glidden, 2018) carried out a study in the USA and derived that 40 percent of families of children living with exceptional health care needs faced financial burdens as a result of the disability of the child. Irrespective of the nature of the disability, the cost of care for a severely disabled child was three times that of a child who was not disabled. In addition, these costs were often long term, even lifelong costs (Nicholl, 2018). It was vital to note that caring for a child with physical disabilities resulted in indirect costs. (Teboho, 2015) stated that indirect cost resulted from the foregoing activities, associated with the degree and intensity of care giving activities. (Thwala et al., 2015) observed that 32 per cent of the mothers were hindered from working because of the special care that they were providing.

The finding was similar to a study done in Kenya that stated that families found that their expenditure increased. High costs were incurred with respect to the special diets, fuel, transport, relocation to more suitable and conducive homes, and all these placed extra financial strain on the families (Michalak, 2013). This appreciably reduced the income of the family while the child’s care expenditures increased, although the costs were varied (Chabeda-Barthe et al., 2019; Oyegbile & Brysiewicz, 2017). Caregivers who had financial problems struggled to afford necessary medical treatments, therapies, and equipment for their child with a disability. They had difficulty affording basic necessities, such as food and housing, which further exacerbated their stress and anxiety.

Moreover, caregivers who had financial problems struggled to balance their care giving responsibilities with employment, which created additional stress and financial strain. Caregivers had to take time off work to attend medical appointments or provide care for their child, which resulted in lost wages and reduced financial stability.

5.2 Conclusion

On the socio-cultural factors, lack of social support system was found to contribute to role strain among caregivers of children with extreme disability.

On the psychological factors, the findings established that caregivers who agreed that it was frustrating that the CWD under their care had to be assisted in doing everything had significant role strain compared to their counterparts. Therefore, we reject the null hypothesis stating that there is no significant association between psychological factors and role strain among caregivers of children with extreme disabilities at Thika level 5 hospital occupational care center, Kenya. Also, emotional distress was found to contribute to role strain among caregivers of children with extreme disabilities.

On the economic factors, caregivers who agreed that there were minimal financial support options for the caregivers and poverty was observed in the standard of the housing, number of meals eaten per day and quantity of food served had significant role strain compared to their counterparts. Therefore, we reject the null hypothesis stating that there is no significant association between economic factors and role strain among caregivers of children with extreme disabilities at Thika level 5 hospital occupational care center, Kenya. Also, financial constraint was found to contribute to role strain among caregivers of children with extreme disabilities.

5.3 Recommendations

The following recommendations were made based on the findings of the study:

1. The healthcare facilities social welfare should facilitate and promote support groups for primary caregivers who are providing full-time care for children with physical disabilities.
2. There is need for the health-care professionals to offer counseling services to individuals, groups or families who have children with disabilities.
3. The ministry of health should foster Private-public partnerships to be used to develop programs or projects that will financially empower primary care givers to be self-employed from home.

REFERENCES

Abeasi, D. A., Nkosi, N. G., Badoe, E., & Adjeman, J. (2024). Caring by default: Experiences of caregivers of children with developmental disabilities in Ghana mirrored in the context of the stress process model. *BMC Nursing*, *23*(1), 482. https://doi.org/10.1186/s12912-024-02142-1

Abudllahi, M. M. (2018). Parental stress coping strategies used by parents of children with Autism Spectrum Disorder and the role of Nurses. *Social and Behavioral Sciences*, *205*(6), 940–944.

Acheampong, M., Owusu, I., & Bediako, O. (2019). Benavides, Ida, "Stress Among Caregivers of Individuals with Special Needs. *International Journal of Environmental Research and Public Health*, *44*(3), 55–61.

Alariefy, M. (2016). Exploring the Impact of having a Child with a Disability in Saudi Arabia: Implications for Family Support Services. *Education and Urban Society*, *20*(9), 32–44.

Allred, D. W. (2013). Caregiver Burden and Sibling Relationships in Families Raising Children with Disabilities. *Journal of Applied Research in Intellectual Disabilities*, *32*(2), 241–246.

Blackwill, T. (2013). Factors Affecting Daily Stress In Siblings Of Children With Special Needs. *Child Development*, *45*(3), 71–77.

Chabeda-Barthe, J., Wambua, T., Chege, W. L., Hwaga, D., Gakuo, T., & Rotich, G. C. (2019). Child developmental disabilities, caregivers' role in Kenya and its implications on global migration. *International Journal of Environmental Research and Public Health*, *16*(6), 15–23. https://doi.org/10.3390/ ijerph 16061010

Cobbinah, B. A. (2015). Stigmatization and Psychological Wellbeing of Primary Caregivers of Children with Developmental Disabilities in. *Journal of Intellectual Disability Research*, *102*(69), 300–312.

Cristea, A. (2016). Right of Children with Disabilities to Primary Education in Uganda: A Case study of Kabale District. *Journal of Social Service Research*, *9*(2), 10–17. https://doi.org/10.5151/cidi2017-060

Cunningham, S. J. (2014). Assessing Family Context of Children with Disabilities. *Journal of Personal & Interpersonal Loss*, *42*(6), 51–55.

Devkota, H. R., Kett, M., & Groce, N. (2019). Societal attitude and behaviours towards women with disabilities in rural Nepal: Pregnancy, childbirth and motherhood. *BMC Pregnancy and Childbirth*. https://doi.org/10.1186/s12884-019-2171-4

Elford, L. (2015). Mothers ’ Lived Experience of Parenting an Infant / Young Child with Special Needs in a Rural Context. *Electronic Theses and Dissertation*, *41*(8), 201–205.

Gatere, B. C., & Shale, N. I. (2014). Challenges Affecting The Implementation Of Access To Government Procurement Opportunities For Special Interest Groups In Kenya: A Case Of Nairobi County. *International Journal of Social Sciences and Entrepreneurship*, *171*(6), 727–735. https://doi.org/10.1530/EJE-14-0355

Ghazawy, E. R., Mohammed, E. S., & Mahfouz, E. M. (2020). Determinants of caregiver burden of persons with disabilities in a rural district in Egypt. *BMC Public Health*, *20*(2), 1156–1163. https://doi.org/10.1186/s12889-020-09266-4

Glidden, L. M. (2018). Ordinary Families, Special Children: A Systems Approach to Childhood Disability. *Intellectual and Developmental Disabilities*, *46*(5), 400–401. https://doi.org/10.1352/2008.46:400-401

Gordon, J. R., Pruchno, R. A., Wilson-Genderson, M., Murphy, W. M., & Rose, M. (2012). Balancing Caregiving and Work: Role Conflict and Role Strain Dynamics. *Journal of Family Issues*. https://doi.org/10.1177/0192513X11425322

Gulabani, M., John, M., & Isaac, R. (2014). Knowledge of diabetes, its treatment and complications amongst diabetic patients in a tertiary care hospital. *Indian Journal of Community Medicine*, *33*(3), 204–206.

Kadungure, T. P., & Dano, U. B. (2017). Experiences Of Caregivers Caring For Children With Different Special Needs In A Cluster Foster Care Village In KZN. *Journal of Social Service Research*, *30*(2), 51–67.

Kamundia, E. (2016). Choice, Support And Inclusion: Implementing Article 19 Of The Convention On The Rights Of Persons With Disabilities In Kenya. *African Disability Right*, *49*(20), 49–72.

Keletwaetse, S., R, M., & Mp, K. (2023). Exploring role strain and experiences of caregivers of children living with disabilities. *Nursing Open*, *10*(5). https://doi.org/10.1002/nop2.1530

Kiambu County Report. (2014). *Thika Level 5 Hospital—Information Cradle*. Kiambu County Report. https://informationcradle.com/kenya/directory/thika-district-hospital/

Kilmer, R. P., Cook, J. R., Munsell, E. P., & Salvador, S. K. (2010). Factors associated with positive adjustment in siblings of children with severe emotional disturbance: The role of family resources and community life. *American Journal of Orthopsychiatry*. https://doi.org/10.1111/j.1939-0025.2010.01050.x

Klutse, K. D. (2018). Quality Of Life Of Caregivers Of Children With Cerebral Palsy In The Accra Metropolis. *Pediatrics*, *120*(7), 1804–1814.

Kohlakali, L. (2016). The lived experiences of young mothers caring for disabled children in South Africa Letu Kohlakali University of Cape Town. *Health Psychology Research*, *5*(9), 227–231.

Lawson, D., Angemi, D., & Kasirye, I. (Eds.). (2020). *What works for Africa's poorest children: From measurement to action*. Practical Action Publishing. https://doi.org/10.3362/9781780448572

Lin, C. (2016). Quality Of Life Among Family Caregivers Of Adults With Intellectual And Developmental Disabilities. *Journal of Intellectual Disability Research*, *50*(3), 184–198.

Litzelman, K., Skinner, H. G., Gangnon, R. E., Nieto, F. J., Malecki, K., & Witt, W. P. (2015). The relationship among caregiving characteristics, caregiver strain, and health-related quality of life: Evidence from the Survey of the Health of Wisconsin. *Quality of Life Research*. https://doi.org/10.1007/s11136-014-0874-6

Mattison, D. R., Wilson, S., Coussens, C., & Gilbert, D. (2017). The Role of Environmental Hazards in the Outcome of Discharged Premature Neonates. In *Advances in Neonatal Care* (Vol. 4, Issue 2). https://doi.org/10.1016/s1536-0903(04)00035-9

McLeod, S. (2024, August 9). *Vygotsky's Sociocultural Theory Of Cognitive Development*. https://www.simplypsychology.org/vygotsky.html

Moosa-Tayob, S., & Risenga, P. R. (2022). Challenges of caregivers providing care to children with disabilities at non-governmental organisations in Tshwane townships, South Africa. *African Journal of Disability*, *11*, 930. https://doi.org/10.4102/ajod.v11i0.930

Muriuki, M. M., Oluchina, S., & Mbithi, B. W. (2023). Assessment of role strain among family caregivers of adult patients with cancer at a national referral hospital in Kenya. *Psycho-Oncology*, *32*(1), 42–46. https://doi.org/10.1002/pon.5868

Ndadzungira, A. (2016). *The Experiences Of Primary Caregivers Caring For Children With Physical Disabilities In Hardap Region Of Namibia*. *36*(3), 63–73.

Ndirangu, E., & Midigo, R. (2018). Caregiving for Children Living with Disability in the Informal Settlements in Kenya: Exploring the Social Experiences of the Urban Poor Living in Mukuru Slums in Nairobi. *Open Access Journal of Nursing*, *1*(7), 33–39.

Ngoma, D. M. (2018). "A Theology Of Human Dignity" For Children Who Are Born With Acute Physical And Mental Challenges Grounded On The Social Teaching Of The Roman Catholic Church In Kwazulu-Natal, South Africa. *Clinical Research and Bioethics*, *222*(100), 574–579.

Nicholl, H. M. (2018). An exploration of mothers ' experiences in caring for children with complex needs. *International Journal of Nursing Sciences*, *206*(33), 1111–1116.

Olusanya, B. O., Kancherla, V., Shaheen, A., Ogbo, F. A., & Davis, A. C. (2022). Global and regional prevalence of disabilities among children and adolescents: Analysis of findings from global health databases. *Frontiers in Public Health*, *10*, 977453. https://doi.org/10.3389/fpubh.2022.977453

Oyegbile, Y. O., & Brysiewicz, P. (2017). Developing An Intervention Model To Manage Caregiver Burden Experienced By Family Caregivers Of Patients Living With End-Stage Renal Disease In Nigeria. *International Journal of Africa Nursing Sciences*, *26*(8), 2624–2632.

Ramsamy, D. (2013). Understanding The Experiences Of Caregivers Of Hiv Infected Children At A Public Hospital In Durban. *Social Science and Medicine Journal*, *30*(3), 573–588.

Rangnamei, L., & Lisham, S. (2017). The challenges face by parents of differently abled children's in senapati dist, Manipur, India. *Disability, CBR & Inclusive Development*, *28*(2), 99–106.

Sakwape, K., Machailo, R., & Koen, M. P. (2023). Exploring role strain and experiences of caregivers of children living with disabilities. *Nursing Open*, *10*(5), 2886–2894. https://doi.org/10.1002/nop2.1530

Smith, A. M., & Grzywacz, J. G. (2014). Health and well-being in midlife parents of children with special health needs. *Families, Systems and Health*, *32*(3), 303–312. https://doi.org/10.1037/fsh0000049

Stylianou, A. (2017). Mothers with disabled children in Cyprus: Experiences and support. *American Journal of Occupational Therapy*, *13*(3), 1576–1580.

Teboho, P. R. T. (2015). An Investigation Into How Rural Children With Disabilities And Their Families In The Qwaqwa Region Experience Their Lives. *Innovations in Developing Countries for People with Disabilities*, *87*(3), 163–198. https://doi.org/10.5860/choice.41-2927.14.

Thwala, S. K., Ntinda, K., & Hlanze, B. (2015). Lived Experiences of Parents' of Children with Disabilities in Swaziland. *Journal of Education and Training Studies*, *3*(4), 206–215. https://doi.org/10.11114/jets.v3i4.902

Tong, H. C., Haig, A. J., Geisser, M. E., Yamakawa, K. S. J., & Miner, J. A. (2017). Comparing pain severity and functional status of older adults without spinal symptoms, with lumbar spinal stenosis, and with axial low back pain. *Gerontology*, *53*(2), 111–115. https://doi.org/10.1159/000096861

Tsai, S. M., & Wang, H. H. (2009). The relationship between caregiver's strain and social support among mothers with intellectually disabled children. *Journal of Clinical Nursing*. https://doi.org/10.1111/j.1365-2702.2008.02524.x

UNICEF. (2021). *Nearly 240 million children with disabilities around the world, UNICEF's most comprehensive statistical analysis finds*. Retrieved from https://www.unicef.org/press-releases/nearly-240-million-children-disabilities-around-world-unicefs-most-comprehensive

Vanegas, S. B., & Abdelrahim, R. (2016). Characterizing the systems of support for families of children with disabilities: A review of the literature. *Journal of Family Social Work*. https://doi.org/10.1080/10522158.2016.1218399

Vechia, A. D. R. D., Mamani, A. R. N., Azevedo, R. C. de S., Reiners, A. A. O., Pauletto, T. T., & Segri, N. J. (2014). Caregiver Role Strain In Informal Caregivers For The Elderly. *Journal of Clinical Psychology*, *855*(314), 901–1003.

World Health Organization. (2023). *Disability*. https://www.who.int/health-topics/disability

Zeeshan, M., Shaikh, S., & Ahmer, Z. (2022). How frequent is burnout among informal caregivers of disabled children? Findings from a cross-sectional study in Karachi, Pakistan. *Child: Care, Health and Development*, *48*(3), 415–422. https://doi.org/10.1111/cch.12941

Zhang, H., & Holden, S. T. (2024). Disability Types and Children's Schooling in Africa. *International Journal of Disability, Development and Education*, 1–21. https://doi.org/10.1080/1034912X.2024.2355621

APPENDICES

Appendix I: Informed Consent Form

Title: **CAREGIVERS ROLE STRAIN IN CARING CHILDREN WITH EXTREME DISABILITIES AT THIKA LEVEL 5 OCCUPATIONAL CENTER, KENYA**

Introduction:

You are being asked to be part of a research study. The study is being carried out by **Consolata Wambua**, a Masters student from the JKUAT. Please take your time deciding to join the study. Carefully consider the following information and ask the study counselor any questions you may have. The information collected from you shall be treated with utmost confidentiality and will only be used for intended purposes only.

Purpose of the study

The purpose of the study is to assess caregivers' role strain in caring children with extreme disabilities at Thika hospital Occupational Care Center Kenya. During this study, you will be asked to fill a semi structured questionnaire which will take approximately 15 minutes of your time.

Benefits

There are no direct benefits or reward but the results obtained will help in identifying the gaps so that measures to reduce the unmet needs can be undertaken

Minimal Risks or Discomforts:

There are minimal risks or discomfort in participating in this study.

Confidentiality:

Confidentiality of participants will be maintained during data collection process and after the study. To ensure anonymity participant will not write their names anywhere in the questionnaire instead codes will be used.

Compensation

There shall be no compensation for taking part in the study

Voluntary participation:

The decision whether or not to take part in this research study is voluntary. If you do decide to take part in this study, you may end your participation at any time without consequence.

Audio Recording:

The study involves audio recording your interview with the researcher. The recording will be transcribed by the researcher. At any time, you may ask to have the audio recording erased and withdraw your consent to participation in this study.

Questions:

You have the right to ask questions about this research before you agree to be in this study and at any time during the study. If you have further questions about this research or if you have research-related problem. You can reach Consolata Wambua, the principle investigator at +2547………………, or through email………………………….., his faculty supervisors; Prof …………….. at………………… and Dr ………………………. at……………………...

I HAVE READ THE CONSENT FORM. MY QUESTIONS HAVE BEEN ANSWERED. MY SIGNATURE ON THIS FORM MEANS THAT I CONSENT TO PARTICIPATE IN THIS STUDY.

_________ *I CONSENT TO PARTICIPATE IN THIS STUDY*

_________ *I CONSENT TO HAVE THE INTERVIEW AUDIO RECORDED.*

Signature of interviewee..Date..............................

Signature of researcher...Date…………....................

Confidentiality	**Please check one**
(1) I wish my interview to remain confidential	
(2) I agree that the researchers may disclose that I participated in this study but may not attribute any statements to me directly	
(3) I agree that the researchers may use my statements in publications and presentations, and attribute these statements to me	

1. If you check (1) above, your part in this research is confidential. That is, the information gathered for this project will not be published or presented in a way that would allow anyone to identify you. Information gathered for this project will be password protected or stored in a locked file cabinet and only the research team will have access to the data.
2. If you check (2) above, I will list you as a participant in this study, but I will not attribute any particular statements for information gathered to you. What you tell me will be confidential. That is, the information gathered for this project will not be published or presented in a way that would allow anyone to identify you. Information gathered for this project will be password protected or stored in a locked file cabinet and only the research team will have access to the data.
3. If you check (3) above, you are agreeing that I can list you as a participant in the study and also use your statements in publications and presentations and attribute these statements to you. You are agreeing to be interviewed on the record.

Appendix II: Questionnaire

Questionnaire: Serial number…................... Dated: ....

Instructions: ***Do not write your name or any other personal data on the questionnaire.***
Please follow instructions while answering questions in each area.
The information given here will remain confidential

SECTION A: Socio- Demographic Information

Please indicate the extent to which you agree to the following statements by ticking (√) the appropriate response.

1. What is your gender? ☐ Male ☐ Female

2. What is your age? (in complete years).
3. What is your marital status? (Optional)
   ☐ Single ☐ Married ☐ Separated ☐ Divorce
4. What is caregiver relationship with child caring relation?
   ☐ Parent ☐ Relative ☐ Sibling ☐ Friend ☐ Others (specify).……………..…
5. What is your level of education? ☐ Primary ☐ Secondary ☐ Tertiary
   ☐ Undergraduate ☐ Postgraduate ☐ Others (specify) What is your occupation? (Please specify) ……..…………………………………………..…

SECTION B: Social- Cultural factors contributing to role strain among Caregivers in Caring Children with Disabilities.

Please indicate the extent to which the role absent strain is present or with the statement related to social- cultural role stain of caregivers in caring children with disabilities. Where, present or absent

Statement on social– cultural role	**present**	**Absent**
Caregivers of children with disabilities often find it difficult to accept their situation as caretakers of CWD		
There are minimal support options for the caregivers such as counseling and respite care		
Most carers engage in looking for alternatives with the hope of getting a cure. The obsession that there could be a cure somewhere facilitates the need to move from healer to healer including traditional healers (‘Mganga’).		
Carers seemed be lonely and without hope, as observed seated alone with one hand on the cheek. According to the culture, one observed seated in that position signifies helplessness.		
Most families bank on their children for future prosperity and well-being. Parents have to clothe them, feed them and me*et al*l their daily needs with less prospects of maximum output from the child. The expectation that a family would support in care as whole		
Due to lack of support from the society, caregiving is burdensome to them and that they hardly even understood the needs of the CWD.is there a certain cultural practice to consider children with extreme disability?		
Poor attitude also exists and that these misconceptions results into myths, self-blames as well as superstitious claims labeled against the parents of the CWD who are in most cases also the caregivers.		
Do family with children with extreme disabilities need have a coping strategy and learn from the others with the same condition		
Forming an institution where we have a good network of different families with the same condition do you feel it can help in managing the condition.		

SECTION C. Economical Role Strain of Caregivers in Caring Children with Disabilities

6. Please indicate the extent to which you agree or disagree with the statement related to environmental role stain of caregivers in caring children with disabilities. Where present or absent

Statement on economic factors	present	Absent
There are minimal support options for the caregivers such as financial support for care		
High cost of materials such as wheelchairs and food		
Poverty is observed in the standard of the housing, number of meals eaten per day, the quantity of food served and hence, difficulties among carers in meeting basic needs like food, clothing, fees and money for drugs.		

7. What financial costs/implications are you facing from caring for the child living with a disability?
…………………………………………………………………………………………
…………………………………………………………………………………………
8. Are there any sources for additional finances to cater for the needs of the child and you as the caregiver? ……………………………………………………………………
…………………………………………………………………………………………

SECTION D: Psychological Role Strain of Caregiver in Caring for Children with Disabilities.

9. Please indicate the extent to which you agree or disagree with the statement related to psychological role stain of caregivers in caring children with disabilities. Where, either present or absent

Statement on psychological role	Present	Absent
Attitudes of caregivers concerning children with disabilities are generally relatively negative		
Lack of choice in becoming the caregiver is associated with higher subjective burden. Intrinsic motivation to care appears to be a protective factor for informal caregiver at least for emotional exhaustion		
Sharing of experiences with one another is a mode of meeting emotional demands. Carers of children with disability talk to each		

other, share experiences and advise each other on how best to cope with the child		
Carers sort spiritual interventions for emotional satisfaction (Prayers)		
Most of the caregivers find it frustrating that the CWD under their care has to be assisted in doing everything.		
Stress in the form of insufficient time for other chores and responsibilities and isolation from community activities because of time spent attending to the child at occupational support center		
Caregiving for CWD as a tasking exercise which if not well understood and addressed may complicate both the social life of the caregivers predisposing them to lifestyle diseases.		
Most of the caregivers has to contend with the stigma labeled against them in the society due to the condition of the children with disabilities.		

10. Will you share how caregiving impacts on you mentally? ....……………………………………………… ………………………………………………………………………………….......
11. Please indicate the type of feelings you experience with regards to care you offer to a child with disability….. ……………………………………………………………………………………… ……..……………………………………………………………………………

……………..END………………………… Thank you!

Appendix III: Modified Caregiver Strain Index

S NO.	**ACTIVITY**	**Yes =2**	**Sometimes =1**	**No =0**
1	My sleep is disturbed (the child I care for is in and out of bed the child does not sleep at night)			
2	Caregiving is inconvenient (do much work)			
3	Caregiving is a physical strain; lifting in or out of a chair; effort or concentration is required)			
4	Caregiving is confining (restricts free time or I cannot go visiting)			
5	There have been family adjustments (helping has disrupted my routine)			
6	There have been other demands on my time (other family members need me)			
7	There have been emotional adjustments (For example: severe arguments about caregiving)			
8	There is family discrimination with the society looks down on the family.			
9	The child I care for has changed so much; is deteriorating in health			
10	I worry about my deteriorating in health and feeling more disturbed psychologically.			
11	There have been work adjustments; left work to care for my child.			
12	There have been changes in personal plans (lack of finance for care)			
13	Caregiving is a financial strain			
14	I depend on relative for hospital bills			
15	I lack specialized equipments of care, lack of consultation fees and support structures e.g., specialized chairs.			
16	I feel completely overwhelmed and the work is a lot.			
	TOTAL			

Yes, On a Regular Basis=2 Yes, Sometimes =1 No=0

Appendix IV: Focus Group Discussion

Title: **CAREGIVERS ROLE STRAIN IN CARING CHILDREN WITH EXTREME DISABILITIES AT THIKA LEVEL 5 OCCUPATIONAL CENTER, KENYA**

General Introduction

Please identify a calm setting for the FGDs

I would like to thank you for agreeing to be a part of this discussion. My name is ……………………………… I will be leading the discussion session. I kindly request you to allow the session to be audio-taped so that I do not miss any of the ideas.

Interview Guide Questions

Questions	**Probe (s)**
Q1. What is the socio-cultural role strain of caregivers in caring children?	**[Probe: difficulty in accepting CWD, lonely, support from communities, support from families, support from government, myths]**
Q2. What is the psychological role strain of caregivers in caring children?	**[Probe: attitude, emotional satisfaction, frustration, anxiety, stigma, depression]**
Q3. What is the environmental role strain of caregivers in caring children?	**[Probe: provision of information, rehabilitation services, housing, feeding, government/NGO/community support]**
Q4. Are there coping strategies?	**[Probe: whether there are strategies used to cope with socio-cultural, psychological and environmental role strains]**