



# Challenges in Caregiving Patterns for Parents of Physically Challenged Children in MSUMI Village, Dar ES Salaam, Tanzania

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## ABSTRACT:

The role of a caregiver is one of the most important and challenging responsibilities that anyone can undertake. For parents who care for children with disabilities, the challenges can be even greater. This research aims to understand the caregiving patterns and challenges faced by parents caring for physically challenged children. This study is crucial as it sheds light on an area that has received little attention in the literature. It seeks to explore the unique challenges that parents face when caring for their physically challenged children, including the physical, emotional, and financial burdens that come with the responsibility of caring for a child with a disability. Additionally, this research aims to identify the coping strategies that parents use to manage these challenges, as well as the resources and support that they require to provide optimal care for their children. Through this study, we hope to increase awareness and understanding of the caregiving patterns and challenges of parents caring for physically challenged children. This knowledge will be valuable in informing the development of policies and programs aimed at supporting parents and caregivers in their caregiving roles.

**KEYWORDS:** Physically Challenged, Caregiving, Disabilities, Children, Family Challenges, Caregiving Patterns and the well-being of Families.

## I.INTRODUCTION

This study is crucial as it sheds light on an area that has received little attention in the literature. It seeks to explore the unique challenges that parents face when caring for their physically challenged children, including the physical, emotional, and financial burdens that come with the responsibility of caring for a child with a disability. Additionally,

this research aims to identify the coping strategies that parents use to manage these challenges, as well as the resources and support that they require to provide optimal care for their children. Caregiving for children with disabilities presents significant challenges and emotional experiences for parents [1]. The role of a parent caregiver can be both rewarding and demanding, impacting their mental and physical well-being. Parents may experience feelings of anger, depression, anxiety, bargaining, and fear as they navigate the complexities of caring for a child with special needs. Additionally, caregivers often face emotional and financial difficulties, high expectations with limited formal support, and the need to learn new roles and responsibilities quickly. The demands of caregiving can lead to stress, isolation, exhaustion, and a toll on the caregiver's overall health. Empowerment strategies are crucial in helping caregivers cope effectively and provide better care to children with disabilities. Recognizing the challenges faced by parent caregivers is essential in fostering understanding, support, and resources to improve the quality of life for both caregivers and the individuals they care for [2].

## II.BACKGROUND OF THE STUDY

Most children have historically been cared for by their families. The most important and most important link in the care, guidance and supervision of children with disabilities are their parents. For parents around the world, the responsibility of raising a child with special needs is extremely difficult [3].

In Tanzania, the task is made even more difficult by an overworked health care system that is inadequate for the special needs of these children, an education system that emphasizes memory and grades, and a superstitious society that sees mental illness as madness. According to 2012 Primary



Health Care Centre data, there were 34,075,839 household members aged 7 years and older in Tanzania, of whom 3,157,516 were disabled (9.3%).

This prevalence is higher than the 2008 Disability Survey prevalence of 7.8% and higher than the 2002 Census prevalence of 2.0%. The prevalence of people with disabilities in Tanzania is 2%. However, the proportion of men with disabilities (2.2%) is higher than the proportion of women with disabilities (1.7%). Common disabilities were leprosy/physical disability (47.9%), mental disability (16.3%), multiple disability (13.3%) and muteness/deafness (13.1%). [Four]

Determining parents' positive attitudes towards raising children with intellectual disabilities is important for professional practice, as is parents' understanding of how they are supported throughout life. The purpose of this study was to investigate how having a child with special needs affects families. In addition, stress factors within families were examined. We explore the feelings and emotions surrounding the diagnosis. It can be scary and stressful when a child enters the family, and circumstances change. New parents often worry

about things like bathing, changing diapers, feeding, and various other parenting rituals. But the birth of a child with special needs can have a profound impact on a family that is often overlooked. A child's diagnosis poses challenges for the whole family, not just the parents, which can significantly increase physical and psychological stress [5].

Parents of children with special needs often feel exhausted and frustrated. Their reserves of time and resources for self-care are even scarcer than that of the average parent. However, the need for energy supplements is also greater. In order to survive the marathon of caring for a child with special needs, parents must take care of their own needs. The Boston University website contains helpful information about taking care of your health and well-being. The most helpful support and information parents receive often comes from parents of children with special needs. A group of BU parents recognized this and established a peer support network to help parents connect with other BU faculty and staff who care for children with disabilities [6].

### III.OBJECTIVES OF THE STUDY

#### Main Objective

To designate the demographic characteristics of caregiving mothers.

#### Specific Objectives

To understand the challenges faced in caregiving.

To find out the psycho-social support required for effective caregiving.

To assist and measure the knowledge on caregiving.

To explore the pattern of caregiving  
A parent caring for physically challenged Children has no clear caregiving technique which leads to caregiver burden. The need of the study is to find if there is any specific technique for caregiving and to find if there is any stress or burden due to caregiving. The study will give an overview of the mental health and well-being of the parents caring for physically challenged children.

1]. The study will build new knowledge on the holistic idea of the mental health and well-being of the parents of physically challenged children. Healthcare practitioners can enhance their understanding of the requirements of both parents and children by gaining insights from research on caring patterns. This can result in better healthcare services and better care coordination.

2]. Recognizing the difficulties involved in caregiving can empower parents by acknowledging their experiences and offering them tools, support systems, and coping mechanisms to help them deal with the intricacies of raising a child with physical disabilities.

3]. By promoting a more inclusive society and advocating for the needs and rights of people with disabilities and their families, research in this field can increase public understanding of the challenges experienced by families with physically challenged children.

4]. Understanding the issues parents face when caring for physically challenged children can help researchers, legislators, and healthcare professionals design interventions and support systems to improve the quality of life for the child and family.

5]. Studying the caring patterns and challenges faced by parents of physically challenged children takes into account a variety of issues that affect the family's overall health as well as the child's. It employs multidisciplinary methods from the fields of psychology, sociology, public health, social work, and policy studies to create all-encompassing plans for assisting families in providing care.



#### IV. LITERATURE REVIEW

‘Challenges in Caregiving Patterns for Parents of Physically Challenged Children’.

##### Physically Challenged

According to the Social Justice Department (2016), “Physically Challenged are often described in terms of lack of normal functioning of physical, mental or psychological processes. It is also defined as learning difficulties or difficulties in adjusting socially, which interfere with a person’s normal growth and development. A physically challenged child has been defined as one who is unable to ensure by himself, wholly or partially the necessities of a normal individual or social life including work because of deficiency whether congenital or not in his physical or mental capabilities”.

##### Caregiving

Swanson et al. (1997) ultimately define family caregiving as: “Provision by a family care provider of appropriate personal and health care for a family member or significant other”.

#### V. TYPES OF DISABILITIES

1. Blindness
2. Low vision
3. Leprosy
4. Hearing Impairment
5. Locomotor Disability
6. Intellectual Disability
7. Autism Spectrum Disorder
8. Cerebral Palsy
9. Muscular Dystrophy
10. Chronic Neurological Conditions
11. Specific learning disability
12. Multiple Sclerosis
13. Speech and language disability
14. Thalassemia
15. Haemophilia
16. Sickle Cell Disease
17. Parkinson’s disease

#### VI. CHALLENGES FOR CAREGIVERS

1]. Carer burnout is a condition characterized by exhaustion at physical, emotional, and mental levels. It can lead to a shift from a loving and positive mindset to a negative and uncaring one. Carer burnout can occur when carers take on more responsibilities than they can handle, either financially or physically, or when they don’t receive the necessary assistance [7-9]. Many individuals who care for the ill or elderly feel guilty when they take time for themselves. Common signs of carer burnout include fatigue, worry, anxiety, and depression.

2]. Due to the challenging nature of their responsibilities, caregivers often neglect their own emotional, physical, and spiritual well-being. The physical, mental, and emotional demands placed on a caregiver can be overwhelming, leading to fatigue, despair, and ultimately burnout. Several factors have been identified as significant predictors of caregiver burden, including the level of children’s dependency, the type of living situation, the caregiver’s overall health, any existing health problems, and their employment status.

3]. Parents and primary caregivers of children with special needs have more difficulties in parenting than those faced by other families.

Among the several difficulties are:

##### a) Fear and anxiety

The agony and sorrow of the child,  
The future of the child.

##### b) Guilty

The limited capacity to shield the youngster,  
The neglect of the caregiver’s spouse, older parents,  
and another child,  
The envy and anger of people who have “normal” kids.

##### c) Feelings of loneliness

Miss out on a lot of family-friendly activities because the child’s condition prohibits them from participating successfully,  
Experiencing judgment and disapproval of parenting from those who don’t comprehend the child’s impairment,  
Feel alienated by parents of children with typical development.

##### d) Grief at the loss of the child’s hopes and dreams

Having a different parenting experience than anticipated,  
Chronic anguish is brought on by repeated reminders of what the child misses out on.

4]. Helen M. Bourke-Taylor & Kahlil S. Joyce (2021) et.al. This research article is entitled Mental Health and Health Behaviour Changes for Mothers of Children with a Disability: effectiveness of a Health and Wellbeing Workshop. The author stated that the Healthy Mother’s Health Family Program helps to educate and empower disabled mothers and improve their health behaviours [10]. The pre-test design was helpful to implementing the online questionnaire with the health-promoting activities scale and depression and anxiety stress scales were used in this study. There 71 observation mothers are experienced in the improvement of HPAS scores  $p < .001$ , miserable symptoms ( $p = .005$ ), anxiety ( $p = .002$ ), improvement in the wellbeing ( $p < .001$ ).



The author also fine-tuned how disabled children's mothers were also experienced with increasing the quality of life ( $p=.042$ ). The mothers with disabled children's lifestyle goals were improved like managing stress, dietary changes, leisure, self-perception, etc. Healthy Mothers Families programs have been important interventions to improve the health status and outcomes of mothers.

5]. Aarthi Ramachandran, Navya Vyas, Dan Isaac Pothiyil (4, December 2020) In his study "Stress among the caregivers of mentally physically challenged children visiting a rehabilitation center in Chennai, Tamil Nadu; A cross-sectional study" From a casual family pastime, caregiving is now a complicated health care activity that plays a significant role in healthcare. Family members care for people with mental disorders most often in India. In the current study, stress among parents of children with mental disabilities including autism spectrum disorder, intellectual disability, and attention deficit hyperactivity disorder was evaluated, and a link between stress and specific socio-demographic factors was discovered. This six-month cross-sectional study was conducted at an institution and lasted from January 2019 to June 2019. The participants in this study were the carers who used the therapies and follow-up appointments at Chennai, Tamil Nadu, National Institute for Empowerment of Persons with Multiple Disabilities. The Kingston Caregiver Stress Scale was used to gauge the degree of stress. The information was gathered from 101 parents of kids with mental impairments. The National Institute for Empowerment of Persons with Multiple Disabilities in Chennai, Tamil Nadu, served as the location for data gathering.

6]. AL Sabah Sayeed (May 2019) In his study "Problems Faced by Parents of Physically Challenged Children in District Anantnag, Kashmir" states that the purpose of the current study was to learn more about the psychological and social issues that plague parents of physically challenged

children, as well as the health and financial issues they face. The study included 40 parents of children with disabilities as its sample. The sample was chosen purposefully, and information was acquired utilizing a self-made interview plan. The findings showed that 80% of respondents had sought a doctor for immediate measures, 87.5% of respondents' children had disabilities from birth (i.e., congenital), and 72.5% of respondents were astonished to learn about their special children. 100% of respondents reported having difficulties getting their kids ready for school, 87.5% reported that family members were caring for the special child, 45% reported experiencing occasional anxiety and stress, 75% reported having normal social relationships, 67.5% reported feeling the need to reduce their social circle, and 60% reported that the mother cared for the special child the majority of the time.

7]. Mubashir Gull (September 2015) In his study "Comparative study of hope and psychological well-being among the parents of physically and intellectually challenged children" Parents of physically challenged children go through a lot of stress. The goal of this study was to investigate how parents of children with physical and intellectual disabilities differed in their perspectives on hope and psychological well. It also looked into if there was any connection at all between hope and psychological health. 200 parents of children between the ages of 35 and 45 who are physically challenged made up the sample. The collection of data was done using a simple random sampling technique. The respondents' psychological well-being and hope were evaluated using the hope and well-being scales, respectively. The collected data were compared using an independent sample t-test, and the correlation between the variables was examined using Pearson's correlation analysis. The findings showed a statistically significant difference between parents of children with physical disabilities and parents of children with intellectual disabilities.

## VII. RESEARCH METHODOLOGY

The research could be the 'Descriptive Research Design'. Because that seeks to gather data to methodically describe a phenomenon and circumstance. The research mainly focuses on describing the demographic characteristics of caregiver mothers. The challenges faced by caregivers where knowledge should be assisted. The pattern of caregiving and psycho-social support required for effective caregiving will be found in the research. The universe of the study is at Msumi village, in Dar Es Salaam district, Tanzania.

According to the Same District profile (2020), there were 1004 people with disability, 331 female and 673 male, in all 34 Wards of the District. The type of study is Descriptive which helps in a clear understanding of what, where, and when the parent's caregivers care for physically challenged Children. The Method of research will be Quantitative method. The research design will be Descriptive research design. The design aims to obtain information to systematically describe a phenomenon and situation about the mental health



and well-being of the parents caring for physically challenged children. The respondents are the parents' caregivers of physically challenged children in the Dar Es Salaam district. The Sampling details where 50 samples will be collected (respondents-50). So, the sampling technique is Probability sampling. As it is mixed method research, a Simple random technique will be used. The research utilizes a questionnaire as the primary tool for data collection. To ensure convenience for both the respondents and the researcher, the questionnaire is offered in both English and the local language. The tool incorporates both open-ended and closed-ended questions to gather a comprehensive data set. A Likert scale structures the questionnaire to facilitate data analysis. Due to the interview format, data

collection for each questionnaire typically takes around 25 minutes.

The primary source of data comes from caregiving mothers in Dar Es Salaam and the surrounding village called Msumi within the Dar Es Salaam District. Secondary data is gathered from national and international articles. Additionally, some data may be collected from department heads through casual discussions. The study focuses on caregivers of physically challenged children within the Dar Es Salaam district. It specifically targets parents with children between the ages of 10 and 15. The study only considers caregiving mothers and excludes male caregivers. It also employs a minimum sample size of 50 parents. The study does not consider male caregivers as a participant group.

### VIII.OBSERVATIONS FROM THE RESEARCH ANALYSIS

	Knowledge	Challenge	Age of the respondents	Monthly income of the family	Educational status of the respondent
Knowledge	1	-.414**	-.107	.249	.233
		.003	.458	.081	.104
	50	50	50	50	50
Challenge	-.414**	1	-.126	-.212	.034
	.003		.383	.140	.813
	50	50	50	50	50
Age of the respondents	-.107	-.126	1	-.152	-.209
	.458	.383		.292	.145
	50	50	50	50	50
Monthly income of the family	.249	-.212	-.152	1	.359*
	.081	.140	.292		.010
	50	50	50	50	50
Educational status of the respondent	.233	.034	-.209	.359*	1
	.104	.813	.145	.010	
	50	50	50	50	50

#### Hypothesis

**H0:** There is no correlation between knowledge and challenges in caregiving. Knowledge and challenges in caregiving do not have a positive correlation with the age, education, and income of the parents.

**H1:** There is a correlation between knowledge and challenges in caregiving. Knowledge and challenges in caregiving have a positive correlation with the age, education, and income of the parents.

**Result:** Since the p-value is less than 0.05 between the knowledge and challenges and the correlation is negative (-.414\*\*), it could be stated that challenges decrease when the parents know caregiving. Hence, the H0 is rejected. When it comes to age, education, and income, there is no correlation and hence, H0 is accepted.



## IX. FINDINGS AND SUGGESTIONS

### Findings:

1. A majority (68%) of people feel that they are always treated differently because of their child's disability, so they feel left out among the group and feel bad about their state.
2. Most of the respondents (72%) feel that there is not sufficient time for them to practice self-care, and they feel stressed that they only have time to take care of their child.
3. Almost all (78%) of the respondents feel that their relationship with their husband is affected by their child's disability, it's not uncommon for having a child with a disability to have a significant impact on the dynamics of a couple's relationship.
4. The majority (64%) of respondents believe that the growth of a child brings new challenges. It is important to note that as a child grows and develops, they encounter new experiences, challenges, and opportunities that require different levels of support, guidance, and attention from parents, caregivers, and educators.
5. More than half (56%) of respondents have someone to call in case of an emergency. This is a positive indication, as it is always important to have a support network and emergency contacts in case of unexpected situations.
6. More than half (58%) of the respondents are aware of the special school. But even though they knew, their children were educated in normal schools due to a lack of awareness of the location of special schools and a lack of financial stability.

### Suggestions:

1. Vocational training should be given to housewives, so that they can work from home in

## X. CONCLUSION

This study specifically examines the psychological well-being and mental health of parents who are responsible for the care of children with physical limitations. Parenting a child with a physical disability can greatly affect a parent's mental health and overall well-being. The objective of this study was to examine the impact of parental care for a kid with a physical disability on their mental well-being, as well as to discover potential factors that may influence overall health. A meta-analysis reveals that parents of children with impairments experience elevated levels of stress, anxiety, depression, and social isolation compared to parents of generally functioning children. The detrimental consequences can be intensified by a dearth of assistance from medical practitioners, restricted availability of suitable resources, and the

addition to taking care of the child it would be more helpful for the women to get empowered and financially independent.

2. A suggestion is that there may be a significant societal stigma surrounding disabilities and that people with disabled children may feel excluded or discriminated against. It's important to recognize that people with disabilities and their families deserve the same respect and opportunities as anyone else and that inclusivity and accessibility should be prioritized in all aspects of society.

3. Parents need to work closely with their child's healthcare provider to manage their health and ensure prompt treatment when needed. Additionally, parents can take steps to promote their children's overall health and well-being, such as ensuring they get enough sleep, eat a healthy diet, and stay active.

4. Parents need to work with their child's healthcare provider to identify the cause of the disability and develop an appropriate treatment and management plan. It may also be helpful for parents to seek support and resources to better understand and navigate their child's disability, as well as to connect with other families who may be going through similar experiences.

5. Caring for someone with a disability can be a challenging and demanding task that requires specialized skills and knowledge. Caregivers must receive adequate training and support to ensure that they can provide the best possible care for their loved ones. This may include identifying specific conditions, medication management, assistive technology, and communications skills, among other things.

societal discrimination linked to disability. However, many studies indicate that implementing constructive methods of dealing with stress, receiving assistance from social networks, and having access to necessary resources can enhance the psychological well-being of parents, particularly women, and facilitate their attainment of financial autonomy.

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