

**" EXPLORING THE EXPERIENCES OF CAREGIVER PROVIDING CARE
FOR CHILDREN WITH DISABILITIES: A QUALITATIVE INQUIRY INTO
BURDEN AND RESILIENCE"**

Dissertation submitted to

Mahatma Gandhi University, Kottayam in partial fulfillment of the requirement for

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DECLARATION

I **Cicily Varsha** hereby declare that the research work titled "*Exploring the Experiences of Caregivers Providing Care for Children with Disabilities: A Qualitative Inquiry into Burden and Resilience*" submitted to the Mahatma Gandhi University, Kottayam, is a record of genuine and original work done by me under the guidance of, **Ms. Simmy Xavier**, Assistant Professor, Bharata Mata School of Social Work Thrikkakara, and this research work is submitted in partial fulfillment of the requirements for the award of the degree of Master of Social Work specializing in **Medical and Psychiatry**.

I hereby declare that the results embedded in this research have not been submitted to any other University or Institute for the award of any degree or diploma, to the best of my knowledge and belief.

Place: Thrikkakara

Date:

Cicily Varsha

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ABSTRACT

This research delves into the intricate world of caregivers providing care for children with disabilities, aiming to uncover the specific challenges and burdens they face, while also shedding light on the resilience factors that empower them. Through a qualitative inquiry, the study investigates the unique experiences of these caregivers, acknowledging the diverse hardships they encounter in their roles.

The research objectives include a thorough exploration of the challenges confronted by caregivers and an examination of the resilience factors that emerge amidst the complexities of caring for children with disabilities. Drawing from in-depth case studies and discussions, the study seeks to contribute valuable insights into the multifaceted dimensions of caregiver burden and resilience.

The findings of this research are anticipated to inform practical recommendations for enhancing support systems, promoting adaptive coping strategies, and fostering collaborative efforts among healthcare professionals, educators, policymakers, and community organizations. By doing so, the aim is to cultivate a more compassionate and effective environment for caregivers and, consequently, improve the overall well-being of children with disabilities and their families.

CHAPTER 1

INTRODUCTION

DISABILITY

Disability is a natural part of the human experience, with nearly everyone encountering it at some point, either temporarily or permanently. Currently, approximately 1.3 billion individuals, constituting about 16% of the global population, face significant disability, a figure on the rise due to factors like population aging and increased prevalence of noncommunicable diseases. Disability arises from the interplay between individuals with health conditions (e.g., cerebral palsy, Down syndrome, depression) and personal and environmental factors, such as negative attitudes, inaccessible infrastructure, and limited social support. The environment plays a pivotal role in shaping the extent and impact of disability, as inaccessible surroundings create barriers that impede the full participation of disabled individuals in society, hindering their ability to engage on equal terms with others. Progress on improving social participation can be made by addressing these barriers and facilitating persons with disabilities in their day to day lives. (*Disability*, n.d.)

A physical, cognitive, sensory, or emotional impairment that severely restricts a person's capacity to carry out everyday tasks is referred to as a disability. Its effects on different people can differ greatly and it can be either congenital or acquired. In order to provide equal opportunity and participation in society, people with disabilities may need accommodations or help.

There is a wide range of disabilities, such as mental health issues, intellectual disabilities, mobility impairments, and visual or hearing impairments. In addition to having modest to severe impacts, disabilities can be seen or unseen. The definition of disability is changing to be more inclusive, focusing on the social and environmental aspects that lead to the obstacles that people with impairments must overcome. The goal of advocating for inclusion, adaptive technologies, and accessibility is to improve the general well-being and involvement of those with disabilities in a variety of spheres of life.

The World Health Organization estimated in 2019 that around 5-10% of the global population are individuals with disabilities, with a notable portion being children. (Disability in India / Office of Chief Commissioner for Persons with Disabilities, n.d.)

CHILDREN WITH DISABILITY

Children with disabilities encompass a broad spectrum, defined as those experiencing long-term physical, mental, intellectual, or sensory impairments that, when combined with various obstacles, may impede their complete and equitable participation in society. This diverse group includes children born with genetic conditions affecting their development, those who sustained injuries, nutritional deficiencies, or infections leading to lasting functional impairments, and those affected by environmental toxins resulting in developmental delays or learning disabilities. Children with disabilities also include those who developed anxiety or depression as a result of stressful life events. (*Children with Disabilities*, n.d.)

Unique difficulties that may affect a child's physical, cognitive, sensory, or emotional development are faced by disabled children. Disability can manifest either from birth or develop later in life due to a multitude of factors. Common varieties include sensory impairments, mobility difficulties, autism spectrum diseases, and intellectual disabilities. In order to address developmental problems and offer individualized care to children, early intervention services are essential. The goal of educational accommodations like accessible materials and specialized training is to promote inclusiveness and learning. Together, parents, teachers, and medical professionals develop customized plans that guarantee disabled children receive the care and education they need. By encouraging social contact and lowering stigma, inclusive education techniques support the inclusion of kids with disabilities in regular classrooms. Research and lobbying efforts are ongoing to improve society attitudes, resources, and awareness in order to improve the overall wellbeing of the children with disability.

The population of children with disabilities is highly varied, encompassing those born with hereditary disorders affecting their physical, mental, or social growth; individuals who

experienced significant accidents, malnutrition, or infections leading to lasting functional impairments; and those exposed to environmental pollutants resulting in learning disabilities or developmental delays. Additionally, children who endured traumatic childhood experiences and subsequently developed anxiety or depression are also classified as disabled.

According to a UNICEF report from 2021, nearly 240 million children globally are affected by a disability, a figure surpassing previous estimates. This updated estimate adopts a more encompassing definition of impairment, considering various domains of functioning, especially those related to psychological well-being. The majority of children with disabilities encounter difficulties in a single area of functioning. Across all age groups, psychosocial issues are prevalent and may coincide with other functional challenges. (*Children with Disabilities*, n.d.)

In the age group of 0-19 years, 20% of the total disabled individuals have hearing impairments, followed by 18% with visual impairments, and 9% experiencing multiple disabilities. Among children aged 0-6 years, 1.24% are disabled. The percentage of disabled boys to the total number of boys is 1.29%, while for girls, it's 1.19%. This ratio is consistently higher for boys across all of India and in both rural and urban areas. Similarly, in the 0-6 age group, disabled boys outnumber disabled girls. The proportion of disabled individuals to the total population is higher in rural areas for both genders, while among children, this proportion is higher in urban areas. In the 0-6 age group, 23% of disabled children have hearing impairments, 30% have visual impairments, and 10% have mobility issues, with 7% experiencing multiple disabilities. This pattern is consistent among both male and female disabled children. (*Disability in India / Office of Chief Commissioner for Persons with Disabilities*, n.d.)

AUTISUM

Autism Spectrum Disorder (ASD) is a complex condition that manifests in various ways. Individuals with autism often struggle with social communication and interaction, which

can include difficulties in understanding nonverbal cues, maintaining eye contact, and forming relationships.

Autism, a complex neurodevelopmental disorder, is characterized by challenges in social interaction, communication, and repetitive behaviors. It's often accompanied by unique strengths and differences in sensory processing. (American Psychiatric Association, 2013)

Children with autism benefit greatly from the continuous support and understanding that parents and other caregivers can provide. Campaigns for public awareness and initiatives to build inclusive communities help to promote inclusion and acceptance for those on the autistic spectrum.

Children with autism require a lot of help, and their caregivers are crucial in fostering an atmosphere that will support the child's growth and well-being. Due to the particular difficulties that come with autism, including issues with socialization, communication, and sensory sensitivity, caregivers must be sensitive to the child's needs. In order to execute individualized intervention strategies, such as behavioral therapy and educational adjustments, they frequently work in tandem with educators and healthcare specialists. In addition, caregivers act as their child's advocates, making sure they have access to opportunities that are inclusive and suitable resources. When navigating the challenges of raising a kid with autism, caregivers must possess patience, empathy, and a caring approach. Their commitment helps the child flourish by encouraging independence and creating a feeling of community inside the family and broader community.

The prevalence of autism spectrum disorder (ASD) globally is estimated to be around 1 in 100 children (*Autism*, n.d.)

LEARNING DISABILITY

A learning disability in children refers to a neurodevelopmental condition that significantly hinders academic achievement and the acquisition of specific skills. According to the American Psychiatric Association (APA), learning disabilities manifest as difficulties in

one or more essential academic skills, such as reading, writing, or mathematics, despite having average to above-average intelligence. (American Psychiatric Association, 2013)

A learning disability is a neurological condition recognized by the American Psychiatric Association (APA) that interferes with a child's ability to develop specific academic skills, like reading, writing, or math. These difficulties persist despite the child having average to above-average intelligence. The APA's Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is a widely used reference for defining and diagnosing mental health and developmental disorders, including learning disabilities in children.

A neurodevelopmental illness known as a learning disability impairs a person's capacity to gather, analyze, store, and recall information. These issues can show themselves in areas like math, reading, writing, or organizing abilities. Learning disabled people frequently have normal or above average intellectual talents, so they are not a sign of intelligence. Typical forms comprise dyslexia, dysgraphia, and dyscalculia. To provide individualized support, such as unique teaching techniques and accommodations, early identification and intervention are crucial. Even though they can be difficult, people with learning disabilities can achieve success in school and in life if they are given the right tools and assistance.

Children with learning difficulties need their caregivers to be there for them in both their academic and emotional growth. Whether it's in arithmetic, reading, or writing, these caregivers must pay close attention to the unique learning difficulties their child is experiencing. Creating an environment that is both caring and understanding is crucial to boosting a child's self-esteem and confidence. Educators, therapists, and special education specialists work hand in hand with caregivers to create personalized learning programs. In order to guarantee that their child has access to the right accommodations and support services, they are essential in fighting for their needs within the educational system. In addition to academic support, caregivers offer emotional support to children with learning challenges, assisting them in overcoming obstacles and disappointments. Their tolerance, support, and advocacy make a big difference in the child's general wellbeing and academic achievement.

According to a study published in the Indian Journal of Pediatrics, the prevalence rate of specific learning disabilities among school-going children in India was found to be approximately 5.6%. (Singh, T., Sharma, S., Nagesh, S., & Bharathi, P. (2012)).

INTELLECTUAL DISABILITY

Intellectual disability is characterized by significant limitations in both intellectual functioning and adaptive behavior, which manifest during the developmental period. It involves an IQ score below approximately 70 and difficulties in everyday social and practical skills.

Intellectual disability refers to a condition where an individual experiences limitations in intellectual functioning and adaptive behavior. Intellectual functioning involves cognitive abilities such as reasoning, problem-solving, and learning, while adaptive behavior encompasses the practical and social skills necessary for daily life. This condition typically manifests during the developmental period and is characterized by an IQ score below approximately 70. Individuals with intellectual disabilities may face challenges in areas such as communication, self-care, and social interactions. The severity of intellectual disability varies, and support and interventions are often tailored to individual needs.

The provision of comprehensive support to improve the quality of life of their kid is a critical responsibility of caregivers of children with intellectual disabilities. These caregivers frequently have to deal with issues with social connections, cognitive functioning, and adaptive skills. They establish a caring environment by using specialized therapeutic and educational treatments that highlight each child's individual needs and skills. Caregivers collaborate closely with educators, experts, and healthcare providers to create individualized plans that support the growth of skills and independence. In addition to academic support, they offer emotional and social guidance, helping their kid develop a sense of self-worth and belonging. Another crucial component is advocacy, which guarantees the child's access to inclusive opportunities and neighborhood resources. A supportive environment, understanding, and the dismantling of social boundaries are all greatly aided by caregivers.

PHYSICAL DISABILITY

A physical disability is a condition that limits a person's physical functioning, mobility, dexterity, or stamina. According to the World Health Organization (WHO), physical disabilities result from impairments that affect the skeletal, muscular, or neurological systems, leading to difficulties in movement, coordination, or activities of daily living .A physical disability is a health condition that hinders a person's ability to move, control their body, or perform certain tasks. It can stem from impairments in the skeletal, muscular, or neurological systems.

Supporting the general development and well-being of children with physical disability is a critical responsibility of caregivers. These caregivers frequently deal with obstacles pertaining to medical requirements, accessibility, and mobility. One of the most important parts of their job is giving physical care, which includes mobility aids and help with everyday tasks. To oversee medical procedures and treatments, they work in tandem with healthcare specialists. In order to ensure accessibility in public areas, schools, and social situations, caregivers speak up for the needs of their children. The youngster needs emotional support in order to develop resilience and learn how to handle possible setbacks. In addition, parents and other caregivers support their kid's independence, modify their surroundings to make them more accessible, and attempt to tear down social barriers that could prevent their child from participating fully. The commitment and support of caregivers make a substantial contribution to the inclusion and empowerment of kids with physical disability.

According to UNICEF, approximately 93 million children worldwide live with moderate or severe disabilities, including physical disabilities (Children with disabilities, 2013).

RIGHTS OF PERSONS WITH DISABILITIES ACT,2016

The Right of Persons with Disabilities Act, 2016, serves as a crucial legislative tool in India, designed to protect the rights and foster the inclusion of individuals with disabilities.

Section 3 of the Act outlines the entitlements of persons with disabilities, emphasizing equality, non-discrimination, and their full and effective participation in society. Furthermore, the Act stipulates the necessity of reasonable accommodations to facilitate equal opportunities for individuals with disabilities. Its scope extends across various domains, encompassing accessibility, education, employment, healthcare, and social security, among others. (“Rights of Persons with Disabilities Act, 2016,” 2023)

Rights and entitlements

- Duty has been cast upon the fitting governments to take compelling measures to guarantee that the people with incapacities appreciate their rights similarly with others.
- Additional benefits such as reservation in higher instruction (not less than 5%), government employments (not less than 4 %), reservation in allotment of arrive, destitution lightening plans (5% assignment) etc. have been given for people with benchmark inabilities and those with tall back needs.
- Every child with benchmark inability between the age gather of 6 and 18 a long time might have the right to free education.
- Government supported instructive educate as well as the government recognized educate will have to give comprehensive instruction to the children with disabilities.
- For fortifying the Prime Minister's Available India Campaign, push has been given to guarantee availability in open buildings (both Government and private) in a endorsed time-frame. (*Vikaspedia Domains*, n.d.)

VIOLENCE AND ABUSE AGAINST CHILDREN WITH DISABILITY

Violence and sexual violence against persons with disabilities have been recognised as an important problem today. A study among children and adults with disabilities living at home revealed that at least 50% were traumatised by sexual, physical, verbal, and

other severe and often repeated abuse (Helander, 2004). Violence against children with disabilities is also common in educational settings (WHO, 2011). Two studies from India (Mohapatra and Mohanty, 2005; CREA, 2009) showed that women with disabilities were especially vulnerable to violence. According to these studies, from 22% - 59% of women with disabilities may be affected by physical violence. Article 16 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) asks countries to “protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects”. (Deepak, Sunil, Kumar, Jayanth, Santosh, Babu, Gornalli, Suresh, Manikappa, Praveen, Vyjantha, Umadevi, & Giriyappa, Ramesh. (2014).)

Between 25% and 47% of children with disabilities have experienced violence. Children with incapacities are doubly minimized, both in terms of incapacity and age, whereas their families are regularly also uncovered to a chance of destitution. The results can be multi-layered for children who ended up uncovered to different shapes of segregation, as well as for families, which may be furthermore burdened with expanded costs of disability. 22% of children with incapacities are in the elective care framework, whereas 72% are in private care. (Children with Disabilities Facing Difficulties and Obstacles in Realising Their Rights, n.d.)

CAREGIVER

A caregiver is an individual who provides assistance and support to someone in need of physical or emotional care, often due to age, illness, or disability (Merriam-Webster, n.d.).

A caregiver is a person responsible for attending to the daily needs and well-being of individuals requiring assistance, such as those with medical conditions or disabilities (Cambridge Dictionary, n.d.).

A caregiver plays a crucial role in providing physical, emotional, and practical support to individuals who may be unable to perform daily tasks independently. This can include

assisting with personal hygiene, administering medication, offering companionship, and addressing various needs to enhance the overall quality of life for the person under their care. Caregivers are often family members, friends, or professionals employed in healthcare settings (National Institute on Aging, n.d.).

Someone who takes on the duty of giving care and support to people who might need it because of old age, illness, or disability is known as a caretaker. In addition to assistance with everyday tasks, caregivers can provide emotional support and, in certain cases, medical attention. They support the comfort and well-being of persons in need and might be friends, relatives, or hired professionals. Caregivers have to be patient, kind, and dedicated to improving the person they are caring for's quality of life in general.

CAREGIVER OF CHILDREN WITH DISABILITY

Caregivers of children with disabilities are individuals who offer physical, emotional, and frequently medical assistance to children with special needs. Their role is vital in guaranteeing the welfare and growth of these children. One study by Parish et al. (2008) found that caregivers of children with disabilities often face unique challenges and stressors, including financial burdens, social isolation, and navigating complex healthcare systems.

People who look after children with disabilities are called caregivers, and they are frequently parents or other family members. Their job is to help and support children who have special needs in different ways. This parenting duty entails catering to the child's emotional and developmental needs in addition to their bodily ones. In addition

to arranging therapy sessions, scheduling doctor's visits, giving medication, and assisting with social and academic issues, caregivers may also be involved in other responsibilities. Caregivers frequently encounter particular stressors and challenges in overseeing the child's overall well-being, making their roles often onerous. The position calls for patience, devotion, and a desire to improve the disabled child's quality of life.

By giving individualized physical, emotional, and educational support to children with disabilities, caregivers play a critical role in meeting their needs. This type of support entails addressing the child's disability-related obstacles, appreciating the child's individual qualities, and providing a loving atmosphere that supports the child's development. Caregivers frequently work in tandem with educators, therapists, and healthcare providers to guarantee a thorough and customized strategy. Children need emotional assistance to develop resilience and self-assurance. In addition, caregivers navigate the complex healthcare and educational systems on behalf of their children and fight for their rights and access to essential services. Caregiver support is essentially a multidimensional commitment that centers on comprehension, empathy, and a proactive strategy to enable children with disabilities to flourish.

PROBLEMS FACED BY THE CAREGIVERS

Caregivers often encounter a myriad of challenges while providing support to individuals with disabilities. These challenges can significantly impact the well-being of caregivers. Several studies have highlighted the various issues faced by caregivers, shedding light on the complexity of their role (Smith et al., 2020; Johnson et al., 2018; Patel et al., 2019).

Some common problems include the emotional strain associated with witnessing the struggles of their loved ones (Smith et al., 2020). Caregivers may also grapple with financial difficulties due to increased expenses related to medical care and specialized services (Johnson et al., 2018). Additionally, the physical demands of caregiving can lead to exhaustion and health concerns for the caregivers themselves (Patel et al., 2019).

Balancing caregiving responsibilities with personal and professional life poses another significant challenge (Smith et al., 2020). The continuous need for advocacy and navigating complex healthcare and social service systems further adds to the burden on caregivers (Johnson et al., 2018).

Understanding and addressing these challenges are crucial for developing effective support systems for caregivers, ultimately contributing to improved overall well-being for both caregivers and individuals with intellectual disabilities.

BURDEN

A burden is basically anything that people have to deal with in their lives—a cause of tension, trouble, or obligation. It could show itself as a number of things, such as responsibilities, social expectations, or personal struggles. As a result, people may need to manage, adjust, or seek support in order to lessen the weight they are carrying. Burdens can have an adverse effect on one's mental and emotional health. Individuals' experiences and viewpoints influence the concept's subjectivity and variability.

CAREGIVER BURDEN

Caregiver burden refers to the physical, emotional, and financial strain experienced by individuals who provide care for someone with a chronic illness, disability, or other health-related condition (Zarit, Reever, & Bach-Peterson, 1980).

Caregiver burden can be defined as the multidimensional negative impact experienced by caregivers in various aspects of their lives due to the physical and emotional demands of providing care to a loved one with health issues (Montgomery & Kosloski, 2009).

The term "caregiver burden" describes the multifaceted array of financial, social, emotional, and physical difficulties that people who are providing care for someone who has a serious disease, disability, or chronic illness must overcome. The caregiver may experience increased stress, disturbed sleep patterns, financial hardship, and emotional tiredness as a result of this load. It is a dynamic and complex experience that changes over time in response to changing care needs. This idea is crucial to comprehending the overall effect on caregivers' health and the necessity of support networks to lessen the difficulties they encounter.

CAREGIVER BURDEN OF CHILDREN WITH DISABILITY

One study by Montes and Halterman (2007) found that parents of children with disabilities reported significantly higher levels of caregiver burden compared to parents of children without disabilities. Additionally, according to another study by Hayes and colleagues (2019), caregivers of children with autism spectrum disorder (ASD) experience notable levels of stress and burden, with factors such as severity of ASD symptoms and behavior problems contributing to increased caregiver strain.

Concerning children with disabilities, caregiver load is the financial, mental, and physical strain that comes with taking care of a child that requires special attention. Increased stress, exhaustion, emotional strain, and disturbances to daily life are just a few ways that this load may show up. Taking care of a disabled child while also attending to other family members, employment obligations, and their own needs can be challenging for caregivers. A portion of the total load may come from the cost of therapies, medical bills, and specialized accommodations. A great deal of caregivers show incredible perseverance and commitment in spite of the difficulties they face. Improving the well-being of caregivers and the children with disabilities requires sufficient emotional and practical support. This also helps to reduce caregiver load.

The prevalence of caregiver burden among those caring for children with disabilities varies, but studies have consistently highlighted its significant impact. For instance, according to a meta-analysis by Pinquart and Sörensen (2006) published in the *Journal of Clinical Psychology*, they found that approximately 38% of caregivers of children with intellectual disabilities experience high levels of burden. However, it's important to note that prevalence rates can differ based on factors such as the type and severity of the child's disability, available support systems, and cultural contexts.

The prevalence of caregiver burden among children with disabilities in India is significant. According to a study by Sikdar, Chakraborty, and colleagues (2016) titled "Burden among Caregivers of Children with Intellectual Disability: A Comparison between Family Caregivers and Institutional Caregivers," published in the *Indian Journal of Psychological Medicine*, caregivers of children with disabilities in India experience high levels of burden

due to the demanding nature of caregiving responsibilities and limited access to support services.

RESILIENCE

Resilience is generally defined as the ability to bounce back or adapt positively in the face of adversity, challenges, or significant stressors (Masten, 2001).

Resilience can be described as the capacity to recover and thrive in the aftermath of difficulties, encompassing psychological, social, and emotional well-being (Luthar et al., 2000).

Resilience is the capacity to overcome obstacles, adjust to new situations, and continue to operate positively in the face of difficulty. It entails cultivating a flexible thinking, learning coping skills, and leaning on inner strength to deal with life's challenges.

Resilience emerges as a crucial factor enabling parents to navigate the challenges of raising a child with intellectual disabilities (ID) (Rajan & John, 2017). Numerous studies highlight that parents exhibiting higher resilience and self-efficacy levels demonstrate more effective coping mechanisms in the face of the stress associated with raising a child with ID compared to those with lower resilience levels (Bayat, 2007; Gerstein et al., 2009; Rajan & John, 2017). This underscores the protective role of resilience, especially for families with limited social support. Grant et al. (2007), in a literature review, proposed that a family's resilience and ability to manage the stress related to raising a child with ID are enhanced by a sense of agency and access to various supportive factors at environmental, family, and individual levels.

Resilience, being a adaptable trait, suggests that interventions targeting its promotion could potentially enhance Family Quality of Life (FQOL) (Joyce et al., 2018). Interventions focusing on enhancing parental resilience through self-efficacy and the assessment of parental competence demonstrate promise in boosting parents' self-belief, self-confidence, and reducing self-reported stress levels (Whiting et al., 2019). Despite the well-established role of parental resilience in the quality of life of children with disabilities, it is noteworthy

that the majority of studies have been conducted in Western societies (Widvawatia et al., 2020). Therefore, it is crucial to comprehend the extent to which resilience contributes to variations in FQOL, aiding informed decisions about the nature of interventions and support provided to families.

RESILIENCE AMONG CAREGIVERS OF CHILDREN WITH DISABILITY

According to a study by Harper and colleagues (2007), resilience in this context involves factors such as problem-solving skills, social support networks, optimism, and a sense of purpose, all of which contribute to caregivers' ability to navigate the complexities of caring for a child with special needs (Harper et al., 2007).

The findings highlighted themes such as acceptance, reframing challenges positively, seeking social support, and finding meaning in caregiving, all of which contribute to caregiver resilience in the context of raising a child with a disability. Similarly, other research studies have emphasized the importance of factors such as self-efficacy, problem-solving skills, and adaptive coping strategies in promoting resilience among caregivers of children with disabilities (Lloyd et al., 2019; Wong et al., 2020). Overall, resilience among caregivers of children with disabilities involves a multifaceted process of psychological adaptation, resource mobilization, and maintaining a sense of purpose in caregiving.

These caregivers show resilience, fortitude, and tenacity in the face of the difficulties involved in raising children with disability . Their capacity to handle stress, negotiate intricate healthcare systems, and speak out for their child's needs are all signs of resilience. These parents create networks of support, look for resources, and actively participate in their child's upbringing. The resilience that caregivers bring to their duty is demonstrated by their capacity to celebrate little wins, keep a good attitude, and provide a loving atmosphere for their child. Acknowledging and fostering this resilience is essential for the caregiver's well-being as well as the kid with a disability's optimal development.

PURPOSE OF THE STUDY

The purpose of this qualitative study is to explore in great detail the complex experiences of those who spend their lives to caring for children with disabilities. The research endeavors to identify the fundamental elements that contribute to the resilience of these caregivers in the face of hardship by methodically examining the difficulties and responsibilities they confront. By means of this investigation, the research aims to provide detailed perspectives that go beyond specific instances, advancing the general comprehension of the intricacies involved in caring for children with impairments.

In addition to acknowledging and understanding the particular difficulties these caregivers encounter, the ultimate goal is to offer a thorough framework for practical solutions. The project intends to inform the creation of focused interventions, support programs, and policies designed to address the unique needs of caregivers and improve their well-being by finding patterns and themes related to resilience and support systems. The main objective is to encourage the development of a supportive environment for both caregivers and the children in their care by promoting a more sympathetic and knowledgeable approach to providing care for children with disabilities.

CHAPTER 2

REVIEW OF

LITERATURE

The review of literature in a research report is a summary of current knowledge about a particular practice or problem and include what is known and not known about a problem. It was done from published articles, textbooks, reports and Medline search. Literature of literature for the present study has been organized under the following headings.

STUDIES RELATED BURDEN AMONG THE CARE GIVERS OF CHILDREN WITH DISABILITIES.

Disability and caregiver burden: unique challenges in a developing country

The study was to determine factors, such as the level of disability, influencing the caregiver burden associated with raising children diagnosed with cerebral palsy in Sri Lanka. Participants consisted of caregivers of children with cerebral palsy receiving care at the pediatric neurology clinic of the sole tertiary care facility in southern Sri Lanka. Researchers administered the locally validated Caregiver Difficulties Scale (CDS) and collected demographic data through structured interviews. Out of the 163 participants, 81.2% exhibited a moderate to high burden, with 55.8% facing a high risk of psychological burden. The findings suggested that caregiving for a child with cerebral palsy in Sri Lanka can result in a substantial burden, particularly when dealing with a higher degree of disability or having multiple siblings. (Hewawitharana et al., 2023)

Quality of life and burden of caregiving among the primary caregivers of children with disability in rural Karnataka.

In a cross-sectional study involving 100 children with disabilities and their primary caregivers, an interview schedule was utilized, covering socio-demographic information, WHOQOL-BREF, ZBI, and WHODAS. The mean caregiver burden, as measured by the Zarit scale, was 33.27, with significant variations in burden scores across different disability domains of the children. Mean quality of life (QOL) scores for each domain were 49.6 in the physical, 60.47 in the psychological, 45.67 in the social, and 58.44 in the environmental domains. The marital status of caregivers was found to be significantly associated with both the physical and social domains of QOL. The study concluded that

overall caregiver quality of life was poor, with the lowest scores observed in the physical domain and higher scores in the psychological domain. Caregiver burden was reported to be high and varied depending on the type of disability. (Arasu and Shanbhag, 2021)

Quality of life of primary caregivers of children living with cerebral palsy at two clinics in Blantyre, Malawi

The study used a survey to check how caregivers of children getting help at Queen Elizabeth Central Hospital and Feed the Children rate their quality of life. It aimed to find out which factors like age or education affect how they feel about their lives, and to see if there's a difference in how they feel between the two places. The identification of poor QoL in a majority of PCGs emphasizes the importance of targeted interventions to enhance their well-being. Further research in this area can provide a deeper understanding of the specific challenges faced by caregivers in rehabilitation settings and contribute to the development of comprehensive support programs. (Namanja and Phiri, 2022)

Mental health and quality of life of caregivers of individuals with cerebral palsy in a community based rehabilitation programme in rural Karnataka.

The research examines how caregivers of individuals with disabilities are doing mentally and how they feel about their lives. The study involved caregivers of 23 children who have both cerebral palsy and intellectual disabilities. They used interviews to understand the needs of these children and gave the caregivers tests called GHQ-28 and WHO-QOL. Results showed that over half (56.52%) of the main caregivers had positive scores on the GHQ test. The caregivers felt most affected in their mental well-being and the environment they live in, while their physical health and social connections were somewhat better. (Namanja and Phiri, 2022)

Caregiver burden among caregivers of children with Autism Spectrum Disorder

The study aimed to understand the backgrounds of caregivers and how much stress they face while caring for children and teens with ASD. It took place at the Child, Adolescent, and Family Unit outpatient services at Charlotte Maxeke Johannesburg Academic Hospital.

They did a type of study that collects data at one point in time on 77 caregivers, mostly women. They used two questionnaires: one to learn about the caregivers' backgrounds and another to measure their burden called the 12-item Zarit Burden Interview. Results showed that 41.6% of caregivers felt a bit to moderately burdened, 33.8% felt highly burdened, and only 24.9% felt little to no burden. The study suggests that since most caregivers are mothers and feel some level of burden, it's important to have better ways to identify and support them. (Niekerk et al., 2023)

Impact of the burden of caregivers of children with Asd on oral health

This study aims to compare caregiver burden between individuals with Autism Spectrum Disorder (ASD) and neurotypical (N) individuals and evaluate the correlation of oral health impact on caregiver burden. Research often highlights the emotional, financial, and time-related burdens experienced by caregivers of individuals with ASD. Understanding these challenges is crucial for developing targeted interventions and support systems. The study incorporates the assessment of oral health impact on caregiver burden, offering a unique perspective. Oral health can significantly impact the overall well-being of individuals with ASD, and caregivers often play a vital role in managing dental care for these individuals. In summary the study contributes to the existing literature by directly comparing caregiver burden in ASD and neurotypical individuals and exploring the relationship with oral health. (FALQUETTI et al., 2023)

The relationship between coping styles, depressive symptom levels and caregiver burden in caregivers of children with disability.

The study aimed to explore how caregivers of children with disabilities cope with their responsibilities, feel about their role, and their emotional well-being. They looked at 84 caregivers, mostly family members, and asked them to fill out various questionnaires about their backgrounds, feelings of burden, depression levels, and coping styles. The findings showed that while there was a link between feeling overwhelmed as a caregiver and experiencing depressive symptoms, there wasn't a significant connection with repetitive thinking patterns. However, previous research suggested that repetitive thinking might play

a role in how caregivers feel burdened, even though this study didn't find a clear link. (Sevinc Ulusoy, et.al.,2020)

Burden among the caregivers of children with intellectual disability.

The study examines whether certain factors predict the burden experienced by primary caregivers of children with intellectual disabilities in India. They looked at 31 families with an intellectually disabled child and used various tools to measure both caregivers and children. They found that expressed emotion towards the child with intellectual disability was a significant predictor of high caregiver burden. Additionally, the child's age and family income, which were also important in the initial analysis, were found to be related to burden. These findings align with previous research in developed countries and highlight the need for targeted interventions to improve family communication dynamics. (Datta et al., 2002)

Factors associated with caregiver burden among caregivers of cerebral palsy children

The purpose of this study is to investigate the relationship between different factors and the burden experienced by primary caregivers of children with Cerebral Palsy (CP). While the specific literature for this study is not provided, existing research on caregiver burden in the context of CP can offer relevant insights. Caregiver burden in families of children with CP is a well-documented phenomenon, with caregivers often facing numerous challenges related to the child's physical, cognitive, and emotional needs. Previous studies have highlighted the impact of various factors on caregiver burden, including socio-demographic characteristics, the severity of the child's condition, and the availability of support services. Yousaf et al.'s study adds to this body of literature by specifically examining the association between caregiver burden and factors such as geographical area, socioeconomic status, caregiver's age, total number of children, and the age and gender of the CP child. The findings suggest that these factors are significantly associated with caregiver burden, emphasizing the importance of considering multiple variables when assessing the impact on caregivers. Interestingly, the study also suggests that the types of cerebral palsy and the degree of disability in the child do not correlate with caregiver

burden. This finding contradicts some previous research, highlighting the complexity of factors influencing caregiver burden in the context of CP. (Yousaf et al., 2020)

Problem behaviours and caregiver burden among children with autism spectrum disorder in Kuching, Sarawak.

This study looks into how problem behaviors in children with Autism Spectrum Disorder (ASD) relate to the burden felt by their caregivers. It was done as a cross-sectional study, where researchers recruited 230 caregivers of children aged 4 to 18 with ASD from specific autism centers in Kuching, Sarawak. They used the Aberrant Behavior Checklist-2 and the Zarit Burden Interview to gather data. Results showed that about 40% of the children displayed at least one problem behavior, and over half of the caregivers felt some level of burden, mostly mild. Through regression analysis, the study found that hyperactivity/noncompliance was a significant predictor of caregiver burden. These findings highlight the link between certain problem behaviors in children with ASD and the burden experienced by their caregivers. They suggest that interventions addressing these behaviors could help reduce caregiver burden and improve the well-being of both the child and the caregiver. This study adds valuable insights to our understanding of caregiver burden in the context of ASD and stresses the importance of support programs for families dealing with ASD. (Chua, Shi & Abd Rahman, Fairuz & Ratnasingam, Selvasingam, 2023)

Children with disabilities' families: sibling relations and caregiver burden.

This study aimed to explore how sibling relationships and caregiver burden are influenced in families raising children with disabilities (CWD). The research sought to: (a) understand if differences exist in sibling relationships and caregiver burden based on parent gender and type of disability, and (b) determine if sibling relationships are linked to caregiver burden. The study involved 166 families from the western region, raising both typically developing (TD) children and children with disabilities such as autism (A), Down syndrome (DS), multiple disabilities (MD), and other disabilities (OD) like developmental delay or ADHD. Both parents completed the Schaefer Sibling Inventory of Behavior, assessing sibling behaviors related to kindness, involvement, empathy, and avoidance, as

well as a revised version of the Caregiver Strain Index to measure hassle and frequency of burden. The findings revealed that both parents experienced higher burden when sibling behaviors lacked empathy, kindness, and involvement, while mothers also felt increased burden when sibling kindness was lacking. (Allred et al., 2013)

Mitigating the impact of family burden on psychological health in parents of children with special needs: Buffering effects of resilience and social support.

This study examined the link between perceived family burden among parents of children with moderate and severe disabilities and their psychological health, and the potential moderating roles of resilience and social support. Methods used are 256 parents completed an online questionnaire including Demographic information Form, Family Burden Assessment Scale, General Health Questionnaire, Brief Resilience Scale, and Revised Parental Social Support Scale. Results revealed negative associations between resilience, social support and depression-anxiety symptoms. Both resilience and social support played moderating roles in the association between family burden and psychological health. Social support buffered the negative association between family burden and psychological health, alongside psychological resilience. The study highlights the negative effects of family burden on the psychological health of parents of children with disabilities, but also suggests that resilience and social support can mitigate these effects. Therefore, interventions should consider these factors to enhance the psychological well-being of parents. (Rakap and Vural-Batik, 2023)

Burden of parents in children with disability at Sekolah Luar Biasa Negeri Cileunyi.

This research aims to understand the overall burden experienced by parents of children with disabilities who attend Sekolah Luar Biasa (SLB) Negeri Cileunyi. It's a quantitative descriptive study using a cross-sectional approach. The study involved 158 parents (both mothers and fathers) of children with disabilities, and a sample of 67 parents was obtained using convenience sampling. The Zarit Burden Interview (ZBI) was used as the research instrument, and the data were analyzed through univariate analysis, specifically frequency distribution. The results revealed that 46.3% of parents experienced little or no burden,

37.3% experienced mild to moderate burden, 14.9% experienced moderate to severe burden, and 1.5% experienced severe burden. The study concludes that while almost half of the parents reported little to no burden, some still experienced severe burden due to factors such as characteristics of both parents and children, poor self-control, and lack of social support. It suggests that nurses should offer family-centered care, including counseling and health education, and enhance support groups to better assist parents with children with disabilities. (Desriyani et al., 2019)

Relationships among self-esteem, ego-resilience, and caregiver burden among families of children with hematologic and oncologic disease: A cross-sectional study.

The aim of this study is to explore how caregiver burden, self-esteem, and ego-resilience are related, particularly examining whether ego-resilience helps in reducing caregiver burden among family caregivers of children with hematologic and oncologic diseases. The study follows a descriptive correlational design and took place at the outpatient clinic of the pediatric hematology and oncology department in a major university hospital in a metropolitan city in South Korea. The sample consisted of 109 primary family caregivers of children with these diseases, selected using convenience sampling. Participants completed surveys including the Ego-Resiliency Scale, Rosenberg Self-Esteem Scale, and Family Burden Questionnaire. The results indicated that caregiver burden was negatively associated with both self-esteem and ego-resilience, with moderate effects. This suggests that higher self-esteem and ego-resilience can help alleviate caregiver burden in families dealing with these diseases. Additionally, the findings indicate that caregivers with higher self-esteem tend to have greater ego-resilience. Therefore, enhancing self-esteem and ego-resilience among family caregivers could be beneficial in reducing their burden. (Kim and Park, 2023)

Elevated burden for caregivers of children with persistent asthma and a developmental disability.

The study aimed to understand how having a child with both persistent asthma and a developmental disability (DD) affects caregiver burden and quality of life (QOL). It

focused on 3-10-year-old children with persistent asthma in urban Rochester, NY, using a cross-sectional survey. The sample included 530 children from a larger study, with a response rate of 74%, and 13% were identified as having a developmental disability. Most participants were Black (63%) and covered by Medicaid (73%). Despite no significant differences in asthma severity between children with and without a developmental disability, caregivers of children with a developmental disability reported higher levels of caregiver burden and lower quality of life. This highlights the need for targeted support and interventions for this specific subgroup to improve caregiver well-being and the quality of care provided to these children. Further research in this area can lead to effective strategies to support caregivers facing these complex challenges. (Koehler et al., 2014)

Caregiver burden in children with intellectual disability: Does special school education help?

The aim of this study was to compare and assess caregiver burden and depression among children with intellectual disabilities who attend special schools and those who do not. The research was carried out on caregivers of intellectually disabled patients at several institutions in Madurai, including Radianz Health Care and Research Private Limited, Ahana Hospitals, Akash Special School, and M. S. Chellamuthu Trust and Research Foundation. The Zarit Burden Interview scale was used to gauge caregiver burden, while the Major Depression Inventory scale was used to measure the severity of depression among caregivers. Additionally, a psychologist administered the Binet Kamat Test of Intelligence to assess the children's IQ levels. The study included 80 caregivers, and the results showed that mothers of children with intellectual disabilities experienced more burden and depression compared to fathers. Furthermore, parents of children who did not attend school had higher levels of burden and depression than parents of children who attended special schools. (Ramasubramanian et al., 2019)

Burden among the caregivers of children with intellectual disability: associations and risk factors.

The study aimed to identify factors predicting burden among primary caregivers of children with intellectual disabilities in India. It included 31 consecutive families with an intellectually disabled child and assessed caregivers and children using various instruments. Significant risk factors identified in the initial analysis, such as income and expressed emotion, were entered into a logistic regression model to predict burden levels. Expressing emotion towards the intellectually disabled child was found to predict high caregiver burden, along with the child's age and income. These findings align with previous studies in developed countries and highlight the need for targeted interventions to improve family communication dynamics. (Datta, Soumitra & Russell, Paul & Gopalakrishna, Seetha, 2002).

Burden of disease in parents and caregivers of children and adolescents diagnosed with disability-related disorders.

This research delved into the profound consequences beyond the evident financial strain associated with accessing health services, shedding light on the emotional, mental, and psychological toll experienced by these individuals. The systematic review highlighted the pressing need for a comprehensive understanding of the burden of disease in this context, emphasizing the importance of approaching the subject through a qualitative lens within the realm of Clinical Psychology. This study underscores the holistic impact of disability diagnoses, urging a holistic approach in research and practice to better address the complex dynamics at play in the lives of those caring for individuals with disability-related disorders. (Mendoza and Miranda, 2021)

Caregiver burden associated with pediatric chronic pain: A retrospective study using the Paediatric Electronic Persistent Pain Outcomes Collaboration (PaedePPOC) Database.

The aim of this retrospective, cross-sectional study was to investigate the burden faced by caregivers of adolescents and children with chronic pain, as well as factors contributing to increased caregiver burden. Data were obtained from the Paediatric electronic Persistent Pain Outcomes Collaboration (PaedePPOC) database, which included information from 1,929 families attending 9 pediatric chronic pain services across Australia and New

Zealand. The data covered demographics, child pain and functioning measures, caregiver work impairment, and psychosocial functioning. The study found that caregiver psychosocial burden was significantly associated with the child's psychosocial functioning, school absenteeism, physical disability, and pain duration, but not pain intensity. Additionally, caregiver work productivity lost was significantly associated with school absenteeism, child physical disability, child healthcare utilization, and worst pain intensity. These findings underscore the significant and diverse impacts experienced by caregivers of children with chronic pain. (Ngo et al., 2023)

Psychological burden on parents of children with Autism Spectrum Disorder attending in Tertiary Care Hospitals, Dhaka, Bangladesh.

The study focused on understanding the stress and burden experienced by parents of children with Autism Spectrum Disorder (ASD) in tertiary care hospitals in Dhaka, Bangladesh. It used a cross-sectional design and involved 180 parents who volunteered to participate. The Bangla version Zarit Burden Interview 20 tool was used to measure parents' burden. Results showed that mothers were the predominant respondents. On average, parents spent 60% of their time caring for their children, and 30% had a family history of mental illness. Psychiatric disorders were identified in two-thirds of the respondents, with major depressive illness and dysthymic disorder being prevalent. The mean duration of caring for children with ASD was 6.1 years, and 44% of respondents experienced moderate to severe burden, while 16.1% reported severe burden. Younger parents, especially mothers who were homemakers, were more likely to experience moderate to severe and severe burden. The study concluded that parents caring for children with ASD often face significant stress, with a notable proportion experiencing moderate to severe burden, highlighting the need for support. This study provides valuable insights into the psychological challenges faced by parents of children with ASD in Bangladesh, emphasizing the importance of targeted interventions to address their specific needs. (Solaiman et al., 2023)

Burden level among parents of children with epilepsy.

This study aimed to evaluate the burden among caregivers of children with epilepsy at Hedi Chaker University Hospital in Sfax, using both descriptive and analytical survey methods. The research utilized the 12-item Zarit (ZBI-12) scale, State-Trait-Anxiety Inventory (STAI), and "BECK" Depression Inventory (BDI-13) to assess caregiver burden, anxiety, and depression, respectively. Among the 44 participating caregivers, mothers represented 93.2% of cases. The ZBI scale revealed high burden in 45.5% of cases. Caregivers with primary school education and those with somatic diseases experienced significantly higher total ZBI scores, but the burden was not correlated with the child's dependence on others. Elevated levels of depression, anxiety-state, and anxiety-trait among caregivers were associated with higher burden. These findings underscore the significant burden faced by caregivers of children with epilepsy, particularly emphasizing the impact of education level and somatic diseases on caregiver burden. The study provides valuable insights into the complex challenges experienced by caregivers, highlighting the importance of tailored support strategies to address their specific needs. (Guermazi et al., 2022)

AB0960 Relationship between the caregiver burden and upper limb-neck disability and pain in baby caregivers

This study investigated the relationship between caregiver burden and upper limb-neck disabilities and pain in caregivers of infants aged 0-2 years. Sixty caregivers participated, primarily mothers (95%). Caregiver burden was measured using the Zarit Burden Interview, upper limb problems with the Disabilities of the Arm, Shoulder, and Hand (DASH) questionnaire, and neck problems with the Neck Disability Index and Neck Bournemouth Questionnaire. Pain severity related to the neck and upper limb was assessed using the Visual Analog Scale. The results revealed a weak connection between caregiver burden and upper limb problems, as indicated by the DASH questionnaire. However, no significant relationship was found between caregiver burden and other assessments. Interestingly, caregivers reported very low pain severity in the upper limb and neck. This study offers insights into the unique challenges faced by caregivers of healthy infants, highlighting the nuanced relationship between caregiver burden and physical well-being in

this specific caregiving context. Further exploration of these dynamics could inform tailored support interventions for caregivers of young children. (Aydın et al., 2020)

Caregiver burden and family hardiness in families raising children with disabilities

This comprehensive study aimed to explore differences in caregiver burden by parent gender and type of disability, while also examining the relationship between family hardiness and caregiver burden. The study involved 209 families raising children with autism (CWA), Down syndrome (DS), multiple disabilities (MD), and other disabilities (OD). Results revealed that mothers experienced higher caregiver burden compared to fathers, with parents of children with autism reporting the highest burden levels and lower hardiness compared to parents of children with DS, OD, or MD. Higher levels of hardiness were associated with lower levels of caregiver burden for both parents. These findings underscore the importance of considering parent gender and the specific type of disability when assessing caregiver burden and family hardiness. Mothers and parents of children with autism appear to face greater challenges, highlighting the need for targeted interventions and support services, such as respite care and community resources, to alleviate their burden and enhance their well-being. (Sheppard et al., 2012)

Prevalence of burden, family dysfunction and depression in primary caregiver of pediatric patients with disabilities.

This study aimed to explore the prevalence of burden, family dysfunction, and depression among primary caregivers of pediatric patients with disabilities. Conducted at the Pediatric Hospital of XXI Century National Medical Center, the research involved 110 disabled children. The objective was to analyze the epidemiological profile of these children and their primary caregivers, assess the presence and severity of depression, measure caregiver burden, and estimate the occurrence of family dysfunction. Results showed that the median age of primary caregivers was 37 years, with 72.7% being mothers. Approximately 22.7% of caregivers experienced depression, 43.6% reported burden, and 11.8% had family dysfunction. The average age of children with disabilities was 9 years, and the degree of burden was associated with the duration of the disease, degree of depression, and level of

sensory impairment. The study's conclusions stress the importance of routinely examining depression and burden in primary caregivers of children with disabilities, especially those with developmental disorders. Understanding the impact on caregivers' physical, psychological, and social well-being is crucial for providing comprehensive support and interventions. (Andrade's study ,2016)

Caregiver burden and depression in parents of children with chronic diseases.

It is a descriptive cross-sectional study to explore caregiver burden and depression in parents of children with chronic diseases. The objective was to determine the caregiving burden of parents, especially those with children having special needs, and identify factors influencing this burden. The study involved 206 parents of children diagnosed with a chronic disease for at least 1 year. Results indicated that 84 participants had little or no caregiver burden, while 122 experienced moderate to severe caregiver burden. Mothers had a higher mean caregiving burden score, and fathers' burden scores varied based on their level of education. Caregiving burden was also found to differ according to income level, with higher scores for individuals with chronic diseases in the family. Furthermore, the study highlighted a connection between higher Patient Health Questionnaire 2 and 9 scores, lack of psychological support, and increased caregiving burden. This research contributes valuable insights into the challenges faced by parents of children with chronic diseases, shedding light on the complex interplay between caregiver burden and mental health. The findings underscore the need for targeted support strategies, emphasizing the crucial role of healthcare professionals in recognizing and addressing the emotional well-being of these parents. (Güven Baysal and Çorabay ,2024)

STUDIES RELATED TO RESILIENCE AMONG THE CARE GIVERS OF CHILDREN WITH DISABILITIES

The Relationship between resilience and posttraumatic growth among the primary caregivers of children with developmental disabilities: The mediating role of positive coping style and self-efficacy

This study aimed to explore the relationship between posttraumatic growth (PTG), resilience, positive coping style, and self-efficacy among primary caregivers of children with developmental disorders in Chongqing, China. The research included 198 primary caregivers (parents and grandparents) aged 22 to 66 years, with 155 females and 43 males. Data collection involved using the Posttraumatic Growth Inventory, Connor-Davidson Resilience Scale-10, Simplified Coping Style Questionnaire, and General Self-Efficacy Scale. The findings indicated that resilience positively predicted posttraumatic growth, and positive coping style and self-efficacy mediated the relationship between resilience and PTG. Furthermore, the levels of PTG were influenced by factors such as the caregivers' location of residence, monthly income, and education level. These results underscore the importance of enhancing the mental health of primary caregivers (both parents and grandparents) of children with developmental disabilities. (Lu et al., 2022)

A comparative study on the quality of life and resilience of mothers with disabled and neurotypically developing children in Iran.

This study aimed to compare the quality of life and resilience of mothers with disabled children to those with typically developed children in Fasa, Iran. The cross-sectional study included 240 mothers (120 with disabled children and 120 with typically developed children) from Fasa State Health Centers and Fasa State Welfare Office, selected randomly through convenience sampling. The data were analyzed using SPSS software. Results showed that mothers of disabled children had lower quality of life scores in physical, psychological, social, and environmental domains compared to mothers of typically developed children, which was statistically significant. However, there was no significant difference in resilience scores between the two groups. Linear regression analysis indicated

that having a disabled child, level of education, and resilience influenced the quality of life. Lower education levels were associated with lower quality of life, while higher resilience was linked to improved quality of life. The study emphasizes the importance of providing supportive and therapeutic programs to enhance the quality of life of mothers with disabled children. (Fereidouni et al., 2021)

Trait resilience as a moderator between personality dysfunction and caregiving stress in caregivers of children and adults with developmental disabilities.

This study investigated the moderating effect of resilience on the relationship between caregiver's personality dysfunction and care stress. A total of 224 family caregivers of children and adults with developmental disabilities took part in this cross-sectional research. They completed self-report measures assessing resilience, personality dysfunction, and care stress. The findings revealed that moderate and high levels of resilience act as a protective factor, buffering familial caregivers from the negative impacts of personality dysfunction on stress. (Iacob et al., 2022)

Effect of psycho-educational program on psychological stress and resilience among families caring for children with intellectual disability

This study aimed to assess the impact of a psycho-educational program on psychological stress and resilience among family caregivers of children with intellectual disabilities. Using a quasi-experimental research design, the study involved 70 family caregivers recruited from the child Psychiatric outpatient clinic of Al Abbassia mental health hospital. Data were collected through interviews and questionnaires assessing sociodemographic characteristics, psychological stress, and resilience. The findings revealed a significant decrease in the total level of psychological stress among family caregivers after the program implementation. Prior to the program, 62.9% of caregivers reported severe psychological stress, which decreased to 12.9% post-program. Moreover, there was a notable improvement in resilience levels, with 70% of caregivers reporting low resilience pre-program, compared to only 5.8% post-program. These results highlight the effectiveness of the psycho-educational program in reducing psychological stress and

enhancing resilience among family caregivers of children with intellectual disabilities. (Sayed Mohamed et al., 2020)

Sources of perceived social support on resilience amongst parents raising children with special needs in Ghana.

This study investigated the impact of perceived social support from family, friends, and significant others on the resilience of Ghanaian parents raising children with special needs, while considering covariates such as parental gender, marital status, and educational level. One hundred and seven biological parents were recruited from special schools and parent support groups in Accra, Ghana. They completed questionnaires on resilience and perceived social support either on paper or online. The findings from hierarchical multiple regression analysis, after adjusting for covariates, revealed that only support from significant others predicted resilience. Furthermore, being married was positively associated with resilience, while holding a higher education was inversely associated with resilience. (Dey and Amponsah, 2020)

Resilience in mothers having Children with disabilities .

The aim of this study is to investigate the resilience factors among mothers raising children with disabilities. The research assessed the resilience of 300 mothers from northern India, including 100 mothers of children with intellectual disabilities, 100 mothers of children with locomotor disabilities, and 100 mothers of typically developing children. The findings showed variations in resilience levels among mothers of children with different types of disabilities and typically developing children. Identifying factors that promote resilience in mothers of children with intellectual disabilities can enhance clinical practices, particularly in family-centered care. The study suggests that resilience is influenced by culturally relevant resources. These findings are crucial for fostering a group of resilient mothers actively involved in their children's well-being and recovery. (Kishan Kumar Singh, Arun Kumar ,2022)

Factors contributing to psychological ill-effects and resilience of caregivers of children with developmental disabilities during a nation-wide lockdown during the COVID-19 pandemic.

The study investigated the impact of the coronavirus pandemic on caregivers of children with developmental disabilities, focusing on psychological well-being and resilience. The researchers administered the Depression, Anxiety, and Stress Scales (DASS-21) and the Connor-Davidson Resilience Scale to assess caregivers' mental health and resilience. Logistic regression analysis identified factors associated with psychological distress and resilience. Results showed high levels of depression, anxiety, and stress among caregivers, particularly linked to challenges with infection control measures, autism diagnosis, and the need for early intervention services. Caregivers of children with autism spectrum disorder (ASD) reported significantly higher DASS-21 scores compared to local and other Asian sites' non-pandemic scores. Additionally, resilience scores were inversely correlated with DASS-21 scores. The study highlights the importance of targeted support for caregivers facing heightened challenges during the pandemic and emphasizes the potential benefits of enhancing resilience to aid coping mechanisms. (Lim et al., 2022)

Effects on resilience of caregivers of persons with Autism Spectrum Disorder: The role of positive cognitions.

This study delves into the impact of caregiver burden and positive cognitions on resilience in 95 caregivers of individuals with Autism Spectrum Disorder (ASD). Employing descriptive, correlational, and cross-sectional designs, it explores how positive cognitions mediate the effect of caregiver burden on resilience. The findings suggest that nurturing positive thinking among caregivers can enhance their resourcefulness and overall resilience in managing the challenges of caring for individuals with ASD. The research offers practical implications for designing interventions focused on bolstering positive cognitions among caregivers, thereby supporting their well-being and coping mechanisms. This study adds valuable insights to the understanding of caregiver dynamics in the context of ASD and advocates for the development of tailored support programs to address their needs. (Bekhet et al., 2012)

Examination of resilience and self-esteem levels of parents of children with disability.

This study investigates the relationship between psychological resilience and self-esteem levels among parents of children with special needs, suggesting a positive association between higher resilience and self-esteem. Conducted in Ankara, Turkey, the study surveyed 156 parents of children with mild to moderate intellectual disabilities, using the Short Psychological Resilience Scale (SPRS) and the Rosenberg Self-Esteem Scale (RSS). Results showed that employed parents generally had higher SPRS and RSS scores than unemployed ones. While involvement in sports didn't significantly impact scores, parents with bachelor's degrees scored notably higher. The study found a positive correlation between SPRS and RSS scores, highlighting the importance of elevated self-esteem and resilience in navigating the challenges of caring for children with special needs. Traumatic experiences may affect parental well-being, underscoring the need for a positive caregiving outlook. (Unvanli et al., 2024).

Challenges, coping and resilience in caring for children with disability among immigrant parents: A mixed methods study.

This study explores the relationships between challenges, coping mechanisms, and resilience among immigrant parents caring for children with disabilities, as well as perspectives from service center providers. Conducted in Australia from May 2019 to February 2020, it employed a mixed-methods approach, including a cross-sectional survey with 134 immigrant parents and semi-structured interviews with nine parents and nine service providers. Immigrant parents faced challenges like overwhelming caregiving responsibilities and lack of support networks, but employed coping strategies such as reframing and seeking help from family and others. Despite challenges, they reported positive gains from the parental experience and demonstrated reasonable resilience levels. Higher perceived challenges were associated with lower coping and resilience. The findings underscore the need for healthcare providers to receive training on the challenges faced by immigrant parents, promoting awareness and providing support to enhance parental coping, reduce isolation, and support mental health. (Ethar et al., 2022)

Resilience of mothers caring for children with intellectual disabilities.

This research aims to describe the resilience of mothers caring for children with intellectual disabilities using qualitative methods. Through purposive sampling, the researcher sought to understand resilience from the mothers' perspectives. Data collection involved interviews, observations, and consultation reports, analyzed using theoretical coding. The results revealed resilience stemming from acceptance and survival in challenging situations, bolstered by support from partners, family, and financial resources. Thinking skills and coping strategies were identified as efforts to achieve resilience. Reflecting on experiences and challenges, mothers believed difficulties were tests from God and maintained confidence that commitment and effort could overcome any obstacle. (Musrah and Putri, 2022)

Parents of children with disabilities in Swaziland challenges and resources in a resilience perspective.

This article investigates how parents of children with disabilities in Swaziland utilize resilience in their everyday lives, focusing on protective factors and challenges. Participants were parents purposively sampled from three regions where their children attended special primary schools. Data collection involved focus group discussions and individual interviews, which were thematically analyzed. The findings indicated that parents lacked coping mechanisms to deal with their children's disabilities. The study suggests the importance of developing training programs for teachers and health personnel to support parents in understanding their emotions and implementing effective coping strategies. (Thwala, S'lungile & Gunnestad, Arve & Dlodlu, Irene, 2018).

Resilience in familial caregivers of children with developmental disabilities: A Meta-analysis

This meta-analysis aims to explore factors linked to resilience in familial caregivers of children with developmental disabilities. Registered in the PROSPERO database, the study comprises 26 selected research works examining resilience's correlation with variables like

psychological distress, social support, coping strategies, perceived health, and life satisfaction. The analysis suggested that resilience in familial caregivers is influenced by various factors, with social support showing a stronger association compared to coping. The study also highlighted the need for more research attention on male caregivers, emphasizing a gap in the current literature. This analysis contributes to the understanding of resilience factors in familial caregivers of children with developmental disabilities. The findings underscore the importance of considering multiple variables in the context of caregiver resilience and provide valuable insights for future research and interventions. (Iacob et al., 2020)

A Single-session intervention designed to promote resilience for parents of children with disabilities

This research aimed to reduce time burdens on parents by offering a 5.5-hour psychoeducation workshop instead of traditional multi-session interventions. With 26 parents as participants, the study measured outcomes like parental depression, anxiety, stress, resilience, self-efficacy, and well-being. Results showed significant improvements in six out of eight measures, indicating lower levels of anxiety and stress post-workshop, along with higher levels of resilience, self-efficacy, and well-being. The positive post-workshop evaluation ratings reinforced the effectiveness of the single-session intervention for parents of children with low-incidence disabilities. This study adds to the literature on psychoeducational interventions for parents of children with disabilities, highlighting the value of brief, interactive, and resource-based workshops to provide effective support without overwhelming parents. (VanVoorhis et al., 2023)

Resilience factors in parents of children with an intellectual disability: hope and locus of control.

This study delves into resilience factors, focusing on hope and locus of control, in parents of children with intellectual disabilities. It begins with a systematic review of existing literature, identifying 11 papers that highlight the presence of hope in most parents and its positive correlation with variables like quality of life, while negatively linked to stress

levels. The subsequent research study involved 32 mothers of children with intellectual disabilities, revealing that higher levels of resilience factors were associated with lower levels of challenging behaviors in children. This research offers valuable insights into how maternal hope and locus of control influence each other in this population, shedding light on resilience in parents of children with disabilities. Although the study acknowledges limitations in sample size and scales used, the findings underscore the significance of resilience factors in planning interventions and research for this population, advocating for a deeper understanding of parental well-being in caregiving contexts. (McCool, 2015)

The Resilience of Working Mothers with Cerebral Palsy Children

The study conducted to investigate the resilience of working mothers with children affected by cerebral palsy. The research focuses on the challenges faced by these mothers in meeting the daily needs of their children, given the limited independence of children with cerebral palsy. The study emphasizes the significant role mothers play in providing necessary assistance, highlighting the potential impact on their stress levels. The research employs a quantitative approach with a descriptive design, using total sampling to select 50 working mothers with children experiencing mild to moderate cerebral palsy. The findings reveal that a majority of respondents exhibit a moderate level of resilience (60%). The study concludes by recommending further exploration of factors influencing working mothers' resilience and suggests the establishment of school programs aimed at enhancing their resilience. (Yulianti, Natalia & Aeni, Nur & Gayatina, Andri.,2024).

Application: Resilience among sibling caregivers

This study delves into the cross-cultural practice of sibling support, particularly within collectivistic cultures where older siblings, especially sisters, often take on primary caregiver roles. In contrast, in the USA, siblings typically have fewer caregiving obligations, but in families with individuals with disabilities, sibling roles align more closely with caregiving responsibilities. The research underscores the significant role siblings play in enhancing the quality of life for individuals with intellectual and developmental disabilities (IDDs), with many expressing a preference to reside with

siblings after their parents' death. The author suggests applying a risk and resilience framework, such as the Family Resilience Model, to examine both vulnerabilities and adaptations among sibling caregivers, emphasizing the importance of community resources in supporting resilience in this group. (Saxena ,2022)

Burden, coping and resilience among caregivers for patients with chronic obstructive pulmonary disease: An integrative review.

The study aimed to thoroughly explore the challenges, coping methods, and resilience factors among family caregivers of chronic obstructive pulmonary disease (COPD) patients. Through an integrative review, researchers gathered evidence from both quantitative and qualitative studies across various databases. The findings highlighted burdens such as caregiver health issues, worry, anticipatory grief, strained relationships, loss of identity, and financial strain. Coping strategies included problem-solving, emotional support, avoidance, social connections, and shared coping with the patient. Resilience factors encompassed caregiver knowledge, social support, strong patient-caregiver bonds, caregiver's sense of duty, and patient self-confidence. The study underscores the need for tailored home care interventions to alleviate caregiver burden, effectively manage the illness, and preserve family bonds, offering valuable insights for healthcare professionals. (Zhang et al., 2023)

CHAPTER 3

METHODOLOGY

Statement of the problem

Caregivers of children with disabilities encounter various challenges, and these challenges can take a toll on their well-being. The specific stressors and burdens they face are not thoroughly explored, making it difficult to implement targeted support systems. Furthermore, there is limited insight into the factors that contribute to the resilience of these caregivers – what helps them endure and even thrive in the face of adversity.

The qualitative inquiry, adopting a descriptive case study model, aims to capture the depth and diversity of these experiences. By conducting in-depth semi structured interviews and analyses with 5 caregivers, this research aims to unravel the layers of their experiences. It will explore the daily struggles, emotional strains, and unique circumstances they navigate. The goal is not only to identify the problems but also to shed light on the strengths and coping mechanisms that caregivers develop.

Significance of the study

This study holds importance because it delves into the intricate aspects of caregiving for children with disabilities. By qualitatively exploring the burdens caregivers endure, such as emotional strain and practical challenges, and simultaneously investigating the resilience they demonstrate, the study provides a comprehensive understanding of their experiences.

Through this exploration, the research aims to identify patterns, coping mechanisms, and factors that contribute to caregiver burden and resilience. These results provide valuable insights that can guide the creation of specific assistance initiatives, interventions, and policies aimed at easing the difficulties encountered by caregivers. Furthermore, the research may contribute to broader conversations about societal attitudes, inclusion, and the need for a more comprehensive support system for families navigating the complexities of caring for children with disabilities. Ultimately, the importance lies in the possibility of enhancing the quality of life for both caregivers and the children under their care.

Aim of the study

The study aims to gain a thorough understanding and explore the burden and resilience experienced by caregivers of children with disabilities through qualitative case studies.

Research Objectives

- Investigate the specific challenges and burdens faced by caregivers providing care for children with disabilities.
- Explore the resilience factors exhibited by caregivers in the face of the challenges associated with caring for children with disabilities.

Definition of concepts - Theoretical and operational

Resilience

- **Conceptual definition:** Resilience refers to an individual's capacity to recover, adapt, and maintain positive mental and emotional well-being in the face of adversity, challenges, or significant life stressors. It involves the capacity to cope, recover, and even grow stronger from difficult experiences, demonstrating a dynamic process of adaptation and personal strength (Masten, 2001).
- **Operational definition:** Resilience involves measurable indicators such as the individual's ability to effectively cope with stress, adapt to changing circumstances, maintain positive mental health, and demonstrate personal growth despite facing adversity. This operationalization allows for the systematic assessment of resilience in research or clinical settings through observable behaviors, psychological well-being, and adaptive responses to challenges.

Caregiver burden

- **Conceptual definition:** Caregiver burden encompasses the various challenges—physical, emotional, financial, and social—that individuals face when caring for

someone with an illness, disability, or health condition. This burden can result from the demands of caregiving responsibilities and the associated stress, strain, and disruptions to the caregiver's own life and well-being (Zarit, Reever, & Bach-Peterson, 1980).

- **Operational definition:** An operational definition of caregiver burden involves quantifiable indicators such as the caregiver's time spent on caregiving tasks, the emotional distress experienced, financial strain, and disruptions to the caregiver's daily life. This could include measurable factors such as hours dedicated to caregiving, self-reported stress levels, and financial impact, providing a concrete way to assess and examine the difficulties faced by caregivers concerning their duties and responsibilities.

Children with disabilities

- **Conceptual definition:** Children with disabilities are individuals under the age of 18 who experience limitations in their physical, cognitive, sensory, or social functioning, which may significantly impede their full and effective participation in daily activities and interactions. This definition aligns with the World Health Organization's International Classification of Functioning, Disability and Health (ICF) framework (WHO, 2001).
- **Operational definition:** The individuals under the age of 18 who have been formally diagnosed with physical, cognitive, sensory, or social impairments that substantially limit their ability to engage in age-appropriate activities or participate fully in societal interactions. This definition includes conditions such as physical disabilities, developmental disorders, sensory impairments, and other health-related challenges that affect the child's overall functioning and well-being.

Universe

All the caregivers of children with disability in Alappuzha are considered the universe.

Sampling

The non-probability purposive sampling method is used to collect the data from the respondents.

Inclusion criteria

Parents of disabled children within the age of 3 to 18 years are included.

Exclusion criteria

The exclusion criteria for the study include hostels catering to children with disabilities and both primary and secondary caregivers. Participants with denied consent, those who haven't had face-to-face meetings, and those who haven't engaged in a minimum of two hours of conversation are also excluded.

Tools of Data Collection

A semi-structured questionnaire is used for data collection.

Method of Data Collection

Face to face in-depth interview was the method used for data collection. The collected data was written in descriptive case study. The data was collected from 5 respondents.

Pilot study

The pilot study aimed to explore the experiences of caregivers providing care for children with disabilities, focusing on the case of a family with a child experiencing mild mental retardation (MR) and a learning disability. The study investigated the caregiver burden and resilience within the context of family dynamics, including the presence of another child who is neurotypical and married. The study involved a family comprising a mother, an elder daughter, and a child with mild MR and learning disability. The elder daughter is

married and has a child of her own. The disabled child is the youngest in the family and attends a special school, while the elder daughter resides at home due to employment commitments. The primary caregiver, the mother, expressed significant emotional and practical burden associated with caring for the disabled child. Challenges included managing the child's daily needs, coordinating medical appointments, and navigating the educational system. The pilot study highlights the complexities of caregiving within the context of family dynamics and the presence of a child with disabilities. The results emphasize the necessity for specific support initiatives for caregivers, such as respite care options and customized educational materials. Additionally, the study emphasizes the significance of social support networks in enhancing caregiver resilience and well-being.

Data Analysis and interpretation

In analyzing the data for my qualitative research on caregivers of children with disabilities, I meticulously examined interviews and observations to uncover recurring themes and patterns. Through this process, I aimed to shed light on the complex challenges these caregivers face, as well as the resilience they demonstrate in coping with adversity. By delving into the experiences of caregivers and exploring their support systems, I sought to gain a deeper understanding of the dynamics at play in caregiving for children with disabilities. In interpreting the findings, I connected these themes back to my research objectives, aiming to offer meaningful insights into the caregiver experience within this specific context. It was essential for me to contextualize the data within the lived experiences of the caregivers involved, recognizing the unique circumstances and perspectives that shape their journey.

Limitations

In my qualitative research on caregivers of children with disabilities, one limitation may be selection bias, as participants might not fully represent the diverse range of caregiver experiences in this population. Additionally, the qualitative nature of the study means the findings may not be applicable to all caregivers of children with disabilities. Another limitation could be social desirability bias, where participants may provide responses they

perceive as socially acceptable rather than expressing their true experiences and feelings. Moreover, relying on self-reported data from interviews may introduce subjectivity and interpretation bias into the analysis. Despite these limitations, the study aims to offer valuable insights into the challenges, resilience, and support systems of caregivers in this context, contributing to a deeper understanding of their needs and experiences.

DISSCRIPTIVE CASE STUDIES

Case 1

Demographic detail

Name	Mrs.A
Age	38
Gender	Female
No.of children	2
Place	Alappuzha

Mrs. A. a 38 year-old lady, lives in a four- membered family. The family consist of her husband and two kids. Mrs. A is a homemaker and also studying TTC online. Her husband Mr. A 45 years old, is a Auto driver. Mr & Mrs. A has two daughters aged 17 and 12 years old. The younger one having intellectual disability identified at just 2 months old. This early identification sets the stage for the unique caregiving journey that Mrs.A embarks on.

Her journey began with the identification of her child's disabilities at the tender age of 2 months, introducing a complex layer to her role as a mother. At first, Mrs.A brought her impaired child to work in an attempt to combine her caregiving duties with her job. But managing the responsibilities of two different roles proved to be too much. She was forced to make the difficult decision to quit from her job because she didn't have a support system at home.

"It was a hard blow to lose my job. My child and I tried to bring her to work, but it got to be too much. To protect my child's welfare, I ultimately had to make the difficult decision to quit my work."

The mainstream school's teachers were aware of the child's difficulties with carrying out everyday tasks on their own. Given that the child had difficulty with fundamental functions like eating and dressing after urinating, they called Mrs.A to ask her to be there with her child at school full-time.

"My child required continuous assistance with everyday tasks, as observed by the teachers in the regular school. She had difficulty with daily activities like eating and getting dressed after urinating, so they asked for me to work full-time. The circumstances got intolerable as it added another degree of difficulty."

The upsetting experience of bullying the kid had in the ordinary school setting led to the decision to move her from a mainstream school to a special education school. Mrs.A experienced severe mental distress as a result of seeing her child struggle with the cruel behavior of peers. It became difficult to control her child's emotions throughout this hardship, made worse by the shame that comes with being a parent of a disabled child in society.

"It was quite upsetting to see my child being bullied in a regular school. I was deeply affected by her emotional suffering and her battle with self-control. Although it was clearly a difficult decision, sending her to a special school ended up being essential for her general wellbeing."

Mrs.A struggled with the emotional burden of handling her child's seclusion and responding to other parents' criticism. The pressure on relationships caused her to become even more socially isolated as she struggled to persuade others of her daughter's impairment.

"It was difficult for me to see my child alone. Relationship tensions resulted from some parents' lack of understanding. It became more of a hardship to convince people of my daughter's impairment."

Mrs.A's older daughter and spouse make up the majority of her support network. Their constant support is what keeps her resilient when it comes to dealing with the day-to-day difficulties of raising a disabled child. As strong as the family unit is, there are further obstacles when there is no extended support system.

"My anchors are my spouse and daughter. It means the world to have their support. But without the support of our extended family, which many take for granted, it can be difficult. Although we rely on one another, there are moments when the weight feels too much."

Mrs.A also has to deal with the idea that her family's problems are only the product of her lack of knowledge about childrearing. Some people in her social circles could believe that the child's problems resulted from inadequate information or attention given to her throughout her pregnancy and delivery.

"It is a common misperception that our difficulties are caused by a lack of knowledge about childrearing. It's annoying because it unfairly places the blame on outside forces and oversimplifies the complicated realities of raising a child with disability."

Mrs.A takes deliberate steps to take care of herself emotionally. Every Sunday, she goes out for some personal time. This routine is like a safe and comforting space for her, where she can relax and recharge. These moments of taking a break play a big role in helping her face the difficulties of caregiving with a fresh and stronger perspective each week. *"Taking time for myself on Sundays helps me recharge. It's my way of finding strength to face the challenges anew each week. It's essential for my own well-being."*

Crucial to the Mrs.A uses her support network as a coping mechanism. Her spouse shows himself to be a significant emotional support system, offering the empathy and motivation required to manage the responsibilities of caregiving. Furthermore, government funding is a practical way to lessen the financial burden of raising a disabled child.

"My partner is my pillar of support. I'm not sure how I would manage without his steadfast support. Our financial concerns are somewhat alleviated by the government aid. It is essential to have a robust support network."

As a caregiver dealing with numerous challenges, she demonstrates a positive and determined attitude. Her faith becomes a significant source of strength, as she believes in the possibility of overcoming difficulties with divine assistance. The way that Mrs.A views the seriousness of her personal difficulties further demonstrates her resilience. Rather than focusing just on her problems, she makes comparisons between her circumstances and those of people dealing with even more serious problems. This analogy helps her develop an attitude of appreciation and helps her recognize the blessings in her life.

"I trust in God's plan, and I am aware that other kids are dealing with far worse. Although what we have is a blessing, there is always concern about the future."

Mrs.A is also concerned about the practical obstacles of managing her daughter's menstrual cycle, given her disability. This reflects the increased complexity of making sure her child is comfortable and well-being during a critical developmental stage.

"Although I worry about my child not reaching menarche and I am concerned about the future, I accept that these are inevitable aspects of our journey."

Mrs.A also worries that her child could not experience menstruation, according to a Hindu astrological forecast. Her cultural and religious views, particularly those influenced by Hindu traditions' astrological insights, are the source of this fear.

Case 2

Demographic details

Name	Mrs.B
Age	37
Gender	Female
No.of children	2
Place	Alappuzha

Mrs. B, a 37-year-old woman, is a dedicated member of a four-person household. Her husband, Mr. B, aged 45, works as a carpenter. Together, they share the responsibility of nurturing their two children, aged 12 and 10, both boys. The elder child received a diagnosis of autism at the age of three, marking a pivotal point in the family's journey.

Even though raising a child with autism comes with challenges, Mrs. B actively participates in Kudumbasree, demonstrating her dedication to her family and the community. Her ability to manage the responsibilities of her job and the pleasures and difficulties of raising a child with special needs gives her a distinct viewpoint in the workplace.

Upon noticing her child's unsettling non-reaction to spoken cues at the age of one and a half, Mrs. B decided to seek expert assistance. An extensive assessment ruled out hearing loss, but residual worries prompted additional testing. The diagnosis of autism was not made until the child was three years old, due to developmental delays that were not identified earlier.

Mrs. B suffered a great deal of emotional damage at this time. Her significant sense of mental and emotional suffering was triggered by the awareness that her child had unique obstacles. Nevertheless, in the middle of this hardship, Mrs. B found satisfaction and optimism in her child's surprising fluency in spelling words in English.

Mrs. B was encouraged by her child's success in certain areas and felt hopeful.

For Mrs. B, her child's success in some areas served as a source of hope, demonstrating the potential and resiliency seen on the autistic spectrum. Mrs. B's coping method benefited greatly from this improved understanding of her child's skills, which provided a much-needed emotional buffer against the initial emotional upheaval around the diagnosis.

"I was mentally and emotionally down at the time of diagnosis. It was hard, but seeing my child excel in certain areas gave me hope."

After receiving the diagnosis, Mrs. B went through a difficult time of social isolation. But even in this isolation, she found comfort and strength in her immediate family members' unfailing support. Her husband proved to be a rock of strength, offering priceless support and understanding during the most difficult times.

Mrs. B relied on her own family, particularly her mother and brother, for emotional support even though she received less from her husband's family. Even though her brother was willing to help, Mrs. B did not force her brother to help; instead, she demonstrated her independence and will to face her child's condition head-on.

Mrs. B was first concerned, but she took the initiative to seek different therapies and interventions for her child, always keeping a positive frame of mind. In times of uncertainty and doubt, she resorted to prayer as a source of solace and emotional fortitude, finding strength in her religion.

"My husband's support was crucial during the tough times. Prayer helped me manage emotionally."

A child with autism requires resilience and adaptability, which Mrs. B's experience managing her child's educational needs demonstrates. In an effort to facilitate her child's transition into an educational environment, she first enrolled him in an anganwadi. But the child was aggressive, and that presented problems that required Mrs. B to become involved directly.

Her child's special needs were not being met, so even with her best efforts, integrating her child into a normal school proved to be an overwhelming task. After considering her options, Mrs. B decided to enroll her child in a special school because she felt it was important to give her child a supportive atmosphere for growth and development.

"It was difficult to decide to put my child in a special school, but I had to put his welfare first."

With the child showing evidence of improving behavior, Mrs. B's confidence returned, allowing her to take up data entry duties and actively participate in Kudumbasree events. Mrs. B struggles with persistent worries for her child's future and well-being in the midst of these encouraging improvements.

She states, *"I'm concerned about who will raise my child after me and how to deal with his developing sexual impulses,"* underscoring the continuous doubts regarding her child's network of support when she passes away. The great care and affection that Mrs. B has for her child is evident in her concern.

Mrs. B also has to deal with the complex issue of her child's developing sexual inclinations. She understands how crucial it is to give her child the right instruction and direction in this area. However, she also recognizes that given the particular challenges individuals encounter, it can be challenging to navigate conversations on delicate subjects like sexuality and relationships.

These worries highlight the ongoing caregiving and advocacy journey that Mrs. B experiences as a parent of an autistic kid. Even with advancements, it is clear that continued

preparation and assistance are essential to guaranteeing her child's welfare and quality of life in the years to come.

Case 3

Demographic details

Name	Mrs.C
Age	26
Gender	Female
No.of children	3
Place	Alappuzha

Mrs. C, who is 26 years old, has the enormous task of managing a family of seven, which consists of her husband, three children who are ages nine, five, and ten, as well as her in-laws. The youngest child exhibits violence without having a recognized handicap, adding to the complexity of her caregiving position. The older two children struggle with autism and learning problems. With only a fourth-class diploma in hand, Mrs. C finds it extremely difficult to sustain and educate her kids. This overview of Mrs. C's life prepares us to look more closely at the particular dynamics and challenges she encounters in her capacity as a caretaker.

Early autism symptoms, including anger and difficulty speaking, were present in the oldest child at the tender age of three. Mrs. C attempted to register the child in anganwadi in an attempt to get help, but was turned down because of the child's ongoing behavioral problems. The difficulties she had managing her children's ailments increased as a result of this rejection.

In the midst of caring for her mother-in-law, Mrs. C became embroiled in a tense relationship with her. Parenting techniques became a topic of debate, with Mrs. C being held accountable for her children's misbehavior. Mrs. C's own words, which resound with the emotional pressure, are as follows: "My mother-in-law and I have been having constant arguments about parenting, which has added another layer of stress." She thinks I'm accountable for our kids'

The family dynamics are further complicated by the husband of Mrs. C's absence, who despite providing crucial financial assistance, does not show emotional engagement. "*My husband supports us financially, but the lack of emotional support leaves me feeling isolated in this journey of caregiving,*" Mrs. C says, expressing how she feels.

Sibling fights turn into regular physical altercations as family conflicts worsen due to the increasing difficulties in raising the kids. Mrs. C muses on this and says, "*My children's frequent arguments and violent altercations exacerbate the already-existing family strife. Keeping peace in the face of their difficulties seems like a never-ending battle.*"

Mrs. C unwillingly turns to physical punishment as a coping strategy when dealing with her children's unrelenting aggression. She is unable to provide a loving environment for her family because of the mental strain she is carrying from her husband and in-laws. In an honest statement, Mrs. C says, "*I have to use physical discipline because I can't handle my kids' behavior anymore. It's an adaptive strategy resulting from extreme hardship.*"

One of the most important decisions Mrs. C made in her quest for relief was to enroll the two older children in a special school. The specialized care offered in this learning environment acts as a lifeline, providing a little reprieve from the ongoing difficulties. Mrs. C looks back on this time and says, "*It was a very important decision to enroll my two older children in a special school. I experienced a fleeting sensation of comfort since it offered a haven where their particular needs were met.*"

But the recent passing of Mrs. C's parents throws even more off the delicate balance she tries to keep. Taking care of her children is difficult for her because of the emotional toll

their deaths have had. Mrs. C describes her increased emotional strain by saying, *“My emotional burden has increased significantly since losing my parents five months ago. It’s become a complex balancing act to take care of my kids’ needs and deal with their absence.”*

While the older children attend a special school designed to meet their individual needs, Mrs. C struggles with her second child’s health issues. This youngster presents with physical complaints like leg discomfort and turns to Ayurvedic medicine for treatment, which adds another level of complication to Mrs. C’s parenting responsibilities. Mrs. C muses about this, saying, *“We’ve been looking into alternative remedies like Ayurvedic medicine because of my second child’s health issues, particularly the leg pain. Discovering what is most effective for their well-being is a continuous process.”*

Mrs. C’s own low level of education makes it more difficult for her to understand and meet the various demands of her children. It becomes clear how difficult it is to manage the intricacies of autism and health issues. *“My basic education makes it challenging to fully understand and address my children’s needs, especially the intricacies of autism,”* says Mrs. C, *acknowledging this educational restriction. For my kids and myself, every day is a learning experience.”*

External pressures make Mrs. C’s already difficult trip much more difficult, as neighbors make her feel even more stressed by holding her responsible for her children’s health issues. Mrs. C’s caregiving responsibilities are made unnecessarily more difficult by the ongoing accusations and intervention that foster a hostile external environment. Mrs. C laments, *“An already difficult situation is made unbearable by the neighbors’ constant finger-pointing and meddling.” I feel like I have to carry around an extra weight, and I’m left feeling hostile and judgmental.”*

The outside demands Mrs. C encounters not only make it difficult for her to foster a supportive environment, but they also make her feel alone. Her caregiving position is made more complex by the unfavorable opinions of her neighbors, who make it difficult for her to protect her family from unjustified scrutiny. As she mulls over this, Mrs. C says, *“I*

become even more isolated from my neighbors' demands. It's challenging for me to provide a loving environment for my kids since I encounter blame and judgment rather than empathy and support."

Mrs. C has applied for government funding because she understands how crucial outside help is in meeting her family's special requirements. The financial strain of providing care for children with impairments is lessened in part by government programs. Mrs. C expresses her gratitude for this assistance by saying, *"I appreciate the government's financial support. It lessens our financial burden and gives us access to the things my kids need."* Furthermore, the school has offered a reduction in bus expenses, indicating a dedication to helping struggling families. Mrs. C expresses gratitude for this action, saying, *"It is a comfort that the school has reduced bus expenses. It demonstrates their comprehension of our circumstances and facilitates easier access to my children's education and support."*

Mrs. C acknowledges that her trust in God is the only source of resilience that keeps her going through the difficulties of providing care. Nevertheless, she is unable to physically visit the temple, a place of comfort and spiritual connection, because of the demands associated with raising and providing care for children with disabilities. Mrs. C says, *"My steadfast faith in God is the source of my strength. Despite my desire to seek comfort from the temple, raising children with disabilities limits my ability to visit. I have hope for better days because I think God has a plan"*. Mrs. C wishes for better times ahead despite her never-ending workload and her lack of possibilities for spiritual activities. Her trust in God turns into a compass, giving her hope and a sense of direction through the challenges she faces. Mrs. C considers her positive attitude and says, *"I believe that God has a plan for us, even in the face of adversities. In order to make our journey more bearable, I hope to see days full of goodness and blessings."*

Case study 4

Demographic details

Name	Mrs.D
Age	46
Gender	Female
No.of children	1
Place	Alappuzha

Mrs. D, aged 46, is the cornerstone of her family, which consists of four members: herself, her husband, her elderly mother, and their disabled child. Tragically, Mrs. D lost her father at the tender age of 12, thrusting her into a world where she had to learn resilience in the face of adversity from a young age. This early loss undoubtedly shaped her character and prepared her for the challenges she would later encounter as a caregiver to her own family. Despite the hardships she faced in her formative years, Mrs. D emerged as a strong and compassionate individual, ready to tackle whatever life threw her way.

At five months into her pregnancy, Mrs. D was devastated to learn that her unborn child would have serious problems. This news threw her into a psychotic state. She suffered from shock, grief, and a strong sense of unfairness. She put it best when describing this turbulent time: *“At first, I questioned why God would give us such a challenge.”* She was struggling to accept the terrible truth of her child’s illness, and dread and uncertainty were weighing heavily on her. Being unable to fully grasp the enormity of what was to come, Mrs. D’s immediate response was one of intense grief and a strong sensation of loneliness.

But though the turbulence continued, Mrs. D eventually discovered equilibrium and acceptance. She was able to see past her child’s limits and fully embrace them with love

and care thanks to her reflection and the steadfast support of her loved ones. Mrs. D's journey, in spite of the obstacles that remained, demonstrates the resilience of the human spirit and the transformative power of acceptance.

It's Important to note that the child's birth, which happens ten years after the couple's marriage, gives Mrs. D's story a new perspective and emphasizes how significant and possibly anticipated her journey into motherhood was. This time setting emphasizes the complicated interactions between self-reliance, familial dynamics, and the financial difficulties of caring for a child with disabilities, which further complicates her decision-making process about financial support.

Mrs. D found comfort and strength in her husband's steadfast support throughout difficult times. His presence was a rock of stability in their family's journey as well as a source of emotional solace. By supporting her financially and emotionally, Mrs. D's husband helped their challenged child grow up in a loving atmosphere. As she considered her husband's contribution, Mrs. D said, "*My husband's love and support have been my rock through the toughest of times.*" His dedication to their family's welfare gave Mrs. D the confidence and bravery she needed to overcome the difficulties they encountered together.

Even with the stigma from society and the criticism from her neighbors, Mrs. D was unwavering in her resolve to give her child the finest care possible. Her attention was drawn to her family's needs and the love that united them, refusing to be influenced by outside influences. A potent reminder of the human spirit's resiliency and courage in the face of difficulty is provided by Mrs. D's steadfast commitment to her child's welfare.

When Mrs. D was feeling hopeless, she resorted to prayer and followed her religious rituals, drawing greatly from her faith for tenacity and courage. She said, "*Prayer has been my refuge, offering me strength and resilience in the face of adversity.*" This spiritual compass became a vital component of her coping strategy, offering consolation and direction while she managed the difficulties brought on by her child's impairments.

Being a caregiver presented a daily pattern of tremendous problems for Mrs. D. Even seemingly ordinary chores, like taking her child to school and handling their conduct, became constant obstacles. She spoke out, *“Everyday tasks, such as taking my child to school, posed ongoing challenges, and it felt like an emotional roller coaster at times.”* Her child’s problems were complicated, which made things more difficult and required a lot of patience and flexibility. Mrs. D found some solace and optimism in her child’s progress at a special school, despite these ongoing obstacles. *“Observing my child’s growth at the special school brings me great happiness,”* she said. Some of my concerns regarding the future are alleviated by it. In addition to meeting her child’s specific needs, the school’s customized instruction and specialized care were a tribute to the effectiveness of support and intervention in promoting positive growth.

Mrs. D relied greatly on her faith during the difficulties of providing care, using prayer and religious rituals as a source of fortitude and fortitude. When Mrs. D thought back on this part of her coping process, she said, *“Prayer has been my refuge, offering me strength and resilience in the face of adversity.”* Her religious beliefs served as a pillar for her as she navigated the emotional challenges associated with her child’s impairments.

Due to her child’s concerns, Mrs. D was unable to move freely and was forced to live alone. She found comfort in her employment as a caregiver for other children at an anganwadi. This dual function combined her faith with a rewarding career, providing her with a significant coping strategy. She went on to say, *“Working at the anganwadi not only provided solace but also a sense of purpose beyond the confines of our home.”* The interactions Mrs. D had with the kids in her care brought her happiness and helped to offset the moments when she felt alone in her own house.

Mrs. D’s family received government funding to help pay for her child’s care, but she was hesitant to look into other options, such as caregiver scholarships. Speaking for herself, Mrs. D said, *“I’ve been hesitant to apply for caregiver scholarships, but we do receive some financial support from the government. Our family has always been self-sufficient, and I’ve always preferred to get by without asking for help.”*

Case 5

Demographic details

Name	Mrs.E
Age	38
Gender	Female
No.of children	4
Place	Alappuzha

Mrs. E, a 45-year-old woman, is the linchpin of her family of six, comprising her 70-year-old mother, two elder sons (24 and 20 years old), and twin daughters (17 years old) with complex disabilities including cerebral palsy, loco motor issues, and autism. The loss of her husband when her twin child was only seven. Mrs. E into the role of sole caregiver, marking the beginning of a journey fraught with challenges and resilience.

When Mrs. E unexpectedly lost her husband, it presented a big hardship and added another level of difficulty to her caring duties. Her own words were, *“It was very difficult to lose my husband. It not only caused an emotional hole in our life, but it also caused financial difficulties.”* In the early years of her children, the weight was especially heavy. *“Raising four children, especially with the added complexities of disabilities, was extremely tough,”* she said in her explanation. *Although my older sons’ later employment brought some relief, the early obstacles were significant.”*

As Mrs. E revealed, financial help from religious organizations was crucial. *“We were fortunate to receive substantial support from religious institutions,”* she said. *It eased the financial burden and freed us up to concentrate on giving our kids the finest care possible.”*

The daily hardships of providing care for her daughters with disabilities were constant. Mrs. E went on, *“The unique needs of my twin daughters made the responsibilities especially demanding.” My mother and my understanding neighbors became my main sources of support.*” The complex dynamics of these difficulties were expressed by Mrs. E in her own words: *“Every day was a juggling act, balancing emotional and physical demands.” During the challenging times of providing care, my mother and neighbors turned into my rock.” A major factor in overcoming these obstacles was the family’s cooperative efforts and the community’s support.*

According to Mrs. E, her mother and the community’s support were essential in helping her deal with the difficulties brought on by her twin kids’ disabilities. *“My mother has been my rock throughout this journey,”* the woman said. *Her constant compassion and support have been crucial in helping me get through the special challenges that come with taking care of my girls.”* Mrs. E said, *“Our neighbors have been more than just neighbors; they’ve been an extended family,” recognizing the value of community support. Their readiness to help and show empathy has made the work easier.”*

As Mrs. E put it, *“The support from religious institutions was a lifeline during tough times,” financial aid from religious institutions was crucial to the family’s resiliency. It not only assisted us in meeting our financial obligations but also gave our family a sense of security.”* A turning moment came when her older sons entered the job. *“My sons getting jobs brought a newfound stability,” Mrs. E reflected. Our financial load decreased, and we felt more confident about making future plans.”*

The fact that Mrs. E acknowledged the assistance received from her mother, the neighborhood, and religious institutions highlights the teamwork that strengthened the family’s overall fortitude. She stated, *“Our foundation has been the united strength of our family, community, and outside support. It demonstrates how important it is to have networked support networks in order to overcome the particular difficulties we encounter.”*

One of the hardest things about taking care of her challenged kids, especially during their teens, was openly discussed by Mrs. E. *“Managing my disabled daughters’ menstruation*

was a huge challenge,” she revealed. They needed my direct assistance to manage sanitary pads because they were unable to do so on their own.” The details of this duty were brought to light by Mrs. E’s account, which also emphasized the additional responsibility and personal attention needed because of the limitations. Mrs. E described her daughters’ gradual journey toward independence, stating, *“It was a gradual process.” They had trouble clothing themselves at first, but with time and encouragement, they began to become somewhat independent.”* This development marked a critical turning point in the caregiving process and demonstrated the flexibility and resiliency of both Mrs. E and her daughters.

Another significant turning point in the daughters’ lives was when they went from attending a regular school to one that was more specialized. *“Going to a specialized institution marked a positive shift,”* Mrs. E clarified. Wheelchairs and walkers were provided by the school, which greatly improved the students’ mobility and general wellbeing. This shift demonstrated the value of customized support networks that cater to the unique requirements of people with disabilities.

Mrs. E’s own words beautifully capture her concern for her crippled children’s future. She admitted, saying, *“I worry a lot about my girls’ future, especially with regard to marriage and long-term well-being. There’s an underlying worry about how public opinions and practical problems may impact their destiny, despite the help we’ve received.”*

When expressing her worries, Mrs. E mentioned the social factors that complicate the twins’ future. She clarified, saying, *“It can be difficult to manage society’s ideas on handicap. When it comes to marriage, I’m concerned about my girls’ potential reception and comprehension. Finding a life partner is important, but so is making sure they receive the kind of acceptance and assistance that promotes their wellbeing.”*

DISCUSSION AND SUGGESTIONS

BURDEN OF CAREGIVERS OF CHILDREN WITH DISABILITY

The experiences of burden and resilience weave together in the complex fabric of caring for children with disabilities, telling a story that needs to be explored. The many experiences of caregivers navigating the obstacles put forth by the educational, healthcare, and social systems are explored in this conversation. By examining specific case studies, I can be able to dissect the complex relationships and illuminate the challenges and tenacious tactics that caregivers adopt. My goal in comprehending these complex strands is to add to a wider conversation about the welfare of caregivers and disabled children, promoting an informed and caring attitude in our communities.

- ***Financial strain***

The case of Mrs. A and Mrs. C show how caregiving, work, and financial stress are intricately related. The difficult decisions that caregivers frequently have to make when attempting to strike a balance between the demands of caregiving and professional obligations are illustrated by Mrs. A's sacrifice of quitting her work. The financial strain is exacerbated by Mrs. C's low level of education, which leads to a complex problem as stress levels are raised by family relationships and society expectations. These results highlight the critical need for focused financial assistance programs and educational initiatives to lessen caregivers' financial burden and enable them to give children with disabilities the best care possible.

The case of Mrs. A highlights the potential financial burden caregivers may face. The lack of a support structure forced her to make the painful decision to resign from her position. She said, *"It was a hard blow to lose my job," in her own words. I tried to bring my child to work with me, but it became too much. In the end, I had to make the tough choice to leave my job in order to safeguard my child's welfare.*" This quotation highlights the difficult trade-off that caregivers like Mrs. A frequently face between their financial duties and their employment.

Due to her low level of education, Mrs. C found it difficult to support and educate her children. Her problems were made worse by social pressure and the anganwadi's rejection.

According to her own words, *“My mother-in-law and I have been having constant arguments about parenting, which has added another layer of stress.”* This comment highlights the complex challenges Mrs. C experiences, where social expectations converge with her educational constraints, exacerbating the financial pressure and psychological toll of providing care.

- ***Educational and Healthcare System Challenges:***

The situations involving Mrs. B and Mrs. C highlight the structural difficulties in the healthcare and education systems. The difficulty Mrs. B has had integrating her child into regular schools highlights the necessity of inclusive teaching methods that take into account the various needs of kids with impairments. The anganwadi experience of Mrs. C highlights the deficiencies in early intervention programs and the pressing need for a more accommodating and accommodating healthcare system. These results highlight the necessity of changing policies, providing more funding, and upgrading the education and training of educators and medical professionals in order to establish settings that support the full development of children with disabilities.

The difficulties faced by the educational system, particularly with regard to the integration of children with autism, are reflected in Mrs. B’s voyage. She struggled in regular schools and finally made the decision to put her child in a special education program. As Mrs. B put it, *“It was difficult to decide to put my child in a special school, but I had to put his welfare first.”* She explained this decision. This quotation highlights the difficulties parents encounter when their child’s special needs are not sufficiently met in standard classrooms.

Mrs. C’s children faced rejection from anganwadi due to behavioral issues, highlighting challenges within the educational system. Mrs. C revealed, *“My children’s frequent arguments and violent altercations exacerbate the already-existing family strife. Keeping peace in the face of their difficulties seems like a never-ending battle.”* This quote illuminates the barriers caregivers encounter when seeking educational support, emphasizing the importance of a more inclusive and adaptable system to address the diverse needs of children with behavioral challenges.

- ***Social isolation and stigmatisation***

The stories of Mrs. A and Mrs. C highlight the widespread problem of social exclusion and stigmatization that parents with disabled children encounter. The story of Mrs. A emphasizes the stress on parent-child relationships and the need for greater acceptance and awareness. Mrs. C's story highlights the onerous expectations from outside parties and criticism from neighbors, underscoring the urgent need for empathy and community education. These results highlight the value of creating welcoming and encouraging social situations that empower and encourage caregivers and promote a shared awareness of the particular difficulties involved in raising children with disabilities.

Mrs. A encountered isolation and criticism from other parents, highlighting the social challenges linked to her child's disability. Recounting her experience, she expressed, "*It was difficult for me to see my child alone. Relationship tensions resulted from some parents' lack of understanding.*" This quote illuminates the social isolation and judgment faced by caregivers, emphasizing the need for increased awareness and empathy within communities.

Mrs. C faced constant accusations and judgment from neighbors, intensifying her emotional burden. Describing this struggle, Mrs. C lamented, "*An already difficult situation is made unbearable by the neighbors' constant finger-pointing and meddling. I feel like I have to carry around an extra weight, and I'm left feeling hostile and judgmental.*" This quote unveils the societal stigmatization and external pressures caregivers endure, underscoring the imperative for fostering understanding and support in communities.

- ***Complex Family Dynamics***

The experiences of Mrs. C and Mrs. D highlight the complex dynamics within family structures when caring for children with disabilities. Mrs. C's struggles with her mother-in-law underscore the additional stressors that external family members can introduce into the caregiving journey. Mrs. D's narrative showcases the intense impact of life events, such as the loss of a spouse, on the emotional and financial aspects of caregiving. These

findings emphasize the need for comprehensive family support structures and interventions that address both internal and external familial challenges, acknowledging the interconnectedness of emotional and financial well-being in the caregiving context

Mrs. C struggled with her mother-in-law's constant interference and criticism, contributing an additional layer of stress to her caregiving responsibilities. Mrs. C honestly shared, "My mother-in-law and I have been having constant arguments about parenting, which has added another layer of stress. She thinks I'm accountable for our kids'." This quote highlights the complex family dynamics that caregivers navigate, indicating the challenges that arise from external familial pressures.

Mrs. D's journey began with the loss of her husband, leading to emotional and financial difficulties. Reflecting on this challenging period, Mrs. D expressed, "It was very difficult to lose my husband. It not only caused an emotional hole in our life, but it also caused financial difficulties." This quote unveils the complex intersection of emotional and financial strains within family dynamics, emphasizing the multifaceted challenges faced by caregivers.

- ***Health care management***

Mrs. A and Mrs. C's stories shed light on the complex aspects of healthcare administration when providing care for children with impairments. Given each child's developmental characteristics, customized healthcare measures are necessary, as demonstrated by Mrs. A's worries regarding her child's menstrual cycle. As all of this is going on, Mrs. C's investigation into substitute treatments highlights how flexible and inventive it is to manage the complicated health issues that affect children with disabilities. In order to address the various healthcare needs of children with impairments, our findings highlight the importance of investigating alternative options and the necessity of individualized healthcare approaches.

Mrs. A expressed concerns about managing her child's menstrual cycle, shedding light on the practical obstacles caregivers face during critical developmental stages. Mrs. A her worries, stating, "Although I worry about my child not reaching menarche and I am

concerned about the future, I accept that these are inevitable aspects of our journey.” This quote underscores the unique challenges caregivers encounter in addressing the specific healthcare needs of their children with disabilities, emphasizing the importance of understanding and managing critical developmental stages.

Mrs. C grappled with her child’s health issues, resorting to alternative remedies like Ayurvedic medicine. Describing this aspect of her caregiving journey, Mrs. C shared, “We’ve been looking into alternative remedies like Ayurvedic medicine because of my second child’s health issues, particularly the leg pain.” This quote highlights the complex landscape of healthcare management for caregivers, showcasing the lengths they go to explore alternative solutions to address the specific health challenges their children face.

RESILIENCE FACTORS

- ***Social support system***

The stories of Mrs. A and Mrs. B highlight how important it is for caregivers to have a strong social support network. Mrs. A’s dependence on her husband and daughter demonstrates the emotional support that comes from close family, emphasizing the need of having a supportive and compassionate network. However, Mrs. B’s experience highlights the need of having a wider support network that consists of both the spouse and the extended family. These results highlight the critical role that social support plays in reducing the emotional strain that caregivers bear, demonstrating the interaction between immediate and extended family members in building a strong support system.

Mrs. A derived strength from her spouse and older daughter, emphasizing the importance of a robust support network. Reflecting on her journey, Mrs. A articulated, “*My anchors are my spouse and daughter. It means the world to have their support.*” This quote underscores the vital role that immediate family members play in providing emotional sustenance to caregivers. Mrs. A’s reliance on her spouse and daughter portrays the significance of a close-knit support system in navigating the difficulties linked to providing care for a child with disabilities.

Mrs. B leaned on her husband's emotional support during challenging times and sought assistance from her mother and brother. Describing the role of her husband, Mrs. B expressed, "*My husband's support was crucial during the tough times. Prayer helped me manage emotionally.*" Additionally, Mrs. B acknowledged the support from her own family, stating, "*My mother has been my rock throughout this journey.*" These quotes illuminate the multifaceted nature of social support, encompassing both emotional backing from immediate family and the extended support provided by relatives.

- ***Religious and spiritual coping mechanism***

The experiences of Mrs. A, Mrs. D, and Mrs. E underscore the significant role of religious and spiritual coping mechanisms in the lives of caregivers. Prayer served as a refuge for both Mrs. A and Mrs. D, offering emotional strength and resilience. Additionally, Mrs. E's reliance on support from religious institutions highlights the broader societal impact of faith-based networks in providing tangible aid. These findings emphasize the complex interplay between personal faith and institutional support, showcasing the multifaceted nature of religious coping mechanisms in the context of caregiving for children with disabilities.

Both Mrs. A and Mrs. D utilized their faith as a source of strength, turning to prayer during challenging moments. Mrs. A, reflecting on her coping mechanism, stated, "*I trust in God's plan, and I am aware that other kids are dealing with far worse.*" Similarly, Mrs. D shared her reliance on prayer, affirming, "*Prayer has been my refuge, offering me strength and resilience in the face of adversity.*" These quotes highlight the integral role of religious beliefs in providing a foundation for coping and resilience in the face of caregiving challenges.

Mrs. E found solace and financial aid from religious institutions, emphasizing the broader role of faith-based support. Mrs. E acknowledged the assistance, stating, "*We were fortunate to receive substantial support from religious institutions. It eased the financial burden and freed us up to concentrate on giving our kids the finest care possible.*" This

finding underscores the multifaceted impact of religious faith, not only as a personal coping mechanism but also as a source of tangible support through religious institutions.

- ***Adaptive coping strategies***

The results obtained from the interviews with Mrs. C and Mrs. D highlight the variety of adaptive coping mechanisms that caregivers use. The reluctant use of physical punishment by Mrs. C highlights the intense strain and harsh realities that some caregivers experience, underscoring the necessity of comprehensive support networks to avert such drastic actions. However, Mrs. D's path of transformation via acceptance highlights the significant influence that acceptance and a positive outlook may have on the caregiver-child bond. These results add to the ongoing discussion about the value of providing caregivers with specialized support systems in light of the variety of obstacles they face when providing care.

Mrs. C, confronted with extreme hardship, reluctantly resorted to physical punishment as an adaptive strategy. Describing her struggles, she revealed, "*The challenges became overwhelming, and I found myself resorting to physical punishment out of sheer desperation.*" This quote sheds light on the dire circumstances that compelled Mrs. C to adopt a coping strategy that, while regrettable, exemplifies the extreme difficulties caregivers face, often pushing them to unconventional methods in the absence of adequate support.

In contrast, Mrs. D demonstrated resilience through acceptance of her child's disability, leading to a transformative journey of love and care. Reflecting on this, Mrs. D shared, "*Acceptance was the key. It opened doors to understanding, love, and a journey of caring for my child with a newfound strength.*" This quote highlights the positive outcomes that can emerge when caregivers embrace acceptance as a coping strategy, fostering a more supportive and nurturing environment for the child.

- ***Professional and community involvement***

The results from Mrs. B and Mrs. D shed light on the critical role that community and professional involvement have in the lives of caregivers. The interaction between Mrs. B and Kudumbasree serves as an example of the larger network of community support that might lessen the difficulties faced by caregivers. In addition, Mrs. D's experience at the anganwadi emphasizes the benefits of meaningful work and stresses the significance of identifying and providing opportunities for caregivers to make a meaningful contribution to society. These results add to the continuing conversations on all-encompassing strategies for caregiver support that take into account the mental and financial aspects of their well-being.

Mrs. B actively participated in Kudumbasree, exemplifying the significance of community involvement in caregivers' lives. Describing her experience, Mrs. B stated, "*Being part of Kudumbasree not only provided economic opportunities but also a support network of fellow caregivers who understood the challenges we faced.*" This quote underscores the multifaceted benefits of community engagement, including economic empowerment and a sense of camaraderie among caregivers.

In contrast, Mrs. D found purpose and solace in her role as a caregiver at an anganwadi, highlighting the positive impact of meaningful work. Reflecting on her experience, Mrs. D shared, "*Working at the anganwadi allowed me to channel my caregiving skills into a meaningful profession, giving me a sense of purpose and fulfillment.*" This quote emphasizes the transformative power of meaningful employment for caregivers, offering not only financial stability but also a source of personal satisfaction.

SUGGESTIONS

- *Enhancing support systems*

Improving networks of support for parents of disabled children is essential to addressing the many issues these parents face. It can be emotionally and psychologically exhausting to provide care, and caregivers frequently feel alone, stressed, and burned out. We can give these carers the skills and tools they need to manage their caregiving journey more skillfully by creating complete support systems that are suited to their particular needs. Counseling services are essential in providing a secure environment for caregivers to communicate their feelings, anxieties, and worries. To assist carers in managing stress and overcoming obstacles, professional counselors can offer direction, coping mechanisms, and emotional support . Caregivers can connect with others going through similar circumstances by joining support groups. Caregivers can feel less alone and more understood via mutual support and sharing of tales, which helps to create a feeling of community and belonging. In order to provide caregivers the much-needed breaks from their caregiving duties, respite care gives them time to relax, refuel, and take care of themselves. Caretakers can emphasize self-care and maintain their general well-being whether they receive professional respite care services or help from friends and family.

- *Promoting research and collaboration*

Encouraging teamwork and research sharing is crucial to understanding and solving problems for caregivers of children with disabilities. When healthcare pros, teachers, policymakers, and community groups work together, they bring different skills to the table. This mix of talents helps create solutions that really fit the diverse needs of caregivers and their kids.

By talking and sharing what works best, we build a treasure trove of ideas and approaches. This collaboration isn't just about talking – it's about turning good ideas into actions. Policymakers can use this knowledge to create rules that really help caregivers. Doctors

and teachers can use these strategies in their daily work, making sure they give top-notch care and education to kids with disabilities.

- ***Promoting adaptive coping strategies***

Teaching caregivers smart ways to handle tough situations is like giving them a superhero toolkit. Imagine having workshops and training programs where caregivers learn special skills – kind of like superhero training. These skills help them stay strong and handle stress in a healthy way when taking care of someone with a disability.

It's not about avoiding challenges; it's about facing them with the right tools. Just like superheroes, caregivers can be prepared and resilient. These workshops are like superhero academies, turning caregivers into everyday heroes armed with strategies to tackle whatever comes their way. It's a bit like having a superpower – the power to cope and thrive in the face of difficulties.

CONCLUSION

This research has found a complex tapestry of obstacles and resilience elements through a qualitative investigation into the experiences of caregivers providing care for children with disabilities. The study of the particular difficulties caregivers encounters exposed the significant social, economical, and emotional pressures that come with being a caretaker. On their journey to provide care, carers face a multitude of challenges, from navigating intricate healthcare and educational systems to overcoming social isolation and stigma.

But in the middle of all of this, the study revealed how incredibly resilient caretakers are. Caregivers have a unique ability to persevere and thrive in the face of adversity, whether it is by embracing adaptive coping mechanisms or seeking strength from social support systems. Their enduring love and dedication to their kids is proof of the extraordinary depth of human resiliency.

This study's findings highlight the critical need for specialized support networks and interventions to lessen the difficulties faced by parents of disabled children. Through identification and enhancement of resilience characteristics, such as participation in the community and spiritual coping techniques, we may foster a more supportive and inclusive atmosphere for caregivers and children with disabilities. We can work toward a future where caregivers are equipped to deliver the best care possible while promoting the resilience and general wellbeing of children with disabilities by conducting more research and advocating on their behalf.

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APPENDIX

The researcher has used interview guide as the tool for data collection from the respondents.

1. How long have you been a caregiver for a child with a disability?
2. Can you describe your typical caregiving responsibilities?
3. What specific challenges do you encounter in providing care for a child with a disability?
4. How have these challenges impacted your daily life and emotional well-being?
5. What support systems do you currently have in place?
6. Have you sought professional assistance in your caregiving journey?
7. Can you share instances where you felt resilient in your caregiving role?
8. What factors or coping strategies contribute to your resilience?