CARING FOR A CHILD WITH CEREBRAL PALSY: EXPERIENCES OF PRIMARY CAREGIVERS FROM A TERTIARY HOSPITAL IN KENYA

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A Thesis Submitted to the Institute of Postgraduate Studies of Kabarak University in Partial Fulfillment of the Requirements for the Award of Master of Medicine in Family Medicine Degree

KABARAK UNIVERSITY

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DECLARATION

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The thesis titled **"Caring for a Child with Cerebral Palsy: Experiences of Primary Caregivers from a Tertiary Hospital in Kenya,"** and written by **Kyakimwa Mbangi**, is presented to the Institute of Postgraduate Studies at Kabarak University. After careful evaluation of the research thesis, we strongly recommend its acceptance as partial fulfillment of the requirements for the Master of Medicine degree in Family Medicine.

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DEDICATION

I want to dedicate this work to the caregivers of adult and pediatric patients with chronic diseases who are dependent on their guardians. I will not forget all family members and friends who have been helpful and encouraging throughout this research journey.

ABSTRACT

Cerebral palsy (CP) is a chronic and non-progressive disability that affects the brain's motor function, posture, and movement. Children with CP rely heavily on caretakers due to the wide range of physical, neurological, and behavioral problems they experience. Caring for a child with a disability presents greater difficulties compared to caring for children without impairments. The demands of caring for a child with cerebral palsy have a direct impact on the mental and physical well-being of the caregiver, necessitating a substantial amount of physical and emotional assistance. The consequences of caregiving include physical, financial, socioeconomic, and emotional strain, all of which affect overall quality of life. The strain from caring for a child with CP can also be the source of marital problems and even isolation from the community. Given the unique needs of children with CP, there is a need for further exploration of the lived experiences of their caregivers. This study aimed to understand the lived experiences of primary caregivers and to explore the sources of support for those caring for children with CP. The study used a qualitative, phenomenological design and employed non-probability purposive sampling to achieve the desired sample size. Data were collected using an in-depth semi-structured interview guide, targeting a sample size of at least 12 participants; however, data collection continued until saturation was achieved. Participants were primary caregivers of children aged 4 years and above, with a documented diagnosis of cerebral palsy, who were on follow-up at AIC Kijabe Hospital at the pediatric outpatient department, specifically at the developmental clinic. The study focused on parents or caregivers who are responsible for the daily care of children with CP and have been in that role for at least 3 months. Data were collected using a digital audio recorder and transcribed. Data from interviews were coded and later translated into themes for analysis. The study revealed that caregiving for children with cerebral palsy is characterized by mixed experiences, where positive moments, such as observing developmental milestones, provided hope, but negative experiences, including financial strain, stigma, emotional stress, and physical exhaustion, dominated caregivers' lives. Significant challenges included high therapy costs, inadequate assistive devices, a lack of inclusive schools, and limited access to professional support, resulting in unmet needs for financial, medical, and psychosocial support. Existing support systems were largely informal, relying on family, friends, and occasional well-wishers, with minimal institutional or government assistance. The study concludes that caregiving imposes significant emotional, financial, and physical burdens, compounded by inadequate structural support. It recommends establishing government-funded financial aid and assistive device programs, expanding inclusive education services, and providing accessible therapy centers to reduce caregiver strain. Additionally, community-based support initiatives and counseling services are necessary to enhance caregiver well-being and promote quality care for children with CP.

Keywords: *Cerebral Palsy, Caregiver Experiences, Unmet Needs, Support Systems, Assistive Devices, Kenya*

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LIST OF ABBREVIATIONS AND ACROYNMS

ADHD	Attention Deficit Hyperactivity Disorder
AIC	Africa Inland Church
APGAR	Appearance Pulse Grimace Activity and Respiration
ASD	Autism Spectrum Disorder
CP	Cerebral Palsy
GMFCS	Gross Motor Function Classification System
KES	Kenyan Shilling
KNBS	Kenya National Bureau of Statistics
LMICs	Low- Middle-Income Countries
MOH	Ministry of Health
NACOSTI	National Commission for Science, Technology and Innovation
NCD	Non-Communicable Disease
NCPWD	National Council for Persons with Disabilities
OPD	Outpatient Department
OT	Occupational Therapy
WHO	World Health Organization

CONCEPTUAL AND OPERATIONAL DEFINITION OF TERMS

A caregiver is a spouse, partner, or other family member who is responsible for the physical, emotional, and often financial support of another person who is unable to care for themself due to illness, injury, or disability. For this study, a caregiver has provided their services for at least 3 months.

Caregiver Burden: The degree to which caregivers believe caregiving has negatively affected their emotional, social, financial, physical, and spiritual well-being.

Child with Cerebral Palsy (CP): A child aged 4–18 years who has been medically diagnosed with cerebral palsy, a group of permanent movement and posture disorders caused by non-progressive disturbances in the developing brain, resulting in activity limitations and varying degrees of physical disability.

Primary Caregiver: The individual, usually a parent, close family member, or paid long-term caregiver, who assumes the primary responsibility for providing day-to-day care, supervision, and support to a child with cerebral palsy, including feeding, mobility assistance, medication management, therapy attendance, and emotional support.

CHAPTER ONE

1.1 Introduction

This chapter encompasses the contextual information, problem statement, study purpose, objectives, research questions, and study assumptions.

1.2 Background of the Study

Cerebral Palsy

Cerebral palsy (CP) is the predominant childhood disability that primarily affects motor function. The majority of children with disabilities have problems with motor function, and CP is one of those conditions. These injuries can lead to cerebral palsy. According to research by teVelde et al. (2019), Stavsky et al. (2017), and Graham et al. (2016), the majority of CP cases do not arise from developmental anomalies but rather from harmful processes that often affect developing brains.

There are three groups of risk factors for cerebral palsy: those that occur before, during, and after pregnancy. Low birth weight, intrapartum and neonatal infections, multiple gestations, and untreated maternal hypothyroidism are the most prominent risk factors for congenital CP (Chen et al., 2022). The most well-known prenatal risk factor is chorioamnionitis. High risk factors of congenital malformations include fetal growth restriction and placental anomalies; however, in term infants, CP is most commonly linked with symptoms of birth depression, such as a low Apgar score. According to Donald et al. (2014), CP in Africa is most commonly caused by birth asphyxia, kernicterus, or neonatal infections. Epilepsy is a common comorbidity with CP. Untreated hyperbilirubinemia, prolonged second stage of labor (more than four hours), vaginal bleeding before delivery, and fetal infections (such as meningitis or ventriculitis) are additional risk factors. According to Sadowski et al. (2020) and Graham et al. (2016), the two most significant risk factors in this context are preterm and hypoxia-ischemia.

According to published statistics, the majority of children with CP have significant impairments and are classified as Gross Motor Function Classification System IV or V (Donald et al., 2014). In addition to impaired motor function, children with cerebral palsy frequently have difficulties with perception, cognition, language, and communication (Farajzadeh et al., 2018). Problems with the oropharynx, gastric reflux disease, constipation, and other gastrointestinal disorders impact most children with CP. To improve their capacity to participate independently in everyday activities, these challenges require continuous care and therapy interventions (Sadowski et al., 2020; Graham et al., 2016; Farajzadeh et al., 2018). A significant proportion of children with CP experience spasticity, which impairs their ability to move and use fine motor skills (Donald et al., 2014).

The reported prevalence of CP varies across countries; for example, it is higher in Mississippi (2.12 per 1000) than in China (1.6 per 1000 children under 7 years) (Stavsky et al., 2017). WHO (1995) and Stavsky et al. (2017) estimate that 2.3-3.3 per 1000 live births involve CP cases. According to research by Graham et al. (2016), the prevalence of this condition in Europe and Australia is 2.0 per 1000 live births. The estimated prevalence of CP in the US is 3-4 cases per 1000 children, according to a study by Braun et al. (2016). The incidence of cerebral palsy (CP) in children between the ages of three and ten is 2.4 per thousand live births. The recorded rates differ between boys and girls. A thorough review of African studies found that community samples show an incidence rate of 2–10 cases per 1000 children (Boixados-Angles et al., 2013).

Studies conducted in Uganda suggest that compared to high-income nations, low- and middle-income countries (LMICs) may have a higher prevalence of CP. The prevalence of CP was estimated to be 2.7 per 1000 children in a 2017 population-based study conducted in Uganda by Kakooza-Mwesige et al. (2017). Kenya lacks official data on the prevalence of cerebral palsy. The Ministry of Health (2015) highlighted the lack of public statistics and information on the prevalence of neurological illnesses in Kenya. Diagnosis of CP is usually delayed, despite the long-standing urge for early detection, which can delay access to early therapies and limit sufficient psychological support from parents (teVelde, 2019).

Caregiving Burden

Adelman et al. (2014) described carers' perceptions of the negative impact of caregiving on their emotional, social, financial, physical, and spiritual functioning as caregiver burden. Additionally, Liu et al. (2020) characterized "the level of multifaceted strain perceived by the carer from caring for a family and/or loved one over time" as carer load. According to Kyeremateng et al. (2019), caring for a disabled child is more difficult than caring for a typically developing youngster. Boixados-Angles et al. (2013) conducted a comprehensive review that classified the burden of caregiving into five types: financial, emotional, psychological, spiritual, and physical.

Emotional and Psychosocial Burden

Multiple studies (Nadhim Suhib & Hashim Mohammed, 2022; Masulani-Mwale et al., 2016) have demonstrated that people who care for impaired children are more likely to experience mental health problems, such as depression, anxiety, and negative life outlooks. Comparative studies in high-income nations show that caring for a child with special needs is stressful because of the unique demands placed on parents, which can lead to burnout, financial strain, guilt, and parenting distress (Dambi et al., 2015; Singogo et al., 2015), while studies in low- and middle-income countries have found instances of stigmatization and discrimination due to children's disabilities. Caregiving is a difficult duty, and studies have shown that mothers whose children have cerebral palsy have less time for themselves and their families, lower marital life quality, greater marital relationship stress, and less family cohesiveness (Ruetti & Pirotti, 2024; Gugala, 2021).

Financial Burden

There is a significant financial impact on parents and carers of children with cerebral palsy (Ismail et al., 2022). Cerebral palsy (CP) and its consequences can affect families, healthcare systems, and the broader economy. Parents from lower socioeconomic origins have a higher chance of having children with CP due to greater prenatal hazards. On the other hand, Dambi et al. (2015) found that carers of children with CP were more likely to be unemployed if they lacked a bachelor's degree. Because they may have fewer job prospects, carers of disabled children often confront financial difficulties. This is in contrast to parents whose children do not have disabilities. They may also need to give up some of their career goals to avoid ignoring their child's demands (Vadivelan et al., 2020; Zuurmond et al., 2015).

Because of the inherent tension between caregiving and paid work, carers are less likely to find gainful employment. Carers often have to make the tough choice of cutting back or stopping their job hours altogether. More importantly, the direct care costs for children with CP are higher than those for children without the disorder because these children require medical attention more frequently and spend more time in the hospital (Dambi et al., 2015). Additionally, the researchers found that compared to non-disabled children, children with CP necessitate much more financial resources, 10 to 26 times more for routine medical follow-up. If the family is already strapped for cash, this can put them in an even more precarious financial position.

Physical Burden

Even though they can cope, parents whose children have CP report a worse quality of life than the overall population, and parents whose children do not have health problems. A caregiver's physical health may take a hit while caring for a disabled child. The added weight of the child can put strain on the back, and other common side effects include insomnia, fatigue, and poor sleep quality (Liu, Shen, Huang, & Zhou, 2023).

Sources of Support and Coping Mechanisms

Caregivers, particularly those who provide care for those with cerebral palsy, experience stress, exhaustion, sadness, and burnout. To ensure their well-being and contentment while delivering exceptional care, caregivers can rely on a support system that may include immediate family members, reliable acquaintances, or an extensive community of caregivers beyond their family circle. These persons possess the ability to actively listen, intervene, and offer assistance as necessary, guaranteeing their accessibility when required. This strategy helps caretakers maintain their equilibrium and fortitude when faced with difficult circumstances. This is an essential form of self-care. Merely because caretakers offer assistance to those who are more restricted than themselves does not imply that they themselves do not require care. Practicing self-care is crucial for preventing stress and burnout. This might involve several activities such as taking a break from work, engaging in regular physical activity, maintaining a healthy diet, or seeking professional guidance from a therapist (Le Roux, 2023).

Community-based organizations play a crucial role in providing support, resources, and advocacy for caregivers of individuals with cerebral palsy. Nonprofit organizations like the Cerebral Palsy Foundation, United Cerebral Palsy, and the Cerebral Palsy Alliance offer educational resources, support groups, advocacy, and connections to local services. Parent-led support groups provide a supportive community where caregivers can share experiences, advice, and emotional support. Disability advocacy organizations promote the rights and inclusion of individuals with disabilities, including those with cerebral palsy (Manalel et al., 2024).

Community centers often host programs and support groups for caregivers, offering respite care services, caregiver training workshops, recreational activities, and referrals to local resources. Therapeutic centers and clinics may also provide support services for caregivers alongside medical treatment, such as counseling, education on caregiving techniques, and access to rehabilitation therapies. Online communities and forums dedicated to cerebral palsy are another source of support for caregivers (Kiani et al., 2021).

National cerebral palsy organizations in Kenya, such as the Cerebral Palsy Society of Kenya, Cheshire Disability Services Kenya, Kenya Society for the Blind, Kenya Association of the Intellectually Handicapped, government agencies and departments, parent support groups, and Community-Based Organizations, collaborate with government agencies, healthcare providers, educational institutions, and other stakeholders to address the diverse needs of individuals with cerebral palsy and their families. These organizations typically offer a range of services, including medical care, therapy, education, vocational training, advocacy, and awareness-raising activities (Taylor et al., 2022).

However, it is essential to note that the landscape of disability services in Kenya is dynamic, and there may be other emerging organizations or initiatives dedicated to supporting individuals with cerebral palsy. By fostering connections, providing information, and advocating for caregivers' needs, these organizations play a crucial role in enhancing the well-being of families affected by cerebral palsy (Fairfax et al., 2019).

1.3 Statement of the Problem

Caregivers of children with cerebral palsy (CP) face significant challenges in raising their children due to the extensive and continuous nature of care required. This long-term caregiving often negatively impacts their quality of life, placing them under immense physical, emotional, and financial strain. Caregivers must not only attend to the demanding needs of their child with CP but also juggle other familial responsibilities, which further escalates their stress levels and compromises their well-being.

Despite the critical role of caregivers, the burden they carry, especially in low-resource settings like Kenya, remains underexplored and largely overlooked. Studies have shown that caregivers of children with CP experience heightened levels of stress and deteriorated well-being (Sherman et al., 2019; Vadivelan et al., 2020). The Kenya National Disability Survey (2018) highlighted that most households caring for persons with disabilities experience increased financial burden and inadequate access to disability-related services, particularly in rural areas. Similarly, the Ministry of Health's 2022 Disability Medical Assessment and Categorization Guidelines emphasize persistent gaps in early assessment, referral pathways, and structured caregiver support, indicating that families are often left to shoulder caregiving responsibilities with minimal institutional assistance.

Despite national policies recognizing disability rights, implementation remains weak, leaving caregivers of children with CP vulnerable, overwhelmed, and largely unsupported. However, there is a notable lack of research specifically addressing the unique caregiving burdens and needs of these individuals in the Kenyan context. This creates a significant knowledge gap, as existing studies fail to examine the specific interventions and support systems needed to address the challenges caregivers face.

Without a clear understanding of the demands placed on caregivers of children with CP in Kenya, healthcare providers and stakeholders lack the necessary insights to offer appropriate and practical support. This gap in knowledge affects both caregivers and the children they care for, potentially leading to suboptimal care and further deterioration of the caregiver's own health. Therefore, this study sought to address this gap by exploring the specific caregiving burdens and needs of caregivers of children with cerebral palsy in Kenya. This will help inform strategies to improve caregiver well-being and ensure they are adequately supported in their critical role.

1.4 Objectives of the Study

i. To explore the positive and negative experiences of primary caregivers of children with cerebral palsy attending the developmental clinic at AIC Kijabe Hospital.

ii. To explore the unmet support needs in relation to caregiving of caregivers of children with cerebral palsy attending the developmental clinic at AIC Kijabe Hospital.

iii. To understand the support system available to the caregivers of children with CP attending the developmental clinic at AIC Kijabe Hospital.

1.5 Research Questions

i. What are the positive and negative experiences of primary caregivers of children with CP attending the developmental clinic at AIC Kijabe Hospital?

ii. What are the unmet support needs of caregivers of children with CP as they provide care to them?

iii. What are the support system services available to the caregivers of children with CP attending the developmental clinic at AIC Kijabe Hospital?

1.6 Justification for the Study/Significance of the Study

There are many obstacles to overcome when caring for children who have physical and intellectual disabilities. There are many demands placed on parents when caring for a child with cerebral palsy, and these demands are substantial and complex (Kuo et al. 2012; Boixados-Angles et al., 2013). The emotional and financial toll that families bear when caring for children with special needs varies widely (Vadivelan et al., 2020).

The burden of caring and its effects on carers have been well documented and highlighted in studies conducted in nations with high per capita income. In Africa, studies focused on patients rather than following their carers' paths. It is well-documented that in contexts with high-income resources, the support systems, impacts, and carer interventions for children with CP are available. But research and action on the continent have been few. Everyone involved in the care of children with CP, including healthcare providers, patients, and carers, will profit from the study's findings.

The study participants would be able to enhance their own well-being with the knowledge and responses to the challenges mentioned above. Ultimately, this will affect the level of care that children with CP receive. The findings from this study will provide evidence to guide national disability and rehabilitation policies, informing strategies to strengthen caregiver support systems in Kenya.

1.7 Scope of the Study

The study participants were selected from AIC Kijabe Hospital, located in Kiambu County. AIC Kijabe Hospital, specifically the outpatient department, serves patients from many regions around the country. However, a significant proportion of the patients originates from Kiambu County and the surrounding areas. The study specifically targeted caregivers of children with cerebral palsy who receive care in the developmental clinic within the pediatric outpatient department. The study was conducted for a duration of two months.

1.8 Limitations of the Study

The main limitation of the study was in the recruitment and data-collection stages. The study was conducted at the outpatient department of a level 6 hospital; thus, the population in the community that cannot afford this level of care was not captured. Furthermore, given the qualitative nature of the research, the study's sample size was limited, making it challenging to generalize the findings to a broader community of caregivers of children with CP. Most of the participants were women. The study findings mainly reflected a female perspective and cannot be extrapolated to the male population. Female caregivers are centered in this case, as in many cultural contexts, particularly in regions like Kenya, women are traditionally expected to take on the primary caregiving role within families. This social expectation often places the responsibility of caring for children with disabilities, such as cerebral palsy, on mothers or female relatives. As a result, female caregivers were more likely to experience the direct challenges and needs associated with caregiving.

1.9 Assumption of the Study

Based on the literature review and personal observations during patient care and with their caregivers, the researcher assumes that the focus has been more on patients and on the effects of caregiving on caregivers. The caregivers might be prioritizing their children’s needs more than their own. This may adversely affect caregivers as individuals, family members, and the community. This warrants a qualitative approach to understand better caregivers’ perspectives on their experience in the caregiving role.

CHAPITER TWO

LITERATURE REVIEW

2.1 Introduction

The current chapter consists of a comprehensive examination of the literature on the fundamental themes, as well as a literature review for each of the three objectives. The conceptual framework is concluded in this chapter.

2.2 General Overview of Literature Related to Perceptions and Experiences of Caregivers of Children with Cerebral Palsy

The purpose of this research is to learn about the daily struggles faced by the primary carers of children with cerebral palsy. The roles of caregivers encompass daily activities such as feeding, transportation, bathing, dressing, administering medications, and assisting with toileting. In addition to these tasks, caregivers often manage the medical needs of care recipients, including routine and acute care, as well as rehabilitation services such as occupational, speech, and physical therapy (Dlamini et al., 2023). Beyond these caregiving responsibilities, caregivers are frequently tasked with managing household duties, meal preparation, and caring for other children (Vadivelan et al, 2020; Elangkovan & Shorey, 2020).

The Kenya National Bureau of Statistics (KNBS) and the National Council for Persons with Disabilities (NCPWD) conducted the Kenya National Disability Survey (2018), which highlights the distribution of disabilities, caregivers' challenges, and service gaps across the country. Similarly, the Ministry of Health (MOH, 2022) issued the National Guidelines on Rehabilitation and Assistive Technology to standardize disability assessments, expand access to rehabilitative services, and promote the provision of assistive devices. Despite these initiatives, implementation remains inconsistent across counties, with many caregivers still struggling to access essential services.

Recent East African studies provide qualitative and quantitative insights into caregiver wellbeing. In Kenya, Mwendwa et al. (2021) highlighted the continuous stress and emotional burden experienced by caregivers of people living with dementia, emphasizing the need for context-specific psychosocial support. Akula et al. (2025) explored the impact of psychological well-being on the quality of life of caregivers of children with autism in Vihiga County, finding that poor mental health was strongly associated with decreased caregiving capacity. In Tanzania, Swai et al. (2024) found high levels of psychological distress among caregivers of children with physical disabilities. Ugandan studies by Komuhangi et al. (2022) and Verity et al. (2021) documented significant caregiver burden and unmet needs among informal carers of persons with severe mental illness, while Amanyire et al. (2025) highlighted the lived experiences of caregivers of adolescents with bipolar disorder, emphasizing social and economic challenges. These studies illustrate persistent caregiver strain, limited access to support services, and diverse coping challenges across East Africa.

2.2.1 Experiences of Caregivers in their Caregiving Role

The first primary objective of this study is to investigate the experiences of carers of children with cerebral palsy in their role as carers. Previous research conducted in countries such as Korea and Canada has looked at caregivers of individuals with conditions like cancer and cerebral palsy. These studies revealed that caregivers often experience both significant rewards and burdens, with their mental and physical health being heavily impacted by the child’s behavior and the demands of caregiving (Biney et al., 2024).

Positive Experiences

Family Relationships

Calvin and Valois (2023) conducted a study that found that carers have expressed favorable emotions towards their caring responsibilities, such as a sense of familial unity and gratification derived from assisting others. Additional perceived advantages of caregiving included the opportunity to contribute, enhanced interpersonal connections, a sense of contentment with the level of care provided, acting as an exemplar for others, heightened self-worth, an augmented sense of meaning, and feelings of joy and gratification (Coon et al., 2023). Individuals who hold more favorable attitudes towards caregiving are likely to experience lower levels of load and depression (Hilgeman, 2019).

Spiritual Experiences

Different studies have reported both positive and negative effects of caregivers of disabled children's involvement in religious activities (Attafuah, 2024). Researchers Toledano-Toledano et al. (2020) and Akbari et al. (2018) highlighted the positive attitudes of carers of children with disabilities. These carers reported improved self-esteem, better quality of life, better psychological adjustment, and a stronger spirituality as a result of their religious affiliation. Nonetheless, Sherman (2019) reported that the demanding nature of caregiving may prevent carers from participating in spiritual activities.

Negative Experiences

Lowes et al. (2016) discovered that parents of children with chronic health issues faced difficulties in managing their work, home, and family responsibilities while caring for their children. Another study found that carers of children with disabilities often feel overwhelmed and have little time for themselves due to the demanding nature of caring for their children. Additionally, disabilities are still commonly viewed as a negative consequence, either as a punishment from God for wrongdoing or as the result of evil spirits (Gona et al., 2011; Masaba et al., 2021).

Caring for a child with cerebral palsy can significantly affect caregivers' physical and psychological health, often resulting in considerable strain and burden (Kadam et al., 2020). In the African context, the challenges of caregiving, unmet needs, and available support systems are still largely underexplored (Zuurmond et al., 2018). A recent study in Kenya found that caregivers of children with disabilities struggled to find time for other responsibilities, as the demands of caring for their children with special needs became their primary focus. This often led to social isolation and reduced community involvement, further affecting their overall well-being (Adoyo et al., 2019).

Psychological and Emotional Needs

Caregiving has been associated with considerable morbidity affecting caregivers, such as depression, and it can lead to feelings of overload and distress (Lindt et al., 2020). Caregivers' psychological well-being depends on the child's behavioral issues, which are also determinants of well-being for the child with disability (Cejalvo et al., 2020). Caregivers who play the role of caregiving for many hours daily for children who are older with complex disabilities and support them financially experience more stress, even though caregivers reported experiencing less depression if provided psychosocial support (Dieleman et al.2021). There were caregivers' concerns about their children's uncertainty for the future and their health, with different feelings like anger due to the children's condition; the children also lacked adequate healthcare from healthcare workers (Yigman et al. 2020). They can also experience more stress due to treatment decision-making, as well as poor emotional well-being due to expected stigma that they go through in the community, as well as their children (Lowes et al., 2016; Sherman, 2019). Singogo et al. (2015) found that some mothers of children with CP separated from their spouses because of conflicts due to having a child with disability, blaming each other for the child’s condition.

Physical Needs

Back pain, migraine headaches, and stomach/intestinal ulcers were more common among parents of children with cerebral palsy (CP), according to research by Lee et al (2020). Parents of children with CP also expressed more overall distress than parents of typically developing children.

Carers were observed to prioritize the health of their children with disabilities over their own well-being, as well as placing lower importance on other family responsibilities (Ojeme, 2021). The sleep deprivation resulting from stress or from being awakened by the patient exacerbates the physical burden on carers, leading to decreased energy levels and subsequent impairment in their physical functioning (Sherman, 2019).

Financial Needs

Informal caregivers were found to live below the poverty threshold, and caregiving was found to impose an additional economic burden (Dambi et al. 2015). Financial demands can affect caregivers in two ways. The first one is taking care of the child with disability with the ongoing daily activities, and the second way is to take care of medical care. According to Vadivelan et al. (2020), the burden of caregiving prevents carers from engaging in gainful activities. He added that even if they can work, it is difficult to save money for the future due to emergency expenses. Nimbalkar et al. (2014) noted that parents of children with CP recognized the importance of having financial means, as raising children with this condition is demanding. Some parents reported that they needed more money because they spent their limited funds on spiritual interventions, such as prayer camps or herbal remedies, to try to improve their children’s conditions, but with little effect, while other parents’ concerns were about accessing funds and insufficient support from different services (Nyante et al. 2019). In the Western world, care for disabled individuals is family-oriented compared to developing countries, where the focus is mainly on people living with disabilities (Nimbalkar et al., 2015).

2.2.2 Unmet Needs of Caregivers

There is a need to support caregivers in coordinating and communicating with health care providers to enable them to carry out their care tasks properly. Support offered to this specific population should not be limited to the time of diagnosis (Schurgin et al., 2021). The carers experience significant hardship due to a scarcity of community supports and resources available to both the child and the family (Lowes et al., 2016). The burden experienced by carers of impaired children can have detrimental effects on their physical and mental health, resulting in a decline in the quality of care provided and unmet requirements of the care recipients (Wijesinghe et al., 2015). According to Farajzadeh et al. (2018), parents of disabled children face the task of managing their children's health concerns while also meeting their everyday requirements.

Caregivers’ Unmet Physical Needs

Playing the caregiving role is tiring. In a study by Lynch et al. (2021), caregivers of children with disabilities were found to need breaks as they assume other responsibilities in their families as parents, spouses, or family members, to provide and maintain high-quality nursing care. In the African context, accessing wheelchairs and other assistive devices by the carers is difficult, which is why carers in LMICs experience fatigue that is more physical and low back pains (Dambi et al.2015)

Psychological and Emotional Caregivers' Unmet Needs

Poor health-related quality of life might affect the care provided by caregivers to the care recipient (Dambi et al., 2015). There was found to be a need to improve the emotional health or well-being of male caregivers of children with special needs, despite the internal tension (Lynch et al., 2021). In a study conducted in Kenya, caregivers reported that health care workers underestimated their emotional distress and information needs (Masaba et al., 2021). These details show why caregivers need support in the care process.

Caregivers' Financial Unmet Needs

Families of children with disabling conditions face decreased financial resources during times of increased financial demands. Parents expressed the need for financial support to purchase specialized assistive equipment for their children, as it is costly. Caregivers felt they received insufficient supportive services to sustain long-term caregiving roles and also expressed unmet needs for transportation, healthcare-related costs, and nutritional information (Mohd et al., 2019; Adejoh et al., 2021). According to Sandy et al. (2013), they also relied on the government's disability payment to fulfill their financial needs. Parents of children with CP can enhance their quality of life by achieving greater financial stability and receiving the resources they need (Elangkovan & Shorey, 2020).

2.2.3 Sources and Resources of Support for Caregivers

The availability of resources for caregivers is insufficient, inconsistent, and fragmented, despite the overwhelming evidence indicating that family caregivers face substantial physical, emotional, and social distress. Additionally, caregivers of patients with chronic illnesses often lack awareness of the support systems available to assist them (Sherman 2019). In HICs, carers of patients with multimorbidity mentioned that access to support services like respite care was hard due to long waitlists or their patients' ineligibility for these services. They also reported poor quality of the services offered, adding financial problems as a barrier to respite care (Price et al., 2020). On the other hand, primary healthcare, vital resources, and accompanying services are scarce in low- and middle-income countries (LMICs). African carers of disabled children get relief from stress through informal support networks, such as friends and religious organizations, and through the use of respite care. Elangkovan and Shorey (2020) noted that when children with severe disabilities were cared for, there were fewer resources available to them. Both the children with impairments and the people who take care of them are negatively impacted by this, making carers an especially vulnerable population (Farajzadeh et al., 2018).

Provision of Health Care Support at Home

To ensure the provision of extended care for children with cerebral palsy, it is imperative to offer support to their informal caregivers. The caregivers of children with cerebral palsy (CP) expressed feelings of loneliness and a lack of support. They also faced significant stigma due to having a disabled kid, and were worried about the long-term dependence of their child (Lee et al., 2020; Schurgin et al., 2021). Communication or information regarding the child's condition must be provided to the parents or caretakers. It was noted that caregivers had no access to specialized equipment for their children with CP and that there was also a delay in support from the government office, specifically the social welfare department, in providing readily available support to caregivers (Mohd et al., 2019). Guardians of disabled children said that the support offered by their local government was insufficient to cover daily expenses; thus, they found it crucial to have other financial sources to meet their daily needs (Sandy et al., 2013).

Community and Social Support for Caregivers

Caregivers feel overwhelmed in their caregiving role. They expressed interest in support groups where they could benefit from a healthy emotional space that aligns with their needs and abilities to contribute their knowledge and experiences, even though they felt a lack of available time due to their caregiving involvement, according to Lynch et al. (2021). It was noted that the interaction between group members during support groups for caregivers of frail elderly can affect caregivers in ways that are not achievable with individual support (Lopez-Hartmann et al., 2012). In the same study, it was reported that group intervention increased caregivers' knowledge of community resources and their social support. Though in a study done in Kenya, parents of children with disability mentioned that support from friends, religious groups, and the use of respite care was difficult to access if the child presents severe disability. Al-Gamal et al. (2013) concluded that this was also observed in some developed countries.

Emotional and Spiritual Support

Spiritual and emotional distress are real concerns for carers of disabled children. Counselling sessions could provide the spiritual and emotional support that parents of children with cerebral palsy need to be more resilient in the face of the challenges they face caring for their children. Research conducted by Mohd et al. (2019) shows that the lack of adequate support for the care of children with cerebral palsy (CP) is a source of concern and anxiety for their carers, according to a study done in Bangladesh (Zuurmond et al., 2015). Parents or guardians of children with disabilities sought spiritual therapies to find emotional fulfillment. They expressed the need to explore many healers, including traditional practitioners, in their search for alternative remedies. The study found that participants embraced spiritual views despite feeling pessimistic (Dlamini et al., 2023). Hope and spiritual beliefs significantly influence individuals' capacity to confront life's obstacles.

2.3 Literature Gaps

Upon reviewing the literature on caregivers' perceptions and experiences of children with cerebral palsy, a few key gaps emerged that the study needed to address. The study identified limited research on positive Caregiving Outcomes in low-resource settings. While some studies mention positive experiences (e.g., familial unity, spiritual growth), there is a lack of research focused specifically on caregivers in low-resource environments, such as those attending clinics like AIC Kijabe Hospital. Research often emphasizes negative experiences, leaving a gap in understanding the specific positive outcomes that may emerge within this particular cultural and social context.

There is insufficient exploration of cultural impact on positive Experiences. While some research highlights religious and spiritual benefits for caregivers, the cultural factors that influence caregivers' positive experiences remain underexplored. The specific role of religious and community beliefs in shaping caregiving perceptions in Kenya, and specifically at AIC Kijabe Hospital, has not been well documented.

Studies tend to overlook how interactions with healthcare professionals and services at developmental clinics, such as AIC Kijabe Hospital, contribute to both positive and negative caregiving experiences. This gap suggests the need to explore the healthcare system's role in shaping caregivers' perceptions.

Most existing research highlights the general unmet needs of caregivers (e.g., emotional, financial, physical). Still, few studies focus specifically on the unmet support needs that arise in the context of attending a developmental clinic. There is a need to investigate the gaps in clinic-based support for caregivers at AIC Kijabe Hospital.

There is limited research on tailored interventions to address caregivers' unmet needs, particularly in clinics in low-resource areas. The existing literature does not adequately explore what specialized programs or interventions could be implemented to help caregivers meet their emotional, physical, and financial needs more effectively.

Studies indicate that caregivers struggle to access wheelchairs and assistive devices, but specific research on the accessibility of these resources within clinics like AIC Kijabe Hospital is lacking. There is limited data on how barriers to accessing equipment and medical services affect caregivers' unmet needs in this context.

On local and community-based Support Systems, there is a lack of research on Community-Based Support Networks in Clinic Settings. Although some studies mention community and religious support, there is a gap in understanding the specific support systems available to caregivers attending developmental clinics in low-resource settings like AIC Kijabe Hospital. Research tends to focus on general caregiver challenges but lacks specificity about the community-based or institutional support available to caregivers in these environments.

While support systems (e.g., respite care, financial support) are often mentioned, there is a lack of in-depth analysis regarding their effectiveness in meeting caregivers' needs, particularly within the context of developmental clinics. Research should assess how these systems address the day-to-day challenges caregivers face in these settings. The coordination between healthcare providers at developmental clinics and external support systems (such as government aid, NGOs, and community networks) is often underexplored in the literature. There is a gap in understanding how integrated care can be provided to caregivers, facilitating better access to support services.

These gaps highlight the need for focused research on the unique experiences, unmet needs, and available support systems for caregivers of children with cerebral palsy in specific clinical settings like AIC Kijabe Hospital. Suppose the situation for caregivers of children with cerebral palsy remains unchanged without any interventions or improvements to their support systems. In that case, the likelihood of these caregivers developing non-communicable diseases (NCDs) is a growing concern. Suppose caregivers of children with cerebral palsy do not receive the support they need. In that case, they are at high risk of developing NCDs due to chronic stress, unhealthy lifestyle behaviors, and lack of mental health care. Interventions aimed at reducing caregiver burden, improving access to health services, promoting healthy lifestyle behaviors, and enhancing social support networks are essential to mitigating this risk. The failure to intervene could contribute to a significant rise in NCDs among caregivers, aligning with the global increase in these diseases.

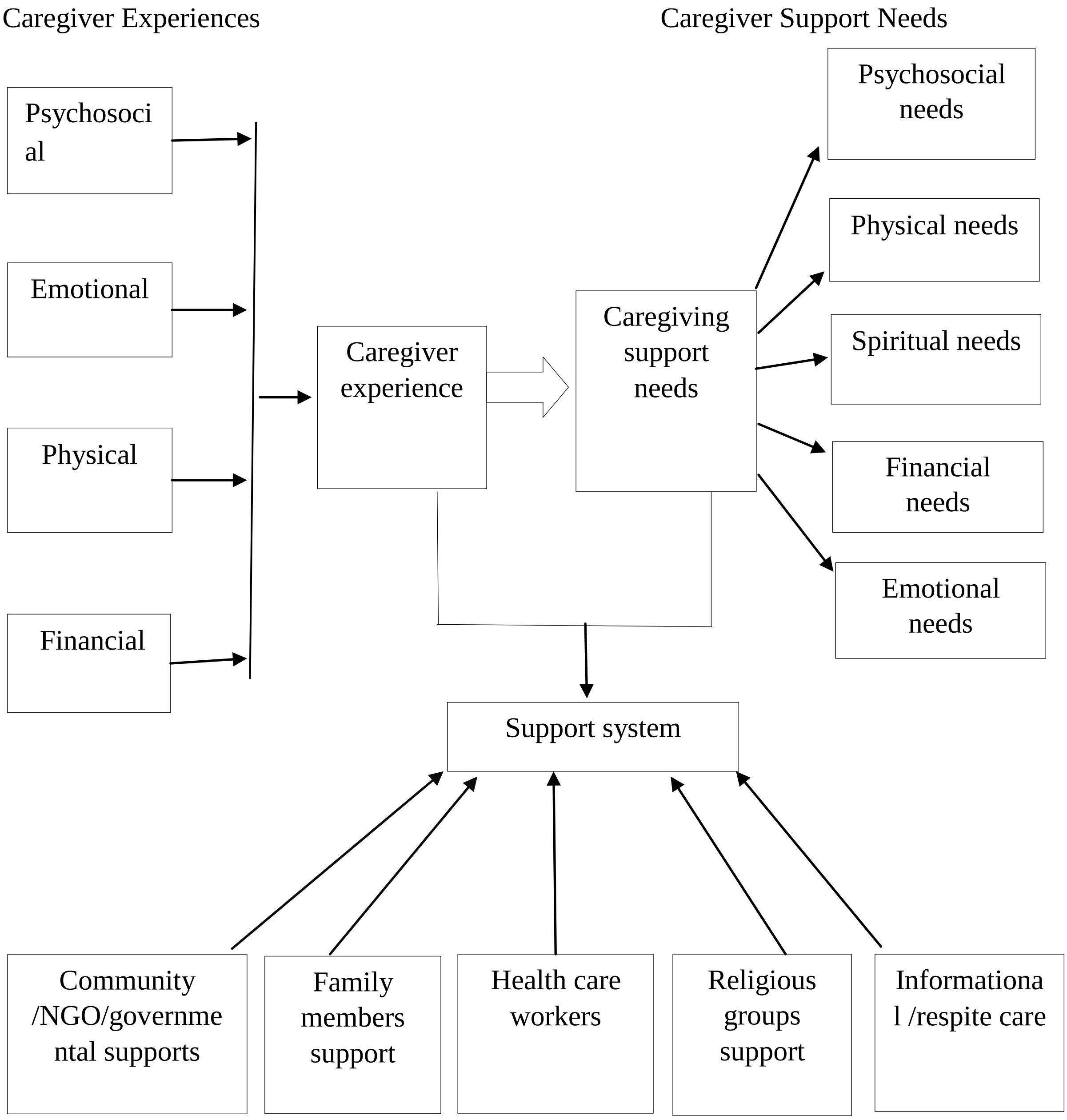
The fact that global studies highlight the importance of comprehensive therapy services and formal support systems in improving caregiver wellbeing, Kenya’s context is characterized by limited access to rehabilitation services, persistent cultural stigma around disability, and gendered expectations that place caregiving primarily on women. This creates a gap between recommended best practices and lived realities. This gap underscores the need for interventions tailored to the social and structural challenges caregivers face in Kenya.

2.4 Conceptual Framework

This conceptual framework illustrates the various factors contributing to caregivers' strain. Additionally, it represents the multiple parties who may contribute to mitigating both the stress on caregivers and the impacts of caregiving.

Figure 1

Conceptual Framework



Source: Author, (2025)

The conceptual framework for this study highlights the interplay between positive and negative caregiving experiences, unmet support needs, and the availability of support systems. These variables provide insight into the overall caregiving environment, helping to identify areas for intervention and support.

Positive caregiving experiences are the emotional and practical rewards caregivers derive from their role. These may include a sense of fulfillment, emotional satisfaction from bonding with the child, and the acquisition of valuable caregiving skills. Caregivers often find purpose and meaning in their caregiving responsibilities, which can strengthen their emotional resilience. The availability of strong support systems, such as family members or healthcare professionals, typically enhances caregivers' positive experiences. These experiences serve as protective factors that buffer against the challenges and hardships of caregiving.

On the other hand, negative caregiving experiences encompass the emotional, physical, and financial burdens faced by caregivers. Common challenges include emotional burnout, physical exhaustion, financial strain due to medical and caregiving expenses, and social isolation. Caregivers often report feelings of stress, anxiety, and depression due to the intense demands of their role. These adverse experiences are likely to be exacerbated when caregivers do not have adequate support, leading to further strain. The interplay between positive and negative experiences ultimately shapes the overall caregiving experience, and understanding this dynamic is key to improving caregiver well-being.

Unmet support needs are the gaps in resources or assistance that caregivers require to care for their children effectively. These may include a lack of respite care, inadequate medical information regarding CP, insufficient financial aid, and a need for emotional and psychological support. When caregivers lack the necessary resources or services, their ability to provide quality care is compromised, leading to increased stress and poorer outcomes for both the caregiver and the child. Identifying and addressing these unmet needs is essential in reducing the caregiving burden and improving the overall experience.

Finally, support systems available to caregivers represent the resources and networks that help alleviate caregiving challenges. These can include family support, community resources, medical services, and peer support groups. A robust support system can significantly enhance caregivers' capacity to manage their responsibilities by providing financial aid, respite care, emotional support, and access to healthcare professionals. On the contrary, insufficient support can leave caregivers feeling overwhelmed, increasing the likelihood of negative experiences and unmet needs. Therefore, the availability and quality of these support systems are crucial for enhancing caregiver well-being and ensuring sustainable care for children with CP.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

The key elements of this chapter are the research design, study region, study population, selection criteria, sampling method, and sample size, data collection procedure, ethical considerations, and data analysis procedures.

3.2 Research Design

The study employed a phenomenological qualitative methodology to investigate the firsthand experiences of caregivers of children with cerebral palsy as they provide care, as well as the support systems accessible to them during the caregiving process. The emphasis was placed on the actual experiences of individuals who provide care.

3.3 Location of the Study

The study participants were selected from the developmental clinic at AIC Kijabe Hospital. The developmental clinic is a component of the pediatric department at AIC Kijabe Hospital. This hospital is a non-profit, faith-based institution with a capacity of 363 beds. It is a level six hospital situated in Kiambu County, Central Kenya. The hospital is located about an hour's drive from Nairobi, in the direction of Nakuru. The interviews took place at the pediatric Outpatient department.

3.4 Population of the Study

The population of this study comprised caregivers of children aged 4 years and above with a documented diagnosis of CP who attend the developmental clinic at the pediatric outpatient department at AIC Kijabe Hospital for routine care, where an average of 8 children with CP are seen weekly. This population included caregivers responsible for the children's daily care. Selecting children aged 4 years and above allows the study to focus on a stage at which the diagnosis of CP is well established, as described by Wang et al. (2021) in a population-based study conducted in Taiwan. This allows for focus on a stage where caregiving demands are more intense and well-established, providing a richer understanding of the challenges and experiences faced by primary caregivers.

As the care recipient's well-being depends on the caregiver, taking care of these caregivers enabled the provision of high-quality care to these children with CP.

3.5 Sample Size and Sampling Procedure

3.5.1 Sampling Procedure

A purposive sample was recruited to obtain a wide range of caregiver experiences. Study participants were recruited from the pediatric and developmental clinics, where they brought their children with CP for routine follow-up.

The participants were contacted by phone by the principal investigator or the research assistant to raise awareness of the study, and preliminary verbal consent was obtained in readiness for the interview day. The principal researcher assured participants that participation in the survey was entirely voluntary.

After participants were informed of the study, written consent was obtained during their routine clinic attendance and signed before the interview. If a participant declined to consent, they were excluded from the study but received complete routine care without any compromise.

3.5.2 Sample Size

An in-depth interview was conducted targeting at least 12 participants; however, the interviews continued until data saturation was reached. Saturation was reached after the sixth interview, though six additional participants were interviewed to confirm it. According to Guest et al. (2006), data saturation was attained after 12 interviews, though sufficient themes emerged after 6 interviews that might be useful for interpretation. Interviews continued until data saturation was reached, and no new themes emerged.

The participants selected were the primary caregiver, whose child was 4 years of age or older and had consistent caregiving responsibilities, such as the biological parent, a legal guardian, a paid caregiver, or an immediate family member responsible for the child's well-being, including decision-making for the child. Daycare workers and those who refused to consent were not included in the study.

3.6 Data Collection Instrumentation

A semi-structured guide was used, with questions that reflected the study objectives. This was adopted from Nimbalkar (2014), a validated tool on "*A qualitative study of psychosocial problems among parents of children with cerebral palsy attending two tertiary care hospitals in western India"* (See Appendix A). Minor modifications were made to ensure relevance to the study population and setting, while maintaining the core domains related to caregiver burden, positive and negative experiences, support needs, and coping mechanisms.

The use of a semi-structured guide adapted from validated caregiver tools is effective in similar research contexts. For example, Diseko (2017) in Botswana used a semi-structured guide informed by established caregiver assessment frameworks to explore the lived experiences of caregivers of children with cerebral palsy, yielding rich, credible narrative data. Similarly, Kisinna, Ohene, and Attafuah (2025) in Ghana employed a structured qualitative interview guide to investigate caregiver burden and coping in a low-resource context, demonstrating the tool's suitability in capturing complex emotional and practical dimensions of caregiving. Additionally, Klankaradi (2008) successfully applied a structured interview framework rooted in recognized caregiver evaluation constructs to explore the ongoing caregiving experiences among parents of children with cerebral palsy in New Zealand. These studies affirm that semi-structured interview tools grounded in validated caregiver measures are appropriate, reliable, and effective for eliciting in-depth caregiver perspectives across diverse settings. Therefore, the adoption of the Nimbalkar (2014) tool in the current study aligns with established methodological practice and enhances the credibility and comparability of the findings.

3.7 Data Collection Procedure

The interviews were held at the developmental clinic, where children with CP receive routine follow-up. Before the interviews, caregivers were contacted by telephone to raise awareness of the research and obtain verbal consent.

Once at the clinic, the written consent was administered and signed by the participants (see Appendix B). Participants were also assured of confidentiality. This happened in a comfortable private setting, before administering the semi-structured interview to the participants. The semi-structured interviews were conducted in one of the consultation rooms, away from the other patients and caregivers. The interviews happened immediately after they finished their clinic, over a cup of tea and snacks.

The researcher had support staff to watch over the child while the caregivers were interviewed. Caregivers who needed more psychological follow-up were linked with the psychologist for consideration of more psychotherapy sessions. The interviews lasted about 30 minutes each. Description notes were taken, particularly those about non-verbal communications and any events or actions that emerged. The researcher, who was fluent in both Kiswahili and English and familiar with medical terms, reviewed the initial transcription due to semantic issues. Data were recorded using an audio recorder, and the interviews were transcribed and translated into English, as well as analyzed and coded.

3.8 Data Analysis

Thematic analysis was conducted to analyze the collected data. Thematic analysis is a qualitative data analysis method that aims to comprehend experiences, thoughts, or actions within a dataset (Kiger & Varpio, 2020). To ensure confidentiality, the voice recorder and all data were securely stored and only accessible by the researcher. According to Braun & Clark (2006), it also enables the identification, analysis, and reporting of recurring patterns within a dataset. The author outlined a set of sequential phases for conducting a thematic analysis that the researcher should follow.

Step 1: The recorded interviews were transcribed verbatim and into text. Notes and observations taken during interviews were compiled.

Step 2: The researcher thoroughly read through the transcripts and notes to immerse themselves in the data, identifying initial thoughts and potential patterns.

Step 3: Open Coding: Segments of text (e.g., sentences or phrases) were labeled with codes representing ideas, concepts, or themes. These codes included categories such as "emotional strain," "support systems," "financial burden," and "positive experiences." Axial Coding: The researchers grouped related codes into broader categories, such as "caregiving challenges" or "health impacts."

After coding, recurring themes and patterns were identified across the data. These themes reflected everyday experiences among caregivers or significant differences in their perspectives. Themes were reviewed to ensure they accurately reflect the data.

Step 5: Using thematic analysis, the researcher organized the themes into a coherent narrative. They explored how the themes relate to one another and how they address the research questions. For example, themes like "lack of emotional support" and "feeling overwhelmed" were linked to a larger theme of "caregiver burden."

Step 6: The Researcher interpreted the themes to derive insights. They considered the implications of the findings, reflecting on how caregivers' experiences are shaped by factors such as their demographics, support systems, and challenges. They compared the findings with existing literature on caregiving.

Step 7: The researcher used techniques like triangulation (comparing multiple sources of data) and peer debriefing (discussing findings with other researchers) to ensure the accuracy and credibility of the analysis.

Step 8: The results were reported in a detailed narrative that highlighted the key themes and provided quotes from participants to support the analysis.

NVivo software was used for data analysis, which began during the first week of data collection. This allowed the researcher to make changes based on whether there was a need for sample selection or for the interview questions, so that more light could be shed on the answers to the research question.

3.9 Ethical Considerations

Participants were contacted 1 week before their hospital visit for preliminary verbal consent to participate in the study, and written consent was obtained from caregivers at the clinic after participants were informed of the study's objectives and purpose. They were contacted after selection from the booking diary. Participants were told that participation in the survey was voluntary and free, and that they could decline to participate or withdraw at any time during the study without affecting their patients' care.

After data collection, confidentiality and privacy of the information provided were maintained throughout the study. All the codes and the participants’ details whose names were recorded in the audio were kept at the research office at AIC Kijabe Hospital.

Participants who were found to need additional support, such as counseling or spiritual support, were referred to the appropriate department within the hospital. The researcher provided tea and snacks during the interview and also reimbursed one-way transport for the participants as a token of appreciation for their participation. The researcher used this criterion; if the participants spend between 200sh and 300sh on transport. A standardized reimbursement of 250 shillings was set for all the participants. This enhanced consistency and fairness for all the eligible participants.

Ethical approvals were obtained from Kabarak University Research and Ethics Committee (KUREC), Kijabe Hospital Institutional Scientific and Research Ethics Committee (KH/ISERC/02718/0054/2025), after which a research permit was issued from the National Commission for Science, Technology and Innovation (NACOSTI-License No: NACOSTI/P/25/4174737) before starting data collection.

CHAPTER FOUR

DATA ANALYSIS, PRESENTATION AND DISCUSSIONS

4.1 Introduction

This chapter presents the analysis, interpretation, and discussion of the study's findings on the experiences and support needs of primary caregivers of children with cerebral palsy (CP) attending the developmental clinic at AIC Kijabe Hospital. The chapter is organized according to the study objectives to provide a logical flow of information and to address each research question comprehensively.

The purpose of this study was to gain an in-depth understanding of caregivers’ lived experiences, the unmet needs they encounter in the caregiving process, and the nature of support systems available to them. Data were collected through qualitative methods using in-depth interviews and thematic analysis. The findings presented in this chapter are structured around the following objectives**:** To explore the positive and negative experiences of primary caregivers of children with cerebral palsy; to explore the unmet support needs in relation to caregiving of caregivers of children with cerebral palsy, and to understand the support systems available to the caregivers of children with CP attending the developmental clinic at AIC Kijabe Hospital.

4.2 Demographic Characteristics of the Respondents

Table 1

Demographic Profile of Primary Caregivers (n=12)

Caregiver ID	Age (Years)	Gender	Kinship to Child	Marital Status	No. of Dependents	Level of Education	Employment Status
CG1	28	Female	Mother	Married	3	Secondary	Unemployed
CG2	35	Female	Mother	Single	2	Primary	Informal Business
CG3	30	Female	Mother	Married	4	Secondary	Housewife
CG4	40	Female	Mother	Married	5	College Diploma	Employed Part-time
CG5	24	Female	Mother	Single	1	Secondary	Student/ Unemployed
CG6	33	Female	Mother	Widowed	3	Primary	Small-scale Farming
CG7	26	Female	Paid Caregiver	Single	1	Secondary	Full-time Caregiver
CG8	38	Male	Father	Married	4	Secondary	Casual Laborer
CG9	42	Female	Grandmother	Widowed	3	No Formal Education	Unemployed
CG10	31	Female	Mother	Married	3	Secondary	Informal Business
CG11	36	Female	Mother	Married	2	College Diploma	Employed Part-time
CG12	29	Female	Mother	Married	4	Secondary	Housewife

4.2.1 Gender Distribution

Table 2

Gender Distribution (n=12)

Gender	Frequency	Percentage
Female	11	91.7%
Male	1	8.3%
Total	12	100%

Table 2 shows that the majority of caregivers were female (91.7%), with only one male caregiver (the father). This suggests caregiving for children with CP is primarily a maternal responsibility in this setting, reflecting cultural norms and societal expectations in Kenya, where women predominantly provide home-based care.

4.2.2 Age Distribution

Table 3

Age Distribution n=12

Age Group	Frequency	Percentage
20–29 years	4	33.3%
30–39 years	6	50.0%
40+ years	2	16.7%
Total	12	100%

Table 3 indicated that half of the caregivers (50%) were aged between 30 and 39 years, while 33.3% were in their 20s. This shows caregiving for CP children largely falls on individuals in their prime productive years, which may impact their economic and social mobility. A smaller proportion (16.7%) were older adults, often grandmothers, indicating intergenerational caregiving when biological parents cannot cope.

4.2.3 Kinship Relationship

Table 4

Kinship Relationship (n=12)

Relationship	Frequency	Percentage
Mother	9	83.3%
Father	1	8.3%
Grandmother	1	8.3%
Paid Caregiver	1	8.3%

Table 4 shows that most caregivers were biological mothers (83.3%), confirming that the caregiving burden falls predominantly on mothers. Fathers and grandparents provided minimal direct care, while paid caregivers were rare due to financial constraints.

4.2.4 Marital Status

Table 5

Marital Status (n=12)

Status	Frequency	Percentage
Married	8	66.7%
Single	2	16.7%
Widowed	2	16.7%

Table 5 indicated that two-thirds (66.7%) of caregivers were married, suggesting some level of spousal support. However, interviews revealed that even married caregivers reported financial strain and inadequate practical support, suggesting that marital status does not always translate into shared caregiving responsibilities.

4.2.5 Level of Education

Table 6

Level of Education (n=12)

Education Level	Frequency	Percentage
No formal education	1	8.3%
Primary	2	16.7%
Secondary	7	58.3%
College Diploma	2	16.7%

Table 6 shows that most caregivers (58.3%) had secondary education, while 16.7% had a diploma. Education level influences caregivers' ability to understand therapy instructions and advocate for services. The one caregiver without formal education faced challenges in navigating healthcare systems, highlighting the need for simplified caregiver education programs.

4.2.6 Employment Status

Table 7

Employment Status (n=12)

Employment Type	Frequency	Percentage
Unemployed/Housewife	5	41.7%
Informal Business	3	25.0%
Employed Part-time	2	16.7%
Paid Caregiver	1	8.3%
Casual Laborer	1	8.3%

Table 7 indicates that nearly half of caregivers (41.7%) were unemployed, with a quarter engaged in low-income informal businesses. Only 16.7% had part-time employment. This limited financial capacity explains the unmet needs for assistive devices, therapy, and nutritional supplements highlighted in interviews. Financial hardship directly contributes to stress and burnout.

4.3 Demographics of children with CP (n = 12)

Table 8

Demographics Characteristics for Children with CP

Variable	Category	Frequency	Percentage
Age Group (Years)	4–6	5	41.7%
	7–9	4	33.3%
	10+	3	25.0%
Gender	Male	7	58.3%
	Female	5	41.7%
Type of CP	Spastic Quadriplegia	6	50.0%
	Spastic Diplegia	3	25.0%
	Hemiplegia	2	16.7%
	Mixed type	1	8.3%
Severity (GMFCS)	Level I–II (Mild)	2	16.7%
	Level III (Moderate)	5	41.7%
	Level IV–V (Severe)	5	41.7%
Comorbidities	Epilepsy	6	50.0%
	Speech difficulties	9	75.0%
	Vision impairment	3	25.0%
School Attendance	Attending school	4	33.3%
	Not attending school	8	66.7%

4.3.1 Age Distribution of the Children

A significant proportion of the children (41.7%) were aged 4–6 years, 33.3% were aged 7–9 years, and 25% were aged 10 years and above**.** This age distribution suggests that most children were in the early developmental stage**,** when early intervention strategies can be most effective in improving motor function and communication skills. The presence of 25% aged 10 years and above indicates that caregivers often face long-term caregiving responsibilities, which can be emotionally and physically exhausting. Older children tend to be heavier, increasing physical strain on caregivers, and they may also experience secondary complications such as joint stiffness or contractures, adding complexity to care.

4.3.2 Gender

Of the 12 children, 58.3% were male, and 41.7% were female. This finding aligns with global epidemiological data showing that cerebral palsy is slightly more prevalent among male children than females, possibly due to differences in vulnerability to perinatal brain injury. For caregivers, this gender difference may have no significant caregiving implications in early childhood, but societal perceptions of disability in boys versus girls may influence stigma or expectations differently.

4.3.3 Type of CP

The most common type was Spastic Quadriplegia (50%)**,** followed by Spastic Diplegia (25%)**,** Hemiplegia (16.7%)**,** and Mixed Type (8.3%)**.** The dominance of spastic quadriplegia highlights the severity of functional impairment in this population. Children with this type often experience severe limitations in mobility and require full-time assistance for daily living. This increases caregiver burden significantly, as these children typically need specialized equipment like wheelchairs and frequent physiotherapy. In contrast, hemiplegic children are more independent, so their caregivers face relatively fewer physical challenges.

4.3.4 Severity (GMFCS Levels)

41.7% of children had moderate functional limitations (GMFCS Level III), while another 41.7% were in severe categories (Levels IV–V). Only 16.7% had mild limitations (Levels I–II). This pattern indicates that the majority of caregivers are caring for children who cannot walk independently or even sit without support, requiring constant supervision and significant physical effort. This has profound implications for caregivers' physical health (back strain and fatigue) and psychological stress, given the round-the-clock nature of the care. Furthermore, severe cases often have associated feeding difficulties, necessitating longer feeding sessions and increasing the risk of malnutrition.

4.3.5 Comorbidities

Speech difficulties were most common (75%), followed by epilepsy (50%) and vision impairment (25%). These comorbidities greatly complicate caregiving. Speech difficulties hinder communication, leading to behavioral challenges and frustration for both child and caregiver. Epilepsy requires medication and emergency preparedness, increasing financial and emotional stress. Vision problems may further restrict independence, making these children entirely dependent on caregivers. These findings suggest that multidisciplinary interventions are essential to address the broad spectrum of needs.

4.3.6 School Attendance

Only 33.3% of children attend school, while 66.7% do not. This low school attendance reflects the lack of inclusive education systems, physical inaccessibility, and caregivers' inability to afford specialized schools. The absence of school attendance not only affects children's educational and social development but also places a continuous burden on caregivers, who receive no break from their caregiving duties**.** This likely contributes to burnout and social isolation among caregivers.

The findings show that most children have severe disabilities, multiple comorbidities, and limited access to education, which escalates caregiving demands**.** This underscores the urgent need for assistive devices, financial support, inclusive schooling, and mental health services for caregivers**.**

The data reveals a dual vulnerability. Caregivers face financial hardship, limited education, and unemployment**,** while children present severe functional limitations and comorbidities, leading to high dependency. These demographic realities underline the urgent need for assistive devices, inclusive education, financial assistance, and psychosocial support programs for both caregivers and their children.

4.4 Positive and Negative Experiences of Primary Caregivers of Children with Cerebral Palsy

The first objective of the study was to explore the positive and negative experiences of primary caregivers of children with cerebral palsy attending the developmental clinic at AIC Kijabe Hospital**.** The findings revealed that caregiving for a child with CP evokes a mixture of positive emotions, such as hope and joy in small milestones**,** alongside negative experiences characterized by financial strain, social stigma, physical exhaustion, and emotional stress**.** The results are presented thematically below.

4.4.1 Positive Experiences

Although caregiving for children with CP is highly demanding, some caregivers reported moments of encouragement and emotional satisfaction, primarily linked to observable developmental progress in their children or emotional bonding. These experiences often provided caregivers with a sense of purpose and resilience in the face of adversity.

Theme 1: Joy in Child's Progress and Developmental Milestones

Several caregivers expressed happiness when they noticed even the most minor signs of progress in their child's health and physical development.

CG1: *"I was thrilled when he first smiled at me, it gave me hope that he understands me(smiling)."*

CG3: *"At first, she was weak, but now I am encouraged that her neck is at least strong. Being encouraged by my neighbor, who has the same problem as my child, that my child will be okay someday."*

CG4: *"Sylvester is doing well, and that encourages me. He tries to reach out to things given to him."*

CG6: *"We shaped our minds towards challenges ahead of us through him. At least he has started to sit down, start a speech, and he can identify people."*

CG10: *"She can now hold a spoon by herself. That makes me proud as a mother."*

These responses suggest that incremental developmental progress serves as a critical source of hope and motivation for caregivers, validating their efforts and giving meaning to their caregiving journey. This aligns with findings by McConnell et al. (2015), who reported that small successes in developmental therapy often provide emotional uplift for caregivers of children with disabilities.

Theme 2: Emotional Bonding and Moments of Calm

Some caregivers also highlighted experiences of peace and connection with the child, especially during calm moments.

CG7: *"When he has eaten, he is very calm, that is the only encouraging part of him."*

CG9: *"When she laughs, I forget all the stress. Those small moments make me strong."*

These statements indicate that moments of tranquility and emotional closeness, however brief, can significantly alleviate caregiver stress and reinforce the emotional attachment between caregiver and child. This resonates with the concept of "caregiver resilience" discussed by Peer & Hillman (2014), in which positive emotions buffer the adverse effects of chronic stress.

Contrasting Experience:

Not all caregivers reported positive experiences.

CG11: *"There is nothing positive I have experienced about him."*

This highlights caregiver burnout and emotional fatigue**,** where the overwhelming burden of care eclipses any perceived benefits. Such perceptions often correlate with high levels of psychological distress (Whittingham et al., 2011).

4.4.2 Negative Experiences

While some caregivers experienced moments of hope, the majority reported significant challenges that negatively impacted their social, economic, and psychological well-being**.** These are categorized into four main subthemes: financial strain, social stigma, lifestyle restrictions, and emotional and physical stress**.**

Theme 1: Financial Strain

The cost of medication, therapy, and specialized food emerged as a significant challenge.

CG2: *"I spend almost all my salary on therapy and special food. It's draining."*

CG3: *"Problem with money, when I ask my family members for money, they don't give me."*

CG4: *"There are so many negatives; it is expensive, and he doesn't eat any food like any other child. The cost of medication is also prohibitive. The child is also vulnerable to other diseases, and treatment is costly."*

CG8: *"Transport to the hospital every week is killing me financially.*

These narratives indicate that financial hardship is a persistent burden for caregivers**,** consistent with studies by Tilahun et al. (2016), which found that caregivers of children with disabilities often face catastrophic healthcare costs due to lack of insurance and inadequate institutional support in low-resource settings.

Theme 2: Social Stigma and Isolation

Some caregivers faced social challenges and discrimination from the community.

CG1: *"Other children comment on why the child has not sat or moved while others of his age have. I was unable to continue with my studies since I was a student."*

CG11: *"People keep asking what is wrong with my child, some even say it is witchcraft."*

This illustrates how stigma from peers and community members exacerbates caregiver distress, often resulting in disrupted educational or career aspirations, as supported by Gona et al. (2011), who reported similar findings in Kenyan contexts.

Theme 3: Lifestyle Restrictions and Role Strain

Caregivers reported being unable to work or engage in personal activities due to constant caregiving demands.

CG6: *"Most of the time I have to take off from work to come and take care of this baby, by taking therapy."*

CG7: *"I don't go to work because I cannot work when I am carrying him to work."*

CG12: *"I had to quit my job. My whole life now revolves around this child".*

These findings reveal role strain and economic vulnerability, as caregivers, especially mothers, often sacrifice employment, reducing household income and increasing dependency. This mirrors observations by Masefield et al. (2020), who found that caregiving limits labor force participation, increasing poverty risk.

Theme 4: Emotional and Physical Exhaustion

Some caregivers expressed stress from aggressive behaviors and constant vigilance.

CG7: *"Sometimes he is very violent, so I have to restrain myself to avoid aggression. Also, he doesn't eat any food."*

CG9: *"I barely sleep at night because she cries and I must watch over her."*

These experiences indicate high psychological distress compounded by behavioral challenges**,** consistent with research by Whittingham et al. (2011), which associates caring for children with CP and behavioral issues with caregiver depression and anxiety.

The findings suggest that although positive experiences exist mainly linked to child progress and emotional bonding, negative experiences dominate the caregiving journey**,** particularly financial strain, stigma, and lifestyle restrictions. These stressors not only impact caregivers' well-being but also have implications for sustainable caregiving and family resilience.

Table 9

Summary of Themes (Positive and Negative Experiences)

Positive experiences	Negative experiences
Joy in the child's progress	Financial strain (therapy, medication)
Emotional bonding moments	Social stigma and isolation
	Lifestyle restrictions and role strain
	Emotional and physical exhaustion

The findings indicate that caregiving for children with CP involves a dual reality: moments of hope and pride from small achievements coexist with overwhelming challenges.

The above findings address the first objective by demonstrating that primary caregivers of children with cerebral palsy experience a mix of both positive and negative caregiving realities, ranging from emotional fulfillment and strengthened bonds to stress, stigma, financial strain, and physical exhaustion. This highlights the coexistence of rewarding and challenging aspects of the caregiving journey, thereby fulfilling the study's first objective.

Positive experiences align with family resilience theory, which posits that hope and meaning-making buffer stress (Walsh, 2016). The joy caregivers feel when observing little developmental progress supports McConnell et al.'s (2015) similar findings.

Therefore, negative experiences dominate, especially financial strain, stigma, and emotional fatigue, echoing studies by Tilahun et al. (2016) and Masefield et al. (2020). The burden of care significantly limits economic participation, reinforcing the need for structured social support programs, such as financial subsidies, caregiver counseling, and inclusive community education campaigns.

This aligns with the work of Alhumaidi et al. (2023), who found that many caregivers reported satisfaction in family interactions and parenting, suggesting that caregiving can strengthen emotional bonds and offer meaningful moments of connection. Similarly, Smith and Blamires (2022) noted that caregivers often develop adaptive strengths and resilience as they adjust to the demands of caring for a child with CP, highlighting that positive experiences can emerge even within challenging circumstances.

However, these positive emotions were overshadowed by significant negative experiences. Consistent with the themes identified by Smith and Blamires (2022), including guilt, cultural blame, and social marginalization, caregivers in this study reported facing stigma, discrimination, and emotional distress. The challenges were not only social but also physical and financial. Ni et al. (2022) described caregivers experiencing exhaustion, isolation, and an overwhelming sense of responsibility, which resonates with accounts of physical strain and emotional stress reported in the current study. In a similar vein, Mwinbam et al. (2023) highlighted economic hardship, job loss, limited access to information, and the physical burden of daily care as significant barriers faced by caregivers in resource-limited settings. These findings mirror the financial strain and restricted support structures reported by caregivers attending the AIC Kijabe Hospital clinic.

Recent studies in African and LMIC contexts continue to reinforce these patterns. Mwinbam et al. (2023) and Karisa et al. (2025) demonstrate that caregivers in Ghana and rural Kenya still experience profound stigma, financial struggle, and limited institutional support despite growing advocacy for disability inclusion. Among male caregivers in Kenya, Karisa et al. (2025) observed that financial burdens and inadequate access to healthcare often forced caregivers to rely on cultural or spiritual solutions, reflecting ongoing systemic gaps in formal support services. The persistence of these challenges across recent studies underscores the enduring structural inequities in low-resource environments.

In contrasting these findings with evidence from higher-resource settings, Smith and Blamires (2022) described caregiver experiences that sometimes involved more structured healthcare engagement and supportive services. However, studies conducted in China, Ghana, and Kenya (Ni et al., 2022; Mwinbam et al., 2023; Karisa et al., 2025) indicate a greater reliance on informal networks due to limited institutional or government support. This contrast highlights the disparity between contexts where formal respite and social support systems exist, and those, such as LMICs, where caregivers shoulder the full burden of care with little external support.

These patterns reinforce the conceptual framework underpinning this study, which suggests that the interaction between caregiving demands, unmet needs, and available social support shapes caregiver experiences. High demands, combined with the limited backing and persistent stigma, contribute to adverse emotional, physical, and financial outcomes, while moments of connection and family support foster positive experiences and resilience.

Therefore, this study contributes to the growing body of African qualitative research by offering context-specific insights into caregivers' lived experiences in a tertiary hospital setting. It helps fill a gap in the literature, which has been predominantly informed by high-income contexts, underscoring the need for culturally sensitive, equitable, and supportive interventions tailored to caregivers in low-resource environments.

4.5 The Unmet Support Needs in Relation to Caregiving of Caregivers of Children With Cerebral Palsy

The second objective was to explore unmet support needs among caregivers of children with cerebral palsy attending the developmental clinic at AIC Kijabe Hospital. Findings reveal three main challenge areas: physical and mental health strain, financial constraints, and lack of self-care opportunities. Additionally, caregivers highlighted critical support and unmet needs, including assistive devices, therapy services, specialized schools, and financial assistance.

4.5.1 Caregiving: Physical, Emotional, And Social Challenges

Caregiving for children with cerebral palsy was reported as physically, emotionally, and socially demanding. Major subthemes include health-related challenges, barriers to self-care, and lifestyle disruptions.

Theme 1: Physical Health Strain

CG1: *"My back aches daily from carrying him everywhere. He cannot sit by himself."*

CG3: *"Since I have a wound through CS, sometimes when I am overwhelmed with stress through responsibilities for the child, it starts to ache."*

CG4: *"I developed mental health issues before I accepted taking care of the child. Also, I get tired of holding him since he is sick all the time and fully dependent on me."*

CG5: *"Due to his weight, I feel tired carrying him around."*

CG7: *"Sometimes I feel chest pains from carrying him everywhere."*

CG9: *"At night, I wake up many times to change his position. This makes me feel worn out."*

CG11: *"My shoulders hurt because I support him whenever we go out."*

These accounts indicate physical exhaustion and musculoskeletal strain, commonly associated with the prolonged lifting and handling of children with disabilities (Nuri et al., 2019).

Theme 2: Psychological Stress and Social Isolation

CG4: *"I developed mental health issues before I accepted taking care of the child."*

CG5: *"I am psychologically stressed. Negative comments from others are also stressing me out. I cannot mingle with people because of stigma."*

CG6: *"The first months after diagnosis were the worst for me; I was even financially drained when taking care of him in the hospital."*

CG10: *"I feel lonely; most friends abandoned me when they realized my child's condition."*

CG11: *"Sometimes I feel depressed when people question why my child cannot walk or talk."*

CG12: *"People think it's a curse. That makes me ashamed to attend social functions."*

Emotional distress and stigma were prominent challenges, confirming findings by Gona et al. (2011) that stigma isolates caregivers and increases mental health risks.

Theme 3: Financial Hardship

Caregiving came with high economic costs**,** particularly for medical care, therapy, and special diets.

CG3: *"When I ask family members for money, they don't give me."*

CG4: *"Food is expensive. He doesn't eat like other children. The cost of medication is very high."*

CG6: *"I have skipped many things for myself to get money to buy drugs."*

CG8: *"Transport to the hospital every week drains me financially."*

CG10: *"We sold a cow to pay for therapy sessions."*

Economic burden remains a significant constraint, confirming findings by Tilahun et al. (2016), who identified financial strain as a primary challenge for caregivers in resource-limited settings.

Theme 4: Barriers to Self-Care

The study found that caregivers rarely prioritize their own health.

CG3: *"I talk with friends to relieve stress."*

CG5: *"When he is sick, I cannot do anything for myself."*

CG6: *"I have skipped so many things to get money to buy drugs and take care of him."*

CG7: *"No barrier. The special* school *helps by taking care of him during the day."*

CG12: "*I never go for checkups because all the money goes to my child's care.*

Limited time and financial resources restrict caregivers' ability to prioritize their own health, increasing burnout risk (Whittingham et al., 2011

4.5.2 Support Needs

Caregivers identified several forms of support needed to ease caregiving burdens.

Theme 1: Assistive Devices

CG3: *"I would need some chair to support the back of the child… assistive devices for the eyes."*

CG5: *"When given a wheelchair, life will be different."*

CG7: *"At least when given a wheelchair, it will assist us so much."*

Theme 2: Therapy services

CG4: *"Speech therapists are what we really need… the one who comes is not satisfactory."*

Theme 3: Specialized Schools:

CG5: *"Schools that support children with cerebral palsy should be opened in the area."*

Theme 4: Financial Support:

CG8: *"Financial support is also what we need."*

The most common requests were assistive devices and therapy services, consistent with studies by Tilahun et al. (2016), which highlight that lack of rehabilitation resources is a significant barrier to effective caregiving in LMICs.

4.5.3 Unmet Needs

Caregivers expressed frustration over critical services that were unavailable, including:

Reliable speech and physical Therapy:

CG4: *"Speech therapists… the one who comes is not satisfactory."*

Locally Available Specialized Schools:

CG5: *"We need schools for children with CP near us."*

Affordable Medication and Supplements:

CG6: *"I have skipped so many things to buy drugs."*

These unmet needs reflect gaps in healthcare access, education infrastructure, and social support systems, underscoring the need for policy interventions.

Table 10

Summary of Themes (Unmet Needs)

Unmet Needs
Affordable therapy services
Specialized schools
Assistive devices (locally)
Nutritional support
Consistent medication supply

The physical strain from lifting children without assistive devices and psychological distress due to stigma and isolation compound their vulnerability. Economic challenges amplify stress, particularly in resource-limited settings where medical care is expensive and social support is minimal.

Despite these challenges, caregivers demonstrated resilience through coping strategies, including peer support and informal counseling. However, the unmet needs assistive devices, quality therapy, financial assistance, and specialized education signal critical service gaps. These gaps hinder both the child's progress and caregiver well-being.

The above findings directly address objective two by demonstrating that caregivers of children with cerebral palsy face significant unmet support needs in the course of caregiving. The identified gaps, including physical and mental health strain, financial challenges, limited self-care opportunities, and inadequate access to assistive devices, therapy services, specialized education, and financial assistance, clearly show that their support needs are not fully met. These results, therefore, fulfill the second objective by highlighting the specific areas where caregivers require additional support to sustain effective caregiving.

The findings indicate the multi-dimensional challenges faced by caregivers, consistent with international literature (Gona et al., 2011; Tilahun et al., 2016).). These findings further align with global evidence showing that caregivers of children with CP routinely face informational, financial, social, and psychological needs. Eloreidi et al. (2021) found that unmet informational and psychosocial needs hinder caregivers' ability to provide optimal care and increase stress levels. Similarly, Ostojic et al. (2025) demonstrated that unmet social needs are widespread and are intensified by fragmented systems and inequitable access to services, resulting in profound impacts on family well-being. In Sub-Saharan Africa, Melak et al. (2025) further reinforce that caregivers commonly experience physical and psychological morbidities alongside financial and emotional support needs.

African/LMIC evidence continues to demonstrate the persistence of these challenges. Recent studies in Kenya (Heng et al., 2023; Samia et al., 2024) report that caregivers experience severe economic hardship, limited access to rehabilitation, and persistent stigma, suggesting that despite advocacy for disability inclusion, systemic gaps remain largely unaddressed. Ongele (2024) notes this reality, showing that although 62% of caregivers were aware of the need for mobility assistive devices, only 16% of children used them, indicating substantial access and affordability barriers.

The findings from AIC Kijabe highlight a stark contrast with research from high-income settings, where caregivers often benefit from government-funded respite services, subsidized therapy, and structured social care programs (Price et al., 2020). In the current study, caregivers described near-total reliance on informal family support, emphasizing how structural inequities between LMIC and high-income contexts shape caregiving experiences and widen the gap in wellbeing and access to services.

These findings also reinforce the study's conceptual framework, which posits that caregiver experiences are shaped by the interplay among caregiving demands, unmet needs, and social support availability. Limited formal support systems amplify caregiver burden, reduce coping capacity, and deepen psychological and financial strain, demonstrating how unmet needs are both consequences of and contributors to caregiving challenges.

Therefore, this study contributes to the expanding body of African qualitative evidence by providing insights into caregiver burden within a tertiary hospital setting in Kenya. It addresses a critical gap in the literature, which remains dominated by studies from high-income countries. It highlights the urgent need for locally responsive interventions, including assistive device programs, financial support mechanisms, and caregiver support groups tailored to LMIC realities.

4.6 Support Systems Available to the Caregivers of Children with CP

This section addresses Objective 3: understanding the support systems available to caregivers of children with cerebral palsy. Findings indicate that caregivers rely primarily on informal family support and occasional well-wishers**,** while formal institutional support is minimal or nonexistent**.** Themes that emerged include informal family support, community and social networks, the role of healthcare facilities, satisfaction with existing support, and the impact on caregiver well-being**.**

4.6.1 Current Support Systems

Theme 1: Informal Family Support

Most caregivers depend on immediate family members for practical and emotional assistance.

CG1: *"My husband helps when he is around, though most of the time I am alone with the child."*

CG4: *"Grandmother supports us greatly with feeding and watching the child when I rest."*

CG5: *"I have only gotten support from my parents. They help me with food sometimes."*

CG8: *"My sisters are the only ones who understand and occasionally assist financially."*

Family is the primary support pillar, but this assistance is often irregular and limited**,** especially in rural setups where economic resources are scarce.

Theme 2: Community and Well-Wishers support

A few caregivers reported sporadic help from neighbors or well-wishers**.**

CG3: *"We received once from a well-wisher some shopping for foodstuffs for the child."*

CG9: *"Sometimes church members visit and pray with us. They also bring food when possible."*

CG11: *"My neighbors are encouraging, but they rarely offer material help."*

Community-based support is inconsistent and primarily emotional**,** providing encouragement but not addressing primary financial or practical needs**.**

Theme 3: Lack of Institutional Support

Several caregivers noted the absence of formal assistance from hospitals or the government**.**

CG6: *"We have never gotten any free support, even from healthcare facilities."*

CG10: *"There is no program for these children in our area; everything is out of pocket."*

CG12: *"No organization has come to our aid since the diagnosis."*

There is a structural gap in institutional support for CP care, consistent with findings from African contexts where rehabilitation services remain underfunded and inaccessible (Tilahun et al., 2016).

4.6.2 Satisfaction with Support Systems

Theme 4: Dissatisfaction and Frustration

Caregivers expressed low satisfaction, citing the limited scope and sustainability of support**.**

CG4: *"The grandmother helps, but it's not enough because therapy and supplements are expensive."*

CG5: *"Support from parents is good, but they also have their own families to take care of."*

CG6: *"We feel abandoned by healthcare and government."*

CG9: *"Prayers are good, but we need more than prayers – real help like equipment."*

Caregivers appreciate emotional and moral support but desire structured, continuous, and material support**,** especially for assistive devices, therapy, and financial aid.

4.6.3 Areas Needing Improvement

When asked what could improve the situation, caregivers highlighted:

Financial Assistance: *"Cash transfers or subsidies for therapy and medication"* (CG8).

Assistive Devices: *"Wheelchairs, special chairs for posture support"* (CG3, CG5).

Therapy Services: *"Qualified therapists to visit homes"* (CG4).

Community Awareness: *"Education campaigns to reduce stigma"* (CG10).

4.6.4 Impact on Health and Well-Being

Caregivers reported mixed emotional outcomes**,** with some feeling encouraged by emotional support**,** while others suffered stress and depression due to inadequate help**.**

CG3: *"Sometimes my mother-in-law visits; that is the only time I feel relieved."*

CG5: *"Lack of help makes me anxious; I can't even sleep sometimes."*

CG7: *"The special school helps because I can do other things during the day."*

CG12: *"Because no one helps, I feel hopeless and tired all the time."*

Table 11

Summary of Themes (Support Systems)

Theme	Indicators
Informal Family Support	Help from parents, spouses, and grandparents
Community Support	Occasional help from neighbors, churches, and well-wishers
Lack of Institutional Support	No free therapy, no assistive devices, no subsidies
Satisfaction Levels	Low satisfaction, appreciation for moral support only
Improvement Needs	Financial aid, devices, therapy, and awareness programs
Impact on Well-Being	Relief from emotional support, stress from lack of help

The above findings directly address objective three by illustrating the nature and extent of support systems available to caregivers of children with cerebral palsy. The results show that caregivers predominantly depend on informal family support, social networks, and occasional assistance from well-wishers, while formal institutional support remains limited or absent. These insights confirm that the existing support structures are largely informal and insufficient, thereby fulfilling the objective of understanding the support systems accessible to caregivers and their impact on caregiver well-being.

Insufficient support systems contribute to caregiver burnout and psychological distress, a finding echoed by Whittingham et al. (2011), who linked lack of social support with high caregiver stress in CP contexts. This aligns with Kenyan studies by Bakesia, Opiyo, and Orinda (2025), who similarly found that caregivers in Western Kenya relied heavily on religion, social support groups, and self-acceptance as coping mechanisms amid financial, physical, and psychosocial burdens. Both studies emphasize that in low-resource settings, primary support remains informal and socially driven rather than structured or system-based, reinforcing the idea that caregivers largely shoulder the caregiving role without reliable institutional support.

However, the evidence is contradictory compared with Samia et al. (2024), who highlighted that although formal systems such as rehabilitation services and schooling theoretically exist, caregivers reported low satisfaction and limited accessibility, particularly for children with severe functional limitations. Unlike the near-absence of institutional support in the current study's context, Samia et al. point to system inefficiencies rather than total unavailability. This contrast suggests that the nature of institutional support may vary across facility types and urban-rural contexts. Urban tertiary settings may offer more services, but barriers such as cost, distance, stigma, and bureaucratic gaps still hinder meaningful access. In the present study, the reliance on informal support may therefore reflect both structural scarcity of services and caregivers' adaptation to environments where formal support is either inaccessible or unknown.

These findings reinforce the conceptual framework guiding this study, which posits that caregiver experiences are shaped by the interplay between caregiving demands, unmet needs, and the availability of social support**.** Limited institutional support amplifies the burden of caregiving and forces families to rely on informal networks, thereby influencing caregiver stress, coping strategies, and overall well-being. In this way, the findings demonstrate how the scarcity of structured support systems exacerbates unmet needs and heightens caregiver vulnerability.

This study contributes to the growing body of African evidence by providing context-specific insights into the support landscape for caregivers of children with cerebral palsy in a clinical setting where formal systems are minimal. Unlike previous studies dominated by urban or better-resourced contexts, this work highlights the reliance on informal support and the near absence of institutional services, filling a critical gap in the literature and emphasizing the urgent need for policy-driven, community-based, and health-system interventions to strengthen caregiver support mechanisms in Kenya.

CHAPTER FIVE

SUMMARY OF FINDINGS, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

This chapter presents a synthesis of the study findings, draws conclusions based on the objectives, identifies existing gaps, and offers recommendations for policy, practice, and future research. The purpose of this study was to explore the lived experiences, caregiving challenges, unmet needs, and available support systems of primary caregivers of children with cerebral palsy (CP) attending the developmental clinic at AIC Kijabe Hospital. The chapter begins by summarizing the study objectives, the conclusions based on those objectives, and the recommendations derived from the gaps identified in those conclusions.

5.2 Summary of Key Findings

5.2.1 Positive and Negative Experiences of Primary Caregivers

The findings revealed that caregivers experienced both positive and negative aspects of caregiving. Positive experiences included feelings of hope and fulfillment when observing developmental progress in their children, such as improved head control, the ability to sit, speech initiation, and social recognition. These milestones provided emotional encouragement to caregivers despite the demanding nature of their roles.

However, negative experiences were predominant and multifaceted. Caregivers reported emotional distress, stigma, and social isolation. The persistent dependency of children limited caregivers’ ability to work or engage in social and economic activities. Financial strain was a recurring concern due to the high costs of therapy, medication, and specialized diets. Caregivers also highlighted psychological stress arising from societal judgment and hostile remarks. The emotional, physical, and financial burdens significantly impacted their quality of life.

5.2.2 Caregiving Challenges and Unmet Support Needs

Caregivers faced significant challenges across physical, psychological, financial, and social dimensions. Physically, the demands of lifting and caring for children with severe mobility limitations caused fatigue, body pain, and, in some cases, aggravated pre-existing health conditions. Psychologically, caregivers struggled with stress, anxiety, and mental health issues, particularly after receiving the diagnosis.

Financially, the cost of treatment, therapy, and nutritional requirements posed a heavy burden, often leading to debt or job loss due to full-time caregiving responsibilities. Unmet needs were numerous, with caregivers emphasizing the necessity for assistive devices such as wheelchairs and posture chairs, access to specialized therapies (e.g., speech therapy), financial assistance, nutritional supplements, and inclusive educational opportunities. Self-care was minimal, as caregivers prioritized their children’s needs over their own well-being, with time and financial constraints as the main barriers.

5.2.3 Available Support Systems for Caregivers

The study revealed that caregivers primarily relied on informal support systems, such as family members, neighbors, and religious groups. These sources provided emotional encouragement; however, material and financial assistance remained inconsistent and inadequate. Institutional support was minimal, and caregivers expressed dissatisfaction with the healthcare system, citing inadequate therapy services and a lack of structured caregiver support programs. Governmental support was virtually nonexistent, leaving caregivers without sustainable assistance for their demanding roles. Overall, caregivers expressed a strong need for formal, organized support systems to address financial, emotional, and logistical challenges.

The findings indicate that caregiving for children with CP is demanding and negatively impacts caregivers’ physical health, mental well-being, and socio-economic stability.

While occasional positive experiences provide emotional resilience, these are overshadowed by persistent challenges and inadequate support. The study emphasizes the urgent need for policy-driven interventions and comprehensive support systems to alleviate caregiver burden and enhance their quality of life.

5.3 Conclusions

Based on the study findings, the following conclusions were drawn under the three research objectives:

5.3.1 Positive and Negative Experiences of Caregivers

Caregivers reported both positive and negative experiences. Positive experiences were primarily linked to observable developmental progress in children, such as sitting, improved head control, and beginning speech. These milestones provided emotional encouragement and strengthened caregiver-child bonds.

However, negative experiences dominated and were characterized by psychological stress, stigma, social isolation, and financial strain. Persistent dependency of children limited caregivers’ ability to engage in income-generating activities or social life. Negative societal attitudes further compounded emotional distress. There is limited institutional and psychosocial support to help caregivers manage emotional stress and societal stigma, leaving them highly vulnerable to mental health problems.

5.3.2 Caregiving Challenges and Unmet Needs

Caregivers experienced multiple challenges, including physical strain from lifting children with mobility limitations, mental health issues related to prolonged stress, and financial difficulties caused by the high cost of treatment and therapy. Unmet needs included assistive devices (wheelchairs, posture chairs), specialized therapy services (e.g., speech therapy), inclusive educational opportunities, and nutritional support for children with feeding difficulties. Barriers to self-care were prevalent, as caregivers prioritized their child’s needs and lacked the resources and time for their own well-being.

There is a lack of accessible assistive devices, specialized therapies, and financial aid programs. Additionally, there are no structured interventions for caregiver self-care, resulting in cumulative burnout and health deterioration.

5.3.3 Available Support Systems for Caregivers

The study found that caregivers relied mainly on informal support networks such as family, neighbors, and religious groups, which provided inconsistent and insufficient assistance. Institutional and government support was minimal, with healthcare services failing to provide adequate therapy sessions or structured caregiver programs.

There is a complete absence of organized, sustainable caregiver support systems at both community and institutional levels. This limits caregivers’ ability to cope with caregiving demands and maintain quality care for children with CP.

5.3.4 Theoretical Implications

The findings of this study align with Lazarus and Folkman’s Stress and Coping Theory (1984), which posits that individuals experience stress when perceived demands exceed their coping resources. Caregivers of children with cerebral palsy continuously appraise their situation as taxing, and their coping strategies, such as prayer, family support, and meaning-making, serve as vital emotional buffers. However, the absence of institutional and financial resources limits their ability to engage in problem-focused coping, intensifying emotional distress and burnout. This underscores the need for multi-level interventions that strengthen both emotional and structural coping resources.

5.4 Recommendations

Based on the identified gaps and findings, the following recommendations are proposed:

5.4.1 Policy-Level Recommendations

i. *Establish Government-Funded Support Programs*: Develop and implement national and county-level programs that provide financial support, therapy cost subsidies, and nutritional supplements for children with CP.

ii. ***Provision of Assistive Devices.*** *Create* mechanisms for the affordable or free provision of essential assistive devices, such as wheelchairs, posture chairs, and feeding aids, to improve mobility and reduce physical strain on caregivers

iii. *Inclusive Education Policies*:Expand and enforce policies for inclusive education to ensure children with CP have access to appropriate learning environments and reduce caregiver stress related to schooling.

Implementing these recommendations would align with Kenya's National Disability Policy and the Universal Health Coverage (UHC) agenda, promoting equity and inclusion for families affected by childhood disability.

5.4.2 Healthcare System Recommendations

*Structured Caregiver Training and Counseling:*Implement regular counseling programs and training sessions to equip caregivers with coping strategies, stress management skills, and caregiving techniques.

Expand Specialized Therapy Services: Increase the availability of physiotherapy, occupational therapy, and speech therapy within hospitals and community health facilities, with affordable or subsidized options.

Create Caregiver Self-Care Programs: Introduce community-based respite care and wellness programs to allow caregivers time for personal health and psychological recovery.

5.4.3 Community and NGO Recommendations

i. *Strengthen Community-Based Support Networks:* Collaborate with NGOs and faith-based organizations to establish caregiver support groups offering psychosocial and material assistance.

ii. *Awareness and Stigma Reduction Campaigns:* Conduct community education initiatives to reduce stigma, promote inclusion, and encourage community support for families raising children with CP.

5.4.4 Recommendations for Further Studies

i. *Broader Quantitative and Mixed-Methods Research*: Future studies should employ quantitative or mixed-method designs with larger samples to allow generalization and the development of targeted caregiver support interventions.

ii. *Longitudinal Impact Studies* :Long-term follow-up studies are needed to assess how structured psychosocial and financial interventions influence caregiver well-being, coping strategies, and child developmental outcomes over time.

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APPENDICES

Appendix I: Semi-structured Interview Guide

Section 1: Demographics

1. **Age:**
   Under 20
   21-30
   31-40
   41-50
   51 and above
2. **Gender:**
   Male
   Female
   Prefer not to say
3. **Relationship to the child:**
   Mother
   Father
   Grandparent
   Sibling
   Other (please specify): _______________

4. **Marital status:**
   Single
   Married
   Divorced/Separated
   Widowed

5. **Level of education:**
   No formal education
   Primary education
   Secondary education
   College/University education

6. **Occupation:**
   Unemployed
   Self-employed
   Employed (part-time)
   Employed (full-time)
7. **Duration of caregiving:**
   Less than 1 year
   1-3 years
   4-6 years
   7-10 years
   More than 10 years
8. **Number of children under your care, including the child with CP:**
   One
   Two
   Three
   Four or more

Section 2: Positive and Negative Experiences in Caregiving

1. **Positive Experiences**
   Can you share some of the positive emotions or experiences you've had while caregiving? (Prompts: Do you feel fulfilled, close to your child, competent as a caregiver? How often do these feelings arise?)

2. **Negative Experiences**
   What challenges or negative emotions have you faced while caregiving? (Prompts: Do you feel overwhelmed, isolated, frustrated, or physically exhausted? How frequently do these feelings occur?)

3. **Other Experiences**
   Is there anything else you would like to share about your positive or negative experiences as a caregiver?

Section 3: Caregiving Challenges and Unmet Needs

4. **Caregiving Challenges**

   What have been some of the biggest challenges you've faced in caring for your child?

5. **Support Needs**

   What types of support do you think would help you better manage your caregiving responsibilities?

6. **Unmet Needs**

   Are there any services or resources that you need but are currently unavailable to you? Can you specify which ones?

Section 4: Support Systems for Caregivers

7. **Current Support Systems**

   Do you have any support to help you with caregiving? If so, who do you rely on?

8. **Satisfaction with Support System**

   How satisfied are you with the support you receive? What areas could be improved?

Section 5: Impact on Health and Well-being

9. **Physical Health**

   How would you describe your physical health since you became a caregiver?

10. **Health Conditions**

    Have you developed any health conditions since becoming a caregiver?

11. **Self-Care**

    How often are you able to take care of your own health and well-being?

12. **Barriers to Self-Care**

    What barriers prevent you from looking after your own health?

Mwongozo wa Mahojiano

Nambari: …….

Sehemu ya 1: Demografia

1. Umri:

   Chini ya miaka 20

   21-30

   31-40

   41-50

   51 a zaidi

2. Jinsia:

   Mwanaume

   Mwanamke

   Napendelea kutosema

3. Uhusiano na mtoto:

   Mama

   Baba

   Babu/Bibi

   Kaka/Dada

   Nyinginezo (tafadhali eleza): ______________

4. Hali ya ndoa:

   Sijaoa/Sijaolewa

   Ndoa

   Nimetalikiwa/Ametengana

   Mjane

5. Kiwango cha elimu:

   Hakuna elimu rasmi

   Elimu ya msingi

   Elimu ya sekondari

   Elimu ya chuo/Chuo kikuu

6. Kazi:

   Sina ajira
   Kazi ya kujiajiri
   Kazi ya muda mfupi
   Kazi ya muda wote

7. Muda wa kutoa huduma ya uangalizi:

   Chini ya mwaka 1
   Miaka 1-3
   Miaka 4-6
   Miaka 7-10
   Zaidi ya miaka 10

8. Idadi ya watoto unaowatunza, pamoja na mtoto mwenye CP:

   Mmoja
   Wawili
   Watatu
   Nne au zaidi

Sehemu ya 2: Uzoefu Mzuri na Mbaya wa Kutoa Huduma ya Uangalizi

Sehemu ya 2: Uzoefu Chanya na Hasi katika Kulea (Caregiving)

i. Uzoefu Chanya

Je, unaweza kushiriki baadhi ya hisia au uzoefu mzuri uliopata wakati wa kulea? (Maswali ya kuchochea: Je, unajisikia umetosheka, karibu na mtoto wako, au kuwa na uwezo kama mlezi? Ni mara ngapi unapata hisia hizi?)

ii. Uzoefu Hasi

Ni changamoto gani au hisia hasi umekutana nazo wakati wa kulea? (Maswali ya kuchochea: Je, unajisikia kuzidiwa, kutengwa, kukasirika, kuchoka kimwili? Ni mara ngapi hisia hizi hujitokeza?)

iii. Uzoefu Mwingine

Je, kuna kitu kingine unachotaka kushiriki kuhusu uzoefu wako mzuri au mbaya kama mlezi?

Sehemu ya 3: Changamoto za Kulea na Mahitaji Ambayo Hayajatimizwa

4. **Changamoto za Kulea**

Ni changamoto gani kubwa zaidi ambazo umekutana nazo katika kumtunza mtoto wako? (Maswali ya kuchochea: Changamoto za kifedha, ukosefu wa msaada wa kihisia, kupata huduma ya matibabu, muda wa kujitunza mwenyewe, mzigo wa kimwili, unyanyapaa, ubaguzi)

5. **Mahitaji ya Msaada**

Ni aina gani za msaada unadhani zinaweza kukusaidia kudhibiti vizuri majukumu yako ya kulea?

(Maswali ya kuchochea: Msaada wa kifedha, msaada wa kihisia, huduma za kupumzika, msaada wa matibabu, rasilimali za kielimu, vikundi vya msaada wa kijamii, msaada katika shughuli za kila siku)

6. **Mahitaji Ambayo Hayajatimizwa**

Je, kuna huduma au rasilimali ambazo unahitaji lakini hazipatikani kwako kwa sasa? Je, unaweza kubainisha ni zipi?

Sehemu ya 4: Mifumo ya Msaada kwa Walezi

7. **Mifumo ya Msaada ya Sasa**

Je, unayo aina yoyote ya msaada ili kukusaidia katika kulea? Ikiwa ndivyo, unamtegemea nani?

(Maswali ya kuchochea: Familia, marafiki, majirani, mashirika ya kidini au ya kijamii, wataalamu wa matibabu, vikundi vya msaada)

8. **Kuridhika na Mifumo ya Msaada**

   Umeridhika kwa kiasi gani na msaada unaopokea? Ni maeneo gani yanaweza kuboreshwa?

Sehemu ya 5: Athari kwa Afya na Ustawi

9. **Afya ya Kimwili**

Unaweza kuelezeaje afya yako ya kimwili tangu ulipoanza kuwa mlezi?

(Maswali ya kuchochea: Bora Sana, Nzuri, Ya Kawaida, Mbaya)

10. **Magonjwa ya Afya**

    Je, umejipata na hali yoyote ya kiafya tangu ulipoanza kuwa mlezi? (Maswali ya kuchochea: Shinikizo la damu, kisukari, maumivu ya muda mrefu, wasiwasi, unyogovu, matatizo ya usingizi)

11. **Kujitunza**

    Ni mara ngapi unaweza kujitunza afya yako na ustawi wako mwenyewe? (Maswali ya kuchochea: Je, unafanya mazoezi, unakula kiafya, unapata usingizi mzuri, unahudhuria mikusanyiko ya kijamii, unachukua muda kwa ajili ya burudani?)

12. **Vikwazo vya Kujitunza**

    Ni vikwazo gani vinavyokuzuia kujitunza afya yako?

    (Maswali ya kuchochea: Ukosefu wa muda, nguvu, upatikanaji wa huduma za afya, changamoto za kifedha)

Appendix II: Informed Consent Form

This informed consent is for caregivers of children with cerebral palsy who are on follow-up at AIC Kijabe Hospital and who are invited to participate in research titled: “Caring for a child with Cerebral Palsy: experiences of caregivers from a tertiary hospital in Kenya”.

Name of the Principal Investigator: Dr Kyakimwa Mbangi
Organization: Kabarak University
Sponsor: Nil
This informed consent consists of 2 parts: the Information sheet and the Certificate of Consent. You will be provided a copy of the complete informed consent form.

Part I: Information Sheet

I am Dr Kyakimwa Mbangi, a master’s student at Kabarak University in the Department of Family Medicine and Community Health.

I am conducting a study on caregivers of children with cerebral palsy to find out their experiences in taking care of children with motor disability due to brain damage.
In this study, participants will be involved in an interview that will last about. Thirty minutes. You have been invited to be part of the study, as we think your participation as a caregiver is crucial to understanding the experiences caregivers go through during caregiving.

Your participation in this study is entirely voluntary. It is your choice whether to participate.
Or not. If you choose not to participate, all the services you and your child receive will be discontinued.

The hospital will continue as usual. We will be asking you to share sensitive information. Information that you may feel uncomfortable or distressed about. You do not have to answer.
Any question if you do not wish to do so. You do not have to Please give us any reason for not answering any question or for refusing to take part in the interview.

Your participation in the study will enable us to obtain findings that we hope could help you in the future, as well as others in a similar situation. The information you give us will be accessed only by the team conducting the research. Any information about you will include a code instead of your name. Your code will be known only to the researchers.

Once we complete the study, we will share the results with you during the hospital reviews. We shall also share the results with the AIC Kijabe Hospital management team. Following the meetings, we will publish the results so that others can benefit and learn from the research.

PART II: Certificate Of Consent.

I have been invited to participate in a study to find out the experiences of caregivers of children with cerebral palsy. I have read the above information, or it has been read to me. I have been allowed to ask questions about it, and any questions I had have been answered.

Answered to my satisfaction.

I voluntarily consent to participate in this study.

Name of Participant……………………………………
Signature/thumb print of participant (caregiver)………………………………….
Date……………………………………

Fomu Ya Makubaliano

Ku mtunza mtoto mwenye ugonjwa wa ku pooza ubongo: mapito ya wauguzi wenye ku hudhuria Hospitali ya juu nchini Kenya.

Sehemu Ya Kwanzamaelezo

Fomu hii ni ya wauguzi wa Watoto wanao ugua ugonjwa wa ku pooza ubongo. Tuna waalika ku jiunga na utafiti huu wenye mada “Ku mtunza mtoto mwenye ugonjwa wa ku pooza ubongo: mapito ya wauguzi wenye ku hudhuria Hospitali ya juu nchini Kenya.”

Jina la mtafiti mkuu: Daktari Kyakimwa Mbangi

Chuo kikuu utafiti unao fanywa: Chuo Kikuu cha Kabarak.

Mfadhili wa utafiti: Hakuna

Fomu hii ina sehemu mbili; fomu ya maelezo na cheti cha makubaliano ambayo utatia sahihi pindi utakapo kubali ku jiunga na utafiti huu.

Fomu Ya Maelezo

Mimi ni Daktari Kyakimwa Mbangi. Nina somea shahada ya juu katika taaluma ya matibabu ya Familia niki zingatia utunzaji sugu. Nina fanya utafiti niki zingatia watu wanao uguza Watoto wenye ku pooza kwa ubongo.

Tunge penda ku fahamu changamoto mnazo pitia ili tutambue namna zaku kabiliana nazo na jinsi zaku wapa motisha watu wengine wanao uguza wapendwa wao. Utafiti huu una hitaji muuguzi mlinzi wa mgonjwa kuhojiwa kwa mda wadakika thelathini ama hata dakika arubaini na tano. Tume ku uliza u jiunge na utafiti huu kwasababu, yale yote ume pitia uki mwuguza mgonjwa wako yata tusaidia ku elewa changamoto nyingi wauguzi wenzako wanapitia.

Kuji unga na utafiti huu ni kwa hiari yako. Uko huru ku amua ku jiunga au kuto jiunga na utafiti huu. Uki amua kuto jiunga na utafiti huu wewe na mgonjwa wako mtaendelea kupata huduma na matibabu yote kama kawaida.

Mahojiano yangu yata kuwa na maswali ya ndani kuhusu hali ya mgonjwa na familia yanayo weza ku ahisia chungu kidogo. Kama swali au mjadala wowote una zua hisia kali/chungu sana kwako, sio lazima u jibu swala hilo au uji unge na mjadala huo. Una weza ku omba tusitishe mahojiano yetu wakati wowote. Pia si lazima utu patie sababu zako kuto jibu maswali yoyote au ku kata kuhojiwa.

Kuna uwezekano kwamba utafiti huu hauta kufaa kwa njia yoyote. Lakini ku jiunga na ku changia utafiti huu uta tu saidia sisi wahudumu wa afya ku pata maelezo tutakayo tumiaku wapa motisha watu wengine wanao uguza wagonjwa wao wenye ku pooza ubongo.

Maelezo utakayo tupatiaya ita wekwa kisiri na yata julikana na sisi tunao endeleza utafiti huu peke yake. Maelezo haya yata hifadhiwa na alama ya siri ya utafiti. Hakuna mahali jina lako ama la mgonjwa wako lita tumika. Alama ya siri hii ita fahamika nami na wa tafiti wenzangu.

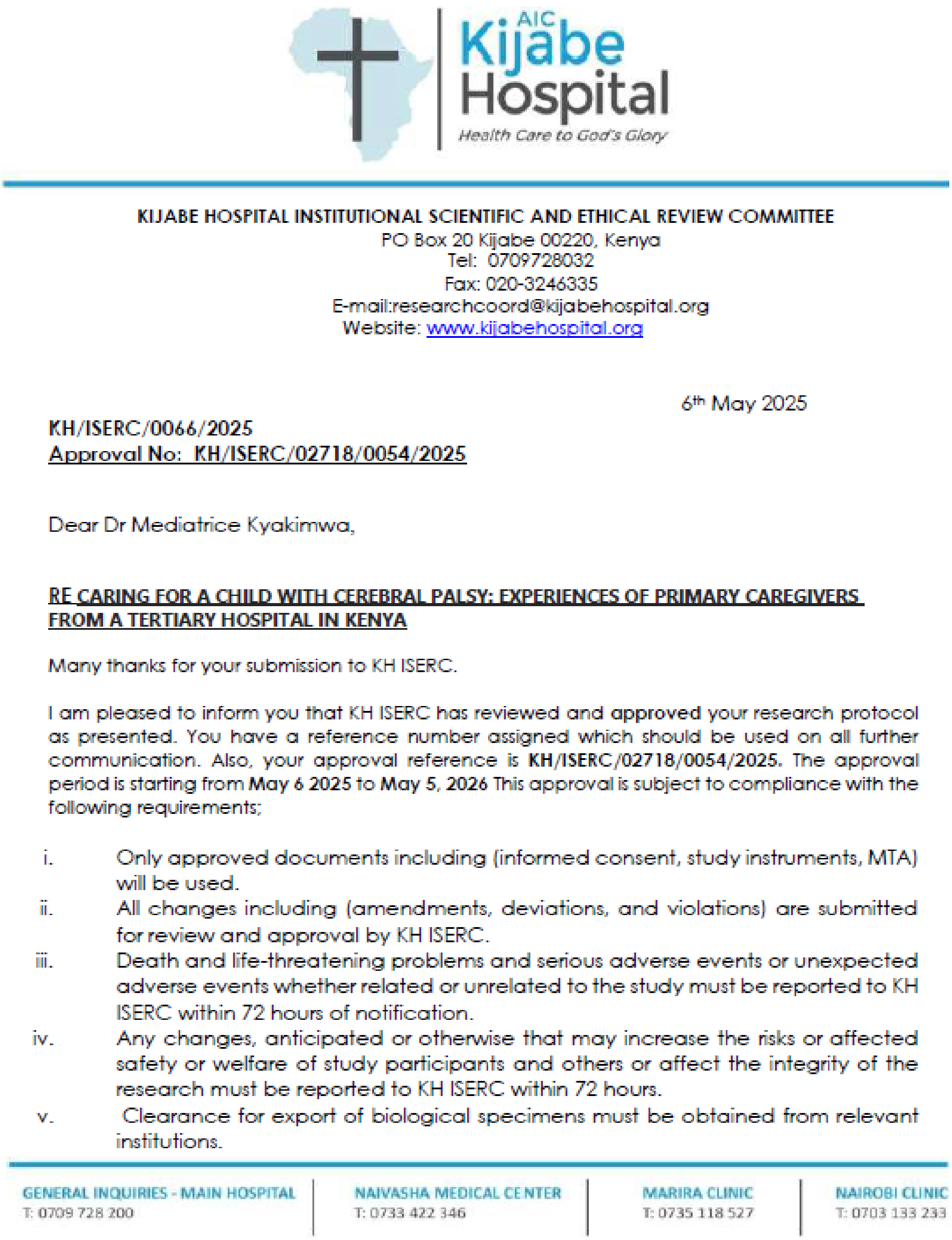
Tuki kamilisha utafiti huu, tuta wa elezea matokeo ya utafiti huu. Tuta eneza matokeo haya ku pitia wakati wa kliniki za wagonjwa humu hospitalini. Pia tuta eleza wauguzi, madaktari na wa hudumu wote wa afya matokeo haya, sanasana wanao hudumia wagonjwa wanao hitaji utunzaji sugu. Pia tuta chapisha matokeo yetu kwenye Makala za utafiti ili wa hudumu wengine wa faidike kutokana na utafiti wetu.

Sehemu Ya Pili: Cheti Cha Makubaliano

Nime alikwa niji unge na utafiti wenye mada “Ku mtunza mtoto mwenye ugonjwa wa ku pooza ubongo: mapito ya wauguzi wenye ku hudhuria Hospitali ya juu nchini Kenya.” Nime soma maelezo haya ama nime somewa na kuelezwa. Nime pewa nafasi ya ku uliza maswali nime kuwa nayo, na yame jibiwa kikamilifu. Naji unga kwa utafiti huu kwa hiari yangu.

Jina la muuguzi ……………………………………………………………….
Sahihi………………………………………………………………………..
Tarehe…………………………………………………………………

Appendix III: Kijabe Hospital Authorization Leter



AIC Kijabe Hospital
Health Care to God's Glory

KIJABE HOSPITAL INSTITUTIONAL SCIENTIFIC AND ETHICAL REVIEW COMMITTEE
PO Box 20 Kijabe 00220, Kenya
Tel: 0709728032
Fax: 020-3246335
E-mail:researchcoord@kijabehospital.org
Website: www.kijabehospital.org

6th May 2025

KH/ISERC/0066/2025
Approval No: KH/ISERC/02718/0054/2025

Dear Dr Mediatrice Kyakimwa,

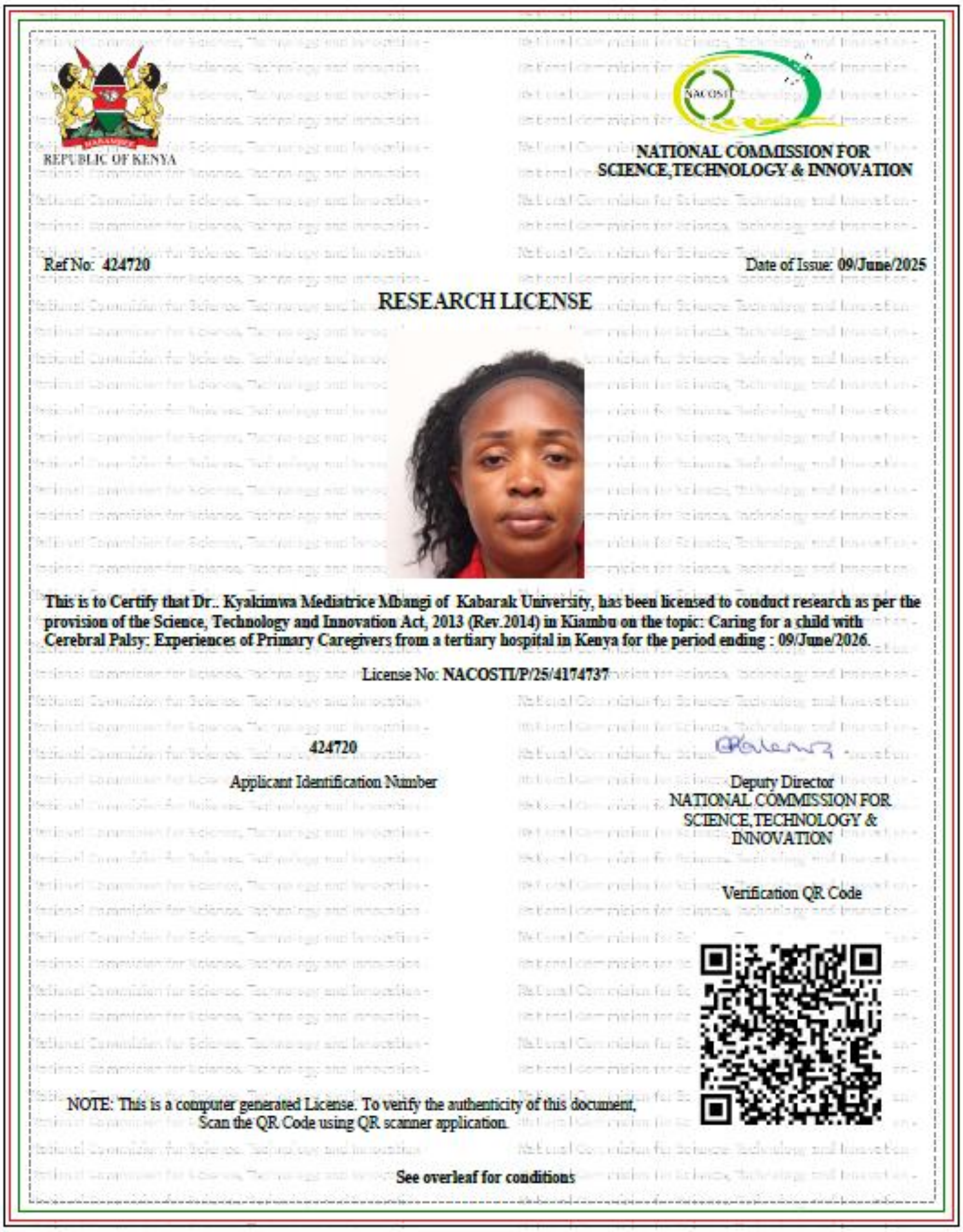
RE CARING FOR A CHILD WITH CEREBRAL PALSY: EXPERIENCES OF PRIMARY CAREGIVERS FROM A TERTIARY HOSPITAL IN KENYA

Many thanks for your submission to KH ISERC.

I am pleased to inform you that KH ISERC has reviewed and **approved** your research protocol as presented. You have a reference number assigned which should be used on all further communication. Also, your approval reference is **KH/ISERC/02718/0054/2025.** The approval period is starting from **May 6 2025** to **May 5, 2026** This approval is subject to compliance with the following requirements;

i. Only approved documents including (informed consent, study instruments, MTA) will be used.
ii. All changes including (amendments, deviations, and violations) are submitted for review and approval by KH ISERC.
iii. Death and life-threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to KH ISERC within 72 hours of notification.
iv. Any changes, anticipated or otherwise that may increase the risks or affected safety or welfare of study participants and others or affect the integrity of the research must be reported to KH ISERC within 72 hours.
v. Clearance for export of biological specimens must be obtained from relevant institutions.

Appendix IV: NACOSTI Research Permit



REPUBLIC OF KENYA

NATIONAL COMMISSION FOR
SCIENCE, TECHNOLOGY & INNOVATION

Ref No: 424720

Date of Issue: 09/June/2025

RESEARCH LICENSE

This is to Certify that Dr.. Kyakimwa Mediatrice Mbangi of Kabarak University, has been licensed to conduct research as per the provision of the Science, Technology and Innovation Act, 2013 (Rev.2014) in Kiambu on the topic: Caring for a child with Cerebral Palsy: Experiences of Primary Caregivers from a tertiary hospital in Kenya for the period ending : 09/June/2026.

License No: NACOSTI/P/25/4174737

424720

Applicant Identification Number

Deputy Director
NATIONAL COMMISSION FOR
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INNOVATION

Verification QR Code

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Scan the QR Code using QR scanner application.

See overleaf for conditions

Appendix V: Evidence of Conference Participation

ST. PAUL'S UNIVERSITY

CERTIFICATE OF PARTICIPATION

THIS IS TO CERTIFY THAT

Mediatrice Mbangi Kyakimwa

PRESENTED A PAPER TITLED

Caring for a Child with Cerebral Palsy: Experiences of Primary Caregivers from a Tertiary Hospital in Kenya

At

St. Paul's University Annual International Research Conference (SPUAIRC), "Re-Conceptualizing Sustainable Development Goals for Today's Challenges and Tomorrow's Possibilities".

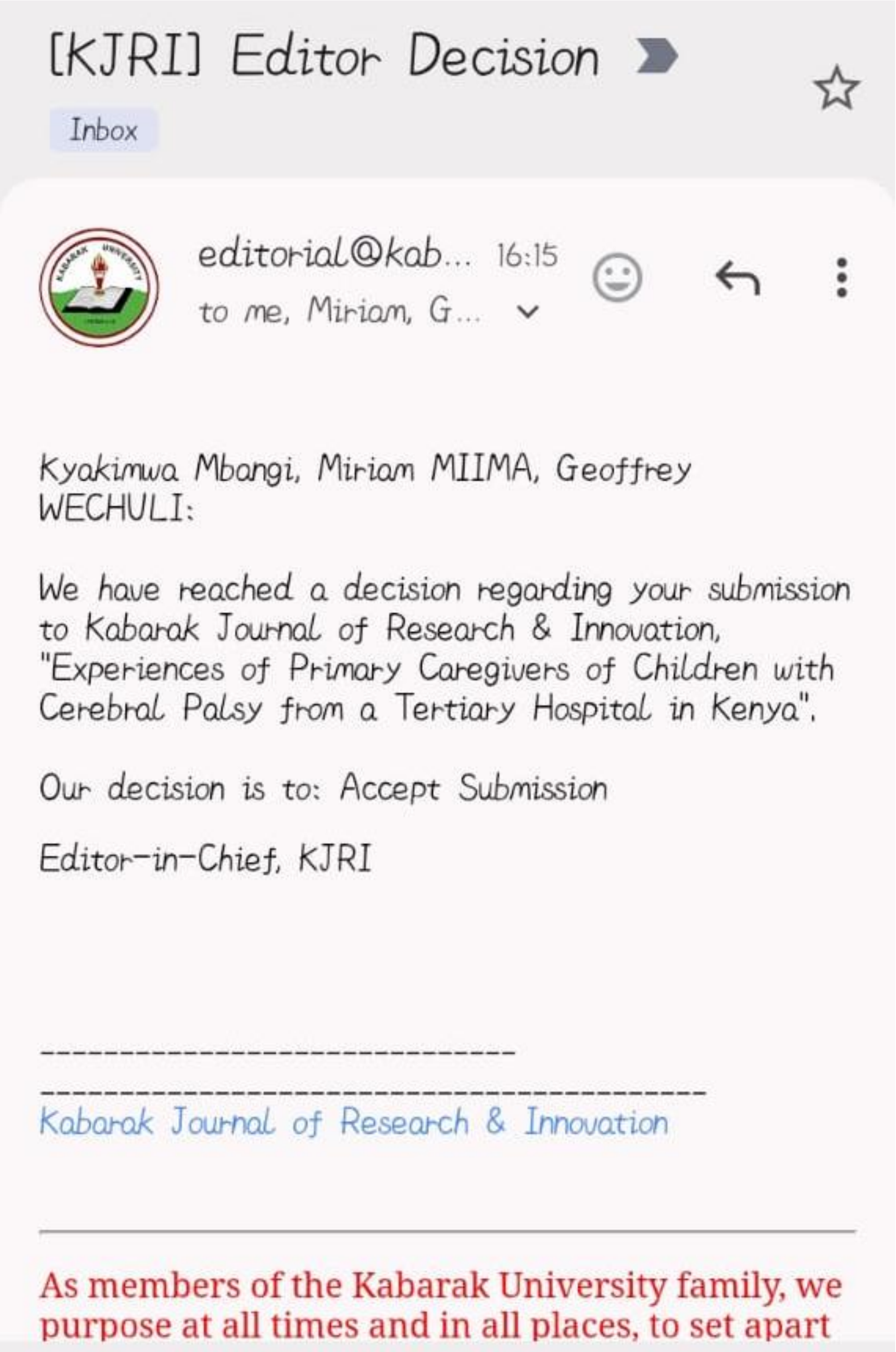
held at St. Paul's University on

1st – 3rd October, 2025

DR. PETRONILA OTUYA
SPUAIRC Conference Chair

PROF. ABRAHAM K. WAITHIMA
DVC- Academic Affairs

Appendix VI: List of Publication



[KJRI] Editor Decision

Kyakimwa Mbangi, Miriam MIIMA, Geoffrey WECHULI:

We have reached a decision regarding your submission to Kabarak Journal of Research & Innovation, "Experiences of Primary Caregivers of Children with Cerebral Palsy from a Tertiary Hospital in Kenya".

Our decision is to: Accept Submission

Editor-in-Chief, KJRI

____
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Kabarak Journal of Research & Innovation

As members of the Kabarak University family, we purpose at all times and in all places, to set apart