PSYCHOSOCIAL SUPPORT FOR FAMILIES CARING FOR CHILDREN WITH DISABILITIES IN TANZANIA: A CASE OF UHURU MCHANGANYIKO PRIMARY SCHOOL

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CERTIFICATION

The undersigned certifies that they have read and hereby recommends for acceptance by the Open University of Tanzania a dissertation titled, **“Psychosocial Support for Families Caring for Children with Disabilities in Tanzania. A Case of Uhuru Mchanganyiko Primary School”** in partial fulfillment of the requirements for the award of the Degree of Master of Social Work of the Open University of Tanzania.

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DECLARATION

I, **Faudhia Ramadhani Kitenge,** declare that the work presented in this dissertation is original. It has never been presented to any other University or Institution. Where other people's works have been used, references have been provided. It is in this regard that I declare this work as originally mine. It is hereby presented in partial fulfillment of the requirement for the Degree of Master of Social Work of the Open University of Tanzania.

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Signature

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Date

DEDICATION

This dissertation is dedicated to all families which cares for children with various disabilities in Tanzania including my beautiful family. These people sacrifice a lot to ensure life of their members with disabilities is possible.

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ABSTRACT

This study aimed to explore psychosocial support for families caring for children with disabilities in Tanzania: a case of Uhuru Mchanganyiko primary school. The study specifically addressed three objectives: to identify the psychosocial support challenges experienced by families, to examine the accessibility of psychosocial support services available to these families, and to investigate evidence-based interventions designed to support them. A qualitative approach, underpinned by an interpretivist research philosophy, was used. The research design followed a case study approach. Data were collected from 36 participants of 12 families using purposive sampling, and a combination of interviews and non-participatory observation was employed. The research findings revealed significant psychosocial challenges faced by these families, including social stigma, emotional distress, strained family relationships, role strain, and a lack of access to specialized services. Furthermore, these families faced considerable barriers to accessing formal psychosocial support, including limited awareness, affordability, and cultural stigma surrounding disability. The study also identified several psychosocial support interventions, including psychological counseling, peer support groups, community awareness programs, parental training, and access to inclusive education. The study recommends that the government prioritize the development of policies and programs that enhance the availability and accessibility of support services for families of children with disabilities.

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LIST OF ABBREVIATIONS

CI - Chronic Illness

CRC - Convention on The Rights of Children

CRPD - Convention on the rights of children with disabilities

CWD - Children with Disabilities

FGD - Focus group discussion

LMIC - Low – Middle income countries

MHPSS - Mental health and Psychosocial support

NGO - Non-Government Organization

NOREC - Norwegian Agency for exchange cooperation

PSS - Psychosocial Support Services

REPSSI - Regional Psychosocial support Initiative

UK - United Kingdom

UN - United Nation

US - United State

UNESCO - The United Nations Educational, Scientific, and Cultural

UNICEF - United Nation Children`s Fund

UPIAS - Union of the physically impaired against segregation

URT - United Republic of Tanzania

CHAPTER ONE

INTRODUCTION

1.0 Chapter Overview

The purpose of this study was to assess the Psychosocial Support for families caring for Children with Disabilities in Tanzania; a case of Uhuru Mchanganyiko Primary School. This study explore psychosocial support challenges, existing psychosocial support opportunities and evidence-based PSS interventions experienced by families caring for children with disabilities.

1.1 Background of the Study

According to UNICEF (2018), the percentage of individuals with disabilities globally has reportedly climbed from 10% in 1970 by March 2023. According to the World Health Survey, over 780 million individuals (15.6%) who are 15 years of age or older experience one of the types of disabilities. According to the World Health Organisation (2011), the same poll revealed that 5.1% of children worldwide—more than 90 million—live with a disability, with 0.7% of them experiencing "severe disability" such as blindness and Intellectual.

In Europe, Couples who care for children with disabilities are more frequently unstable, more often sacrifice their fertility intentions, more frequently suffer from economic difficulties, show more traditional gender role arrangements are more frequently in bad health, and have lower well-being than families without disabilities. According to Giulio (2016) explain in his study that, the consequences are different for mothers and fathers: fathers of children with disabilities have fewer emotional exchanges, while mothers tend to suffer more in terms of social contact. Feelings of emptiness, loneliness and rejection. In a small-scale Norwegian study on the parents of children with behavioral problems, which can be frequent in children with disabilities, mothers with low education, more often unemployed, less content with social support and with lower scores on comprehensibility were significantly more stressed than parents in the different status (Solem et al. 2011). Disabilities in Sweden (where government and community support are higher than in other countries) experience the same kind of stress, especially in terms of a restricted social life and time constraints, as parents in other countries. The only exception is the financial burden, and it may be that public aid might allow the parents to spend less time at work and more time with the child (Olsson and Hwang 2003). In America A longitudinal study of the Fragile Families and Child Wellbeing Study (1998–2000), a survey of mostly unmarried parents, found that having a child with a severe disability decreased by 10 percentage points the probability that parents who were living together at the time of the child’s birth were still together twelve to eighteen months later.75 Overall, studies consistently report negative effects of having a child with disabilities on family structure. The development of physical or mental disabilities in early childhood can have both immediate and longer-term consequences for human capital accumulation and economic well-being. It is not surprising that the parents of children with disabilities generally exhibit higher stress levels and poorer mental health than other parents. When comparing children with developmental disabilities and the general population, Byrne et al. (2010), Guyard et al. (2011), and Rentnick et al. (2007), among others, found this to be true in the case of cerebral palsy. But the impact of children's disability on the family seems to be related not only to the child's characteristics, but also with personal, social, and economic variables of the family.

In Asia and the Pacific regions, 650 million people are estimated to live with a disability, meaning one in every six persons lives with a disability Paola (2016). The number is predicted to increase by virtue of population ageing, poor working condition and chronic health condition, among other factors Paola (2016). Indonesia is one of the countries in South-East Asia region where the prevalence of people with disabilities continues to increase. The 2012 national socioeconomic survey reported that the percentage of people with a disability in the country increased from 1.38% in 2006 to 2.45% in 2011. In 2017, same survey reported that over 37.1 million people live with a disability, and about 10% (3.2 million) are children [Unescap,2013].

Caring for a child or children with a disability within family may cause various challenges to parents, caregivers and other family members (Unescap 2020). Psychosocial issues that face parents and caregivers of children with a disability include stress, feeling of guilt, low self-esteem, negative emotions and behavior.

In Africa, disability is prevalent among children but is seldom recognized and often deliberately hidden. Children with disabilities and their families constantly face social, political and economic barriers that adversely affect their development and prevent them from being included in society and enjoying their basic human rights to the fullest. Consequently, the strengths and abilities of children with disabilities go unnoticed, their potential is underestimated, and their needs are given low priority in the allocation of resources (UNICEF, 2007).

For African caregivers' other challenges, families have been reported to have high rates of single parenthood, child-headed households, fatherlessness, alcohol abuse and domestic violence (Scior et al. 2015). In South Africa several children with disabilities are excluded from education and health services, alongside additional support structures essential to their development. Caring for a child requires significant resources, and the demands on those resources are often increased when a child is born with a disability (Zahaika et al., 2021). Bingham (2017) points out that caregivers who care for these children typically face a shortage of resources to care for themselves and their children. Study done in Zambia showed that parents of children with disabilities experienced physical problems because of having to lift and carry their children while doing other useful activities (Singongo et al., 2015). Moreover, parents experience social isolation because of fear that community would not acknowledge their children or hold them responsible for the children's condition. Another important observation was that some of the marriages were broken up because of lack of acceptance of the children and humiliation especially by the male relatives, thus poor spousal support and hence poor coping mechanisms (Singongo et al., 2015).

Another study in Kenya indicates that parents of children with disabilities experience challenges including disgrace, lack of suitable treatment, financial and caring burden regardless their religion and cultural background. Parents applied various mechanisms including beliefs in supernatural powers, prayers and spiritual healing of their children’s disabilities (Gona et al, 2015). Like other parents elsewhere, parents of children with disabilities in Tanzania are also facing challenges in nurturing children with disabilities (Msangi, 2008; Mbwilo, 2010). This is because of disability or persistent illness of a member that affect the entire family as an interactive unit.

The Ministry of Community development, gender, women, children and people with special needs and the local government that include social welfare departments in all districts of Tanzania are expected to provide support for citizen including families caring children with disabilities so as to adhere to Disabilities Act of 2010 article 20(3) that could have administered in the form of providing counseling services to parents, guardians, relatives and persons with disabilities for the purpose of wiping out stigma among them.

Furthermore, different social organizations such as organizations of persons with disabilities, Non-Governmental Organizations, Community Based and Faith Based Organizations and some international organizations as for instance UNICEF, work hand in hand with the Ministry to ensure quality provision of psychosocial support and services for those who are in need. However, availability of all the mentioned laws, policies, government and non-government standards in Tanzania that protect and promote life of children with disabilities and their families still there is a variation of human experience on the aspect of psychosocial wellbeing. Parents, stakeholders, practitioners and government at large miss the feedback on what is working well and what need more efforts to improve life of caregivers as frontline responsible and their children. The central concern of this study was to bring on board those human experiences by looking upon the psychological and social experiences of families caring children with disabilities.

1.2 Statement of the Problem

Despite of having government attention and many stakeholders who work to support children with disabilities and their families in Tanzania, still their psychological and social experience varies and continue to have visible impact to other family members and to children with disabilities.

According to Tanzania Basic Education Statistics (2021), Tanzania has a total number of 56,785 children with disabilities in primary schools. These children have parents who need to be given support to make it possible for education of these children. The government of Tanzania has assigned the Ministry and Social Welfare under the district social welfare departments the task of assisting individuals facing life crisis including parents of children with disabilities (Tanzania Disability Act, 2010). This is because procreating and bearing children with disabilities are an ascribed task which bring with it challenges and opportunities for parents to sacrifice part of their responsibilities for the well-being of children. Parents may encounter financial constraints for education and other upbringings costs of children with disabilities which may urgently require assistance that could enable meet the demands well in their situation. This is in line with Freedman and Boyer (2000) and Nielsen (2002) thought that parents of children with disabilities appear to have taken on an addition responsibility and unexpected challenges that require support and information to make sound decision about their lifestyle in general. This study wanted to look on all the aspects within psychosocial support matters which families experience while caring for children with disabilities.

1.3 General Objective

The general objective of this study was to explore the psycho-social support for families caring for children with disabilities.

1.4 Specific Objective

1. To identify the psychosocial support challenges experienced by families caring for children with disabilities
2. To examine the accessibility of existing psychosocial support opportunities available to families caring for children with disabilities
3. To investigate on the evidence based psychosocial support interventions designed for families caring for children with disabilities

1.5 Research Questions

1. What were the psychosocial support challenges experienced by families caring for children with disabilities?
2. How accessible were the existing psychosocial support opportunities for families caring for children with disabilities in Tanzania?
3. What were the evidence based psychosocial support interventions designed in Tanzania for families caring children with disabilities?

1.6 Significant of the study

This study represented an initial qualitative understanding of impacts of childhood disability experienced by families in the context of Dar es salaam, Ilala district and Uhuru Mchanganyiko primary school. Findings of this study contributed to stakeholders who advocate for human rights and wellbeing of people with disabilities to design training, workshops and capacity building at schools and communities.

Also, this study informed social workers and other primary service providers for families on what was missing to add on their practice and what was working well so as to maintain for the best interest of children with disabilities, their parents and entire family. This study played a significant role to academician who train various practitioners and researchers but also policy makers who engaged in psychosocial support matters by ensure their thinking is informed by what families experience on the psychosocial support aspect after start caring for children with disabilities. The aim was to smoothen life of families caring for children with disabilities and realize best interest of all children at the family context.

1.7 Limitation of the study

There were some possible limitations that needed consideration. Firstly, children with disabilities receive care from other people like neighbors, teachers just to mention few who also have experience to share and impact better practice, but this study focused only on the family so as to set a starting point for other studies. Secondly, nature of families and their schedules time for data collection could be limited. Also, this session involved expression of emotions so it could be time consuming. Mitigation strategies were to let the part as a gap and for time consuming everything was in time we ensured early communication with family members and arrived early than planned time. Also, we engaged sweepers to clear emotional breakdown.

1.8 Organization of the Study

This study constitutes five chapters. The first chapter is composed background of the study, a statement of the research problem, the objectives of the study, research questions, significance of the study and scope of the study. The second chapter consists of an overview, the definition of key terms, theoretical literature review, an empirical literature review research gap, and a conceptual framework. The third chapter constitutes the research methodology which covers the research philosophy, research design, research approach, population of the study, sampling procedures, and sample size. Other components of chapter three are data collection methods, data analysis, validity and reliability of the research instruments, and ethical considerations. The fourth chapter involves data analysis, interpretation, presentation, and discussion of the findings. The fifth chapter presents the summary, conclusion, and recommendations of the study.

CHAPTER TWO

LITERATURE REVIEW

This chapter covers the conceptualization of key concepts, theoretical literature review, empirical literature review and research gap.

2.1 Conceptualization of Key Terms

This is the process of defining and specifying the meaning of key concepts used in a study (William, 2020). By clearly defining concepts, researchers ensure that everyone involved in the study shares a common understanding of what is being studied. This helps to avoid confusion and ensures focus and consistent

2.1.1 Psychosocial Support

Psychosocial support is a continuum of love, care and protection that enhances the cognitive, emotional and spiritual wellbeing of a person and strengthens their social and cultural connectedness REPSSI (2016). Psychosocial care and support illustrate a continuum of services and facilities that addresses social, emotional and psychological problems to safeguard the well-being of individuals, their families and communities (National PSS guidelines 2020). To this study Psychosocial support refers to continuous processes and actions that promote holistic wellbeing of individuals, families and communities. The psychological and social support include guidance and counseling, trainings and awareness, community engagement, activities support, setting friendly way to access social services, support groups and others of that direction can be provided by family members, friends and professionals.

2.1.2 Family

Family can be described as nuclear (parents and children) or extended (the conjugal family as well as encompassing other relatives or descendants of the husband and/or wife) (SADC, 2010). In Tanzania Family also defined as a social unit created by blood, marriage, adoption or defined by a common line of kinship or relationship of a paternal or maternal nature. This can be biological or adoptive (REPSSI, 2016). To this study, family refers to persons united by the ties of marriage, blood, kingship or adoption, creating a single household and interacting with each other in their respective social positions. These people live under one roof and care for each other.

2.1.3 Children with Disabilities

According to CRPD 2009 defines as children who are having a long-term physical, mental, intellectual or sensory impairment that hinders one’s participation in society on an equal basis with others. Children with disabilities refers to children who have disability (REPSS 2016). According to National Policy on disability (2004) refers to a child with loss or limitation of opportunities to take part in the normal life of the community on an equal level with other children due to physical, mental or social factors. To this study Children with disability refers to a person below the age of 18 years, enrolled to primary school who are having long term physical, intellectual or sensory impairment and stay with their families. The impairment maybe present from birth or acquired later in life before starting school.

2.1.4 Care

According to Collins (2014), refers to provision of what is necessary for the health, welfare, maintenance and protection of someone or something. Also, care refers to feel concern or interest, attach importance to something. Care means something is important and start to feel worried about it (Cambridge Press 2024). To this study Care refers to the process of providing support, assistance and being responsible for lives of children with disabilities.

2.2 Theoretical Literature Review

This study and its specific objectives will be directed by the social model of disability. The social model was extended and developed by academics and activists in Australia, the UK, the US, and other countries to include all people with disabilities, including those who have learning disabilities, intellectual disabilities, emotional, mental health or behavioral problems. In 1975, the UK organization Union of the physically impaired against segregation (UPIAS) claimed that society has a great role to play on disability rights. Therefore in 1983 the academic Mike Oliver who was a person with disability invented the phrase social model of disability in reference to those ideological developments. Michael James Hoiles Oliver, disability activist and academic, born 3rd February 1945 and died 2nd March 2019 (Brindle 2019).

2.2.1 Social Model of Disability

In this model, disability was seen as one aspect of a person’s identity**,** much like race/ethnicity, gender, etc. From this perspective, disability is believed to result from a mismatch between the disabled person and the environment (both physical and social). It is this environment that creates the handicaps and barriers, not the disability (Abbay 2015).

The model gained steam over the next three decades as society shifted from trying to “fix” an individual with a disability and instead created best practices from the family level for equity, like universal design and social inclusivity (Black 2016). There is a shift from medical model of disability due to its challenges to social model of disability. This model focuses to change the environment in which people with disabilities live, work and play. The model emphases on changing society and not on curing the person (United Nations, 2008).

2.2.2 Significance of Social Model of Disability to this Study

Social Model provides a route map that identifies both Physical, attitudinal, information and communication barriers that people with impairments can experience and how these barriers can be removed, minimized or countered by other forms of support from the family level (Amstrong, 2015).

The social model of disability can be used to identify psychosocial support opportunities for families caring children with disabilities because it is focusing on removing societal barriers and promoting inclusion (Amstrong 2015). This approach recognizes that many challenges faced by families caring children with disabilities are not inherent to the disability itself, but rather stem from societal attitudes and structures. By addressing these barriers, opportunities for psychosocial support can arise. This model emphasizes on matters like, advocacy for Inclusive Policies on equal access to education, healthcare, and community resources. Creating Support Networks which facilitates connections with other families as well as emphasize on participation and decision making. On Psychosocial support for families caring children with disabilities, this model will offer support by advocating for inclusive policies, accessible infrastructure, and societal attitudes that promote acceptance and accommodate diverse needs. It encourages empowerment, collaboration, and resource allocation towards creating environments where children with disabilities can thrive alongside their families (REPSSI, 2016).

The social model of disability helps identify psychosocial challenges experienced by families caring for children with disabilities by highlighting how societal attitudes, lack of accessibility, and general barriers impact their lives. By recognizing that disability is not solely a medical issue but also a result of societal constructs, it prompts a holistic approach to understanding and addressing these challenges (Antony 2013). For instance, it may reveal struggles with stigma, isolation, inadequate support services, or barriers to education and employment opportunities. By addressing these societal factors, interventions can be designed to support families more effectively, promoting their well-being and resilience. The Social Model of Disability is dynamic and effective, Therefore, by incorporating the social model of disability to this study matters on psychosocial challenges, opportunities and interventions can be identified and leveraged to enhance the well-being not only for families caring for children with disabilities but to society and national at large.

2.3 Empirical Literature Review

In this section, the researcher reviewed various studies related to Psychosocial support for families caring children with disabilities. The researcher reviewed different books, articles, journals and findings from other researchers published within and outside Tanzania.

2.3.1 Psychosocial Support Challenges Experienced by Families Caring for Children with Disabilities

Families are an important source of support for children with disabilities. Family members absorb the added demands on time, emotional resources, and financial resources that are associated with having a child with a disability (Stahmer, 2005). Yet, rewards from having a family member with a disability, such as personal and spiritual growth, have been overlooked (Scorgie & Sobsey, 2002).

According to Dalia (2021) from Palestine, conducted a study on Challenges facing family caregivers of children with disabilities. This study aimed to examine the challenges facing caregivers of CWD during the pandemics, and to explore these challenges from various physical, social, psychological, and financial aspects. In this study researcher conducted a cross-sectional design whereby 130 caregivers for CWD completed a survey between March- May 2021. In this study they came up with the findings that most of caregivers were mothers (76.9%), the mean age of the children was (6.09 ± 3.43 years). The majority (88.5%) of the caregivers felt physically exhausted, about (75.4%) had decreased living standards, and (86.2%) indicated that caregiving is taking their strength. A high burden score was recorded based on the type of disability, and child’s ability to take care of oneself. The total scores were positively correlated with the physical, social, psychological, and financial challenges facing the caregivers.

In South Africa there is a study conducted by Toyab (2022) This study aim to explore and describe the experiences of caregivers providing care to children with disabilities at non-governmental organizations (NGOs) in townships. Experience in South Africa cement on the idea that; Caregivers of children with disabilities are vital stakeholders when it comes to safeguarding the health, well-being and overall survival of the children that they care for. Caregivers, however, face many challenging conditions that make it difficult for them to optimally fulfil their caregiving role. Understanding these challenges is crucial for developing empowerment programs for caregivers, which will ensure that children with disabilities receive comprehensive, optimal care and that caregivers experience a good quality of life. In this study researcher used an exploratory, descriptive and contextual research design within a qualitative methodology. The population in this study included caregivers who care for children with disabilities at NGOs ($n = 10$). Participants for the study were selected using the purposive sampling technique. Data were collected by conducting semi structured interviews with caregivers. Data were analyzed according to thematic analysis procedures. Additionally, this study revealed six (6) themes that represent the PSS challenges experienced by caregivers, namely, initial impressions, rendering care, stress, lack of outside support, coping and poor community recognition. In Tanzania there is study conducted by (ISESELO et al 2016), about Mental illness and how it may cause a variety of psychosocial challenges, these challenges are enhanced by the stigma attached to mental illness, which is a problem affecting not only the patient of mental illness but also the family. The aim of the study was to determine the psychosocial problems of mental illness on the family including the coping strategies utilized by family members caring for a person with mental illness. This study methodologically was a qualitative study, involving four focus group discussions and 2 in-depth interviews of family members who were caring for patient with mental illness at Temeke Municipality, Dar es Salaam. Purposive sampling procedure was used to select participants for the study. Audio-recorded interviews in Swahili were conducted with all study participants. The recorded interview was transcribed, and qualitative content thematic analysis was used to analyze data. At the results part this study reveals financial constraints, lack of social support, disruption of family functioning, stigma, discrimination, and patients' disruptive behavior emerged as the main themes in this study. Therefore, according to various literature reviewed in different regions, families caring for children with disabilities experience PSS challenges while assuming their roles at the family level. Most of PSS challenges mentioned include decreasing their strengths, physical exhausted, decrease living standards, experiencing financial hardships and stress level increase. In addition, Identification of these challenges in Tanzania only focus on specific kind of disability like intellectual, cerebral palsy and other mental based aspects but still when it comes to PSS challenges for caregivers of mental illness patient`s themes like stigma, discrimination, poor social support and financial constrains revealed.

2.3.2 Psychosocial Support Opportunities Available for Families Caring for Children with Disabilities

These encompass a broad range of activities aimed at promoting psychological and social well-being. They often involve family and community-based initiatives, peer support programs, support groups, and other resources that offer individuals avenues for connecting, sharing experiences, and gaining support. Mostly no professionalism needed in the realization of these opportunities. There are limited number of studies on PSS opportunities for families caring children with disabilities but in most cases, challenges go with opportunities in many studies.

According to Diva (2022) who conducted a study on Challenges and Opportunities for Culturally Sensitive Mental Health and Psychosocial Support in the African Context. This was a qualitative study explores the opportunities and challenges encountered when adopting a cultural and faith sensitive approach within MHPSS interventions in the context of Zambia, Ghana, Niger, and South Africa. Based on in-depth interviews with key informants from the mentioned countries, the results provide insights into the strengths and opportunities of adapting to local cultural norms and practices and cooperating with faith-based and traditional community leaders during the implementation of MHPSS. The study concludes on the potential of such an approach to strengthen the local capacities of faith-based actors and reduce the stigmatization of mental illness.

In Tanzania, National guideline for provision of PSS care and services (2022) emphasize on the PSS opportunities available at the family level, whereby, traditional family system (both nuclear and extended) is an important and immediate support system for any client who is need of PSS services. Thus, PSS service providers should Work closely with client’s family; and utilize the available potentials in the family in serving and supporting members. Also, coordinate role and performances by family members, then, Support the family to identify PSS needs of the client in need and lastly to assist the family to access appropriate PSS referral services for their family members within or outside the community. It includes all families regardless of their diversities.

2.3.3 Psychosocial Support Interventions Designed for Families Caring for Children with Disabilities

The burden of caring for children with disabilities in low- and middle-income countries (LMIC) is high and is associated with parental psychological distress. There are few services for children and parents in most developing countries and few interventions have been created that target the psychological issues among parents of the mentioned children (Mwale 2019).

In Europe there is the study conducted in Netherlands by Douma (2020) On feasible interventions matching PSS needs for parents of children with chronic illnesses. Parents of children with a chronic illness (CI) are at risk for psychosocial problems. The aim of this study was to refine an existing face-to-face intervention into an online psychosocial group intervention for parents by exploring which themes are important, then to determine what type of intervention parents would like and to assess parents’ practical preferences. In this study researcher used mixed method approach, both quantitative (questionnaire) and qualitative (focus groups/interviews). The only inclusion criterion was being a parent of a child between the ages of 0 and

18 years with a CI diagnosis. More than one parent per family could participate when desired.

The study finding was as follows, based on parental support needs and the themes parents considered as important to address in an intervention, an innovative parent-focused *intervention* on online program for parents was developed to use in clinical practice. Online program for parents *can* be offered to parents after receiving the child's diagnosis. This intervention is an important contribution to the field, because the focus is on parents themselves, as opposed to existing parental interventions that focus on teaching parents how to support their children. Furthermore, because the intervention has a generic approach, parents of children with rare illnesses can participate in a group intervention. Additionally important finding is the fact that some parents are reluctant about the online aspect of the intervention.

In Africa there is a study conducted in Malawi by Mwale C (2019) which focus on development of PSS Interventions for reducing distress among parents of children with Intellectual disabilities. This study aimed to develop a contextualized intervention to provide psychological support for parents of children with intellectual disabilities in African. Whereby Six steps were adopted from the Medical Research Council framework for designing complex interventions. This includes literature review of similar interventions and models, qualitative studies to gain insights of lived experiences of parents of such children. Study reveal that 21 intervention modules were found from a systematic search of the literature which were listed for possible use in our intervention along with four themes from qualitative studies. Also, an expert panel formed consensus on the eight most related and relevant modules for African setting. This formed the intervention; “Titukulane.” This intervention was piloted and found to have high acceptability and practicability when contextualized in the field of disabilities. Therefore, the use of a systematic framework for designing a complex intervention for supporting the mental health of parents of children with disabilities enables good acceptability and practicability for future use in low resource settings.

In Tanzanian there was the study conducted by Christopher (2021) This study investigated psychosocial challenges facing orphaned children and caregivers as well as possible intervention strategies that could be adopted to mitigate these challenges in the institutionalized orphaned children centres in Ubungo Municipal, Dar es Salaam. The study used a qualitative research approach and a descriptive research design. A purposive sampling technique was employed to select six orphanage centres. The study had a sample of 67 participants including children receiving orphanage care at the institutionalized orphaned children centres, caregivers and directors of the centres who were selected through purposive sampling technique. Data were collected using in-depth interviews and a non-observation method and were sorted and coded based on themes and presented according to the research questions. Findings from the study revealed that orphaned children were supported with various services including food, clothes, accommodation, health services, spiritual and educational support, life skills, sports and games. It was found further that the orphans were faced with a lack of adequate health facilities including health insurance coverage, educational materials, sports gear and, in some centers, inadequate clean and safe water. Caregivers lack counselling knowledge and skills.

2.4 Research Gap

The literature review showed that studies conducted to explore matters related to PSS and caring for children with disabilities. Studies projected challenges faced by families caring for children with disabilities both globally and national wise. Also, studies projected opportunities available for families although not in specific field of disabilities, most on mental health and culture related aspect. Additionally, there were many interventions designed on the area of PSS other interventions where online programs others were indigenous practices and others were community based. All these studies paved a way to well understood PSS and how families caring for children with disabilities receive it to support their daily life experiences.

Despite of PSS being a global term and used in different fields as far as human development and wellbeing concerned there were content gap when it comes to families caring for children with disabilities. Looking at the Study conducted by Dalia (2021) focus on PSS for parents caring children with disabilities, it only focusses on parents while children with disabilities receive care to people whom they share household. Also, many studies according to the review focus on mental health part and leave aside the social support and other aspects of psychological support. In Tanzania many studies cover mental health and specific type of disability like Intellectual disability, Autism and cerebral palsy whereby according to Tanzania persons with disability act 2010 there are other types of disabilities mentioned. Therefore, the study on PSS for families caring children with disabilities covered the content gap and geographical gap since Dar es salaam regardless of its diverse there were limited studies covered families caring children with disabilities and PSS.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Chapter Overview

This chapter presented the research methodology, it specifically presented research philosophy, research paradigm, research approach, research design, area of the study, and study population. It further presented the sampling technique, data collection methods, data analysis techniques, inclusion and exclusion criteria, reliability and validity of the research instruments, and ethical considerations

3.2 Research Philosophy

Research philosophy encompasses the beliefs and assumptions that underpin knowledge development. This framework dictates the methodology, procedures, data collection, and conceptual definitions relevant to the study (Saunders, Lewis, and Thornhill, 2009). The present investigation informed by the principles of Interpretivism, which speculated that knowledge and truth are contextually and culturally bound, derived from individual experiences and understandings. This philosophy aligns with qualitative research, emphasizing the importance of values and beliefs in the data collection process (Gemma, 2018). In the context of this study, Interpretivism served as the guiding philosophy to analyze psychosocial support (PSS) for families caring for children with disabilities. A focus on exploring the challenges, opportunities, and interventions available for these families necessitates the engagement of their unique perspectives to enhance the depth and relevance of the findings.

3.3 Research Design

Research design constituted the overarching strategy that integrated various components of the study in a coherent manner, effectively addressing the research problem. It served as a blueprint for data collection, measurement, analysis, and reporting (Thakur, 2021). An effective research design enabled the collection of evidence that logically addressed the stated research problem. Various designs existed within research, including Descriptive, Explanatory, and Exploratory designs. The current study adopted case study research design which emphasized life experiences, specifically focusing on families caring for children with disabilities and their psychosocial well-being in Tanzania, particularly in the Uhuru Mchanganyiko context.

3.4 Research Approach

The research approach refers to the structured methods employed to conduct the study, ensuring reliability, validity, and utility (Hassan, 2024). Three primary approaches exist: Deductive, Inductive, and Abductive. The Deductive approach aims to confirm or reject hypotheses through quantitative methodologies, while the Inductive approach seeks to generate new theories or refine existing ones using qualitative methods. For this investigation, an Inductive approach was employed, utilizing qualitative methods to obtain rich descriptions of participants' thought processes and explore the “why” behind certain phenomena (Creswell, 2003). The goal was to assess the PSS challenges, opportunities, and interventions available for families caring for children with disabilities, necessitating visits to families in their natural settings.

3.5 Study Area

The study area refers to the geographical context that the research will investigate (Lindsay, 2023). This investigation aimed to inform various practices, including the NOREC project, which focused on empowering children and individuals with disabilities, particularly in Arusha and Dar es Salaam. The primary site for data collection was Dar es Salaam, the largest city in Tanzania (Sensa, 2022), boasting a population exceeding six million inhabitants. Although not the capital, Dar es Salaam served as the country's financial and commercial hub, hosting the headquarters of numerous national and international agencies. Within this city, the Ilala District was the focal point of the research, which was home to established social service institutions delivering education and health services, including Ocean Road Hospital and Muhimbili National Hospital. Uhuru Mchanganyiko, the study’s specific site, was one of the oldest schools in the region. Established in 1921, it was the first to integrate students with disabilities into regular classrooms. This school served as a practical site for NOREC participants and possessed a substantial history of interaction with families caring for children with disabilities. Thus, the objectives of the study effectively addressed PSS challenges, opportunities and evidence based interventions available for these families.

3.6 Study Population

The study population comprises a subset of the target population from which the sample will be drawn (Kumar, 2011). As of January 2024, Uhuru Mchanganyiko Primary School has a total enrollment of 150 students come from different families which care for children with disabilities. This figure includes 68 students with visual impairment, 14 with deaf-blind conditions, 70 with intellectual disabilities, and 5 with albinism.

3.6.1 Sampling Procedures

Sampling procedures refer to strategies employed to select participants from a defined population (Kothari, 2004). This study utilized non-probability sampling techniques whereby participants were not selected randomly, resulting in unequal chances of selection.

3.6.1.1 Purposive Sampling Procedure

Purposive sampling was employed to identify 12 families, each family was presented by 3 members which resulted to 36 participants with willingness and readiness to participate to the study as supported by (Creswell, 2014). Teachers assisted in identifying three families from each unit with children enrolled at the school, selecting those that could provide meaningful insights regarding the research objectives. Despite the potential for bias inherent in purposive sampling (Combes, 2013), the unique circumstances and readiness of participants facilitated efficient data collection.

3.7 Inclusion and Exclusion Criteria

Inclusion criteria referred to the characteristics required for participation in the study, while Exclusion criteria identified attributes leading to disqualification (Nakolopoulou, 2022). For this study, inclusion criteria stipulated that participants must have been individuals aged 18 or older residing with a child with disabilities (blindness, deaf-blindness, intellectual disability, or albinism) attending Uhuru

Mchanganyiko Primary School. Exclusion criteria encompassed individuals who chose to withdraw from the study after initial inclusion

3.8 Method of Data Collection

The methods of data collection involve various strategies employed to gather data from diverse sources, whether primary or secondary (Kothari, 2004). The chosen methods aligned with the research design and objectives, ensured the collection of relevant and accurate information.

3.8.1 Interview

Interviews involve a series of open-ended questions posed by the interviewer, allowing participants to provide detailed responses (Morgan and Harmon, 2018). This method enabled in-depth exploration of contentious issues and facilitated clarification of respondents' views. Interviews were conducted with biological parents, grandparents, siblings, and extended family members of children with disabilities, focusing on their experiences and perceptions of psychosocial support.

3.8.2 Observation

Observation serves as a complementary data collection method, permitting direct monitoring of participant behaviors and the surrounding social and physical environment (Gall, Gall, and Borg, 2007). Non-participatory observation was employed, focusing on the actions, reactions, and interactions of participants in their familial context. This approach aided in identifying the psychosocial support challenges faced by families caring for children with disabilities.

3.8 Data Analysis Methods

Data analysis involves examining and synthesizing large amounts of information to identify trends and support decision-making (Bhatia, 2017). This study utilized thematic analysis as a qualitative analysis method designed to identify common themes within collected data, such as interview transcripts and observational notes. The analysis followed a six-step process developed by Braun and Clarke (2006), including familiarization with the data, coding, theme generation, theme review, defining and naming themes, and writing up the findings, maintaining objectivity throughout.

3.9 Reliability and Validity of Data

3.9.1 Reliability of Data

Reliability refers to the consistency and precision of research findings. It assesses the stability of measurements across different instances and the equivalence of different test items (Kumar, 2017). To enhance reliability, attention was paid to the interview procedures, ensuring clarity in the timing and content of the interviews, comprehensive profiling of family caregivers, and meticulous preparation of interview questions aimed at caregivers of children with disabilities.

3.9.2 Validity of Data

Validity measures the effectiveness and accuracy of the research instruments (Creswell, 2010). It encompassed the credibility of the conclusions drawn from the perspectives of the participants. Ensuring validity required adherence to established principles, including detailed explanations of interview procedures to participants and careful consideration of how tools were utilized in generating research findings.

3.9.3 Dependability

It refers to the consistency, stability, and replicability of the research findings (Wayls.2021). it is a crucial aspect of qualitative research. To ensure dependability researcher was very consistent with research procedures from the beginning. Findings are dependable.

3.9.4 Trustworthiness

Refers to the overall quality and credibility of a study. It ensures that the findings are accurate, reliable, and meaningful. To establish trustworthiness researchers was focusing on being more engaging with caregivers during interview, persistent observation of caregivers' interaction and debriefing of caregivers' ideas and experiences (Lincoln, 2005).

3.10 Research Ethical Considerations

Ethical considerations encompass guidelines designed to protect the rights, safety, and well-being of research participants, as well as the overall integrity of the study (Hassan, 2023). Adherence to ethical research protocols was paramount throughout the field investigation and data handling.

3.10.1 Data Clearance from the OUT

This is an introductory letter given to students, presenting specific authority that enable student to conduct research and collect data obtained from The Open University. Indicating the researchers identity and intention. Moreover, before collecting data the researcher obtained a clearance letter from The Open University of Tanzania which was presented to Ilala district Authorities to allow the researcher to collect data. Therefore, written permission to conduct research was obtained from the responsible authorities.

3.10.2 Confidentiality

This is a crucial ethical principle that involves protecting the privacy of research participants by keeping their information confidential. It means that the researcher should not disclose any information that could identify the participant without their explicit consent (Bhandari 2024). It this study researcher prioritize confidentiality of participants through out discussions and findings meaning their valuable experience will be accessible to people who will be interested with their wellbeing as caregivers of children with disabilities. This was a priority because it was an ethical responsibility, legal requirement and source of trust with participants.

3.10.3 Do not Harm Principle

This is a fundamental guideline that emphasizes the researcher's responsibility to minimize potential harm to research participants (Hassan, 2024).This study involved sharing of experiences for caregivers and to some extent it was direct life review and recall, researcher ensured the availability of sweepers to support participants at times of breakdown also, clear information about the study intention and the use of study results was an important component to participants.

3.10.4 Voluntary Participation

This is another fundamental ethical principle in research, meaning that individuals should freely choose whether or not to participate in a study. There should be no coercion, pressure, or influence to encourage participation (Hassan, 2024). Researcher who guided by non-probability sampling, ensured that not only people who were mentioned or recommended to fit in the study were involved but also their readiness to participate and share their experiences concerning PSS challenges, available opportunities and interventions when caring for children with disabilities.

CHAPTER FOUR

FINDINGS AND DISCUSSION

4.1 Overview

This chapter presents results and discussion of the findings. The chapter is composed of the following subsections: Participants demographic profile, psychosocial support challenges experienced by families when caring for children with disabilities, Psychosocial support opportunities available for families and psychosocial support interventions available for families caring for children with disabilities. The discussion and presentation of the research finding was carried out according to each interview guide by pinpointing different issues about each research question. The study constituted 12 families which have 3 participants per family.

4.2 Demographic Characteristic of the participants

According to Hendrik & Ken (2012) demographic profile involves the study of a population based on race, age, sex, marital status, income, economic status, employment and education level. In the context of this study demographic profile comprised of; participants type, age, sex, occupation, and education level.

4.2.1 Age of Participants

The researcher analyzed the age demographics of the study population to assess the age group involved in the research and their potential understanding of the study topic, as shown in the table below.

Table 4.1: Age of participants

Age	Frequency	Percentage
18-25	2	6
26-35	8	22.2
36-45	10	28
46-55	12	33.3
Above 56	4	11
Total	36	100

Source: Field Data, 2024

The above table interpretation the age profile of participants into frequency and percentage, the finding revealed the percentage of participants by age whereby 33.3% of the participants which is equal to 12 participants out of 36 had the age ranging 46-55 years, while 28% of the total participants which equal to 10 participants out of 36 has the age range of 36-45 years. 22.2% of participants which equal to 8 participants out of 36 had the age range of 26-35 years. Then 11% of participants which equal to 4 participants out of 36 had the age range of above 56 and the rest 6% of participants which equal to 2 participants out of 36 had the age ranging 18-25 years. The majority of participants had the age ranging from 26-35 years, 36-45 years and 46-55 years which are the age group of caregivers who were involved with children with disabilities, and they were willing to share their experiences. This helped the researcher to get a good understanding of psychosocial support experiences for family members who care for children with disabilities.

This demographic pattern aligns with previous studies that highlight the role of middle-aged individuals as primary caregivers for children with disabilities, as they often possess a balance of life experience, emotional resilience, and the ability to access resources necessary for caregiving (Mwamwenda, 2015; Nyundo, 2018). The diverse age distribution of participants allowed for a comprehensive understanding of the psychosocial support experiences across different stages of life, providing a rich context for exploring the support needs of families caring for children with disabilities.

4.2.2 Sex of Participants

The concept of sex for participants was categorized as Male and Female presented in the table below.

Table 4.2: Sex of Participants

Sex	Frequency	Percentage
Male	9	25%
Female	27	75%
Total	36	100%

Source: Field data, 2024

The findings on the sex of participants, as shown in Table 4.2, reveal a notable gender disparity, with 75% of participants being female and 25% male. This suggests that women, as primary caregivers, were more available and willing to participate in the study, sharing their experiences regarding the psychosocial support they receive. The predominance of female participants is consistent with previous research that indicates women are typically the primary caregivers for children with disabilities, particularly in settings like Tanzania, where traditional gender roles often place caregiving responsibilities on women (Fritz, 2016; Mussa, 2020). The study also found that males were less represented, likely due to their daytime work commitments or busy schedules, which limited their availability for caregiving. This aligns with gender norms in many societies where men are often the primary breadwinners and spend more time in paid employment, leaving caregiving largely to women (Kalemera & Kalimba, 2017). Interestingly, the presence of younger males (under the age of 18) who were at home during the day could indicate the evolving role of younger generations in supporting caregiving roles. Overall, the gender imbalance in the study reflects the broader societal patterns where women are the backbone of caregiving for children with disabilities, and their voices and experiences are critical for shaping policies and support systems in these contexts.

4.2.3 Types of Disabilities

The study participants care for children who were categorized into four types of disabilities namely: Intellectual, visual impairment, Deaf blind and albinism.

Table 4.3: Types of Disabilities

Disability	**Frequency**	**Percentage**
Albinism	3	8.3%
Deaf blind	11	30.5%
Intellectual	17	47.2%
Visual impairment	5	13.8%

Source: Field data 2024

The findings presented in Table 4.3 reveal the types of disabilities that participants are caring for, with intellectual disabilities being the most common, as 47.2% of participants reported caring for children with intellectual disabilities. This aligns with the global prevalence of intellectual disabilities, where studies have shown that a significant proportion of children with disabilities have intellectual impairments, often requiring specialized caregiving (Murray et al., 2017). The second largest group, 30.5% of participants, cared for children with a combination of deaf and blindness, highlighting the challenges caregivers face when supporting children with dual sensory impairments. This condition requires specialized care and attention, as children with deaf blindness often face greater communication barriers and social isolation, demanding additional support from caregivers (Tebbutt & Nott, 2018).

Additionally, 13.8% of participants cared for children with visual impairments, a disability that often requires adaptations in the home environment and specialized educational support. The smaller percentage of caregivers looking after children with albinism (8.3%) further indicates the diversity of disabilities among children in this sample. Children with albinism often face unique challenges, including societal stigma and health risks related to their condition, such as skin cancer due to the lack of melanin, which necessitates increased vigilance from caregivers (Mwaikambo & Namboze, 2020). Overall, the findings suggest that caregivers are responsible for children with a wide range of disabilities, each with distinct care needs. These varying disabilities contribute to the complexity of caregiving roles, highlighting the need for tailored psychosocial support services that address the specific requirements of children with different disabilities.

4.2.4 Level of Education of Participants

The study participants were categorized into four levels of education namely no school, primary, secondary, collage/university as indicated in Table 4.4

Table 4.4: Level of Education of Participants

Education Level	Frequency	Percentage
No school	7	19.4%
Primary level	13	36.1%
Secondary Level	10	27.7%
Collage/University level	6	16.6%
Total	36	100%

Source: Field data 2024

The findings presented in Table 4.4 indicate that most participants (36.1%) had only primary education, with 27.7% having completed secondary education, and a significant portion (19.4%) had never attended school. Only 16.6% of participants had received higher education at the college or university level. These indicate that in this study we have people attend school and those who didn't attend any level all of them play part on caring for children with disabilities and were willing to participate in the study. These findings suggest that many caregivers may not have a comprehensive understanding of the scientific aspects of disabilities, including their children's specific conditions, and may lack the knowledge to effectively advocate for their children's needs. Research indicates that education plays a critical role in caregivers' ability to access appropriate resources, understand disability, and advocate for services (Purdue & White, 2019).

Furthermore, caregivers with limited education may struggle with understanding the complex and often technical aspects of disability-related support services. This lack of knowledge can lead to difficulties in navigating systems for healthcare, social services, and educational support, which are essential for children with disabilities.

The findings echo studies that have shown the importance of education in empowering caregivers, enabling them to make informed decisions and take appropriate action to ensure their children's well-being (Teresinski et al., 2020). For caregivers with limited formal education, the lack of awareness about available support systems and intervention programs can hinder their ability to effectively care for children with disabilities. Therefore, there is a need for targeted education and training programs that can enhance caregivers' understanding of disabilities, psychosocial support, and advocacy, particularly for those with lower levels of education.

4.3 Psychosocial Support Challenges Experienced by Families Caring for Children with Disabilities

4.3.1 Social Stigma and Discrimination

This study reveals that social stigma and discrimination pose significant challenges for families caring for children with disabilities. Families often encounter negative attitudes, stereotypes, and exclusion from communities their living in. Social stigma results to feelings of shame, guilt, and isolation, making it difficult for families to seek support or access necessary services. Additionally, discrimination can be even from the people who expected to care and support these families caring for children with disabilities. A brother of children with disabilities shared.

> *"I am okay to support my young brother who had visual impairment, and I really try to help my friends understand this but I declare to fail and I feel very bad about it because I have to choose between my young brother and my friends so I choose my brother.*

> *The issue is they mistreat him by teasing him and I can`t take it."*

A mother of a child with Albinism said.

> *"I am struggling a lot with my child stigma and discrimination from relatives is really a challenge for me because I expect to receive care from them but some of them are busy to discriminate us since I give birth to my child. How is this even possible, it is overwhelming experience but God give us strength to continue with life but I wish for them not to discriminate my child at least they could get to know his condition first."*

A grandfather of a child with deaf-blind condition said.

> *"My heart aches to see the way society treats my grandchild. Their disability doesn't define him, but the community's ignorance does. It's a painful reality that our love and care can't shield him from the harsh judgment and exclusion."*

Uncle of a child with intellectual disability said.

> *"My sister changed a lot after giving birth to her child with this condition. She was very different compared to the way she used to be, so the only relief at the family level was to assist her with caring for the child, now I can see a lot of progress and now she shares with us how social isolation impacted her negatively. Now we stay together and focus on her wellbeing and wellbeing of the child although it is not easy."*

A father of a child with intellectual disability explains.

> *"The community and people around us changed a lot after having a child who is different, we are struggling a lot with*

> *how society view us. It is hard to us as parents, but we experience new things every day. I have one friend who support me and I really appreciate and wondered how easy would life be when all of our community member opt to support us?."*

Many families caring for children with disabilities experience social stigma and discrimination to people who used to be very close to them. Stigma and discrimination leaves families feeling isolated, with limited people to talk to. Even when they come from good families or middle-income families their aloneness after having children with disabilities has direct impact to family members and to children themselves. These reflections highlight a pressing need for increased awareness raising about different types of disabilities in communities, similar studies like those by Green (2023) on stigma and the lives of families of children with disabilities; found that community awareness could decrease the level of stigma and discrimination. The social model of disability as reviewed by PWDA (2023) directly addresses stigma and discrimination as central issues. It argues that disability is not solely a medical condition, but rather a social construct created by societal barriers and negative attitudes. These barriers, such as discriminatory practices, and harmful stereotypes, limit the opportunities of families to participate peaceful in the community.

4.3.2 Family Relationship and Dynamics

The presence of a child with disabilities can strain family relationships, leading to conflicts, resentment, and breakdown of families. Family members have a lot to share in this theme and it was really reflecting challenges associate with caring for children with disabilities as explained below.

Sister of a child with intellectual disability said.

> *"The more I grow the more responsibilities, I miss to be alone I must think about my sister all the time. They say it is my task to care for her but I have things to do and if I stop caring her only mother do that while she is tired. My cousins are not here every day, so I feel alone with my young sister I think a lot about her."*

Mother of a child with Albinism said.

> *"I love my child, but I stayed single for 5 years and take care of him alone, my husband left me the time I needed him a lot."*

Auntie of a child with deaf blind condition said.

> *"It was difficult to handle the child of my brother and my children, I supposed to put more attention to him and careless about my two children. I was the only person to take care of him because his mother left and my brother is too young still need to live his life without responsibilities, so I must take responsibilities, my husband complained before but now he supports me although it was not easy."*

The brother of a child with intellectual disability said.

> *"I used to hate my mother so much for prioritizing my sister and be with her everywhere because she was different, I was very loved and cared for but after her existence everything changed. Now after joining college, I understand that my sister is not normal and she is more vulnerable than the rest of the family, I am*

> *trying to forgive my mother and support my sister by taking her to school and make sure she is safe."*

A grandmother also said that,

> *"My daughter left her child with me since she was two months, the child was not normal and that is the reason why she left. Life is not easy with a child with disability, and we are old here we also need care; I wonder why she decide like that. Her child is in class 3 now and she is nowhere to be found."*

The experiences shared by the family members in this study highlight the significant impact that caring for a child with a disability can have on family relationships and dynamics. Caregivers often experience heightened levels of stress, anxiety, and depression due to the constant demands of caregiving. The physical demands of caregiving can lead to fatigue and burnout. Caregivers experience role strain as they balance caregiving responsibilities with other roles, such as wife and mother to other children. Siblings report to feel neglected, resentful and burdened with additional responsibilities. Grandparents called upon to provide care, which can impact their own health and well-being. Many participants were the victim of family breakdown although others survived it. Studies like Gray (2022) shows that families experience divorce soon after having a child with disability. Family breakdown threatening many caregivers. Social model of disability emphasizes systems to interplay while supporting children with disabilities and family is one of the primary systems to care aand support children with disabilities. If families disconnect then supportive environment will be unrealistic. It is crucial to provide comprehensive support services to families, including counseling, respite care and promoting social awareness. By understanding these factors, policymakers, healthcare providers, and community organizations can develop effective interventions to support families and improve the quality of life for children with disabilities and other family members.

4.3.3 Emotional Distress and Mental Health Issues

Families caring for children with disabilities often experience significant emotional distress and mental health issues. These challenges have many faces as per caregiver`s. They shared different areas on how emotional distress and mental health issues affect them.

Father of a child with intellectual and visual impairment said.

> *"It's a heavy burden to carry and I am a man who supposed to be strong, but it is not easy my child has many issues and as a poor parent it is stressful."*

Brother of a child with visual impairment said.

> *"Seeing my sibling struggle, feeling helpless, and knowing I can't take away their pain, it's a constant emotional drain. It's hard to stay positive sometimes."*

Mother of a child with Intellectual disability said.

> *"The fear of the unknown, the constant stress of providing care, and the guilt of not being able to do more, it's a heavy burden on my mental health. I often feel overwhelmed and alone."*

Grandmother of a child with Deaf condition said,

> *Growing up in the family with no person with disability, my grandchild bring a lot of impression every day we like to care for*

> *our grandchildren but this child look different and a lot has been going on until his age of five when all family members accept and agree to care for her. I was very sad most of the time because my daughter suffered a lot other than pressure from the family, she experienced burnout, guilt and blame.”.*

Aunty of a child with Intellectual disability said.

> *“The emotional rollercoaster of joy and sorrow, hope and despair, it's exhausting. I often feel like I'm on the verge of breaking point, my brother`s child taught me a lot about parenting especially because he looks different compared to others. Fears and uncertainty, sleepless nights and a lot of cries I will never forget."*

The experiences shared by these family members highlight the profound emotional clang that caring for a child with a disability can take. Caregivers experience many triggers to the point they feel alone. Uhuru Mchanganyiko is one of the old schools with inclusion practice but still parents struggle and have emotional distress caused by caring for children with different disabilities. Studies like REPSSI (2019) support the concept of stress and mental issues for families in South Africa. A social model of disability perspective offers a valuable framework for understanding this challenge and many factors attached to it. The social model emphasizes that disability is not solely a medical condition but rather a social construct. Societal barriers can significantly contribute to the emotional distress experienced by families. In the context of caring for a child with a disability. By adopting a social model approach and implementing its strategies towards reducing the emotional distress and mental health issues experienced by families caring for children with disabilities will be well handles.

4.3.4 Uncertainty and Fear for the Future

This is the state of anxiety and worry about what the future holds for a child with disabilities. This can be a significant source of neglect and psychological challenges. Family members explained a lot about this.

Father of the child with Deaf-blind condition said,

> *"Thinking about our child`s health condition it is impossible, we are coming from low-income family and this child demand extra medical care and assistive devices to support him. We are trying but in a long run his health complications, and the need for ongoing medical care. we don't know how to go about it."*

The Aunty of a child with Intellectual disability said,

> *"I am very worried about the future of this child. Will he become independent in his life? Although that is what am praying for, but the possibilities are uncertain. After finish Uhuru Mchanganyiko will he be able to get school to accommodate his need I don't know."*

Brother of a child with visual impairment condition said,

> *"We are very concerned about the social life and the ability to form friends and relationship many people don't know her unique ability to talk and share her views. At the family level she has many people whom she can talk to but moving outside our family people think a little different and we cant tell everyone if this is not true and this is true. My friends said that my young*

> *sister is different, I agree with them but that doesn't limit her from getting friends they have to understand and support her."*

Grandfather of a child with Intellectual disability said.

> *"As I am getting old and my daughter just left the child with us, what will happen to the child after we are no longer able to provide the needed care. This child needs someone to care very close because of the disability condition. Thinking about the future really my heart hurts."*

This uncertainty and fear can lead to significant emotional distress for families, affecting their mental health and overall well-being. The findings align with previous research on the psychological and emotional toll of caregiving for children with disabilities. According to studies by McConnell et al. (2017) and Firth et al. (2020), uncertainty about the future is a common source of stress for caregivers, particularly regarding their children's independence and social participation. This sense of uncertainty can lead to heightened anxiety and depression, negatively impacting the mental health of caregivers (Schumacher et al., 2020). The fear of not being able to meet the needs of a child with disabilities, especially as parents and caregivers age, is a concern often voiced in similar studies (Gougeon, 2019). The findings also suggest that without adequate support systems, such as financial aid, specialized services, and social support networks, these caregivers are left to cope with their anxiety and fears in isolation. As such, the findings call for interventions that can alleviate the uncertainty caregivers face by offering more accessible services, clear pathways for advocacy, and comprehensive long-term planning for children with disabilities and their families.

4.3.5 Limited Availability of Specialized Services

Family members report to experience shortage of specialized healthcare providers, therapists, and educators trained to work with children with disabilities. This result to a significant challenge for families, as it limits access to essential services and support when needed. Here are some of the consequences mentioned by family members with their children at Uhuru Mchanganyiko Primary. Mother of a child with visual impairment said.

> *"Delays in knowing why my child was behaving different led to the loss of vision. I trusted hospitals so much but after the experience with my child I have learned to trust God more."*

Mother of a child with albinism said.

> *"We have experienced poor quality of care, and they don't even have specialist to educate us about Albinism or maybe they were very busy to do that. I have learned about my child`s condition very late while I live close to the hospital. They assume we don't need to know, or we are okay with what we know but we are not. Due to that my child had wounds on the legs because of sun burn but am sure if we could get timely support then he could be fine."*

The Uncle of a child with intellectual disability explained.

> *"Burden to the family is very big as we care to a family member with disability, at least he is going to school although her mother has to follow close to every step. When she is at home extra care is needed. To get specialized doctor to assist her is very challenge."*

Father of a child with Deaf-blind condition said.

> *"I experience financial burden to meet the need of our child. I am not sure if the government is aware of all the expenses we are going through. We wish to get support to these expenses but if you depend on free items, they don't have quality at all."*

Findings reveal that family members report to experience limited access to specialized services while they care for children with special needs. This is a barrier for children with disabilities at Uhuru Mchanganyiko. Many families struggle to find qualified professionals, such as therapists, educators, and healthcare providers, who can provide the specialized care and support their children need. This lack of access lead to delayed interventions, reduced quality of life, and increased burden on families. Additionally, the cost of specialized services can be prohibitive for many families even those urban located ones, especially those living in poverty. These challenges highlight the urgent need for increased investment in the development of specialized services and support systems to ensure that children with disabilities have the opportunity to reach their full potential. These finding supported by report from the guardian News (2024) which said limited access to specialized health care services hinder the life of people with disabilities and their families. The social model of disability emphasizes that societal barriers, rather than individual impairments, are the primary cause of disability. For the matter of limited access to specialized services, social model highlights the role of systemic factors, such as inadequate infrastructure, discriminatory policies, and lack of awareness, in hindering the inclusion and participation of individuals with disabilities and for this matter then children with disability Jenny (2019). By focusing on removing these barriers, the social model advocates for creating a more inclusive society where everyone, regardless of their abilities, can access the services and support they need to thrive. This includes ensuring that specialized services are accessible, affordable, and culturally appropriate.

4.4 Accessibility of Existing Psychosocial Support Opportunities Available to Families Caring for Children with Disabilities

4.4.1 Awareness and Availability of Psychosocial Support Services

This study reveals that many families caring for children with disabilities are largely unaware of existing psychosocial support services or encounter geographic barriers that restrict their access. This lack of awareness often leads families to navigate their caregiving responsibilities alone, with minimal guidance. A mother of a child with an intellectual disability shared.

> *"I didn't even know that support groups existed until recently. We've been on our own for so long, trying to figure things out without any guidance. It's only by chance that I found out there might be services that could help us, but they're still too far away to reach easily."*

Similarly, a grandfather of a child with albinism added by saying that;

> *In our place, there's no one to explain what services are available, if any. We're told some help exists, but it's expensive. For us, traveling is a challenge, and we just don't have the resources to go back and forth, hoping for answers that may not even be there ocean road is far."*

Another participant who is Aunt of a child with intellectual disability said;

> *"I have looked everywhere to find a support group for families like ours, but they're so rare. It feels like the government isn't interested in making these resources accessible to people who are poor. We're left to struggle alone."*

Similar, a father of a child with physical disability:

> *"We don't hear about these services unless we meet someone who's been through it. There's no information or awareness here, and most of us don't even know where to start looking. It's as if they expect us to know things that are hidden."*

Many families caring for children with disabilities are either unaware of available psychosocial support services or face barriers to accessing them. This lack of awareness and availability leaves families feeling isolated, with limited guidance on how to seek help. Even when services exist, their concentration in urban centers creates a challenge for those in remote areas, who often cannot access the support they need. These reflections highlight a pressing need for increased outreach, particularly in rural and underserved areas where awareness is low. Similar studies, like those by Diva (2022) on mental health and psychosocial support in Africa, found that culturally sensitive community initiatives could increase access and reduce stigma. The Social Model of Disability further supports these findings, emphasizing the need for an inclusive societal approach that enhances service accessibility through structural and informational outreach (Antony, 2013). This finding underscores the need for greater outreach and information dissemination in the communities.

4.4.2 Affordability of the Services

This study found that many families struggle to afford psychosocial support services, and the high costs often mean families with lower incomes are left without vital support. A mother of a child with intellectual explained:

> *"Therapy sessions are so costly; we can't afford them regularly. It's heartbreaking to see that there's help out there, but only for people who have the money. Families like ours are left out, and my child misses out on the support they need to thrive."*

Similarly, Uncle of a child with visual impairment:

> *"We have to make tough choices every month. Do we pay for clinic or buy food? These services are essential, but they're priced like luxuries. There's no consideration for families with limited means, who end up sacrificing basic needs."*

Also, a grandmother of a child with intellectual disability:

> *"I'm on a pension, and there's no way I can afford extra help for my grandchild. We do our best at home, but without financial assistance, formal support remains just a dream. It's only those with money who can access the best services."*

Similarly, a father of a child with albinism:

> *"We've reached out to clinics for support, but it's always a matter of paying first for better service. It's painful to know that there are resources, but we're shut out simply because we don't have the means to pay upfront. It's a constant struggle."*

Financial barriers significantly hinder families' access to essential psychosocial support services, such as counseling and therapy. The high costs associated with these services create a divide, where only families with higher incomes can afford the support, their children need. This economic barrier leaves many families feeling helpless and excluded, as they must forgo potentially life-changing services due to cost constraints. This financial constraint is echoed in the National Guideline for PSS in Tanzania (2022), which emphasizes family-level support as a cost-effective alternative. The Social Model of Disability aligns with this finding by advocating for inclusive policies and financial support structures to ensure equitable access to services across income levels. Addressing affordability, through subsidies or financial assistance, would increase access to support services for families of all income levels.

4.4.3 Cultural and Social Stigma Around Disability and Support Seeking

The study found that cultural stigma around disability and seeking help poses another major barrier, leading families to avoid seeking formal support for fear of judgment or shame.

A mother of a child with an intellectual disability said:

> *"People around here think going to therapy is something to be ashamed of. I'm afraid to ask for help because of what others will say. They judge us, thinking it's our fault, and that keeps us from seeking the support we need."*

Similar; An aunt of a child with intellectual shared:

> *"In our community, people think disabilities are curses, and anyone who seeks help is looked down on. They don't understand what my*

> *nephew needs, and it makes us feel like outcasts just for trying to support him."*

Also, a grandfather of a child with deaf-blind disability said that;

> *"We avoid discussing our grandson's condition because people don't understand. They look at us differently, and it's a shame that even asking for help is seen as something to hide. Stigma has taken away our right to seek support openly."*

Similar; a father of a child with albinism said that;

> *"The community talks, saying that if we were better parents, we wouldn't need counseling. It's like they don't understand that disabilities aren't something anyone chooses. This stigma stops us from getting the support we really need."*

Cultural and social stigma surrounding disability and support-seeking behavior creates a significant barrier to families accessing psychosocial support. In many communities, seeking help is viewed as shameful or indicative of personal failure, preventing families from obtaining the necessary support for their children. This stigma results in isolation, as families avoid public discussions about disabilities to escape judgment. The social stigma that accompanies disabilities can deter families from accessing crucial services. Studies, such as Diva (2022), confirm the value of culturally informed approaches to mitigate stigma. The Social Model of Disability addresses this need by encouraging changes in societal attitudes and increasing public awareness, thus creating a supportive environment for families and children with disabilities. Increased education and community awareness are essential to reduce stigma, creating a more accepting environment that encourages families to access support.

4.4.4 Quality and Suitability of Available Services

The quality of available services is often insufficient, as families find that professionals lack the necessary training to address the specific needs of children with disabilities. A mother of a child with a deaf blind noted

> *"We tried counseling, but the staff didn't understand our challenges. They weren't trained for families like ours, and it felt like they were just going through the motions without addressing what we really needed, they generalize everything."*

Similar, a grandmother of a child with intellectual:

> *"The few services that are available don't always understand intellectual disability. It's frustrating because we leave feeling more confused. We need specialized help, but what's offered doesn't fit our specific situation."*

Also, another participant of a child with albinism quoted said that;

> *"It seems like these services are for general issues, not for families like ours with unique needs. They don't give us practical advice on what to do. It's disappointing to go for help and feel misunderstood."*

Similar another participant of a child with intellectual disability said that:

> *"We've tried to access support, but they don't really understand disabilities. It feels impersonal, like a one-size-fits-all service, and they miss out on the real issues we face every day."*

Families feel that the quality and suitability of available psychosocial support services often fall short, as these services are not adequately tailored to meet the unique needs of children with disabilities. This disconnects between families' needs and the support offered leads to frustration, with families feeling misunderstood or overlooked by professionals. This highlights the need for specialized training to make services relevant to families' needs. The Social Model of Disability supports this by advocating for specialized and adaptable support that addresses specific disabilities. Empirical studies also support the call for professional training tailored to unique family situations (Antony, 2013). Addressing these concerns would require better training for support providers, enabling them to provide more specialized and empathetic assistance that resonates with families' lived experiences.

4.4.5 Informal Support Networks as a Supplement to Formal Services

In the absence of accessible formal support, families often rely on informal networks of extended family and friends to meet emotional and practical needs. A mother of a child with an intellectual disability expressed:

> *"Without the help of my sisters and parents, I don't know how I'd manage. They're there when things get tough, offering the support that formal services can't provide, even though it's not always enough."*

Similar, another participant quoted said that;

> *"Our family and neighbors have been the only support we have. We lean on each other for strength, even if it's not professional help. It fills a gap but doesn't solve everything we thank God."*

Similar, another participant who is Aunt of a child with albinism said that:

> *"We've become our own support system. The family comes together to give my niece what she needs because formal help is out of reach. Still, it's tiring and not sustainable without other resources."*

Sibling of a child with deaf-blind also said that

> *"Friends and family pitch in whenever they can. It's not the same as getting real support, but we have no choice. We just do the best we can with what we have around us."*

In the absence of accessible formal support, families rely heavily on informal support networks, drawing on the help of extended family and friends. While this informal support is invaluable, it is not a substitute for professional psychosocial services. These networks provide critical emotional and practical assistance, yet families express that relying solely on informal help is insufficient and unsustainable in the long term. While these informal networks are invaluable, they are not sustainable or sufficient for long-term support. This finding aligns with the Social Model of Disability, which emphasizes the importance of formal support structures. Studies, including Tanzania's PSS guidelines (2022), affirm the importance of incorporating informal networks alongside formal services to build a comprehensive support system. Enhancing formal support services would help alleviate the pressure on families and allow for more comprehensive care and assistance for children with disabilities.

4.5 Evidence based Psychosocial Support Interventions for Families Caring Children with Disabilities

The findings presented in this section were obtained through in-depth interviews with parents, grandmothers, fathers, and extended family members, such as uncles and aunts, who are actively involved in caring for children with disabilities. These findings have been organized thematically to highlight the evidence-based psychosocial support interventions for families with children with disabilities.

4.5.1 Psychological Counseling

The study revealed that counseling sessions offered the parents and guardians who live with children with disability a safe space to share their struggles, receive guidance, and find comfort among others with similar experiences. Parents often expressed that, without this support, they would feel overwhelmed and isolated in their roles as caregivers. Here are some of their reflections. During interview a father of a child with an intellectual disability said that;

> *"Having a child with an intellectual disability brings constant worry. Counseling sessions have helped me understand that I'm not alone, and I don't have to carry this weight by myself. Hearing from others with similar challenges has been uplifting, but sometimes I still wish we had more opportunities for regular sessions."*

The grandmother of a child with albinism shared her perspective:

> *For us as grandparents, it's been challenging. We never expected our grandson to be born with albinism, and it came as a shock to the entire family. Counseling helped us accept him for who he is and taught us ways to protect him, especially from social*

> *stigma. It's been a relief to have social worker at the hospital who help us."*

Another participant who is a mother of blind child said that;

> *"When my son lost his vision, I felt like I failed him as a mother. Counseling has allowed me to express these fears without judgment. Talking to someone has given me strength, though sometimes it's still hard to cope with his needs and my own feelings."*

Additionally, an uncle of a child with deaf blindness expressed his thoughts;

> *"My niece has deaf-blindness, and it's like we are living in two worlds. The counselor helped me understand her way of seeing things, even though she cannot see or hear. The sessions taught us how to communicate with her through touch and simple signals. This has improved our bond."*

Another participant, a father of a child with an intellectual disability, shared his perspective

> *"Living in a busy community, we had very few people who understood our struggles. Having someone listen to us and guide us has been invaluable. Our family has benefited from counseling, and we've come a long way in accepting our son's disability."*

The findings above revealed that psychological counseling serves as a crucial support system for families caring for children with disabilities, addressing the emotional and mental health needs of parents, grandparents, and extended family members. This insight concurs the study by Mwale (2019) demonstrates that parents often endure significant psychological burdens, and this research corroborates that counseling serves as a crucial intervention. The caregivers' experiences of finding relief and connection through counseling resonate with Douma’s (2020) assertion that psychosocial interventions effectively address emotional needs. This aligns with the Social Model's emphasis on changing societal attitudes and structures that contribute to caregiver distress, thus promoting a more supportive environment for families.

4.5.2 Peer Support Groups

Peer support groups were highlighted by participants as a vital source of comfort and strength. Families emphasized that connecting with others who understand their unique challenges reduced feelings of isolation and provided an outlet for sharing both struggles and successes. Many caregivers found that these groups helped them view their children’s disabilities in a more positive light. Below are some reflections from participants:

One mother expressed deep appreciation for the empathy and understanding she found within her support group:

> *"Joining a support group at the hospital we go for clinic has been a blessing. Hearing stories from other parents who are also raising children with disabilities gives me hope. It’s a place where I feel understood, especially when sharing challenges others don’t always see."*

A grandfather described how the group helped him feel included and provided him with ways to support his family:

> *"We grandparents sometimes feel left out. But these groups have shown us that we are part of the journey, too. We share ideas on how to support our grandchildren without overburdening their parents. It's a unique space where we feel heard."*

Another parent shared how attending support group meetings strengthened both his marriage and his perspective on his child's abilities:

> *"My wife and I go together to the meetings, and it's been good for our marriage. We've learned to support each other through the difficult days. Talking to others who understand helps me see my child's potential, rather than just the disability."*

An aunt shared how connecting with others helped her cope with the feelings of isolation in caring for her niece with deaf-blindness:

> *"I have a niece who is deaf-blind, and it's easy to feel like no one understands the isolation we experience. But in our support group, I met others who shared similar challenges. It's a relief knowing I'm not alone in this."*

A mother of a child with intellectual disability spoke about how the group provided a judgment-free space to express her feelings:

> *"Sometimes I feel like there's a wall between me and other parents. But in the support group, there's no judgment. We laugh, we cry, and we give each other courage to continue caring for our children, even on tough days."*

The findings indicate that peer support groups play a vital role in providing emotional relief, shared understanding, and empowerment for families of children with disabilities. These groups create a sense of community, allowing family members to connect with others who truly understand their challenges. The emergence of peer support groups as a vital psychosocial intervention concurs with the Social Model that focus on community and social networks. Participants' experiences of connecting with others facing similar challenges reflect the literature indicating that such networks enhance emotional well-being (Douma, 2020). The model encourages the dismantling of isolation through community engagement, aligning with the identified need for general support structures that foster these peer connections in Tanzania. From an observation parents and caregivers were very happy to express about group and how they are very helpful

4.5.3 Community Awareness Programs

Many caregivers shared that community awareness initiatives have played a critical role in transforming how their children are perceived and treated. These programs have fostered positive changes in some community attitudes, reducing stigma and fostering a more inclusive environment for children with disabilities. Here are reflections from caregivers on the impact of these programs. A father of a child with albinism expressed relief at the change in community attitudes toward his son:

> *"Raising a child with albinism, I fear for his safety. Community awareness programs have helped reduce misconceptions about his condition. People are starting to accept him as part of the community rather than seeing him as a bad luck."*

One mother highlighted the shift in community support for her blind child after attending local awareness programs by one of NGO:

> *"At first, people didn't understand my child's blindness, thinking it was a curse. After awareness programs, there's been a positive change. Neighbors have become more supportive, and I don't feel as alone in this."*

An uncle shared how awareness initiatives have helped his nephew, who is deaf-blind, gain acceptance and a sense of safety within the community:

> *"Programs that educate others about disabilities are life-changing. As an uncle to a boy with deaf-blindness, I can see how the community has become more accepting. My nephew can now play safely with other children."*

A mother of a child with an intellectual disability spoke about how community awareness has also strengthened family support:

> *"It took some time, but the awareness programs have helped my parents understand that my child's disability is not their fault. They're more supportive now, and it's strengthened our family."*

Another father reflected on the transformation in his village's attitudes toward his daughter with albinism:

> *"The village used to treat my daughter with albinism as an outsider. After several meetings and education sessions, she is now accepted, and people have learned to treat her with respect. It's made such a difference for us."*

The findings reveal that community awareness programs are essential for reshaping public perceptions of disabilities and fostering an inclusive environment for families of children with disabilities. The transformative effect of community awareness programs is critical in reshaping societal perceptions of disabilities. As Mwale (2019) noted, these initiatives play a significant role in reducing stigma and promoting inclusivity. The caregivers’ narratives affirm that increased community awareness fortifies families' support systems, aligning with the Social Model's goal of creating a more inclusive society where barriers are dismantled, allowing for greater acceptance and support (United Nations, 2008).

4.5.4 Parental Training Programs

Participants in this study emphasized the transformative impact of parental training programs on their caregiving abilities. These programs not only empowered parents and relatives with practical skills but also boosted their confidence in handling daily challenges. Below are insights shared by caregivers who benefited from such training. A father caring for his deaf-blind son reflected on how the training gave him essential tools and confidence in managing his son’s needs:

> *"Learning how to care for my son’s needs was overwhelming. Training sessions have given me tools I didn’t have before from communication techniques to basic medical care. It’s empowering as a parent."*

A mother described how training programs improved her ability to understand and manage her son’s behavior:

> *"As a mother, I used to struggle with my son’s behavior. The training programs taught me strategies to handle his outbursts and engage him better. Now, I feel more capable of understanding his needs."*

Another mother shared the relief and confidence she gained from learning how to protect her child with albinism from sun exposure:

> *"They trained us on how to ensure our child with albinism is safe from harmful sun exposure. It may seem small, but it's been life-changing for us, and we feel more confident as parents."*

A father expressed his gratitude for learning specialized communication methods to connect with his blind daughter:

> *"I didn't know how to communicate with my blind child. The training at Uhuru Mchanganyiko gave me new techniques, like tactile signs and creating routines, so she feels secure. These skills have made parenting easier."*

A grandfather spoke about how the training enabled him to support his grandchild with an intellectual disability in a meaningful way:

> *"Through the sessions, I learned how to calm my grandchild with an intellectual disability and help him focus. I'm glad I can be there for him in ways I never thought possible."*

The findings underscore the significant benefits of parental training programs, which empower caregivers with essential skills and knowledge to effectively support their children with disabilities. The profound impact of parental training programs on caregivers' abilities to support their children reflects the model's advocacy for skill development and empowerment. This finding is consistent with Mwale (2019), who emphasized that structured training enhances caregivers' confidence and efficacy. By equipping families with practical skills, these programs address the societal barriers identified by the Social Model, empowering families to navigate their unique challenges effectively.

4.5.5 Educational and Inclusive Schooling Opportunities

Parents and caregivers reported that gaining access to educational and inclusive schooling opportunities was crucial for their children's development. These experiences not only provided children with a sense of belonging but also empowered families to advocate for their rights within the education system. Below are reflections from caregivers about their experiences with inclusive education. A mother shared her journey of advocating for her blind daughter’s education and the positive impact of inclusive schooling at Uhuru:

> *"We had to fight to get our daughter with blindness enrolled at Uhuru. The training on advocacy gave us the confidence to demand her rights, and now she’s thriving in an inclusive classroom level three."*

A father expressed his joy at seeing his son with an intellectual disability included in school activities:

> *"My son, who has an intellectual disability, was often left out. But with support from coordinator for inclusive programs, he’s now learning and making friends. It’s a joy seeing him included."*

An aunt reflected on her niece's educational journey and the transformation it brought to their family`s outlook:

> *"Having a niece with visual impairment, I always feared for her future. But now, she’s in school and excelling. Education has changed our perspective on what she can achieve."*

A father noted the significance of advocacy training in securing an appropriate educational setting for his deaf-blind child:

> *"We were trained on how to advocate for our child with deaf blindness. Now, he attends a school that respects his needs, and we can see his confidence growing every day."*

A mother emphasized the transformative power of education and supportive programs for her son with albinism:

> *"Education has made all the difference. The programs at Uhuru helped us get our son with albinism into a supportive school, and his progress has been amazing."*

The findings highlight the critical importance of educational and inclusive schooling opportunities in fostering the development and well-being of children with disabilities. Caregivers emphasized that access to inclusive educational programs not only facilitates academic learning but also nurtures social connections and self-esteem among children. Access to quality education for children with disabilities is crucial, as indicated by participants in this study. The findings reflect a growing consensus in the literature about the importance of educational inclusion in promoting acceptance and empowerment among children with disabilities. By advocating for inclusive policies and training caregivers to engage proactively with the education system, the study highlights a shift towards removing barriers in educational contexts, echoing the Social Model's emphasis on societal change (Armstrong, 2015). The sense of belonging significantly impacts the families' outlook, instilling hope and changing perceptions about the potential achievements of their children.

CHAPTER FIVE

SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.1 Overview

This chapter presents an overview, summary, conclusion, and recommendations of the study.

5.2 Summary of the Findings

This study revealed a range of psychosocial support challenges faced by families caring for children with disabilities, revealing deeply rooted issues related to stigma, family dynamics, emotional distress, future uncertainties, and limited access to specialized services. Social stigma and discrimination are major barriers, as families experience isolation and judgment from communities and even close relatives, making it difficult to seek support or connect with others. Family relationships are often strained, with caregivers experiencing resentment, role strain, and, in some cases, family breakdowns. The ongoing care responsibilities result in high levels of emotional distress, including anxiety, guilt, and burnout among caregivers. Families also experience significant uncertainty and fear for the child’s future, given the demanding medical and social needs. Additionally, there is a severe shortage of specialized services, including trained healthcare professionals and educators, limiting children’s access to essential care and support. These findings underscore the need for more awareness, inclusive policies, and dedicated resources to alleviate the challenges faced by families, with a strong emphasis on societal and systemic support through the social model of disability.

Furthermore, the study reveals significant barriers to accessing psychosocial support services for families caring for children with disabilities, highlighting issues related to awareness, affordability, stigma, quality, and reliance on informal networks. Many families are unaware of available services or are hindered by geographical and financial constraints, leaving them isolated and without adequate support. Cultural stigma around disabilities and seeking help adds to this isolation, as families often avoid formal services due to fear of judgment. Even when services are available, their quality is often poor, with a need for specialized training to meet the unique needs of these children. As a result, families increasingly depend on informal networks of friends and extended family for support, though these networks are insufficient for long-term needs. The Social Model of Disability underscores the need for inclusive societal structures and improved outreach to ensure that families receive accessible, affordable, and culturally sensitive services, while recognizing the complementary role of informal support networks.

In the other hand, the findings reveal a range of psychosocial support interventions that empower families caring for children with disabilities. Psychological counseling emerged as a vital support, offering caregivers a safe space to express fears and find relief from isolation. Participants, including parents, grandparents, and extended family members, expressed that counseling helps them manage emotional struggles and fosters acceptance of their child’s needs. Peer support groups also provide a sense of community and reduce isolation, enabling caregivers to share experiences and gain encouragement. Community awareness programs were found to positively influence public attitudes, decreasing stigma and fostering inclusivity. Parental training programs empower caregivers by equipping them with practical skills for managing disabilities, boosting confidence, and enhancing caregiving abilities. Finally, access to inclusive education was identified as essential for children's development, providing social connections, academic growth, and enabling caregivers to advocate for educational rights. Together, these interventions contribute to dismantling societal barriers, fostering a supportive environment, and aligning with the Social Model's emphasis on societal and attitudinal change.

5.3 Conclusion

In conclusion, this study sheds light on the complex psychosocial challenges that families face while caring for children with disabilities, marked by stigma, strained family dynamics, emotional burdens, and insufficient support services. The unescapable social stigma and discrimination not only isolate these families from their communities but also add to the strain within family relationships, often leading to role strain and, in severe cases, family breakdowns. Caregivers face heightened emotional distress, including anxiety and burnout, due to their continuous caregiving responsibilities and fears surrounding the future. These challenges are caused by a shortage of specialized services, including trained healthcare professionals and educators, which hinders children’s access to necessary care and support.

Moreover, the study highlights significant barriers in accessing psychosocial support services, which are compounded by limited awareness, affordability concerns, cultural stigma, and inadequate service quality. Families often remain unaware of available services and lack the resources to access them, which further isolates them and deprives them of essential support. Even when services are available, their quality is frequently insufficient due to a lack of specialized training to cater to the unique needs of children with disabilities. Consequently, families increasingly turn to informal networks of friends and extended family for support; however, these networks are rarely sufficient to meet their long-term needs. The findings underscore the need for inclusive societal structures that can provide accessible, affordable, and culturally sensitive services, aligning with the Social Model of Disability to address systemic barriers.

Finally, the study identifies a range of psychosocial support interventions that can empower families and help them cope more effectively with their caregiving responsibilities. Key interventions include psychological counseling, peer support groups, community awareness programs, parental training, and inclusive education. These resources provide caregivers with emotional support, skills for managing disabilities, and a sense of community that helps reduce isolation. Additionally, access to inclusive education not only benefits children academically but also supports caregivers by providing a platform for advocacy and social inclusion. Together, these interventions contribute to dismantling societal barriers and fostering an environment that aligns with the Social Model of Disability, promoting societal and attitudinal change to better support families and their children with disabilities.

5.4 Recommendations of the Study

5.4.1 Recommendations for Government

Based on these findings, it is recommended that the government prioritize policies and programs that enhance psychosocial support services for families of children with disabilities. This could include increasing funding for specialized healthcare and educational services, ensuring that these services are accessible and affordable for families regardless of geographical or economic barriers. Implementing nationwide awareness campaigns would also be beneficial to reduce stigma and promote inclusivity, helping communities understand and support the unique needs of these families. Additionally, the government should invest in training healthcare and education professionals on disability-specific needs, which would enhance the quality of services and improve outcomes for children. Integrating the Social Model of Disability into policy frameworks would further strengthen these efforts, emphasizing systemic changes that remove barriers and foster a more inclusive environment for all families.

5.4.2 Recommendations for Best Practice

For best practices, institutions and organizations providing psychosocial support are encouraged to adopt comprehensive, family-centered approaches. Establishing peer support groups and psychological counseling services within communities can offer caregivers a much-needed support network, reducing isolation and enabling shared learning and encouragement among families facing similar challenges. Programs that provide parental training can empower caregivers with practical skills and confidence, equipping them to manage their child’s needs more effectively. Inclusive education programs should be actively promoted and supported, as they offer social and academic benefits for children with disabilities while fostering advocacy opportunities for their caregivers. Lastly, building strong partnerships between formal support services and informal community networks can create a sustainable support system, ensuring that families receive both professional and community-based assistance in managing the complexities of disability care.

5.5 Areas for Further Studies

The focus of the current study was on psychosocial support for families caring for children with disabilities in Tanzania: A case of uhuru mchanganyiko primary school, where it examined the challenges, accessibility of opportunities and interventions available to these families. Areas for further studies could explore the long-term effects of psychosocial support interventions on the well-being of both caregivers and children with disabilities, providing insights into how sustained support impacts family dynamics and caregiver resilience. Another area could examine the effectiveness of inclusive education in promoting social acceptance and reducing stigma for children with disabilities within different cultural contexts. Research could also focus on the role of informal support networks, such as community and faith-based groups, in supplementing formal psychosocial services for families.

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APPENDICES

Appendix I: Interview Guide to Families Caring Children with Disabilities

Dear Participant,

I am Faudhia Ramadhani Kitenge, a student pursuing Master's degree in Social Work at the Open University of Tanzania. I am currently conducting research titled: "Psychosocial Support for Families Caring Children with Disabilities in Tanzania a case of Uhuru Mchanganyiko Primary School". I kindly request you to take a few moments to discuss with me in this interview by providing the relevant required information. Please be assured that all information provided will be held confidentially and will be used only for research purposes.

Guiding Questions

I. In one sentence can you tell me how did you felt the first time after realizing your child/ children have a disability?

II. Based on your experience as a caregiver for children with disabilities, what are the major PSS challenges faced at home?

III. From your interactions with the community and school, what are the PSS challenges experienced as caregiver of children with disabilities?

IV. Are you aware of PSS opportunities available for families' caring children with disabilities in Tanzania?

V. In your opinion which opportunities are very close and easily available to your family?

VI. What are the PSS opportunities that are very important but not available to your family?

VII. in your family How do you think Psychological and social issues are handled?

VIII. What are some of the long-term benefits your family experience after having a child/ Children with disability which you think it`s souse was designed by government or other institutions?

IX. Which interventions you think are very important to support your family`s Psychosocial wellbeing but they cannot be easily accessed?

X. Do you have any recommendation to other families caring children with disability or to Government and non-Government entities supporting PSS wellbeing of families caring children with disabilities?

Kiambatisho I: Muongozo Wa Majadiliano Kwa Familia Zinazolea Watoto Wenye Ulemavu

Mpendwa mshiriki,

Jina langu ni Faudhia Ramadhani Kitenge, mwanafunzi wa ngazi ya shahada ya uzamili kwenye social work kutoka chuo kikuu huria cha Tanzania. Kwasasa nafanya utafiti kwenye mada: "Msaada wa kisaikolojia na kijamii kwa familia zinazolea Watoto wenye ulemavu nchini Tanzania, eneo la utafiti ni Shule ya msingi Uhuru Mchanganyiko ". Nakuomba muda wako kuweza kujadili na kutoa taarifa zinazohusiana na mada na zilizo sahihi. Tafadhali kuwa na uhakika kwamba taarifa zote utakazotoa zitatunzwa kwenye usiri na zitatumika kwa madhumuni ya utafiti pekee.

Maswali ya muongozo

I. Unaweza kuniambia namna ulivyohisi mara baada ya kujua mtoto/Watoto wako ana ulemavu?

II. Kutokana na uzoefu wako kama mlezi unaelea mtoto mwenye ulemavu, ni changamoto gani kubwa unakutana nazo nyumbani?

III. Kutokana na kujumuika kwako na jamii Pamoja na shule, ni changamoto zipi unazipitia kama mlezi wa Watoto wenye ulemavu?

IV. Je unauelewa wa fursa za huduma za kisaikolojia na kijamii zinazopatikana kwa familia zinazolea Watoto wenye ulemavu Tanzania?

V. Kwa maoni yako ni fursa zipi za kijamii na kisaikolojia zipo karibu na zinapatikana kirahisi na familia yako?

VI. Ni fursa zipi za kisaikolojia na kijamii ambazo ni muhimu sana lakini hazipatikani kwenye familia yako?

VII. Ni kwa namna gani unahisi masuala ya kisaikolojia na kijamii wanatatuliwa kwenye familia yako?

VIII. Ni faida gani za muda mrefu ambazo familia yako imezipitia baada ya kuwa na mtoto/Watoto mwenye ulemavu ambazo unadhani chanzo chake kimetengenezwa na serikali au taasisi zingine?

IX. Ni afua zipi unadhani zina umuhimu kwenye kuisaidia familia yako kisaikolojia na kijamii lakini hazipatikani kiurahisi?

X. Je unamapendekezo yoyote kwa fanilia nyingine zinazolea Watoto wenye ulemavu au kwa serikali na taasisi nyingine binafsi zinazosaidia kijamii na kisaikolojia ustawi wa familia zinazolea Watoto wenye ulemavu?

Appendix II: Observation guide

In this study researcher will focus attention to the following areas:

i. Actions of children and the caregivers
ii. Reactions of children and the caregivers
iii. General environment of the family and interaction of family members.

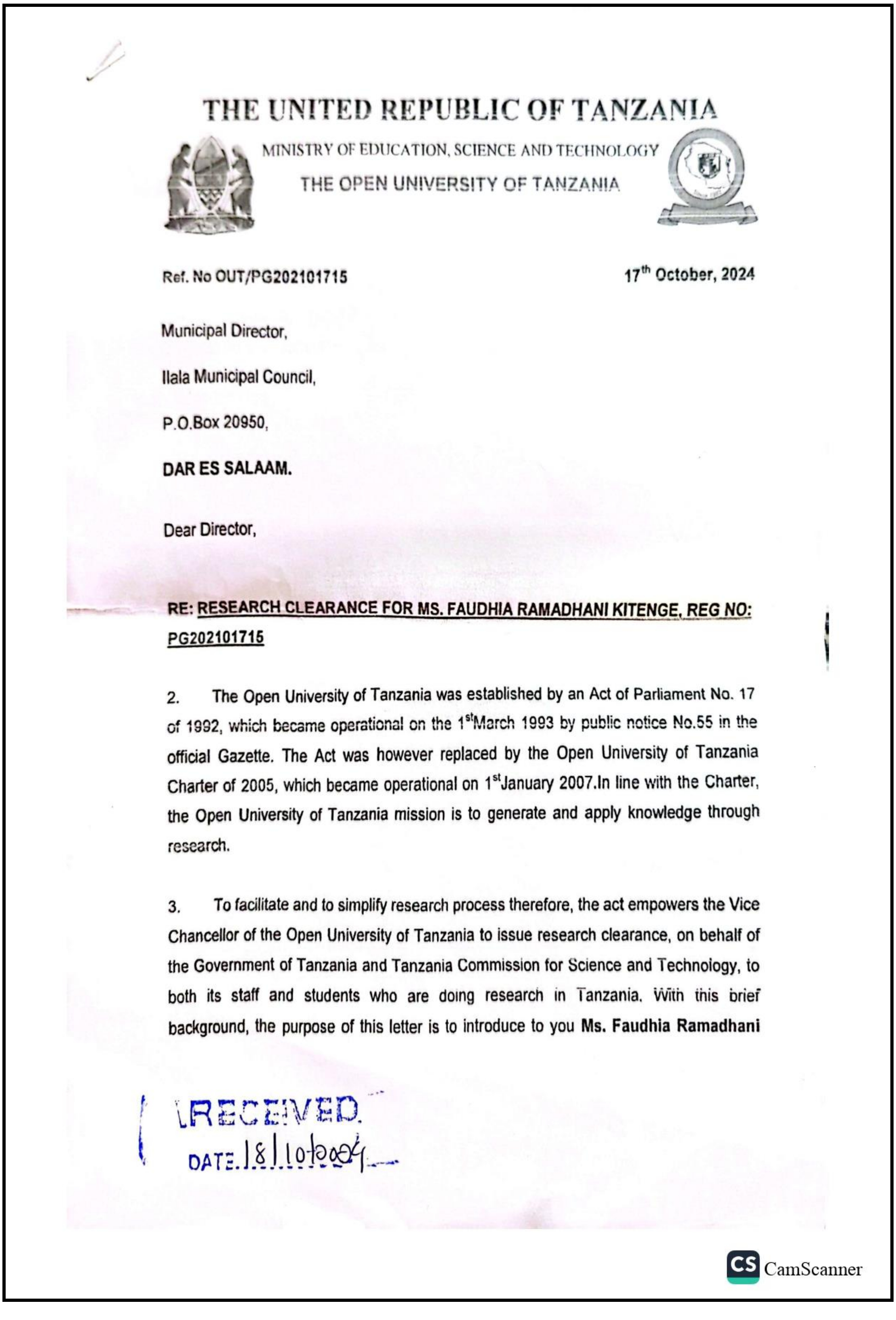
Appendix III: Research Work Plan

Activity	Month	December 2023 January				May-July 2024				August 2024				September 2024				November-2024				January-2024				March-2024			
	Week	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
Title selection		🟨																											
Concept note writing and submission			🟦	🟦	🟦																								
Proposal writing and submission						🟧	🟧	🟧	🟧																				
Proposal Defense										🟪																			
Data collection										🟧	🟧	🟧	🟧																
Data entry and analysis of findings														🟦	🟦	🟦	🟦												
Report																		🟩	🟩	🟩	🟩								

writing and submission																	🟩	🟩	🟩	🟩								
Final Dissertation Defense and submission																					🟨	🟨	🟨	🟨				
Dissertation and manuscript publication																									▨	▨	▨	▨

Appendix IV: Budget Size and Break-down Estimates

Activities	**Tentative Budget**
1.**Stationary**	Costs (Tshs)
Flash disc 1	30,000
Printing, photocopies	150,000
Sub total	**180,000**
2.Internet	Costs (Tshs)
Airtime Bundle	100,000
Sub total	**100,000**
3.Field activities	Costs (Tshs)
Meal allowance 52 days @ 5000	260,000
Transport allowance	110,000
Sub total	**370,000**
4.Reporting writing	Costs (Tshs)
Meal allowance 21days @ 5000	105,000
Spira Binding 4 copies @30000	120,000
Black Book Binding 4 copies @50000	200,000
Publication	800,000
Overheads	150,000
Subtotal	**1,375.000**
Grand Total	2,025,000



THE UNITED REPUBLIC OF TANZANIA
MINISTRY OF EDUCATION, SCIENCE AND TECHNOLOGY
THE OPEN UNIVERSITY OF TANZANIA

Ref. No OUT/PG202101715 17th October, 2024

Municipal Director,

Ilala Municipal Council,

P.O.Box 20950,

DAR ES SALAAM.

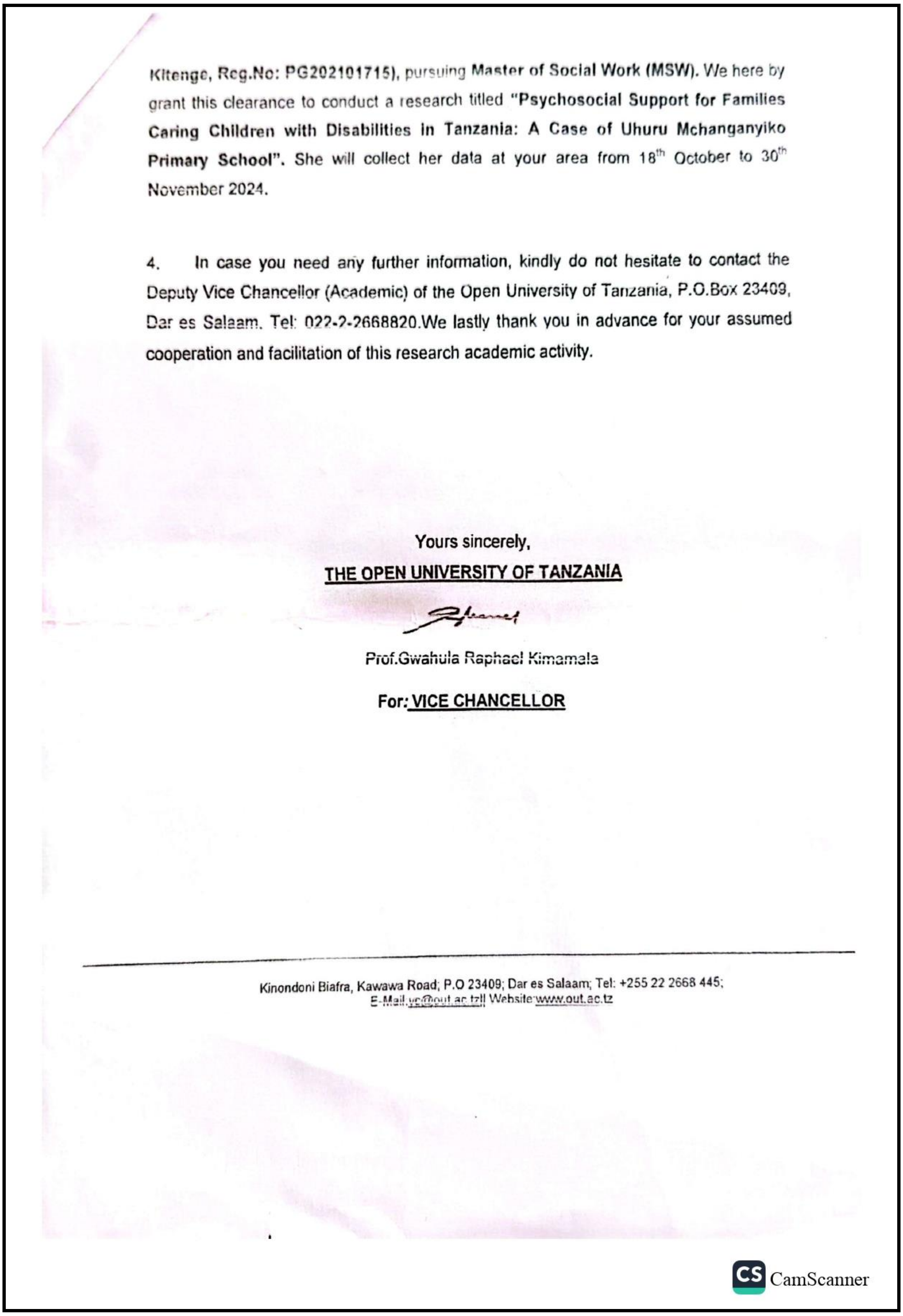
Dear Director,

RE: RESEARCH CLEARANCE FOR MS. FAUDHIA RAMADHANI KITENGE, REG NO: PG202101715

2. The Open University of Tanzania was established by an Act of Parliament No. 17 of 1992, which became operational on the 1st March 1993 by public notice No.55 in the official Gazette. The Act was however replaced by the Open University of Tanzania Charter of 2005, which became operational on 1st January 2007.In line with the Charter, the Open University of Tanzania mission is to generate and apply knowledge through research.

3. To facilitate and to simplify research process therefore, the act empowers the Vice Chancellor of the Open University of Tanzania to issue research clearance, on behalf of the Government of Tanzania and Tanzania Commission for Science and Technology, to both its staff and students who are doing research in Tanzania. With this brief background, the purpose of this letter is to introduce to you **Ms. Faudhia Ramadhani**

RECEIVED
DATE: 18/10/2024



Kitenge, Reg.No: PG202101715), pursuing **Master of Social Work (MSW).** We here by grant this clearance to conduct a research titled **"Psychosocial Support for Families Caring Children with Disabilities in Tanzania: A Case of Uhuru Mchanganyiko Primary School".** She will collect her data at your area from 18th October to 30th November 2024.

4. In case you need any further information, kindly do not hesitate to contact the Deputy Vice Chancellor (Academic) of the Open University of Tanzania, P.O.Box 23409, Dar es Salaam. Tel: 022-2-2668820.We lastly thank you in advance for your assumed cooperation and facilitation of this research academic activity.

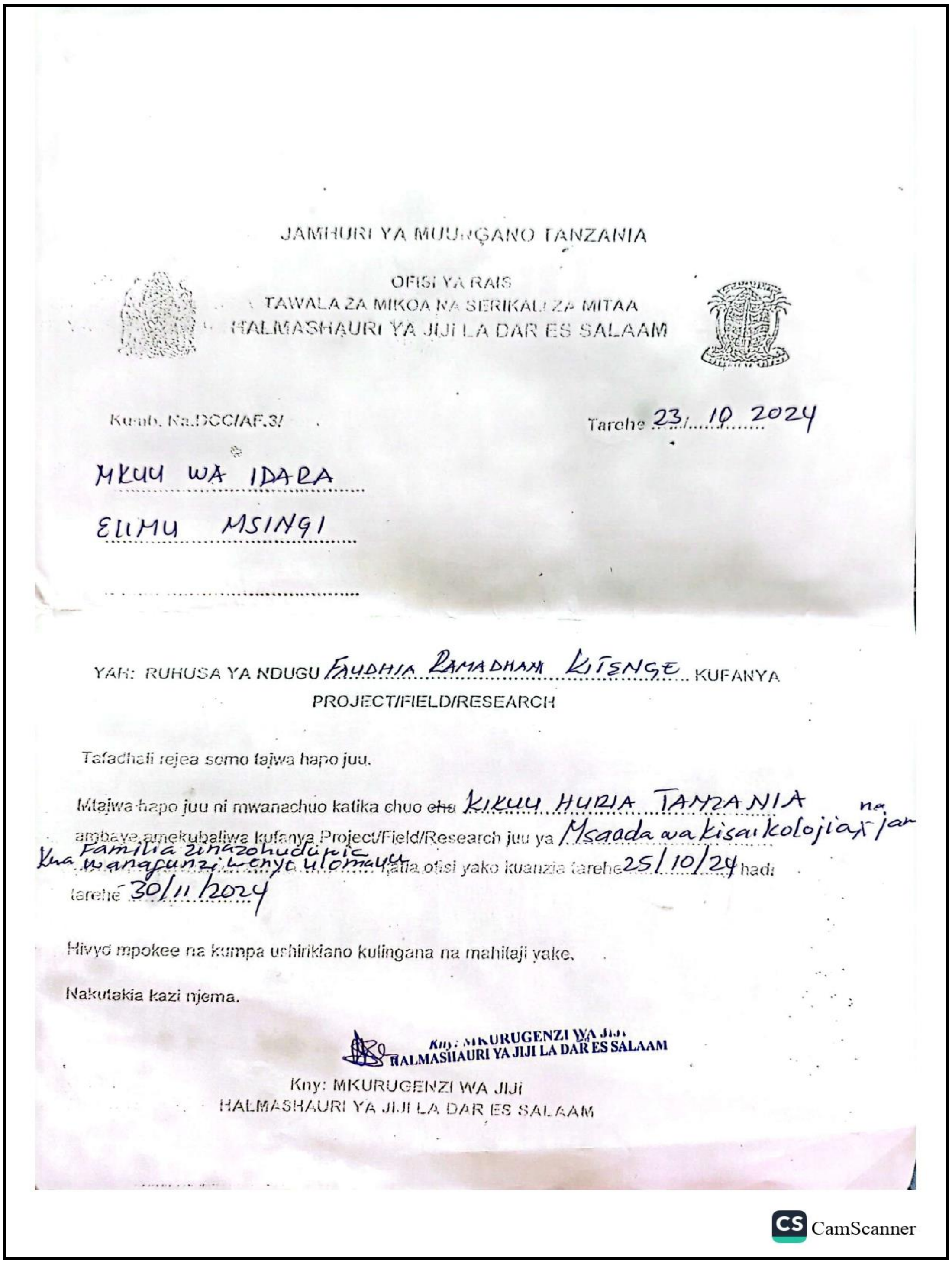
Yours sincerely,

THE OPEN UNIVERSITY OF TANZANIA

Prof.Gwahula Raphael Kimamala

For: VICE CHANCELLOR

Kinondoni Biafra, Kawawa Road; P.O 23409; Dar es Salaam; Tel: +255 22 2668 445;
E-Mail:vc@out.ac.tz|| Website:www.out.ac.tz



JAMHURI YA MUUNGANO TANZANIA

OFISI YA RAIS
TAWALA ZA MIKOA NA SERIKALI ZA MITAA
HALMASHAURI YA JIJI LA DAR ES SALAAM

Kumb. Na.DCC/AF.3/ Tarehe 23/10 2024

MKUU WA IDARA
ELIMU MSINGI
....

YAH: RUHUSA YA NDUGU FAUDHIA RAMADHANI KITENGE KUFANYA PROJECT/FIELD/RESEARCH

Tafadhali rejea somo tajwa hapo juu.

Mtajwa hapo juu ni mwanachuo katika chuo ~~cha~~ KIKUU HURIA TANZANIA na ambaye amekubaliwa kufanya Project/Field/Research juu ya Msaada wa kisaikolojia [illegible] kwa familia zinazohudumia wanafunzi wenye ulemavu katia ofisi yako kuanzia tarehe 25/10/24 hadi tarehe 30/11/2024

Hivyo mpokee na kumpa ushirikiano kulingana na mahitaji yake.

Nakutakia kazi njema.

Kny: MKURUGENZI WA JIJI
HALMASHAURI YA JIJI LA DAR ES SALAAM

Kny: MKURUGENZI WA JIJI
HALMASHAURI YA JIJI LA DAR ES SALAAM

IDENTIFYING THE PSYCHOSOCIAL SUPPORT CHALLENGES EXPERIENCED BY FAMILIES CARING FOR CHILDREN WITH DISABILITIES IN TANZANIA: A CASE OF UHURU MCHANGANYIKO PRIMARY SCHOOL

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Corresponding Author: Faudhia Kitenge

kitengefaudhia@gmail.com

Lecturer: Department of Sociology and Social Work (SOSW), Faculty of Arts and Social Science (FASS), The Open University of Tanzania (OUT), P.O.Box 23409, Dar es salaam, Tanzania.

ABSTRACT

This study aimed to explore psychosocial support challenges experienced by families caring for children with disabilities in Tanzania: a case of Uhuru Mchanganyiko primary school. Using a qualitative approach, underpinned by an interpretivist philosophy. The study design followed a case study approach. Data were collected from 36 participants of 12 families using purposive sampling, and a combination of interviews and non-participatory observation was employed. The study guided by social model of disability which revealed that disability is believed to result from a mismatch between people and their surroundings. The study findings highlights significant psychosocial support challenges faced by families, including social stigma, emotional distress, strained family relationships, role strain, and a lack of access to specialized services. Based on these findings, it is recommended that the government prioritize policies and programs that enhance national wide awareness campaigns which would be beneficial to reduce stigma and promote inclusivity, helping communities understand and support the unique needs of families caring for children with disabilities. Additionally, Integrating the Social Model of Disability into policy frameworks would further strengthen these efforts, emphasizing systemic changes that remove barriers and foster a more inclusive environment for all families.

Keywords

Psychosocial support, families, care, children with disability, Tanzania, Uhuru Mchanganyiko primary school.

INTRODUCTION

Families who care for children with disabilities are more frequently unstable, more often sacrifice their fertility intentions, more frequently suffer from economic difficulties, show more traditional gender role arrangements are more frequently in bad health, and have lower well-being than families without disabilities. According to Giulio (2016) explain in his study that, the consequences are different for mothers and fathers: fathers of children with disabilities have fewer emotional exchanges, while mothers tend to suffer more in terms of social contact. Feelings of emptiness, loneliness and rejection. In a small-scale Norwegian study on the parents of children with behavioral problems, which can be frequent in children with disabilities, mothers with low education, more often unemployed, less content with social support and with lower scores on comprehensibility were significantly more stressed than parents in the different status (Solem et al. 2011) this is from Europe.

In Asia and the Pacific regions, 650 million people are estimated to live with a disability, meaning one in every six persons lives with a disability Paola (2016). The number is predicted to increase by virtue of population ageing, poor working condition and chronic health condition, among other factors Paola (2016). Indonesia is one of the countries in South-East Asia region where the prevalence of people with disabilities continues to increase. The 2012 national socioeconomic survey reported that the percentage of people with a disability in the country increased from 1.38% in 2006 to 2.45% in 2011. In 2017, same survey reported that over 37.1 million people live with a disability, and about 10% (3.2 million) are children [Unescap,2013].

Caring for a child or children with a disability within family may cause various challenges to parents, caregivers and other family members (Unescap 2020). Psychosocial issues that face parents and caregivers of children with a disability include stress, feeling of guilt, low self-esteem, negative emotions and behavior.

In Africa, disability is prevalent among children but is seldom recognized and often deliberately hidden. Children with disabilities and their families constantly face social, political and economic barriers that adversely affect their development and prevent them from being included in society and enjoying their basic human rights to the fullest. Consequently, the strengths and abilities of children with disabilities go unnoticed, their potential is underestimated, and their needs are given low priority in the allocation of resources (UNICEF, 2007). Like other parents elsewhere, parents of children with disabilities in Tanzania are also facing challenges in nurturing children with disabilities (Msangi, 2008; Mbwilo, 2010). This is because of disability or persistent illness of a member that affect the entire family as an interactive unit.

Furthermore, different social organizations such as organizations of persons with disabilities, Non-Governmental Organizations, Community Based and Faith Based Organizations and some international organizations as for instance UNICEF, work hand in hand with the Ministry to ensure quality provision of psychosocial support and services for those who are in need. However, availability of all the mentioned laws, policies, government and non-government standards in Tanzania that protect and promote life of children with disabilities and their families still there is a variation of human experience on the aspect of psychosocial wellbeing. Parents, stakeholders, practitioners and government at large miss the feedback on what is working well and what need more efforts to improve life of caregivers as frontline responsible and their children. The central concern of this study was to bring on board those human experiences by looking upon the psychological and social challenges experiencing by families caring for children with disabilities.

LITERATURE REVIEW

Families are an important source of support for children with disabilities. Family members absorb the added demands on time, emotional resources, and financial resources that are associated with having a child with a disability (Stahmer, 2005). Yet, rewards from having a family member with a disability, such as personal and spiritual growth, have been overlooked (Scorgie & Sobsey, 2002).

According to Dalia (2021) from Palestine, conducted a study on Challenges facing family caregivers of children with disabilities. This study aimed to examine the challenges facing caregivers of CWD during the pandemics, and to explore these challenges from various physical, social, psychological, and financial aspects. In this study researcher conducted a cross-sectional design whereby 130 caregivers for CWD completed a survey between March- May 2021. In this study they came up with the findings that most of caregivers were mothers (76.9%), the mean age of the children was (6.09 ± 3.43 years). The majority (88.5%) of the caregivers felt physically exhausted, about (75.4%) had decreased living standards, and (86.2%) indicated that caregiving is taking their strength. A high burden score was recorded based on the type of disability, and child’s ability to take care of oneself. The total scores were positively correlated with the physical, social, psychological, and financial challenges facing the caregivers.

In South Africa there is a study conducted by Toyab (2022) This study aim to explore and describe the experiences of caregivers providing care to children with disabilities at non-governmental organizations (NGOs) in townships. Experience in South Africa cement on the idea that; Caregivers of children with disabilities are vital stakeholders when it comes to safeguarding the health, well-being and overall survival of the children that they care for. Caregivers, however, face many challenging conditions that make it difficult for them to optimally fulfil their caregiving role.

In Tanzania there is study conducted by (ISESELO et al 2016), about Mental illness and how it may cause a variety of psychosocial challenges, these challenges are enhanced by the stigma attached to mental illness, which is a problem affecting not only the patient of mental illness but also the family. The aim of the study was to determine the psychosocial problems of mental illness on the family including the coping strategies utilized by family members caring for a person with mental illness. This study methodologically was a qualitative study, involving four focus group discussions and 2 in-depth interviews of family members who were caring for patient with mental illness at Temeke Municipality, Dar es Salaam. Purposive sampling procedure was used to select participants for the study. Audio-recorded interviews in Swahili were conducted with all study participants. The recorded interview was transcribed, and qualitative content thematic analysis was used to analyze data. At the results part this study reveals financial constraints, lack of social support, disruption of family functioning, stigma, discrimination, and patients' disruptive behavior emerged as the main themes in this study. Therefore, according to various literature reviewed in different regions, families caring for children with disabilities experience PSS challenges while assuming their roles at the family level. Most of PSS challenges mentioned include decreasing their strengths, physical exhausted, decrease living standards, experiencing financial hardships and stress level increase.

Research Gap

The literature review showed that studies conducted to explore matters related to PSS and caring for children with disabilities. Studies projected challenges faced by families caring for children with disabilities both globally and national wise. although not in specific field of disabilities, most on mental health and culture related aspect.. All these studies paved a way to well understood PSS and how families caring for children with disabilities receive it to support their daily life experiences.

There were content gap when it comes to families caring for children with disabilities. Looking at the Study conducted by Dalia (2021) focus on PSS for parents caring children with disabilities, it only focusses on parents while children with disabilities receive care to people whom they share household. Also, many studies according to the review focus on mental health part and leave aside the social support and other aspects of psychological support. In Tanzania many studies cover mental health and specific type of disability like Intellectual disability, Autism and cerebral palsy whereby according to Tanzania persons with disability act 2010 there are other types of disabilities mentioned. Therefore, the study on PSS for families caring children with disabilities covered the content gap and geographical gap since Dar es salaam regardless of its diverse there were limited studies covered families caring children with disabilities and PSS.

THEORETICAL FRAMEWORK

This study was directed by the social model of disability. In this model, **disability was seen as one aspect of a person's identity,** much like race/ethnicity, gender, etc. From this perspective, disability is believed to result from a mismatch between the disabled person and the environment (both physical and social). It is this environment that creates the handicaps and barriers, not the disability (Abbay 2015).

Relevance of Social Model of disability to this study

Social Model provides a route map that identifies both Physical, attitudinal, information and communication barriers that people with impairments can experience and how these barriers can be removed, minimized or countered by other forms of support from the family level (Amstrong, 2015).

This approach recognizes that many challenges faced by families caring children with disabilities are not inherent to the disability itself, but rather stem from societal attitudes and structures. By addressing these barriers, opportunities for psychosocial support can arise.. On Psychosocial support for families caring children with disabilities, this model will offer support by advocating for inclusive policies, accessible infrastructure, and societal attitudes that promote acceptance and accommodate diverse needs. It encourages empowerment, collaboration, and resource allocation towards creating environments where children with disabilities can thrive alongside their families (REPSSI, 2016).

The social model of disability helps identify psychosocial challenges experienced by families caring for children with disabilities by highlighting how societal attitudes, lack of accessibility, and general barriers impact their lives. By recognizing that disability is not solely a medical issue but also a result of societal constructs, it prompts a holistic approach to understanding and addressing these challenges (Antony 2013). For instance, it may reveal struggles with stigma, isolation, inadequate support services, or barriers to education and employment opportunities. By addressing these societal factors, interventions can be designed to support families more effectively, promoting their well-being and resilience. The Social Model of Disability is dynamic and effective, Therefore, by incorporating the social model of disability to this study matters on psychosocial challenges can be identified and leveraged to enhance the well-being not only for families caring for children with disabilities but to society and national at large.

RESEARCH METHODOLOGY

The present investigation informed by the principles of Interpretivism, which speculated that knowledge and truth are contextually and culturally bound, derived from individual experiences and understandings (Gemma, 2018). The study utilized case study design under qualitative method. The primary site for data collection was Dar es Salaam, the largest city in Tanzania (Sensa, 2022), boasting a population exceeding six million inhabitants. Although not the capital, Dar es Salaam served as the country's financial and commercial hub, hosting the headquarters of numerous national and international agencies. Within this city, the Ilala District was the focal point of the research, which was home to established social service institutions delivering education and health services, including Ocean Road Hospital and Muhimbili National Hospital. Uhuru Mchanganyiko, the study’s specific site, was one of the oldest schools in the region. Established in 1921, it was the first to integrate students with disabilities into regular classrooms.

The study population comprises a subset of the target population from which the sample will be drawn (Kumar, 2011). As of January 2024, Uhuru Mchanganyiko Primary School has a total enrollment of 150 students come from different families which care for children with disabilities. This figure includes 68 students with visual impairment, 14 with deaf-blind conditions, 70 with intellectual disabilities, and 5 with albinism.

Sampling procedures refer to strategies employed to select participants from a defined population (Kothari, 2004). This study utilized non-probability sampling techniques whereby participants were not selected randomly, resulting in unequal chances of selection. The methods of data collection involve various strategies employed to gather data from diverse sources, whether primary or secondary (Kothari, 2004). The chosen methods aligned with the study design which is in depth interview and non-participatory observation.

FINDINGS AND DISCUSSIONS

This study reveals that social stigma and discrimination pose significant challenges for families caring for children with disabilities. Families often encounter negative attitudes, stereotypes, and exclusion from communities their living in. A brother of children with disabilities shared.

> *"I am okay to support my young brother who had visual impairment, and I really try to help my friends understand this but I declare to fail and I feel very bad about it because I have to choose between my young brother and my friends so I choose my brother. The issue is they mistreat him by teasing him and I can`t take it."*

A grandfather of a child with deaf-blind condition said.

> *"My heart aches to see the way society treats my grandchild. Their disability doesn't define him, but the community's ignorance does. It's a painful reality that our love and care can't shield him from the harsh judgment and exclusion."*

Uncle of a child with intellectual disability said.

> *"My sister changed a lot after giving birth to her child with this condition. She was very different compared to the way she used to be, so the only relief at the family level was to assist her with caring for the child, now I can see a lot of progress and now she shares with us how social isolation impacted her negatively. Now we stay together and focus on her wellbeing and wellbeing of the child although it is not easy."*

Many families caring for children with disabilities experience social stigma and discrimination to people who used to be very close to them. Stigma and discrimination leaves families feeling isolated, with limited people to talk to. Even when they come from good families or middle-income families their aloneness after having children with disabilities has direct impact to family members and to children themselves. These reflections highlight a pressing need for increased awareness raising about different types of disabilities in communities, similar studies like those by Green (2023) on stigma and the lives of families of children with disabilities; found that community awareness could decrease the level of stigma and discrimination. The social model of disability as reviewed by PWDA (2023) directly addresses stigma and discrimination as central issues. It argues that disability is not solely a medical condition, but rather a social construct created by societal barriers and negative attitudes. These barriers, such as discriminatory practices, and harmful stereotypes, limit the opportunities of families to participate peaceful in the community.

This study revealed another challenge which is Family Relationship and dynamics. The presence of a child with disabilities can strain family relationships, leading to conflicts, resentment, and breakdown of families. Family members have a lot to share in this theme and it was really reflecting challenges associate with caring for children with disabilities as explained below.

Sister of a child with intellectual disability said.

> *"The more I grow the more responsibilities, I miss to be alone I must think about my sister all the time. They say it is my task to care for her but I have things to do and if I stop caring her only mother do that while she is tired. My cousins are not here every day, so I feel alone with my young sister I think a lot about her."*

Mother of a child with Albinism said.

> *"I love my child, but I stayed single for 5 years and take care of him alone, my husband left me the time I needed him a lot."*

Auntie of a child with deaf blind condition said.

> *"It was difficult to handle the child of my brother and my children, I supposed to put more attention to him and careless about my two children. I was the only person to take care of him because*

> *his mother left and my brother is too young still need to live his life without responsibilities, so I must take responsibilities, my husband complained before but now he supports me although it was not easy.”*

The experiences shared by the family members in this study highlight the significant impact that caring for a child with a disability can have on family relationships and dynamics. Caregivers often experience heightened levels of stress, anxiety, and depression due to the constant demands of caregiving. The physical demands of caregiving can lead to fatigue and burnout. Caregivers experience role strain as they balance caregiving responsibilities with other roles, such as wife and mother to other children. Siblings report to feel neglected, resentful and burdened with additional responsibilities. Grandparents called upon to provide care, which can impact their own health and well-being. Many participants were the victim of family breakdown although others survived it. Studies like Gray (2022) shows that families experience divorce soon after having a child with disability. Family breakdown threatening many caregivers. Social model of disability emphasizes systems to interplay while supporting children with disabilities and family is one of the primary systems to care aand support children with disabilities. If families disconnect then supportive environment will be unrealistic. It is crucial to provide comprehensive support services to families, including counseling, respite care and promoting social awareness. By understanding these factors, policymakers, healthcare providers, and community organizations can develop effective interventions to support families and improve the quality of life for children with disabilities and other family members.

Also, this study revealed that families caring for children with disabilities often experience significant emotional distress and mental health issues. These challenges have many faces as per caregiver`s. They shared different areas on how emotional distress and mental health issues affect them.

Mother of a child with Intellectual disability said.

> *"The fear of the unknown, the constant stress of providing care, and the guilt of not being able to do more, it's a heavy burden on my mental health. I often feel overwhelmed and alone."*

Grandmother of a child with Deaf condition said,

> *Growing up in the family with no person with disability, my grandchild bring a lot of impression every day we like to care for our grandchildren but this child look different and a lot has been going on until his age of five when all family members accept and agree to care for her. I was very sad most of the time because my daughter suffered a lot other than pressure from the family, she experienced burnout, guilt and blame.".*

Aunty of a child with Intellectual disability said.

> "*The emotional rollercoaster of joy and sorrow, hope and despair, it's exhausting. I often feel like I'm on the verge of breaking point, my brother`s child taught me a lot about parenting especially because he looks different compared to others. Fears and uncertainty, sleepless nights and a lot of cries I will never forget."*

The experiences shared by these family members highlight the profound emotional clang that caring for a child with a disability can take. Caregivers experience many triggers to the point they feel alone. Uhuru Mchanganyiko is one of the old schools with inclusion practice but still parents struggle and have emotional distress caused by caring for children with different disabilities. Studies like REPSSI (2019) support the concept of stress and mental issues for families in South Africa. A social model of disability perspective offers a valuable framework for understanding this challenge and many factors attached to it. The social model emphasizes that disability is not solely a medical condition but rather a social construct. Societal barriers can significantly contribute to the emotional distress experienced by families. In the context of caring for a child with a disability. By adopting a social model approach and implementing its strategies towards reducing the emotional distress and mental health issues experienced by families caring for children with disabilities will be well handles.

This study revealed that families experienced uncertainty and fear for the future. This is the state of anxiety and worry about what the future holds for a child with disabilities. This can be a significant source of neglect and psychological challenges. Family members explained a lot about this.

Father of the child with Deaf-blind condition said,

> *"Thinking about our child`s health condition it is impossible, we are coming from low-income family and this child demand extra medical care and assistive devices to support him. We are trying but in a long run his* health complications, and the need for ongoing medical care. *we don't know how to go about it."*

The Aunty of a child with Intellectual disability said,

> **"***I am very worried about the future of this child. Will he become independent in his life? Although that is what am praying for, but the possibilities are uncertain. After finish Uhuru Mchanganyiko will he be able to get school to accommodate his need I don't know."*

Brother of a child with visual impairment condition said,

> *"We are very concerned about the social life and the ability to form friends and relationship many people don't know her unique ability to talk and share her views. At the family level she has many people whom she can talk to but moving outside our family people think a little different and we cant tell everyone if this is not true and this is true. My friends said that my young sister is different, I agree with them but that doesn't limit her from getting friends they have to understand and support her."*

This uncertainty and fear can lead to significant emotional distress for families, affecting their mental health and overall well-being. The findings align with previous research on the psychological and emotional toll of caregiving for children with disabilities. According to studies by McConnell et al. (2017) and Firth et al. (2020), uncertainty about the future is a common source of stress for caregivers, particularly regarding their children's independence and social participation. This sense of uncertainty can lead to heightened anxiety and depression, negatively impacting the mental health of caregivers (Schumacher et al., 2020). The fear of not being able to meet the needs of a child with disabilities, especially as parents and caregivers age, is a concern often voiced in similar studies (Gougeon, 2019). The findings also suggest that without adequate support systems, such as financial aid, specialized services, and social support networks, these caregivers are left to cope with their anxiety and fears in isolation. As such, the findings call for interventions that can alleviate the uncertainty caregivers face by offering more accessible services, clear pathways for advocacy, and comprehensive long-term planning for children with disabilities and their families.

Family members report to experience shortage of specialized healthcare providers, therapist and people to work with children with disabilities. This result to a significant challenge for families, as it limits access to essential services and support when needed. Here are some of the consequences mentioned by family members with their children at Uhuru Mchanganyiko Primary. Mother of a child with visual impairment said.

> *"Delays in knowing why my child was behaving different led to the loss of vision. I trusted hospitals so much but after the experience with my child I have learned to trust God more."*

The Uncle of a child with intellectual disability explained.

> *"Burden to the family is very big as we care to a family member with disability, at least he is going to school although her mother has to follow close to every step. When she is at home extra care is needed. To get specialized doctor to assist her is very challenge."*

Findings reveal that family members report to experience limited access to specialized services while they care for children with special needs. This is a barrier for children with disabilities at Uhuru Mchanganyiko. Many families struggle to find qualified professionals, such as therapists, educators, and healthcare providers, who can provide the specialized care and support their children need. This lack of access lead to delayed interventions, reduced quality of life, and increased burden on families. Additionally, the cost of specialized services can be prohibitive for many families even those urban located ones, especially those living in poverty. These challenges highlight the urgent need for increased investment in the development of specialized services and support systems to ensure that children with disabilities have the opportunity to reach their full potential. These finding supported by report from the guardian News (2024) which said limited access to specialized health care services hinder the life of people with disabilities and their families. The social model of disability emphasizes that societal barriers, rather than individual impairments, are the primary cause of disability. For the matter of limited access to specialized services, social model highlights the role of systemic factors, such as inadequate infrastructure, discriminatory policies, and lack of awareness, in hindering the inclusion and participation of individuals with disabilities and for this matter then children with disability Jenny (2019). By focusing on removing these barriers, the social model advocates for creating a more inclusive society where everyone, regardless of their abilities, can access the services and support they need to thrive. This includes ensuring that specialized services are accessible, affordable, and culturally appropriate.

Conclusion

In conclusion, this study sheds light on the complex psychosocial challenges that families face while caring for children with disabilities, marked by stigma, strained family dynamics, emotional burdens, and insufficient support services. The unescapable social stigma and discrimination not only isolate these families from their communities but also add to the strain within family relationships, often leading to role strain and, in severe cases, family breakdowns. Caregivers face heightened emotional distress, including anxiety and burnout, due to their continuous caregiving responsibilities and fears surrounding the future. These challenges are caused by a shortage of specialized services, including trained healthcare professionals and educators, which hinders children’s access to necessary care and support.

Recommendations

Based on these findings, it is recommended that the government prioritize policies and programs that enhance nationwide awareness campaigns this would be beneficial to reduce stigma and promote inclusivity, helping communities understand and support the unique needs of these families. Additionally, the government should invest in training healthcare and education professionals on disability-specific needs, which would enhance the quality of services and improve outcomes for children. Integrating the Social Model of Disability into policy frameworks would further strengthen these efforts, emphasizing systemic changes that remove barriers and foster a more inclusive environment for all families.

To the best practice it is recommended for the primary service providers to seek feedback on services especially for families caring for children with disabilities. There are many things happening as interventions but to hear from them emerging challenges will ensure proper review and adjustment of social interventions as far as disability is concerned.

Area for further study

The focus of the current study was on psychosocial support for families caring for children with disabilities in Tanzania: A case of uhuru mchanganyiko primary school, where it examined the challenges to these families. Areas for further studies could explore the long-term effects of psychosocial support challenges experienced by families caring for children with disabilities. Also, another area of study could be to explore male engagement in to caring for children with disability so as to see how culture and tradition impact life from the family level.

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